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INSULIN PRICING AND OTHER MAJOR DIABETES-RELATED CONCERNS IN THE USA: A STUDY OF 46,407 TWEETS BETWEEN 2017 AND 2019

Short title: Concerns around diabetes in the USA

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ABSTRACT

Introduction

Little research has been done to systematically evaluate concerns of people living with diabetes through social media, which has been a powerful tool for social change and to better understand perceptions around health-related issues. This study aims to identify key diabetes-related concerns in the USA and primary emotions associated with those concerns using information shared on Twitter.

Research Design and Methods

A total of 11.7 million diabetes-related tweets in English were collected between April 2017 and July 2019. Machine learning methods were used to filter tweets with personal content, to geolocate (to the US) and to identify clusters of tweets with emotional elements. A sentiment analysis was then applied to each cluster.

Results

We identified 46,407 tweets with emotional elements in the USA from which 30 clusters were identified; five clusters (18% of tweets) were related to insulin pricing with both positive emotions (*joy, love)* referring to advocacy for affordable insulin and *sadness* emotions related to the frustration of insulin prices, five clusters (12% of tweets) to solidarity and support with a majority of *joy* and *love* emotions expressed. The most negative topics (10% of tweets) were related to diabetes distress (24% *sadness*, 27% *anger*, 21% *fear* elements), to diabetic and insulin shock (45% *anger*, 46% *fear*) and comorbidities (40% *sadness*).

Conclusions

Using social media data, we have been able to describe key diabetes-related concerns and their associated emotions. More specifically, we were able to highlight the real-world concerns of insulin pricing and its negative impact on mood. Using such data can be a useful

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addition to current measures that inform public decision making around topics of concern and burden among people with diabetes.

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Significance of Study

What is already known about this subject?

- It is very challenging to collect representative data at a population level to understand what are the key concerns of people with diabetes in real life.
- Social media platforms, such as Twitter, may serve as a relevant source of information to supplement traditional population health studies.
- There are worldwide inequalities in access to insulin.

What are the new findings?

- With 18% of the tweets related to insulin pricing, this is a major concern in the diabetes community in the USA.
- People regularly express fear, anger and sadness about potential diabetes-related complications and comorbidities.
- However, there is a lot of support and solidarity among the diabetes online community, with numerous posts related to positive emotions

How might these results change the focus of research or clinical practice?

- Our work presents a reproducible approach to easily capture information about key diabetes-related concerns, that is usually not available in typical clinical or epidemiological studies. This information can supplement data from clinical or epidemiological studies to inform public health strategies to deal with diabetes-related prevention, management and treatment

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INTRODUCTION

Stress, fears and negative emotions are considered to be the most important psychosocial health factor in the management of diabetes.[1] Diabetes distress is associated with decisional conflict and therefore has an impact on day-to-day disease management and the long term risk of diabetes-related complications.[2] Reducing diabetes-related distress may improve HbA1c and reduce the burden of disease among people with diabetes.[3,4] However, there is still limited knowledge about the sources of stress, anxiety and concerns among people with diabetes and it is difficult to capture them with existing evaluation scales such as the Problem Areas in Diabetes Scale (PAID or PAID-T for adolescents) or the Diabetes Distress Scale (DDS).[5–9]

Social media data offer a unique opportunity to supplement current measures of diabetes-related distress and assess the sentiments of people with diabetes, given the very active online diabetes community in particular on Twitter.[10,11] Twitter is a microblogging and social networking service with 321 million monthly active users.[12]

Using social media to explore psychological information related to diabetes and associations between socioeconomic factors and diabetes-related concerns based in real-life is currently unchartered territory. However, using this resource may provide important insights and allow future interventions regarding prevention, management and treatment of diabetes to be more appropriately tailored.

Using Twitter data, the aims of the current study are to identify diabetes-related concerns in the USA and to identify the primary emotions and sentiments associated with them.

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METHODS

Data collection

A tweet extraction engine was developed in April 2017 and since then has collected more than 11.7 million (status July 2019) diabetes-related tweets in English, via Twitter's Streaming Application Programming Interface (API), based on a list of diabetes-related keywords, such as *diabetes, hypoglycemia, hyperglycemia* and *insulin*, from all over the world (see Supplementary Materials S1 for the full list of keywords used). All data collected in this study were publicly posted on Twitter. Therefore, according to the privacy policy of Twitter, users agree to have this information available to the general public.[13] In this study, we restricted the analysis to 46,407 US-based tweets, with personal and emotional content (see Figure 1 for an overview over the workflow).

For further details concerning data representation, data preprocessing, training of machine learning classifiers to filter tweets with personal content, from institutional tweets (organisations, advertisement, research news, etc.) related to diabetes; detect and exclude jokes; predict the gender and type of diabetes of users as well as the geolocation algorithm to determine tweets in the USA, please refer to Supplementary Material S2. For the present work, the statistical unit considered is a tweet and not a user profile. Thus a user may have several tweets that are included.

