

Analyzing Autism Spectrum Disorders through Social Media

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Abstract- Social media channels, such as Instagram and Twitter, have been increasingly used to communicate about healthcare and to connect caregivers. Despite the large focus on epidemiological trends, little is known about how social media facilitate peer support, in special for caregivers of patients with Autism Spectrum Disorder (ASD). To shed light in this domain, this paper provides a comprehensive analysis of how Autism Spectrum Disorder is discussed in two social media channels, Instagram and Twitter. We analyze and compare + posts published with the hashtag #autismmom. We analyze the users' profiles that adopt the hashtag to post, the types of contents users post, the level of engagement the posts receive and its variability. Users also emphasize the ability to conciliate caregiving with self-care and professional development. A few influencers (public persons such as singers, writers, and coaches) may also be responsible for a higher level of engagement of the autism mom community.

CCS Concepts: Computer systems organization → Embedded systems; Redundancy; Robotics; Networks → Network reliability;

Keywords: autism, social media analytics, caregivers, Instagram, Twitter

I. INTRODUCTION

Social media channels have been extensively used in healthcare[1], primarily to promote awareness campaigns, to share information, and to advertise services, products, treatments, and organizations. In an effort to connect remote peers and build a network of support, the number of online posts related to medical conditions has been growing. Still, there are important risks faced by users that cannot be ignored, including issues related to privacy [2], harassment, cyberbullying [3]and misinformation [4].

There are numerous motivations and goals that lead users to actively share medical posts and engage with social media channels, including [1] the dissemination of updated information about epidemics, therapies and prevention strategies; [2] raising funds to support patients' treatments; and [3] promoting public health campaigns to disseminate legitimate information, raise awareness and reduce stigma.

The scientific community has begun to investigate how users express themselves through social network channels, focusing on mental health[5], epidemiology [6], communication [7], and stress management [8]. Despite the risks involved with lack of privacy and misinformation, social media channels still offer many advantages to patients seeking support and information, as the services are continuously available thus accessible on demand. In addition to that, users can remain anonymous, the discourse is more accessible, and the cost to access information and resources is low.

Individuals with neurodevelopmental disorders and their caregivers face many challenges, as involving impairments have life-long impacts in the individual's life, affecting them in different aspects and varying severity levels, hindering their executive functioning, daily planning, scheduling of activities, communication skills, self-

assessment, regulation of affective states, among other abilities. To provide peer support and information exchange, social media channels have a promising potential –they assist caregivers to retrieve information of interest and find social support, besides also promoting awareness and fund-raising campaigns as well as connecting remote peers on demand.

Social support is essential for caregivers of patients in neurodiversity, aiding them to share personal experiences, struggles, seek for advice and disseminate relevant information. Web-based solutions and social media specifically, have a large potential to facilitate these activities, enabling users to exchange social support and information of interest and to discuss their personal experiences through an inexpensive, and accessible solution [9],[10],[11]. While no dedicated application has been created to meet these requirements, caregivers have already been relying on social media channels, such as Facebook, Twitter, and Instagram, to search for medical information online, seek for advice, provide recommendations and connect with their peers.

Web-based solutions are versatile, accommodating users' needs on demand. In addition to that, social media channels can be particularly beneficial to promote quick dissemination of updated contents and to enable information sharing adopting a more user-centered, affordable and accessible perspective.

The key findings of this study will indicate the similarities and differences across channels. How ASD caregivers focus on sharing their thoughts and feelings, raising awareness and reducing discrimination, while demonstrating the ability to balance caregiving activities with self-care. Do the contents posted include motivational quotes, everyday life documentation or novel treatments? To check how the sentiments, change from Twitter to Instagram.

For research questions were selected to guide this study:

- 1) What are the profile characteristics of the users who employ SMCs to communicate about Autism?
- 2) How caregivers appropriate the channel to communicate about the conditions?
- 3) What types of contents do they commonly share

online?

- 4) What are the main similarities and differences in sentiments between Twitter and Instagram users?

II. RELATED WORK:

To understand how social media analytics has been explored in healthcare, we analyzed previous work that particularly studies that investigated social media analytics to address disease prevention [12], monitoring of epidemics [13], and treatment support [13].

