UNIVERSITY OF LEEDS

This is a repository copy of *Mobilising identity through social media: psychosocial support for young people with life-limiting conditions*.

White Rose Research Online URL for this paper:
http://eprints.whiterose.ac.uk/131348/

Version: Accepted Version

---

**Article:**

Peat, G orcid.org/0000-0002-0293-2456, Smith, J orcid.org/0000-0003-0974-3591 and Rodriguez, A orcid.org/0000-0001-9104-1999 (2018) Mobilising identity through social media: psychosocial support for young people with life-limiting conditions. Evidence-based nursing, 21 (3). pp. 60-62. ISSN 1367-6539

https://doi.org/10.1136/eb-2018-102938

---

© 2018, Article author(s) (or their employer(s) unless otherwise stated in the text of the article). This is an author produced version of a paper published in Evidence-based nursing. Uploaded in accordance with the publisher's self-archiving policy.

**Reuse**
Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

**Takedown**
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

White Rose
university consortium
Universities of Leeds, Sheffield & York

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

# Mobilising identity through social media: psychosocial support for young people with life limiting conditions outside of the care setting.

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 https://blogs.bmj.com/ebn/ and the Storify 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 generation's, 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 NICE (2017) guidelines on end of life care, 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 psychosocial support for young people with life limiting conditions. The evidence largely sits within the realm of oncology related conditions and therefore whilst offers important insight; neglects the experiences of young people with other life limiting conditions, with different illness trajectories and symptom management (Murray et al, 2005). 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 (Ventola, 2014). Examples of HCP's viewing online content generated by young people were provided and there was a general consensus that HCPs 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 HCP insight into psychosocial support for young people.

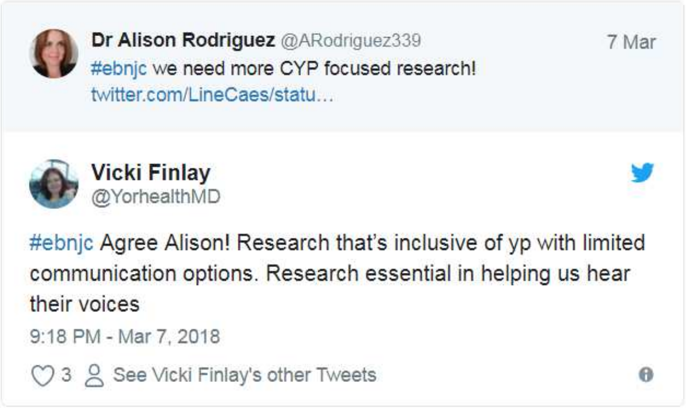
**Lucy Watts MBE**
@LucyAlexandria

A3 Definitely! I wish HSCPs & researchers harnessed this. Understood the vast resource social media creates. User-led engagement, peer support, communities & the endless stream of information which can be highly informative, but could also be better utilised by profs #ebnjc twitter.com/gpeat1/status/…

9:33 PM - Mar 7, 2018

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 was perceived 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: Current evidence base needs developing relating to social media as a support mechanism.

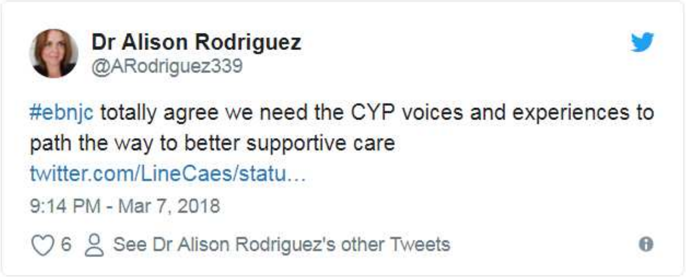


**Dr Alison Rodriguez** @ARodriguez339 7 Mar
#ebnjc we need more CYP focused research! twitter.com/LineCaes/statu…

**Vicki Finlay**
@YorhealthMD

#ebnjc Agree Alison! Research that’s inclusive of yp with limited communication options. Research essential in helping us hear their voices

9:18 PM - Mar 7, 2018



**Dr Alison Rodriguez**
@ARodriguez339

#ebnjc totally agree we need the CYP voices and experiences to path the way to better supportive care twitter.com/LineCaes/statu…

9:14 PM - Mar 7, 2018

part of care.

