Diabetes Stigma
Who feels it, what’s the impact, and what can we do about it?
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Diabetes may be “invisible,” but it does have socially identifiable characteristics

Research Methods
Online survey sent to 12,000 people with diabetes in December 2013 (dQ&A Patient Panel)
n=5,422 responded to questions on stigma
• n=1,572 with type 1
• n=3,850 with type 2

Does diabetes come with social stigma?

Type 2

Type 1

(p<0.0001)

Does diabetes in the US come with social stigma?
Who feels it the most?
How does stigma impact patients?
What can we do about it?

Wait, type 1s feel way more stigma than type 2s? Huh?!
Stigma = Deviance
T1D more visible

In type 2, stigma actually increases as therapy intensity (visibility) rises!

Most widely reported forms of stigma (all respondents)
- Having a character flaw or failure of personal responsibility: 81%
- Being a burden on the healthcare system: 65%

Parents of children with type 1 feel the most stigma – by far!

Parents of children with type 2 feel:
- No insulin: 51% No, 49% Yes
- Intensive Insulin: 39% No, 61% Yes

“Fat and lazy and overeat all the time.”

“...It is always the person’s fault by being overweight and eating too much sweets and candy.”

Parents of children with type 1 feel:
- No: 17% Yes: 83%

Parents of children with type 2 feel:
- No: 51% Yes: 49%

Parents of children with type 2 on Intensive Insulin:
- No: 39% Yes: 61%
“Insurers don't like diabetics, due to perceived costs to them.”

“I have been fired for having Diabetes. People act like Diabetes is contagious ... I have had boyfriends break up with me ... People act like I have the plague and more.”

How have others’ perceptions of your diabetes impacted your emotional life?

“Diabetes can be depressing – to feel like you have done everything right and still get a 225 mg/dl on the meter.”

– Lyft driver on way to SFO
Females = more likely to feel guilt, shame, blame, embarrassment, isolation

I’m in “poor control” vs. “excellent control”: ~1.5-3x feel guilt, shame, blame, embarrassment, isolation

A1c >9% vs. <6% = more likely to feel guilt, shame, blame, embarrassment, isolation

More intense therapy
Female
Higher BMI
Higher A1c
Poorer self-reported control

The people with diabetes most in need of help are also the most impacted by stigma!
Do people with type 1 & type 2 feel the same kind of stigma? Guess which box is which type:

<table>
<thead>
<tr>
<th>I wish...</th>
<th>I wish...</th>
</tr>
</thead>
<tbody>
<tr>
<td>That my family would not try to monitor my food and exercise.</td>
<td>That people knew how dangerous it can be.</td>
</tr>
<tr>
<td>That people knew how to help me when I’m hypoglycemic.</td>
<td>That people knew that I’m doing fine.</td>
</tr>
<tr>
<td>That people knew we didn’t ask for this disease.</td>
<td>That a cure could be found.</td>
</tr>
<tr>
<td>… people knew how much it cost to buy strips, meters, lancets, medications, quality food choices.</td>
<td>That I did not have to hide when I take insulin outside the house.</td>
</tr>
<tr>
<td>That my doctor recognized my efforts to manage my diabetes and respected my choices more.</td>
<td>That society understood that my diabetes is my business.</td>
</tr>
<tr>
<td></td>
<td>That people did not equate diabetes with being fat or lazy.</td>
</tr>
<tr>
<td></td>
<td>That people knew how diabetes wears me out.</td>
</tr>
</tbody>
</table>

Ways to reduce diabetes stigma

- Increase public knowledge about the general causes of diabetes
- Increase education on the management of diabetes (e.g., different therapies)
- Change the wording? (19% of type 1s, 0% of type 2s)

If there were one thing you would recommend to reduce the stigma associated with diabetes, what would it be?

“People need to be enlightened on how difficult it is to live with it each day.”

“Counter the false claims that are popular (reversing diabetes).”

“Teach children in schools about diabetes as they did with HIV. Don’t hide your diabetes: Test and inject wherever and whenever you need to.”
“Nationwide PSAs on primetime network TV aimed at removing stigma. I am strong. I am healthy. I have diabetes. It chose me, I did not choose it.”

Conclusion
1. A disturbingly high percentage of people with diabetes experience stigma, particularly those on intensive insulin therapy, females, and parents.
2. Stigma disproportionately impacts those with a higher BMI, higher A1c, and poorer self-reported BG control: those that need the most help are also the most impacted by stigma.
3. We can do a much better job of educating the public about diabetes, what causes it, and how hard it is to live with.

Study Limitations
Self-reported data
Online survey
Not enough ethnic diversity
Parents’ reported stigma may not reflect child’s experience

Future Questions
How is stigma different in type 1 vs. type 2?
How does diabetes stigma impact daily life?
What therapies & technologies reduce feelings of stigma?
How can we reduce feelings of failure and guilt?
How do healthcare providers promote stigma? How can they improve?
How might we better educate the media about diabetes?
What can we learn from other therapeutic areas?

If you would like to sign up to be part of the dQ&A Diabetes Educator Panel, contact Richard.wood@d-qa.com

www.diaTribe.org
Appendix