The stigma towards dementia on Twitter: A sentiment analysis of Dutch language tweets

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People living with dementia are often faced with stigmatic attitudes. Social media platforms, such as Twitter, can allow for self-expression and support, but can also be used to disseminate misinformation, which can reinforce existing stigma. In the present study we explore whether the stigma towards dementia is present in Dutch language tweets. In total, 969 tweets containing dementia related keywords were collected during a period of five months in 2019 and 2020. These were analyzed by means of a sentiment analysis, which we approached as a classification task. The tweets were coded into seven dimensions, i.e. information, joke, metaphor, organization, personal experience, politics, and ridicule, using a semi-automatic machine learning approach originally developed by Oscar et al. (2017). The emerging correlations with the sentiment analysis of the Linguistic Inquiry and Word Count software validate our approach. In the present study, 9.29% of tweets contain ridicule, propagating stigmatic attitudes on Twitter.

Keywords: dementia; stigma; social media; Twitter; sentiment analysis; machine learning; LIWC

Introduction

The neurocognitive disorder dementia has become more and more prevalent in our ageing society. Nonetheless, people living with dementia do not only face the stigma of mental illness, but also ageism (i.e. negative attitudes towards old age), as the condition mostly affects people older than 65. This double stigmatization creates large barriers for help seeking, receiving an early diagnosis and accepting care, among other things (Amjad et al., 2018). Moreover, it has a negative impact on the general well-being of people living with dementia, which could lead to them experiencing self-stigma. This could cause lowered self-esteem, feelings of shame, and social isolation (Evans, 2018). By means of a survey including data from Belgium and the Netherlands, Evans-Lacko et al. (2019) found evidence of the stigma surrounding dementia with the general public.

The scope of the present study is to verify whether the stigma is being propagated in tweets written in Dutch, by means of a sentiment analysis. This method is a type of content analysis often used in both computer science and computational linguistics. The purpose is to detect whether the content of texts is subjective or not, and if so, whether the message it conveys is a positive or a negative one (Taboada, 2016). In the present study, we will analyze the sentiment of the tweets using the Linguistic Inquiry and Word Count (LIWC) software. In order to verify more closely whether the stigma of dementia is present in tweets, however, we will also consider sentiment analysis as a classification task, classifying each tweet according to seven pre-set dimensions (see further). In order to do so, we will use a semi-automatic statistical machine learning approach, which was developed and validated by Oscar et al. (2017).

We analyze content from social media as these new social environments create the possibility to promote self-expression and to offer acceptance on the one hand, but they “offer a sense of anonymity”, which can lead to negative behavior on the other hand (Lydecker et al., 2016, 230). We decided to focus on Twitter, as the micro-blogging platform allows only for a limited number of characters per post, which makes it a suitable medium for a sentiment analysis.

Background

Stigma on Twitter

Twitter is a popular online social media platform that is increasingly used in the field of social media analysis (Weber & Syed, 2019). It allows users to post messages, “tweets”, that have a maximum length of 280 characters. Users have the possibility to include hashtags to categorize their own messages thematically. In addition, the platform is interactive, as users can follow each other. All tweets are public (unless specifically marked as private), and they can be favorited, replied to, and even retweeted (i.e. reposted by other users). Twitter's public nature makes the platform suitable and easily accessible for research.

Previous research has already shown that Twitter is often used to raise awareness or share research about mental health, but that mental health conditions are also trivialized and stigmatized (Pavlova & Berkers, 2020). Possible indications for this stigma are, for instance, the usage of derogatory terms, such as "senile", "crazy", or "demented", whereas discourse about treatment or personal narratives can be indications of destigmatization frames (Pavlova & Berkers, 2020).

