

Identifying network structure, influencers and social mood in digital spheres: A sentiment and content analysis of down syndrome awareness

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Suggested Citation:

Sani-Bozkurt, S. (2018). Identifying network structure, influencers and social mood in digital spheres: A sentiment and content analysis of Down syndrome awareness. *World Journal on Educational Technology: Current Issues*. 10(1), 10–19.

Received date August 02, 2017; revised date November 05, 2017; accepted date December 22, 2017.

Selection and peer review under responsibility of Prof. Dr. Servet Bayram, Yeditepe University, Istanbul, Turkey.
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Abstract

Down syndrome is a sensitive subject and one that requires efforts being made to improve conditions of individuals with Down syndrome across multiple dimensions. Social awareness is one of the important dimensions for the inclusion of individuals with Down syndrome. Online spaces as well as offline spaces are an important part of our daily lives, and these spaces provide numerous opportunities to create, increase and sustain awareness of Down syndrome. From this perspective, this study examines the awareness of Down syndrome in online spaces. With this objective in mind, the research examined 4,168 conversations from 2,430 individuals that were posted in a microblogging service on WDS. The research findings indicate that the Down syndrome network is distributed in time and space with diverse backgrounds. Key influencers were those who were already associated with Down syndrome. Furthermore, the social mood for Down syndrome was found to be positive.

Keywords: Down syndrome, World Down Syndrome Day, Down syndrome awareness, social network analysis, sentiment analysis.

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1. Introduction: Extra +1 chromosome

Down syndrome is a genetic disorder that is also known as trisomy 21 (Patterson, 2009). The British doctor John Langdon Down initially named the disorder in 1866; however, French researchers first identified the genetic cause of Down syndrome, an extra copy of chromosome 21, in 1959 (Hickey, Hickey & Summar, 2012). Trisomy 21 (AKA the karyotype 47, XX,+21 for females and 47, XY,+21 for males) (Reynolds & Fletcher-Janzen, 2007) is caused by a failure of the 21st chromosome to separate during an egg or sperm development. As a result, a sperm or an egg cell is produced with an extra copy of chromosome 21; consequently, this cell has 24 chromosomes. When combined with a normal cell from the other parent, the baby has 47 chromosomes, with three copies of chromosome 21 (Rubin & Reisner, 2013).

According to the Centers for Disease Control and Prevention (CDC), Down syndrome is the most common chromosomal condition diagnosed in the United States. Accordingly, each year, about 6,000 babies born in the United States have Down syndrome. Based on this data, Down syndrome occurs in about 1 out of every 700 babies (CDC, 2014).

Even though people with Down syndrome are similar in some aspects, individuals with Down syndrome have diverse abilities. It is generally associated with intellectual disability, a characteristic facial appearance and weak muscle tone in infancy. All affected individuals experience cognitive delays, but the intellectual disability usually ranges from mild to moderate. Individuals with Down syndrome may also have a variety of birth defects. For instance, about half of all the affected children are born with a heart defect, while digestive abnormalities, such as a blockage of the intestine, are less common (Genetics Home Reference, 2016). Some other common physical features of Down syndrome are (CDC, 2016):

- A flattened face, especially the bridge of the nose
- Almond-shaped eyes that slant up
- A short neck
- Small ears
- A tongue that tends to stick out of the mouth
- Tiny white spots on the iris (coloured part) of the eye
- Small hands and feet
- A single line across the palm of the hand (palmar crease)
- Small fifth digits that sometimes curve toward the thumb
- Poor muscle tone or loose joints
- Shorter in height as children and adults

Down syndrome is a condition that necessitates lifelong attention. Services in early life will often help young individuals with Down syndrome to improve their physical and intellectual abilities. Most of these services focus on helping individuals with Down syndrome develop to their full potential in order to improve their life quality. These services may include speech, occupational and physical therapy, and they are typically offered through early intervention programmes in each state (CDC, 2016; Fidler, Hodapp & Dykens, 2002). Children with Down syndrome may also need extra help or attention in school, although many children are included in regular classes (CDC, 2016; de Graaf, Hove & Haveman, 2013). With this in mind, supporting the individuals with Down syndrome is an important issue, as it is raising awareness in an effort to support the individuals with Down syndrome.