Identifying emotions

To identify emotions among diabetes-related tweets, we combined detailed Parrot's classification of emotions with a dictionary of emotional keywords present in the two most common tools to assess psychological health in people with diabetes, namely the Problem Areas in Diabetes questionnaire and the Diabetes Distress Scale.[14] Parrot identified over 100

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emotions and conceptualized them as a tree structured list (full list Supplementary Material S3) with the six primary emotions being *joy*, *love*, *surprise*, *sadness*, *anger* and *fear*. To capture as many tweets as possible containing emotions, we hypothesized that the synonyms of the words from Parrot's classification should be included as well. Synonyms were identified using the WordNet database.[15]

Moreover, due to the nature of Twitter as a microblogging service (short messages), people use emoticons and emojis that express special meanings. Emoticons constitute a metacommunicative pictorial representation of a facial expression using punctuation marks and letters, such as ':-)' or ':D'.[16] Emojis are incorporated into sets of characters available in mobile phones, such as ' ' or ' '. We used Wolny's categorisation of emojis and emoticons into emotional categories similar to the six primary emotions defined by Parrot.[17] This allowed us to determine a subset of *emotional* tweets containing either emotional words or emojis/emoticons.

Sentiment Analysis

Sentiment analysis is commonly used to investigate the positive or negative opinion within a tweet. We used a widely accepted human-validated sentiment analysis tool Valence Aware Dictionary for Sentiment Reasoning (VADER).[18–21] VADER was specifically developed for social media data and combines a lexicon and the processing of the sentence characteristics to determine sentence polarity. VADER computes sentiment and valence for each word level and provides positive, negative and neutral scores at the sentence level. We used the compound score as our main metric for the sentiment analysis (referred to as the *SA score* later in the text), which is unidimensional and a normalized measure of sentiment between -1 (most negative) and +1 (most positive).

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Topic extraction

All tweets are represented via their word vector representations, with the consequence that words similar in semantics are also similar in the word vector space (see Supplementary Material 2 for more details). We applied the unsupervised machine learning algorithm K-means, using cosine similarity as distance measure, to group the emotional tweets that are close to each other based on their word vector representations into topics/clusters.[22] In order to define the right number of clusters *k*, the Silhouette score, measuring how on average each data point is closer to its cluster's center than to any other cluster, was used as input parameter for the K-means algorithm.[23] We obtained the highest score for *k=30* clusters. All tweets were then assigned to one of the 30 clusters/topics. Each topic/cluster was then given a label by two authors (AA, GF) according to the 10 most contributing tweets (those closest to the topic center) and the most frequent words (top words) in the cluster.

Assessment of the mean income

We studied the associations between the topics of interest for people with or talking about diabetes and the mean income of the city, based on data from the 2017 American Community Survey.[24] The tertiles for the mean household income were calculated: low income - [$24,609, $67,224], medium income - [$67,225, $86,758], high income - [$86,759, $394,259]. Each geolocated tweet was associated with the mean income for its corresponding city and then assigned to its respective tertile: low income, medium (med) income, high income. Associations between topics and mean income tertile groups were assessed with Chi-squared tests. For each topic the p-value was calculated using a Chi2 test between the binary variable if a tweet belongs to the corresponding topic and the tertile categories of the city-level mean income from the tweet's origin.

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Python (version > 3.6) and the packages scikit-learn (machine learning algorithms and data preprocessing methods) and gensim (text processing, word representation) were used to implement the methods described above.[25,26] Algorithms related to the present study are open source under the following address: https://github.com/WDDS/Tweet-Diabetes-Classification.

RESULTS

Spatial distribution of diabetes-related tweets

This analysis was based on 167,743 geolocated, diabetes-related tweets from the USA, see Figure 2. The highest number of tweets were seen in California (N: 18,551) and Texas (N: 14,237), whereas Vermont (N: 197) and Wyoming (N: 131) had a low number of tweets. At the city level, New York City (N: 9,663), Los Angeles (N: 5,301) and Chicago (N: 4,884) had the highest number of tweets.

Topics of interest

Among all US diabetes-related tweets, 46,407 were identified as *emotional* tweets (28% of tweets) of which 14,485 (31%) were written by men, 20,228 (44%) by women and 11,694 (25%) from unknown sex; 20,285 (44%) were predicted as from people with type 1 diabetes, 4,375 (9%) from type 2 diabetes and 21,747 (47%) diabetes type unknown. Table 1 shows the detailed description of the 30 topics of interest about diabetes.