Lydecker et al. (2016) analyzed weight stigma on Twitter, coding all tweets containing the term "fat", based on sentiment (positive/neutral/negative) and by dividing them bottom-up up in themes. Their analysis confirmed the presence of weight stigma on the social media platform. McNeil et al. (2012) looked at the stigma surrounding epilepsy on Twitter by collecting tweets during a one week period and categorising those tweets according to the bottom-up identified dimensions "information", "metaphorical", "personal account", and "ridicule/joke". They found that most users on Twitter seemed to propagate negative attitudes, instead of using the platform to disseminate accurate information about seizures. Mental health conditions, however, carry more stigma on Twitter than physical health conditions, which was shown by Robinson et al. (2019) by comparing tweets on five mental health conditions (schizophrenia, obsessive compulsive disorder, depression, autism, and eating disorders) with tweets on five physical health conditions (asthma, diabetes, HIV/AIDS, cancer, and epilepsy). They identified schizophrenia as the most stigmatized condition. However, no tweets were included on neurocognitive disorders, such as dementia. The tendency to discuss other mental health conditions more often than neurocognitive disorders on Twitter has also been noted by Pavlova & Berkers (2020). Reavley & Pilkington (2014) also found that schizophrenia was more often stigmatized on Twitter than depression, by categorizing tweets in five categories: stigmatizing, personal experience of stigma, supportive, neutral, or anti-stigma. Alvarez-Mon et al. (2019) collected non-medical tweets about psychosis, and compared them to tweets referring to breast cancer, diabetes, Alzheimer's disease, and human immunodeficiency disease, based on hashtags. They verified whether tweets were pejorative or positive and found more pejorative tweets about psychosis than about the other conditions. Only a small percentage of the tweets about Alzheimer's were pejorative (7.60%, 38/506). It has to be noted, however, that they only looked at Alzheimer's disease, and not at neurocognitive disorders in general. Furthermore, they found fewer tweets about Alzheimer's than about the other conditions.

Recently, more studies have investigated stigma on Twitter, and more specifically the stigma surrounding COVID-19 (Budhwani & Sun, 2020; Li et al., 2020). Jimenez-Sotomayor et al. (2020) specifically investigated tweets written during the crisis in order to detect ageist attitudes in their content. They found that almost 25% of their collected tweets contained ridicule or potentially offensive content towards older adults. As our sample also contains tweets written during the pandemic, we expect to find similar or worse stigma towards people with dementia, who face the double stigma of ageism and mental health.

In 2017, Oscar et al. investigated the presence of the stigma surrounding Alzheimer's disease on Twitter. Their data were collected during a sample period of 10 consecutive days in 2014. They built a classifier, which allowed them to annotate their corpus semi-automatically according to six dimensions. These dimensions were based on the dimensions created by McNeil et al. (2012) to detect epilepsy stigma:

informative, joke/ridicule, metaphorical, and personal accounts. They separated joke and ridicule and added a sixth dimension indicating whether the tweet was written by an organization or an individual. They found that 21.13% of the collected tweets perpetuated public stigma, by ridiculing the condition. In the present study, we will adopt a similar method. However, even though Oscar et al. (2017) also researched the stigma surrounding Alzheimer's disease, their aim was to demonstrate the use of their method. Additionally, they looked at English data during a shorter period of time. In the present study, we will focus on Dutch tweets, with the specific aim to measure the stigma. Building a classifier is not the main aim, and we will use the existing open-source tool built by Oscar et al. (2017).

Methodology

Data handling

First, we gained access to Twitter's Application Programming Interface ("Twitter API Documentation", 2020), in order to extract tweets that fitted our criteria. We collected data during two separate time periods, and in total for a period of five months, and more specifically, 148 days. We collected from the first of November until the 8th of December in 2019, and then from the 25th of March until the 12th of July in 2020. Twitter's API has a limit on the amount of tweets that can be accessed during a search, therefore it does not allow us to find all tweets that meet our criteria.

All extracted tweets are written in Dutch, and contain one or more of the following keywords: "alzheimer" (Alzheimer's), "dementie" (dementia), "dement" (demented), "dementerend" (growing demented), "geheugenverlies" (memory loss), "seniel" (senile), "seniliteit" (senility), and their derivatives. These keywords are identified based on extensive research on the topic of dementia and cognitive decline, as well as on the language use in Flanders and the Netherlands. The keywords had to be present in the body of the text, and thus not exclusively in the user's handle (for instance, with a fictional example: "mevrouw_dementie"). In our search, we excluded replies to other tweets and retweets. After the search, we also extracted the duplicates, such as cases where more than one keyword was present in the same tweet. In total, 969 tweets were collected that matched our criteria.

For each of these tweets, we extracted the text of the tweet, the date, the hashtags, and the hyperlinks. We did not include the exact time, location, or usernames.

