

OP-0166–Perceptions of Stigma in the Diabetes Online Community: Challenges of day-to-day living shared during Twitter chats



Deborah A. Greenwood, PhD, RN, BC-ADM, CDE; Perry M. Gee, PhD, RN; Mila Ferrer, BA; Mariana Gomez, BA; Corinna Cornejo, BA; Kathy Fatkin-Nelson, PhD; James Ferrer, BA; Kelly Kunik; Rui Santos; Lisa Soederberg Miller, PhD



Background: The diabetes online community (DOC) creates a safe place where people can share experiences and not feel alone while living with a chronic condition. In a 2015 study of Tweet chat data, the theme of stigma surfaced as a key reason why people with type 2 diabetes do not engage in the DOC. Self-management of diabetes is challenging, more so when there are feelings of stigma created by misinformation and/or lack of empathy.

Aims: The objective of this research project was to discuss the theme of stigma in diabetes during online social networking discussions to identify common perceptions and opportunities to raise awareness.

Methods: Questions adapted from the Diabetes Stigma Assessment Scale (DSAS-1 and DSAS-2) were used to develop a survey completed by English and Spanish speaking DOC members. They were asked to rank the questions that resonated with them the most regarding their experience of diabetes and stigma. The top seven questions were presented during two Tweet chats. A verbatim transcript of publicly available Twitter data (Symplur LLC, Pasadena, CA), during 2 Tweet Chats (1107 tweets from 150 individual participants) in English and Spanish in November 2016, were evaluated using a qualitative content analysis, completed first manually and then using NVivo Version 11 qualitative analysis software (QSR International Pty Ltd. Version 11, 2017). The analysis began with open coding to analyze the data as a whole. The data were then grouped into broad categories and sub-categories within the context of the Twitter discussion topics. Data were coded by two independent researchers and discrepancies were resolved through discussion and mutual reevaluation of the data. Last, the findings were shared with Twitter chat participants to verify accuracy.

Results: The major themes identified are as follows:

1) Many people are judgmental about diabetes (including some healthcare providers): “Don't blame me, don't blame my mom, blame my pancreas.”

- People judge my eating habits
- People judge my size and especially my weight
- Some say I have a personal lack of control
- People blame me for my diabetes

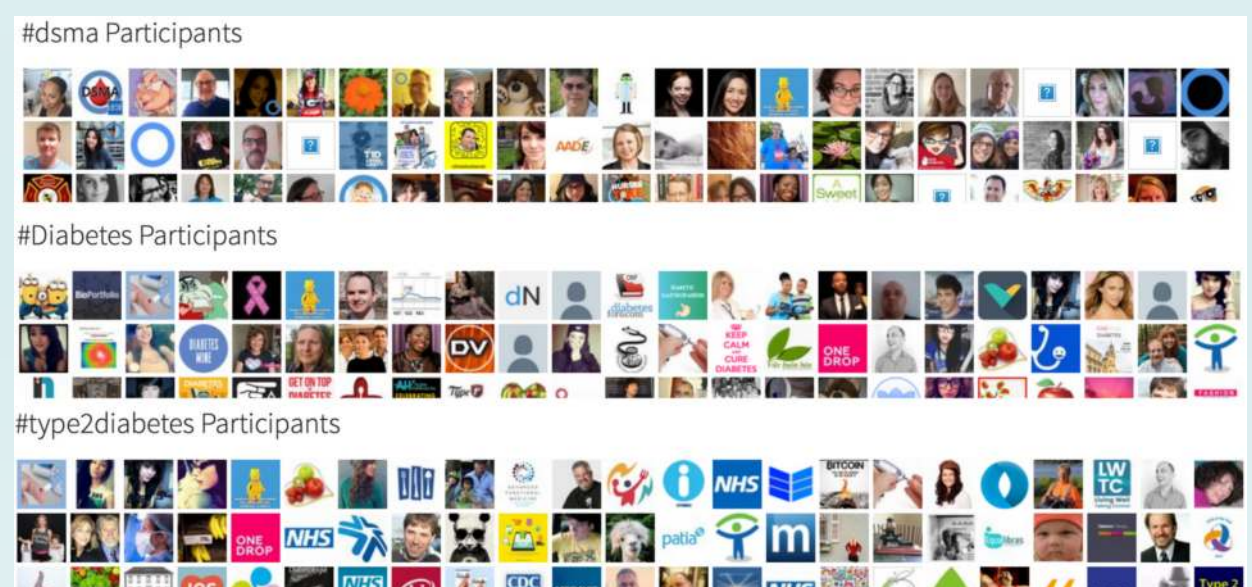
2) People with diabetes feel compelled to educate others about the condition: “It's hard to stop stigma when diabetes is associated with obesity, poverty, and skin color.”

- Many are uninformed about diabetes (the public and providers)
- Diabetes is a complicated and difficult to understand condition
- They think Diabetes is my fault
- They think it is all lifestyle
- The media creates false impressions and misinformation
- The language we use when talking about diabetes is important

3) Productive patient and provider teams are important: “The goal of my care team has to make me as independent and self managed as possible”

- Some providers are better at dealing with diabetes and those touched by diabetes
- Diabetes is a challenging and difficult condition
- Peer support is essential, in person or online
- People need to advocate for themselves

Sample of participants in the Tweet Chats:



Discussion:

We found that DOC participants identified judgement, education and healthcare teams as the primary themes associated with stigma. One participant summarized her feelings succinctly: “It takes a lot of self-confidence & strength to not internalize any/all of the misinfo & stigma out there in media & society.” Being connected is an important benefit of the DOC for social support, to educate the greater community and to advocate for people affected by diabetes.

Partners:

