

Like, Retweet, Repeat: The use of social media in healthcare, illustrated by three stakeholder perspectives

Simon R. Stones, Wendy Costello, Elena Nikiphorou and George Peat*

**PhD Candidate, University of Leeds*

Introduction

In its simplest terms, social media is any interactive communication platform that enables people to interact and converse (Stones and Smith, 2018). In the last decade, social media has emerged as a channel for seeking and exchanging information in ways previously unimaginable. However, with a generation of young people who are more likely to seek initial medical advice from the internet, it remains the responsibility of the current generation of patients, carers and healthcare professionals to embrace social media and ensure that accessible, evidence-informed information is readily available (Stones and Smith, 2018).

During a workshop at the Sixth Children's Research Network for Ireland and Northern Ireland conference, several anxieties about social media were raised. The importance of social media being complementary, and not a replacement for existing communication mediums was highlighted. While the benefits of social media were clearly recognised, many individuals also worried that excessive technology usage by young people could be disruptive to children's social interactions, clouding their judgement between the real and virtual world. Since social media has moved into spaces it may not have originally been designed for, such as health and wellbeing, it is also less clear as to how the voice of young people in relation to social media can be heard now and in the future. For example, if young people (or their parents/carers) consent to a video being published on social media, what impact does this have on their adult selves, and how do young people revoke permission for such publications in the future? Such questions remain unanswered; however, technology should not be criticised for the issues that young people are currently facing, and will

continue to face, as a result of social media. Rather, it is a lack of current resource to mitigate against negative social media uses that may prevent individuals and organisations from using social media to its maximum potential.

Placing the Social in Social Media

Digital analyst Brian Solis said that “social media is about sociology, not technology” (Solis, 2007). Indeed, Fuchs (2017) emphasises that the “media” in social media is not about technology, but techno-social systems in which information and communication technologies enable and constrain the creation, dissemination and absorption of knowledge. The underlying social processes of social media are often overlooked in current practice; however, they can help to demystify some of the common confusion that exists. According to Fuchs (2017), the three notions of sociality (Durkheim’s social facts, Weber’s social actions/relations, and Marx’s and Tönnies’ co-operation) (Table 1) can be integrated into a model of human social activity, whereby knowledge is viewed as a threefold dynamic process of cognition, communication, and co-operation (Hofkirchner, 2013). In simplified terms, in order to co-operate, you need to communicate, and in order to communicate, you need to cognise (Fuchs and Sandoval, 2013; Fuchs, 2017). A common pitfall in practice is enabling individuals to co-operate via social media, which is reliant on mutual, engaging conversations. Enabling and encouraging co-operation through social media is indeed a challenge, but one which has been taken on board within healthcare, which forms the focus of this article. In order to illustrate how social media has been used in healthcare, three European perspectives, representing different stakeholders in healthcare, will be discussed, illuminating how social media has been used to share information, engage in dialogue, develop identities, and foster co-operative partnerships, for example, between patients and healthcare professionals.

Table 1. The three notions of sociality integrated into a model of human society activity (Fuchs, Hofkirchner, Schafranek, Raffl, Sandoval and Bichler, 2010; Fuchs and Sandoval, 2013; Fuchs, 2017).

Sociological theory		Application to social media
Emile Durkheim's social facts (Durkheim, 1982)	Social facts are fixed and objectified social structures that constantly condition social behaviour.	Social media platforms are 'social' since they represent structures that objectify human interests, understandings, goal and intentions, influencing society and social behaviour.
Max Weber's social actions and social relations (Weber, 1978)	Social behaviour is a reciprocal symbolic interaction.	Social media enables communication over spatio-temporal distances.
Karl Marx's and Ferdinand Tönnies' co-operation (Tönnies, 1988, Marx and Engels, 2016)	Communities are social systems working together, based on feelings of togetherness, mutual dependence, and values, resulting in a shared sense of ownership.	Social media enables the collaborative production of digital knowledge in the form of collective intelligence (more than the sum of individual knowledge). It also brings people together, mediating virtual togetherness.

Perspective: Social Media and Young People's Identity

Identity and social media are now somewhat intrinsically interlinked (Durante, 2011). Social connectivity via smartphones, tablets, and computers has led to a gradual intrusion of social media into the lives of young people, transforming the way in which they interact and converse. As a consequence, the identities of many young people are formed, influenced, and shaped online. Identity development in adolescence can be a confusing and challenging time (Kroger, 2007). For young people with life-limiting and life-threatening conditions, their identity can often be constructed, shaped, and influenced by their condition, to the point where for many, it is viewed as an internalised part of their self (Brown and Sourkes, 2006). The capacity for social media to reduce social isolation (Nesby and Salamonsen, 2016),