Manikonda and Choudhury (2017) studied the usage of social media among users concerned about mental health [14]. An analysis of visual imagery from Instagram shows that the platform is employed for self-disclosure, to express emotional distress and call for help [14]. [15] Goldbeck et al. also analyzed tweets to predict relapse in patients with alcoholism [16] and to detect different types of coping mechanisms when users are dealing with stressful situations [17]. Chung et al. (2017) investigated the usage of Instagram as a social media channel to share information about eating habits. Results show that users mainly sought social support to acquire information and educate others about healthier nutritional habits [18]. They also investigated the use of social networks to promote weight loss among college students. The results indicate that social media apps aided study participants to hold themselves accountable and provided peer motivation for weight loss.

III. PROPOSED APPROACH

To answer the research questions selected for this study, and interpret the data collected, we employed a mixed-method approach. To address qualitative aspects, we conducted a thematic analysis of the image contents. The codes generated emerged from a bottom-up empirical approach, inspired by grounded theory and resulting in a codebook. We report the findings of an exploratory analysis of users' behaviors when using Instagram and Twitter to communicate about caregiving and autism. Then, we discuss the benefits and drawbacks that social media entails for online posts of medical information, from a user-centered perspective including a patient, caregiver, and

organizations.

We focus on ASD conditions and on how caregivers appropriate SMCs to express their thoughts and feelings about the conditions. Finally, we discuss the implications, risks and potential threats concerning patients' privacy and publicly sharing medical information online. Once the contents of interest are extracted, a textual and a graphic analysis was performed. We will combine an exploratory analysis to gather a general view of the contents extracted as well as an in-depth analysis investigating the images posted and specificities. The data analysis will also combine quantitative and qualitative metrics for syntactic and semantic interpretation of the contents. The data retrieval in this project for Twitter and Instagram is done with the help of the R Programming Language. Sentiment and Network analysis proceed with the help of the Python Programming language. Visualizations are this project is done using Tableau, Python, and Gephi.

IV. System Design

A. Architecture

Our system design is explained in various milestones in the below flow diagram, Dataset has been gathered from Twitter using R programming with a Rtweet package and Twitter API. For the twitter data to be extracted, firstly twitter account needs to be created, then Twitter will provide API keys and they will be used to extract the data. The data was generated as CSV files, we have collected 18000 records. In a similar way, Instagram data has been collected using the web crawler and the dataset is stored in the CSV format for Instagram, we gathered 9000 records of data.

The Twitter dataset has several metadata fields, but we consider only a few of them which are Tweet/text, Location, status URL, retweet count, favorite count, Source of the tweets. Unnecessary columns will be removed in the Data preprocessing and functions will be defined to clean the data, to remove @ from the user name, removal of the punctuations, special characters, and emoji symbols. Hashtags will be extracted as well. After the preprocessing is done, Tweet will be appended to the new list. On the cleaned tweet, sentiment

analysis is performed using AFINN lexicon. Lexicon has a list of the English summary where they are predefined with a valence factor -5 to + 5 range of valence factor. Using this lexicon, polarities will be calculated. Depending on the polarity we are classifying the sentiments into 5 different categories, such as - very negative, negative, neutral, positive and very positive. Once the sentiment and its respective polarity list are appended to the original dataset, we will generate a new CSV file. Sentiment analysis is performed using the Python programming language.

Once it generates the results, we have performed exploratory manual analysis on the user profiles and the kind of posts users are sharing and using the location variable, will find out from which place posts are shared. After the manual analysis, we are performing the network analysis to find out the relationship between networks, to find the most retweet counts, and the top profile user, active users. Tableau is used to display all the results of the sentimental analysis and the manual analysis is performed on the datasets. The tweets which are analyzed and visualized the results. Top- tweets are visualized using the tableau.

B. Languages

Programming will be done in R and Python. R will be used for acquiring the tweets from Twitter. To acquire the data from the Instagram Python will be used. For Sentiment Analysis, Python will be used to classify the sentiments. For Network analysis, the R programming language will be used and the Gephi is also used.

C. Software Tools

RStudio will be used to extract the tweets from the Twitter dataset using R programming. The Jupyter notebook will be used for the sentiment analysis, cleaning the dataset and for extracting the dataset from Instagram using Python programming language. For network analysis, R programming will be used using the network API. For visualizations of the data, Tableau will be used.

