Analyzing Informal Caregiving Expression in Social Media

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Abstract—Caregiving is the act of providing assistance to an individual unable to perfom some daily living activities [1]. Caregiving can be either paid or unpaid. An informal caregiver is an unpaid caregiver to an older, sick, or disabled family member or friend on a daily basis [2]. Informal caregiving is associated with increased physical, mental, and emotional stressors contributing to poor health outcomes, caregiver burnout, and increased risk for institutionalization of the older adult care recipient. Informal caregivers manage their stressors through supportive services such as support groups or respite care, but little is known about how they use social media to share their caregiving experience. No work to our knowledge has investigated caregiver use of Twitter to share the caregiving experience. We collect and analyze tweets related to Alzheimer's and Dementia. We present some insights on sentiment of the tweets, statistics of United States geographical locations of the tweeters, and the relationships of the care recipients. In our analysis we found that the majority of tweet sentiment was negative. Moreover, female care recipients are mentioned at a higher frequency than male care recipients in the tweets.

Index Terms—Social Media, Tweet Analysis, Alzheimer's and Dementia, Sentiment analysis

I. Introduction

With the older adult population rapidly growing, caregiving is a leading public health concern. Over 30 million adults currently provide an average of 24.4 hours per week of unpaid (informal) caregiving services to an older adult in the United States [3]. Informal caregiving is often associated with chronic physical and emotional stress [4] and 22% of caregivers report their own health has worsened as a result of caregiving [5]. By 2030, the older adult population is projected to rise by 101%, however, the number of family members available to provide informal care is only expected to rise 25% [6]. As such, there will be increasing demands and stressors on informal caregivers. Unfortunately, health care providers do not often address caregivers health. Only 16% of caregivers report that a health care provider has addressed caregiver's own personal health [7]. Importantly, 72% of all caregivers report using the Internet to gather health information and sharing their personal health experiences on social media, suggesting the Internet can become a mechanism for addressing caregiver health [8]. However, the content of what caregivers share on the Internet is currently not known.

Social media use is integrated into the daily lives of most people and is emerging as a resource for healthcare users as well [9]. Specifically, Twitter has been used by the breast cancer patients to share their care experience, and the collection of tweets has been mined to identify those with depression or at-risk for suicide. [9]. Twitter also provides an opportunity for social activism in coordinating activities and linking groups together [9]. However, the use of Twitter in promoting help seeking behaviors is not well understood, especially for caregivers who are members of the Millennial and Generation X cohorts.

While there are a variety of interventions and support services available for caregivers, it is often difficult to proactively identify those caregivers at risk for burnout. Frequently, symptoms are under-reported and providers do not routinely screen for signs and symptoms of burnout. Existing screening mechanisms for caregiver burnout traditionally occur through physician visits that occur infrequently, and can be subject to social desirability bias. Re-orienting the healthcare system to provide preventative support rather than costly patient care for caregivers who have reached the point of burnout is needed. Innovative approaches leveraging new non-traditional sources of data, such as Twitter, can capture the real-time expression of the caregiving experience, track and monitor symptoms, and drive proactive intervention.

Thus, the purpose of this paper is to outline how Twitter content can be mined to gather experiences from caregivers and to report on the analysis of such content. In this study we identified Alzheimer's and Dementia care recipient and analyzed patient-caregiver relationship presence in the data. Moreover, we identified a spike in tweet activity around holiday season. Finally, we analyzed the sentiment of the tweets.

The rest of the paper proceeds as follows. In Section 2, we provide a literature review of related work. We present the data collection process, describe the infrastructure, tweet collection, and detailed work of tweet cleanup and tweet analysis in Section 3. We describe the results of analyzing sentiment, geographical location, and care recipient identification in Section 4. In Section 5, we discuss insights from our analysis and limitations to our approaches. Finally, in section 6 we conclude with future work.

II. Related Work

Swan [10] presented Health Social Networks as a mean to find others in similar health situations. Emotional support and information sharing was one of the described services that

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these networks provide. Twitter is a social media platform that has been used for surveying and intervening on large groups of people in real time. Due to publicly available tweets, Twitter has been used for health surveillance in conditions such as flu, suicide, and depression.