Table 1: Overview of the 30 topics of interest for people with or talking about diabetes and their gender and type of diabetes distributions

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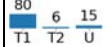
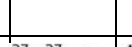
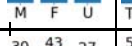
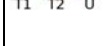
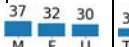
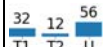
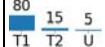
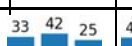
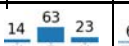
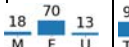
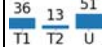
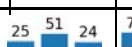
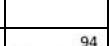
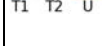
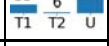
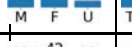
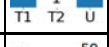
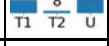
No.	Topic label	Top words	Gender (%)	Diabetes Type (%)	Tweet description
1	Support/solidarity in diabetes community	happy, birthday, day, #dsma,#t1d, insulin			- Happy birthday wishes - Affection / Support / Solidarity messages
2	Inspiring relatives living with diabetes	love, t1d, amazing, #t1d, awesome			- Inspiring friends and families when living with diabetes or helping to live a better life - Pointing to people campaigning for diabetes issues and affordable insulin
3	Sharing hope and encouraging	hope, well, #dsma, get, soon, better			- Encouraging people with diabetes - Hoping to find a cure for diabetes
4	Diabetes awareness / Support / Donation	help, love, please, us, let, awareness			- Supporting each other within the diabetes community - Raising awareness for diabetes and its complications - Donations to get insulin
5	DSMA* enjoying online support	#dsma, good, :), glad, tonight, love			- Friendly exchanges within the DSMA* online community - Being thankful for the people's effort and activity - Questions within the DSMA online community
6	Sharing diabetes related stories	good, bad, news, really, know, like			- People telling stories about diabetes or diabetes treatment - Messages about daily struggle with diabetes
7	T1D hashtags	#t1d, #diabetes, #type1diabetes, love			Mainly short, incoherent messages with several hashtags relating to type 1 diabetes, such as #t1d, #t1dlife, #t1dmom, or #Dexcom
8	Diabetes care	care, take, health, insulin, one, taking			- Talking about diabetes care or mental health with diabetes - Indignation about the healthcare system
9	Bloodsugar palette (beauty products)	#bloodsugar, got, palette, excited, love,			"Spam" about the beauty product "Blood Sugar Palette" palette
10	Advocacy for affordable insulin	#insulin4all, insulin, good, thank, love, us			- Encouraging people advocating for affordable insulin - Talking about healthcare activism
11	Life with and without diabetes	would, love, could, insulin, like, one			- Hypothetical life without diabetes - Frustration about how people without diabetes poorly understood their conditions
12	Life with type 1 diabetes	#t1d, #diabetes, love,#type1diabetes			- Messages about Dexcom devices - Seeking for encouragement - Life with type 1 diabetes
13	Glucose guardian	glucose, guardian, need, love, father			Looking for glucose guardians. This is a gender neutral term for a person who is giving money, often to buy insulin, in exchange for some favor or something in return.
14	Chatting about insulin	love, insulin, #dsma good, glucose, one			Talking about insulin
15	Insulin and insulin pump complications	insulin, pump, love, hope, got, new, feel			- Unhappiness about having to manage the insulin pump - Insulin had no effect or was bad
16	Diabetes in family	family, runs, friends, know, type, history			- Worries about getting diabetes because of family predisposition - Family support
17	Diaversary	years, ago, two, type, one, insulin			Celebrating birthday of diabetes diagnosis
18	Day-to-day stories about diabetes	day, today, insulin, glucose, good, last			Day-to-day stories about diabetes or insulin adjustment
19	Confusion between T1D and T2D	type, one, two, good, love, people, feel			Frustration about people's inability to distinguish between type 1 and type 2 diabetes
20	Diagnosis	diagnosed,type, old, two, since, year, one			Talking about their own diabetes diagnosis or the one of their child
21	Glycemic instability	glucose, blood, high, sugar, insulin, levels			- Difficulty to keep blood sugar levels stable - Suffering from low or high blood sugar - Reliefs about keeping blood sugar levels normal

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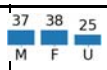
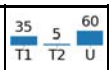
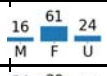
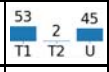
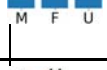
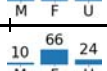
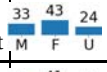
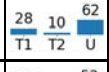
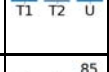
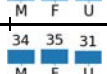
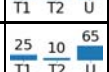
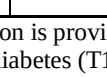
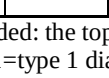
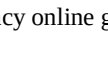
22	Insulin	insulin, good, like, need, people, feel			- Talking about expensive insulin and people who cannot afford treatment - Insecurity about insulin
23	Diabetes pop star Nick Jonas	nick, jonas, cried, remember, found			Talking about pop star Nick Jonas who has type 1 diabetes and wrote a song about it
24	Misunderstandings of diabetes	people, know, like, one, understand			- Complaining about the public view on diabetes - Unclear relationship for many people between food and blood sugar / diabetes
25	Frustration with insulin prices	insulin, afford, cost, cannot, insurance			- Frustration with high insulin prices - Insurance as elementary factor to get insulin
26	OGTT**	glucose, test, hour, today, tomorrow			Dreading glucose drink and glucose tests (mostly during pregnancy)
27	Parents and diabetes	mom, dad, got, died, insulin, one, bad, lost			Parents-children stories related to diabetes
28	Diabetes Distress	feel, like, hate, sick, really, bad, feeling			- Sharing feelings of sadness and depressive symptoms - Feeling scared or anxious about insulin use - Hate towards own diabetes
29	Diabetic/Insulin Shock	shock, insulin, went, going, coma, would			- Going into diabetic shock after eating sweet food - Sharing experience of going into insulin shocks
30	Diabetes-related comorbidities	anxiety, depression, pain, neuropathy, heart, cancer			Talking about diabetes-related complications such as depression, anxiety, heart diseases, nerve pain, chronic pain and other health issues