1.1. World Down Syndrome Day

The French Association for Research on Trisomy 21 (AFRT) was established in 1990 for supporting research and informing on medical and scientific advances in the field of Down syndrome. In 2005, AFRT selected the date of 21st March (21/3 in French and 3/21 in US English) as a symbolic date for

the day of trisomy 21 (Strippoli, 2014). As a result, World Down Syndrome Day (WDSD) is dedicated to individuals with Down syndrome and observed on 21st March every year. Its logo signifies the genetic cause of Down syndrome (Figure 1). On this day, various activities and events are organised around the world to raise public awareness and create a single global voice for advocating for the rights, inclusion and well-being of people with Down syndrome (Down syndrome International, 2016).



Figure 1. Logo of the World Down Syndrome Day (WDSD)

WDSD is important because it serves to raise awareness and create a single global voice for advocating for the rights, inclusion and well-being of individuals with Down syndrome (WDSD, 2016). However, these efforts are not limited only to offline worlds. Considering that the 21st century is called the 'digital knowledge age', there is a need to investigate awareness of Down syndrome in online worlds, as well as in offline worlds.

Based on the above-mentioned situation and requirements, the main objective of this research is to examine awareness of Down syndrome. In this regard, the research questions of this paper are as follows:

- What is the network structure of Down syndrome community in digital spaces?
- Who are the influencers for Down syndrome awareness?
- What is the social mood of the Down syndrome community in digital spaces?

2. Methodology

2.1. Research design

The research uses the convergent (also known as parallel or concurrent) mixed method design. The purpose of the convergent mixed methods design is to collect both quantitative and qualitative data simultaneously, merge the data and use the results to understand a research problem. A basic rationale for this design is that one form of data collection supplies the strengths to offset the weaknesses of the other form, and that a more complete understanding of a research problem results from collecting both quantitative and qualitative data (Creswell, 2012). For this purpose, the research employed quantitative social network analysis metrics and qualitative sociograms to explore network structure and global influencers. Additionally, qualitative sentiment analysis was used to explore social mood in these networks.

Social network analysis (SNA) can be used to study, track and compare the dynamics of communities and the influence of individual contributions. It is also helpful to map, summarise and visualise networks and identify key vertices (Hansen, Shneiderman & Smith, 2010). Sentiment analysis is an opinion mining technique (Pang & Lee, 2008) to identify positive and negative opinions, emotions and evaluations (Wilson, Wiebe & Hoffmann, 2005).

2.2. Data collection and analysis procedures

SNA was used to map the structure of the network, identify influencers and collect textual data. In order to do this, participants using Twitter with the ‘Down syndrome’ and ‘World Down Syndrome Day’ hashtags were tracked by using NodeXL software on WDSO. To gain an insight of the network structure, global network metrics, such as graph density, geodesic distance and modularity were calculated (Table 1). To visualise the network, the Clauset-Newman-Moore cluster and Harel-Koren fast multiscale layout algorithms were used (Figure 2). In order to identify key influencers, local metrics, such as in-degree, out-degree and betweenness centrality values were calculated for each participant (n = 2,430) (Table 3). In order to identify mood in the network, sentiment analysis was applied to the textual data. Following these steps, the textual data was analysed using word clouds and content analysis to reveal the discourse in the sampled network.

2.3. Research context

The research context is Twitter, which is a widely used microblogging platform. It uses a bird logo that represents freedom, hope and limitless possibilities and highlights the importance of flocking with other birds to achieve a common purpose (Bozkurt, Aydin, Taskiran & Koral, 2016). Based on Twitter’s features and popularity, it is considered as a convenient medium for the research to analyse interactions in microblogsphere.

