Fake news, influencers and health-related professional participation on the Web: A pilot study on a social-network of people with Multiple Sclerosis

L. Lavorgna[a,*,1], M. De Stefano[a,1], M. Sparaco[a], M. Moccia[b], G. Abbadessa[a], P. Montella[a],
D. Buonanno[a], S. Esposito[a], M. Clerico[c], C. Cenci[d], F. Trojsi[a], R. Lanzillo[b], L. Rosa[b],
V. Brescia Morra[b], D. Ippolito[a], G. Maniscalco[e], A. Bisecco[a], G. Tedeschi[a], S. Bonavita[a]

[a] Ist Clinic of Neurology, University of Campania "Luigi Vanvitelli", Italy
[b] Department of Neurosciences, Reproductive Sciences and Odontostomatology, Federico II University, Naples, Italy
[c] Department of Biological and Clinical Sciences, University of Torino, Italy
[d] Center for Digital Health Humanities, Rome, Italy
[e] Multiple Sclerosis Center, Cardarelli Hospital, Naples, Italy

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ABSTRACT

Background: Over the last few decades, patients have increasingly been searching for health information on the Internet. This aspect of information seeking is important, especially for people affected by chronic pathologies and require lifelong treatment and management. These people are usually very well informed about the disease but are nonetheless vulnerable to hopes of being cured or saved, often amplified by misinformation, myths, legends, and therapies that are not always scientifically proven. Many studies suggest that some individuals prefer to rely on the Internet as their main source of information, often hindering the patient-doctor relationship. A professional approach is imperative to maintain confidentiality, honesty, and trust in the medical profession.

Objective: we aimed to examine, in a medically supervised Italian web community (SMsocialnetwotk.com) dedicated to people with Multiple Sclerosis (pwMS), the posts shared by users and to verify the reliability of contents of posts shared by users pinpointed as Influencers through an online questionnaire.

Methods: we grouped the posts published on SMsocialnetwork from April to June 2015 into those with medical content (scientifically correct or fake news), and those related to social interactions. Later, we gave a questionnaire to the community asking to identify the three users/Influencers providing the most reliable advice for everyday life with MS and the three users/Influencers providing the most useful information about MS treatments.

Results: 308 posts reported scientific and relevant medical information, whereas 72 posts included pieces of fake news. 1420 posts were of general interest. Four out of the 6 Influencers had written only posts with correct medical information (3 were pwMS, 1 was a Neurologist) and never any fake news. The remaining 2 appointed Influencers (2 pwMS) had written only posts about general interests.

Conclusion: the identification of fake news and their authors has shown that the latter are never appointed as Influencers. SMsocialnetwork.com acted as a "web safe environment" where the Influencers contributed by sharing only correct medical information and never fake news. We speculate that the presence of neurologists and psychologists supervising the information flow might have contributed to reduce the risk of fake news spreading and to avoid their acquisition of authoritative meaning.

1. Introduction

In the age of the Internet, social media are the most important places to share interests, information and personal experiences, overcoming daily limitations of space and time (Dowerah Baruah, 2012).

People with health issues may use social media to increase their knowledge about disease and treatments (McMullan, 2006; White and Dorman, 2001; Lavorgna et al., 2017), frequently considering the web as their main source of information, often hindering patient-doctor relationships (McMullan, 2006; Moorhead et al., 2013; Bartlett et al.,

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2012; Hesse et al., 2005), in particular for chronic conditions (Bartlett et al., 2012) requiring lifelong treatment and management. Multiple Sclerosis (MS) is a complex and heterogeneous neurological disease, with different levels of disability and clinical courses (relapsing-remitting or progressive).

MS usually starts in young adulthood and nowadays newly-diagnosed people are the millennials (Hansen and Okuda, 2018; Hart and Joing, 2011). They belong to the digital native generation and therefore they are used to surfing on the web for all aspects of their daily life (e.g. wishes, studies, sports, care, diet, etc.), so the millennial people with MS (pwMS) tend to subscribe to forums, chats, blogs and/or social networks, to share their experiences as User/Patients (UP). pwMS are usually very well informed about the disease but are nonetheless vulnerable to hopes of being cured or saved, often amplified by misinformation, myths, legends on therapies whose efficacy is not scientifically proven. Therefore, searching on the web puts them at risk to accessing fake news i.e. deceiving stories containing partial truths or stories that are speculative and not based on evidence (Prakash, 2017).

There are some models and theories to explain UP's behaviours towards social networks. Among these, we based our study on the theoretical framework of Boyd and Ellison (Boyd and Ellison, 2008), implemented with the model of Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh et al., 2002), on four predictors for use behaviour (performance expectancy, social influences, effort expectancy, and facilitating conditions), and extension thereof (Shen and Khalifa, 2010).