provide a platform for emotive expression (Treadgold and Kuperberg, 2010), and increase feelings of empowerment (Griffiths, Panteli, Brunton, Marder and Williamson, 2014), has resulted in young people with life-limiting and life-threatening conditions being able to showcase and illuminate the diverseness and richness of their identities online. One example of how social media can allow young people to showcase different aspects of their identity (Price and Alinden, 2017) was demonstrated through the late Adam Bojelian, a young person with cerebral palsy (Bojelian, 2018). Despite the restrictions of his condition, Adam did not let his identity be defined by his condition. Instead, Adam used social media to showcase his skills as a poet, where he was known as “AdsthePoet”; therefore, providing him with a platform to showcase his unique and imaginative identity with an audience who may never have had the opportunity to communicate and learn from Adam outside of social media.

Perspective: Social Media and Charitable Organisations

Extending beyond individuals, charitable organisations who have evolved to advocate for people living with a variety of health conditions have benefited from using social media to communicate and co-operate with a variety of individuals (Courtney, Shabestari and Kuo, 2013). In Ireland, healthcare services for young people with arthritis have been inadequate, with the first Irish paediatric rheumatologist only appointed in 2006. Since then, patient referrals and assessments have increased by almost 400% (Health Service Executive, 2015). However, outside of the Dublin area, there are limited services for these young people, meaning that the vast majority have their diagnosis confirmed and their treatment planned in Dublin (Health Service Executive, 2015). With such inadequate services, parents of young people have found peer and parental support through social media, managed by the Irish Children's Arthritis Network (iCAN). Using social media, iCAN have, and continue to address their core goals of support, advocacy and awareness (Irish Children's Arthritis Network, 2018). iCAN's closed Facebook group is its most utilised resource used by parents and carers of young people with arthritis in Ireland, since it provides a space for people to ask questions to other parents and carers with lived experiences in a safe and supportive

environment. This reflects the three notions of sociality, involving cognition of knowledge about arthritis and how it affects children, non-judgmental communication between parents and carers, and co-operation in the form of guidance and support that is otherwise suboptimal or absent for families. The organisation also has a public Facebook page which is used to inform and foster dialogue between iCAN and other stakeholders. Combined, iCAN's Facebook presence reaches more people than the charity could realistically achieve in a face-to-face environment; so, they actively use social media as a complementary component of their engagement strategy, alongside face-to-face events. iCAN also find that Twitter is a useful way to raise awareness, in addition to facilitating discussion and interaction with a broader community of stakeholders. For younger individuals, more contemporary social networking sites, such as Instagram and Snapchat (Vaterlaus, Barnett, Roche and Young, 2016) consist of the creation and dissemination of images and instant messages, which are increasingly important mechanisms for engagement with these individuals, since young people are interacting daily through these platforms with each other. Social media was something iCAN had not thought about prior to establishing the charity; however, the organisation realised that it is an integral component of the organisation's identity, as has shown to be the case for other charitable organisations (Barnes, 2011) and stakeholder groups, out of the need for people to feel part of a community beyond physical environments.

Perspective: Social Media and Healthcare Professionals

Similar to patients and charitable organisations, social media has become an increasingly popular means of communication among the healthcare professional community, enabling fast and easy dissemination and absorption of scientific and clinical knowledge (Nikiphorou, Studenic, Ammitzbøll, Canavan, Jani, Ospelt and Berenbaum, 2017a). In the world of rheumatology, healthcare professionals use social media to communicate with colleagues; identify job opportunities; and to keep updated with the latest advances, amongst other activities (Nikiphorou et al., 2017a). Beyond individual use, many organisations, including European and American societies, have demonstrated a strong social media presence to

Children's Research Network
Research Digest
Edition: Conference 2017
Published: 4th Mar 2019

promote activities at conferences and other educational events, as well as for reaching out to patients and healthcare professionals; however, co-operation is commonly missing from such social media strategies, since according to the threefold dynamic process of sociality, co-operation is reliant on reciprocal conversations, which is not the same as conventional advertising approaches using unidirectional conversation. Novel uses of social media in an educational manner inspired Marx's and Tönnies' co-operation model include journal club discussions on Twitter (e.g. [@EULAR_JC](#)). These possibilities have made social media particularly attractive to healthcare professionals, and while examples from the rheumatology community have been highlighted, the use of social media by healthcare professionals to facilitate communication (Hamm, Chisholm, Shulhan, Milne, Scott, Klassen and Hartling, 2013) and postgraduate education (Bullock and Webb, 2015) is not restricted to rheumatology. Indeed, there appears to be a general "wave" of social media engagement across primary and secondary care settings and specialities, helping to bridge boundaries in communication, thus demonstrating the power of social media in helping healthcare professionals to keep up-to-date, share knowledge and improve the quality of patient care (McGowan, Wasko, Vartabedian, Miller, Freiherr and Abdolrasulnia, 2012).