3. Findings and discussion

The research findings examined network structure to identify interaction pattern and investigate influencers for Down syndrome awareness. Following that, findings related to the social mood were reported and discussed.

3.1. Network structure and influencers

The data was gathered from a social network site, used for microblogging, on 21 March 2016, which is accepted as the WDSO. The interactions captured on Twitter were analysed using NodeXL. As a first step, the network metrics of WDSO were revealed (Table 1).

Table 1. Network metrics of WDSO

Nodes	2,430
Unique Ties	2,572
Ties with Duplicates	1,596
Total Ties	4,168
Self-Loops	1,077
Reciprocated Node Pair Ratio	0.018062
Reciprocated Tie Ratio	0.0354838
Connected Components	671
Single-Node Connected Components	452
Maximum Nodes in a Connected Component	1,294
Maximum Ties in a Connected Component	2,804
Maximum Geodesic Distance (Diameter)	15
Average Geodesic Distance	4.465512
Graph Density	0.000420
Modularity	0.600368

Accordingly, the dataset consisted of 2,430 nodes (Twitter users) and 4,168 ties (interaction observed). Of all the 4,168 ties, 2,572 were unique (61.8%) while 1,596 (38.2%) were duplicates of unique tweets. This finding shows that around 61.8% of the people are active supporters who have a

high awareness, while 32.8% are partly active supporters of the efforts to raise an awareness regarding Down syndrome. The average geodesic distance was 4.46, while the maximum geodesic distance was 15. Considering that the ideal geodesic distance is accepted as 6, this finding indicates that most of the participants come from diverse backgrounds and are loosely linked to each other. This finding is confirmed with single-node connected components metric, which was found to be 452. As a result, 18.6% of the nodes in the network did not connect to each other in any way, while the rest of the 81.4% connected to each other in network clusters. The modularity metric was found to be 0.600, which indicates the strength of division of a network into modules. Graph density value, which indicates the density of the interactions among the nodes in a network, was found to be 0.000420, which is considered to be very low. The findings reveal that nodes in the WSD network come from diverse backgrounds and tend to build a loosely connected network.

In order to see the network structure and the positions of the nodes in the network, a sociogram (network graph) was created using Clauset-Newman-Moore cluster and Harel-Koren fast multiscale layout algorithm (Figure 2).

Accordingly, the structure of the WSD network is identified as a ‘community cluster’ network type (Rainie, 2014; Smith, Rainie, Shneiderman & Himelboim, 2014). In this type of network structure, some popular topics may develop multiple smaller groups, which often form around a few hubs, each with its own audience, influencers and sources of information. These Community Cluster conversations look like bazaars with multiple centres of activity. Global news stories often attract coverage from many news outlets, each with its own following. This creates a collection of medium-sized groups and a fair number of isolates. In the ‘clustered/community cluster’ network type, some information sources and subjects ignite multiple conversations, each cultivating its own audience and community. These can illustrate diverse angles on a subject, based on its relevance to different audiences, revealing a diversity of opinions and perspectives on a social media topic (Rainie, Shneiderman & Himelboim, 2014).

The network structure indicates two important aspects of WSD network: First, diversity of opinions, perspectives, speakers and audiences demonstrates that Down syndrome is of interest to people coming from a diverse background. Secondly, influencers and their roles are important to raise and increase awareness of Down syndrome.

