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“I call it the blame and shame disease”: A qualitative study about perceptions of social stigma surrounding type 2 diabetes

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Abstract

Objectives: While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes. The aim of the current study was to conduct an exploratory, in-depth interview study of the social experiences of Australian adults living with type 2 diabetes (T2DM), with a particular focus on the perception and experience of diabetes-related stigma.

Design: A qualitative study using semi-structured interviews, which were audio-recorded, transcribed, and subject to thematic analysis.

Setting: This study was conducted in the Australian state of Victoria in non-clinical settings in metropolitan and regional areas.

Participants: All adults aged ≥ 18 years with T2DM living in Victoria were eligible to take part. Participants were recruited primarily through the state consumer organisation representing people with diabetes. 25 adults with T2DM participated (12 women; mean age= 59 ± 14 years; mean diabetes duration= 7 ± 7 years).

Results: A total of 21 (84%) participants indicated that they believed T2DM was stigmatised, or reported evidence of stigmatisation. This was evident in feeling blamed by others for causing their own condition, being subject to negative stereotyping, being discriminated against or having restricted opportunities in life. The media, healthcare professionals, friends, family and colleagues were all identified as sources of stigmatising attitudes and practices. The consequences of this stigma included participants' unwillingness to disclose their condition to others, and psychological distress. Participants believed that people with type 1 diabetes do not experience similar stigmatisation.

Conclusions: It is evident that people with T2DM experience or perceive diabetes-related social stigma. Further research is needed to examine these issues in people with type 1 diabetes, and explore ways to measure and minimise diabetes-related stigma at both individual and societal levels.

Article Summary

Article focus

- While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes.
- The aim of the current study was to conduct an exploratory, in-depth interview study of the social experiences of Australian adults living with type 2 diabetes (T2DM), with a particular focus on the perception and experience of diabetes-related stigma.

Key messages

- People with T2DM experience stigmatising practices and attitudes, such as being blamed for their condition, being subject to negative stereotyping, and being discriminated against. Sources of stigma include the media, healthcare professionals, friends, family and work colleagues.
- Consequences of stigma reported by participants include becoming unwilling to disclose their condition, and experiencing psychological distress.
- Further research is needed to examine these issues in people with type 1 diabetes, and explore ways to measure and minimise diabetes-related stigma at both individual and societal levels.

Strengths and limitations

- This qualitative study is the first to describe, in detail, the perceptions and experiences of diabetes-related stigma from the perspective of adults with T2DM.
- While the small sample size may limit the representativeness of the findings, efforts were made to include a broad cross-section of adults with T2DM and data saturation was achieved.
- All participants were members of the state organization representing people with diabetes and most were tertiary educated. These people may be more engaged in their diabetes care and in diabetes issues than the general population.

Introduction

Type 2 diabetes (T2DM) affects more than 220 million worldwide and is increasing in prevalence[1]. Its physical impact is well-documented, with diabetes management and complications having substantial implications for individual and societal health, psychological well-being and quality of life, as well as for the global economy[2-6]. In the past decade, landmark studies have demonstrated that T2DM can be prevented[7 8], highlighting the role of behaviour and personal responsibility in the development of the condition. As the increasing prevalence of T2DM has achieved prominence in the media, and in the consciousness of the general public, so perceptions of T2DM appear to be changing, with anecdotal evidence of social stigma and discrimination now apparent[9]. While the fact that the person has T2DM may not be immediately evident, certain risk factors (e.g. obesity) and the need for daily self-management (e.g. medication-taking, checking blood glucose, modifying diet, injecting insulin) may be conspicuous to others and lead to undesirable consequences such as stigmatisation. Health-related social stigma is a negative 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[10 11]. Stigma has been extensively researched in other conditions such as obesity[12-15] and HIV/AIDS[16-18], but has yet to be the focus of a systematic program of research in diabetes.

Our recent review[19] highlighted the lack of research about stigma in diabetes, but did find some evidence that people with type 1 diabetes (T1DM) and T2DM perceive and experience diabetes-related stigma, and that this stigma has negative consequences across many aspects of their life. We proposed a framework for understanding diabetes-related stigma that hypothesised the features of diabetes and its management that may be the focus of this phenomenon, the sources and psychological mechanisms driving it, and the possible experiences and consequences of stigma[19].

A necessary starting point for building on the findings of this review and commencing a research program in this area is to conduct an in-depth exploration of the perceptions and experiences of diabetes-related stigma from the perspective of the person living with the condition[20]. This will provide a comprehensive understanding of perceived diabetes-related stigma to inform quantitative surveys of people with and without diabetes, and lead to the development, evaluation and implementation of intervention strategies to reduce stigma. We conducted an interview study with the aim of exploring the social experiences of Australian adults living with T2DM, with a particular (but concealed) focus on the perception and experience of diabetes-related stigma.

Methods

Participants and Recruitment

Adults aged ≥ 18 years with T2DM who spoke English and who lived in the Australian state of Victoria were eligible to take part in this interview study. Participants were recruited into this study primarily from the membership list of Diabetes Australia – Vic (DA – Vic; peak consumer body representing people affected by diabetes in Victoria, Australia). The study was also advertised state-wide in diabetes-related media and social media. The study was advertised as an investigation of “the social experience of living with type 2 diabetes”. Study advertisements purposefully did not refer to “stigma” in order to minimise the risk of inadvertently attracting participants with extreme negative experiences, and to avoid biasing participants’ interview responses.

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3 A total of 147 people enquired about the study by telephone or email: 108 were emailed or posted
4 study information sheets; 39 made contact only after recruitment had closed. Purposive selection
5 was used to ensure the sample reflected a wide range of ages, a gender balance, and a combination
6 of people from metropolitan and regional areas of the state. We aimed to recruit 20 people into the
7 study, with the possibility of conducting additional interviews if necessary to achieve data
8 saturation. Ultimately, 26 people were recruited and took part in interviews. One participant was
9 subsequently excluded on the basis that he had not received a diagnosis of T2DM (which became
10 evident during the interview), and because he presented with cognitive impairment. One participant
11 (#20) made it known to the research team after the study had been completed that her diagnosis
12 had been revised to T1DM, though it was clear that her presentation was atypical. However, we
13 decided to retain her data in this study as, at the time of participation, she had a diagnosis of T2DM
14 and she believed that she had this condition, and so her social experiences of living with the
15 condition were as real as those of the other participants. Thus, this paper reports on data from 25
16 interviews.
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21 Interview schedule and procedure

22 Informed by our literature review[19], we developed a semi-structured interview schedule to elicit
23 participant narratives of perceived or experienced diabetes-related stigma. Indirect questioning (i.e.
24 not explicitly referring to 'stigma') invited participants to discuss their own social experience in a
25 range of contexts, including healthcare settings, the workplace, their social and/or family
26 environments, and in the media. Interviewers did not use the word 'stigma' until either the
27 participant had used it spontaneously, or until the last question to address this concept directly.
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30 All interviews were conducted between May and July 2012 in non-clinical settings. All interviews
31 were audio-recorded and lasted an average of 55 minutes (range: 25 – 103 minutes). At the
32 conclusion of the interview, participants completed a short questionnaire to provide demographic
33 and clinical information. A participant ID was used to distinguish audio files and questionnaires. All
34 participants received a \$AU20 department store gift voucher as a token of appreciation for
35 participating.
36
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38 Transcription and analysis

39 All audio recordings were transcribed verbatim by a professional transcription service. The research
40 team checked each transcript against the recording for accuracy. The de-identified transcripts were
41 imported into NVivo 10 to facilitate data coding, retrieval and analysis.
42
43

44 A thematic analysis using an inductive (data driven) approach was used to examine the data[21].
45 Two researchers (JB and AV) read and re-read the transcripts to develop two initial coding
46 frameworks, which were then compared across coders, and reviewed by the full research team.
47 Following revision, an integrated framework was developed and piloted (by JB and AV) by
48 independently coding a random selection of four transcripts. Final modifications were made to
49 improve utility and comprehensibility. Using the final coding framework, JB and AV then coded two
50 transcripts collaboratively to ensure agreement on coding rules, and then coded five additional
51 transcripts independently. Inter-coder agreement for each code was determined by summing the
52 percentage of content in each code identified by both coders and the percentage of content in each
53 code identified by neither coder. A mean agreement rating (averaging agreement ratings across
54 codes) of 99.5% was achieved for these five transcripts, indicating a high level of consistency in
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3 coding decisions. Minor discrepancies were resolved through discussion, raising the agreement level
4 to 100%. AV then coded the remaining 17 transcripts independently.
5

6 The content of each code was then examined by all authors to determine whether some codes could
7 be subsumed by others due to overlapping content, and to explore relationships between codes. For
8 the purposes of this analysis, we coded according to the key topics described below. Participant
9 quotes are provided to illustrate our findings.
10

11 This study received ethics approval from the Deakin University Human Research Ethics Committee
12 (2012-072).
13

14 Results

15 Sample characteristics

16 Of the final sample of 25 participants, 12 (48%) were women. The mean \pm standard deviation age
17 was 59 \pm 14 years (range: 22-79 years), and T2DM duration was 7 \pm 7 years (range: 0-29 years). These
18 characteristics are representative of Australian adults with T2DM as documented in a large-scale
19 national survey[22]. Further sample characteristics are displayed in Table 1.
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24 ---- insert Table 1 here----
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30 Perceptions of social stigma

31 When asked explicitly, 15 participants (60%) indicated they believed there was social stigma
32 surrounding T2DM. Some gave specific examples of personally experiencing or feeling the effects of
33 diabetes-related stigma, while others described it as something they perceived in society generally.
34 A few indicated that they did not experience stigma themselves but believed that others with T2DM
35 did.
36
37

38 *"I think the stigma is that it's a lifestyle disease, that somehow you've been lazy and*
39 *you've allowed this to happen to yourself. I think to me that must come through very*
40 *strongly, that's the judgment that I think that is made."* (#19; woman, 54yrs)
41
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44
45 Ten (40%) participants believed there was no stigma surrounding T2DM but six of these had
46 described evidence of diabetes-related stigma throughout the interview. Four indicated that they
47 firmly believed there was no stigma and that they were surprised that this was a topic of interest, as
48 they had never experienced it nor considered it to be an issue. Interestingly, these four were some
49 of the oldest participants in the study (aged 67-73).
50
51

52 *"I don't believe there would be any stigma at all to having type 2 diabetes. I just can't*
53 *imagine how it would arise"* (#13; man, 69yrs)
54

55 Two people felt that while obesity was stigmatised, T2DM was not, and any stigma people with
56 T2DM experienced was due to their weight alone.
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3 *"Their appearance might be fat, they might look unhealthy and, when they're applying*
4 *for jobs or trying to interact socially that might be the main reason they've got a stigma*
5 *rather than the diabetes." (#1, man, 67yrs)*
6

7
8 In contrast, others raised the issue of diabetes-related stigma unprompted during the initial stages
9 of the interview. For example, when asked the first question about what it was like to be diagnosed
10 with T2DM, one woman responded:

11
12 *"I thought then, and I still think now, that there is still somehow a feeling of stigma*
13 *attached to getting type 2 diabetes because you feel it's your fault and you did it to*
14 *yourself, so initially I was very upset." (#5, woman, 59yrs)*
15

16
17 Evidence of diabetes-related stigma was reflected in participants' accounts of blame and shame,
18 being associated with negative stereotypes, discrimination and restriction of opportunities. The
19 media, healthcare professionals, family, and friends were identified as sources of stigma and
20 stigmatising practices. Many participants compared their own experiences unfavourably with those
21 who have type 1 diabetes. Each of the key themes and sub-themes are identified in Table 2, and
22 explored in more detail below.
23

24
25
26
27 ----Table 2----

30 31 **Evidence of diabetes-related stigma**

32 33 *Blame and shame*

34 The concepts of blame and shame were highly salient. Participants described feeling judged and
35 blamed by others for bringing T2DM on themselves through over-eating, poor dietary habits, being
36 inactive, or being overweight. There was a sense that this reflected negatively on their personal
37 character.
38

39
40 *"There's this message that diabetes is this terrible thing that terrible people get because*
41 *they do terrible things" (#11, woman, 61yrs)*
42

43 Whilst perceptions of blame were described by most a general perception of society's views, some
44 described specific instances of their direct experiences of this blame, for example:

45
46 *"I find a lot of people, they like to think of you as being the culprit. In fact I actually had*
47 *one person say 'well you've dug your grave with your own teeth'." (#12, man, 67yrs)*
48

49
50 Self-blame and feeling guilty for having developed T2DM was common, though it was unclear
51 whether this was the result of internalising perceived societal attitudes, or whether self-blame
52 influenced the perception of attitudes. Some participants, who had a strong family history of T2DM,
53 some of whom reported a healthy lifestyle and were not visibly overweight, still had a strong sense
54 that there was something they should have done to avoid developing the condition.
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3 *"I felt guilty in the early days for the first, probably 10 to 15 years, I felt guilty because it*
4 *was my fault." (#14, woman, 59yrs)*

6 *Negative stereotyping*

7 There was a strong sense that people with T2DM were subjected to negative stereotyping, such as
8 *"fat", "obese", "overweight", "lazy", "slothful", "couch potato", "over-eater", and "glutton".* Once
9 again, there was a strong sense that the stereotype reflected the idea that *"you brought it on*
10 *yourself"*. Less frequently reported were stereotypes of people with T2DM being *"poor people", "not*
11 *terribly intelligent"*, as well as being a *"bad person"* and *"injecting insulin"*. Responses to these
12 stereotypes were mixed. Some people expressed concern, frustration or unease about being
13 automatically labeled in this way, while others endorsed the stereotypes themselves.
14

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17 *"I always worry that people must have thought I was some big fat pig gorging on cakes*
18 *and lollies and was a shocking person and that's why I developed it, I was lazy." (#15,*
19 *woman, 60yrs)*

20
21 *"It can be frustrating because you know damn well it's [the stereotype] not necessarily*
22 *the case." (#18, woman, 42yrs)*

23 *Discrimination and restricted opportunities*

24 While very few examples of discrimination were reported, there were a few notable cases. For
25 instance, one woman (who stated a strong desire to have a child) described restrictions against
26 people with diabetes who want to become adoptive parents:
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30 *"I looked up the adoption [criteria]...a couple of the countries said 'no type 1 or type 2*
31 *diabetes'...I suppose if adoption agencies are saying no diabetes then that's not going to*
32 *happen." (#16, woman, 35yrs)*

33
34
35 While no-one described personal experience of workplace discrimination due to T2DM, people were
36 concerned about the issue. They admitted a general reluctance to disclose the condition during a job
37 interview or application for fear of discrimination in the selection process. In contrast, most were
38 not concerned about disclosing their T2DM once in the workplace.
39

40 The concept of discrimination was perhaps most prominent when discussed in the context of the
41 whole diabetes community, with perceptions that people with T1DM receive more empathy,
42 opportunities and support than people with T2DM:
43

44
45 *"But they're [people with type 1 diabetes] generally quite looked after. They have access*
46 *to pumps, they have heaps of support groups out there and workshops ...if I tried to get*
47 *into the same type of thing because I'm on insulin they say "no, because you're type 2"*
48 *so they automatically exclude you just because of your diagnosis and not because of the*
49 *way you're managing your diabetes. So that segregates the diabetes community as a*
50 *whole." (#20, woman, 22yrs)*

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52
53 More prominent than discrimination per se was a sense of restricted or lost opportunities in life as a
54 result of having T2DM. Limitations in travel or career prospects, and lapsed friendships with people
55 who were unsupportive were described as examples of the negative impact T2DM has on life
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opportunities. For example, one woman described how T2DM had affected her pursuit of career advancement:

"It did kind of slow down my drive to better myself in that job. I didn't leave purely because I was unwell but I wanted to seek a healthier lifestyle" (#23, woman, 37yrs)

Sources of stigma

Media

While some participants could not recall any specific media stories or campaigns about T2DM, those that could held one of two key views. The first view was that the emphasis on T2DM being a lifestyle disease, and therefore within an individual's control, was a helpful and socially responsible preventative health message.

"I think it's great the emphasis they have at the moment talking about your lifestyle and your diet, exercise and that sort of thing. I think it's very, very good" (#2, man, 73yrs)

The second view was that the emphasis on lifestyle factors (such as being overweight or physically inactive) as causal in T2DM served to generate or reinforce blaming attitudes in the community, perpetuate negative stereotypes, and elicit negative emotional reactions from people with T2DM.

"I don't want people to think I developed this disease because I was some big fat that never got off her chair... I was active, exercised, worked, everything...it doesn't have to be from your lifestyle but I think most, well that's how they portray it in the media...they show all the time 'there's this diabetics epidemic' and all you see is fat people, not their heads, these big bums and tummies and all that and you think 'do people think I was like that, that I looked like that?'" (#15, woman, 60yrs)

Those who firmly believed there was a stigma surrounding T2DM were more likely to critique the media's approach to T2DM in this way. Participants who held this view also described sensationalism in the media around the T2DM epidemic, and expressed dissatisfaction with the "scare tactics" often used in public health campaigns. They wanted more positive messages about living with diabetes to be incorporated into the media.

"There's no good news stories about type 2 diabetes. Perhaps there should be. Perhaps it should be 'it isn't necessarily a death sentence'." (#3, man, 54yrs)

Healthcare professionals

Most participants described a combination of both positive / helpful and negative / discouraging interactions with healthcare professionals. Many participants reported stigmatising practices and attitudes among healthcare professionals, who were seen to focus on what was being done 'wrong' (e.g. failure to lose weight or reduce HbA1c since the last consultation) rather than finding ways to encourage behaviour change efforts. This was experienced as discouraging and judgmental:

"The dietician was awful... she asked me if I exercise and I said 'I do the gym twice a week and I have consistently since November' 'that's not enough, you need to go five times a week'...this makes me really angry" (#16, woman, 35yrs)

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3 These negative experiences with healthcare professionals led to changing providers, seeking advice
4 from other sources (e.g. friends, the internet), and avoidance of consultations with healthcare
5 professionals.
6

7 *Family, friends, colleagues*

8 While, in general, participants reported that they had supportive families, friends and workplaces
9 (where relevant), most described at least one example of unhelpful, annoying or discouraging
10 behaviour from their families or peers. This behaviour was described as being hurtful, judgmental,
11 and interfering, particularly regarding dietary choices and weight management.
12
13

14 *"I just say to them 'I know what I can put in my mouth and what I can't, thanks all the*
15 *same'... 'I'd love it if you offer me what you're handing around and I can say 'yes' or 'no*
16 *thanks', that would be nice really'. That makes me feel excluded." (#25, woman, 59yrs)*
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18

19 *Consequences of stigma*

20 *Unwillingness to disclose condition*

21 Many participants were not concerned about other people knowing they had T2DM. This was
22 particularly true of older participants, perhaps because, as one man commented, living with diabetes
23 was a relatively common experience amongst their peers:
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26 *"It's a non-issue really...most of my colleagues are of the same age as I am and many of*
27 *them have relatives or spouses or people who are diabetic" (#12, man, 67yrs).*
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30 Reasons for disclosure included helping other people understand more about diabetes, explaining
31 self-management behaviour or dietary choices in public, seeking support, and for safety in case of a
32 medical emergency.
33

34 Participants tended to describe specific times in their diabetes journey, or specific people or
35 circumstances, that made them reluctant to disclose their condition. Common examples included
36 the period soon after diagnosis, a particular family member or friend they anticipated would
37 respond unhelpfully, or during a job interview or in the workplace, for example:
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39

40 *"I think the problem was more in corporate life...I was in a very senior role and I felt the*
41 *need to hide it from that particular situation." (#24, woman, 68yrs).*
42
43

44 The key reasons for non-disclosure were fear of being judged or blamed for having T2DM or an
45 overwhelming sense of self-blame. Some also described a fear of being discriminated against or a
46 desire to distance oneself from society's negative portrayals of people with diabetes.
47

48 *"When I first got it I wouldn't tell anybody. I didn't even tell my husband. I told nobody.*
49 *I actually felt so ashamed to have diabetes. I felt completely ashamed of myself." (#19,*
50 *woman, 54yrs)*
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52

53 *"Apart from me, none of the people I know [who] have diabetes ever say they have*
54 *diabetes, they never say it, they never speak up, they never say a word and I reckon it's*
55 *because the messages that are put out by [patient organisation] are shutting them up*
56 *because they're hurt and are mortified." (#22, man, 56yrs)*
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3 Other reasons included not wanting to deal with people's misconceptions about the condition
4 (particularly around the dietary management), and not wanting to answer lots of questions about
5 diabetes, worry or shock people, or attract sympathy.
6

7 *Psychological distress*

8 The psychological consequences of stigma included emotional distress such as shame, guilt, regret,
9 and hopelessness. Other psychological consequences that were frequently noted included feelings
10 of low self-worth and self-confidence. Some participants felt that having T2DM reflected poorly on
11 their personal character. Women were more likely to report feeling this way than men. The
12 psychological distress experienced made it even harder to cope with and adjust to life with T2DM.
13
14