D. Data Sources

Twitter - It is the primary source of the data; data is gathered using the Twitter API using the R programming language and it is stored as CSV files

for the purpose of speed and it will be used further for the analysis. In the Twitter dataset, the fields we are considering would be the tweets, location, status URL, the user profile name for the analysis.

Instagram - it is the secondary source; data is gathered using the web crawler in the python platform and stored as CSV files for the purpose of speed. In this dataset, for analysis Description column will be considered.

V. Preliminary Experimental Results

1. Data Preprocessing:

Initially, data has been extracted from Twitter and Instagram using the Twitter API and web scrawler from the R programming and Python languages respectively.

	created_at	screen_name	text	source	favorite_count	url
1	2019-04-23T07:43:16	unbornmel	How beautiful to hear Greta Thunberg talking about Autism as a gift and pointing out that society is the problem	Twitter Web Client	8695	https://twitter.com/unbornmel/status/11205998
2	2019-04-20T20:21:15	NaturalisticDana	I go into the forest when life gets too much - because I feel everything with a 1,000,000x intensity.	Twitter Web App	2243	https://twitter.com/NaturalisticDana/status/111
3	2019-04-23T07:25:55	SophieHunting	Greta Thunberg on #tuesday demonstrating the value of different minds to progress for all of us. Our lives	Twitter Web App	540	https://twitter.com/SophieHunting/status/112
4	2019-04-23T11:54:15	MileyKayNYC	#MileyKayNYCBrother Kamp! My film chasing Spen around the mountains of North Wales has 7	Twitter for iPhone	532	https://twitter.com/MileyKayNYC/status/1120
5	2019-04-23T17:39:55	jason_carl_fox	This is the story of @MileyKayNYC and his brother Spen. It needs to be seen. #Autism	Twitter for iPhone	361	https://twitter.com/jason_carl_fox/status/112
6	2019-04-24T13:54:33	cobaeu	Just like there were no cuts to autism?	Twitter for iPhone	313	https://twitter.com/cobaeu/status/11204981
7	2019-04-22T09:00:05	MicMacGuinness	5 days to go. #Worldleakit #Wala	Twitter for iPhone	264	https://twitter.com/MicMacGuinness/status/1
8	2019-04-22T01:16:43	StacyLuffyThyrd	My friend Ashken from Grandmaster Flash Remix: The Furious 5 with a special shout out to the Toronto	Twitter for Android	228	https://twitter.com/StacyLuffyThyrd/status/1
9	2019-04-23T17:24:03	TheKapeWorld	@KEEMSTAR What the actual shit are you talking about! Social Anxiety is a real issue that me and the 8	Twitter for iPhone	171	https://twitter.com/TheKapeWorld/status/11
10	2019-04-23T17:24:03	Kevin_Healey	@GaryLieber Gary n.Ads a long shot, but I sincerely hope you see this tweet, and RT, we need this petti	Twitter for iPhone	170	https://twitter.com/Kevin_Healey/status/112
11	2019-04-24T13:10:22	keeyahworth	I have long looked at my son's diagnosis as a gift and for him to see it as a positive part of him not a	Twitter for iPhone	158	https://twitter.com/keeyahworth/status/11
12	2019-04-20T18:58:03	TheKapeWorld	This disgrace of a youtuber @KEEMSTAR saying autism, dyslexia and ADHD are made up and 'AlzrencyA	Twitter for iPhone	154	https://twitter.com/TheKapeWorld/status/11
13	2019-04-23T02:50:13	hollyperce	I #Autism.	Twitter for iPhone	140	https://twitter.com/hollyperce/status/11205
14	2019-04-23T10:38:43	autismhooday	Sometime ago, I figured out that 95% of what son does is only a problem if I make it one.	Twitter for Android	116	https://twitter.com/autismhooday/status/111
15	2019-04-24T18:39:43	kathleenegrady	Public hospitals in Canada now charging kids with disabilities for access to health services. This is the @	Twitter for iPhone	110	https://twitter.com/kathleenegrady/status/11
16	2019-04-23T18:05:41	TeriGrtt	April is AutismAwarenessMonth	Twitter Web Client	108	https://twitter.com/Terigratt/status/111966
17	2019-04-24T09:58:33	and_ell	Measles, measles, measles... That is ALL #vaccinationists are about. Autism isn't even on their radar.	Twitter for Android	104	https://twitter.com/and_ell/status/11205904
18	2019-04-20T19:37:11	loveiswalmart	Corporate essays on Autism and loving the autistic superstar! Alysa Joquin. Via @MAGASentinel, cc: @Nash	Twitter for iPad	104	https://twitter.com/loveiswalmart/status/11
19	2019-04-23T23:23:21	autistic	#Autism means noticing I Am hungry, dizzy, tired, in pain etc., going to the kitchen to make some	Twitter for iPad	97	https://twitter.com/autistic/status/1120830
20	2019-04-23T07:43:16	unbornmel	How beautiful to hear Greta Thunberg talking about Autism as a gift and pointing out that society is the	Twitter Web Client	8695	https://twitter.com/unbornmel/status/11205998