Manual coding

In a second phase, a random subset of the collected tweets was manually coded based on seven dimensions. Six dimensions were identical to the dimensions of Oscar et al. (2017), namely "information", "joke", "metaphor", "organization", "personal experience", and "ridicule". We have added "politics" as a seventh dimension, since an exploratory search in English in 2019 identified several tweets on presidential candidates Joe Biden and Donald Trump using the keywords "senile" and "demented".

"Ridicule" was defined broadly, as the "subjection of someone or something to contemptuous and dismissive language or behavior" (Ridicule, 2020). This includes not only derisive remarks, but also the use of (one of) the aforementioned keywords as insults. The presence of ridicule would then indicate stigmatic attitudes. Table 1 contains examples for each of the dimensions.

These dimensions were coded using a 5-point Likert scale, (e.g. "Does this tweet contain a personal experience?", 0 = no, 1 = somewhat, 2 = fairly, 3 = significantly, 4 = completely). Contrary to Oscar et al. (2017), we have opted for three raters. Two researchers that can be considered experts in the field, and one external rater. In total

289 tweets were manually coded. Next, we assessed whether the inter-rater reliability was acceptable.

Automated coding

As mentioned above, we used the model built by Oscar et al. (2017). We used the manually coded tweets as training data, in order to train seven classifiers, one for each dimension, by means of feature extraction and accuracy assessment. The classifiers were n-gram based, selected by means of a grid search. The importance of the presence of a feature (in this case an n-gram) was estimated by means of a linear estimator, and the mean was used as a threshold to discard features with a low weight. A subset of the manually coded tweets was then used to test the classifier, and the accuracy was assessed by means of 50 randomized trials of cross validation. Finally, each trained classifier was used to predict whether a uncoded tweet belonged to that dimension. For a more detailed explanation of the model, see Oscar et al. (2017).

As Oscar et al. (2017), we also used the LIWC software in order to verify whether the classification of tweets in the “ridicule” dimension is correlated with negative emotions, and whether the classification of tweets in the “personal experience” dimension is correlated with personal pronouns. The LIWC software calculates the percentage of words fitting into each category, by means of a dictionary. We used the Dutch translation of the LIWC 2007 dictionary (Boot, Zijlstra, & Geenen, 2017). For the present study, we will focus on three LIWC dimensions: positive emotions, negative emotions, and personal pronouns.

Results

Manual coding

The inter-rater reliability was assessed by means of a two-way mixed, consistency, average-measures intra-class correlation. This way, we assessed the degree that the three coders provided consistency in their ratings for each category across subjects (Hallgren, 2012). The inter-rater reliability was good for the “ridicule” dimension (*ICC* = 0.73), and excellent for all other dimensions: “joke” (*ICC* = 0.75), “metaphor” (*ICC* = 0.77), “personal experience” (*ICC* = 0.80), “information” (*ICC* = 0.85), “organization” (*ICC* = 0.90), and “politics” (*ICC* = 0.96) (Cicchetti, 1994). The high inter-rater reliability indicates that the manually coded data could be used to train our automated tagger, with a minimal amount of measurement error (Hallgren, 2012).

As mentioned earlier, the manually coded data was used as the input for the machine learning algorithm used by Oscar et al. (2017). The annotated data that were originally rated by means of a 5-point Likert scale, were collapsed into a binary format, this way we indicated whether a metaphorical reference was present in the tweet (= 1) or not (= 0).

The manually coded tweets (N = 289) were mostly written by individuals (54.67%), and overall highly informative (59.86%). On the other hand, 1 in 5 tweets related personal experiences with dementia (20.76%). 14.88% of the tweets concerned politics, affirming the relevance of the dimension. Only 31 tweets were metaphorical (10.73%), and 2.08% contained jokes. Ridicule -and consequently stigmatising attitudes- were present in the manually annotated data (16.96%).

Automated coding

In order to evaluate the models, we tested their performance on a subset of the tagged tweets. Overall, the seven classifiers performed well (see Table 2). As in Oscar et al. (2017), the classifier that determined whether a tweet was written by an organization or an individual had the lowest performance. In Table 2, we compared the performance of the seven classifiers to a baseline, namely the performance of a Simple Majority Classifier (SMC). In a SMC, each item is classified as belonging to the class that is the most present in the training set. Overall, our classifiers outperformed the SMC, except for the identification of jokes (-0.02%). Presumably, this is caused by the low presence of this dimension in the manually annotated data, as the difference between our classifiers identifying politics and metaphors and the equivalent SMCs is also small (+1.88% and +2.03% respectively). For dimensions that were more present in the training set, the difference between the SMC and our classifier was larger (e.g. for the information category +24.94% or for the organization category +17.63%).

