Investigation of the Presence and Impact of Social Stigma on Patients with Diabetes in the USA
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Introduction
Social stigma is described as a set of negative beliefs, or a mark of disapproval, that society has about a person or group with a particular characteristic (e.g., a health condition). Society’s perception of a health condition may often lead to a particular stigma, and how patients feel socially about their disease can have a significant impact on treatment. Our study’s goals were to determine whether patients felt a social stigma was attached to diabetes, and to explore the impact of perceptions of diabetes on the dQ&A Panel (n=5,410) of Type I diabetes (T1D) and Type 2 diabetes (T2D) patients in the USA. We data demonstrate that both T1D and T2D patients believe diabetes is accompanied by social stigma — a feeling that increases with intensity of disease and disease treatment — and this stigma ultimately influences the disease management and social interactions of individual patients.

Figure 1. Characteristics of the dQ&A USA Patient Panel (typical survey response).

Does diabetes come with social stigma? Who feels it?

Figure 2. Diabetes stigma presence in the USA. Percentage of respondents who believe diabetes comes with social stigma. Three quarters of T1D respondents (including parents of children with T1D (T1K n =199) and adults with T1D (T1A n = 1,344)) and more than half of T2D respondents (on insulin (T2NI n = 2,130), and T2D on a pump or multiple daily insulin injections (MDI) (n=550)) felt there was a diabetes stigma presence in the USA.

Figure 3. Diabetes stigma presence by demographic group. Percentage of T1 (n=1,178) and T2 (n=3,060) respondents who feel diabetes comes with a social stigma did not vary significantly* by annual household income (below) or by region, education, or duration of diabetes. ( *Statistical significance tested at the 90% confidence level)

<table>
<thead>
<tr>
<th>Income Level</th>
<th>T1</th>
<th>T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;$51K</td>
<td>74%</td>
<td>76%</td>
</tr>
<tr>
<td>$51K-$99K</td>
<td>76%</td>
<td>79%</td>
</tr>
<tr>
<td>$100K-$149K</td>
<td>81%</td>
<td>78%</td>
</tr>
<tr>
<td>$150K-$199K</td>
<td>56%</td>
<td>52%</td>
</tr>
<tr>
<td>$200K+</td>
<td>51%</td>
<td>53%</td>
</tr>
</tbody>
</table>

Figure 4. Types of diabetes stigma. Share of respondents who believe people with diabetes face the following forms of stigma (Base: respondents who believe that diabetes comes with social stigma n=3,154).

- Perception of failure of personal responsibility: 72%
- Perception of being a burden on the healthcare system: 65%
- Perception of having a character flaw or fault: 52%

How are the lives of those with diabetes affected by other people’s perceptions of diabetes?

Figure 5. Diabetes management and social impact of perceptions of diabetes. Percentage of respondents who strongly agree that “other people’s perception of diabetes made it more difficult for me to...”

- 24% strongly agree (A1C levels 9 or more only)

What feelings have people with diabetes experienced?

Figure 6. Emotional impact of diabetes: by diabetes type and therapy. Percentage of adult respondents strongly agreeing* that they have experienced ONE of the following: guilt, shame, embarrassment, isolation or blame by diabetes type and therapy.

- T1K: 76%
- T1A: 52%
- T2N: 61%
- T2P: 52%

Conclusions
The answer to whether diabetes comes with social stigma in the USA was a resounding ‘yes’ among patients who are T1D (76%), T2D on MDI/pump therapy (61%), and T2D who are not on insulin (49%). Additionally, respondents felt other people’s perceptions of diabetes have had a negative impact on their diabetes management (27% of T1A, 42% of T2I, and 37% of T2NI) and more notably, in their social lives (53% of T1A, 76% of T2I, and 58% of T2NI). How diabetes stigma is experienced did not vary by demographics or duration of diabetes, but increased with intensity of disease type and therapy. We found that one third of T1 (38-39%) and T2 on MDI/pump (35%) were more likely to experience guilt, embarrassment, shame, isolation, or blame, while this result was lower in respondents on less intensive therapies (30% in non-MDI T2 insulin users, 21% in T2 on oral only, and 20% in T2NI). The feeling of stigmatization also increased with poorer glucose control (39% for A1C>8%), higher BMI (29% for BMI >35) and lower self-reported diabetes control. Collectively these data highlight factors that affect the social stigma associated with diabetes and point to the need for more public education to shift perceptions about diabetes, alongside advances in patient treatment.