Figure 1 Twitter Data Set

After the data has been extracted, functions are defined to clean the tweet and the description of Instagram. The functions will remove the pattern where it starts with @ and for removing special characters, replace function has been used and the hashtags are extracted as a separate column. Similarly, the same process is performed on the Instagram dataset.

2. Sentimental Analysis:

After cleaning the Tweet message, sentimental analysis is performed using the AFINN lexicon. AFINN is a list of English words rated for valence with an integer between minus five (negative) and plus five (positive). The word is manually labeled by Finn Arup Nielsen. We have two versions of this AFINN-111: Newest version with 2477 words and phrases. AFINN-96: it has 1468 unique words and phrases on 1480 lines. The words list is not entirely in the alphabetical order. Using the AFINN library, the sentence will get a polarity score. The polarity was in the range from -18 to 21, so the sentiments are classified into 5 different categories which are

very negative, negative, neutral, positive, and very positive. In a similar way, the analysis is performed on Instagram data as well.

Sentimental Analysis

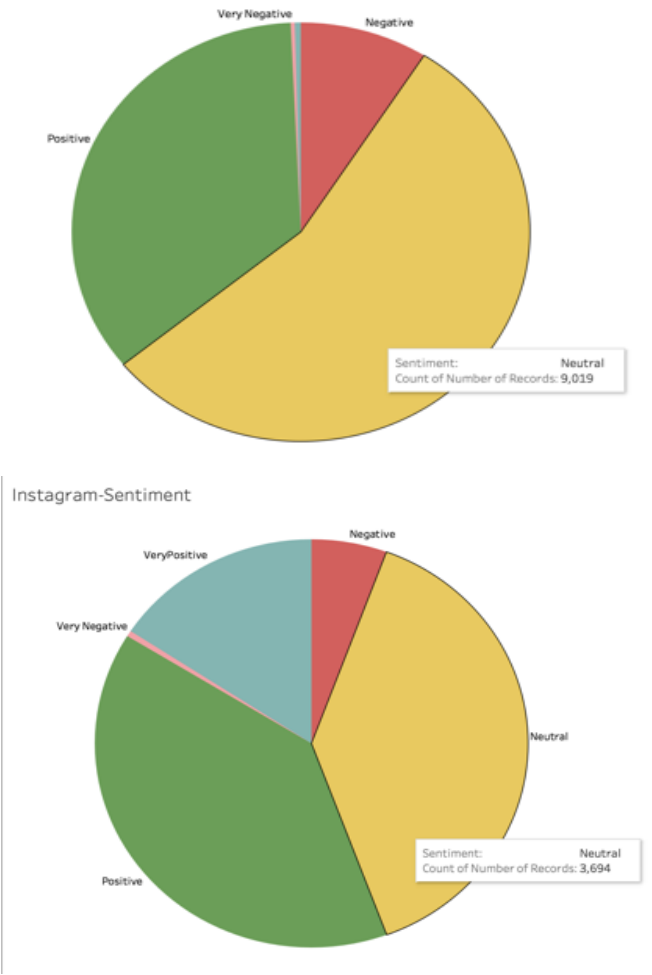


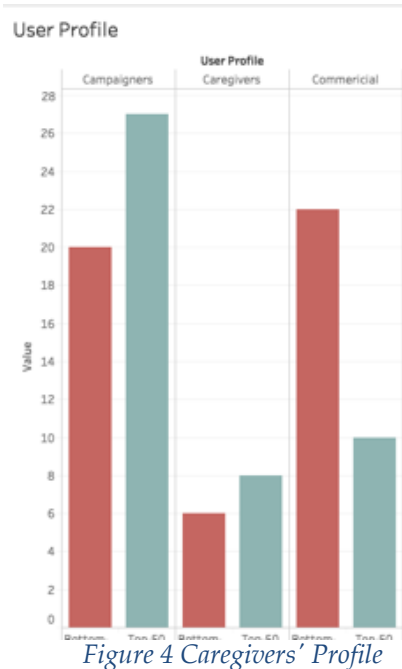
Figure 2 & 3 Sentimental Analysis

From the pie charts, we can say that the Instagram platform is used in a more positive way compared to Twitter. The positive and very positive is higher on Instagram, Negative tweets are more on Twitter, Neutral percentage is more on Twitter and less on Instagram.

3. Exploratory Analysis:

Through the manual analysis, three general categories were noted in analyzing the profile of the users who posted contents related to autism: caregivers(mother/father/brother/family), commercial (services, products, organizations, and institutions), and campaigns (advocates, activism, to raise awareness). The analysis performed on the Twitter data on the top-50 tweets we could say

there were more campaigners and a smaller number of caregivers. In the bottom-50 tweets analysis, commercials were more, and caregivers were less. But in both Top- 50 and bottom-50 the caregivers were more in the top-50 when compared to bottom-50.