As expected, we find similar tendencies in the automated coded tweets as in the manually coded tweets, as illustrated in Figure 1. Dimensions that were not very present in the training set, and where the accuracy of the SMC and our classifiers were most similar, decreased further in number to a near absence (i.e. joke and metaphor). Secondly, more tweets were classified as informative, and as written by individuals. We also notice fewer stigmatizing tweets containing ridicule in the automated tweets: 9.29% contain ridicule (n = 90).

We collected data at two separate time periods, in 2019 in November and December (n = 658) and from the end of March until July in 2020 (n = 311). In the first period, 8.97% of tweets contained ridicule, which was only slightly less than in the second period (9.97%). The keyword has more influence on whether or not the message contains ridicule in our data set. Tweets with the keywords “geheugenverlies” (memory loss), “dement” (demented), and “seniel" (senile) were more stigmatizing, with respectively 46.15%, 18.75%, and 16.67% ridicule. Dementia, the most common keyword in our data, follows in fourth place, with 6.96% ridicule. The term “alzheimer” (Alzheimer’s) was not often used in tweets containing ridicule (only 2.25%).

Most of the tweets in our corpus (52.01%, *n* = 502) were classified as belonging to two or more dimensions. 10.73% represented more than two dimensions, but none of them represented more than four dimensions. Finally, according to the automated classifier, only 1.96% of the tweets fitted none of the dimensions. As illustrated in Figure 2, tweets containing ridicule in our corpus were always written by an individual, never by organizations. Most of these tweets are considered political (88.89%), as in (1), and generally do not combine ridicule with an informative message.

(1) *Geheugenverlies Rutte? Dan maar snel oprotten. Een minister met dementie kunnen wij niet hebben.*

Memory loss, Rutte? So beat it. We cannot have a minister with dementia.

In Table 3, we take a closer look at the correlations of all dimensions in our data set. The three dimensions of the LIWC data set show that information is strongly positively correlated with organizations, and negatively correlated with personal experiences and ridicule. Informative messages were thus often spread by organizations as in (2), with some exceptions, such as in (3). The amount of personal pronouns (“PPron”) is positively correlated with personal experiences, as in example (4). The use of dementia related keywords in a metaphorical context is correlated with ridicule and politics. Also, as expected, ridicule is significantly positively correlated with negative emotions, and with politics, and negatively correlated with tweets written by organizations.

(2) *Dementie zorgt voor een grote verandering in het leven van mensen en hun naasten. Vanuit de #SocialeBenadering proberen we samen te zoeken wat de*

werkelijke behoefte is en op welke manier iemand daar in ondersteund kan worden.

Dementia brings about major changes in the lives of people and their loved ones. Using the #SocialApproach, we try to find out together what the real needs are and how someone can be supported in this.

(3) *Afgelopen week aanwezig geweest symposium #levensverhaalcentraal2 […] Mooie waardevolle verhalen gehoord van o. 't vlierhuis uit Ommen […], toepassen vanverhaalcirkel. betekenis van verhalen van mensen met dementie.*

Attended last week's symposium #levensverhaalcentraal2 [...] Heard some beautiful and valuable stories from 't vlierhuis from Ommen […], the application of "story circle". Meaning of stories of people with dementia.

(4) *Ze praat amper nog, maar nu zegt ze ineens (glimlachend) tijdens de wisselligging: 'Help jij mij integendeel?'*

She hardly talks anymore, but now she suddenly says (smiling) while repositioning: 'Will you help me rather?'

Discussion

In the present study, we found that 9.29% of Dutch language tweets collected during a period of five months use stigmatizing language when discussing dementia, which is slightly more than the 7.60% of pejorative tweets found by Alvarez-Mon et al. (2019) concerning Alzheimer, but less than the 21.13% of stigma found by Oscar et al. (2017). In our corpus, stigmatizing tweets were written by individuals, and often combined with politics. Dementia related keywords were used to ridicule politicians, after certain events or decisions, and in that manner often combined with metaphors. Overall, Table 2 shows the validity of our machine learning approach. Tweets classified as containing personal experiences, often contained more personal pronouns according to the LIWC output. Ridicule, then, was also correlated with negative emotions.

