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Mobilising identity through social media: psychosocial support for young people with life limiting conditions

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This month's opinion draws on an EBN Twitter chat that focused on psychosocial support for young people with life limiting conditions. Access the blog at <http://blogs.bmj.com/ebn/2018/03/04/mobilising-identity-through-social-media-psychosocial-support-for-young-people-with-life-limiting-conditions-outside-of-the-care-setting/> and the summary of the twitter chat at <https://wakelet.com/wake/82675d41-c504-40a7-964c-82205a836858>.

Background

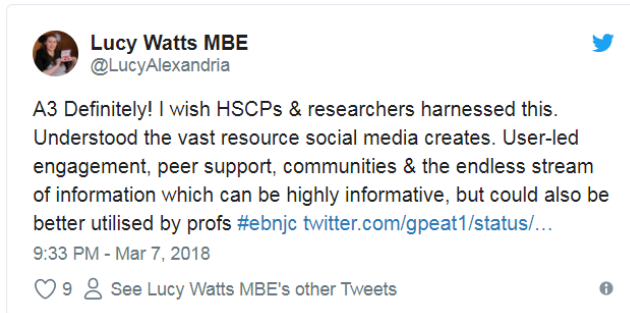
Identity and social media are becoming increasingly intertwined as our dependence on social media as a means of interacting, particularly for millennial generations, increases. Consequently, questions around how young people make sense of their identity and the role social media plays in shaping identity are emerging. Supported by the current National Institute for Health and Care Excellence guidelines on end of life care,¹ which highlights a need for emotional and psychological support for young people, there is a move towards understanding the role of social media in providing psychosocial support for young people with life limiting conditions. However, there is a paucity in the current evidence base on the effectiveness of social media as a psychosocial support intervention for young people with life limiting conditions. The evidence largely sits within the realm of oncology related conditions and while offers important insights into the support needs for people with life limiting conditions it may not reflect the experiences of young people with different illness trajectories and symptom management.² The Twitter chat provided a number of discussion threads around how supportive care could be improved and to what extent social media is a mechanism for psychosocial support and maintaining identity.

Key messages from the Twitter Chat (#ebnjc)

A range of issues were discussed during the Twitter chat with four key themes emerging. The first related to how young people with life limiting conditions engage with and use social media with health care professionals (HCPs). Young people are now more actively engaged in online discussions about their healthcare.³ Examples of HCP's viewing online content generated by young people were provided and there was a general consensus that HCP's should have some understanding of how young people use social media. Patient participants who contributed to the chat were more cautious about direct engagement with HCP's online and the need to respect the privacy of the young person. However, both HCPs and young people perceived that in order for HCP's to become more actively engaged with young people online they need to adopt a less clinical and more personal approach to the way they engage with young people, while maintaining professional boundaries (figure 1). Participants highlighted a lack of training and awareness on how to best use online resources to offer

psychosocial support to young people with life limiting conditions. Whilst difficulties were raised relating to HCP's and the use of social media, it was acknowledged that social media is a valuable resource in allowing HCP's to gain insight into the support systems used by young people online. This understanding could influence the future direction of support interventions.

Figure 1: Social media can facilitate insights into psychosocial support for young people.



The second theme related to the need for further research to understand the psychosocial needs of young people with life limiting conditions and how they can be best supported. Participants, both HCP's and patients, suggested that in depth research involving young people as co-researchers is essential, especially with young people with limited communication ability. There was an identified need to build a comprehensive evidence base that could accurately inform future interventions targeting improving psychosocial support for young people with conditions that are life limiting (figure 2). Young people who participated in the chat were highly vocal in highlighting that psychosocial support is not recognised as an essential part of their care plan (figure 3). Furthermore, social media should not to be viewed as a 'one box fits all' solution to providing psychosocial support and as a means of helping young people make sense of their illness. Therefore, future research is required to illuminate both the individual needs and general commonalities within this group as to how best to provide psychosocial support.

Figure 2: Social media as a support mechanism requires a robust evidence base.