We took in consideration the following UP attitudes: (1) willingness to chat, share with friends, not really considering health-related information (Boyd and Ellison, 2008); (2) visiting social networks occasionally as a mean of communication (White and Dorman, 2001); (3) looking for a specific response to a question or for specific information (Van de Belt et al., 2013); (4) being an Influencer (Morone et al., 2016). The latter can be considered as a web-version of opinion leader (Bodendorf and Kaiser, 2010).

Traditionally the opinion leader is defined as "someone whose opinions are highly respected and utilized by the respondents to help in decision making across a variety of situations, such as what types of clothes to wear, where to have major household items repaired, how to discipline children, and who to vote for in political election (Cosmas and Shet, 1980) or as "individuals who exert an unequal amount of influence on the decisions of others" (Rogers and Cartano, 1962). On the other hand, Nogueira et al. (2017) defined Influencers in the web as "individuals who exert influence within certain social groups".

Therefore, the Influencers can be considered the web version of opinion leaders, as they influence the group they belong to.

The role of Influencers in the web communities of patients could be critical for the risk of spreading fake news. Thus, in 2012, a social-network completely dedicated to pwMS was created (SMsocialnet-work.com) by a group of neurologists and psychologists of the Ist Clinic of Neurology of the University of Campania "Luigi Vanvitelli" with vast experience in MS. This social network aimed to protect UP from fake news, while preserving their right to expectancy and sharing their fears.

SMsocialnetwork.com is a true social network with active users (AU), people with MS/users (pwMSU), Neurologists and Psycologists who are fully registered on the website, and visitors (accessing open-access content of the website) (Lavorgna et al., 2017). In this virtual environment pwMSU can write, read, and listen to everything they may be interested in; however, the exchange of medical information is under the supervision of MS neurologists and psychologists, who oversee the public activities of users, posts with relevant information about MS, and answer questions via private or public messages. The intervention does not include banning pwMSU or the cancellation of posts with inaccurate medical information but involves explaining why that specific post is fake news.

In the present study, by analyzing the posts contents of AU and by asking them to identify Influencers in the platform, we aimed to verify whether AU pinpointed as Influencers shared reliable posts or fake news.

2. Methods

This cross-sectional web-based study was performed in accordance with good clinical practice and the Declaration of Helsinki. The study was approved by the local ethics committee of University of Campania "Luigi Vanvitelli". All participants consented to the use of recorded questionnaires for scientific purposes on an aggregate level. To protect the anonymity of the participants (because they use a pseudonym), the Internet protocol codes of the computers were not registered, and no electronic "cookies" were embedded.

2.1. Data collection and analysis

In the first part of the study, we collected the posts published on the public wall of SMsocialnet- work from April to June 2015 and two experts (one neurologist and one psychologist with specific MS knowledge) classified the posts into those with scientific or medical content, and those concerning social interactions or of general interest. The two experts were blind to the users/authors of the posts, as previously performed in similar studies (Mathieu et al., 2013).

Afterwards, among the posts with scientific or medical content, experts distinguished those with fake news from those with scientifically-correct content. In particular, any post including information that did not reflect a scientific truth or partially including scientifically based information th at might have generated possible misinterpretation, was appointed as "fake news".

In the second part of the study we gave a two items questionnaire to the SMsocialnetwork community: considering the last three months (April, May and June 2015) (1) who the three users providing the most reliable advice for daily life with MS are (2) who the three users providing the most useful information about MS treatment are.

The questionnaire was available on SMsocialnetwork.com in the two months (July–August 2015) following the period of post collection. Each user could fill out the survey only once and was blind to other users' answers.

3. Results

From April to June 2015, SMsocialnetwork.com included 1020 AU.

We collected 1800 posts from the SMsocialnetwork public wall. Among these, the two experts identified 380 posts with medical content (126 posts per month, on average). Among them, 308 reported scientific and relevant medical information, whereas 72 posts included fake news. The remaining 1420 posts were of general interest, such as movies, the weather, music, walks, travels etc.

Considering the second part of the study, 130 questionnaires were completed (31% UP males and 69% UP females). According to a previous study, (Dong and Peng, 2013) we excluded the questionnaires with > 20% missing data (35,6%) from the final analysis.

Regarding the first query (the users providing the most reliable advice for daily life with MS) the appointed users were TT (appointed 69 times), CM (57 times) and PV (56 times). Regarding the second query (the users providing the most useful information about MS treatment) the appointed users were LL (70 times), VT (60 times) and MO (53 times). Lastly, we disclosed the authors of the posts.

Four of the six appointed AU had written only posts with relevant medical information and never fake news: three of these (VT, MO and TT) were patients and 1 (LL) was a Neurologist.

The remaining two (CM and PV) had written only posts about general interests (movies, the weather, music, walks, travels etc.).

The average number of posts for AU were 47. The CM and PV users published 270 and 480 posts respectively on the public wall.