

**Manuscript title:**

A discussion paper on stigmatizing features of diabetes

**Running title:**

Stigmatizing features of diabetes

**Authors:**

- Samereh Abdoli, PhD, RN, Assistant Professor, College of Nursing, University of Tennessee, Knoxville, TN, 37996. Email: [sabdoli@utk.edu](mailto:sabdoli@utk.edu)
- Mehri Doosti Irani, PhD, Assistant Professor, Shahr-e-Kourd University of Medical Sciences, Shahr-e-Kourd, Iran. [doost@nm.mui.ac.ir](mailto:doost@nm.mui.ac.ir)
- Lynda R. Hardy, PhD, RN, Professor, Associate Dean of Research, College of Nursing, University of Tennessee, Knoxville, TN, 37996. Email: [lhardy5@utk.edu](mailto:lhardy5@utk.edu)
- Martha Funnell, MS, RN, CDE, FAAN, Associate Research Scientist, Department of Learning Health Sciences, University of Michigan Medical School, Ann Arbor, MI. Email: [mfunnell@med.umich.edu](mailto:mfunnell@med.umich.edu)
- **Corresponding Author:**

Samereh Abdoli, PhD, RN, Assistant Professor, College of Nursing, University of Tennessee, Knoxville, TN, 37996. Email: [sabdoli@utk.edu](mailto:sabdoli@utk.edu)

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DR. SAMEREH ABDOLI (Orcid ID : 0000-0002-1247-6554)

Article type : Review Article

**Title:** A discussion paper on stigmatizing features of diabetes

**Aim:** This manuscript aims to describe stigmatizing features of diabetes.

**Design:** This article presents a narrative review of literature pertaining to stigma surrounding diabetes in different contexts.

**Methods:** A literature search was conducted in CINAHL, PubMed, and Web of Science for qualitative studies published between 2007-2017. The search was completed using various combinations of diabetes, T1DM, T2DM, stigma, social/public stigma, internalized/self-stigma, stigmatization, and diabetes-related stigma in English. The reviewers then independently reviewed the eligible studies (N=19) to extract data.

**Results:** From the 18 studies included in this narrative review, seven features related to stigma in diabetes were identified. People with diabetes were most notably considered and stigmatized as being “sick,” “death reminder,” “rejected marriage candidate,” “self-inflicting,” “contagiousness,” “requiring a dietary modification,” and “drunk or drug abuser.”

**Key words:** Stigma, Diabetes, Diabetes-Related Stigma

29

30

31 **Introduction:**

32 Diabetes, a major chronic health condition, is increasing healthcare challenges nationally and  
33 globally. It is estimated that, globally, 387 million people have diabetes; this number is expected  
34 to rise to 592 million by 2035 (International Diabetes Federation, n.d.). In response to a world  
35 pandemic of diabetes, it is crucial to consider that people living with diabetes are stigmatized by  
36 their illness (Abdoli, Ashktorab, Ahmadi, Parvizy, & Dunning, 2014; Anderson-Lister &  
37 Treharne, 2014; Hapunda, Abubakar, Van de Vijver, & Pouwer, 2015; Kato, Takada, &  
38 Hashimoto, 2014; Schabert, Browne, Mosely, & Speight, 2013; Singh, Cinnirella, & Bradley,  
39 2015), especially those living with T1DM (Abu Hassan et al., 2013; Jaacks, Liu, Ji, & Mayer-  
40 Davis, 2015; Spencer, Cooper, & Milton, 2014; Vishwanath, 2014).

41 Stigma, a discrediting attribute minimizing a person's value, is a multi-dimensional construct  
42 including interpersonal and intrapersonal experiences (Goffman, 1963). It is defined as  
43 discriminatory behaviors directed towards people with the stigmatized condition (Bogart et al.,  
44 2008), although it is not limited only to the behaviors. Weiss, Ramakrishan, and Somma (2006)  
45 have suggested Stigma is typically a social process, experienced or anticipated, characterized by  
46 exclusion, rejection, blame, or devaluation that result from experience, perception, or reasonable  
47 anticipation of an adverse social judgment about a person or group. This judgment is based on an  
48 enduring feature of identity conferred by a health problem or health-related condition, and the  
49 judgment is in some essential way medically unwarranted. (p.279)