15 *"I felt a little bit inferior" (#14, woman, 59yrs)*

16 *"I call it the 'blame and shame disease' because I think that people get blamed and*
17 *shamed and I think that makes it worse...they feel hopeless...it's just another layer."*
18 *(#11, woman, 61yrs)*
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21

22 *Comparisons with type 1 diabetes*

23 There was a distinct feeling among participants that social stigma was specific to T2DM, and that
24 those with T1DM were not judged so harshly. The main reason suggested for this was that those
25 with T1DM were not perceived to be at fault, or to have done anything to cause their condition.
26 Other reasons included that T1DM is perceived to be a more serious condition than T2DM, and
27 because T1DM is often associated with a diagnosis in childhood. One man identified the difference
28 as:
29
30

31 *"Type 1 is 'you poor thing', type 2 is 'you stupid thing'" (#4, man, 57yrs)*
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34 *Discussion*

35 To our knowledge, this study is the first qualitative investigation of the experiences and perceptions
36 of diabetes-related stigma from the perspective of people living with T2DM. Based on commonly-
37 used definitions of health-related stigma, we defined diabetes-related stigma to be an adverse social
38 judgement based on a feature of diabetes or its management that may lead to perceived or
39 experienced exclusion, rejection, blame, stereotyping and / or status loss[10 11]. Our findings
40 indicate that stigmatising attitudes and practices, consistent with this definition, are part of the
41 social experience of living with T2DM.
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45 *Evidence of type 2 diabetes-related stigma*

46 All but four participants either explicitly identified a social stigma surrounding T2DM, or described
47 evidence of this stigma. Those who did not were some of the oldest participants in the study,
48 suggesting that perhaps younger people with T2DM are more likely to experience, or be sensitive to,
49 diabetes-related stigma. Examples of this stigma given by participants included blaming and shaming
50 attitudes towards those with T2DM (including self-blame), negative stereotyping, discrimination and
51 lost opportunities as a result of having T2DM. While the well-recognised obesity stigma[23-25] was
52 seen to play some part in diabetes-related stigma, the latter cannot be wholly explained by the
53 former.
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56 While study participants reserved their most scathing criticism for the media, the people with whom
57 participants had personal relationships were also described as contributing to the diabetes-related
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3 stigma. Consistent with previous research in obesity[25 26], this was particularly evident with
4 regards to interactions with healthcare professionals. Comments or behaviour that revealed
5 judgment, blame, or other negative attitudes towards the person with T2DM were remembered by
6 many participants, sometimes years later. Participants described not returning for a repeat
7 consultation as a direct result of these interactions.
8

9
10 Consistent with previous research[27-29], perceiving and experiencing diabetes-related stigma had
11 both behavioural and psychological consequences. Participants described an unwillingness to
12 disclose their T2DM to others, which has potentially dangerous ramifications for medical
13 emergencies. Also of concern is the possibility that essential self-care will be compromised (e.g.
14 skipping or delaying medications / insulin, not checking blood glucose levels, succumbing to social
15 pressure to eat unhealthy foods) or undertaken in unhygienic environments (e.g. public toilets) to
16 avoid being noticed.
17

18
19 People also described strong feelings of low self-worth and self-esteem, shame and guilt in response
20 to the perceived or experienced stigma. Previous research has demonstrated the associations
21 between emotional distress and sub-optimal self-management, and ultimately, poorer physical
22 health outcomes[4 30-32]. Therefore the potential consequences of stigma are perhaps even more
23 far-reaching than described by our study participants.
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25

26 **Implications for a proposed framework of diabetes-related stigma**

27
28 The findings from this study lend support to our proposed model of diabetes-related stigma[19].
29 Consistent with our model, people with T2DM identified individuals in their lives, including
30 healthcare professionals, as sources of stigma. However, our proposed model did not capture the
31 role of the media in driving and reinforcing the diabetes-related stigma, which was a key concern for
32 participants in this study, raised spontaneously and in response to direct questioning. While self-
33 blame and blame by others was a key theme identified in the current study and a driving mechanism
34 of stigma described in our model, other mechanisms included in our model were less evident (e.g.
35 fear, disgust).
36
37

38
39 The examples and evidence of stigma identified in this study are also consistent with those proposed
40 in the model (e.g. stereotyping, discrimination/restrictions, being judged), as are some of the
41 psychological and behavioural consequences of stigma. On the whole, the proposed model
42 continues to provide a useful 'road map' for diabetes-related stigma research, though some minor
43 modifications (e.g. including media as a source of stigma) are warranted in light of the current
44 study's findings.
45

46 **Implications and future directions**

47
48 Our findings indicate that not only is obesity-related stigma likely to be a barrier to diabetes
49 management in a healthcare setting[33], but that diabetes-specific stigma may be an additional
50 barrier. Given that the obesity and diabetes stigmas seem to be somewhat distinct, further research
51 in the area of diabetes-related stigma is required. Considerable research has already been
52 undertaken with regard to understanding, combating, or minimising the impact of the obesity stigma
53 in healthcare or health education settings[33-36]. Similar work must now be undertaken with
54 reference to diabetes-related stigma, with a view to healthcare settings being a potential target for
55 anti-stigma interventions, and influencing the way T2DM is portrayed in the media.
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3 It is apparent from our findings that the perception or experience of diabetes-related stigma may
4 lead to sub-optimal biomedical and psychological outcomes for people with T2DM. Interventions for
5 people with T2DM that focus on enhancing coping and resilience in the face of stigmatising attitudes
6 and practices may be beneficial. At a minimum, healthcare professionals need to consider
7 stigmatisation as a possible issue that is causing distress that needs to be addressed.
8
9

10 Participants in this study did not perceive that people with T1DM were subject to stigmatising
11 attitudes and practices but that does not mean that people with T1DM do not perceived it to be a
12 stigmatised condition. Research is needed to explore the social experiences of people with T1DM to
13 enable comparison with the experiences reported by people with T2DM.
14

15 **Limitations**

16 As with all qualitative studies, the emphasis is on in-depth exploration of an issue or experience.
17 Consequently, small sample sizes must be used, which may limit the representativeness of the
18 findings. Care was taken to recruit a diverse sample and this was achieved but people with a tertiary
19 education were over-represented in the sample, and all were members of Diabetes Australia – Vic,
20 the state’s consumer organisation. These people may be more engaged in their diabetes care and in
21 diabetes issues than the general population. However, this study has enabled the identification of
22 issues to inform the design of a novel measure of diabetes-related social stigma, so that large-scale,
23 representative quantitative studies can be undertaken.
24
25
26

27 **Conclusions**

28 This study is the first to examine in depth the perceptions and experiences of social stigma of adults
29 living with T2DM. These findings indicate that stigmatisation is an issue of substantial concern for
30 people with T2DM, and has harmful consequences. Future research needs to focus on how to dispel
31 stigmatising attitudes and practices, particularly in healthcare settings, and how to minimise the
32 impact of diabetes-related stigma by enhancing coping amongst people with T2DM.
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Tables

Table 1. Demographic and clinical characteristics of participants (N=25)

<i>Sample characteristics</i>	<i>M ± SD (range) or n (%)</i>
<i>Age</i>	59±14 (22-79)
<i>Age at diagnosis</i>	52±14 (19-76)
<i>Diabetes duration</i>	7±7 (0-29)
<i>Women</i>	12 (48)
<i>Primary treatment</i>	
Insulin injections	5 (20)
OHAs	14 (56)
Lifestyle	6 (24)
<i>Highest qualification</i>	
School or intermediate certificate	1 (4)
High school or leaving certificate	2 (8)
Trade / apprenticeship	2 (8)
Certificate / diploma	4 (16)
Bachelor's degree or higher	16 (64)
<i>Employment</i>	
Full time work	6 (24)
Part time work	7 (28)
Retired/Not working	12 (48)
<i>Metropolitan region</i>	19 (76)
<i>English language</i>	25 (100)

SD: standard deviation

Table 2. Summary of themes and sub-themes identified

<i>Theme</i>	<i>Sub-themes</i>
Evidence of stigma	Blame and shame Negative stereotyping Discrimination / restricted opportunities
Sources of stigma	Media Healthcare professionals Family, friends, colleagues
Consequences of stigma	Unwillingness to disclose condition Emotional distress
Comparisons with type 1 diabetes	-

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Author contributions and acknowledgements

JS, JB and KM conceptualised the study. All authors contributed to the development of the interview schedule. AV, JB and JS conducted the participant interviews. AV checked the transcripts against the audio files, and AV and JB developed the coding framework (in consultation with JS and KM) and conducted the data analysis. JB prepared the first draft of this manuscript. All authors provided feedback and contributed to subsequent revisions of the manuscript. All authors approved the final version of this manuscript. We thank Diabetes Australia – Vic, particularly the membership team, for their assistance with recruitment for this study. We also thank all the people with diabetes who expressed an interest or took part in this study.

Declaration of competing interests

None declared.

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“I call it the blame and shame disease”: A qualitative study about perceptions of social stigma surrounding type 2 diabetes

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“I call it the blame and shame disease”: A qualitative study about perceptions of social stigma surrounding type 2 diabetes

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Abstract

Objectives: While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes. The aim of the current study was to explore the social experiences of Australian adults living with type 2 diabetes (T2DM), with a particular focus on the perception and experience of diabetes-related stigma.

Design: A qualitative study using semi-structured interviews, which were audio-recorded, transcribed, and subject to thematic analysis.

Setting: This study was conducted in non-clinical settings in metropolitan and regional areas in the Australian state of Victoria. Participants were recruited primarily through the state consumer organisation representing people with diabetes.

Participants: All adults aged ≥ 18 years with T2DM living in Victoria were eligible to take part. Twenty-five adults with T2DM participated (12 women; median age 61 years; median diabetes duration 5 years).

Results: A total of 21 (84%) participants indicated that they believed T2DM was stigmatised, or reported evidence of stigmatisation. Specific themes included feeling blamed by others for causing their own condition, being subject to negative stereotyping, being discriminated against or having restricted opportunities in life. Other themes focused on sources of stigma, which included the media, healthcare professionals, friends, family and colleagues. Themes relating to the consequences of this stigma were also evident, including participants' unwillingness to disclose their condition to others, and psychological distress. Participants believed that people with type 1 diabetes do not experience similar stigmatisation.

Conclusions: Our study found evidence of people with T2DM experiencing and perceiving diabetes-related social stigma. Further research is needed to explore ways to measure and minimise diabetes-related stigma at both individual and societal levels, and also to explore perceptions and experiences of stigma in people with type 1 diabetes.

Article Summary

Article focus

- While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes.
- The aim of the current study was to explore the social experiences of Australian adults living with type 2 diabetes (T2DM), with a particular focus on the perception and experience of diabetes-related stigma. This was achieved by conducting semi-structured interviews.

Key messages

- People with T2DM experience stigmatising practices and attitudes, such as being blamed for their condition, being subject to negative stereotyping, and being discriminated against. Sources of stigma include the media, healthcare professionals, friends, family and work colleagues.
- Consequences of stigma reported by participants include becoming unwilling to disclose their condition, and experiencing psychological distress.
- Further research is needed to examine these issues in people with type 1 diabetes, and explore ways to measure and minimise diabetes-related stigma at both individual and societal levels.

Strengths and limitations

- This qualitative study is the first to describe, in detail, the perceptions and experiences of diabetes-related stigma from the perspective of adults with T2DM.
- While the small sample size may limit the representativeness of the findings, efforts were made to include a broad cross-section of adults with T2DM and data saturation was achieved.
- All participants were members of the state organization representing people with diabetes and most were tertiary educated. These people may be more engaged in their diabetes care and in diabetes issues than the general population.

Introduction

Type 2 diabetes (T2DM) affects more than 220 million worldwide and is increasing in prevalence[1]. More than one million Australians have diabetes, with most of these having T2DM[2]. Its physical impact is well-documented, with diabetes management and complications having substantial implications for individual and societal health, psychological well-being and quality of life, as well as for the global economy[3-7]. In the past decade, landmark studies have demonstrated that T2DM can be prevented[8 9], highlighting the role of behaviour and personal responsibility in the development of the condition. As the increasing prevalence of T2DM has achieved prominence in the media, and in the consciousness of the general public, perceptions of T2DM appear to be changing, with anecdotal evidence of social stigma and discrimination apparent (e.g. public comments posted online in response to articles in the media[10]). While the fact that the person has T2DM may not be immediately evident, certain risk factors (e.g. obesity) and the need for daily self-management (e.g. medication-taking, checking blood glucose, modifying diet, injecting insulin) may be conspicuous to others and lead to undesirable consequences such as stigmatisation. Health-related social stigma is a negative 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[11 12]. Stigma has been extensively researched in other conditions such as obesity[13-16] and HIV/AIDS[17-19], but has yet to be the focus of a systematic program of research in diabetes.

Our recent review[20] highlighted the lack of research about stigma in diabetes, but did find some evidence that people with type 1 diabetes (T1DM) and T2DM perceive and experience diabetes-related stigma, and that this stigma has negative consequences across many aspects of their life. We proposed a framework for understanding diabetes-related stigma that hypothesised the features of diabetes and its management that may be the focus of this phenomenon, the sources and psychological mechanisms driving it, and the possible experiences and consequences of stigma[20].

A necessary starting point for building on the findings of this review and commencing a research program in this area is to conduct an in-depth exploration of the perceptions and experiences of diabetes-related stigma from the perspective of the person living with the condition[21]. This will provide a comprehensive understanding of perceived diabetes-related stigma to inform quantitative surveys of people with and without diabetes, and lead to the development, evaluation and implementation of intervention strategies to reduce stigma. We conducted an interview study with the aim of exploring the social experiences of Australian adults living with T2DM, with a particular (but concealed) focus on the perception and experience of diabetes-related stigma.

Methods

Participants and Recruitment

Adults aged ≥ 18 years with T2DM who spoke English and who lived in the Australian state of Victoria were eligible to take part in this interview study. Participants were recruited into this study primarily from the membership list of Diabetes Australia – Vic (DA – Vic; peak consumer body representing people affected by diabetes in Victoria, Australia). The study was also advertised state-wide in diabetes-related media and social media. The study was advertised as an investigation of “the social experience of living with type 2 diabetes”. Study advertisements purposefully did not refer to “stigma” in order to minimise the risk of inadvertently attracting only participants with extreme

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3 negative experiences (which would have resulted in unrepresentative data), and to avoid biasing
4 participants' interview responses.
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6 A total of 147 people enquired about the study by telephone or email: 108 were emailed or posted
7 study information sheets; 39 made contact only after recruitment had closed. Purposive selection
8 was used to ensure the sample reflected a wide range of ages, a gender balance, and a combination
9 of people from metropolitan and regional areas. We aimed to recruit 20 people into the study, with
10 the possibility of conducting additional interviews if necessary to achieve data saturation. Data
11 saturation was achieved at participant #11 (see Table 2), though purposive recruitment continued to
12 ensure a sufficiently varied sample. Ultimately, 26 people were recruited and took part in interviews.
13 One participant (#6) was subsequently excluded on the basis that he had not received a diagnosis of
14 T2DM (which became evident during the interview), and because he presented with cognitive
15 impairment. One participant (#20) made it known to the research team after the study had been
16 completed that her diagnosis had been revised to T1DM, though it was clear that her presentation
17 was atypical. However, we decided to retain her data in this study as, at the time of participation,
18 she had a diagnosis of T2DM and she believed that she had this condition, and so her social
19 experiences of living with the condition were as real as those of the other participants. Thus, this
20 paper reports on data from 25 interviews.
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25 **Interview schedule and procedure**

26 Informed by our literature review[20], we developed a semi-structured interview schedule to elicit
27 participant narratives of perceived or experienced diabetes-related stigma. Indirect questioning (i.e.
28 not explicitly referring to 'stigma') invited participants to discuss their own social experience in a
29 range of contexts, including healthcare settings, the workplace, their social and/or family
30 environments, and in the media. Interviewers did not use the word 'stigma' until either the
31 participant had used it spontaneously, or until the last question to address this concept directly. This
32 approach was used to avoid confusing participants with jargon, and to avoid introducing bias in the
33 questioning, thus maximising opportunities for participants to discuss both their positive and
34 negative social experiences.
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39 All interviews were conducted between May and July 2012 in non-clinical settings by interviewers
40 with a background in health psychology (JB, AV, and JS). A selection of interviews (four) were
41 conducted by one interviewer and observed by another for the purposes of enabling reflective
42 discussions about the interviews, and the role and influence of the interviewer in each one, and
43 identification of any potential bias or stereotypes about T2DM that the interviewer may hold.
44 Interviewers also wrote notes and reflections immediately after every interview. All interviews were
45 audio-recorded and lasted an average of 55 minutes (range: 25 – 103 minutes). At the conclusion of
46 the interview, participants completed a short questionnaire to provide demographic and clinical
47 information. A participant ID was used to distinguish audio files and questionnaires. All participants
48 received a \$AU20 department store gift voucher as a token of appreciation for participating.
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52 **Transcription and analysis**

53 All audio recordings were transcribed verbatim by a professional transcription service. The research
54 team checked each transcript against the recording for accuracy. The de-identified transcripts were
55 imported into NVivo 10 to facilitate data coding, retrieval and analysis.
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3 A thematic analysis using an inductive (data driven) approach was used to examine the data[22].
4 Two researchers (JB and AV, both with postgraduate qualifications in health psychology) read and
5 re-read the transcripts to develop two initial coding frameworks, which were then compared across
6 coders, and reviewed by the full authorship team. Following revision, an integrated framework was
7 developed and piloted (by JB and AV) by independently coding a random selection of four
8 transcripts. Final modifications were made to improve utility and comprehensibility. Using the final
9 coding framework, JB and AV then coded two transcripts collaboratively to ensure agreement on
10 coding rules, and then coded five additional transcripts independently. Inter-coder agreement for
11 each code was determined by summing the percentage of content in each code identified by both
12 coders and the percentage of content in each code identified by neither coder. A mean agreement
13 rating (averaging agreement ratings across codes) of 99.5% was achieved for these five transcripts,
14 indicating a high level of consistency in coding decisions. Minor discrepancies (e.g. where AV had
15 coded data into code A and B, whereas JB had coded only into code A) were resolved through
16 discussion, raising the agreement level to 100%. AV then coded the remaining 17 transcripts
17 independently.
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22 The content of each code was then examined by all authors to determine whether some codes could
23 be subsumed by others due to overlapping content, and to explore relationships between codes. For
24 the purposes of this analysis, we coded according to the key topics described below. Participant
25 quotes are provided to illustrate our findings.
26
27

28 This study received ethics approval from the Deakin University Human Research Ethics Committee
29 (2012-072).
30

31 Results

32 Sample characteristics

33 Of the final sample of 25 participants, 12 (48%) were women. The median age was 61 years (range
34 22-79 years; interquartile range = 15.00), and T2DM duration was 5 years (range 0-29 years;
35 interquartile range = 7.25). These characteristics are representative of Australian adults with T2DM
36 as documented in a large-scale national survey[23]. Further sample characteristics are displayed in
37 Table 1.
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44 ---- Table 1 ----
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48 Perceptions of social stigma

49 When asked explicitly, 15 participants (60%) indicated they believed there was social stigma
50 surrounding T2DM. Some gave specific examples of personally experiencing or feeling the effects of
51 diabetes-related stigma, while others described it as something they perceived in society generally
52 or that others with T2DM experienced. One woman described the personal experience of stigma as
53 follows:
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3 *"I think the stigma is that it's a lifestyle disease. That somehow you've been lazy and*
4 *you've allowed this to happen to yourself. I think to me that must come through very*
5 *strongly, that's the judgment that I think that is made."* (#19; woman, 54yrs)
6

7
8 Ten (40%) participants believed there was no stigma surrounding T2DM but six of these had already
9 described evidence of diabetes-related stigma throughout the interview. Four indicated that they
10 firmly believed there was no stigma and that they were surprised that this was a topic of interest, as
11 they had never experienced it nor considered it to be an issue. Interestingly, these four were some
12 of the oldest participants in the study (aged 67-73).
13

14 *"I don't believe there would be any stigma at all to having type 2 diabetes. I just can't*
15 *imagine how it would arise"* (#13; man, 69yrs)
16

17
18 Two people felt that while obesity was stigmatised, T2DM was not, and any stigma people with
19 T2DM experienced was due to their weight alone.
20

21 *"Their appearance might be fat, they might look unhealthy and, when they're applying*
22 *for jobs or trying to interact socially that might be the main reason they've got a stigma*
23 *rather than the diabetes."* (#1, man, 67yrs)
24

25
26 In contrast, others raised the issue of diabetes-related stigma unprompted during the initial stages
27 of the interview. For example, when asked the first question about what it was like to be diagnosed
28 with T2DM, one woman responded:
29