The opportunity for "live" discussions among healthcare professionals and patients on social media has taken professional interaction beyond the clinic walls and beyond one's own physical working environment. The ease and speed of access of information on social media therefore provides a dynamic medium for professional interaction and co-operation with potential benefits to both the provider and consumer of information (Nikiphorou, Studenic, Alunno, Canavan, Jani and Berenbaum, 2017b). However, this interaction does not come without risks. A key concern for healthcare professionals is how such information may be interpreted by others. So whereas acceptance of social media use seems to be increasing, concerns remain over the blurring of professional boundaries, breaching patient confidentiality and misusing and misinterpreting information (Bukhari and Galloway, 2017, Stones and Smith, 2018). The large amounts of information provided on social media can be perceived as a strength, especially in view of the difficulty in manually obtaining similar information from physical sources. Yet, it can also be perceived as a weakness, since it can

lead to information overload (Eckler, Worsowicz and Rayburn, 2010) when it is not disseminated and absorbed in an optimal manner. While the lack of control of what and how information is shared on social media can be a limitation, the advantages of instant access to a wealth of information are considerable, when used wisely. Social media use in the healthcare professional world therefore poses new possibilities but also new challenges, necessitating caution and appropriate use within professional boundaries, without jeopardising the social interaction and co-operation that underpins the very function of social media.

Conclusions

Social media is increasingly used as a means of identifying and disseminating health-related information by various stakeholders (Scanfeld, Scanfeld and Larson, 2010). Despite obvious caveats, social media continues to provide young people, their families, healthcare professionals and organisations with an accessible space to discuss, learn, and develop their thoughts, identities and personas. While research reinforces the stance that patients use social media mainly for social support (Smailhodzic, Hooijsma, Boonstra and Langley, 2016), this is evidently not the sole use of social media as illustrated in this article, since in these situations, social media is a supplementary platform to real-world interactions. However, what can be learned from social media use in the patient community is that the principles of sociality must underpin the very essence of social media use if it is to continue gathering pace (Chaffey, 2016). Whatever the future holds, cognition, communication, and co-operation must underpin social media activities by all stakeholders (Hofkirchner, 2013) for it to be effective in facilitating conversation, embodying the definition of human social activity in a connected era.

References

Barnes, N. G. 2011. Social media usage now ubiquitous among us top charities, ahead of all other sectors. *Dartmouth, MA, USA: Center for Marketing Research, University of Massachusetts.*

- Bojelian, A. 2018. "In the blink of an eye" poems by adam bojelian [Online]. Available: <http://intheblinkofaneyepoemsbyadambojelian.blogspot.co.uk/> [Accessed 23 March 2018].
- Brown, M. R. and Sourkes, B. 2006. Psychotherapy in pediatric palliative care. *Child and Adolescent Psychiatric Clinics*, 15 (3), pp. 585-596.
- Bukhari, M. and Galloway, J. 2017. Twitter, #alternativefacts, careless whispers and rheumatology. *Rheumatology*, kex091.
- Bullock, A. and Webb, K. 2015. Technology in postgraduate medical education: A dynamic influence on learning? *Postgraduate Medical Journal*, 91 (1081), pp. 646-650.
- Chaffey, D. 2016. *Global social media research summary 2016* [Online]. Available: http://c.ymcdn.com/sites/www.productstewardship.us/resource/resmgr/Phone_Books/Global_Social_Media_Statisti.pdf [Accessed 28 March 2018].
- Courtney, K. L., Shabestari, O. and Kuo, A. 2013. *Enabling health and healthcare through ict: Available, tailored and closer*, Amsterdam, The Netherlands: IOS Press.
- Durante, M. 2011. The online construction of personal identity through trust and privacy. *Information*, 2 (4), pp. 594-620.
- Durkheim, E. 1982. What is a social fact? In: LUKES, S. (ed.) *The rules of sociological method: And selected texts on sociology and its method*. London, UK: Macmillan Education UK.
- Eckler, P., Worsowicz, G. and Rayburn, J. W. 2010. Social media and health care: An overview. *PM and R*, 2 (11), pp. 1046-1050.
- Fuchs, C. 2017. *Social media: A critical introduction*, London, UK: SAGE Publications.
- Fuchs, C., Hofkirchner, W., Schafrank, M., Raffl, C., Sandoval, M. and Bichler, R. 2010. Theoretical foundations of the web: Cognition, communication, and co-operation. Towards an understanding of web 1.0, 2.0, 3.0. *Future Internet*, 2 (1), pp. 41-59.
- Fuchs, C. and Sandoval, M. 2013. *Critique, social media and the information society*, New York, NY, USA: Taylor and Francis.
- Griffiths, C., Panteli, N., Brunton, D., Marder, B. and Williamson, H. 2014. Designing and evaluating the acceptability of realshare: An online support community for teenagers and young adults with cancer. *Journal of Health Psychology*, 20 (12), pp. 1589-1601.
- Hamm, M. P., Chisholm, A., Shulhan, J., Milne, A., Scott, S. D., Klassen, T. P. and Hartling, L. 2013. Social media use by health care professionals and trainees: A scoping review. *Academic Medicine*, 88 (9), pp.1376-1383.
- Health Service Executive. 2015. *A national model of care for paediatric healthcare services in ireland chapter 43: Paediatric rheumatology* [Online]. Available: <https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/paediatric-rheumatology.pdf> [Accessed 28 March 2018].
- Hofkirchner, W. 2013. *Emergent information: A unified theory of information framework*, Singapore: World Scientific Publishing.
- Irish Children's Arthritis Network. 2018. *About us* [Online]. Available: <http://icanireland.ie/> [Accessed 24 March 2018].
- Kroger, J. 2007. *Identity development: Adolescence through adulthood*, Thousand Oaks, CA, USA: Sage.
- Marx, K. and Engels, F. 2016. *Die deutsche ideologie*, Berlin, Germany: Hofenberg.

