Perceived Stigmatization among Younger and Older American Adults with Type 1 Diabetes

*Sangeeta Singg, Taylor Johnson
*Professor of Psychology, Angelo State University, San Angelo, Texas 76909, USA

Abstract

Although there is a plethora of studies dealing with health-related stigma of many diseases, Type 1 Diabetes (T1D) has been neglected in this respect. The purpose of the present exploratory study was to devise a preliminary scale to measure the health-related stigma and compare younger and older individuals with T1D with regard to the length of time since diagnosis. A 12-item Type 1 Diabetes Stigma Scale (T1DSS-12) was created and used with 61 college students enrolled in an American university. All of these students were diagnosed with T1D and were members of the university chapter of the College Diabetes Network. The T1DSS-12 included questions about perceived health-related stigma and psychosocial effects of T1D. Perceived health-related stigma was found to be frequent among the participants of the current study. A 2x2 factorial analysis of variance results showed that younger participants experienced more health-related stigma after being diagnosed with T1D than the older participants regardless of the length of time since diagnosis. Most of the participants felt that the public did not have much knowledge about T1D, which contributed to stigmatization of the disease. It was concluded that the T1DSS-12 would be a useful tool to assess the level of health-related stigma one experienced after being diagnosed with the T1D. It was suggested that the persons with TID and their families need to be educated soon after the diagnosis and the T1D treatment programs should include psychosocial support components.

Keywords

Type 1 Diabetes; Health-Related Stigma; Social Stigma; Type 1 Diabetes Stigma; Type 1 Diabetes Awareness; Diabetes Education; Type 1 Diabetes Stigma Scale; T1DSS-12

Introduction

The process of stereotyping in which a person or group is linked to undesirable characteristics is termed as stigmatization [1]. Stigmatization of a disease involves “devaluation, judgment, or social disqualification” of persons with a health condition such as diabetes, AIDS, schizophrenia, etc. [2]. Diabetes, one of the stigmatized diseases continues to be a growing problem not only in the U.S. but also in the rest of the world. According to the World Health Organization (WHO) [3], the global prevalence of diabetes among adults (18 years or older) rose from 4.7% (108 million) in 1980 to 8.5% (422 million) in 2014. The Centers for Disease Control and Prevention (CDC) [4] reported that 9.4% (30.3 million) of U.S. adults have a diagnosis of diabetes (seventh leading cause of death), which is about 1 in 10 adults. Only 5% of these have Type 1 diabetes (T1D) which is about 1.25 million adult U.S. population.
Both T1D and T2D are chronic diseases that affect the way one’s body regulates blood sugar or glucose. However, there are some important differences, in T1D, the body makes little or no insulin due to an overactive immune system, while in T2D, the body prevents the insulin it makes from working right. T1D cannot be cured, while T2D can be reversed with lifestyle changes. T1D requires a highly regimented, self-regulated treatment plan needing either multiple injections of insulin daily or an insulin pump, which delivers insulin subcutaneously at all times [5]. T2D may be managed with medication and lifestyle changes. Historically, the outcome for people with T1D was grim with much shorter life expectancies. They were advised not to have children and were considered unable to have normal and fulfilling lives [6]. With better technology and medical advancement, the treatment options have improved for insulin delivery and blood glucose monitoring allowing people with T1D to lead full and active lives. Notwithstanding all of the advancement, stereotypes about diabetics have not changed [6].

Because of the epidemic of obesity and its strong correlation to T2D, researchers have focused mainly on the health-related stigma about T2D [7] while T1D has been neglected with only a few studies addressing this issue. Also, the earlier studies of diabetes only examined causes of “diabetes distress” and reasons for lack of treatment adherence among persons with T1D and T2D [8]. However, a recent study of over 5000 people living with diabetes reported that 76% of people with T1D felt stigmatized compared to 52% of people with T2D [9]. Thus, the focus of the present study is the perceived health-related stigma by persons diagnosed with T1D because of the paucity of research in this respect.