For each topic the following information is provided: the topic label, the most frequent words, gender (M=men, F=women, U=unknown) and type of diabetes (T1=type 1 diabetes, T2=type 2 diabetes, U=unknown) distribution and a tweet description.
* DSMA refers to Diabetes Social Media Advocacy online group
** Oral glucose tolerance test

In most topics, an over-representation of women was observed, in particular in topics 10, 23 and 26 related to the importance of affordable insulin and the oral glucose tolerance test (OGTT). In contrast, men more frequently discussed topics around diabetes-related stories (topic 6) and 'diabetic/insulin shock' (topic 29). Discussions about 'advocacy for affordable insulin' (topic 10) and enjoying the exchange in the diabetes online community (topic 5) were almost exclusively dominated by people with type 1 diabetes. The only topics where people with type 2 diabetes had significantly more tweets than on average, is topic 19 related to the confusion between type 1 and type 2 diabetes or in topic 17 when they tweeted about the anniversary of their diagnosis. The Diabetes Social Media Advocacy (#DSMA) group on Twitter is a community of people exchanging about diabetes related topics, in which the price of insulin is a central concern.

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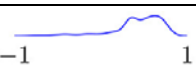
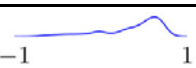
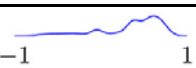
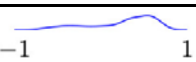
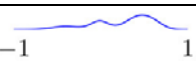
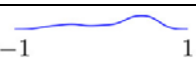
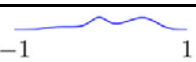
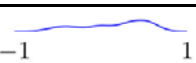
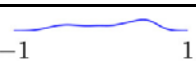
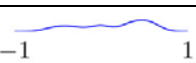
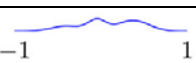
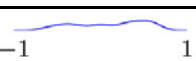
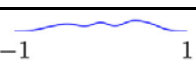
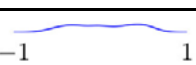
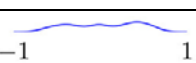
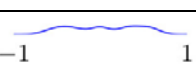
Primary emotions related to the topics of interest

Table 2 illustrates the sentiment and emotions distribution over the 30 topics.

Table 2: Sentiment and emotion distributions of the 30 topics of interest of people with or talking about diabetes

No.	Topic label	% (N)	SA score	SA distr. neg=[-1,1]=pos	Primary emotions (%) joy || love || surprise || sad || anger || fear
1	Support/solidarity in diabetes community	1.3 (613)	0.68		0.72 0.19 0.02 0.04 0.02 0.02
2	Inspiring relatives living with diabetes	3.3 (1552)	0.67		0.36 0.31 0.21 0.05 0.03 0.05
3	Sharing hope and encouraging	1.2 (542)	0.54		0.45 0.45 0.01 0.05 0.01 0.03
4	Diabetes awareness / Support / Donation	3.2 (1499)	0.48		0.35 0.38 0.4 0.12 0.05 0.08
5	DSMA* enjoying online support	3.1 (1459)	0.47		0.48 0.26 0.06 0.09 0.04 0.07
6	Sharing diabetes related stories	3.3 (1513)	0.36		0.3 0.24 0.06 0.17 0.08 0.15
7	T1D hashtags	1.8 (812)	0.33		0.37 0.38 0.06 0.08 0.07 0.05
8	Diabetes care	2.9 (1353)	0.28		0.05 0.44 0.01 0.05 0.03 0.43
9	Bloodsugar palette (beauty products)	1.8 (818)	0.26		0.28 0.49 0.03 0.13 0.02 0.04
10	Advocacy for affordable insulin	1.1 (505)	0.22		0.24 0.29 0.09 0.15 0.13 0.1
11	Life with and without diabetes	2.7 (1239)	0.19		0.31 0.26 0.06 0.16 0.08 0.13
12	Life with type 1 diabetes	3.3 (1514)	0.18		0.3 0.27 0.04 0.16 0.11 0.11
13	Glucose guardian	0.7 (343)	0.16		0.37 0.25 0.01 0.25 0.06 0.05
14	Chatting about insulin	5.0 (2302)	0.14		0.32 0.23 0.04 0.18 0.12 0.11
15	Insulin and insulin pump complications	4.4 (2036)	0.09		0.35 0.23 0.03 0.18 0.13 0.09
16	Diabetes in family	0.9 (436)	0.07		0.22 0.26 0.03 0.18 0.1 0.22
17	Diaversary	3.6 (1685)	0.07		0.28 0.2 0.06 0.21 0.11 0.14
18	Day-to-day stories	5.7	0.05		0.28 0.17 0.04 0.21 0.15 0.15