In our data set, the time period did not seem to have a large influence on the amount of stigmatising tweets, with only a slight increase in ridiculing tweets in 2020 compared to 2019. For future research, it would be interesting to verify whether important political and social events, such as COVID-19, have an influence on the stigmatising use of dementia related keywords. In Belgium and the Netherlands, as in other countries, the elderly, who are the largest risk group for dementia, have suffered greatly from the pandemic. Diachronic research would thus help measure the effect of the crisis on the stigma of dementia.

Our analysis shows that certain keywords were more often used in combination with ridicule. Almost half of the tweets collected with the keyword “geheugenverlies” (memory loss) contained ridicule. Memory loss is not exclusively connected with dementia, but as Oscar et al. (2017), we have included it in our data collection as it is the most well-known symptom of the condition.

The dimensions chosen in our corpus were based on those used by Oscar et al. (2017). “Information”, however, was perhaps too broadly defined. The dimension does not account for fake news, and tweets spreading wrong information, such as pointing to aluminium as a cause for dementia, were coded as informative. In further research, “information” could perhaps be split into two subcategories (false/true), that would need to be manually annotated.

The choice for a machine learning approach also entails some limitations. The automated coding had a visible effect on the prevalence of certain dimensions in our corpus, which was related to the frequency in the manually coded subset of tweets. A possible solution could be to increase the size of the selected subset.

As a final consideration, we should mention that the LIWC dictionary did not contain all words present in our corpus. Twitter makes use of a character limit, which is why the social media platform is prone to the usage of abbreviations. This limitation might have weakened the strength of the correlations. This could be remedied by further pre-processing, and more specifically by lemmatizing the data set.

Disclosure statement

The authors report there are no competing interests to declare.

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Appendices

Table 1. The seven dimensions and an example of each. The Dutch tweets are presented verbatim, as written by the users who originally posted them.

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Dimension	**Original (part of) tweet**	**English translation**
Information	[…] Wat kunnen ouderen, hun mantelzorgers en verzorgenden doen? Lees het hier: [..]	[…] What can the elderly, their informal carers, and caregivers do? Read it here: […]
Joke	Heb ik nou al geplast? Lol ik wil geen alzheimer krijgen	Have I peed yet? Lol I don't want to get Alzheimer's
Metaphor	Gelukkig is Opstelten tegenwoordig zo dement als een zwangere dronken haas […]	Fortunately, nowadays Opstelten is as demented as a pregnant drunk hare […]
Organization	Interview met #NicciGerrard over dementie, ouder worden, en euthanasie naar aanleiding van haar boek Woorden schieten te kort, over de ziekte van haar vader. @Meulenhoff	Interview with #NicciGerrard about dementia, ageing, and euthanasia on the occasion of her book *What Dementia Teaches Us about Love*, about her father's illness. @Meulenhoff
Personal experience	#dementie #rouw #afscheid gisteren hebben we besloten dat mijn vader naar een verpleeghuis gaat, er is helaas geen andere optie meer…	#dementia #grief #goodbye yesterday we decided that my father will go to a nursing home, unfortunately there is no other option left...

Politics	Wanneer het @markrutte uitkomt, heeft hij wel vaker dementie. En is dit de manier van @VVD ? Als je in het nauw komt, gewoon roepen dat je het niet meer weet?! Wat een walgelijke vent. Want een walgelijke partij.	When it suits @markrutte, he often has dementia. And is this the way of @VVD ? When you get cornered, just shout that you don't remember it?! What a disgusting guy. What a disgusting party.
Ridicule	We zijn 'n volk van lemmingen met Alzheimer gedrag dat alles voor zoete oranjekoek aanneemt en gemakkelijk te herenspoelen is	We are a nation of lemmings with Alzheimer's behavior that swallows everything whole and is easy to brainwash.

Table 2. Accuracy of the classifiers on the test set and comparison to a Simple Majority Classifier (SMC).

Classifier	**Accuracy (in %)**	**Baseline (SMC) (in %)**	**Difference (in %)**
Information	84.80	59.86	+ 24.94
Joke	97.80	97.82	- 0.02
Metaphor	91.30	89.27	+ 2.03
Organization	72.30	54.67	+ 17.63
Personal experience	87.40	79.24	+ 8.16
Politics	87.00	85.12	+ 1.88
Ridicule	90.00	83.04	+ 6.96

Table 3. Correlations across the seven dimensions and the three LIWC elements (n= 969).