It is important to note that emotional distress experienced by persons with diabetes affects their overall physical health. Emotional distress and social or relational problems associated with diabetes have been linked to poorer control of blood glucose levels which can lead to short-term and long-term complications that can significantly reduce the lifespan of persons with diabetes [10]. Two meta-analyses highlight this link and reiterate why there is an urgent need to address the psychosocial aspects of diabetes in order to improve physical health. Lustman et al. [11] conducted a meta-analysis of 24 studies published between 1975 and 1999 that explored the connection between depression and poor glycemic control. They concluded that the literature overwhelmingly supported a link between depression or depressive symptoms and hyperglycemia or high blood glucose levels. The authors also pointed out that in other research trials, treatment of depression has shown improvements in glycemic control. Anderson et al. [12] conducted a meta-analysis of 11 studies published prior to 2002 that explored anxiety experienced by persons with T1D and T2D. They found a correlation between anxiety and hyperglycemia. They proposed that the treatment of anxiety could lead to improved hemoglobin A1c levels that would lead to a longer lifespan and healthier quality of life for persons with diabetes. The psychological problems experienced by persons with diabetes may increase the likelihood of serious long-term complications such as blindness, loss of limb, coma, or death. Because the focus of the present study is T1D, psychological problems associated with T1D identified by previous research are summarized below.

In a study of 35 young adults diagnosed with T1D, researchers [8] reported that stigma and self-consciousness play a role in the development of psychosocial problems in young people. The patients tend to feel “awkward” managing their diabetes in front of others, for example taking insulin injections. Another study [13] of 18-28 years old 92 adults in Western Australia diagnosed with T1D examined the psychological well-being and behavioral problems and concluded that young adults seem to be particularly vulnerable to psychosocial problems associated with T1D. Depressive symptoms were found to be associated with poorer glycemic control. Interestingly, and perhaps alarmingly, Hislop et al. also found that the use of insulin pump therapy, most advanced and preferred method of treatment for T1D, was associated with a greater number of depressive symptoms, greater number of psychological problems overall, and externalization of distress. A study of 123 adolescents with T1D examined psychosocial barriers to treatment adherence [14]. The results showed that the adolescents experienced frustration, stress, anxiety and a lack of motivation to manage their T1D. Perceived stigma was found to be an indicator of poorer overall metabolic control.

One’s quality and satisfaction with relationships can also affect treatment adherence and level of adjustment to a chronic illness [15]. In a survey of 70 adolescents with T1D and their peers attending a summer camp, the peers reported that they needed more information on T1D to help their friends manage their illness. Youth with T1D reported that they lost friends because of their diagnosis and felt hesitant to disclose to their friends about their diabetes. While this study focused on how diabetes affected the relationships with peers of adolescents with T1D, a study of 76 adolescents by Helgeson, Lopez, and Kamarck [16]
examined how peer relationships and social support were connected to diabetes management and overall health of individuals with T1D. The results of this study indicated that negative interactions and conflict along with the presence of depressive symptoms were linked to poorer self-care and metabolic control among adolescents with T1D. Shifting gears from platonic peer interactions, there have been relatively few studies that have looked at the effect T1D can have on romantic relationships or on how the quality of those relationships can affect metabolic control/diabetes management. Helgeson et al. [17] collected annual surveys from 117 with and 122 without T1D high school seniors for three years. Each year participants completed a battery of surveys that measured friendship and relationship variables, disturbed eating behaviors, psychological distress, lifestyle satisfaction, and diabetes outcomes for diabetic participants. The results showed that women with T1D in emerging adulthood had fewer romantic relationships and less social support than did men and their non-diabetic peers. Similar to Helgeson et al. [16], the results of the study by Helgeson et al. [17] also support that the presence and quality of social relationships are important for health outcomes among persons with diabetes. A study [18] of 20 adults with T1D in Denmark found that peer support was highly relevant to reduce a burdensome feeling of diabetes-specific loneliness. Participants reported peer support to be of particular importance in relation to big changes in family life, at work, or through treatment events such as getting an insulin pump.

Because the daily burdens, required lifestyle changes to manage diabetes, and lack of public awareness have led to the diabetes related stigma, more research is needed to fully understand and control this issue. Browne et al. [7] and Browne, Mosely, Speight, and Ventura [19] conducted studies exploring the social experiences of Australian adults living with T2D and T1D respectively. In a study of 25 adults with T2D, 84% of the participants reported feeling socially stigmatized. The stigma involved blame, negative social judgement, stereotyping, exclusion, rejection and discrimination. Browne et al. [7] suggested that future research should explore this problem with persons with T1D. Thus, they conducted another study [19] of 27 individuals with T1D and stigma. In this study, 93% of participants felt that T1D was a stigmatized condition. The media, family/friends, healthcare professionals and schoolteachers were identified as sources of stigma. The effects of this stigma included impact on relationships/social identity, emotional wellbeing, and management of T1D. This study was limited to people in Victoria, Australia.