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	about diabetes	(2666)									
19	Confusion between T1D and T2D	3.9 (1804)	0.04		0.22	0.21	0.05	0.22	0.14	0.17
20	Diagnosis	2.2 (1023)	0.02		0.24	0.21	0.06	0.21	0.13	0.16
21	Glycemic instability	5.1 (2363)	0.01		0.22	0.19	0.04	0.24	0.15	0.17
22	Insulin	8.6 (3970)	0.01		0.27	0.18	0.05	0.2	0.14	0.16
23	Diabetes pop star Nick Jonas	0.5 (218)	-0.07		0.19	0.19	0.01	0.49	0.04	0.09
24	Misunderstandings of diabetes	7.0 (3244)	-0.08		0.16	0.17	0.04	0.29	0.14	0.2
25	Frustration with insulin prices	6.3 (2916)	-0.12		0.15	0.17	0.03	0.24	0.21	0.2
26	OGTT**	4.3 (2012)	-0.13		0.2	0.1	0.02	0.31	0.18	0.19
27	Parents and diabetes	4.0 (1859)	-0.14		0.16	0.17	0.04	0.29	0.14	0.21
28	Diabetes Distress	4.5 (2067)	-0.19		0.14	0.11	0.04	0.24	0.27	0.21
29	Diabetic/Insulin Shock	0.6 (284)	-0.33		0.03	0.02		0.03	0.45	0.46
30	Diabetes-related comorbidities	3.8 (1760)	-0.36		0.09	0.08	0.02	0.4	0.19	0.22

For each topic the following information is provided: the topic label, the frequency of the topic, the average sentiment analysis score (SA score), the sentiment analysis distribution (SA distr.) and the frequency of primary emotions.
* DSMA refers to Diabetes Social Media Advocacy online group
** Oral glucose tolerance test

In Supplementary Material S4, the most common emotional words and emojis/emoticons have been listed for each topic. Overall, we found that the most positive topics were related to support and solidarity within the diabetes online community (topic 1) with 72% of emotions related to *joy* and about inspiring relatives living with diabetes (topic 2) with *joy* (36%) and *love* (31%) elements. In contrast, the most negative topics were related to 'diabetes-related comorbidities' (topic 30) of which 40% of the emotions were related to *sadness*, 19% to *anger* and 22 % to *fear*; 'diabetic/insulin shock' (topic 29) with an over-representation of

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anger (45% of all emotions) and *fear* (46%); and "diabetes distress" (topic 28) with *sadness* (24%), *anger* (27%) and *fear* (21%) emotions expressed. Topics 2 ("Inspiring relatives living with diabetes") and 4 ("Diabetes awareness / Support / Donation") showed a higher percentage of *surprise* emotions. The topics in which people with or talking about diabetes exchange, support each other and show solidarity (topics 1, 2, 3, 4, 5) contained *joy* and *love* emotions most frequently. Topic 9 was related to beauty products with diabetes-related names and was considered irrelevant for our analyses and disregarded.

Insulin pricing

Insulin pricing is a major topic of interest mentioned in 5 of the 30 topics (18% of tweets). A key topic associated with insulin pricing was related to the frustration of not being able to afford insulin (topic 25), in which many tweets expressed sadness (24%), anger (21%) and fear (20%). Topic 13 regrouped tweets in which people are looking for "glucose guardians", a gender neutral term for a person who is giving money, often to buy insulin, in exchange for some favor or something in return. Topic 10 described the tweets of people who are fighting for affordable insulin, which are represented by the hashtag '#insulin4all'. The positive emotions in this group showed mutual support.

Associations between topics of interest and mean income

We observed that topics such as 10 'advocacy for affordable insulin', 22: 'insulin' and 25: 'frustration with insulin prices' were positively associated with mean household city income such that cities with higher incomes were more likely to post tweets about these topics ($P<0.001$ for all) (see Supplementary Material S5). Similarly, we found that topics 24: 'misunderstandings of diabetes' ($P<0.001$), 19: 'confusion between type 1 and type 2 diabetes' ($P<0.05$), 12: 'life with type 1 diabetes' ($P<0.01$) and 21: 'Glycemic instability'

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(P<0.05) were positively associated with mean city income. Likewise, positive associations were found between topics 24 and 19 which are related to language use and the way people talk about type 1 and type 2 diabetes, with cities with higher incomes being more likely to talk about these subjects.

In contrast, we observed that topics 5: 'diabetes social media advocacy' (#DSMA) group enjoying online support (P<0.001), 18: 'day-to-day stories about diabetes' (P<0.001) and 26: 'oral glucose tolerance test (OGTT)' (P<0.001) were negatively associated with mean city income, such that cities with lower income were more likely to post these tweets. Furthermore, cities with medium mean income tweet about topic 15: 'Insulin and insulin pump complications', were more frequently (P<0.001).

DISCUSSION

Our findings suggest that Twitter is a useful tool to capture key diabetes-related topics and the emotions associated with those topics. Our key findings suggest that there is a lot of support and solidarity among the diabetes online community with numerous tweets related to *joy* and *love* emotions observed. In contrast, Twitter users expressed fear, anger and sadness related to insulin pricing and diabetes-related complications and comorbidities, as well as considerable frustration about the inability of people to distinguish between type 1 and type 2 diabetes.