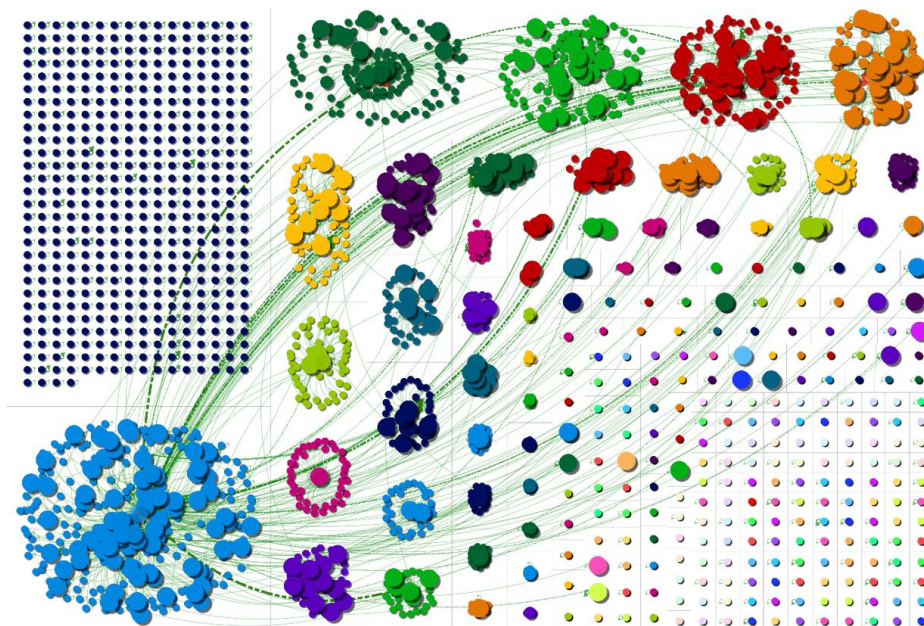


Figure 2. Sociogram of WSD

In order to identify influencers and their behaviour pattern, nodes were analysed according to their betweenness centrality and PageRank (Table 2). Betweenness centrality is a score that indicates a node’s ability to bridge different subnetworks in a network and measures a node’s centrality in the network while the PageRank algorithm is a metric that indicates influence score (Bozkurt et al., 2016).

Table 2. Comparison of the most powerful 15 influencers according to betweenness centrality and PageRank

Node	TA	D	ID	OD	Betweenness centrality	Node	TA	D	ID	OD	Page Rank
elianatardio	P	226	1	225	1320421.149	elianatardio	P	226	1	225	57.147
ontspecialneeds	O	125	122	3	388515.048	ontspecialneeds	O	125	122	3	43.123
worldsday	O	64	62	2	185273.852	c_gulselam54	P	52	52	0	20.449
c_gulselam54	P	52	52	0	154552.740	gigis_playhouse	O	53	10	44	19.416
bcmac7	P	24	16	10	132396.889	elmundosalud	O	44	43	1	19.199
gigis_playhouse	O	53	10	44	120524.957	worldsday	O	64	62	2	15.830
aliyarasool	P	13	0	13	116750.698	newsflicks	O	36	35	1	13.917
eluna95	P	5	0	5	107219.264	cathymcmorris	P	30	30	0	12.959
elmundosalud	O	44	43	1	104304.000	devinder_sharma	P	28	28	0	12.880
oliviawilde	P	21	21	0	102461.452	easter_seals	O	28	27	1	10.352
lumindrds	O	12	6	7	101281.915	cdndownsyndrome	O	31	30	1	9.189
easter_seals	O	28	27	1	93794.586	gdsfoundation	O	32	28	5	9.154
hdssg1	O	30	19	11	81141.248	upsndownsuk	O	25	24	2	8.348
cathymcmorris	P	30	30	0	78386.265	hdssg1	O	30	19	11	8.114
newsflicks	O	36	35	1	78350.309	hazlo_tuyo	O	18	17	1	8.111
devinder_sharma	P	28	28	0	69066.000	nrlc	O	20	19	1	7.417
gdsfoundation	O	32	28	5	68528.097	bloguerossd	P	28	0	28	6.484
righttolifeaust	O	10	4	6	63578.299	debruaruh	P	33	22	14	6.441
kimberlymmurphy	O	23	8	15	58140.110	baaamkrys_	P	16	15	1	6.380
upsndownsuk	O	25	24	2	48252.888	parenting	O	14	13	1	6.276

TA, type of the account; P, personal; O, organization; D, degree; ID, in-degree; OD, out-degree.