- Mcgowan, B. S., Wasko, M., Vartabedian, B. S., Miller, R. S., Freiherr, D. D. and Abdolrasulnia, M. 2012. Understanding the factors that influence the adoption and meaningful use of social media by physicians to share medical information. *Journal of Medical Internet Research*, 14 (5), e117.
- Nesby, L. and Salamonsen, A. 2016. Youth blogging and serious illness. *Medical Humanities*, 42 (1), pp. 46-51.
- Nikiphorou, E., Studenic, P., Ammitzbøll, C. G., Canavan, M., Jani, M., Ospelt, C. and Berenbaum, F. 2017a. Social media use among young rheumatologists and basic scientists: Results of an international survey by the emerging eular network (emeunet). *Annals of the Rheumatic Diseases*, 76 (4), pp. 712-715.
- Nikiphorou, E., Studenic, P., Alunno, A., Canavan, M., Jani, M. and Berenbaum, F. 2017b. 'Twitterland': A brave new world? *Annals of the Rheumatic Diseases*, Published Online First: 04 December 2017.
- Price, J. and Alinden, O. M. 2017. *Essentials of nursing children and young people*, London, UK: SAGE Publications.
- Scanfled, D., Scanfled, V. and Larson, E. L. 2010. Dissemination of health information through social networks: Twitter and antibiotics. *American Journal of Infection Control*, 38 (3), pp. 182-188.
- Smailhodzic, E., Hooijsma, W., Boonstra, A. and Langley, D. J. 2016. Social media use in healthcare: A systematic review of effects on patients and on their relationship with healthcare professionals. *BMC Health Services Research*, 16 (1), pp. 442.
- Solis, B. 2007. *Social media is about sociology not technology* [Online]. Brian Solis. Available: <http://www.briansolis.com/2007/08/social-media-is-about-sociology-not/> [Accessed 04 December 2017].
- Stones, S. R. and Smith, J. 2018. Social media supremacy: A force of change paving the way for the next generation of healthcare and research. *Evidence Based Nursing*, 21 (1), pp. 2-3.
- Tonnies, F. 1988. *Community and Society*. New Brunswick, NJ, USA: Transaction Books.
- Treadgold, C. L. and Kuperberg, A. 2010. Been there, done that, wrote the blog: The choices and challenges of supporting adolescents and young adults with cancer. *Journal of Clinical Oncology*, 28 (32), pp. 4842-4849.
- Vaterlaus, J. M., Barnett, K., Roche, C. and Young, J. A. 2016. "Snapchat is more personal": An exploratory study on snapchat behaviors and young adult interpersonal relationships. *Computers in Human Behavior*, 62594-601.
- Weber, M. 1978. *Economy and society: An outline of interpretive sociology*, Oakland, CA, USA: University of California Press.

Authors

- **Simon Stones** is a patient researcher and ambassador for young people with chronic conditions, who is currently undertaking his PhD at the University of Leeds.
- **Wendy Costello** is the Chair and Co-founder of the Irish Children's Arthritis Network (iCAN), as well as the Chair of the European Network for Arthritis in Children.

Children's Research Network
Research Digest
Edition: Conference 2017
Published: 4th Mar 2019

- **Elena Nikiphorou** is a Consultant Rheumatologist at the Whittington Hospital, London, and is a Clinical Researcher at King's College London.
- **George Peat** is a PhD student at the University of Leeds with a background in psychology. His research explores how young men with life-limiting conditions.