50 **Background:**

51 Stigma in diabetes contributes to a hidden burden of the chronic condition affecting multiple  
52 aspects of life of those with diabetes (Abdoli, Abazari, & Mardanian, 2013; Benedetti, 2014;  
53 Broom & Whittaker, 2004). Diabetes-related stigma may preclude diabetes management  
54 (Salamon, Hains, Fleishcman, Davies, & Kichler, 2010), diabetes adherence (Mulvaney et al.,  
55 2011), multiple daily injections, participation in research studies, general health-seeking  
56 behaviors (DiZazzo-Miller et al., 2017; Jaacks et al., 2015), and insulin injections in unsanitary  
57 places (Abdoli, Doosti Irani, Parvizi, Seyed Fatemi, & Amini, 2013; Browne, Ventura, Mosley,  
58 & Speight, 2014). In general, stigma may make individuals with diabetes frustrated by feeling  
59 different, keeping their diabetes a secret, avoiding self-management activities, and seeking

60 health-promotion choices (Abdoli, Doosti Irani et al., 2013; Elissa, Bratt, Axelsson, Khatib, &  
61 Sparud-Lundin, 2016; Fritz et al., 2016). This can place them at a higher risk for poor diabetes  
62 management and high prevalence of acute and chronic diabetes complications (Abdoli, Abazari  
63 et al., 2013; Browne et al., 2014).

64 Stigma in chronic illnesses such as HIV/AIDS has received considerable attention, but there  
65 has been limited attention given to stigma and diabetes (Browne et al., 2014). A small body of  
66 research exists related to understanding stigma as a social construct in different cultures. Culture  
67 affects how people exhibit alternate thinking, feeling, and behaving processes that may affect  
68 stigmatization and discrimination towards people with diabetes. Such differences may affect the  
69 definition and manifestation of stigma (Weiss et al., 2006). A comprehensive understanding of  
70 stigma surrounding diabetes is important for informing policy and practice to improve the quality  
71 of care and quality of life for those living with diabetes (Schabert et al., 2013).

72 The literature review about stigma in diabetes aimed to describe stigmatizing features of diabetes  
73 in different countries around the world. The review of findings may provide a foundation for  
74 future research related to stigmatization in living with diabetes.

75 The Study:

76 **Design:** This article presents a narrative review of literature related to stigma in diabetes.

77 **Method:**

78 **Search Strategy:** Each search was completed using various combinations of these search words:  
79 diabetes, T1DM, T2DM, stigma, social/public stigma, internalized/self-stigma, stigmatization,  
80 and diabetes-related stigma. An electronic search of CINAHL, PubMed, and Web of Science was  
81 conducted by two reviewers (S.A. and M.D.I.) to identify manuscripts published between 2007  
82 and 2017 on diabetes and stigma.

83 **Inclusion Criteria:** Qualitative studies were included in this review of literature. Articles had to  
84 focus on stigmatization against people diagnosed with T1DM, T2DM, or both. Studies  
85 describing the stigmatized perception of people without diabetes toward those living with  
86 diabetes also were included. Studies that were excluded were not peer-reviewed, did not provide  
87 enough information about stigmatized features of diabetes, or described insufficient data related  
88 to stigma in diabetes for data extraction. Nineteen qualitative manuscripts were identified for  
89 inclusion in the review. Figure 1 shows the PRISMA flow diagram of this review.

90 **Data Extraction:** Two reviewers (S.A. and M.D.I.) evaluated abstracts to identify articles  
91 meeting the inclusion criteria. Then, eligible studies and full text of relevant articles to stigma in  
92 diabetes were carefully read by each reviewer independently. A data extraction form was adapted  
93 from the literature. Discrepancies between the two reviewers in the extracted data were resolved  
94 in consensus discussion.

95 **Ethical Statement:** The research team comprehensively reviewed all the relevant work and  
96 judged research quality and relevance. All the references also were acknowledged and fully  
97 cited.

98 **Results:**

99 Description of studies: Nineteen qualitative studies were analyzed in this narrative review. Ten  
100 studies included T1DM participants, eight studies included T2DM, and four studies included  
101 participants without diabetes. Five studies were conducted in an Asian population; two studies in  
102 Africa; and the remaining studies were conducted in the United States, Australia, and the UK.  
103 Study characteristics can be found in Table 1.