Coming to the analysis of the posts shared by the users on the Twitter platform, we classified them as Motivational posts, Advertising fundraising campaigns, Daily Routine, Events, Celebrating Milestones, Raising Awareness, share feelings, and Tips. In terms of the goals of the posts, users were focused on highlighting their own individual story and celebrating the milestone of the children. We will have a detailed explanation of each category on what basis tweets are classified.

- Share Feelings** - the posts mostly included in this category related to challenges faced by the caregivers and the mother or father having difficulties when raising the children who have autism.
- Motivational Posts** - it would include the posts shared by a user sharing the photo of motivational quotes. For example, we can consider that for an advertisement of autism walk for one boy organized by a family to support autism children and other parents.
- Advertising Fund Raising campaign** - it will have several posts related to donations, crowdfund

- donations. In terms of the campaigns where #autism if it is a trending hashtag it will involve in the communication listen to what individual will say about it.
- Daily Routine** - It is about how the autistic children need to be brought up and the games they are playing games about how to identify the blocks. Parties are also shared, hygiene habits of children.
- Events** - In this category users, organizations will share the content about the autism awareness month, autism awareness day by whereby posting a picture on the platforms and announcing the campaigns to join the community to raise awareness about the condition, incentivizing the users to join a special dance class for families. Other flyers aimed at announcing events to raise awareness such as a workshop, an Autism walk event (for social support of the community), support for children with autism by teaching community, and community support for autistic children who had other conditions too.

- Milestones celebrating**- it would be related to the educational achievements, game events, and they are documented and analyzed using the behavior analysis. Where tips will be shared as well.
- Raising Awareness** - campaigners will raise an event and TV show which will be related to autism. Parents will also share the posts and facts to raise awareness about autism in the online platform.
- Tips** - Among this mother shares their experience about schooling the kids, speech therapy held by health practitioners for autistic children, workshops held for the children to make them learn in an easier way.