When compared in terms of betweenness centrality and PageRank, it is found that the 13 greatest influencers in the WSD network are common in these different metrics. In terms of betweenness centrality, 60% of the nodes were organisation accounts while the rest of 40% were individual accounts. In terms of PageRank, 65% of the nodes were organisation accounts, while the rest of the 35% were individual accounts. In general, both organisational and individual accounts were those who are already interested in Down syndrome. This finding was interpreted due to the lack of support from out of Down syndrome circle, because those in Down syndrome circle already have high awareness. However, it is also promising to see the efforts by those in the circle to raise and increase the awareness. This shows that there is a need for support to raise and increase Down syndrome awareness from politicians, celebrities and NGO's as they have the ability to inform societies within local and global dimensions. It is also worth noting that when examined in terms of in-degree (consuming the interaction) and out-degree (producing the interaction), it is seen that these influential nodes' in-degree metrics are lower than expected, which demonstrates that they should take more responsibility to raise and increase Down syndrome awareness.

3.2. Social mood

In order to see the WSD network, a word cloud based on the frequencies of the words used in 4,168 tweets was examined (Figure 3). The word cloud provides a descriptive analysis of how the WSD network perceives Down syndrome. Accordingly, as can be seen in Figure 3, words related to love/affection; support/awareness and stories/reflections regarding Down syndrome are salient.



Figure 3. Word cloud for the most used expressions

It is also worth mentioning the hashtags are used (Table 3). Twitter uses hashtags to tag a topic. When examined, it can be seen that hashtags are naturally related to 'Down syndrome' or 'World Down Syndrome Day.' For instance, hashtags such as #downsyndrome, #wdsd16, #worlddownsyndromeday, #downsyndromeawarenessday, #wdsd2016 and #wdsd are directly related to WSD. Other hashtags such as #howdoyouseeme, #inclusion, #myfriendsmycommunity and #uncomplicatedlife reflects how Down syndrome is accepted in the WSD network. Other hashtags, such as #generationg, #gigisplayhouse, #321ec, #lotsofsocks and #rockysocks emphasise movements, community awareness and efforts to increase awareness. For example, people were invited to wear colourful socks to increase awareness through #lotsofsocks and #rockysocks hashtags. The hashtags, #generationg and #gigisplayhouse, were about institutional efforts to increase

the acceptance of people with Down syndrome. Finally, #321ec was about supporting Down syndrome efforts by donating, which was explained as ‘You have 3 days 2 make 1 donation to #downsyndrome #research Now-3/21’.

Table 3. Analysis of hashtags used in the WSDS

Hashtags used	Frequency
#downsyndrome	2,990
#wdsd16	629
#worlddownsyndromeday	286
downsyndromeawarenessday	84
#wdsd2016	84
#howdoyouseeme	82
#wdsd	76
#inclusion	73
#generationg	72
#gigisplayhouse	60
#321ec	48
#lotsofsocks	42
#myfriendsmycommunity	36
#uncomplicatedlife	27
#rockyoursocks	23

3.3. Sentiment analysis

The intention of the final analysis was to identify social mood on the digital networks. In order to do so, a sentiment dictionary was used to analyse public tweets by means of a software package. A total of 40,292 words were analysed according to their lexical meanings (Table 4). Of all the words used in tweets, 95% was non-categorised words. 4.06% words were positive while 0.94 were negative words.

Sentiment analysis is important in terms of identifying social mood of the Down syndrome network. The analysis demonstrated that Down syndrome network have a positive mood (4.06%), which can be interpreted as hope for the future. Only 0.94% have a negative mood, which will hopefully reduce to a lower percentage in future. This finding also confirms the finding demonstrated in word cloud in which the words that emerged generally had positive meanings.