Although there is a plethora of studies dealing with health-related stigma of many other diseases [20], the research with T1D is limited. No study to our knowledge has compared young and older adults with regard to their perceived stigma of having T1D. Therefore, the purpose of the present exploratory study was to devise a preliminary scale to measure the T1D-related stigma and compare younger and older individuals with T1D with regard to the length of time since diagnosis. This was accomplished by examining the participants’ perception about negative treatment due to their T1D and constructing a tool to measure their perception of stigma associated with the disease. The two independent variables of the study were Age and Length of Time since Diagnosis (LTSD). The dependent variable was Perceived Health-Related Stigma measured by the Type 1 Diabetes Stigma Scale-12 (T1DSS-12).

Methods
Participants

Eighty university students who were members of the College Diabetes Network (CDN) [21] at a university in Texas, USA were invited to participate in the current study. The CDN is a non-profit national organization with chapters on various campuses that provide resources for persons with diabetes in college. All students were diagnosed with T1D. Of these 80 students, 6 did not respond and 13 surveys were incomplete. Thus, the study retained 61 participants (Age M = 22.02, SD = 6.25; LTSD M = 8.86 years, SD = 6.97; 87% women). They were divided into two age groups, Younger (18-20 years of age) and Older (21 years or older), and two groups of LTSD, diagnosed less than 10 Years and 10 or More Years (<10 and 10+).

Instruments

The online survey included an informed consent statement for participants to read and voluntarily agree to participate, demographic questions, and the T1DSS-12. The T1DSS-12 consists of 12 items (see Table 1) to be answered, “strongly disagree” to “strongly agree” on a five-point Likert scale with scores ranging from 12 (low) to 60 (high; the higher the score, the greater the perceived health-related stigma).

The T1DSS-12 was modeled after Link and Phelan’s [1] “Stigma Consciousness Scale” and...
after Neumark-Sztainer, Story, and Faibisch’s [22] “Stigmatization Among Overweight Adolescents Interview Questionnaire.” These two questionnaires address health-related stigma. The data yielded an Alpha coefficient of .72 for the T1DSS-12 showing an acceptable level of internal consistency.

Table 1: Type 1 Diabetes Stigma Scale-12 (T1DSS-12) Items

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
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<tbody>
<tr>
<td>1. Stereotypes about people with Type 1 Diabetes have not affected me personally.</td>
<td></td>
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<tr>
<td>2. People have treated me in a negative or hurtful way because I have Type 1 diabetes.</td>
<td></td>
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<tr>
<td>3. Others sometimes make negative assumptions about me because I have Type 1 diabetes.</td>
<td></td>
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<tr>
<td>4. Some people assume I am unhealthy because I have Type 1 diabetes.</td>
<td></td>
</tr>
<tr>
<td>5. I think that people have judged me based on stereotypes of people with Type 2 diabetes.</td>
<td></td>
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<tr>
<td>6. People have assumed that I am not healthy because they don’t know enough about Type 1 diabetes.</td>
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<tr>
<td>7. Type 1 diabetes has affected my relationships with family members.</td>
<td></td>
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<tr>
<td>8. I sometimes hesitate to disclose that I have Type 1 diabetes to new friends or coworkers.</td>
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<tr>
<td>9. My friends have excluded me from some social events due to my Type 1 diabetes.</td>
<td></td>
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<tr>
<td>10. The media contributes to misconceptions of Type 1 diabetes such as “only children are diagnosed with Type 1 diabetes.”</td>
<td></td>
</tr>
<tr>
<td>11. There are currently no realistic depictions of Type 1 diabetics in popular culture (movies, television, etc.).</td>
<td></td>
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<tr>
<td>12. I feel like health professionals blame me for complications with my diabetes.</td>
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Procedure

After the approval from the university institutional review board, CDN posted the invitation to participate in the study on Facebook, Twitter, and their organization’s blog. Participants were informed about the purpose of the study and were asked to complete a short online survey. They could only access the survey if they indicated that they read the consent information and voluntarily agreed to participate in the study. The participants were asked to complete the demographic questions and T1DSS-12 by choosing one of the following five responses: “strongly disagree,” “disagree,” “neither agree nor disagree,” “agree,” and “strongly agree.” In order to gain more insight into the experiences of persons with T1D, participants were given the option to elaborate on their experiences in a box next to each item.