To our knowledge, this is the first study using social media data to capture information regarding key diabetes-related concerns. We are, therefore, unable to compare and contrast the results of this study with others. Nonetheless, the importance of understanding emotions and self-control (regulation of thoughts, emotions, and behavior) for health outcomes in

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people with diabetes has been previously documented in several other studies.[27] Hagger et al. reviewed diabetes distress among adolescents with type 1 diabetes and found a substantial proportion experienced elevated diabetes distress and that it is often associated with suboptimal glycemic control.[28] Richman et al. also suggested that positive emotions such as hope and curiosity may play a protective role in the development of disease.[29] Ogbera et al. showed that higher levels of emotional distress are associated with poor self-care in type 2 diabetes.[30] Another study conducted by Iturralde et al. showed that anxiety is highly comorbid with depression among individuals with type 2 diabetes.[4] Our study aligns with these results showing that emotions and diabetes distress topics are frequent and concern people with diabetes or people talking about diabetes on social media.

Similar to Nguyen et al., who showed that individuals living in zip codes with high percentages of happy and physically-active tweets had lower obesity prevalence based on geolocated Twitter data, we have shown gradients between topics related to diabetes on Twitter and the household income level of their city.[31]

Insulin pricing

We found that insulin pricing was a major concern among tweets shared in the US (18% of all tweets were related to insulin pricing) and is associated with both positive (*joy*, *love*) and negative (*sadness*, *anger*, *fear)* emotions. People frequently shared their frustration with insulin prices, access to insulin, and identifying sources of insulin including “glucose guardians” or donations, which represent major obstacles for people with diabetes.[32,33] Positive emotions are present when it comes to solidarity in the fight for affordable insulin in the community. We observed associations of topics addressing insulin pricing to be more frequent in cities with high mean incomes. This does not necessarily indicate that people

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living in cities with a high mean household income feel more concerned about insulin prices, but rather they probably have a greater ability to tweet around this issue. A large number of tweets geolocated in cities with a high mean household income included the hashtag '#insulin4all', a campaign that unites the diabetes community around the access to treatment for everyone.[34]

It is known that there are key challenges for a global and fair access to insulin.[35] With respect to insulin pricing, we are the first to exhibit and quantify, on a large sample of people with or talking about diabetes, the extent of the crisis in the USA based on social media data. In addition, we have also been able to highlight the different emotions and fears associated with the crisis around insulin pricing.

Strengths and Limitations

This study has numerous strengths. First, a major advantage of using social media data is that information is expressed spontaneously, on a large scale, and in real-time, in what can be considered as an open digital space with flat role hierarchy for information sharing and development of online communities. This potentially minimizes biases such as responder bias that you would observe in traditional and observational studies. We evaluated tweets related to diabetes from a large number of people with a large variability in their profiles. The methodologies developed in this study present an innovative way to concentrate on relevant (personal, emotional) geolocated tweets (US), to identify topics of interest and emotions shared within topics. This approach is able to capture trends in the online diabetes community as well as socioeconomic factors that can be associated with social media data at the ecological level. This new way of capturing data supplements the detection of topics which are less medically oriented.

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There are, however, several limitations to consider. First, diabetes-related concerns expressed on Twitter may not be representative of all people with diabetes. However, it has been previously suggested that it can be partially offset by the large variability in the social media profiles, a key strength in digital epidemiology.[36] While we did observe large variability in our Twitter profiles, we found an over-representation of people with type 1 diabetes and women in our study when compared to known diabetes epidemiology literature.[36] The greater representation of type 1 diabetes may be explained by the younger demographics of Twitter users.[37] Alternatively, type 1 diabetes may have more involved care, more devices, more challenging medication and more frustrations to report on Twitter as compared with type 2 diabetes. Regardless, our results should be interpreted in the context of the Twitter population only. Second, the precision of our filter classifiers (personal content, jokes), gender and type of diabetes classifiers, is not perfectly accurate, which means that we cannot guarantee that 100% of tweets are posted by actual people with diabetes and it was often impossible to define the sex or type of diabetes. Third, we were unable to account for several clinical and environmental factors that may help to tease out these associations. The label provided by the researchers for each topic is not exclusive. By refining the tweets in each topic, more subtopics could be defined. This could be a future direction to investigate. Fourth, the geolocation of tweets was partially based on locations the users provided, which might not be their true location. Fifth, emotion detection is still a challenge in the machine learning field due to the occurence of sarcasm and irony. It is one of the open research questions. Last, causal inference between the mean household income per city and the topics of interest of people residing in the corresponding city cannot be made as it is subject to ecological fallacy.

A perspective of our work is to extend our analyses to include more countries and languages.

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Conclusion

In this study we investigated diabetes-related topics and their associated emotions. We showed that insulin pricing is a central concern and comes with feelings of sadness, anger and fear. We have shown that using social media posts to capture emotions and concerns of individuals in real life is feasible, and is an efficient way of augmenting psychosocial, behavioral and epidemiological research. Our work should encourage future studies to consider social media data as supplementary information.