30 *"I thought then, and I still think now, that there is still somehow a feeling of stigma*
31 *attached to getting type 2 diabetes because you feel it's your fault and you did it to*
32 *yourself, so initially I was very upset."* (#5, woman, 59yrs)
33

34
35 Each of the key themes and sub-themes are explored in more detail below, and the structure of
36 these key themes is summarised in Table 2, with indications of which participants discussed which
37 themes. Evidence of diabetes-related stigma was reflected in participants' accounts of blame and
38 shame, being associated with negative stereotypes, discrimination and restriction of opportunities.
39 The media, healthcare professionals, family, and friends were identified as sources of stigma and
40 stigmatising practices. Many participants compared their own experiences unfavourably with those
41 who have type 1 diabetes.
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46 ----Table 2----
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50 Evidence of diabetes-related stigma

51 *Blame and shame*

52
53 The concepts of blame and shame were highly salient. Participants described feeling judged and
54 blamed by others for bringing T2DM on themselves through over-eating, poor dietary habits, being
55 inactive, or being overweight. There was a sense that this reflected negatively on their personal
56 character.
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2
3 *"There's this message that diabetes is this terrible thing that terrible people get because*
4 *they do terrible things" (#11, woman, 61yrs)*
5

6 Whilst perceptions of blame were described by most a general perception of society's views, some
7 described specific instances of their direct experiences of this blame, for example:
8

9
10 *"I find a lot of people, they like to think of you as being the culprit. In fact I actually had*
11 *one person say 'well you've dug your grave with your own teeth'." (#12, man, 67yrs)*
12

13 Self-blame and feeling guilty for having developed T2DM was common, though it was unclear
14 whether this was the result of internalising perceived societal attitudes, or whether self-blame
15 influenced the perception of attitudes. Some participants, who had a strong family history of T2DM,
16 some of whom reported a healthy lifestyle and were not visibly overweight, still had a strong sense
17 that there was something they should have done to avoid developing the condition.
18

19
20 *"I felt guilty in the early days for the first, probably 10 to 15 years, I felt guilty because it*
21 *was my fault." (#14, woman, 59yrs)*
22

23 *Negative stereotyping*

24 Every participant spoke of negative stereotypes being associated with T2DM. Some of the most
25 common negative stereotypes that were used or described were "fat", "obese", "overweight", "big
26 fat pig", "lazy", "slothful", "shocking person", "couch potato", "over-eater", and "glutton". Once
27 again, these stereotypes reflected the idea that "you brought it on yourself". Less frequently
28 reported were stereotypes of people with T2DM being "poor people", "not terribly intelligent", as
29 well as being a "bad person" and "injecting insulin". Responses to these stereotypes were mixed.
30 Some people expressed concern, frustration or unease about being automatically labeled in this
31 way, while others endorsed the stereotypes themselves.
32
33

34 *Discrimination and restricted opportunities*

35 While very few examples of discrimination were reported, there were a few notable cases. For
36 instance, one woman (who stated a strong desire to have a child) described restrictions against
37 people with diabetes who want to become adoptive parents:
38
39

40 *"I looked up the adoption [criteria]...a couple of the countries said 'no type 1 or type 2*
41 *diabetes'...I suppose if adoption agencies are saying no diabetes then that's not going to*
42 *happen." (#16, woman, 35yrs)*
43
44

45 The concept of discrimination was perhaps most prominent when discussed in the context of the
46 whole diabetes community, with perceptions that people with T1DM receive more empathy,
47 opportunities and support than people with T2DM:
48

49
50 *"But they're [people with type 1 diabetes] generally quite looked after. They have access*
51 *to pumps, they have heaps of support groups out there and workshops ...if I tried to get*
52 *into the same type of thing because I'm on insulin they say "no, because you're type 2"*
53 *so they automatically exclude you just because of your diagnosis and not because of the*
54 *way you're managing your diabetes. So that segregates the diabetes community as a*
55 *whole." (#20, woman, 22yrs)*
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3 More prominent than discrimination per se was a sense of restricted or lost opportunities in life as a
4 result of having T2DM. Limitations in travel or career prospects, and lapsed friendships with people
5 who were unsupportive were described as examples of the negative impact T2DM has on life
6 opportunities. For example, one woman described how T2DM had affected her pursuit of career
7 advancement:
8

9
10 *"I guess it did sort of stop me from pushing myself as much as I usually do, so I did leave*
11 *the position at a time when I was really enjoying it and was hoping to better myself in*
12 *that position" (#23, woman, 37yrs)*
13

14 Sources of stigma

15 Media

16
17 While some participants could not recall any specific media stories or campaigns about T2DM, those
18 that could held one of two key views. The first view was that the emphasis on T2DM being a lifestyle
19 disease, and therefore within an individual's control, was a helpful and socially responsible
20 preventative health message.
21

22
23 *"I think it's great the emphasis they have at the moment talking about your lifestyle and*
24 *your diet, exercise and that sort of thing. I think it's very, very good" (#2, man, 73yrs)*
25

26
27 The second view was that the emphasis on lifestyle factors (such as being overweight or physically
28 inactive) as causal in T2DM served to generate or reinforce blaming attitudes in the community,
29 perpetuate negative stereotypes, and elicit negative emotional reactions from people with T2DM.
30

31
32 *"I don't want people to think I developed this disease because I was some big fat that*
33 *never got off her chair... I was active, exercised, worked, everything...it doesn't have to*
34 *be from your lifestyle but I think most, well that's how they portray it in the media...they*
35 *show all the time 'there's this diabetics epidemic' and all you see is fat people, not their*
36 *heads, these big bums and tummies and all that and you think 'do people think I was like*
37 *that, that I looked like that?'" (#15, woman, 60yrs)*
38

39
40 Those who firmly believed there was a stigma surrounding T2DM were more likely to critique the
41 media's approach to T2DM in this way. Participants who held this view also described sensationalism
42 in the media around the T2DM epidemic, and expressed dissatisfaction with the "scare tactics" often
43 used in public health campaigns. They wanted more positive messages about living with diabetes to
44 be incorporated into the media.
45

46
47 *"There's no good news stories about type 2 diabetes. Perhaps there should be. Perhaps*
48 *it should be 'it isn't necessarily a death sentence'." (#3, man, 54yrs)*
49

50 Healthcare professionals

51
52 Most participants described a combination of both positive / helpful and negative / discouraging
53 interactions with healthcare professionals. Some participants reported stigmatising practices and
54 attitudes among healthcare professionals, who were seen to focus on what was being done 'wrong'
55 (e.g. failure to lose weight or reduce HbA1c since the last consultation) rather than finding ways to
56 encourage behaviour change efforts. This was experienced as discouraging and judgmental:
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3 *"The dietician was awful... she asked me if I exercise and I said 'I do the gym twice a*
4 *week and I have consistently since November' 'that's not enough, you need to go five*
5 *times a week'...this makes me really angry" (#16, woman, 35yrs)*
6

7 These negative experiences with healthcare professionals led to changing providers, seeking advice
8 from other sources (e.g. friends, the internet), and avoidance of consultations with healthcare
9 professionals.
10

11 *Family, friends, colleagues*

12 While, in general, participants reported that they had supportive families, friends and workplaces
13 (where relevant), most described at least one example of unhelpful, annoying or discouraging
14 behaviour from their families or peers. This behaviour was described as being hurtful, judgmental,
15 and interfering, particularly regarding dietary choices and weight management.
16

17 *"I just say to them 'I know what I can put in my mouth and what I can't, thanks all the*
18 *same'... 'I'd love it if you offer me what you're handing around and I can say 'yes' or 'no*
19 *thanks', that would be nice really'. That makes me feel excluded." (#25, woman, 59yrs)*
20
21
22

23 **Consequences of stigma**

24 *Unwillingness to disclose condition*

25 Participants tended to describe specific times in their diabetes journey, or specific people or
26 circumstances, that made them reluctant to disclose their condition. Common examples included
27 the period soon after diagnosis, a particular family member or friend they anticipated would
28 respond unhelpfully, or during a job interview or in the workplace, for example:
29

30 *"I think the problem was more in corporate life...I was in a very senior role and I felt the*
31 *need to hide it from that particular situation." (#24, woman, 68yrs).*
32
33
34

35 The key reasons for non-disclosure were fear of being judged or blamed for having T2DM or an
36 overwhelming sense of self-blame. Some also described a fear of being discriminated against or a
37 desire to distance oneself from society's negative portrayals of people with diabetes.
38

39 *"When I first got it I wouldn't tell anybody. I didn't even tell my husband. I told nobody.*
40 *I actually felt so ashamed to have diabetes. I felt completely ashamed of myself." (#19,*
41 *woman, 54yrs)*
42
43
44

45 *"Apart from me, none of the people I know [who] have diabetes ever say they have*
46 *diabetes, they never say it, they never speak up, they never say a word and I reckon it's*
47 *because the messages that are put out by [patient organisation] are shutting them up*
48 *because they're hurt and are mortified." (#22, man, 56yrs)*
49
50

51 Other reasons included not wanting to deal with people's misconceptions about the condition
52 (particularly around the dietary management), and not wanting to answer lots of questions about
53 diabetes, worry or shock people, or attract sympathy.
54

55 However, many participants were not concerned about other people knowing they had T2DM. This
56 was particularly true of older participants, perhaps because, as one man commented, living with
57 diabetes was a relatively common experience amongst their peers:
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3 *"It's a non-issue really...most of my colleagues are of the same age as I am and many of*
4 *them have relatives or spouses or people who are diabetic" (#12, man, 67yrs).*
5

6 Reasons for disclosure included helping other people understand more about diabetes, explaining
7 self-management behaviour or dietary choices in public, seeking support, and for safety in case of a
8 medical emergency.
9

10 11 12 **Psychological distress**

13 The psychological consequences of stigma included emotional distress such as shame, guilt, regret,
14 and hopelessness. Other psychological consequences that were frequently noted included feelings
15 of low self-worth and self-confidence. Some participants felt that having T2DM reflected poorly on
16 their personal character. The psychological distress experienced made it even harder to cope with
17 and adjust to life with T2DM.
18

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20
21 *"I felt a little bit inferior" (#14, woman, 59yrs)*
22

23 *"I call it the 'blame and shame disease' because I think that people get blamed and*
24 *shamed and I think that makes it worse...they feel hopeless." (#11, woman, 61yrs)*
25

26 **Comparisons with type 1 diabetes**

27 There was a distinct feeling among participants that social stigma was specific to T2DM, and that
28 those with T1DM were not judged so harshly. The main reason suggested for this was that those
29 with T1DM were not perceived to be at fault, or to have done anything to cause their condition.
30 Other reasons included that T1DM is perceived to be a more serious condition than T2DM, and
31 because T1DM is often associated with a diagnosis in childhood. One man identified the difference
32 as:
33

34
35
36 *"Type 1 is 'you poor thing', type 2 is 'you stupid thing'" (#4, man, 57yrs)*
37

38 **Discussion**

39 To our knowledge, this study is the first qualitative investigation of the experiences and perceptions
40 of diabetes-related stigma from the perspective of people living with T2DM. Based on commonly-
41 used definitions of health-related stigma, we defined diabetes-related stigma to be an adverse social
42 judgement based on a feature of diabetes or its management that may lead to perceived or
43 experienced exclusion, rejection, blame, stereotyping and / or status loss[11 12]. Our findings
44 indicate that stigmatising attitudes and practices, consistent with this definition, are part of the
45 social experience of living with T2DM.
46
47

48 **Evidence of type 2 diabetes-related stigma**

49 All participants bar four either explicitly identified a social stigma surrounding T2DM, or described
50 evidence of this stigma. Those who did not were some of the oldest participants in the study,
51 suggesting that perhaps younger people with T2DM are more likely to experience, or be sensitive to,
52 diabetes-related stigma. Younger adults with T2DM face many pressures unique to their age group
53 and perceive that existing T2DM services are not relevant to them[24]. These factors may contribute
54 to the more pronounced stigma experienced by younger participants. Examples of this stigma given
55 by participants included blaming and shaming attitudes towards those with T2DM (including self-
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3 blame), negative stereotyping, discrimination and lost opportunities as a result of having T2DM.
4 While the well-recognised obesity stigma[25-27] was seen to play some part in diabetes-related
5 stigma, the latter cannot be wholly explained by the former.
6

7
8 While study participants reserved their most scathing criticism for the media, the people with whom
9 participants had personal relationships were also described as contributing to the diabetes-related
10 stigma. Consistent with previous research in obesity[27 28], this was particularly evident with
11 regards to interactions with healthcare professionals. Comments or behaviour that revealed
12 judgment, blame, or other negative attitudes towards the person with T2DM were remembered by
13 many participants, sometimes years later. Participants described not returning for a repeat
14 consultation as a direct result of these interactions.
15

16
17 Consistent with previous research[29-31], perceiving and experiencing diabetes-related stigma had
18 both behavioural and psychological consequences. Participants described an unwillingness to
19 disclose their T2DM to others, which has potentially dangerous ramifications for medical
20 emergencies. An unwillingness to disclose also raises the possibility that essential self-care will be
21 compromised (e.g. skipping or delaying medications / insulin, not checking blood glucose levels,
22 succumbing to social pressure to eat unhealthy foods) or undertaken in unhygienic environments
23 (e.g. public toilets) to avoid being noticed.
24
25

26
27 People also described strong feelings of low self-worth and self-esteem, shame and guilt in response
28 to the perceived or experienced stigma. Previous research has demonstrated the associations
29 between emotional distress and sub-optimal self-management, and ultimately, poorer physical
30 health outcomes[5 32-34]. Therefore the potential consequences of stigma are perhaps even more
31 far-reaching than described by our study participants.
32

33 **Implications for a proposed framework of diabetes-related stigma**

34
35 The findings from this study lend support to our proposed model of diabetes-related stigma[20].
36 Consistent with our model, people with T2DM identified individuals in their lives, including
37 healthcare professionals, as sources of stigma. However, our proposed model did not capture the
38 role of the media in driving and reinforcing diabetes-related stigma, which was a key concern for
39 participants in this study, raised both spontaneously and in response to direct questioning. In Figure
40 1, we propose a revised model of diabetes-related stigma to include this important issue. While self-
41 blame and blame by others was a key theme identified in the current study and a driving mechanism
42 of stigma described in our model, other mechanisms included in our model were less evident (e.g.
43 fear, disgust).
44
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46
47 The examples and evidence of stigma identified in this study are also consistent with those proposed
48 in the model (e.g. stereotyping, discrimination/restrictions, being judged), as are some of the
49 psychological and behavioural consequences of stigma. On the whole, the proposed model
50 continues to provide a useful 'road map' for diabetes-related stigma research, though some minor
51 modifications (e.g. including media as a source of stigma) are warranted in light of the current
52 study's findings.
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54

55 ----- Figure 1 -----
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Implications and future directions

Our findings indicate that not only is obesity-related stigma likely to be a barrier to diabetes management in a healthcare setting[35], but that diabetes-specific stigma may be an additional barrier. This was illustrated by the fact that much of what was discussed by participants was specific to having T2DM, and not only about being overweight or obese. Given that the obesity and diabetes stigmas are not one and the same, further research into diabetes-related stigma is required, and we cannot solely rely on the obesity stigma literature to inform future work in diabetes. Considerable research has already been undertaken with regard to understanding, combating, or minimising the impact of the obesity stigma in healthcare or health education settings[35-38]. Similar work is now needed in diabetes, with a view to conducting research that examines correlates and outcomes of diabetes-related stigma for the person living with the condition, using findings to inform anti-stigma interventions in healthcare settings, and influencing the way T2DM is portrayed in the media. We have previously commented on the unintended negative consequences of a sole emphasis on the role of individual responsibility with regards to obesity and associated conditions such as T2DM [10]. In any anti-stigma intervention, attention will need to be paid to the subtle distinction between empowerment to take personal responsibility for diabetes self-care, and blaming the individual for causing their own health problems.

Interventions for people with T2DM that focus on enhancing coping and resilience in the face of stigmatising attitudes and practices may be beneficial in terms of improving psychological outcomes and minimising barriers to optimal self-care. At a minimum, healthcare professionals need to consider stigmatisation as a possible issue that is causing distress that needs to be addressed.

Participants in this study did not perceive that people with T1DM were subject to stigmatising attitudes and practices but that does not mean that people with T1DM do not perceived it to be a stigmatised condition. Research is needed to explore the social experiences of people with T1DM to enable comparison with the experiences reported by people with T2DM.

Limitations

As with all qualitative studies, the emphasis is on in-depth exploration of an issue or experience. Consequently, small sample sizes must be used, which may limit the representativeness of the findings. Care was taken to recruit a diverse sample and this was largely achieved (in terms of ...) but people with a tertiary education were over-represented in the sample, and all were members of Diabetes Australia – Vic, the state's consumer organisation. These people may be more engaged in their diabetes care and in diabetes issues than the general population. Participants' ethnicity was not recorded, and therefore the ethnic diversity of the sample cannot be assured. However, this study has enabled the identification of issues to inform the design of a novel measure of diabetes-related social stigma, so that large-scale, representative quantitative studies can be undertaken.

Conclusions

This study is the first to examine in depth the perceptions and experiences of social stigma of adults living with T2DM. These findings indicate that stigmatisation is an issue of substantial concern for people with T2DM, and has harmful consequences. Future research needs to focus on how to dispel stigmatising attitudes and practices, particularly in healthcare settings, and how to minimise the impact of diabetes-related stigma by enhancing coping amongst people with T2DM.

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For peer review only

Tables and figures

Table 1. Demographic and clinical characteristics of participants (N=25)

<i>Sample characteristics</i>	median (IQR) or n (%)
<i>Age: years</i>	61 (15.00)
<i>Diabetes duration: years</i>	5 (7.25)
<i>Gender: women</i>	12 (48)
<i>Primary treatment</i>	
Insulin injections	5 (20)
OHAs	14 (56)
Lifestyle	6 (24)
<i>Highest qualification</i>	
School or intermediate certificate	1 (4)
High school or leaving certificate	2 (8)
Trade / apprenticeship	2 (8)
Certificate / diploma	4 (16)
Bachelor's degree or higher	16 (64)
<i>Employment</i>	
Full time work	6 (24)
Part time work	7 (28)
Retired/Not working	12 (48)
<i>Living in metropolitan region</i>	19 (76)
<i>English language</i>	25 (100)

IQR: interquartile range

Table 2. Themes and subthemes, and demonstration of data saturation

ID	Evidence of stigma			Sources of stigma			Consequences of stigma		Comparisons with type 1
	Blame and shame	Negative stereotyping	Discrimination / restricted opportunities	Media	Healthcare professionals	Family / friends / colleagues	Unwillingness to disclose	Emotional distress	
1		✓							
2		✓							
3	✓	✓	✓	✓		✓	✓		✓
4	✓	✓				✓			✓
5	✓	✓		✓		✓	✓		✓
7	✓	✓	✓	✓					✓
8	✓	✓	✓			✓		✓	
9	✓	✓		✓					
10	✓	✓	✓						✓
11	✓	✓		✓	✓	✓	✓	✓	✓
12	✓	✓	✓	✓		✓			✓
13		✓		✓					✓
14	✓	✓		✓		✓	✓		✓
15	✓	✓	✓	✓		✓		✓	✓

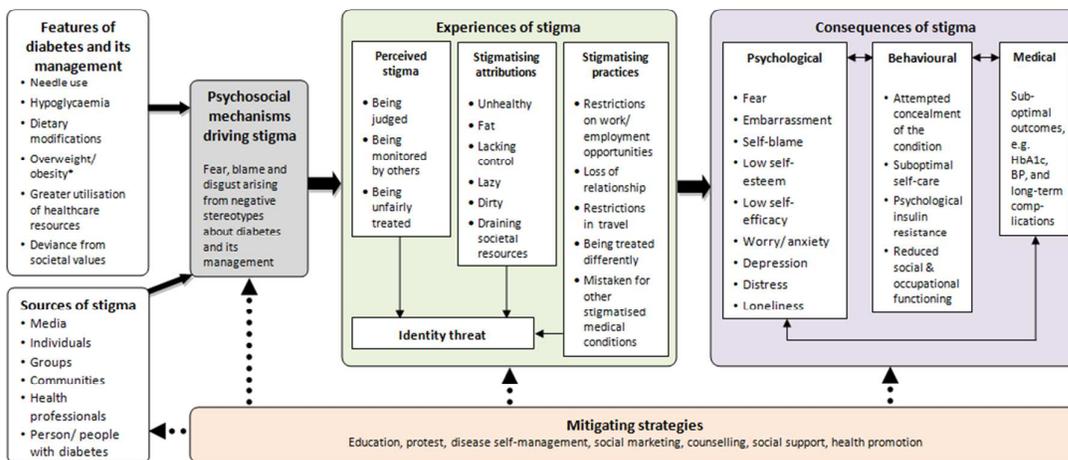
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16	✓	✓	✓	✓	✓	✓	✓	✓	✓
17	✓	✓		✓					
18		✓		✓					
19	✓	✓	✓	✓		✓	✓	✓	✓
20	✓	✓	✓	✓			✓	✓	✓
21	✓	✓				✓		✓	
22	✓	✓		✓	✓			✓	✓
23	✓	✓		✓		✓	✓	✓	✓
24	✓	✓	✓	✓	✓		✓	✓	
25	✓	✓	✓			✓	✓	✓	
26		✓							

NB: Participant 6 was excluded from the analysis.

For peer review only

Figure 1. A revised framework for understand diabetes-related stigma



* Type 2 diabetes only

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JS, JB and KM conceptualised the study. All authors contributed to the development of the interview schedule. AV, JB and JS conducted the participant interviews. AV checked the transcripts against the audio files, and AV and JB developed the coding framework (in consultation with JS and KM) and conducted the data analysis. JB prepared the first draft of this manuscript. All authors provided feedback and contributed to subsequent revisions of the manuscript. All authors approved the final version of this manuscript. We thank Diabetes Australia – Vic, particularly the membership team, for their assistance with recruitment for this study. We also thank all the people with diabetes who expressed an interest or took part in this study.

Declaration of competing interests

None declared.

Data sharing

The unpublished data are not publically available.

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“I call it the blame and shame disease”: A qualitative study about perceptions of social stigma surrounding type 2 diabetes

14 Jessica L. Browne PhD^{1,2}, Adriana Ventura BA GDipPsych^{1,3}, Kylie Mosely PhD⁴, &
15 Jane Speight PhD^{1,2,5}

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Abstract

Objectives: While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes. The aim of the current study was to explore the social experiences of Australian adults living with type 2 diabetes (T2DM), conduct an exploratory, in-depth interview study of the social experiences of Australian adults living with type 2 diabetes (T2DM), with a particular focus on the perception and experience of diabetes-related stigma.

Design: A qualitative study using semi-structured interviews, which were audio-recorded, transcribed, and subject to thematic analysis.

Setting: This study was conducted in the Australian state of Victoria in non-clinical settings in metropolitan and regional areas in the Australian state of Victoria. Participants were recruited primarily through the state consumer organisation representing people with diabetes.

Participants: All adults aged ≥ 18 years with T2DM living in Victoria were eligible to take part. Participants were recruited primarily through the state consumer organisation representing people with diabetes. Twenty-five participants were recruited primarily through the state consumer organisation representing people with diabetes. Twenty-five adults with T2DM participated (12 women; median age $= 61.59 \pm 14$ years; median diabetes duration $= 5.7 \pm 7$ years).

Results: A total of 21 (84%) participants indicated that they believed T2DM was stigmatised, or reported evidence of stigmatisation. This was evident in Specific themes included feeling blamed by others for causing their own condition, being subject to negative stereotyping, being discriminated against or having restricted opportunities in life. Other themes focused on the sources of stigma, which included the media, healthcare professionals, friends, family and colleagues were all identified as sources of stigmatising attitudes and practices. The themes around relating to the consequences of this stigma were also evident, which included participants' unwillingness to disclose their condition to others, and psychological distress. Participants believed that people with type 1 diabetes do not experience similar stigmatisation.

Conclusions: It is evident that Our study found evidence of people with T2DM experience experiencing or and perceiving diabetes-related social stigma. Further research is needed to explore ways to measure and minimise diabetes-related stigma at both individual and societal levels, and also to examine explore these the perceptions and experiences of stigma issues in people with type 1 diabetes, and explore ways to measure and minimise diabetes-related stigma at both individual and societal levels.

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Article Summary

Article focus

- While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes.
- The aim of the current study was to [explore the social experiences of Australian adults living with type 2 diabetes \(T2DM\)](#), ~~conduct an exploratory, in-depth interview study of the social experiences of Australian adults living with type 2 diabetes (T2DM)~~, with a particular focus on the perception and experience of diabetes-related stigma. [This was ~~done~~ achieved through by conducting in-depth semi-structured interviews.](#)

Key messages

- People with T2DM experience stigmatising practices and attitudes, such as being blamed for their condition, being subject to negative stereotyping, and being discriminated against. Sources of stigma include the media, healthcare professionals, friends, family and work colleagues.
- Consequences of stigma reported by participants include becoming unwilling to disclose their condition, and experiencing psychological distress.
- Further research is needed to examine these issues in people with type 1 diabetes, and explore ways to measure and minimise diabetes-related stigma at both individual and societal levels.

Strengths and limitations

- This qualitative study is the first to describe, in detail, the perceptions and experiences of diabetes-related stigma from the perspective of adults with T2DM.
- While the small sample size may limit the representativeness of the findings, efforts were made to include a broad cross-section of adults with T2DM and data saturation was achieved.
- All participants were members of the state organization representing people with diabetes and most were tertiary educated. These people may be more engaged in their diabetes care and in diabetes issues than the general population.

Introduction

Type 2 diabetes (T2DM) affects more than 220 million worldwide and is increasing in prevalence[1]. [More than 1.1 million Australians have diabetes, with most of these having T2DM](#)[2]. Its physical impact is well-documented, with diabetes management and complications having substantial implications for individual and societal health, psychological well-being and quality of life, as well as for the global economy[3-7]. In the past decade, landmark studies have demonstrated that T2DM can be prevented[8 9], highlighting the role of behaviour and personal responsibility in the development of the condition. As the increasing prevalence of T2DM has achieved prominence in the media, and in the consciousness of the general public, ~~so~~ perceptions of T2DM appear to be changing, with anecdotal evidence of social stigma and discrimination ~~now~~ apparent (e.g. [observations of public comments posted online in response to about articles in the media](#)[10]). While the fact that the person has T2DM may not be immediately evident, certain risk factors (e.g. obesity) and the need for daily self-management (e.g. medication-taking, checking blood glucose, modifying diet, injecting insulin) may be conspicuous to others and lead to undesirable consequences such as stigmatisation. Health-related social stigma is a negative 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[11 12]. Stigma has been extensively researched in other conditions such as obesity[13-16] and HIV/AIDS[17-19], but has yet to be the focus of a systematic program of research in diabetes.

Our recent review[20] highlighted the lack of research about stigma in diabetes, but did find some evidence that people with type 1 diabetes (T1DM) and T2DM perceive and experience diabetes-related stigma, and that this stigma has negative consequences across many aspects of their life. We proposed a framework for understanding diabetes-related stigma that hypothesised the features of diabetes and its management that may be the focus of this phenomenon, the sources and psychological mechanisms driving it, and the possible experiences and consequences of stigma[20].

A necessary starting point for building on the findings of this review and commencing a research program in this area is to conduct an in-depth exploration of the perceptions and experiences of diabetes-related stigma from the perspective of the person living with the condition[21]. This will provide a comprehensive understanding of perceived diabetes-related stigma to inform quantitative surveys of people with and without diabetes, and lead to the development, evaluation and implementation of intervention strategies to reduce stigma. We conducted an interview study with the aim of exploring the social experiences of Australian adults living with T2DM, with a particular (but concealed) focus on the perception and experience of diabetes-related stigma.

Methods

Participants and Recruitment

Adults aged ≥ 18 years with T2DM who spoke English and who lived in the Australian state of Victoria were eligible to take part in this interview study. Participants were recruited into this study primarily from the membership list of Diabetes Australia – Vic (DA – Vic; peak consumer body representing people affected by diabetes in Victoria, Australia). The study was also advertised state-wide in diabetes-related media and social media. The study was advertised as an investigation of “the social

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7 experience of living with type 2 diabetes". Study advertisements purposefully did not refer to
8 "stigma" in order to minimise the risk of inadvertently attracting only participants with extreme
9 negative experiences (which would have resulted in unrepresentative data), and to avoid biasing
10 participants' interview responses.

11
12 A total of 147 people enquired about the study by telephone or email: 108 were emailed or posted
13 study information sheets; 39 made contact only after recruitment had closed. Purposive selection
14 was used to ensure the sample reflected a wide range of ages, a gender balance, and a combination
15 of people from metropolitan and regional areas of the state. We aimed to recruit 20 people into the
16 study, with the possibility of conducting additional interviews if necessary to achieve data
17 saturation. Data saturation was achieved at participant #11 (see Table 2)2, though purposive
18 recruitment continued to ensure a sufficiently varied sample. Ultimately, 26 people were recruited
19 and took part in interviews. One participant (#6) was subsequently excluded on the basis that he had
20 not received a diagnosis of T2DM (which became evident during the interview), and because he
21 presented with cognitive impairment. One participant (#20) made it known to the research team
22 after the study had been completed that her diagnosis had been revised to T1DM, though it was
23 clear that her presentation was atypical. However, we decided to retain her data in this study as, at
24 the time of participation, she had a diagnosis of T2DM and she believed that she had this condition,
25 and so her social experiences of living with the condition were as real as those of the other
26 participants. Thus, this paper reports on data from 25 interviews.

28 Interview schedule and procedure

29 Informed by our literature review[20], we developed a semi-structured interview schedule to elicit
30 participant narratives of perceived or experienced diabetes-related stigma. Indirect questioning (i.e.
31 not explicitly referring to 'stigma') invited participants to discuss their own social experience in a
32 range of contexts, including healthcare settings, the workplace, their social and/or family
33 environments, and in the media. Interviewers did not use the word 'stigma' until either the
34 participant had used it spontaneously, or until the last question to address this concept directly. This
35 approach was used so as to avoid confusing participants with jargon, and to avoid introducing bias in
36 the questioning, thus maximising opportunities for participants to discuss both their positive and
37 negative social experiences.

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39 All interviews were conducted between May and July 2012 in non-clinical settings by interviewers
40 with a background in health psychology (JB, AV, and JS). A selection of interviews (four) were
41 conducted by one interviewer and observed by another for the purposes of enabling reflective
42 discussions about the interviews, and the role and influence of the interviewer in each one, and
43 identification of any potential bias or stereotypes about T2DM that the interviewer may hold.
44 Interviewers also wrote notes and reflections immediately after every interview. All interviews were
45 audio-recorded and lasted an average of 55 minutes (range: 25 – 103 minutes). At the conclusion of
46 the interview, participants completed a short questionnaire to provide demographic and clinical
47 information. A participant ID was used to distinguish audio files and questionnaires. All participants
48 received a \$AU20 department store gift voucher as a token of appreciation for participating.
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Transcription and analysis

All audio recordings were transcribed verbatim by a professional transcription service. The research team checked each transcript against the recording for accuracy. The de-identified transcripts were imported into NVivo 10 to facilitate data coding, retrieval and analysis.

A thematic analysis using an inductive (data driven) approach was used to examine the data[22].

Two researchers (JB and AV, both with postgraduate qualifications in health psychology) read and re-read the transcripts to develop two initial coding frameworks, which were then compared across coders, and reviewed by the full research-authorship team. Following revision, an integrated framework was developed and piloted (by JB and AV) by independently coding a random selection of four transcripts. Final modifications were made to improve utility and comprehensibility. Using the final coding framework, JB and AV then coded two transcripts collaboratively to ensure agreement on coding rules, and then coded five additional transcripts independently. Inter-coder agreement for each code was determined by summing the percentage of content in each code identified by both coders and the percentage of content in each code identified by neither coder. A mean agreement rating (averaging agreement ratings across codes) of 99.5% was achieved for these five transcripts, indicating a high level of consistency in coding decisions. Minor discrepancies (e.g. where one coder AV had coded data into code A and B, whereas another coder JB had coded only into code A) were resolved through discussion, raising the agreement level to 100%. AV then coded the remaining 17 transcripts independently.

The content of each code was then examined by all authors to determine whether some codes could be subsumed by others due to overlapping content, and to explore relationships between codes. For the purposes of this analysis, we coded according to the key topics described below. Participant quotes are provided to illustrate our findings.

This study received ethics approval from the Deakin University Human Research Ethics Committee (2012-072).

Results

Sample characteristics

Of the final sample of 25 participants, 12 (48%) were women. The mean median age ± standard deviation age was 59±14.61 years (range = 22-79 years; interquartile range = 15.00), and T2DM duration was 5.7±7 years (range = 0-29 years; interquartile range = 7.25). These characteristics are representative of Australian adults with T2DM as documented in a large-scale national survey[23]. Further sample characteristics are displayed in Table 1.

---- ~~insert~~ Table 1 ~~here~~ ----

Perceptions of social stigma

When asked explicitly, 15 participants (60%) indicated they believed there was social stigma surrounding T2DM. Some gave specific examples of personally experiencing or feeling the effects of diabetes-related stigma, while others described it as something they perceived in society generally

or that others with T2DM experienced. A few indicated that they did not experience stigma themselves but believed that others with T2DM did. One woman described the personal experience of stigma as follows:

"I think the stigma is that it's a lifestyle disease, that somehow you've been lazy and you've allowed this to happen to yourself. I think to me that must come through very strongly, that's the judgment that I think that is made." (#19; woman, 54yrs)

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Ten (40%) participants believed there was no stigma surrounding T2DM but six of these had already described evidence of diabetes-related stigma throughout the interview. Four indicated that they firmly believed there was no stigma and that they were surprised that this was a topic of interest, as they had never experienced it nor considered it to be an issue. Interestingly, these four were some of the oldest participants in the study (aged 67-73).

"I don't believe there would be any stigma at all to having type 2 diabetes. I just can't imagine how it would arise" (#13; man, 69yrs)

Two people felt that while obesity was stigmatised, T2DM was not, and any stigma people with T2DM experienced was due to their weight alone.

"Their appearance might be fat, they might look unhealthy and, when they're applying for jobs or trying to interact socially that might be the main reason they've got a stigma rather than the diabetes." (#1, man, 67yrs)

In contrast, others raised the issue of diabetes-related stigma unprompted during the initial stages of the interview. For example, when asked the first question about what it was like to be diagnosed with T2DM, one woman responded:

"I thought then, and I still think now, that there is still somehow a feeling of stigma attached to getting type 2 diabetes because you feel it's your fault and you did it to yourself, so initially I was very upset." (#5, woman, 59yrs)

~~Evidence of diabetes-related stigma was reflected in participants' accounts of blame and shame, being associated with negative stereotypes, discrimination and restriction of opportunities. The media, healthcare professionals, family, and friends were identified as sources of stigma and stigmatising practices. Many participants compared their own experiences unfavourably with those who have type 1 diabetes. Each of the key themes and sub-themes are explored in more detail below, and the structure of these key themes is summarised and sub-themes are identified in Table 2, with indications of which participants discussed which themes and explored in more detail below. Evidence of diabetes-related stigma was reflected in participants' accounts of blame and shame, being associated with negative stereotypes, discrimination and restriction of opportunities. The media, healthcare professionals, family, and friends were identified as sources of stigma and stigmatising practices. Many participants compared their own experiences unfavourably with those who have type 1 diabetes.~~

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----Table 2----

Evidence of diabetes-related stigma

Blame and shame

The concepts of blame and shame were highly salient. Participants described feeling judged and blamed by others for bringing T2DM on themselves through over-eating, poor dietary habits, being inactive, or being overweight. There was a sense that this reflected negatively on their personal character.

"There's this message that diabetes is this terrible thing that terrible people get because they do terrible things" (#11, woman, 61yrs)

Whilst perceptions of blame were described by most a general perception of society's views, some described specific instances of their direct experiences of this blame, for example:

"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, 67yrs)

Self-blame and feeling guilty for having developed T2DM was common, though it was unclear whether this was the result of internalising perceived societal attitudes, or whether self-blame influenced the perception of attitudes. Some participants, who had a strong family history of T2DM, some of whom reported a healthy lifestyle and were not visibly overweight, still had a strong sense that there was something they should have done to avoid developing the condition.

"I felt guilty in the early days for the first, probably 10 to 15 years, I felt guilty because it was my fault." (#14, woman, 59yrs)

Negative stereotyping

Every participant spoke of the negative stereotypes being that are associated with T2DM. Some of the most common negative stereotypes that were used or described were ~~There was a strong sense that evidence to suggest that people with T2DM were subjected to negative stereotyping, such as "fat", "obese", "overweight", "big fat pig", "lazy", "slothful", "shocking person", "couch potato", "over-eater", and "glutton".~~ Once again, ~~these there was a strong sense that the~~ stereotypes reflected the idea that "you brought it on yourself". Less frequently reported were stereotypes of people with T2DM being "poor people", "not terribly intelligent", as well as being a "bad person" and "injecting insulin". Responses to these stereotypes were mixed. Some people expressed concern, frustration or unease about being automatically labeled in this way, while others endorsed the stereotypes themselves.

~~*"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, 60yrs)*~~

~~*"It can be frustrating because you know damn well it's [the stereotype] not necessarily the case." (#18, woman, 42yrs)*~~

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Discrimination and restricted opportunities

While very few examples of discrimination were reported, there were a few notable cases. For instance, one woman (who stated a strong desire to have a child) described restrictions against people with diabetes who want to become adoptive parents:

"I looked up the adoption [criteria]...a couple of the countries said 'no type 1 or type 2 diabetes'...I suppose if adoption agencies are saying no diabetes then that's not going to happen." (#16, woman, 35yrs)

~~While no one described personal experience of workplace discrimination due to T2DM, people were concerned about the issue. They admitted a general reluctance to disclose the condition during a job interview or application for fear of discrimination in the selection process. In contrast, most were not concerned about disclosing their T2DM once in the workplace.~~

The concept of discrimination was perhaps most prominent when discussed in the context of the whole diabetes community, with perceptions that people with T1DM receive more empathy, opportunities and support than people with T2DM:

"But they're [people with type 1 diabetes] generally quite looked after. They have access to pumps, they have heaps of support groups out there and workshops ...if I tried to get into the same type of thing because I'm on insulin they say "no, because you're type 2" so they automatically exclude you just because of your diagnosis and not because of the way you're managing your diabetes. So that segregates the diabetes community as a whole." (#20, woman, 22yrs)

More prominent than discrimination per se was a sense of restricted or lost opportunities in life as a result of having T2DM. Limitations in travel or career prospects, and lapsed friendships with people who were unsupportive were described as examples of the negative impact T2DM has on life opportunities. For example, one woman described how T2DM had affected her pursuit of career advancement:

~~*"I guess it did sort of stop me from pushing myself as much as I usually do, so I did leave the position at a time when I was really enjoying it and was hoping to better myself in that position. It did kind of slow down my drive to better myself in that job. I didn't leave purely because I was unwell but I wanted to seek a healthier lifestyle" (#23, woman, 37yrs)*~~

Sources of stigma

Media

While some participants could not recall any specific media stories or campaigns about T2DM, those that could held one of two key views. The first view was that the emphasis on T2DM being a lifestyle disease, and therefore within an individual's control, was a helpful and socially responsible preventative health message.

"I think it's great the emphasis they have at the moment talking about your lifestyle and your diet, exercise and that sort of thing. I think it's very, very good" (#2, man, 73yrs)

The second view was that the emphasis on lifestyle factors (such as being overweight or physically inactive) as causal in T2DM served to generate or reinforce blaming attitudes in the community, perpetuate negative stereotypes, and elicit negative emotional reactions from people with T2DM.

"I don't want people to think I developed this disease because I was some big fat that never got off her chair... I was active, exercised, worked, everything...it doesn't have to be from your lifestyle but I think most, well that's how they portray it in the media...they show all the time 'there's this diabetics epidemic' and all you see is fat people, not their heads, these big bums and tummies and all that and you think 'do people think I was like that, that I looked like that?'" (#15, woman, 60yrs)

Those who firmly believed there was a stigma surrounding T2DM were more likely to critique the media's approach to T2DM in this way. Participants who held this view also described sensationalism in the media around the T2DM epidemic, and expressed dissatisfaction with the "scare tactics" often used in public health campaigns. They wanted more positive messages about living with diabetes to be incorporated into the media.

"There's no good news stories about type 2 diabetes. Perhaps there should be. Perhaps it should be 'it isn't necessarily a death sentence'." (#3, man, 54yrs)

Healthcare professionals

Most participants described a combination of both positive / helpful and negative / discouraging interactions with healthcare professionals. ~~Many~~ Some participants reported stigmatising practices and attitudes among healthcare professionals, who were seen to focus on what was being done 'wrong' (e.g. failure to lose weight or reduce HbA1c since the last consultation) rather than finding ways to encourage behaviour change efforts. This was experienced as discouraging and judgmental:

"The dietician was awful... she asked me if I exercise and I said 'I do the gym twice a week and I have consistently since November' 'that's not enough, you need to go five times a week'...this makes me really angry" (#16, woman, 35yrs)

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These negative experiences with healthcare professionals led to changing providers, seeking advice from other sources (e.g. friends, the internet), and avoidance of consultations with healthcare professionals.

Family, friends, colleagues

While, in general, participants reported that they had supportive families, friends and workplaces (where relevant), most described at least one example of unhelpful, annoying or discouraging behaviour from their families or peers. This behaviour was described as being hurtful, judgmental, and interfering, particularly regarding dietary choices and weight management.