Results

A 2 x 2 factorial ANOVA results (see Table 2) showed a significant main effect of Age on T1DSS-12 scores ($F_{1,57} = 4.19, p < .045$) with higher mean T1DSS-12 score for younger participants ($M = 43.69, SD = 5.42$) than the older participants ($M = 40.03, SD = 7.16$). The main effect of LTSD ($F_{1,57} = .17, ns$) and interaction between Age and LTSD ($F_{1,57} = .01, ns$) were not significant. A descriptive analysis of the data yielded some interesting outcomes presented below.

Table 2: Mean Type 1 Diabetes Stigma Scale-12 (T1DSS-12) Scores, Standard Deviations, and F Values for Age x Length of Times since Diagnosis (LTSD)

<table>
<thead>
<tr>
<th>Variable Description</th>
<th>M</th>
<th>SD</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td>4.19*</td>
</tr>
<tr>
<td>Younger (18-20 years old)</td>
<td>43.69</td>
<td>5.38</td>
<td></td>
</tr>
<tr>
<td>Older (21+ years old)</td>
<td>40.03</td>
<td>7.16</td>
<td></td>
</tr>
<tr>
<td>LTSD</td>
<td></td>
<td></td>
<td>0.17</td>
</tr>
<tr>
<td>Less than 10 years (&lt;10)</td>
<td>41.49</td>
<td>6.89</td>
<td></td>
</tr>
<tr>
<td>10 or more years (10+)</td>
<td>42.24</td>
<td>5.78</td>
<td></td>
</tr>
<tr>
<td>Age x LTSD</td>
<td></td>
<td></td>
<td>0.01</td>
</tr>
<tr>
<td>Younger/&lt;10</td>
<td>43.39</td>
<td>5.38</td>
<td></td>
</tr>
<tr>
<td>Younger/10+</td>
<td>44.00</td>
<td>5.94</td>
<td></td>
</tr>
<tr>
<td>Older/&lt;10</td>
<td>39.60</td>
<td>8.42</td>
<td></td>
</tr>
<tr>
<td>Older/10+</td>
<td>40.47</td>
<td>5.61</td>
<td></td>
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*p < .045
Of the 61 participants, 53% felt that T1D-related stigma affected them personally, 49% reported being treated in hurtful way, 59% indicated that sometimes others made negative assumptions about them because of their diagnosis, and 85% felt judged because of people’s stereotypes about T2D and lack of knowledge about T1D. Several elaborations by participants indicated others having misinformati on about diabetes especially regarding dietary habits and weight. A few of the elaborations are presented below.

“People try to police what I eat when they find out I have diabetes.”

“People just always assume they know what I can/can’t eat. Or that my diabetes is curable by losing some weight,”

“Denied dessert publicly at a function.”

“I’ve been told I can’t eat something, asked not to inject in public, been angry with me for not sharing food.”

“It's because you ate too much sugar, right?" "Eww needles, I could never do that”

“People assume I have diabetes due to my weight. I am overweight but I do not see myself as huge or gross, but some people do and think I must have given it to myself.”

With regard to social relationships and interactions, 54% of participants reported that their diagnosis had affected their relationships with family members and 62% hesitated to disclose their condition to new friends or coworkers. About media representation, 84% agreed that the media contributed to misconceptions about T1D, for example the misconception about children being the only ones diagnosed with T1D. Further, 85% agreed that persons with T1D were not depicted realistically in popular culture (movies or on television, etc.) and 84% believed that others considered them unhealthy due to their lack of knowledge about T1D. In response to the treatment by healthcare professionals, 51% felt that they were blamed for their complications with T1D.

Discussion

The results of the present study indicated that majority of the people with T1D do report experiences of health-related stigma which supports the findings by Brown et al. [19]. However, in our study this finding is tempered by age. The statistical results showed a significant difference between T1DSS-12 mean scores of Younger and Older adults regardless of the length of time since their diagnosis of T1D. Interestingly, the Younger persons with T1D tended to perceive greater health-related stigma than the Older persons with T1D. Thus, it did not matter how long one was diagnosed with T1D. Instead, what mattered was one’s age in perceiving the health-related stigma. It makes sense because age related maturity and experience help persons deal better with difficult health related situations. Although not directly related, this finding coincides with the findings by Adams [20]) and Piazza, Charles, and Almeida [23] who compared younger and older persons with multiple chronic diseases including diabetes. Adams found that younger adults were more likely to report depression and worse quality of life than did the older adults. Piazza et al. found that at every level of illness, younger adults reported lower levels of global affective wellbeing and higher levels of daily negative affect than did older adults. Their explanation was that younger adults might be facing a greater number of personal challenges compared to older adults that affected their perception of things.