Table 4. Sentiment analysis of tweets from the WSDS

Words	Count	Saliency	Percentage
Words in Sentiment List#1: Positive	1,639	0.041	4.06
Words in Sentiment List#2: Negative	380	0.009	0.94
Non-categorized Words	38,273	0.950	95
Total Words	40,292	1.000	100

3.4. Discourse analysis

The tweets in the research corpus had different discourses. Some were about promoting a campaign, reflecting a story/experience, just to support or celebrate the WSDS. However, some of the tweets’ discourses demonstrated that Down syndrome is perceived not as a syndrome, but something cute, a special gift, an extra +1 chromosome, or people with abilities (Table 5).

Table 5. Sample tweets

-
- ‘My extra chromosome makes me extra cute!’ #downsyndrome #DownSyndromeAwarenessDay <https://t.co/ZSav5k3FFs>
 - ‘Out of all the parents in the world, He has chosen us to care for and raise this special gift’. #downsyndrome <https://t.co/XYMvTzvHO4>
 - #WDS16 - Love doesnt count Chomosomes #downsyndrome #HowDoYouSeeMe <https://t.co/GFsoSOKhjU> <https://t.co/3kj52HWpeX>
 - ‘Happy World #DownSyndrome Day! So much more than an extra +1 chromosome. Spread Awareness, Spread Support!’
 - Happy World Down Syndrome Day! One of the most beautiful little girls I know has an extra chromosome! @tucsondreaming #WDS16 #DownSyndrome
 - RT @ONTSpecialNeeds: People with #downSyndrome often share some physical
 - features, but this varies greatly between individuals.
 - People with #DownSyndrome have their own unique talents and abilities just like everybody else! #WorldDownSyndromeDay #WDS16
 - Tomorrow in honor of #WDS16 wear your crazy socks & spread the word about #Downsyndrome! #lotsofsocks <https://t.co/NgDZrxAm69>
 - I accept you as you are #GenerationG is about acceptance! <https://t.co/qyUaYyAv9H> <https://t.co/qlgFB2PCGV> #Downsyndrome
 - Cutest. Moment. Ever. ❤️👶 #benthroughitall #downsyndrome #downsyndromeawareness... <https://t.co/q6D9m8hM1e>
 - See the ability! We're celebrating World Syndrome Day! #wsd2016 #downsyndrome #specialneeds #VarietyKidsCan <https://t.co/GT3B4ugNYr>
 - See the person, not the syndrome! 🙌 Happy Down syndrome Day!! #downsyndrome #21
 - ‘She’s my hiking buddy! Her abilities are more than her disabilities. #DownSyndrome #MoreAlikeThanDifferent #WDS16 <https://t.co/kUVIb7larG>’
 - The difference between ordinary and extraordinary is just that little ‘extra’. 🙌 #downsyndrome <https://t.co/iYxkAkDrCn>
 - Totally unique, always amazing n full of spirit. celebrating #WorldDownsSyndromeDay. #downsyndrome #kidshealth #occupationaltherapy
-

4. Conclusion and future implications

In the twenty-first century world, online and offline spaces co-exist and online spaces provide a considerable number of opportunities to create, increase and sustain awareness for Down syndrome. Besides, online spaces have potential to reach a global audience for Down syndrome awareness as barriers in time and space have diminished through information and communication technologies. The research findings reveal that it is possible to reach audiences from diverse backgrounds, which is important for raising awareness about Down syndrome. However, influencers in Down syndrome network are somehow related to Down syndrome. For this reason, there should be made efforts to raise awareness by individuals or organisations from the outer circle of the Down syndrome community in order not to be merely an echo chamber. In general, the social mood is positive for Down syndrome and it is perceived to be more than a syndrome, but the reality of a life that should be accepted with love and care.

Based on findings of this article, researchers can carry out longitudinal studies to track and identify state of the art in Down syndrome awareness. It is important to track changes in Down syndrome awareness to define or update strategies, policies and implementations regarding Down syndrome awareness. It is also important to carry out research that compares cultural perspectives to map both global and local Down syndrome awareness.

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