Lee et al. have successfully developed a real-time flu surveillance system using social media [11], where it was found that the mention of a sore throat on Twitter peaks 3-4 days before mentions of cough and fever, indicating that sore throat tweets are an early sign for a flu outbreak. Another study uses Twitter data to analyze posts of individuals at-risk for suicide. Jashinsky et al. analyzed 1,659,274 tweets over a period of 3 months and identified that Midwestern and Western States had higher suicide tweet activity [12].

Xie et al. [13] were able to detect and track epidemic outbreaks in real-time. They also released a verity of datasets: "Social Media" (e.g., Facebook), discussion forums, and expert blog sites (e.g., USA Today Health blog). An influenza Twitter-based epidemics detection method using Natural Language Processing (NLP) was proposed by Aramaki et al. [14]. They could catch the influenza outbreak with high accuracy, outperforming the state-of-the-art Google method at the time. Many papers have used Twitter as a platform to predict disease outbreaks [15]–[18].

III. DATA COLLECTION

A set of initial keywords were identified from the literature to represent Alzheimer's and dementia, the difficulties associated with caregiving, and relationships between caregivers and care recipients. After examining a sample tweets and analyzing their content a decision was made to cluster the keywords into three separate groups: people, condition, and Alzheimer's and Dementia terms. Figure 1 shows how links between these groups informed our selection of keyword sets to track on Twitter. Words were combined from each pair of sets and formed search terms to track using Twitter's Application Program Interface (API) [19]. Focusing on tracking caregiver tweets, the data collection process consists of the following steps. A general overview is presented in Figure 2.

1) We handcrafted a set of initial key words to track on twitter based on keywords identified through clinical expertise.
2) Through the Twitter API, we collect tweets that contain the keywords. The Twitter API provides us with a sample, a random selection of tweets, about 1% of all tweets. By carefully selecting the tracking key words one may actually receive a majority of the tweets, if not all of them, as long as they account for less than roughly 1% of the tweets at a given time.
3) The collected tweets by the Python program are then stored in a MySQL database for further analysis.
4) Each downloaded tweet contains information, such as user location, verified status, time stamp, in addition to the tweet contents. The metadata and contents of tweets are extracted from the raw format and stored in the database.
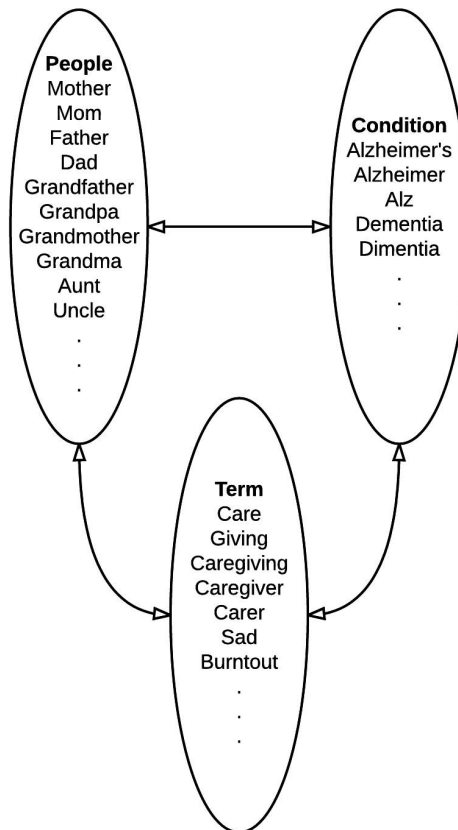

Fig. 1. The process of creating meaningful keywords to track to capture tweets related to informal caregiving.

5) We monitored the number of tweets collected per set of tracked words.
6) With the help of clinical expertise we refined the set of tracked words to download more tweets. The goal of this step is to have a general enough set of words to cover as much as we can without missing words or phrases that we are interested in tracking.
7) We repeated steps 4 and 5 every couple of months. These two steps are important; they help us include new words and avoid words that result in unrelated tweets.
8) We ran data collection for a 12 month period between January 1, 2016 and December 31, 2016