Dimensions	**Inform.**	**Joke**	**Metaphor**	**Org.**	**Pers. Exp.**	**Politics**	**Ridicule**	**Pos. Emo**	**Neg. Emo**	**PPron**
Inform.										
Joke	-0.10*									
Metaphor	-0.10*	-0.01								
Org.	0.41**	-0.07*	-0.05							
Pers. Exp.	-0.36**	0.12**	-0.04	-0.24**						
Politics	-0.34**	-0.03	0.17**	-0.16**	-0.03					
Ridicule	-0.36**	0.06	0.22**	-0.18**	-0.04	0.61*				
Pos. Emo	0.08*	0.03	-0.01	0.08*	-0.03	-0.12**	-0.12**			
Neg. Emo	-0.20**	0.03	0.02	-0.15**	0.06*	0.21**	0.19**	-0.12**		
PPron	-0.34**	0.14**	-0.03	-0.26**	0.40**	-0.04	0.03	0.01	0.08*	

** = p < 0.05, ** = p < 0.001*

Figure 1. Percentage of manually and automated coded tweets representing each dimension.

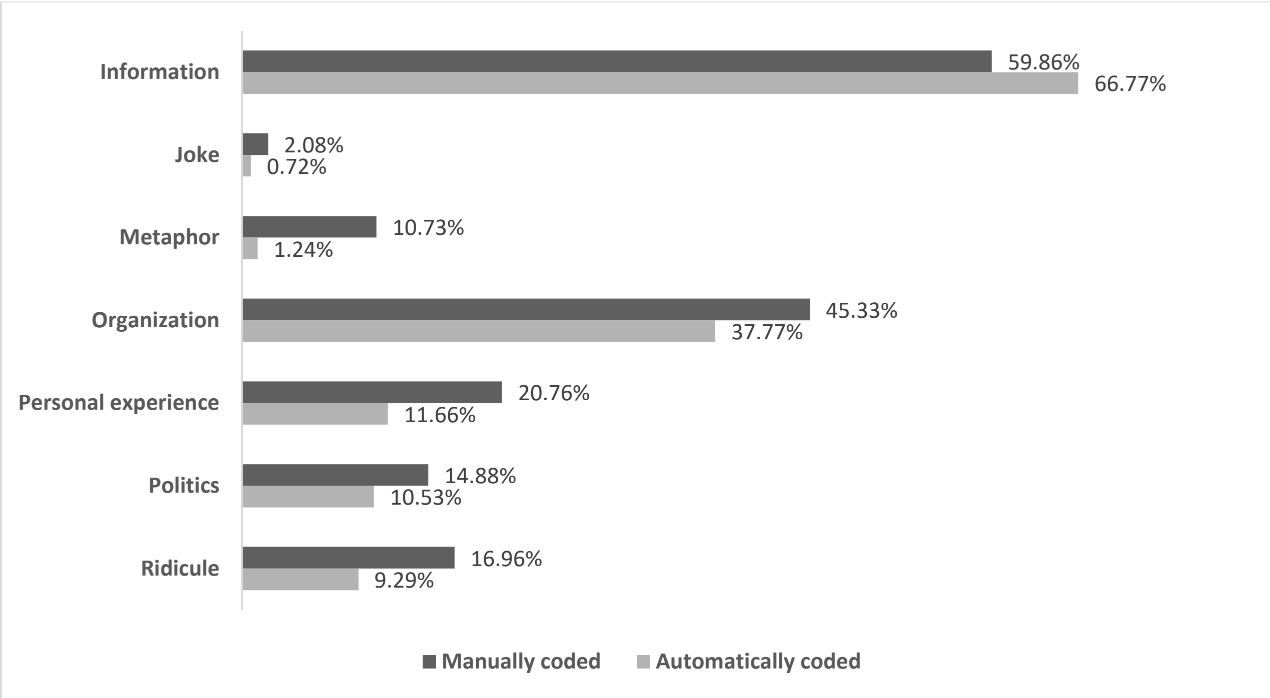

Figure 2. Percentage of tweets (n = 969) per dimension and prevalence of tweets containing ridicule (n = 90) across dimensions.