## **EPILEPSY & BEHAVIOR IN SOCIAL MEDIA: TOP PUBLISHED PAPERS IN 2016**

# Marco Mula

Atkinson Morley Regional Neuroscience Centre, St George's University Hospitals NHS Foundation Trust, London, United Kingdom

Institute of Medical and Biomedical Education, St George's University of London, United Kingdom

<u>Correspondence:</u> Marco Mula MD, PhD Atkinson Morley Regional Neuroscience Centre St George's University Hospitals NHS Foundation Trust Blackshaw Road London SW17 0QT United Kingdom

Tel. +442087254322 Fax +442087254591

Email: mmula@sgul.ac.uk

#### Word count for the text: 1258; Number of references: 19; Number of Tables: 1

Key words: epilepsy, social media, EEG, suicide, marijuana, spirituality

Social media are currently dominating communication in every aspect of life and the epilepsy community seems to be one of the most active ones. A recently published study [1] showed that there are about 840 Facebook pages dedicated to epilepsy and followed by more than 3 million people around the world. In addition, there are 137 Twitter accounts about epilepsy with more than 300,000 users and these figures are exceptionally higher than those reported for any other neurological condition.

Papers published in Epilepsy & Behavior in 2016 performed quite well among social media. Although the most frequently twitted paper was the fascinating case described by Arzy and Schurr of a religious conversion in a telemetry unit under continuous EEG monitoring [2], the most popular paper, with the highest Altimetric score (**Table 1**), is the one by Tatum et al. about EEG rhythm during smartphone text messaging [3]. The Altimetric Score for the paper by Tatum and collaborators is 80% higher than the top paper published in 2014 [4] and 4 times higher than the top paper published in 2015 [5] and this is mainly due the high resonance in the press and news. In their study, Tatum et al. identified a specific EEG rhythm associated with active text messaging with smartphone in patients undergoing prolonged video EEG monitoring [3]. Mobile phones have become an integral part of our lives and this has obviously stimulated research in order to understand the potential impact on our health and our brain. A PubMed search (as per 27<sup>th</sup> July 2017) using the key words "mobile phone" and "brain" shows more than 200 papers published during the last 5 years and a Google search (27<sup>th</sup> July 2017) using "effects of smartphone on the brain" shows 458,000 results with a number of forums and blogs dedicated to this issue. It is, therefore, easy to understand why this paper reached so quickly a high interest in the public domain. However, the paper by Tatum and collaborators has relevant clinical implications in terms of reporting prolonged EEG monitoring that go beyond the public interest on the impact of mobile phones on the brain.

The third most popular paper in social media presents new data about suicide in epilepsy. This study by Tian and collaborators [6] is a population-based analysis of data from the U.S. National Violent Death Reporting System. The authors show that suicide rate among people with epilepsy is 22% higher than that reported in the general population and people with epilepsy are twice as likely to poison themselves. Suicide is still an unmentionable problem in epilepsy, although it accounts for 11.5% of all deaths in epilepsy as compared to 1% of the general population. A population-based study in England has shown that 25% of patients with epilepsy have a lifetime history of suicidal thoughts and more than 10% have a lifetime history of suicidal attempts [7]. Similar figures have been reported by another population-based study from Canada [8]. Several studies have attempted to identify reasons for such an increased risk but it is likely that a combination of different variables, including biological and psychosocial factors, contribute to the increased risk of suicide in epilepsy [9]. Prevention is the only real treatment for suicide but research on screening and prevention strategies in epilepsy are still inadequate and at a very early stage [10]. Further studies exploring integrated pathways for suicide prevention are urgently needed.

The fourth most popular paper discusses the "voices" of Joan of Arc [11]. Interestingly enough, this is a letter commenting on another paper by Nicastro and Picard [12], published in a Special Issue of Epilepsy & Behavior on Epilepsy, Art and Creativity edited by Dale Hesdorffer and Michael Trimble. Joan of Arc remains a fascinating but at the same divisive personality in Western World. She became the main subject of world literature, theatre, and movies extending from Shakespeare to Voltaire, Mark Twain and George Bernard Shaw. As a symbol, Joan of Arc has been embraced by Napoleon, Nazi Germany, Marxist ideology and French political parties. The Catholic Church has also claimed her as a Saint. Competing interpretations have strived to capture her enduring mystery with a number of medical theories and interpretations by Sigmund Freud, Carl Jung and Albert Schweitzer. The letter by D'Orsi and Tinuper [11] discusses the possible epileptic origin of Joan of Arc's voices with particular reference to genetic neocortical temporal lobe epilepsies.