A. Data Cleanup

Duplicate tweets were removed from the dataset. Meta-data of the tweets was parsed to obtain location information. To get users locations the self-stated locations were used for the US only. From the meta-data we obtained the state information. In cases where the location information was not obvious, we resorted to reverse geo-coding using Nominatim. Nominatim is an OpenStreetMap search engine. After identifying to which
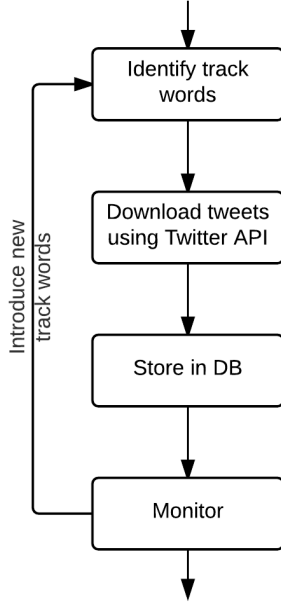
Fig. 2. The process flow of identifying track words, obtaining tweets, and refining the set of words used to extract tweets

TABLE I
EXAMPLES OF REVERSE SEARCHED LOCATIONS IN THE US

Location	State Code
Phoenix Sky Harbor International Airport (PHX)	AZ
Seattle-Tacoma International Airport (SEA)	WA
The Columbia Restaurant	FL
Atlanta Tech Village	GA

state does the location belong to we store the data in the database. Examples of some reverse searched locations are shown in Table I.

B. Template matching to Reduce Noise

A total of 3,000,530 tweets were collected for the calendar year of 2016. Despite these tweets matching the Twitter keyword search, much of these tweets were noise. This is due to matching sets of keywords that cover a broad range of meaning specifically combinations of keywords between the People and Term sets (see Figure 1). Templates relevant to this study were applied to match tweets of interest. Tweets of interest have keywords such as: ("my","i'm", or "am") and ("alzheimer", or "dementia") in the same tweet. Tweets with URLs were mostly job postings or article retweets, a decision was made to have them excluded from this study. From here onward the set resulting from applying these templates will be referred to as the filtered tweets set.

IV. METHODOLOGY USED FOR DATA ANALYSIS

A. Sentiment Analysis

Sentiment analysis is the process of extracting opinions expressed in text. Most commonly categorizing text in 3 categories: negative, neutral, or positive. This task becomes complicated with shorter text without knowledge of the context. In this study we randomly sampled a subset of 200 tweets, then we had these tweets hand labeled by three different people. Labels were assigned based on majority vote. There were no consensus for 7 votes out of the 200 tweets and there was agreement on 71 tweets out of the 200. These hand labeled tweets were used for validation purposes[1]. The following two tweets are examples of tweets where no consensus was reached.

1) "so I was going to take the dog w me to my parents , but Dad has dementia & thinks every1 has murderous intent. And the dog actually DOES."
2) "As my grandpas dementia gets worse my grandma has to give him extra attention with everything. Sometimes she's good about it."

We considered two approaches for predicting the sentiment of the tweets in our study. The first approach is a simple keyword based strategy, where we scored the tweet by counting the number of negative and positive words that appeared in the tweet. In the second approach we consumed the Sentiment140 API to analyze the tweets. Sentiment140 is a machine learning approach using distant supervision based on the work of Go et al. [20].

B. Informal Care Recipient Identification

We devised an approach that utilizes part-of-speech to identify the care recipients in the tweets. We used a pre-trained SyntaxNet model, Parsey McParseface, for part-of-speech (POS) tagging. SyntaxNet is a Natural Language Processing neural-network framework based on TensorFlow [21]. We identify care recipients by following a simple approach of tracking pronouns followed by nouns and nouns followed by verbs, and then inspecting the surrounding words. Table II shows an example of SyntaxNet output.

Note that these can include additional 'people' terms than the ones we started off (depicted in Figure 1), since these are automatically identified from the collected tweets using part-of-speech tagging. Figure 3 shows the top five care recipients. We found that users use different forms for the same relationship, for instance grandma and grandmother. This deems identifying care recipients a hard task. In the Figure, we total the top ten recipient by gender and represent female by red and male by blue.