The finding that a large portion of participants (85%) felt that the stigma they experienced was directly related to people’s stereotypes about T2D also supports the results of the study by Brown et al. [19]. Several participants expressed frustration that the general public is unaware of the differences between T1D and T2D and that more emphasis needs to be placed on differentiating the two conditions especially in mainstream media.

While the majority of participants agreed that T1D affected their relationships with family members, the family relationships were not the typical elaborations given when recalling stigmatizing experiences. Participants instead focused on friendships and romantic relationships as relationships that were difficult to navigate in light of their diagnosis. Some participants gave detailed information about romantic partners who criticized them for diabetes management practices such as wearing their insulin pumps, taking insulin shots, or checking their blood sugar in public. Participants cited similar difficulties in platonic relationships as well.
Another interesting aspect of T1D-related stigma that emerged in this study was concept of "health." Both in treatment of people with T1D by health professionals and assumptions made by family and friends about their health were provided as examples of times when they felt stigmatized. Of the 61 participants, 84% agreed with the statement - "People have assumed that I am not healthy because they don’t know enough about Type 1 diabetes.” The following examples were given of being questioned about their diet, weight, and control of their blood glucose levels: “People often try to police what I eat when they find out I have diabetes” and “People ask me why I have diabetes because I’m not fat.”

There were some unexpected topics broached in open-ended response items. A number of participants responded that they were stigmatized or discriminated against in the workplace: “I’ve also had jobs where I was told I wasn’t allowed to have food on me or where taking an early bathroom break wasn’t an option,” “And then if you are allowed any of those things, there’s this air of ‘you should have thought of that earlier’ that makes it difficult to take care of myself properly.” It would be interesting for future research to examine the workplace or school discrimination experiences of people with T1D.

The results of the present study contribute to the literature on perceived health-related stigma among adults with T1D. However, a few limitations of the study need to be noted. First, participants were recruited from an organization of persons with diabetes. It is possible that those who are members of such an organization have worked through many of their uncomfortable feelings about experiencing health-related stigma. In addition, the small sample size with a small number of males, limits the extent to which results can be generalized. It may be that men and women have different experiences regarding stigma; thus, the differences should be examined in future research. Further, in order to help maintain anonymity of the respondents, some of the demographic information was not obtained, which prevented analyzing data by ethnic groups because perceived health-related stigma might vary among different ethnic groups with T1D.

Overall, the biggest trend in this study was that a lack of public knowledge about diabetes and diabetes care has led to experiences of stigma and discrimination. Participants expressed frustration at being frequently misunderstood and shamed because of their illness. Unfortunately, in addition to being emotionally draining, these experiences have a very real impact on the health of people with T1D who are not comfortable performing the actions necessary to manage their illness. As stated previously, glucose control is imperative to reducing diabetes complications and improving the quality of life for those diagnosed so any efforts to reduce psychological discomfort or educate the non-diabetic population about diabetes would be a step forward. One participant aptly stated how persons with T1D feel about their illness and how they are treated: “We are human beings with feelings who had no control over being diagnosed with type one diabetes. It would be nice if people treated us as such.”

Since most of the participants felt that the public did not have much knowledge about T1D that led to stigmatization, it was concluded that the T1DSS-12 would be a useful tool to assess the level of health-related stigma one experiences after being diagnosed with T1D. This would be helpful with the management of the disease and planning awareness programs. Perceived health-related stigma is frequent and is experienced more when one is younger. Efforts to alleviate the stigma related to T1D are needed. TID treatment program should include educational and psychosocial support components for patients and their families. Since Age is an important factor when it comes to perceived health-related stigma, professionals need to support and educate individuals with T1D as early as possible.

Stigmatization is one of the major obstacles to good care of persons with any stigmatized illness. The health care industry and government agencies of many countries have begun to recognize this fact by launching campaigns to raise awareness and creating laws to protect against discrimination in areas such as housing and the work place [24]. However, as the present study indicates, these efforts are far from optimal. Persons with T1D face criticism and confrontation for simply having their diagnosis, and when they take actions to treat their condition, they are met with impatience and intolerance. This state of affairs is unacceptable. Additional efforts by schools, universities, and work places and more effective policies are needed to combat T1D stigma; otherwise, persons with T1D will continue to experience suboptimal treatment, decreased quality of life, and discrimination.

References
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