"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, 59yrs)

Consequences of stigma

Unwillingness to disclose condition

Many participants were not concerned about other people knowing they had T2DM. This was particularly true of older participants, perhaps because, as one man commented, living with diabetes was a relatively common experience amongst their peers:

"It's a non-issue really...most of my colleagues are of the same age as I am and many of them have relatives or spouses or people who are diabetic" (#12, man, 67yrs).

Reasons for disclosure included helping other people understand more about diabetes, explaining self-management behaviour or dietary choices in public, seeking support, and for safety in case of a medical emergency.

Participants tended to describe specific times in their diabetes journey, or specific people or circumstances, that made them reluctant to disclose their condition. Common examples included the period soon after diagnosis, a particular family member or friend they anticipated would respond unhelpfully, or during a job interview or in the workplace, for example:

"I think the problem was more in corporate life...I was in a very senior role and I felt the need to hide it from that particular situation." (#24, woman, 68yrs).

The key reasons for non-disclosure were fear of being judged or blamed for having T2DM or an overwhelming sense of self-blame. Some also described a fear of being discriminated against or a desire to distance oneself from society's negative portrayals of people with diabetes.

"When I first got it I wouldn't tell anybody. I didn't even tell my husband. I told nobody. I actually felt so ashamed to have diabetes. I felt completely ashamed of myself." (#19, woman, 54yrs)

"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 [patient organisation] are shutting them up because they're hurt and are mortified." (#22, man, 56yrs)

Other reasons included not wanting to deal with people's misconceptions about the condition (particularly around the dietary management), and not wanting to answer lots of questions about diabetes, worry or shock people, or attract sympathy.

However, many participants were not concerned about other people knowing they had T2DM. This was particularly true of older participants, perhaps because, as one man commented, living with diabetes was a relatively common experience amongst their peers:

"It's a non-issue really...most of my colleagues are of the same age as I am and many of them have relatives or spouses or people who are diabetic" (#12, man, 67yrs).

Reasons for disclosure included helping other people understand more about diabetes, explaining self-management behaviour or dietary choices in public, seeking support, and for safety in case of a medical emergency.

Psychological distress

The psychological consequences of stigma included emotional distress such as shame, guilt, regret, and hopelessness. Other psychological consequences that were frequently noted included feelings of low self-worth and self-confidence. Some participants felt that having T2DM reflected poorly on their personal character. ~~Women were more likely to report feeling this way than men.~~ The psychological distress experienced made it even harder to cope with and adjust to life with T2DM.

"I felt a little bit inferior" (#14, woman, 59yrs)

"I call it the 'blame and shame disease' because I think that people get blamed and shamed and I think that makes it worse...they feel hopeless...it's just another layer." (#11, woman, 61yrs)

Comparisons with type 1 diabetes

There was a distinct feeling among participants that social stigma was specific to T2DM, and that those with T1DM were not judged so harshly. The main reason suggested for this was that those with T1DM were not perceived to be at fault, or to have done anything to cause their condition. Other reasons included that T1DM is perceived to be a more serious condition than T2DM, and because T1DM is often associated with a diagnosis in childhood. One man identified the difference as:

"Type 1 is 'you poor thing', type 2 is 'you stupid thing'" (#4, man, 57yrs)

Discussion

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. Based on commonly-used definitions of health-related stigma, we defined diabetes-related stigma to be an adverse social judgement based on a feature of diabetes or its management that may lead to perceived or experienced exclusion, rejection, blame, stereotyping and / or status loss[11 12]. Our findings indicate that stigmatising attitudes and practices, consistent with this definition, are part of the social experience of living with T2DM.

Evidence of type 2 diabetes-related stigma

All ~~bar four~~ participants bar four either explicitly identified a social stigma surrounding T2DM, or described evidence of this stigma. Those who did not were some of the oldest participants in the study, suggesting that perhaps younger people with T2DM are more likely to experience, or be sensitive to, diabetes-related stigma. ~~Younger adults with T2DM face many pressures unique to their age group and, perceivee that existing T2DM services are not relevant to them~~[24]. ~~These factors may contribute to the more pronounced stigma experienced by younger participants.~~ Examples of this stigma given by participants included blaming and shaming attitudes towards those with T2DM (including self-blame), negative stereotyping, discrimination and lost opportunities as a result of having T2DM. While the well-recognised obesity stigma[25-27] was seen to play some part in diabetes-related stigma, the latter cannot be wholly explained by the former.

While study participants reserved their most scathing criticism for the media, the people with whom participants had personal relationships were also described as contributing to the diabetes-related

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7 stigma. Consistent with previous research in obesity[27 28], this was particularly evident with
8 regards to interactions with healthcare professionals. Comments or behaviour that revealed
9 judgment, blame, or other negative attitudes towards the person with T2DM were remembered by
10 many participants, sometimes years later. Participants described not returning for a repeat
11 consultation as a direct result of these interactions.

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13 Consistent with previous research[29-31], perceiving and experiencing diabetes-related stigma had
14 both behavioural and psychological consequences. Participants described an unwillingness to
15 disclose their T2DM to others, which has potentially dangerous ramifications for medical
16 emergencies. ~~Also of concern is~~An unwillingness to disclose also raises the possibility that essential
17 self-care will be compromised (e.g. skipping or delaying medications / insulin, not checking blood
18 glucose levels, succumbing to social pressure to eat unhealthy foods) or undertaken in unhygienic
19 environments (e.g. public toilets) to avoid being noticed.

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21 People also described strong feelings of low self-worth and self-esteem, shame and guilt in response
22 to the perceived or experienced stigma. Previous research has demonstrated the associations
23 between emotional distress and sub-optimal self-management, and ultimately, poorer physical
24 health outcomes[5 32-34]. Therefore the potential consequences of stigma are perhaps even more
25 far-reaching than described by our study participants.

26 27 Implications for a proposed framework of diabetes-related stigma

28 The findings from this study lend support to our proposed model of diabetes-related stigma[20].
29 Consistent with our model, people with T2DM identified individuals in their lives, including
30 healthcare professionals, as sources of stigma. However, our proposed model did not capture the
31 role of the media in driving and reinforcing the diabetes-related stigma, which was a key concern for
32 participants in this study, raised both spontaneously and in response to direct questioning. In Figure
33 1, ~~we propose a revised model of diabetes-related stigma in light of~~to include this important issue,
34 ~~which is presented in Figure 1.~~ While self-blame and blame by others was a key theme identified in
35 the current study and a driving mechanism of stigma described in our model, other mechanisms
36 included in our model were less evident (e.g. fear, disgust).

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38 The examples and evidence of stigma identified in this study are also consistent with those proposed
39 in the model (e.g. stereotyping, discrimination/restrictions, being judged), as are some of the
40 psychological and behavioural consequences of stigma. On the whole, the proposed model
41 continues to provide a useful 'road map' for diabetes-related stigma research, though some minor
42 modifications (e.g. including media as a source of stigma) are warranted in light of the current
43 study's findings.
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47 48 49 Implications and future directions

50 Our findings indicate that not only is obesity-related stigma likely to be a barrier to diabetes
51 management in a healthcare setting[35], but that diabetes-specific stigma may be an additional
52 barrier. This was illustrated by the fact that much of what was discussed by participants was specific
53 to having T2DM, and not only about being overweight or obese. Given that the obesity and diabetes
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stigmata ~~seem to be somewhat distinct~~ are not one and the same, further research ~~in the area of~~ into diabetes-related stigma is required, ~~and we cannot solely rely on the obesity stigma literature to inform future work in the area of diabetes~~. Considerable research has already been undertaken with regard to understanding, combating, or minimising the impact of the obesity stigma in healthcare or health education settings[35-38]. Similar work ~~must now be undertaken with reference to~~ is now needed in diabetes-related stigma, with a view to ~~conducting research that examines correlates and outcomes of diabetes-related stigma for the person living with the condition, using findings to inform healthcare settings being a potential target for~~ anti-stigma interventions in healthcare settings, and influencing the way T2DM is portrayed in the media. ~~We have previously commented on the unintended negative consequences of a sole emphasis on the role of individual responsibility with regards to obesity and associated conditions such as T2DM [10]. In any anti-stigma intervention, attention will need to be paid to the subtle distinction between empowerment to take personal responsibility for diabetes self-care, and blaming the individual for causing their own health problems.~~

~~It is apparent from our findings that the perception or experience of diabetes-related stigma may lead to sub-optimal biomedical and psychological outcomes for people with T2DM.~~ Interventions for people with T2DM that focus on enhancing coping and resilience in the face of stigmatising attitudes and practices may be beneficial ~~in terms of improving psychological outcomes and minimising barriers to optimal self-care~~. At a minimum, healthcare professionals need to consider stigmatisation as a possible issue that is causing distress that needs to be addressed.

Participants in this study did not perceive that people with T1DM were subject to stigmatising attitudes and practices but that does not mean that people with T1DM do not perceived it to be a stigmatised condition. Research is needed to explore the social experiences of people with T1DM to enable comparison with the experiences reported by people with T2DM.

Limitations

As with all qualitative studies, the emphasis is on in-depth exploration of an issue or experience. Consequently, small sample sizes must be used, which may limit the representativeness of the findings. Care was taken to recruit a diverse sample and this was largely achieved (in terms of ...) but people with a tertiary education were over-represented in the sample, and all were members of Diabetes Australia – Vic, the state's consumer organisation. ~~Ethnicity of participants was not recorded, and therefore the ethnic diversity of the sample cannot be assured.~~ These people may be more engaged in their diabetes care and in diabetes issues than the general population. ~~Ethnicity of participants' ethnicity was not recorded, and therefore the ethnic diversity of the sample cannot be assured.~~ However, this study has enabled the identification of issues to inform the design of a novel measure of diabetes-related social stigma, so that large-scale, representative quantitative studies can be undertaken.

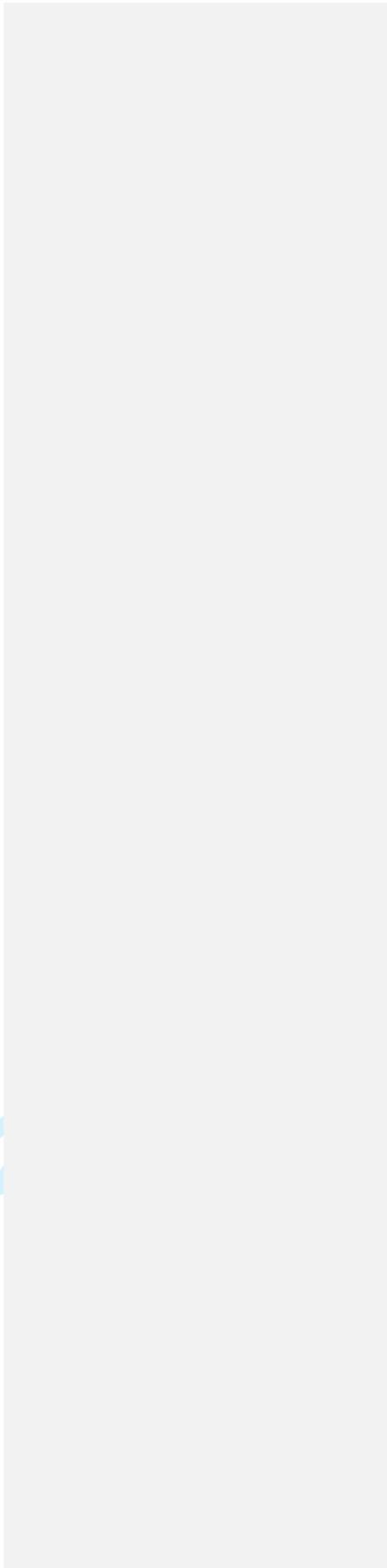
Conclusions

This study is the first to examine in depth the perceptions and experiences of social stigma of adults living with T2DM. These findings indicate that stigmatisation is an issue of substantial concern for people with T2DM, and has harmful consequences. Future research needs to focus on how to dispel stigmatising attitudes and practices, particularly in healthcare settings, and how to minimise the impact of diabetes-related stigma by enhancing coping amongst people with T2DM.

Comment [JS2]: Age, gender-split????

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Tables and figures

Table 1. Demographic and clinical characteristics of participants (N=25)

Sample characteristics	M ± SD median (range) or n (%)
Age: years	59 ± 14 (22-79) 61 (15.00)
Age at diagnosis	52 ± 14 (19-76)
Diabetes duration: years	7 ± 7 (0-29) 5 (7.25)
Gender: women	12 (48)
Primary treatment	
Insulin injections	5 (20)
OHAs	14 (56)
Lifestyle	6 (24)
Highest qualification	
School or intermediate certificate	1 (4)
High school or leaving certificate	2 (8)
Trade / apprenticeship	2 (8)
Certificate / diploma	4 (16)
Bachelor's degree or higher	16 (64)
Employment	
Full time work	6 (24)
Part time work	7 (28)
Retired/Not working	12 (48)
Living in metropolitan region	19 (76)
English language	25 (100)

IQR: standard deviation; interquartile range

Table 2. Summary of themes and sub-themes identified

Theme	Sub-themes
Evidence of stigma	Blame and shame Negative stereotyping Discrimination / restricted opportunities
Sources of stigma	Media Healthcare professionals

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	Family, friends, colleagues
Consequences of stigma	Unwillingness to disclose condition Emotional distress
Comparisons with type 1 diabetes	-

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Table 2. Themes and subthemes, and demonstration of data saturation

ID	Evidence of stigma			Sources of stigma			Consequences of stigma		Comparisons with type 1
	Blame and shame	Negative stereotyping	Discrimination / restricted opportunities	Media	Healthcare professionals	Family / friends / colleagues	Unwillingness to disclose	Emotional distress	
1		✓							
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3	✓	✓	✓	✓		✓	✓		✓
4	✓	✓				✓			✓
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10	✓	✓	✓						✓
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13		✓		✓					✓
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21	✓	✓				✓		✓	
22	✓	✓		✓	✓			✓	✓
23	✓	✓		✓		✓	✓	✓	✓
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25	✓	✓	✓			✓	✓	✓	
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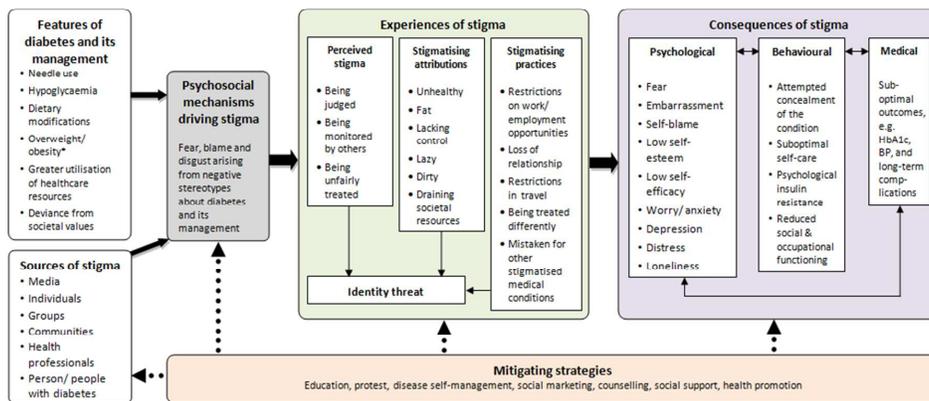
NB: Participant 6 was excluded from the analysis.

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Figure 1. A revised framework for understand diabetes-related stigma



* Type 2 diabetes only

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Funding Statement

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Author contributions and acknowledgements

JS, JB and KM conceptualised the study. All authors contributed to the development of the interview schedule. AV, JB and JS conducted the participant interviews. AV checked the transcripts against the audio files, and AV and JB developed the coding framework (in consultation with JS and KM) and conducted the data analysis. JB prepared the first draft of this manuscript. All authors provided feedback and contributed to subsequent revisions of the manuscript. All authors approved the final version of this manuscript. We thank Diabetes Australia – Vic, particularly the membership team, for their assistance with recruitment for this study. We also thank all the people with diabetes who expressed an interest or took part in this study.

Declaration of competing interests

None declared.

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“I call it the blame and shame disease”: A qualitative study about perceptions of social stigma surrounding type 2 diabetes

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Primary Subject Heading:	Diabetes and endocrinology
Secondary Subject Heading:	Mental health, Patient-centred medicine, Public health, Qualitative research
Keywords:	General diabetes < DIABETES & ENDOCRINOLOGY, SOCIAL MEDICINE, PUBLIC HEALTH

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“I call it the blame and shame disease”: A qualitative study about perceptions of social stigma surrounding type 2 diabetes

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Keywords: type 2 diabetes; social stigma; health-related stigma; discrimination; psychosocial; qualitative methods; interview study

Word count: 4,848

Tables / figures: 3

Abstract

Objectives: While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes. The aim of the current study was to explore the social experiences of Australian adults living with type 2 diabetes (T2DM), with a particular focus on the perception and experience of diabetes-related stigma.

Design: A qualitative study using semi-structured interviews, which were audio-recorded, transcribed, and subject to thematic analysis.

Setting: This study was conducted in non-clinical settings in metropolitan and regional areas in the Australian state of Victoria. Participants were recruited primarily through the state consumer organisation representing people with diabetes.

Participants: All adults aged ≥ 18 years with T2DM living in Victoria were eligible to take part. Twenty-five adults with T2DM participated (12 women; median age 61 years; median diabetes duration 5 years).

Results: A total of 21 (84%) participants indicated that they believed T2DM was stigmatised, or reported evidence of stigmatisation. Specific themes about the experience of stigma were feeling blamed by others for causing their own condition, being subject to negative stereotyping, being discriminated against or having restricted opportunities in life. Other themes focused on sources of stigma, which included the media, healthcare professionals, friends, family and colleagues. Themes relating to the consequences of this stigma were also evident, including participants' unwillingness to disclose their condition to others, and psychological distress. Participants believed that people with type 1 diabetes do not experience similar stigmatisation.

Conclusions: Our study found evidence of people with T2DM experiencing and perceiving diabetes-related social stigma. Further research is needed to explore ways to measure and minimise diabetes-related stigma at both individual and societal levels, and also to explore perceptions and experiences of stigma in people with type 1 diabetes.

Article Summary

Article focus

- While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes.
- The aim of the current study was to explore the social experiences of Australian adults living with type 2 diabetes (T2DM), with a particular focus on the perception and experience of diabetes-related stigma. This was achieved by conducting semi-structured interviews.

Key messages

- People with T2DM experience stigmatising practices and attitudes, such as being blamed for their condition, being subject to negative stereotyping, and being discriminated against. Sources of stigma include the media, healthcare professionals, friends, family and work colleagues.
- Consequences of stigma reported by participants include becoming unwilling to disclose their condition, and experiencing psychological distress.
- Further research is needed to examine these issues in people with type 1 diabetes, and explore ways to measure and minimise diabetes-related stigma at both individual and societal levels.

Strengths and limitations

- This qualitative study is the first to describe, in detail, the perceptions and experiences of diabetes-related stigma from the perspective of adults with T2DM.
- While the small sample size may limit the representativeness of the findings, efforts were made to include a broad cross-section of adults with T2DM and data saturation was achieved.
- All participants were members of the state organization representing people with diabetes and most were tertiary educated. These people may be more engaged in their diabetes care and in diabetes issues than the general population of adults with diabetes.

Introduction

Type 2 diabetes (T2DM) affects more than 220 million worldwide and is increasing in prevalence[1]. More than one million Australians have diabetes, with most of these having T2DM[2]. Its physical impact is well-documented, with diabetes management and complications having substantial implications for individual and societal health, psychological well-being and quality of life, as well as for the global economy[3-7]. In the past decade, landmark studies have demonstrated that T2DM can be prevented[8 9], highlighting the role of behaviour and personal responsibility in the development of the condition. As the increasing prevalence of T2DM has achieved prominence in the media, and in the consciousness of the general public, perceptions of T2DM appear to be changing, with anecdotal evidence of social stigma and discrimination apparent (e.g. public comments posted online in response to articles in the media[10]). While the fact that the person has T2DM may not be immediately evident, certain risk factors (e.g. obesity) and the need for daily self-management (e.g. medication-taking, checking blood glucose, modifying diet, injecting insulin) may be conspicuous to others and lead to undesirable consequences such as stigmatisation. Health-related social stigma is a negative 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[11 12]. Stigma has been extensively researched in other conditions such as obesity[13-16] and HIV/AIDS[17-19], but has yet to be the focus of a systematic program of research in diabetes.

Our recent review[20] highlighted the lack of research about stigma in diabetes, but did find some evidence that people with type 1 diabetes (T1DM) and T2DM perceive and experience diabetes-related stigma, and that this stigma has negative consequences across many aspects of their life. We proposed a framework (a revised version of which is illustrated in Figure 1) for understanding diabetes-related stigma that hypothesised the features of diabetes and its management that may be the focus of this phenomenon, the sources and psychological mechanisms driving it, and the possible experiences and consequences of stigma[20].