The impact of ketogenic diet (KD) on cognitive functions and behaviour of children with drugresistant epilepsy is the fifth paper in the Top 10 [13]. As correctly stated by the authors of this paper, KD was developed in the 1920s when not many pharmacological options were available. However, KD can still represent an option in selected cases. Interestingly enough, this paper shows that not only children on KD were more alert than those randomised to treatment-as-usual but they were also less anxious and with less behavioural problems.

The sixth paper in the top ten is a report from the US Centers for Disease Control and Prevention, Epilepsy Program, showing that among adults with epilepsy reporting recent seizures, one of four on antiepileptic drugs and three of four not on treatment, had not seen a neurologist/epilepsy specialist within the last year [14]. This is one of several papers coming from the US Centers for Disease Control and Prevention, Epilepsy Program, collected under the name of Epilepsy by the Numbers. This series is aimed at presenting "facts and statistics" about epilepsy focusing each time on different aspects. This paper highlights gaps in quality care among people with uncontrolled epilepsy and reinforces the need for implementing epilepsy services and connections with community services/organisation [14].

The following paper in the Top 10 [15], despite having a lower Altimetric score than other papers, is among those most frequently twitted on Twitters. This is an interesting basic pathology paper showing that specific response to electrical stimulation in living human brains within specific regions of the right temporal (parahippocampal) region may persist for decades if the cerebral tissue has been fixed appropriately [15]. The authors dedicated this paper to Pierre Gloor and his memorable monograph "The temporal lobe and limbic system" that represents a culmination of Gloor's life interest in the anatomy and physiology of the temporal lobe and its disorders [16].

The last three papers show very similar Altimetric scores but discuss completely different topics. One paper comes from the Norwegian Mother and Child Cohort Study pointing out that pregnant woman with epilepsy and their partners should receive emotional support and better integrated care during and after pregnancy [17]. A paper from Canada presents data on marijuana use among patients with epilepsy or non-epileptic attacks [18], showing that more than 50% of patients with epilepsy have tried marijuana in the past and at least 1 in 3 patients have used it over the last year. Interestingly enough, marijuana users reported perceived improvement in seizure control, stress, sleep, and antiepileptic drug-related side effects and these may be due to perceived improvement in stress [18]. The last paper in this Top 10 investigated the potential advantage of bilingualism on executive functions in childhood onset epilepsies and showed that bilingual children perform significantly better on working memory tasks than do monolingual children, controlling for socioeconomic status and ethnicity [19].

In conclusion, popular papers in social media give an idea of the wide range of diverse interests in the public domain about epilepsy that not always match the interest of researchers and academics but definitely represent new potential ideas for discussion, research and development.

# DISCLOSURE AND ACKNOWLEDGMENTS

No conflict of interests.

## REFERENCES

- Meng Y, Elkaim L, Wang J, Liu J, Alotaibi NM, Ibrahim GM, Fallah A, Weil AG, Valiante TA, Lozano AM, Rutka JT. Social media in epilepsy: A quantitative and qualitative analysis. Epilepsy Behav. 2017 Jun;71(Pt A):79-84
- 2. Arzy S, Schurr R. "God has sent me to you": Right temporal epilepsy, left prefrontal psychosis. Epilepsy Behav. 2016;60:7-10.
- 3. Tatum WO, DiCiaccio B, Yelvington KH. Cortical processing during smartphone text messaging. Epilepsy Behav. 2016;59:117-21.
- 4. Mula M. The impact and dissemination of scientific research: From impact factor to social media. The Top 10 articles in Epilepsy & Behavior published in 2014. Epilepsy Behav. 2015;50:113-5.
- 5. Mula M. New trends and hot topics in epileptology: An analysis of top articles published in Epilepsy & Behavior in 2015. Epilepsy Behav. 2016;63:125-126.
- Tian N, Cui W, Zack M, Kobau R, Fowler KA, Hesdorffer DC. Suicide among people with epilepsy: A population-based analysis of data from the U.S. National Violent Death Reporting System, 17 states, 2003-2011. Epilepsy Behav. 2016;61:210-7.
- 7. Rai D, Kerr MP, McManus S, Jordanova V, Lewis G, Brugha TS. Epilepsy and psychiatric comorbidity: a nationally representative population-based study. Epilepsia. 2012;53(6):1095-103
- 8. Tellez-Zenteno JF, Patten SB, Jetté N, Williams J, Wiebe S. Psychiatric comorbidity in epilepsy: a population-based analysis. Epilepsia. 2007;48(12):2336-44
- 9. Mula M. Depression in epilepsy. Curr Opin Neurol. 2017;30(2):180-186.
- 10. Mula M, McGonigal A, Micoulaud-Franchi JA, May TW, Labudda K, Brandt C. Validation of rapid suicidality screening in epilepsy using the NDDIE. Epilepsia. 2016;57(6):949-55.
- 11. d'Orsi G, Tinuper P. The "voices" of Joan of Arc and epilepsy with auditory features. Epilepsy Behav. 2016;61:281.
- 12. Nicastro N, Picard F. Joan of Arc: Sanctity, witchcraft or epilepsy? Epilepsy Behav. 2016;57(Pt B):247-50.
- 13. IJff DM, Postulart D, Lambrechts DA, Majoie MH, de Kinderen RJ, Hendriksen JG, Evers SM, Aldenkamp AP. Cognitive and behavioral impact of the ketogenic diet in children and adolescents with refractory epilepsy: A randomized controlled trial. Epilepsy Behav. 2016;60:153-7.
- 14. Cui W, Kobau R, Zack MM; US Centers for Disease Control and Prevention, Epilepsy Program. Among adults with epilepsy reporting recent seizures, one of four on antiseizure medication and three of four not on medication had not seen a neurologist/epilepsy specialist within the last year, the 2010 and 2013 US National Health Interview Surveys. Epilepsy Behav. 2016;61:78-9.