104 The literature review highlighted that diabetes-related stigma is a complex issue. Some themes  
105 are interrelated and could not be separated. In these manuscripts, people with diabetes were  
106 mostly stigmatized as “sick and disabled,” “death reminder,” “rejected marriage candidate,”  
107 “self-inflicting,” “contagious,” “requiring dietary modification,” and “drunk or drug abuser.”

108

109 **Sick**

110 Seven studies in different countries (the United States, Canada, Australia, India, Iran, and  
111 Palestine) reported that people with diabetes are stigmatized as being sick. The designation of  
112 “being sick” affects an individual’s ability to experience a normal independent life, and is a  
113 common diabetes-related stigma in Australia (Browne et al., 2014). One study in Iran found that  
114 young adults with diabetes perceive the social stigma of diabetes as being sick and disabled  
115 (Abdoli et al., 2013a). A similar result was found in Palestinian children with T1DM, who  
116 perceived diabetes as a stigmatizing condition that spoiled their identity as a healthy individual,  
117 making them feel like an outsider and not a normal person (Elissa et al., 2016). A study  
118 performed in a U.S. Arab American community found that individuals often viewed diabetes as a  
119 weakness or breakdown (DiZazzo-Miller et al., 2017). Indian mothers of children with diabetes  
120 experienced diabetes-related stigma when other people labeled their child as a “sick kid” (Verloo

121 et al., 2016). This finding is similar to Weiler’s study in 2007 and Weiler and Crist’s study in  
122 2009, where Mexican American participants with diabetes experienced stigmatization as “being  
123 sick” and referred to the stigma as “The Big D.”

#### 124 **Death reminder**

125 In three studies (Tajikistan, Iran, and Soweto), individuals with diabetes were stigmatized as  
126 a “death reminder.” Being a “death reminder” has a strong connection of being stigmatized as  
127 “sick.” Children with T1DM in Tajikistan described their experiences of how people predict  
128 their premature death by saying, “You are very sick! You will die soon; you will not have a long  
129 life” (Haugvik et al., 2016), which is similar to Abdoli et al. study (2013a) in Iran. Some  
130 participants in Mendenhall and Norris’s (2015) study also indicated how some people feel  
131 diabetes is a “death panel” by whispering about amputations due to diabetes and negative stories  
132 surrounding diabetes.

#### 133 **Marriage rejected candidate**

134 Diabetes-related stigmatization is considerably greater for younger, unmarried women,  
135 particularly in Asian countries. Delayed marriage is reported in people with diabetes in different  
136 countries such as Iran and India (Abdoli et al., 2013a). Iranians believe that women with diabetes  
137 are not suitable candidates for marriage due to high-risk pregnancies, the potential of having a  
138 child with diabetes, and the role of a woman in the Iranian family (Abdoli et al., 2013b). In a  
139 similar study in the UK, the South Asian community described public perception that views  
140 diabetes as a sign of physical inadequacy to traditional marriage (Singh et al., 2012). An  
141 unmarried Arab male in Australia described diabetes as a “disaster,” which makes both males  
142 and females with diabetes less desirable candidates for marriage due to a perceived connection  
143 between diabetes, erectile dysfunction, and the passing of diabetes to their children (Alzubaidi et  
144 al., 2013).

145 Marriage in India is a source of stress for individuals with diabetes and their families. Some  
146 Indian adolescents, especially girls with diabetes, experienced social stigmatization and were not  
147 wanted for marriage (Hapunda et al., 2015). This is also true for Indian mothers, who consider  
148 diabetes as a barrier for their daughters getting married (Verloo et al., 2016). Individuals with  
149 diabetes in London are thought to be unable to conceive or to have a normal pregnancy (Winkley  
150 et al., 2015).

151 A 2014 Australian study noted that participants experienced the termination (or threat of  
152 termination) of a romantic relationship due to diabetes. Fear of the negative impact of diabetes  
153 on their relationship was one of the main reasons highlighted by participants. They were worried  
154 about disclosing their diabetes to their partners or potential partners. It also was mentioned as a  
155 marriage barrier by some participants (Browne et al., 2014).