A necessary starting point for building on the findings of this review and commencing a research program in this area is to conduct an in-depth exploration of the perceptions and experiences of diabetes-related stigma from the perspective of the person living with the condition[21]. This will provide a comprehensive understanding of perceived diabetes-related stigma to inform quantitative surveys of people with and without diabetes, and lead to the development, evaluation and implementation of intervention strategies to reduce stigma. We conducted an interview study with the aim of exploring the social experiences of Australian adults living with T2DM, with a particular (but concealed) focus on the perception and experience of diabetes-related stigma.

Methods

Participants and Recruitment

Adults aged ≥ 18 years with T2DM who spoke English and who lived in the Australian state of Victoria were eligible to take part in this interview study. Participants were recruited into this study primarily from the membership list of Diabetes Australia – Vic (DA – Vic; peak consumer body and leading charity representing people affected by diabetes in Victoria, Australia). The study was also advertised state-wide in diabetes-related media and social media. The study was advertised as an investigation of “the social experience of living with type 2 diabetes”. Study advertisements

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3 purposefully did not refer to “stigma” in order to minimise the risk of inadvertently attracting only
4 participants with extreme negative experiences (which would have resulted in unrepresentative
5 data), and to avoid biasing participants’ interview responses.
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8 A total of 147 people enquired about the study by telephone or email: 108 were emailed or posted
9 study information sheets; 39 made contact only after recruitment had closed. Purposive selection
10 was used to ensure the sample reflected a wide range of ages, a gender balance, and a combination
11 of people from metropolitan and regional areas. We aimed to recruit 20 people into the study, with
12 the possibility of conducting additional interviews if necessary to achieve data saturation. No new
13 themes emerged after (and therefore data saturation was achieved at) participant #11 (see Table 2),
14 though purposive recruitment continued to ensure a sufficiently varied sample. Ultimately, 26
15 people were recruited and took part in interviews. One participant (#6) was subsequently excluded
16 on the basis that he had not received a diagnosis of T2DM (which became evident during the
17 interview), and because he presented with cognitive impairment. One participant (#20) made it
18 known to the research team after the study had been completed that her diagnosis had been revised
19 to T1DM, though it was clear that her presentation was atypical. However, we decided to retain her
20 data in this study as, at the time of participation, she had a diagnosis of T2DM and she believed that
21 she had this condition, and so her social experiences of living with the condition were as real as
22 those of the other participants. Thus, this paper reports on data from 25 interviews.
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27 **Interview schedule and procedure**

28 Informed by our literature review[20], we developed a semi-structured interview schedule to elicit
29 participant narratives of perceived or experienced diabetes-related stigma. Indirect questioning (i.e.
30 not explicitly referring to ‘stigma’) invited participants to discuss their own social experience in a
31 range of contexts, including healthcare settings, the workplace, their social and/or family
32 environments, and in the media. Interviewers did not use the word ‘stigma’ until either the
33 participant had used it spontaneously, or until the last question to address this concept directly. This
34 approach was used to avoid confusing participants with jargon, and to avoid introducing bias in the
35 questioning, thus maximising opportunities for participants to discuss both their positive and
36 negative social experiences.
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40 All interviews were conducted between May and July 2012 in non-clinical settings by interviewers
41 with a background in health psychology (JB, AV, and JS). A selection of interviews (four) were
42 conducted by one interviewer and observed by another for the purposes of enabling reflective
43 discussions about the interviews, and the role and influence of the interviewer in each one, and
44 identification of any potential bias or stereotypes about T2DM that the interviewer may hold.
45 Interviewers also wrote notes and reflections immediately after every interview. All interviews were
46 audio-recorded and lasted an average of 55 minutes (range: 25 – 103 minutes). At the conclusion of
47 the interview, participants completed a short questionnaire to provide demographic and clinical
48 information. All participants received a \$AU20 department store gift voucher as a token of
49 appreciation for participating.
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53 **Transcription and analysis**

54 All audio recordings were transcribed verbatim by a professional transcription service. The research
55 team checked each transcript against the recording for accuracy. The de-identified transcripts were
56 imported into NVivo 10 to facilitate data coding, retrieval and analysis.
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3 A thematic analysis using an inductive (data driven) approach was used to examine the data[22].
4 Two researchers (JB and AV, both with postgraduate qualifications in health psychology and training
5 and experience in qualitative interviewing) read and re-read the transcripts to develop two initial
6 coding frameworks, which were then compared across coders, and reviewed by the full authorship
7 team. Following revision, an integrated framework was developed and piloted (by JB and AV) by
8 independently coding a random selection of four transcripts. Final modifications were made to
9 improve utility and comprehensibility. Using the final coding framework, JB and AV then coded two
10 transcripts collaboratively to ensure agreement on coding rules, and then coded five additional
11 transcripts independently. Inter-coder agreement for each code was determined by summing the
12 percentage of content in each code identified by both coders and the percentage of content in each
13 code identified by neither coder. A mean agreement rating (averaging agreement ratings across
14 codes) of 99.5% was achieved for these five transcripts, indicating a high level of consistency in
15 coding decisions. Minor discrepancies (e.g. where AV had coded data into code A and B, whereas JB
16 had coded only into code A) were resolved through discussion, raising the agreement level to 100%.
17 AV then coded the remaining 17 transcripts independently.

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21
22 The content of each code was then examined by all authors to determine whether some codes could
23 be subsumed by others due to overlapping content, and to explore relationships between codes. For
24 the purposes of this analysis, we coded according to the key topics described below. Participant
25 quotes are provided to illustrate our findings.

26
27
28 This study received ethics approval from the Deakin University Human Research Ethics Committee
29 (2012-072).

30 31 **Results**

32 **Sample characteristics**

33
34 Of the final sample of 25 participants, 12 (48%) were women. The median age was 61 years (range
35 22-79 years; interquartile range = 15.00), and T2DM duration was 5 years (range 0-29 years;
36 interquartile range = 7.25). These characteristics are representative of Australian adults with T2DM
37 as documented in a large-scale national survey[23]. Further sample characteristics are displayed in
38 Table 1.
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44 ---- Table 1 ----
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48 **Perceptions of social stigma**

49 When asked explicitly, 15 participants (60%) indicated they believed there was social stigma
50 surrounding T2DM. Some gave specific examples of personally experiencing or feeling the effects of
51 diabetes-related stigma, while others described it as something they perceived in society generally
52 or that others with T2DM experienced. One woman described the personal experience of stigma as
53 follows:
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3 *"I think the stigma is that it's a lifestyle disease. That somehow you've been lazy and*
4 *you've allowed this to happen to yourself. I think to me that must come through very*
5 *strongly, that's the judgment that I think that is made."* (#19; woman, 54yrs)
6

7
8 Ten (40%) participants believed there was no stigma surrounding T2DM but six of these had already
9 described evidence of diabetes-related stigma throughout the interview. Four indicated that they
10 firmly believed there was no stigma and that they were surprised that this was a topic of interest, as
11 they had never experienced it nor considered it to be an issue. Interestingly, these four were some
12 of the oldest participants in the study (aged 67-73).
13

14 *"I don't believe there would be any stigma at all to having type 2 diabetes. I just can't*
15 *imagine how it would arise"* (#13; man, 69yrs)
16

17
18 Two people felt that while obesity was stigmatised, T2DM was not, and any stigma people with
19 T2DM experienced was due to their weight alone.
20

21 *"Their appearance might be fat, they might look unhealthy and, when they're applying*
22 *for jobs or trying to interact socially that might be the main reason they've got a stigma*
23 *rather than the diabetes."* (#1, man, 67yrs)
24

25
26 In contrast, others raised the issue of diabetes-related stigma unprompted during the initial stages
27 of the interview. For example, when asked the first question about what it was like to be diagnosed
28 with T2DM, one woman responded:
29

30 *"I thought then, and I still think now, that there is still somehow a feeling of stigma*
31 *attached to getting type 2 diabetes because you feel it's your fault and you did it to*
32 *yourself, so initially I was very upset."* (#5, woman, 59yrs)
33

34
35 Each of the key themes and sub-themes are explored in more detail below, and the structure of
36 these key themes is summarised in Table 2, with indications of which participants discussed which
37 themes. Evidence of diabetes-related stigma was reflected in participants' accounts of blame and
38 shame, being associated with negative stereotypes, discrimination and restriction of opportunities.
39 The media, healthcare professionals, family, and friends were identified as sources of stigma and
40 stigmatising practices. Many participants compared their own experiences unfavourably with those
41 who have type 1 diabetes.
42
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45

46 ----Table 2----
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50 Evidence of diabetes-related stigma

51 *Blame and shame*

52
53 The concepts of blame and shame were highly salient. Participants described feeling judged and
54 blamed by others for bringing T2DM on themselves through over-eating, poor dietary habits, being
55 inactive, or being overweight. There was a sense that this reflected negatively on their personal
56 character.
57
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59
60

1
2
3 *"There's this message that diabetes is this terrible thing that terrible people get because*
4 *they do terrible things" (#11, woman, 61yrs)*
5

6 Whilst perceptions of blame were described by most a general perception of society's views, some
7 described specific instances of their direct experiences of this blame, for example:
8

9
10 *"I find a lot of people, they like to think of you as being the culprit. In fact I actually had*
11 *one person say 'well you've dug your grave with your own teeth'." (#12, man, 67yrs)*
12

13 Self-blame and feeling guilty for having developed T2DM was common, though it was unclear
14 whether this was the result of internalising perceived societal attitudes, or whether self-blame
15 influenced the perception of attitudes. Some participants, who had a strong family history of T2DM,
16 some of whom reported a healthy lifestyle and were not visibly overweight, still had a strong sense
17 that there was something they should have done to avoid developing the condition.
18

19
20 *"I felt guilty in the early days for the first, probably 10 to 15 years, I felt guilty because it*
21 *was my fault." (#14, woman, 59yrs)*
22

23 *Negative stereotyping*

24 Every participant spoke of negative stereotypes being associated with T2DM. Some of the most
25 common negative stereotypes that were used or described were "fat", "obese", "overweight", "big
26 fat pig", "lazy", "slothful", "couch potato", "over-eater", and "glutton". Once again, these
27 stereotypes reflected the idea that "you brought it on yourself". Less frequently reported were
28 stereotypes of people with T2DM being "poor people", "not terribly intelligent", as well as being a
29 "shocking person" or "bad person" and "injecting insulin". Responses to these stereotypes were
30 mixed. Some people expressed concern, frustration or unease about being automatically labeled in
31 this way, while others endorsed the stereotypes themselves.
32
33

34 *Discrimination and restricted opportunities*

35 While very few examples of discrimination were reported, there were a few notable cases. For
36 instance, one woman (who stated a strong desire to have a child) described restrictions against
37 people with diabetes who want to become adoptive parents:
38
39

40
41 *"I looked up the adoption [criteria]...a couple of the countries said 'no type 1 or type 2*
42 *diabetes'...I suppose if adoption agencies are saying no diabetes then that's not going to*
43 *happen." (#16, woman, 35yrs)*
44

45 More prominent than discrimination per se was a sense of restricted or lost opportunities in life as a
46 result of having T2DM. Limitations in travel or career prospects, and lapsed friendships with people
47 who were unsupportive were described as examples of the negative impact T2DM has on life
48 opportunities. For example, one woman described how T2DM had affected her pursuit of career
49 advancement:
50
51

52
53 *"I guess it did sort of stop me from pushing myself as much as I usually do, so I did leave*
54 *the position at a time when I was really enjoying it and was hoping to better myself in*
55 *that position" (#23, woman, 37yrs)*
56
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Sources of stigma

Media

While some participants could not recall any specific media stories or campaigns about T2DM, those participants that could held one of two key views. The first view was that the emphasis on T2DM being a lifestyle disease, and therefore within an individual's control, was a helpful and socially responsible preventative health message.

"I think it's great the emphasis they have at the moment talking about your lifestyle and your diet, exercise and that sort of thing. I think it's very, very good" (#2, man, 73yrs)

The second view was that the emphasis on lifestyle factors (such as being overweight or physically inactive) as causal in T2DM served to generate or reinforce blaming attitudes in the community, perpetuate negative stereotypes, and elicit negative emotional reactions from people with T2DM.

"I don't want people to think I developed this disease because I was some big fat that never got off her chair... I was active, exercised, worked, everything...it doesn't have to be from your lifestyle but I think most, well that's how they portray it in the media...they show all the time 'there's this diabetes epidemic' and all you see is fat people, not their heads, these big bums and tummies and all that and you think 'do people think I was like that, that I looked like that?'" (#15, woman, 60yrs)

Those who firmly believed there was a stigma surrounding T2DM were more likely to critique the media's approach to T2DM in this way. Participants who held this view also described sensationalism in the media around the T2DM epidemic, and expressed dissatisfaction with the "scare tactics" often used in public health campaigns. They wanted more positive messages about living with diabetes to be incorporated into the media.

"There's no good news stories about type 2 diabetes. Perhaps there should be. Perhaps it should be 'it isn't necessarily a death sentence'." (#3, man, 54yrs)

Healthcare professionals

Most participants described a combination of both positive / helpful and negative / discouraging interactions with healthcare professionals. Some participants reported stigmatising practices and attitudes among healthcare professionals, who were seen to focus on what was being done 'wrong' (e.g. failure to lose weight or reduce HbA1c since the last consultation) rather than finding ways to encourage behaviour change efforts. This was experienced as discouraging and judgmental:

"The dietician was awful... she asked me if I exercise and I said 'I do the gym twice a week and I have consistently since November' 'that's not enough, you need to go five times a week'...this makes me really angry" (#16, woman, 35yrs)

These negative experiences with healthcare professionals led to changing providers, seeking advice from other sources (e.g. friends, the internet), and avoidance of consultations with healthcare professionals.

Family, friends, colleagues

While, in general, participants reported that they had supportive families, friends and workplaces (where relevant), most described at least one example of unhelpful, annoying or discouraging

behaviour from their families or peers. This behaviour was described as being hurtful, judgmental, and interfering, particularly regarding dietary choices and weight management.

"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, 59yrs)

Consequences of stigma

Unwillingness to disclose condition

Participants tended to describe specific times in their diabetes journey, or specific people or circumstances, that made them reluctant to disclose their condition. Common examples included the period soon after diagnosis, a particular family member or friend they anticipated would respond unhelpfully, or during a job interview or in the workplace, for example:

"I think the problem was more in corporate life...I was in a very senior role and I felt the need to hide it from that particular situation." (#24, woman, 68yrs).

The key reasons for non-disclosure were fear of being judged or blamed for having T2DM or an overwhelming sense of self-blame. Some also described a fear of being discriminated against or a desire to distance oneself from society's negative portrayals of people with diabetes.

"When I first got it I wouldn't tell anybody. I didn't even tell my husband. I told nobody. I actually felt so ashamed to have diabetes. I felt completely ashamed of myself." (#19, woman, 54yrs)

"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 [patient organisation] are shutting them up because they're hurt and are mortified." (#22, man, 56yrs)

Other reasons included not wanting to deal with people's misconceptions about the condition (particularly around the dietary management), and not wanting to answer lots of questions about diabetes, worry or shock people, or attract sympathy.

However, many participants were not concerned about other people knowing they had T2DM. This was particularly true of older participants, perhaps because, as one man commented, living with diabetes was a relatively common experience amongst their peers:

"It's a non-issue really...most of my colleagues are of the same age as I am and many of them have relatives or spouses or people who are diabetic" (#12, man, 67yrs).

Reasons for disclosure included helping other people understand more about diabetes, explaining self-management behaviour or dietary choices in public, seeking support, and for safety in case of a medical emergency.

Psychological distress

The psychological consequences of stigma included emotional distress such as shame, guilt, regret, and hopelessness. Other psychological consequences that were frequently noted included feelings of low self-worth and self-confidence. Some participants felt that having T2DM reflected poorly on their personal character. The psychological distress experienced made it even harder to cope with and adjust to life with T2DM.

"I felt a little bit inferior" (#14, woman, 59yrs)

"I call it the 'blame and shame disease' because I think that people get blamed and shamed and I think that makes it worse...they feel hopeless." (#11, woman, 61yrs)

Comparisons with type 1 diabetes

There was a distinct feeling among participants that social stigma was specific to T2DM, and that those with T1DM were not judged so harshly. The main reason suggested for this was that those with T1DM were not perceived to be at fault, or to have done anything to cause their condition. Other reasons included that T1DM is perceived to be a more serious condition than T2DM, and because T1DM is often associated with a diagnosis in childhood. One man identified the difference as:

"Type 1 is 'you poor thing', type 2 is 'you stupid thing'" (#4, man, 57yrs)

It was also perceived that people with T1DM received more support and assistance than people with T2DM, which results in division between these two groups:

"But they're [people with type 1 diabetes] generally quite looked after. They have access to pumps, they have heaps of support groups out there and workshops ...if I tried to get into the same type of thing because I'm on insulin they say "no, because you're type 2" so they automatically exclude you just because of your diagnosis and not because of the way you're managing your diabetes. So that segregates the diabetes community as a whole." (#20, woman, 22yrs)

Discussion

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. Based on commonly-used definitions of health-related stigma, we defined diabetes-related stigma to be an adverse social judgement based on a feature of diabetes or its management that may lead to perceived or experienced exclusion, rejection, blame, stereotyping and / or status loss[11 12]. Our findings indicate that stigmatising attitudes and practices, consistent with this definition, are part of the social experience of living with T2DM.

Evidence of type 2 diabetes-related stigma

All participants bar four either explicitly identified a social stigma surrounding T2DM, or described evidence of this stigma. Those who did not were some of the oldest participants in the study, suggesting that perhaps younger people with T2DM are more likely to experience, or be sensitive to, diabetes-related stigma. Younger adults with T2DM face many pressures unique to their age group and perceive that existing T2DM services are not relevant to them[24]. These factors may contribute

1
2
3 to the more pronounced stigma experienced by younger participants. Examples of this stigma given
4 by participants included blaming and shaming attitudes towards those with T2DM (including self-
5 blame), negative stereotyping, discrimination and lost opportunities as a result of having T2DM.
6 While the well-recognised obesity stigma[25-27] was seen to play some part in diabetes-related
7 stigma, the latter cannot be wholly explained by the former.
8
9

10 While study participants reserved their most scathing criticism for the media, the people with whom
11 participants had personal relationships were also described as contributing to the diabetes-related
12 stigma. Consistent with previous research in obesity[27 28], this was particularly evident with
13 regards to interactions with healthcare professionals. Comments or behaviour that revealed
14 judgment, blame, or other negative attitudes towards the person with T2DM were remembered by
15 many participants, sometimes years later. Participants described not returning for a repeat
16 consultation as a direct result of these interactions.
17
18

19 Consistent with previous research[29-31], perceiving and experiencing diabetes-related stigma had
20 both behavioural and psychological consequences. Participants described an unwillingness to
21 disclose their T2DM to others, which has potentially dangerous ramifications for medical
22 emergencies. An unwillingness to disclose also raises the possibility that essential self-care will be
23 compromised (e.g. skipping or delaying medications / insulin, not checking blood glucose levels,
24 succumbing to social pressure to eat unhealthy foods) or undertaken in unhygienic environments
25 (e.g. public toilets) to avoid being noticed.
26
27
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29 People also described strong feelings of low self-worth and self-esteem, shame and guilt in response
30 to the perceived or experienced stigma. Previous research has demonstrated the associations
31 between emotional distress and sub-optimal self-management, and ultimately, poorer physical
32 health outcomes[5 32-34]. Therefore the potential consequences of stigma are perhaps even more
33 far-reaching than described by our study participants.
34
35

36 **A framework of diabetes-related stigma**

37 The findings from this study lend support to our proposed model of diabetes-related stigma[20].
38 Consistent with our model, people with T2DM identified individuals in their lives, including
39 healthcare professionals, as sources of stigma. However, our proposed model did not capture the
40 role of the media in driving and reinforcing diabetes-related stigma, which was a key concern for
41 participants in this study, raised both spontaneously and in response to direct questioning. In Figure
42 1, we propose a revised model of diabetes-related stigma to include this important issue. While self-
43 blame and blame by others was a key theme identified in the current study and a driving mechanism
44 of stigma described in our model, other mechanisms included in our model were less evident (e.g.
45 fear, disgust).
46
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49 The examples and evidence of stigma identified in this study are also consistent with those proposed
50 in the model (e.g. stereotyping, discrimination/restrictions, being judged), as are some of the
51 psychological and behavioural consequences of stigma. On the whole, the proposed model
52 continues to provide a useful 'road map' for diabetes-related stigma research, though some minor
53 modifications (e.g. including media as a source of stigma) are warranted in light of the current
54 study's findings.
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58 ----- Figure 1 -----
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Implications and future directions

Our findings indicate that not only is obesity-related stigma likely to be a barrier to diabetes management in a healthcare setting[35], but that diabetes-specific stigma may be an additional barrier. This was illustrated by the fact that much of what was discussed by participants was specific to having T2DM, and not only about being overweight or obese. Given that the obesity and diabetes stigmas are not one and the same, further research into diabetes-related stigma is required, and we cannot solely rely on the obesity stigma literature to inform future work in diabetes. Considerable research has already been undertaken with regard to understanding, combating, or minimising the impact of the obesity stigma in healthcare or health education settings[35-38]. Similar work is now needed in diabetes, with a view to conducting research that examines correlates and outcomes of diabetes-related stigma for the person living with the condition, using findings to inform anti-stigma interventions in healthcare settings, and influencing the way T2DM is portrayed in the media. We have previously commented on the unintended negative consequences of a sole emphasis on the role of individual responsibility with regards to obesity and associated conditions such as T2DM [39]. In any anti-stigma intervention, attention will need to be paid to the subtle distinction between empowerment to take personal responsibility for diabetes self-care, and blaming the individual for causing their own health problems.