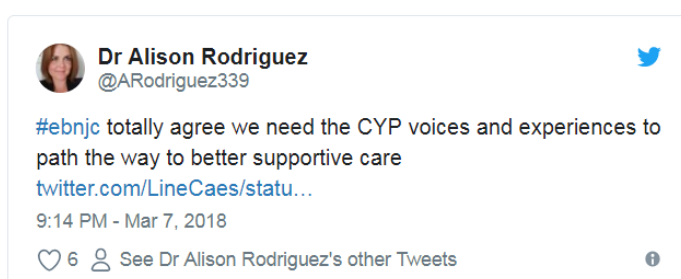
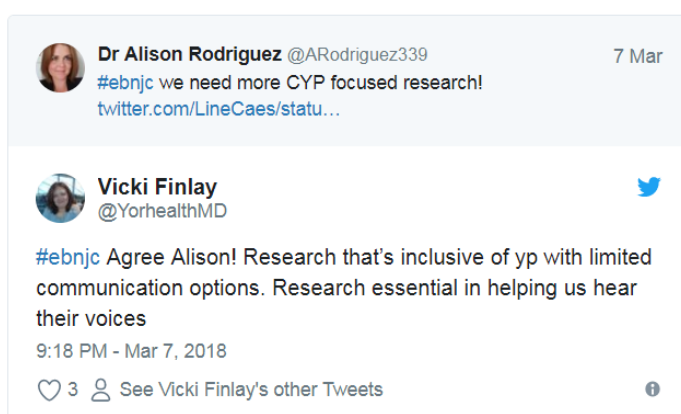
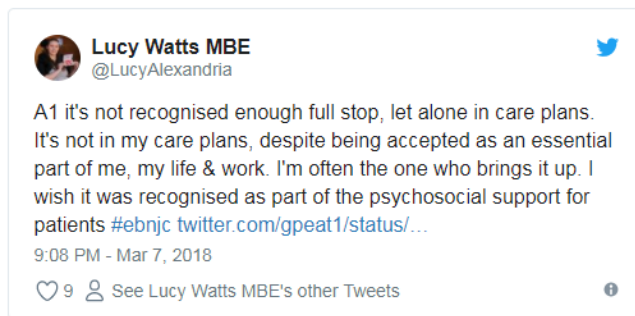
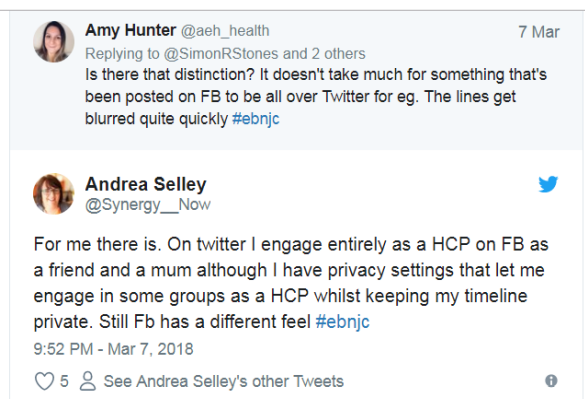


Figure 3: Recognising psychosocial support an integral part of care.



The third theme related to the types of social media platforms used and the content shared. Participants noted a different 'feel' or purpose across social media platforms (figure 4). For some, Facebook and Instagram were perceived to be more private and personal, with Twitter viewed as being more open and therefore could be a potential online platform to network professionally as opposed to connecting personally. The intent of the interaction and audience can influence the social media platform used. Different social media accounts have been identified as having differing purposes in terms of interacting with different audiences and posting different content.⁴ Contributors to the chat offered insights into why accounts specifically dedicated to a young person's illness are created; accounts where access is restricted allow young people to retain control of what aspects of their identity they share. Sharing aspects of the self via social media has the potential for young people to identify with and express their identities that are not solely reflective of being a young person with a life limiting condition.

Figure 4: Different social media platforms useful for different types of support.



The final theme related to the negative side of social media, in particular relating to the fabrication of illness symptoms or the need to enter into competition with other social media users regarding the severity of symptoms; one participant labelled as the 'Illness Olympics'. There was lack of clarity among participants as to why users choose to engage in such activities; however some perceived it was related to the need to validate or prove the severity of their condition to others (figure 5). Significantly, participants felt that this deterred them from engaging with and seeking support from the illness community via groups that currently exist on sites such as Facebook. Similar concerns are evident within the literature with negative and harmful postings deterring young people with long-term conditions seeking support from online support groups and forums.⁵

Figure 5: Drawbacks of social media in relation to illness support.



Conclusion

Psychosocial support must become an integral part of the care plan for a young person with a life limiting condition. Whether social media can play a role in providing psychosocial support remains contentious and has many challenges highlighted by contributors to the chat and the wider literature.⁶ In summary, there is a need for a robust and comprehensive evidence base that offers a clear direction to how social media can be used as a supportive and meaningful resource to provide psychosocial support to young people with life limiting conditions.

References

- ¹National Institute for Health and Care Excellence. End of life care for infants, children and young people. 2017; <https://www.nice.org.uk/guidance/gs160>
- ²Murray SA, Kendall M, Boyd K, *et al.* Illness trajectories and palliative care. *Clinical Review* 2005; **330**: 1007-11.
- ³Ventola CL. Social media and health care professionals: benefits, risks, and best practices. *Pharmacy and Therapeutics* 2014; **39**: 491.
- ⁴Myrick JG, Holton AE, Himelboim I, *et al.* #Stupidcancer: Exploring a typology of summary and the role of emotional expression in a social media community. *Health Communication* 2016; **31**: 596-605.
- ⁵Kohut AS, LeBlanc C, O'Leary K, *et al.* The internet as a source of support for youth with chronic conditions: A qualitative study. *Journal of Child Care and Health Development* 2017; **44**: 212-220.
- ⁶Crook B, Love, B. Examining the light and dark of an online young adult cancer support community. *Qualitative Health Research* 2016; **6**: 938-948.