### 156 **Self-inflicting**

157 Nine studies have noted that the community's perception about the cause and nature of  
158 diabetes can be stigmatizing. In several countries such as Iran (Abdoli et al., 2013a), Australia  
159 (Browne et al., 2013), Taiwan (Lin et al., 2008), Ireland (Balfe et al., 2013), and the United  
160 States (Vishwanath, 2014), individuals with diabetes are considered to be self-inflicting the  
161 disease. There are two common beliefs about diabetes that can be stigmatizing for people with  
162 diabetes: (1) diabetes is an illness of over-indulgence with food (Lin et al., 2008) and (2) diabetes  
163 is a result of an individual's own actions (Brown et al., 2013; Vishwanath, 2014). For example,  
164 the findings of Vishwanath's (2014) U.S. study suggested that most participants described  
165 diabetes as a disease that affects children who are lazy, unhealthy, fat, obese, lacking exercise,  
166 and having an eating disorder (p. 516).

167 Overweight people, particularly in T2DM, are stigmatized for getting diabetes because of  
168 their lack of self-control. In some cultures such as Hispanic or Latino, diabetes is seen as a  
169 punishment from God. Weiler et al. (2007) wrote that the punishment ideology imposed a self-  
170 associated stigmatization, which is similar to the Abdoli et al. study (2013b) in Iran and the  
171 Brown et al. (2014) study in Australia.

### 172 **Drunk or drug abuser**

173 Social stigma attached to insulin injections as a form of drug abuse is another important  
174 feature of stigmatization in living with diabetes. For example, negative social connotations about  
175 insulin injections are seen in different countries. Insulin injections can be misunderstood as drug  
176 abuse in Iran (Abdoli et al., 2013b), Taiwan (Lin et al., 2008), and Australia (Browne et al.,  
177 2014). Tajukestani's children expressed being stigmatized as drug abusers while trying to inject  
178 insulin in public places (Haugvik et al., 2016). Australian participants also described being  
179 worried about, or having experienced, being mistaken for a drug abuser while injecting insulin.  
180 This was particularly the case for those who injected insulin with a vial and a syringe before the  
181 advancement of insulin pens and pumps (Browne et al., 2014). Participants with T2DM in Kuala



182 Lumpur also expressed their feelings of stigmatization as a barrier for insulin injection, which  
183 can be misunderstood or stigmatized as drug abuse (Abu Hassan et al., 2013).

#### 184 **Requiring dietary modification**

185 Reviewed articles referred to the stigmatization of people with diabetes due to life  
186 modifications, especially dietary modifications and restrictions. The required treatment regimen  
187 for diabetes management includes actions that often are noticeable by others. This includes  
188 eating at specified times, which may be associated with some degree of stigma (Chatterjee &  
189 Biswas, 2013). For example, in the United States, African American women in the Willig et al.  
190 study (2014) expressed their frustration towards family and friends who make decisions for them  
191 about what they can eat. Iranian participants also pointed to the stigma of people with diabetes  
192 because of dietary restrictions (Abdoli et al., 2013b).

#### 193 **Having a Contagious Disease**

194 A few of the reviewed articles indicated people without diabetes may stigmatize those living  
195 with diabetes as being contagious. For example, the Lin et al. (2008) study on Taiwanese  
196 individuals with T2DM found that some people believe diabetes is an infectious disease, and  
197 they stigmatize people with diabetes as contagious. Hapunda et al. (2015) noted that in Zambia  
198 there is a fear of getting diabetes in a social setting. Therefore, some children who participated in  
199 a study mentioned that the community perceived them as “infectious” and some of their peers  
200 would deny playing with them because they may catch diabetes (Hapunda et al., 2015).

201 **Limitations:** The limitation of this manuscript is having a retrospective review of previously  
202 published manuscripts chosen at the authors’ discretion and selected electronic databases.

#### 203 **Discussion**

204 Individuals with diabetes are stigmatized as sick and disabled (Browne et al., 2014; Weiler et  
205 al., 2007), which can be the underlying foundation of most of the stigma surrounding diabetes  
206 (Weiler & Crist, 2009). Being stigmatized as sick and disabled is itself a stigma in some cultures.  
207 This feature of stigma has the ability to make people dependent on others throughout their life  
208 and impose a financial burden on family and society (Abdoli et al., 2011). It also leads to a  
209 greater burden for people with diabetes in certain population sub-groups such as young adults  
210 and women, particularly in Asian countries (Abdoli et al., 2013a; Doosti Irani, 2014). Some  
211 Asian countries view diabetes as a sign of physical inadequacy rooted in being sick and disabled.  
212 This perspective leads to a disproportionate burden of diabetes on young adults, particularly