Interventions for people with T2DM that focus on enhancing coping and resilience in the face of stigmatising attitudes and practices may be beneficial in terms of improving psychological outcomes and minimising barriers to optimal self-care. At a minimum, healthcare professionals need to consider stigmatisation as a possible issue that is causing distress that needs to be addressed.

Participants in this study did not perceive that people with T1DM were subject to stigmatising attitudes and practices but that does not mean that people with T1DM do not perceive it to be a stigmatised condition. Research is needed to explore the social experiences of people with T1DM to enable comparison with the experiences reported by people with T2DM.

Limitations

As with all qualitative studies, the emphasis is on in-depth exploration of an issue or experience. Consequently, small sample sizes must be used, which may limit the representativeness of the findings. Care was taken to recruit a diverse sample and this was largely achieved but people with a tertiary education were over-represented in the sample, and all were members of Diabetes Australia – Vic, the state's consumer organisation. These people may be more engaged in their diabetes care and in diabetes issues than the general population of adults with diabetes. Participants' ethnicity was not recorded, and therefore the ethnic diversity of the sample cannot be assured. Future diabetes research in Australia would benefit from attempts to recruit ethnically diverse samples which better represent the community, and culturally sensitive collaboration with indigenous communities [40]. However, this study has enabled the identification of issues to inform the design of a novel measure of diabetes-related social stigma, so that large-scale, representative quantitative studies can be undertaken.

Conclusions

This study is the first to examine in depth the perceptions and experiences of social stigma of adults living with T2DM. These findings indicate that stigmatisation is an issue of substantial concern for

1
2
3 people with T2DM, and has harmful consequences. Future research needs to focus on how to dispel
4 stigmatising attitudes and practices, particularly in healthcare settings, and how to minimise the
5 impact of diabetes-related stigma by enhancing coping amongst people with T2DM.
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For peer review only

Tables and figures

Table 1. Demographic and clinical characteristics of participants (N=25)

<i>Sample characteristics</i>	median (IQR) or n (%)
<i>Age: years</i>	61 (15.00)
<i>Diabetes duration: years</i>	5 (7.25)
<i>Gender: women</i>	12 (48)
<i>Primary treatment</i>	
Insulin injections	5 (20)
OHAs	14 (56)
Lifestyle	6 (24)
<i>Highest qualification</i>	
School or intermediate certificate	1 (4)
High school or leaving certificate	2 (8)
Trade / apprenticeship	2 (8)
Certificate / diploma	4 (16)
Bachelor's degree or higher	16 (64)
<i>Employment</i>	
Full time work	6 (24)
Part time work	7 (28)
Retired/Not working	12 (48)
<i>Living in metropolitan region</i>	19 (76)
<i>English language</i>	25 (100)

IQR: interquartile range

Table 2. Themes and subthemes, and demonstration of data saturation

ID	Evidence of stigma			Sources of stigma			Consequences of stigma		Comparisons with type 1
	Blame and shame	Negative stereotyping	Discrimination / restricted opportunities	Media	Healthcare professionals	Family / friends / colleagues	Unwillingness to disclose	Emotional distress	
1		✓							
2		✓							
3	✓	✓	✓	✓		✓	✓		✓
4	✓	✓				✓			✓
5	✓	✓		✓		✓	✓		✓
7	✓	✓	✓	✓					✓
8	✓	✓	✓			✓		✓	
9	✓	✓		✓					
10	✓	✓	✓						✓
11	✓	✓		✓	✓	✓	✓	✓	✓
12	✓	✓	✓	✓		✓			✓
13		✓		✓					✓
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15	✓	✓	✓	✓		✓		✓	✓

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20	✓	✓	✓	✓			✓	✓	✓
21	✓	✓				✓		✓	
22	✓	✓		✓	✓			✓	✓
23	✓	✓		✓		✓	✓	✓	✓
24	✓	✓	✓	✓	✓		✓	✓	
25	✓	✓	✓			✓	✓	✓	
26		✓							

NB: Participant 6 was excluded from the analysis

For peer review only

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Author contributions and acknowledgements

JS, JB and KM conceptualised the study. All authors contributed to the development of the interview schedule. AV, JB and JS conducted the participant interviews. AV checked the transcripts against the audio files, and AV and JB developed the coding framework (in consultation with JS and KM) and conducted the data analysis. JB prepared the first draft of this manuscript. All authors provided feedback and contributed to subsequent revisions of the manuscript. All authors approved the final version of this manuscript. We thank Diabetes Australia – Vic, particularly the membership team, for their assistance with recruitment for this study. We also thank all the people with diabetes who expressed an interest or took part in this study.

Declaration of competing interests

None declared.

Data Sharing

The unpublished data are not publically available.

Figure legend

Figure 1. A revised framework for understand diabetes-related stigma

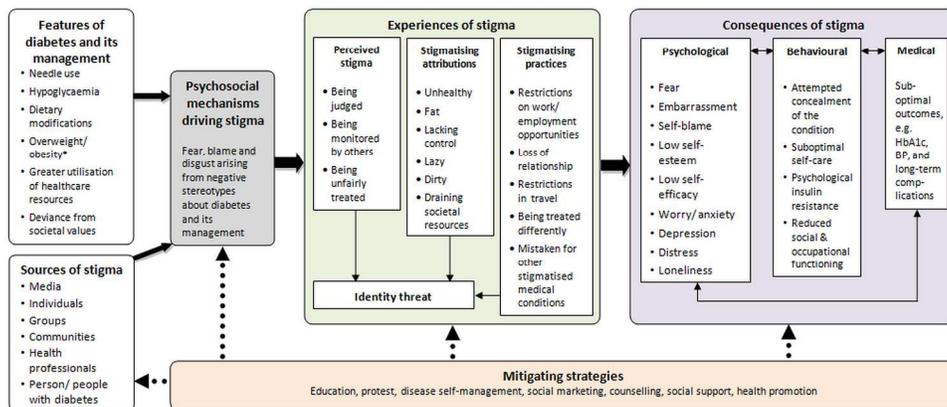
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* Type 2 diabetes only

Figure 1. A revised framework for understand diabetes-related stigma

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“I call it the blame and shame disease”: A qualitative study about perceptions of social stigma surrounding type 2 diabetes

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Abstract

Objectives: While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes. The aim of the current study was to explore the social experiences of Australian adults living with type 2 diabetes (T2DM), conduct an exploratory, in-depth interview study of the social experiences of Australian adults living with type 2 diabetes (T2DM), with a particular focus on the perception and experience of diabetes-related stigma.

Design: A qualitative study using semi-structured interviews, which were audio-recorded, transcribed, and subject to thematic analysis.

Setting: This study was conducted in the Australian state of Victoria in non-clinical settings in metropolitan and regional areas in the Australian state of Victoria. Participants were recruited primarily through the state consumer organisation representing people with diabetes.

Participants: All adults aged ≥ 18 years with T2DM living in Victoria were eligible to take part. Participants were recruited primarily through the state consumer organisation representing people with diabetes. Twenty-five participants were recruited primarily through the state consumer organisation representing people with diabetes. Twenty-five adults with T2DM participated (12 women; median age $= 61.59 \pm 14$ years; median diabetes duration $= 5.7 \pm 7$ years).

Results: A total of 21 (84%) participants indicated that they believed T2DM was stigmatised, or reported evidence of stigmatisation. This was evident in Specific themes about the experience of stigma were -feeling blamed by others for causing their own condition, being subject to negative stereotyping, being discriminated against or having restricted opportunities in life. Other themes focused on the sources of stigma, which included the media, healthcare professionals, friends, family and colleagues were all identified as sources of stigmatising attitudes and practices. The mes around relating to the consequences of this stigma were also evident, which included participants' unwillingness to disclose their condition to others, and psychological distress. Participants believed that people with type 1 diabetes do not experience similar stigmatisation.

Conclusions: It is evident that Our study found evidence of people with T2DM experience experiencing or and perceiving diabetes-related social stigma. Further research is needed to explore ways to measure and minimise diabetes-related stigma at both individual and societal levels, and also to examine explore these the perceptions and experiences of stigma issues in people with type 1 diabetes, and explore ways to measure and minimise diabetes-related stigma at both individual and societal levels.

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Article Summary

Article focus

- While health-related stigma has been the subject of considerable research in other conditions (obesity, HIV/AIDS), it has not received substantial attention in diabetes.
- The aim of the current study was to [explore the social experiences of Australian adults living with type 2 diabetes \(T2DM\)](#), ~~conduct an exploratory, in-depth interview study of the social experiences of Australian adults living with type 2 diabetes (T2DM)~~, with a particular focus on the perception and experience of diabetes-related stigma. ~~This was done~~ [achieved throughby conducting in-depthsemi-structured interviews.](#)

Key messages

- People with T2DM experience stigmatising practices and attitudes, such as being blamed for their condition, being subject to negative stereotyping, and being discriminated against. Sources of stigma include the media, healthcare professionals, friends, family and work colleagues.
- Consequences of stigma reported by participants include becoming unwilling to disclose their condition, and experiencing psychological distress.
- Further research is needed to examine these issues in people with type 1 diabetes, and explore ways to measure and minimise diabetes-related stigma at both individual and societal levels.

Strengths and limitations

- This qualitative study is the first to describe, in detail, the perceptions and experiences of diabetes-related stigma from the perspective of adults with T2DM.
- While the small sample size may limit the representativeness of the findings, efforts were made to include a broad cross-section of adults with T2DM and data saturation was achieved.
- All participants were members of the state organization representing people with diabetes and most were tertiary educated. These people may be more engaged in their diabetes care and in diabetes issues than the general population [of adults with diabetes.](#)

Introduction

Type 2 diabetes (T2DM) affects more than 220 million worldwide and is increasing in prevalence[1]. [More than 1.5 million Australians have diabetes, with most of these having T2DM](#)[2]. Its physical impact is well-documented, with diabetes management and complications having substantial implications for individual and societal health, psychological well-being and quality of life, as well as for the global economy[3-7]. In the past decade, landmark studies have demonstrated that T2DM can be prevented[8 9], highlighting the role of behaviour and personal responsibility in the development of the condition. As the increasing prevalence of T2DM has achieved prominence in the media, and in the consciousness of the general public, ~~so~~ perceptions of T2DM appear to be changing, with anecdotal evidence of social stigma and discrimination ~~now~~ apparent (e.g. [observations of public comments posted online in response to about articles in the media](#)[10]). While the fact that the person has T2DM may not be immediately evident, certain risk factors (e.g. obesity) and the need for daily self-management (e.g. medication-taking, checking blood glucose, modifying diet, injecting insulin) may be conspicuous to others and lead to undesirable consequences such as stigmatisation. Health-related social stigma is a negative 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[11 12]. Stigma has been extensively researched in other conditions such as obesity[13-16] and HIV/AIDS[17-19], but has yet to be the focus of a systematic program of research in diabetes.

Our recent review[20] highlighted the lack of research about stigma in diabetes, but did find some evidence that people with type 1 diabetes (T1DM) and T2DM perceive and experience diabetes-related stigma, and that this stigma has negative consequences across many aspects of their life. We proposed a framework ([a revised version of which is illustrated in Figure 1](#)) for understanding diabetes-related stigma that hypothesised the features of diabetes and its management that may be the focus of this phenomenon, the sources and psychological mechanisms driving it, and the possible experiences and consequences of stigma[20].

A necessary starting point for building on the findings of this review and commencing a research program in this area is to conduct an in-depth exploration of the perceptions and experiences of diabetes-related stigma from the perspective of the person living with the condition[21]. This will provide a comprehensive understanding of perceived diabetes-related stigma to inform quantitative surveys of people with and without diabetes, and lead to the development, evaluation and implementation of intervention strategies to reduce stigma. We conducted an interview study with the aim of exploring the social experiences of Australian adults living with T2DM, with a particular (but concealed) focus on the perception and experience of diabetes-related stigma.

Methods

Participants and Recruitment

Adults aged ≥ 18 years with T2DM who spoke English and who lived in the Australian state of Victoria were eligible to take part in this interview study. Participants were recruited into this study primarily from the membership list of Diabetes Australia – Vic (DA – Vic; peak consumer body [and leading charity](#) representing people affected by diabetes in Victoria, Australia). The study was also

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advertised state-wide in diabetes-related media and social media. The study was advertised as an investigation of “the social experience of living with type 2 diabetes”. Study advertisements purposefully did not refer to “stigma” in order to minimise the risk of inadvertently attracting only participants with extreme negative experiences (which would have resulted in unrepresentative data), and to avoid biasing participants’ interview responses.

A total of 147 people enquired about the study by telephone or email: 108 were emailed or posted study information sheets; 39 made contact only after recruitment had closed. Purposive selection was used to ensure the sample reflected a wide range of ages, a gender balance, and a combination of people from metropolitan and regional areas of the state. We aimed to recruit 20 people into the study, with the possibility of conducting additional interviews if necessary to achieve data saturation. No new themes emerged after (and therefore data saturation was achieved at) participant #11 (see Table 2)2, though purposive recruitment continued to ensure a sufficiently varied sample. Ultimately, 26 people were recruited and took part in interviews. One participant (#6) was subsequently excluded on the basis that he had not received a diagnosis of T2DM (which became evident during the interview), and because he presented with cognitive impairment. One participant (#20) made it known to the research team after the study had been completed that her diagnosis had been revised to T1DM, though it was clear that her presentation was atypical. However, we decided to retain her data in this study as, at the time of participation, she had a diagnosis of T2DM and she believed that she had this condition, and so her social experiences of living with the condition were as real as those of the other participants. Thus, this paper reports on data from 25 interviews.

Interview schedule and procedure

Informed by our literature review[20], we developed a semi-structured interview schedule to elicit participant narratives of perceived or experienced diabetes-related stigma. Indirect questioning (i.e. not explicitly referring to ‘stigma’) invited participants to discuss their own social experience in a range of contexts, including healthcare settings, the workplace, their social and/or family environments, and in the media. Interviewers did not use the word ‘stigma’ until either the participant had used it spontaneously, or until the last question to address this concept directly. This approach was used so as to avoid confusing participants with jargon, and to avoid introducing bias in the questioning, thus maximising opportunities for participants to discuss both their positive and negative social experiences.

All interviews were conducted between May and July 2012 in non-clinical settings by interviewers with a background in health psychology (JB, AV, and JS). A selection of interviews (four) were conducted by one interviewer and observed by another for the purposes of enabling reflective discussions about the interviews, and the role and influence of the interviewer in each one, and identification of any potential bias or stereotypes about T2DM that the interviewer may hold. Interviewers also wrote notes and reflections immediately after every interview. All interviews were audio-recorded and lasted an average of 55 minutes (range: 25 – 103 minutes). At the conclusion of the interview, participants completed a short questionnaire to provide demographic and clinical information. A participant ID was used to distinguish audio files and questionnaires. All participants received a \$AU20 department store gift voucher as a token of appreciation for participating.

Transcription and analysis

All audio recordings were transcribed verbatim by a professional transcription service. The research team checked each transcript against the recording for accuracy. The de-identified transcripts were imported into NVivo 10 to facilitate data coding, retrieval and analysis.

A thematic analysis using an inductive (data driven) approach was used to examine the data[22].

Two researchers (JB and AV, both with postgraduate qualifications in health psychology and training and experience in qualitative interviewing) read and re-read the transcripts to develop two initial coding frameworks, which were then compared across coders, and reviewed by the full research authorship team. Following revision, an integrated framework was developed and piloted (by JB and AV) by independently coding a random selection of four transcripts. Final modifications were made to improve utility and comprehensibility. Using the final coding framework, JB and AV then coded two transcripts collaboratively to ensure agreement on coding rules, and then coded five additional transcripts independently. Inter-coder agreement for each code was determined by summing the percentage of content in each code identified by both coders and the percentage of content in each code identified by neither coder. A mean agreement rating (averaging agreement ratings across codes) of 99.5% was achieved for these five transcripts, indicating a high level of consistency in coding decisions. Minor discrepancies (e.g. where one coder AV had coded data into code A and B, whereas another coder JB had coded only into code A) were resolved through discussion, raising the agreement level to 100%. AV then coded the remaining 17 transcripts independently.

The content of each code was then examined by all authors to determine whether some codes could be subsumed by others due to overlapping content, and to explore relationships between codes. For the purposes of this analysis, we coded according to the key topics described below. Participant quotes are provided to illustrate our findings.

This study received ethics approval from the Deakin University Human Research Ethics Committee (2012-072).

Results

Sample characteristics

Of the final sample of 25 participants, 12 (48%) were women. The mean median age ± standard deviation age was 59±14.61 years (range = 22-79 years; interquartile range = 15.00), and T2DM duration was 5.7±7 years (range = 0-29 years; interquartile range = 7.25). These characteristics are representative of Australian adults with T2DM as documented in a large-scale national survey[23]. Further sample characteristics are displayed in Table 1.

---- ~~insert~~ Table 1 ~~here~~ ----

Perceptions of social stigma

When asked explicitly, 15 participants (60%) indicated they believed there was social stigma surrounding T2DM. Some gave specific examples of personally experiencing or feeling the effects of diabetes-related stigma, while others described it as something they perceived in society generally

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7 or that others with T2DM experienced. A few indicated that they did not experience stigma
8 themselves but believed that others with T2DM did. One woman described the personal experience
9 of stigma as follows:

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11 *"I think the stigma is that it's a lifestyle disease, that somehow you've been lazy and*
12 *you've allowed this to happen to yourself. I think to me that must come through very*
13 *strongly, that's the judgment that I think that is made."* (#19; woman, 54yrs)

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16 Ten (40%) participants believed there was no stigma surrounding T2DM but six of these had already
17 described evidence of diabetes-related stigma throughout the interview. Four indicated that they
18 firmly believed there was no stigma and that they were surprised that this was a topic of interest, as
19 they had never experienced it nor considered it to be an issue. Interestingly, these four were some
20 of the oldest participants in the study (aged 67-73).

21
22 *"I don't believe there would be any stigma at all to having type 2 diabetes. I just can't*
23 *imagine how it would arise"* (#13; man, 69yrs)

24
25 Two people felt that while obesity was stigmatised, T2DM was not, and any stigma people with
26 T2DM experienced was due to their weight alone.