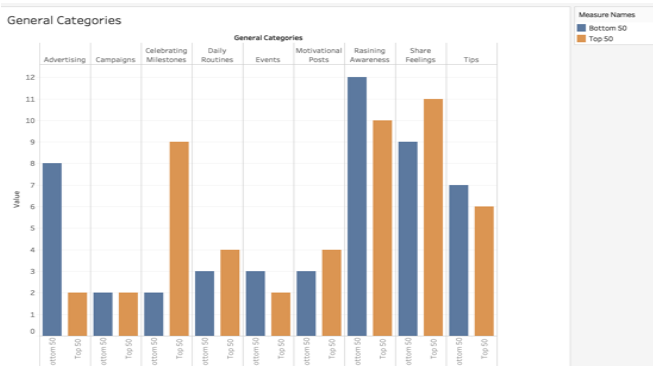
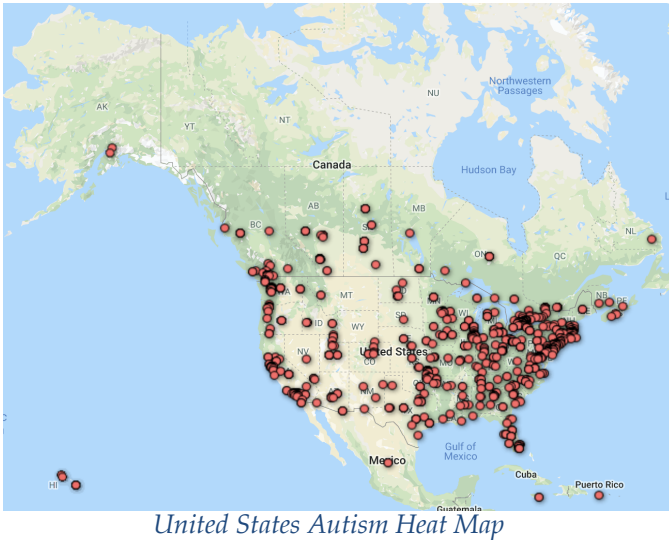


Figure 5 Affordance of Twitter (autism)

4. Visualization:



In this visualization using the GoogleFusion, the tweets tend to be in more number towards the East Coast of the United States.

hashtag is presented in Fig-6, Fig-9, and Fig-8.
20 active users by centrality are presented in Fig-2.

Retweet Relationships

Most retweeted screen names labeled. Darker edges == more retweets

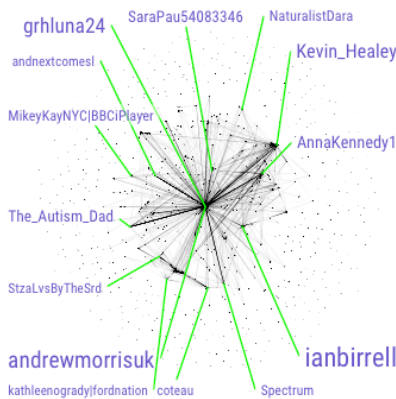
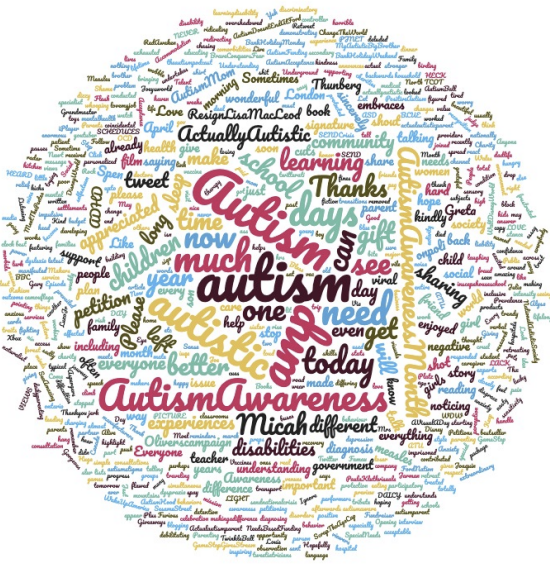


Figure 6 Network Analysis



Top 50 Tweets Word Cloud

5. Network Analysis

For network analysis, we constructed a network visualization using R. The network is composed of 52500 nodes and 21170 edges. Each node represents a user meanwhile each edge represents a user whose tweet has been retweeted.

The node size represents the number of retweets a user has received. Network analysis, Betweenness centrality and Eigen centrality of the Autism



Top 20 active users (by centrality)

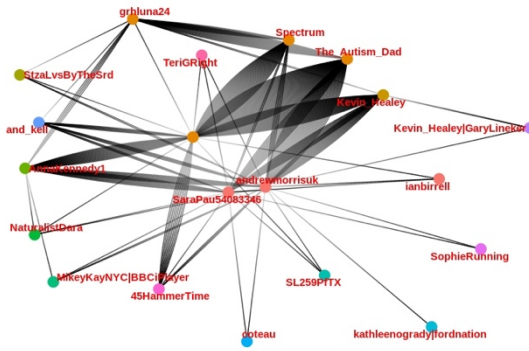


Figure 7 Top 20 Active Users by Centrality

In network analysis, there are two key measures including degree and betweenness centrality. These metrics are used to recognize and map the contribution of different entities within the network.