Social media provides a useful observatory for diabetes issues, as it is a direct source to capture information about people with diabetes feelings, emotions, beliefs and fears related to diabetes, diabetes treatment and complications among the large and active diabetes online community. The use of Twitter analysis on diabetes could inform the public debate about diabetes issues and help to contribute directly to public and clinical decision making. Social media data will help develop policies and interventions that consider key concerns among people with diabetes to ultimately improve health outcomes.

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Guy Fagherazzi takes full responsibility for the work as a whole, and for the decision to submit and publish the manuscript.

The authors' contributions were as follows: G.F. designed the research; A.A. and G.F. conducted the research; F.O. and A.A collected the data; A.A., F.O. and G.F. analyzed data; A.A., G.F., F.O., T.C, X.T interpreted the data; A.A. and G.F. drafted the article; G.F., F.O., T.C., X.T., B.B., J.L.H. , C.P. and S.P. revised the manuscript critically; GF had primary responsibility for the final content of the manuscript. All authors read and approved the final manuscript.

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Declaration of Interest

The authors declare that they have no competing interests. The study sponsors had no role in the study design, analyses and interpretation of the results.

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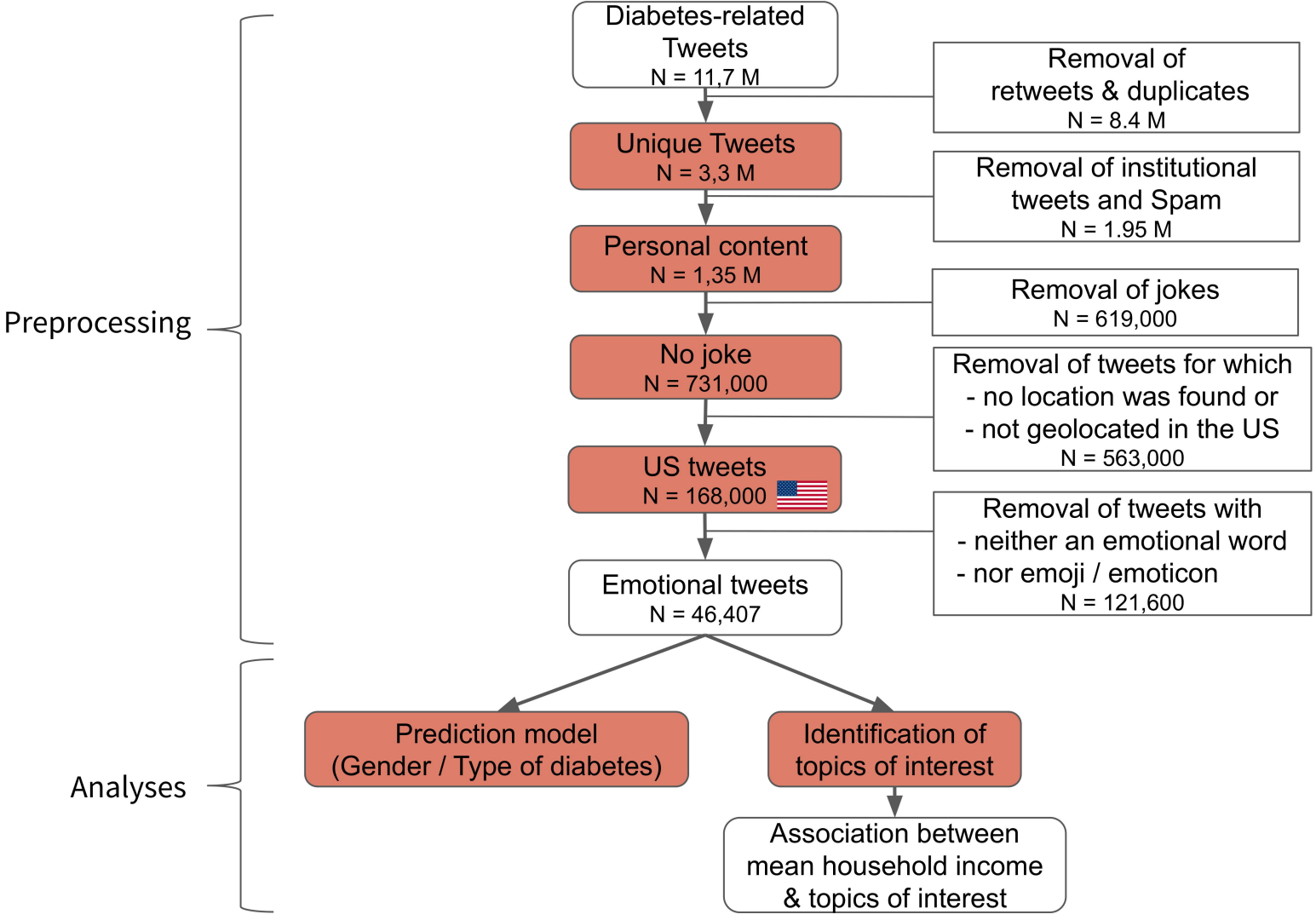
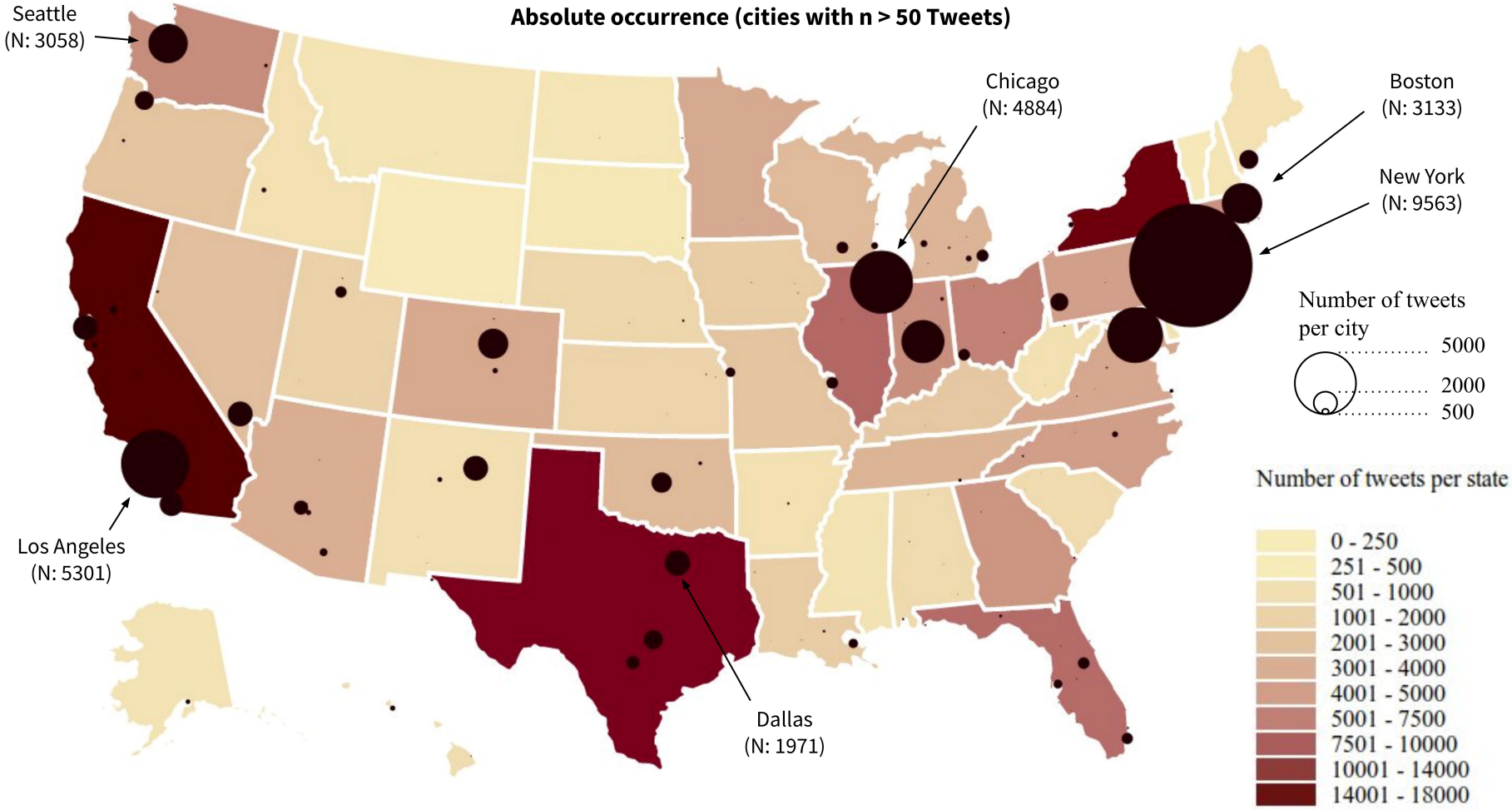
Figure 1: Workflow: from the data collection to the analysis