C. Descriptive Statistics

During 2016 we collected 3,006,975 unique tweets generated by 1,697,050 distinct Twitter users. Figure 4 shows daily activity for all tweets versus filtered tweets for the 12

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[1]These hand labeled tweets can be found at https://github.com/ralbahra/informal_caregiving_tweets
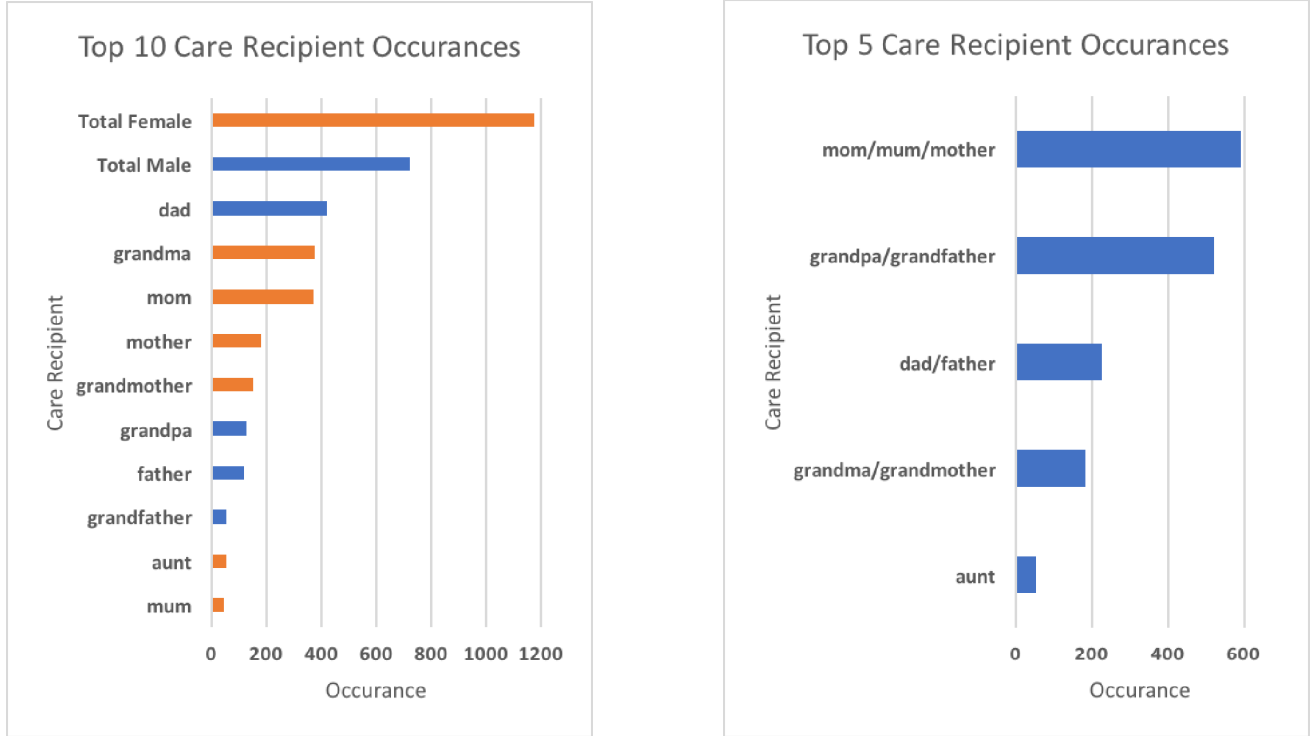
Fig. 3. The left barchart shows the different relationship forms present in the tweets for example mum, mom, mother are all referring to the same relationship. Also, it shows the gender of the recipient ratio. The barchart on the left presents the collapsed relationships.

1	@	ADP	IN	6	prep
2	user	ADJ	JJR	1	pobj
3	my	PRON	PRP$	4	poss
4	mom	NOUN	NN	6	nsubj
5	has	VERB	VBZ	6	aux
6	advanced	VERB	VBN	7	amod
7	alzheimer	NOUN	NN	9	poss
8	's	PRT	POS	7	possessive
9	disease	NOUN	NN	15	nsubj
10	and	CONJ	CC	9	cc
11	caregiving	NOUN	NN	9	conj
12	is	VERB	VBZ	15	cop
13	a	DET	DT	15	det
14	real	ADJ	JJ	15	amod
15	maze.	NOUN	NN	0	ROOT
16	I	PRON	PRP	17	nsubj
17	think	VERB	VBP	15	rcmod
18	they	PRON	PRP	20	nsubj
19	should	VERB	MD	20	aux
20	teach	VERB	VB	177	ccomp
21	some	DET	DT	227	det
22	basics	NOUN	NNS	20	dobj
23	in	ADP	IN	20	prep
24	college.	NOUN	NN	25	nn
25	blessings	NOUN	NNS	23	pobj

month period between January 1, 2016 and December 31, 2016. There have been a few short periods where our tweet collection process failed due to unplanned server shutdowns and several problems (May 30, July 13-14 , July 18-20, August 5-6, and October 22-24). By looking at the collected tweets we found that a small subset of these tweets have geographical information. We identify 178 different countries. The United States of America alone has 87,854 tweets which include geographical information. In Section 4.4 we focus on tweets generated within the United States of America.