High out-degree detects the entities initiating the most conversations, meanwhile high in-degree show the members having most of the conversations about the specific hashtag. Betweenness centrality discovers the most influential members in a social network or a specific discussion topic.

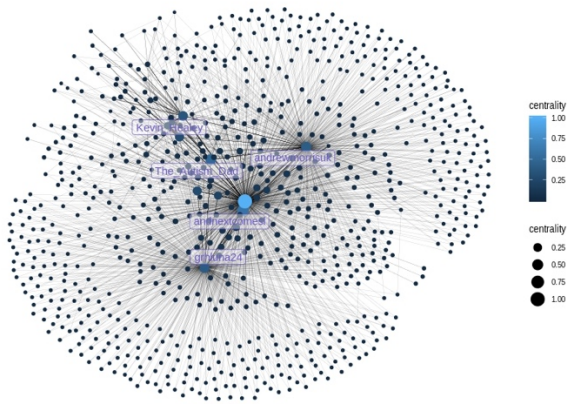


Figure 8 Eigen Centrality

Node-level metrics of the highlighting the top 20 entities are presented in Table 1,2,3.

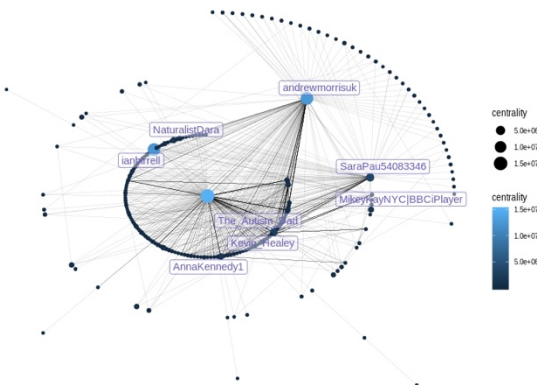


Figure 9 Betweenness Centrality

From the accounts analyzed from Twitter, concerning the top 20 profiles which are considered the most influential member by betweenness centrality, there were 10 accounts from caregivers, 7 were dedicated accounts for campaigns, 3 for organizations and commercial purposes

For the top 20 profiles which are considered the most important members by in-degree measurement, there were 3 accounts from caregivers, 11 were dedicated accounts for campaigns, 6 for organizations for commercial purposes.

Table 2

Highly Sociable		
User	Indegree	Role
ianbirrell	1722	Campaign(Advocate)
kevin_healey	293	Campaign(Advocate)
naturalistdara	189	Campaign(Advocate)
fordnation	184	Campaign(Advocate)
mikeykaynyc	176	Caregiver
annakennedy1	160	Commercial
macleodlisa	149	Caregiver
bbcone	147	Commercial
bbciplayer	145	Commercial
autism	123	Campaign(Advocate)
bbcbreakfast	116	Commercial
stzalvsbythesrd	115	Campaign(Advocate)
mrscmcguinness	101	Campaign(Advocate)
kathleenogrady	100	Campaign(Advocate)
sl259pftx	100	Campaign(Advocate)
ontliberal	98	Commercial
coteau	97	Campaign(Advocate)
livepdfans	96	Commercial
the_autism_dad	92	Caregiver
extinctionr	84	Campaign

For the top 20 profiles which are considered the most important members by Out-degree measurement, there were 6 accounts from caregivers, 13 were dedicated accounts for campaigns, 1 for organizations and commercial purposes.