213 women, and affects their marriage potential. People in Asian countries assume that those living  
214 with diabetes cannot perform duties as a mother or as a marital partner since they are considered  
215 “sick and disabled” (Abdoli et al., 2013b). Individuals with or without diabetes think that women  
216 with diabetes are infertile or at a high risk for pregnancy (Abdoli et al., 2011). Women are  
217 thought to transmit diabetes to their child, who will inevitably suffer fetal death or be born with  
218 other congenital disorders. Men are considered to be sexually dysfunctional due to diabetic  
219 impotency. The financial burden of diabetes medication and associated complications is of great  
220 concern to men and women affected with diabetes (Browne et al., 2014).

221 Even in the 21st century, communities are not aware of diabetes etiology and some consider  
222 diabetes a punishment or a result of one’s lack of self-control (Browne et al., 2013; Lin et al.,  
223 2008; Viswanathan, 2014). Individuals also do not feel safe to inject insulin in public places  
224 because they might be misunderstood as a drug abuser or drunk while they are experiencing  
225 symptoms of hypoglycemia (Abdoli et al., 2013b; Browne et al., 2014; Lin et al., 2008).

## 226 **Conclusion**

227 This review of articles indicates the issue of stigmatization for people with diabetes has been  
228 an ongoing significant psychosocial issue associated with diabetes globally. Although an  
229 increasing number of declarations and laws are aimed at health equality of people with diabetes,  
230 discrimination and stigmatization is still broadly diffused (Benedetti, 2014). The review  
231 highlighted misconceptions and negative or exaggerated beliefs about diabetes in different  
232 countries continue and must be addressed to end diabetes-related stigma. Creating a world  
233 knowledgeable about diabetes would alleviate the stigma surrounding diabetes in different  
234 cultures. Healthcare professionals, especially those working with people with diabetes, must  
235 consider strategic and worldwide policies including community education, family education,  
236 and education for healthcare providers as a core component in all destigmatizing programs and  
237 activities. It is also necessary to discuss stigma and help individuals identify strategies addressing  
238 stigma related to diabetes as well as the pivotal role of individual involvement in advocacy and  
239 policy efforts related to diabetes.

240

241 Diabetes self-management education requires addressing the stigma while trying to empower  
242 those living with diabetes, particularly in Asian, Middle Eastern, and African-American  
243 communities.

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**Table 1: Included studies related to stigma in diabetes**

<b>Authors</b>	<b>Study design</b>	<b>Samples population</b>	<b>Sample size</b>	<b>Study setting</b>
Abdoli et al. (2013a)	Content analysis	Adults with T1DM and without diabetes	26	Iran
Abdoli et al. (2013b)	Content analysis	Adults with T1DM	33	Iran
Alzubaidi et al. (2015)	Content analysis	Arab and Caucasian adults with T2DM	100	Australia
Browne et al. (2013)	Content analysis	Adults with T2DM	25	Australia
Browne et al. (2014)	Content analysis	Adults with T1DM	27	Australia
DiZazzo-Miller et al. (2017)	Content analysis	Arab American health care providers	8	U.S.
Elissa et al. (2016)	Content analysis	Children with T1DM	10	Palestine
Hallgren et al. (2015)	Content analysis	Marshallese with T2DM	15	U.S.
Hapunda et al. (2015)	Content analysis	Adolescence with T1DM, caregivers, health care providers	22	Zambia
Haugvik et al. (2016)	Content	Children with T1DM,		Tajikistan

	analysis	parents and endocrinologist	41	
Lin et al. (2008)	Content analysis	Adults with T2DM	41	Taiwan
Mendenhall & Norris (2015)	Content analysis	Adults with T2DM	27	Soweto
Singh et al. (2012)	Content analysis	Adults with diabetes	20	UK
Verloo et al. (2016)	Content analysis	Children with T1DM and parents	11	India
Vishwanath, A. (2014)	Content analysis	T1DM	N/A	U.S.
Weiler (2007)	Content analysis	Latino adults with T2DM	10	U.S.
Weiler, & Crist (2009)	Content analysis	Latino adults with T2DM	10	U.S.
Willig, A. L. et al. (2014)	Content analysis	African American	35	U.S.
Winkley et al. (2015)	Content analysis	Adults with T2DM	30	UK

Figure 1-PRISMA flow diagram for manuscript related to stigma in diabetes