D. Tweets within The US

In our study we mainly focused on tweets within the United States of America. By looking at both the full and filtered tweet sets we found 87,854 and 364 containing geographical information. 3% of the full set of tweets have US locations, while the filtered set has 5%. Figures 5 and 6 show the un-filtered and filtered tweet counts per state respectively. These counts are by condition: the red bars represent Dementia counts and the blue bars represent Alzheimer's.

The tweets were also analyzed based on State tweet activity. Figures 7 and 8 show tweet counts per state and tweet activity normalized by state population (These population estimates are from July 1, 2016 [22])

E. Sentiment

We present the sentiment results from two approaches: keyword and Sentiment140. Tables III and IV present sentiment of the filtered set of tweets and the hand labeled set
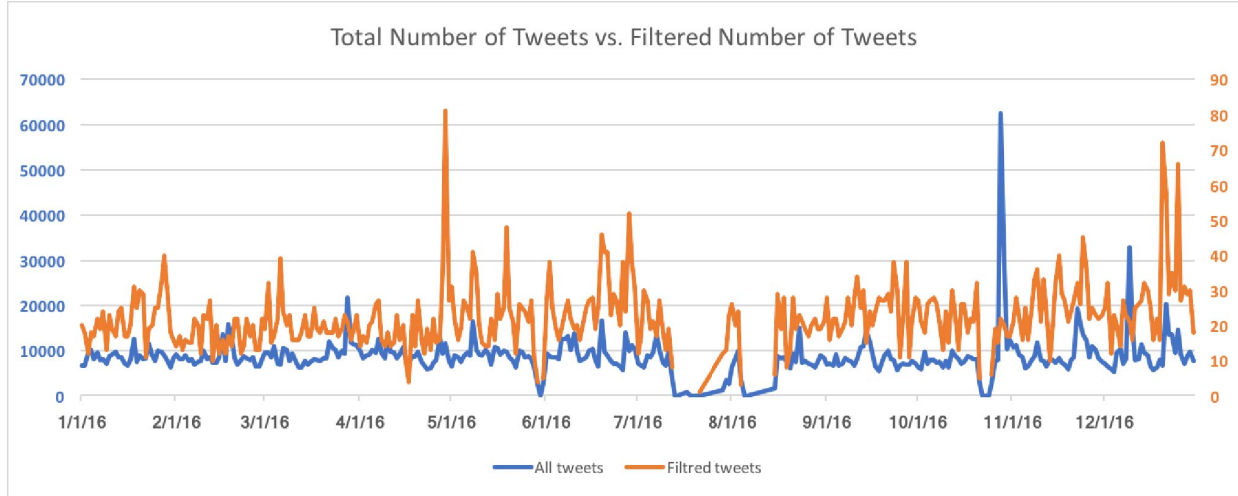
Fig. 4. Daily tweet count of all tweets vs. filtered tweets (the left axis is for tweets and the right axis is for filtered tweets).
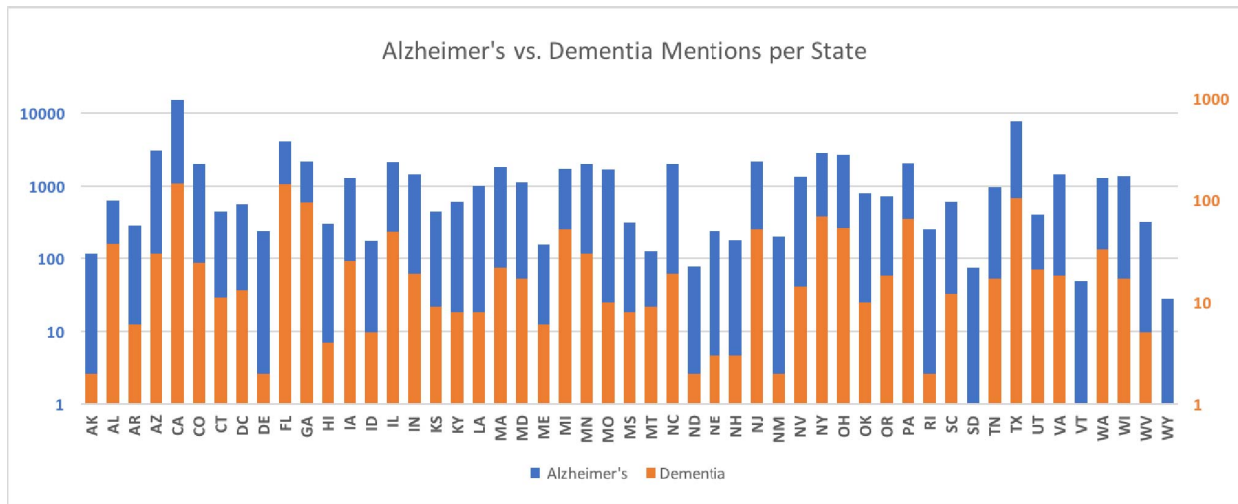