Highly Influential		
User	Betweennesscentrality	Role
annakennedy1	2120519.272	Caregiver
andrewmorrisuk	2112237.3	Caregiver
autismallstars	1915869.725	Commercial
kevin_healey	1725059.871	Campaign(Advocate)
eldertine	1363540.598	Campaign(Advocate)
shoutywhisper	1355528.598	Caregiver
tracyjtanner	1310841.739	Campaign(Advocate)
autismtalkaspie	415551.6656	Commercial
ratleytamara	383384.0063	Caregiver
luminaryobsrty	259191.4818	Caregiver
lauriemit	227307.8278	Caregiver
mrscmcguinness	222236.2031	Advocate
nancy_marchese	217896.7333	Caregiver
just4thecause	213714.3093	Caregiver
drfixus	212989.7834	Campaign(Advocate)
helenashby72	201711.1252	Caregiver
paulamc007	186713.4016	Campaign(Advocate)
a_crazymama	166543.0133	Commercial
shonadav	119352.2713	Caregiver
qlmentoring	106985.610101	Campaign

Table 1

fingers or shake the phone so as to get the user get going on the presentation of the prototype.

Once the previous instructions are taken care of, the user will have to enter #autism to proceed with the analyzation of the particular hashtag. The user has to previously be aware of that, it shall work only in case of the autism hashtag, as the projects' data is related to Autisms' data. Once the user inputs the autism hashtag, the user will be able to download, analyze and share the dataset. The various analysis is shown on the prototype, including network analysis, word Cloud, word Trees, heatmaps, platform analysis and some more. The user will have to select one of these to proceed with the results.

Table 3

Highly Referred		
User	Outdegree	Role
andrewmorrisuk	1294	Caregiver
grhluna24	504	Campaigner
sarapau54083346	294	Caregiver
kevin_healey	163	Campaigner
beckyjohanson222	94	Campaign(Advocate)
strawberryasd	94	Caregiver
coercedtaxslave	82	Commercial
luma923	76	Campaign(Advocate)
45hammertime	75	Campaigner
sharontiday	68	Campaign
danaelizabeth69	62	Campaign(Advocate)
doritmi	57	Campaign(Advocate)
meeksvs	57	Campaign
drfixus	52	Campaign(Advocate)
tracyjtanner	52	Campaign(Advocate)
cplbart	51	Campaign(Advocate)
ldslibertarian1	51	Caregiver
lesbiananarchy	50	Campaign(Advocate)
jasonmchicago	49	Caregiver
lia_crowley	49	Caregiver

Prototype:

The prototype for this project can be run either on the Web Browser or on the Proto.io app. The Proto.io application shall be downloaded prior to the execution. A link is to be shared to the user if the user needs to get inside this projects' prototype. Once the project opens through the Proto.io application, the user is prompted to tap with three

VI. Limitation

The one challenged we faced was with data collection, as we could not gather many tweets data related to #autism from the Twitter and Instagram platforms. There were a smaller number of posts related to this particular hashtag. As the study was conducted using a hashtag in English, the results also correspond mostly to English speaking countries.

VII. Conclusion

Through analyzing the results, Firstly, we classified the sentiments into 5 categories, which are Very negative, negative, neutral, positive and very positive. Using this sentiment, we concluded that Instagram had more positive tweets compared to Twitter, the Twitter platform had a greater number of neutral tweets. In Instagram people are more positive about the autism, the posts, and the responses. Coming to negative tweets the ratio is more in the Twitter and its same as with Instagram. From the exploratory analysis, we concluded that for profile users there were more campaigners in the Top-50, in Bottom-50 commercial users were more. For the posts shared by users are classified into different categories, we concluded that in Top - 50 share feelings contents were more and in Bottom - 50 more raising awareness posts shared by the users. The least was the campaign in both Top and Bottom 50 tweets. From the network analysis, we got Top - 20 Profiles which are considered as most influential using the betweenness centrality, there were 10 profiles are

caregivers, 7 for campaigns and 3 are from organizations. From the Word cloud obtained, we have figured People has most common hashtags are related to autism awareness, autism speaks, learning, help, children and autism.

The analysis of social media channels conducted in this study, helped to understand how on demand communication enables users to express their feelings, concerns, and coping mechanisms. By focusing on users that use Instagram and Twitter to communicate about ASD we learned that the hashtag autism is mostly adopted in the US coasts (California and New York), that overall the tone of the users' communication tends to be positive, especially in Instagram, that influencers (users with a high number of followers and actively posting contents) use the hashtag #autism to share information about their daily routines and to stand up for their causes by showing that despite the burden of caregiving, they are capable of dedicating time for self-care and to advance their careers.

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