Figure 2: Spatial distribution of the diabetes-related tweets over the USA


Preprocessing
Diabetes-related Tweets
N = 11,7 M
Removal of retweets & duplicates
N = 8.4 M
Unique Tweets
N = 3,3 M
Removal of institutional tweets and Spam
N = 1.95 M
Personal content
N = 1,35 M
Removal of jokes
N = 619,000
No joke
N = 731,000
Removal of tweets for which
- no location was found or
- not geolocated in the US
N = 563,000
US tweets
N = 168,000
Removal of tweets with
- neither an emotional word
- nor emoji / emoticon
N = 121,600
Emotional tweets
N = 46,407
Analyses
Prediction model
(Gender / Type of diabetes)
Identification of topics of interest
Association between mean household income & topics of interest


Absolute occurrence (cities with n > 50 Tweets)
Seattle
(N: 3058)
Chicago
(N: 4884)
Boston
(N: 3133)
New York
(N: 9563)
Los Angeles
(N: 5301)
Dallas
(N: 1971)
Number of tweets
per city
5000
2000
500
Number of tweets per state
0 - 250
251 - 500
501 - 1000
1001 - 2000
2001 - 3000
3001 - 4000
4001 - 5000
5001 - 7500
7501 - 10000
10001 - 14000
14001 - 18000