Fig. 5. Tweet counts broken down by state. Across all states Alzheimer's is tweeted more than Dementia

of tweets respectively. A confusion matrix for the hand labeled sentiment and the sentiment obtained by Sentiment140 API is presented in Table V.

TABLE III
SENTIMENT RESULTS OF THE KEYWORD APPROACH AND
SENTIMENT140.COM ON THE FILTERED SET OF TWEETS.

Sentiment	Keyword	Sentiment140
Negative	2,896 (38.45%)	3,711 (49.27%)
Neutral	2,825 (37.51%)	2,713 (36.02%)
Positive	1,811 (24.04%)	1,108 (14.71%)

V. DISCUSSION

A. Insights

We discover the following interesting insights from analyzing the collected tweets.

TABLE IV
SENTIMENT RESULTS OF THE KEYWORD APPROACH AND
SENTIMENT140.COM ON THE RANDOMLY SAMPLED SET OF TWEETS USED
FOR VALIDATION.

Sentiment	Keyword	Sentiment140
Negative	66 (32.84%)	95 (47.26%)
Neutral	72 (35.82%)	72 (35.82%)
Positive	63 (31.34%)	34 (16.92%)

Sentiment ambiguity. Table V illustrates the difficulty in analyzing sentiment of informal caregiver tweets. There is agreement between the human annotation and the sentiment analyzer in the negative category. The analyzer faced difficulties with neutral and positive sentiment. The following tweet is an example where the assigned sentiment is positive while the determination of the actual sentiment is difficult.

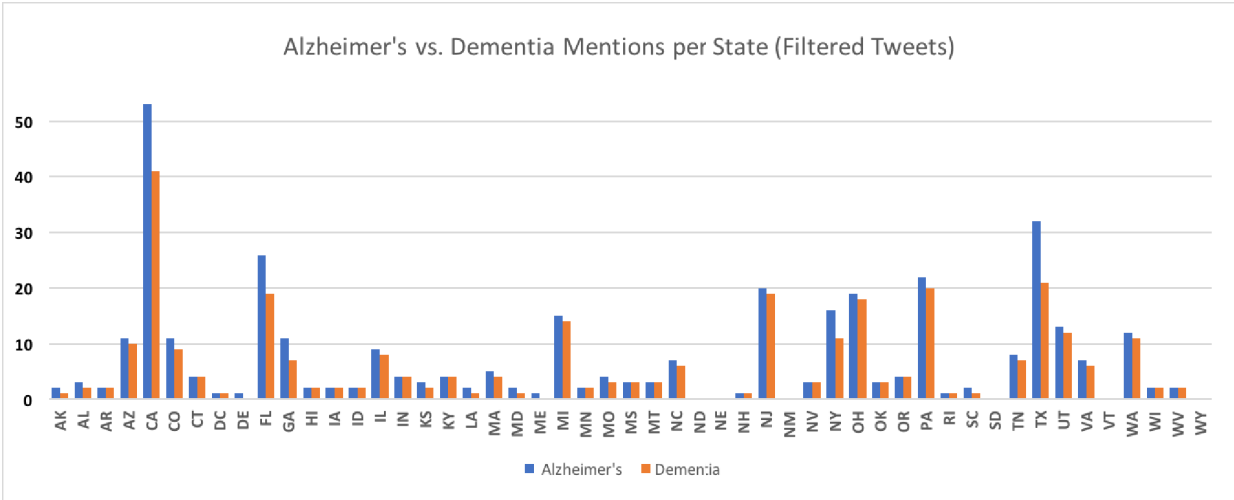"AND to even further express my hatred for the holidays...