27
28 *"Their appearance might be fat, they might look unhealthy and, when they're applying*
29 *for jobs or trying to interact socially that might be the main reason they've got a stigma*
30 *rather than the diabetes."* (#1, man, 67yrs)

31
32 In contrast, others raised the issue of diabetes-related stigma unprompted during the initial stages
33 of the interview. For example, when asked the first question about what it was like to be diagnosed
34 with T2DM, one woman responded:

35
36 *"I thought then, and I still think now, that there is still somehow a feeling of stigma*
37 *attached to getting type 2 diabetes because you feel it's your fault and you did it to*
38 *yourself, so initially I was very upset."* (#5, woman, 59yrs)

39
40 Evidence of diabetes-related stigma was reflected in participants' accounts of blame and shame,
41 being associated with negative stereotypes, discrimination and restriction of opportunities. The
42 media, healthcare professionals, family, and friends were identified as sources of stigma and
43 stigmatising practices. Many participants compared their own experiences unfavourably with those
44 who have type 1 diabetes. Each of the key themes and sub-themes are explored in more detail
45 below, and the structure of these key themes is summarised and sub-themes are identified in
46 Table 2, with indications of which participants discussed which themes and explored in more detail
47 below. Evidence of diabetes-related stigma was reflected in participants' accounts of blame and
48 shame, being associated with negative stereotypes, discrimination and restriction of opportunities.
49 The media, healthcare professionals, family, and friends were identified as sources of stigma and
50 stigmatising practices. Many participants compared their own experiences unfavourably with those
51 who have type 1 diabetes.
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7 ----Table 2----

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10 **Evidence of diabetes-related stigma**

11 ***Blame and shame***

12 The concepts of blame and shame were highly salient. Participants described feeling judged and
13 blamed by others for bringing T2DM on themselves through over-eating, poor dietary habits, being
14 inactive, or being overweight. There was a sense that this reflected negatively on their personal
15 character.
16

17
18 *"There's this message that diabetes is this terrible thing that terrible people get because*
19 *they do terrible things" (#11, woman, 61yrs)*

20 Whilst perceptions of blame were described by most a general perception of society's views, some
21 described specific instances of their direct experiences of this blame, for example:

22
23 *"I find a lot of people, they like to think of you as being the culprit. In fact I actually had*
24 *one person say 'well you've dug your grave with your own teeth'." (#12, man, 67yrs)*

25
26 Self-blame and feeling guilty for having developed T2DM was common, though it was unclear
27 whether this was the result of internalising perceived societal attitudes, or whether self-blame
28 influenced the perception of attitudes. Some participants, who had a strong family history of T2DM,
29 some of whom reported a healthy lifestyle and were not visibly overweight, still had a strong sense
30 that there was something they should have done to avoid developing the condition.
31

32
33 *"I felt guilty in the early days for the first, probably 10 to 15 years, I felt guilty because it*
34 *was my fault." (#14, woman, 59yrs)*

35 ***Negative stereotyping***

36 ~~Every participant spoke of the negative stereotypes being that are associated with T2DM. Some of~~
37 ~~the most common negative stereotypes that were used or described were. There was a strong sense~~
38 ~~that evidence to suggest that people with T2DM were subjected to negative stereotyping, such as~~
39 ~~"fat", "obese", "overweight", "big fat pig", "lazy", "slothful", "couch potato", "over-eater", and~~
40 ~~"glutton". Once again, these there was a strong sense that the stereotypes reflected the idea that~~
41 ~~"you brought it on yourself". Less frequently reported were stereotypes of people with T2DM being~~
42 ~~"poor people", "not terribly intelligent", as well as being a "shocking person" or "bad person" and~~
43 ~~"injecting insulin". Responses to these stereotypes were mixed. Some people expressed concern,~~
44 ~~frustration or unease about being automatically labeled in this way, while others endorsed the~~
45 ~~stereotypes themselves.~~
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48 ~~*"I always worry that people must have thought I was some big fat pig gorging on cakes*~~
49 ~~*and lollies and was a shocking person and that's why I developed it, I was lazy." (#15,*~~
50 ~~*woman, 60yrs)*~~

51
52 ~~*"It can be frustrating because you know damn well it's [the stereotype] not necessarily*~~
53 ~~*the case." (#18, woman, 42yrs)*~~
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Discrimination and restricted opportunities

While very few examples of discrimination were reported, there were a few notable cases. For instance, one woman (who stated a strong desire to have a child) described restrictions against people with diabetes who want to become adoptive parents:

"I looked up the adoption [criteria]...a couple of the countries said 'no type 1 or type 2 diabetes'...I suppose if adoption agencies are saying no diabetes then that's not going to happen." (#16, woman, 35yrs)

~~While no one described personal experience of workplace discrimination due to T2DM, people were concerned about the issue. They admitted a general reluctance to disclose the condition during a job interview or application for fear of discrimination in the selection process. In contrast, most were not concerned about disclosing their T2DM once in the workplace.~~

~~The concept of discrimination was perhaps most prominent when discussed in the context of the whole diabetes community, with perceptions that people with T1DM receive more empathy, opportunities and support than people with T2DM:~~

~~*"But they're [people with type 1 diabetes] generally quite looked after. They have access to pumps, they have heaps of support groups out there and workshops ...if I tried to get into the same type of thing because I'm on insulin they say "no, because you're type 2" so they automatically exclude you just because of your diagnosis and not because of the way you're managing your diabetes. So that segregates the diabetes community as a whole." (#20, woman, 22yrs)*~~

More prominent than discrimination per se was a sense of restricted or lost opportunities in life as a result of having T2DM. Limitations in travel or career prospects, and lapsed friendships with people who were unsupportive were described as examples of the negative impact T2DM has on life opportunities. For example, one woman described how T2DM had affected her pursuit of career advancement:

"I guess it did sort of stop me from pushing myself as much as I usually do, so I did leave the position at a time when I was really enjoying it and was hoping to better myself in that position. It did kind of slow down my drive to better myself in that job. I didn't leave purely because I was unwell but I wanted to seek a healthier lifestyle" (#23, woman, 37yrs)

Sources of stigma

Media

While some participants could not recall any specific media stories or campaigns about T2DM, those participants that could held one of two key views. The first view was that the emphasis on T2DM being a lifestyle disease, and therefore within an individual's control, was a helpful and socially responsible preventative health message.

"I think it's great the emphasis they have at the moment talking about your lifestyle and your diet, exercise and that sort of thing. I think it's very, very good" (#2, man, 73yrs)

The second view was that the emphasis on lifestyle factors (such as being overweight or physically inactive) as causal in T2DM served to generate or reinforce blaming attitudes in the community, perpetuate negative stereotypes, and elicit negative emotional reactions from people with T2DM.

"I don't want people to think I developed this disease because I was some big fat that never got off her chair... I was active, exercised, worked, everything...it doesn't have to be from your lifestyle but I think most, well that's how they portray it in the media...they show all the time 'there's this diabetics epidemic' and all you see is fat people, not their heads, these big bums and tummies and all that and you think 'do people think I was like that, that I looked like that?'" (#15, woman, 60yrs)

Those who firmly believed there was a stigma surrounding T2DM were more likely to critique the media's approach to T2DM in this way. Participants who held this view also described sensationalism in the media around the T2DM epidemic, and expressed dissatisfaction with the "scare tactics" often used in public health campaigns. They wanted more positive messages about living with diabetes to be incorporated into the media.

"There's no good news stories about type 2 diabetes. Perhaps there should be. Perhaps it should be 'it isn't necessarily a death sentence'." (#3, man, 54yrs)

Healthcare professionals

Most participants described a combination of both positive / helpful and negative / discouraging interactions with healthcare professionals. ~~Many~~ Some participants reported stigmatising practices and attitudes among healthcare professionals, who were seen to focus on what was being done 'wrong' (e.g. failure to lose weight or reduce HbA1c since the last consultation) rather than finding ways to encourage behaviour change efforts. This was experienced as discouraging and judgmental:

"The dietician was awful... she asked me if I exercise and I said 'I do the gym twice a week and I have consistently since November' 'that's not enough, you need to go five times a week'...this makes me really angry" (#16, woman, 35yrs)

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These negative experiences with healthcare professionals led to changing providers, seeking advice from other sources (e.g. friends, the internet), and avoidance of consultations with healthcare professionals.

Family, friends, colleagues

While, in general, participants reported that they had supportive families, friends and workplaces (where relevant), most described at least one example of unhelpful, annoying or discouraging behaviour from their families or peers. This behaviour was described as being hurtful, judgmental, and interfering, particularly regarding dietary choices and weight management.

"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, 59yrs)

Consequences of stigma

Unwillingness to disclose condition

Many participants were not concerned about other people knowing they had T2DM. This was particularly true of older participants, perhaps because, as one man commented, living with diabetes was a relatively common experience amongst their peers:

"It's a non-issue really...most of my colleagues are of the same age as I am and many of them have relatives or spouses or people who are diabetic" (#12, man, 67yrs).

Reasons for disclosure included helping other people understand more about diabetes, explaining self-management behaviour or dietary choices in public, seeking support, and for safety in case of a medical emergency.

Participants tended to describe specific times in their diabetes journey, or specific people or circumstances, that made them reluctant to disclose their condition. Common examples included the period soon after diagnosis, a particular family member or friend they anticipated would respond unhelpfully, or during a job interview or in the workplace, for example:

"I think the problem was more in corporate life...I was in a very senior role and I felt the need to hide it from that particular situation." (#24, woman, 68yrs).

The key reasons for non-disclosure were fear of being judged or blamed for having T2DM or an overwhelming sense of self-blame. Some also described a fear of being discriminated against or a desire to distance oneself from society's negative portrayals of people with diabetes.

"When I first got it I wouldn't tell anybody. I didn't even tell my husband. I told nobody. I actually felt so ashamed to have diabetes. I felt completely ashamed of myself." (#19, woman, 54yrs)

"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 [patient organisation] are shutting them up because they're hurt and are mortified." (#22, man, 56yrs)

Other reasons included not wanting to deal with people's misconceptions about the condition (particularly around the dietary management), and not wanting to answer lots of questions about diabetes, worry or shock people, or attract sympathy.

However, many participants were not concerned about other people knowing they had T2DM. This was particularly true of older participants, perhaps because, as one man commented, living with diabetes was a relatively common experience amongst their peers:

"It's a non-issue really...most of my colleagues are of the same age as I am and many of them have relatives or spouses or people who are diabetic" (#12, man, 67yrs).

Reasons for disclosure included helping other people understand more about diabetes, explaining self-management behaviour or dietary choices in public, seeking support, and for safety in case of a medical emergency.

Psychological distress

The psychological consequences of stigma included emotional distress such as shame, guilt, regret, and hopelessness. Other psychological consequences that were frequently noted included feelings of low self-worth and self-confidence. Some participants felt that having T2DM reflected poorly on their personal character. ~~Women were more likely to report feeling this way than men.~~ The psychological distress experienced made it even harder to cope with and adjust to life with T2DM.

"I felt a little bit inferior" (#14, woman, 59yrs)

"I call it the 'blame and shame disease' because I think that people get blamed and shamed and I think that makes it worse...they feel hopeless...it's just another layer." (#11, woman, 61yrs)

Comparisons with type 1 diabetes

There was a distinct feeling among participants that social stigma was specific to T2DM, and that those with T1DM were not judged so harshly. The main reason suggested for this was that those with T1DM were not perceived to be at fault, or to have done anything to cause their condition. Other reasons included that T1DM is perceived to be a more serious condition than T2DM, and because T1DM is often associated with a diagnosis in childhood. One man identified the difference as:

"Type 1 is 'you poor thing', type 2 is 'you stupid thing'" (#4, man, 57yrs)

It was also perceived that people with T1DM received more support and assistance than people with T2DM, which results in division between these two groups:

"But they're [people with type 1 diabetes] generally quite looked after. They have access to pumps, they have heaps of support groups out there and workshops ...if I tried to get into the same type of thing because I'm on insulin they say "no, because you're type 2" so they automatically exclude you just because of your diagnosis and not because of the way you're managing your diabetes. So that segregates the diabetes community as a whole." (#20, woman, 22yrs)

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Discussion

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. Based on commonly-used definitions of health-related stigma, we defined diabetes-related stigma to be an adverse social judgement based on a feature of diabetes or its management that may lead to perceived or experienced exclusion, rejection, blame, stereotyping and / or status loss[11 12]. Our findings indicate that stigmatising attitudes and practices, consistent with this definition, are part of the social experience of living with T2DM.

Evidence of type 2 diabetes-related stigma

All ~~bar four~~ participants bar four either explicitly identified a social stigma surrounding T2DM, or described evidence of this stigma. Those who did not were some of the oldest participants in the

study, suggesting that perhaps younger people with T2DM are more likely to experience, or be sensitive to, diabetes-related stigma. [Younger adults with T2DM face many pressures unique to their age group and perceive that existing T2DM services are not relevant to them](#)[24]. [These factors may contribute to the more pronounced stigma experienced by younger participants](#). Examples of this stigma given by participants included blaming and shaming attitudes towards those with T2DM (including self-blame), negative stereotyping, discrimination and lost opportunities as a result of having T2DM. While the well-recognised obesity stigma[25-27] was seen to play some part in diabetes-related stigma, the latter cannot be wholly explained by the former.

While study participants reserved their most scathing criticism for the media, the people with whom participants had personal relationships were also described as contributing to the diabetes-related stigma. Consistent with previous research in obesity[27 28], this was particularly evident with regards to interactions with healthcare professionals. Comments or behaviour that revealed judgment, blame, or other negative attitudes towards the person with T2DM were remembered by many participants, sometimes years later. Participants described not returning for a repeat consultation as a direct result of these interactions.

Consistent with previous research[29-31], perceiving and experiencing diabetes-related stigma had both behavioural and psychological consequences. Participants described an unwillingness to disclose their T2DM to others, which has potentially dangerous ramifications for medical emergencies. [Also of concern is an unwillingness to disclose also raises](#) the possibility that essential self-care will be compromised (e.g. skipping or delaying medications / insulin, not checking blood glucose levels, succumbing to social pressure to eat unhealthy foods) or undertaken in unhygienic environments (e.g. public toilets) to avoid being noticed.

People also described strong feelings of low self-worth and self-esteem, shame and guilt in response to the perceived or experienced stigma. Previous research has demonstrated the associations between emotional distress and sub-optimal self-management, and ultimately, poorer physical health outcomes[5 32-34]. Therefore the potential consequences of stigma are perhaps even more far-reaching than described by our study participants.

Implications for a proposed framework of diabetes-related stigma

The findings from this study lend support to our proposed model of diabetes-related stigma[20]. Consistent with our model, people with T2DM identified individuals in their lives, including healthcare professionals, as sources of stigma. However, our proposed model did not capture the role of the media in driving and reinforcing the diabetes-related stigma, which was a key concern for participants in this study, raised [both](#) spontaneously and in response to direct questioning. [In Figure 1, we propose a revised model of diabetes-related stigma in light of to include this important issue, which is presented in Figure 1.](#) While self-blame and blame by others was a key theme identified in the current study and a driving mechanism of stigma described in our model, other mechanisms included in our model were less evident (e.g. fear, disgust).

The examples and evidence of stigma identified in this study are also consistent with those proposed in the model (e.g. stereotyping, discrimination/restrictions, being judged), as are some of the psychological and behavioural consequences of stigma. On the whole, the proposed model continues to provide a useful 'road map' for diabetes-related stigma research, though some minor

modifications (e.g. including media as a source of stigma) are warranted in light of the current study's findings.

----- Figure 1 -----

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Implications and future directions

Our findings indicate that not only is obesity-related stigma likely to be a barrier to diabetes management in a healthcare setting[35], but that diabetes-specific stigma may be an additional barrier. ~~This was illustrated by the fact that much of what was discussed by participants was specific to having T2DM, and not only about being overweight or obese.~~ Given that the obesity and diabetes stigmas ~~seem to be somewhat distinct are not one and the same,~~ further research ~~in the area of~~ into diabetes-related stigma is required, ~~and we cannot solely rely on the obesity stigma literature to inform future work in the area of diabetes.~~ Considerable research has already been undertaken with regard to understanding, combating, or minimising the impact of the obesity stigma in healthcare or health education settings[35-38]. Similar work ~~must now be undertaken with reference to is now needed in~~ diabetes-related stigma, with a view to ~~conducting research that examines correlates and outcomes of diabetes-related stigma for the person living with the condition, using findings to inform healthcare settings being a potential target for~~ anti-stigma interventions ~~in healthcare settings,~~ and influencing the way T2DM is portrayed in the media. ~~We have previously commented on the unintended negative consequences of a sole emphasis on the role of individual responsibility with regards to obesity and associated conditions such as T2DM [39]. In any anti-stigma intervention, attention will need to be paid to the subtle distinction between empowerment to take personal responsibility for diabetes self-care, and blaming the individual for causing their own health problems.~~

~~It is apparent from our findings that the perception or experience of diabetes-related stigma may lead to sub-optimal biomedical and psychological outcomes for people with T2DM.~~ Interventions for people with T2DM that focus on enhancing coping and resilience in the face of stigmatising attitudes and practices may be beneficial ~~in terms of improving psychological outcomes and minimising barriers to optimal self-care.~~ At a minimum, healthcare professionals need to consider stigmatisation as a possible issue that is causing distress that needs to be addressed.

Participants in this study did not perceive that people with T1DM were subject to stigmatising attitudes and practices but that does not mean that people with T1DM do not perceive it to be a stigmatised condition. Research is needed to explore the social experiences of people with T1DM to enable comparison with the experiences reported by people with T2DM.

Limitations

As with all qualitative studies, the emphasis is on in-depth exploration of an issue or experience. Consequently, small sample sizes must be used, which may limit the representativeness of the findings. Care was taken to recruit a diverse sample and this was ~~largely~~ achieved but people with a tertiary education were over-represented in the sample, and all were members of Diabetes Australia – Vic, the state's consumer organisation. ~~Ethnicity of participants was not recorded, and therefore the ethnic diversity of the sample cannot be assured.~~ These people may be more engaged in their diabetes care and in diabetes issues than the general population ~~of adults with diabetes.~~ ~~Ethnicity of~~

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7 Participants' ethnicity was not recorded, and therefore the ethnic diversity of the sample cannot be
8 assured. Future diabetes research in Australia would benefit from attempts to recruit ethnically
9 diverse samples which better represent the community, and culturally sensitive collaboration with
10 indigenous communities [40]. However, this study has enabled the identification of issues to inform
11 the design of a novel measure of diabetes-related social stigma, so that large-scale, representative
12 quantitative studies can be undertaken.

13 14 **Conclusions**

15 This study is the first to examine in depth the perceptions and experiences of social stigma of adults
16 living with T2DM. These findings indicate that stigmatisation is an issue of substantial concern for
17 people with T2DM, and has harmful consequences. Future research needs to focus on how to dispel
18 stigmatising attitudes and practices, particularly in healthcare settings, and how to minimise the
19 impact of diabetes-related stigma by enhancing coping amongst people with T2DM.
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Tables and figures

Table 1. Demographic and clinical characteristics of participants (N=25)

Sample characteristics	M ± SD (range) or n (%)
Age: years	59 ± 14 (22-79) 61 (15.00)
Age at diagnosis	52 ± 14 (19-76)
Diabetes duration: years	7 ± 7 (0-29) 5 (7.25)
Gender: women	12 (48)
Primary treatment	
Insulin injections	5 (20)
OHAs	14 (56)
Lifestyle	6 (24)
Highest qualification	
School or intermediate certificate	1 (4)
High school or leaving certificate	2 (8)
Trade / apprenticeship	2 (8)
Certificate / diploma	4 (16)
Bachelor's degree or higher	16 (64)
Employment	
Full time work	6 (24)
Part time work	7 (28)
Retired/Not working	12 (48)
Living in metropolitan region	19 (76)
English language	25 (100)

IQR: standard deviation; interquartile range

Table 2. Summary of themes and sub-themes identified

Theme	Sub-themes
Evidence of stigma	Blame and shame Negative stereotyping Discrimination / restricted opportunities
Sources of stigma	Media Healthcare professionals

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	Family, friends, colleagues
Consequences of stigma	Unwillingness to disclose condition Emotional distress
Comparisons with type 1 diabetes	-

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Table 2. Themes and subthemes, and demonstration of data saturation

ID	Evidence of stigma			Sources of stigma			Consequences of stigma		Comparisons with type 1
	Blame and shame	Negative stereotyping	Discrimination / restricted opportunities	Media	Healthcare professionals	Family / friends / colleagues	Unwillingness to disclose	Emotional distress	
1		✓							
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7	✓	✓	✓	✓					✓
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9	✓	✓		✓					
10	✓	✓	✓						✓
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25	✓	✓	✓			✓	✓	✓	
26		✓							

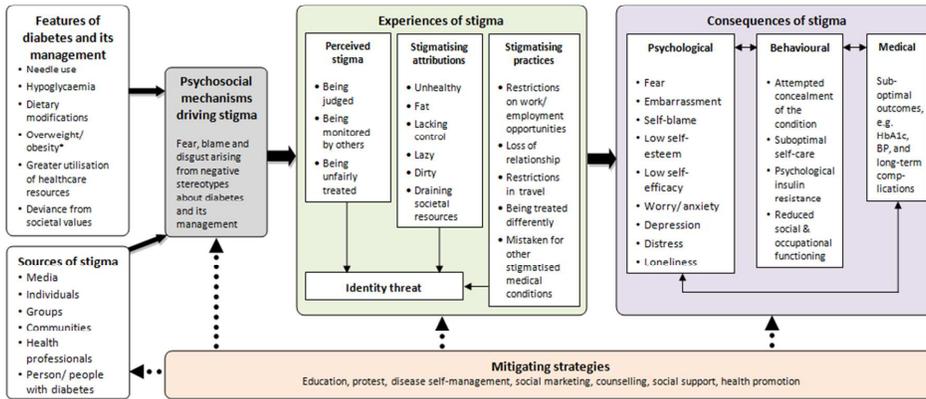
NB: Participant 6 was excluded from the analysis.

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Figure 1. A revised framework for understand diabetes-related stigma



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JS, JB and KM conceptualised the study. All authors contributed to the development of the interview schedule. AV, JB and JS conducted the participant interviews. AV checked the transcripts against the audio files, and AV and JB developed the coding framework (in consultation with JS and KM) and conducted the data analysis. JB prepared the first draft of this manuscript. All authors provided feedback and contributed to subsequent revisions of the manuscript. All authors approved the final version of this manuscript. We thank Diabetes Australia – Vic, particularly the membership team, for their assistance with recruitment for this study. We also thank all the people with diabetes who expressed an interest or took part in this study.

Declaration of competing interests

None declared.

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