- 15. Rouleau N, Persinger MA. Differential responsiveness of the right parahippocampal region to electrical stimulation in fixed human brains: Implications for historical surgical stimulation studies? Epilepsy Behav. 2016;60:181-6.
- 16. Gloor P. The temporal lobe and limbic system. New York: Oxford University Press 1997
- 17. Reiter SF, Bjørk MH, Daltveit AK, Veiby G, Kolstad E, Engelsen BA, Gilhus NE. Life satisfaction in women with epilepsy during and after pregnancy. Epilepsy Behav. 2016;62:251-7
- 18. Massot-Tarrús A, McLachlan RS. Marijuana use in adults admitted to a Canadian epilepsy monitoring unit. Epilepsy Behav. 2016;63:73-78.
- **19.** Veenstra AL, Riley JD, Barrett LE, Muhonen MG, Zupanc M, Romain JE, Lin JJ, Mucci G. The impact of bilingualism on working memory in pediatric epilepsy. Epilepsy Behav. 2016;55:6-10

Paper	Title	Publication date	Bloggers	Twitters	Google	News outlets	Facebook walls	F1000	Peer review sites	Mendeley readers	Altimetric score
Tatum et al. 2016 [3]	Cortical processing during smartphone text messaging.	01/06/2016	7	40	3	53	10	0	0	17	454
Arzy and Schurr 2016 [2]	"God has sent me to you": Right temporal epilepsy, left prefrontal psychosis.	01/07/2016	4	46	1	8	2	0	0	28	115
Tian et al. 2016 [6]	Suicide among people with epilepsy: A population-based analysis of data from the U.S. National Violent Death Reporting System, 17 states, 2003- 2011.	01/08/2016	1	18	0	14	2	0	0	22	101
D'Orsi and Tinuper 2016 [11]	The "voices" of Joan of Arc and epilepsy with auditory features.	01/08/2016	0	3	0	9	2	0	0	1	85
ljff et al. 2016 [13]	Cognitive and behavioral impact of the ketogenic diet in children and adolescents with refractory epilepsy: A randomized controlled trial.	01/07/2016	0	28	0	1	7	0	0	10	28
Cui et al. 2016 [14]	Among adults with epilepsy reporting recent seizures, one of four on antiseizure medication and three of four not on medication had not seen a neurologist/epilepsy specialist within the last year, the 2010 and 2013 US National Health Interview Surveys.	01/08/2016	0	2	0	3	0	0	0	8	24
Rouleau and Persinger 2016 [15]	Differential responsiveness of the right parahippocampal region to electrical stimulation in fixed human brains: Implications for historical surgical stimulation studies?	01/07/2016	0	23	0	0	0	0	0	2	18
Reiter et al. 2016 [17]	Life satisfaction in women with epilepsy during and after pregnancy.	01/09/2016	1	4	0	1	0	0	0	6	17

 Table 1. Top 10 Epilepsy & Behavior 2016 papers in social media (only most relevant social media listed).

Massot-	Marijuana use in adults admitted to a		0	17	0	0	2	0	0	21	16
Tarrus and	Canadian epilepsy monitoring unit.										
McLachlan											
2016 [18]		30/08/2016									
Veenstra et	The impact of bilingualism on working		1	2	0	1	3	0	0	18	16
al. 2016 [19]	memory in pediatric epilepsy.	01/01/2016									