Fig. 6. Filtered tweet counts broken down by state. Users tweet the same amount about the two diseases. This could be due to the fact that most people do not differentiate between Alzheimer's and Dementia.
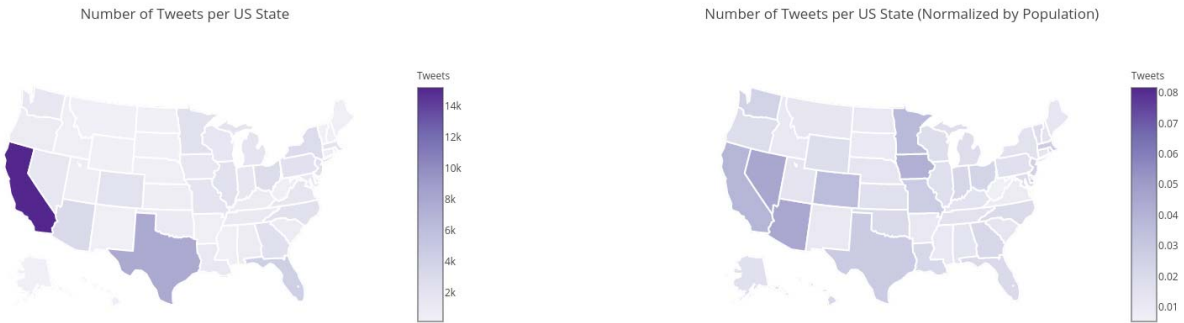

Fig. 7. All tweets with geographical information mapped according to state. The left map shows the number of tweets per state, while the map on the right shows the number of tweets normalize by state population. The normalization by population brings more insight and provides better estimation Alzheimer's and Dementia across the US.

TABLE V
CONFUSION MATRIX FOR THE ACTUAL HAND LABELS AND THE PREDICTIONS MADE BY THE SENTIMENT140 API. THE DIAGONAL NUMBERS ARE MAXIMUM IN EACH ROW AND EACH COLUMN.

(Predicted)	Negative	Neutral	Positive
(Actual) Negative	**59**	23	3
Neutral	24	**31**	9
Positive	11	14	**20**

I found out that my grandma has DEMENTIA on CHRIST-MAS. LOL LIFE YOU SO FUNNY"

Need of context. Looking at Tables III and IV we noticed that negative sentiment seems to be higher in the Sentiment149 API results. The distribution is almost the same in the keyword approach results on the filtered set. This is a result of the difficulty of analyzing the content of the tweets based on words only.

Higher stress levels during US Holidays. Looking at Figure 4 we noticed multiple spikes in the number of tweets in the filtered set. There was higher activity around holiday seasons. To be precise around US Thanksgiving, a few days before Christmas, and on Christmas day. Table VI shows that tweets around the holiday season are dominated by negative sentiment. The percentage of negative tweets is higher when compared to Tables III and IV. These spikes make sense taking into consideration that families tend to gather during these holidays and meet with loved ones [23]. Interestingly the biggest spike happened on April 29, 2016 not falling on a national holiday.

Higher Alzheimer's mentions. Figure 5 shows that Alzheimer's tweets are much higher than Dementia counts across all states, while in Figure 6 the counts are almost equivalent across all states in the second figure. This could be due to the people often use the two interchangeably [24].
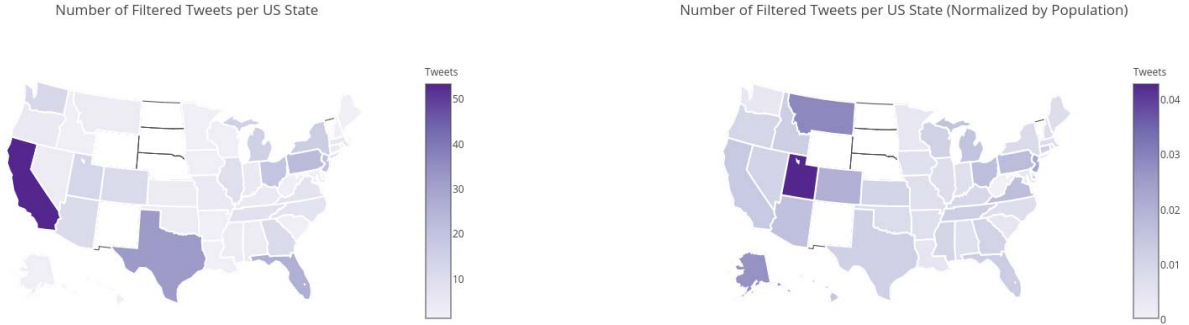
Fig. 8. Filtered tweets with geographical information mapped according to state. The left map shows the number of tweets per state, while the map on the right shows the number of tweets normalize by state population. Some state have no activity.

TABLE VI
HOLIDAY SENTIMENT OBTAINED BY RUNNING SENTIMENT140 API ON TWEETS FROM THANKSGIVING (11/23-27/2016) AND CHRISTMAS (12/23-27/2016)

	Negative	Neutral	Positive
Thanksgiving	67 (51.94%)	45 (34.88%)	17 (13.18%)
Christmas	93 (58.86%)	48 (30.38%)	17 (10.76%)

Another explanation for the higher counts in Alzheimer's counts in the full set could be that Alzheimer's is not a reversible disease and users tend to promote it aggressively either for job posting, or news articles and activism.

Southwestern states have neutral sentiment. We analyzed the tweet sentiment of the United States by clustering results of states in regions. Table VII shows that most regions lean towards negative sentiment.

TABLE VII
SENTIMENT OF INFORMAL CAREGIVER TWEETS BY UNITED STATES REGION. ALL US REGIONS ARE LEANING TOWARDS NEGATIVE SENTIMENT EXCEPT THE SOUTHWEST IS MORE NEUTRAL.)

US Region	Negative	Neutral	Positive
Midwest	**33 (53.23%)**	24 (38.71%)	5 (8.06%)
Northeast	**35 (48.61%)**	28 (38.89%)	9 (12.50%)
Southeast	**46 (59.74%)**	26 (33.77%)	5 (6.49%)
Southwest	17 (36.96%)	**20 (43.48%)**	9 (19.57%)
West	**66 (62.86%)**	27 (25.71%)	12 (11.43%)

Higher female presence. The data presented in Figure 3 shows that our care recipient counts are higher in females than in males, and the overall ratio is approximately 1.6 women to men. In the individual categories we can also find that grandmothers are mentioned more often than grandfathers; this could be related to the fact that women tend to live longer than men do [25]. According to the Alzheimer's Association [26] the risk of a woman to develop Alzheimer's at age 65 is 1 in 6, compared with 1 in 11 for a man. Women statistically have a higher chance to develop a form of Alzheimer's.

B. Limitations

Our approach to identify care recipients works well for the most part, but we noticed the complexity of the relationships in the tweets. A simple approach such as the one we presented is unable to capture all care recipients. For example complex relationships as: Husband parents, 80 year old mother etc. Also, to better model and analyze sentiment a larger set of tweets needs to be labeled. The results we show in our study are based on a small set consisting of 200 randomly selected tweets.

VI. CONCLUSION

In this study we present our preliminary findings of analyzing tweets related to Alzheimer's and Dementia. The data was collected for the period between January 1, 2016 and December 31, 2016. We proposed an approach to identify care recipients and analyzed tweets based on the gender of the recipients and the location of the posted tweets, as well as performed sentiment analysis on the collected tweets using pre-trained sentiment models from prior work. The work provides valuable insights about the unique characteristics of informal caregiving expression on Twitter, which could be very helpful in the development of a future social media health promotion intervention to prevent caregiver burnout. Future work includes building new sentiment analysis models taking into account the unique features of caregiving tweets beyond traditional three categories of positive, neutral, and negative. This work brings us close to the development of a social media health promotion intervention to prevent caregiver burnout.

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