**Lucy Watts MBE**
@LucyAlexandria

A1 it's not recognised enough full stop, let alone in care plans. It's not in my care plans, despite being accepted as an essential part of me, my life & work. I'm often the one who brings it up. I wish it was recognised as part of the psychosocial support for patients #ebnjc twitter.com/gpeat1/status/…

9:08 PM - Mar 7, 2018

9 See Lucy Watts MBE's other Tweets

The third theme related to the types of social media platforms used and content shared. Participants noted a different ‘feel’ or purpose across social media platforms (Figure 4). For some, sites such as 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 oppose 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 (Myrick et al, 2016). Contributors to the chat offered insights into how accounts specifically dedicated to a young person’s illness are o 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 may be useful for different types of support.

**Amy Hunter** @aeh_health 7 Mar
Replying to @SimonRStones and 2 others
Is there that distinction? It doesn't take much for something that's been posted on FB to be all over Twitter for eg. The lines get blurred quite quickly #ebnjc

**Andrea Selley**
@Synergy__Now

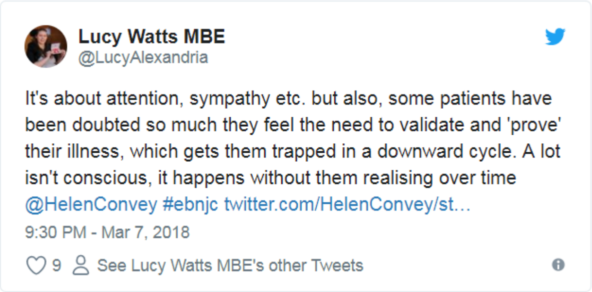
For me there is. On twitter I engage entirely as a HCP on FB as a friend and a mum although I have privacy settings that let me engage in some groups as a HCP whilst keeping my timeline private. Still Fb has a different feel #ebnjc

9:52 PM - Mar 7, 2018

5 See Andrea Selley's other Tweets

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; which one participant labelled as the ‘Illness Olympics’. There was a 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. (Kohut et al, 2017)

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



**Lucy Watts MBE**
@LucyAlexandria

It's about attention, sympathy etc. but also, some patients have been doubted so much they feel the need to validate and 'prove' their illness, which gets them trapped in a downward cycle. A lot isn't conscious, it happens without them realising over time @HelenConvey #ebnjc twitter.com/HelenConvey/st…

9:30 PM - Mar 7, 2018

## Conclusion

In order for psychosocial support to become an integral part of the care plan for a young person with a life limiting condition, understanding psychosocial support from their perspective is essential, if services are to respond to their needs. Whether social media can play a role in providing psychosocial remains contentious. Undoubtedly, social media is a tool that harbours the capacity to provide such support, and has many challenges as highlighted by contributors to the chat such as the posting of inaccurate and misleading health information (Crook et al, 2016), as well as content and user behaviour that can diminish rather than improve patient's well-being. Further questions need to be answered as to how HCP's best approach the use of social media as a way of enhancing care. In summary, the Twitter chat highlighted that for social media platforms to become supportive and meaningful there is a need for a robust and comprehensive evidence base that offers a clear direction on how best to use social media as a supportive and meaningful resource to provide psychosocial support to young people with life limiting conditions.

## References

- Crook, B., & Love, B. (2016). Examining the light and dark of an online young adult cancer support community. Qualitative health research. 6 (1). 938-948.
- Kohut, A, S., LeBlanc, C., O'Leary, K., McPherson, A.C., McCarthy, E. (2017). The internet as a source of support for youth with chronic conditions: A qualitative study. Journal of child care and health development. 44 (2). 212-220.
- Murray, S. A., Kendall, M., Boyd, K., Sheikh, A. (2005). Illness trajectories and palliative care. Clinical Review. 330 (1). 1007-11.
- Myrick, J. G., Holton, A. E., Himelboim, I., & Love, B. (2016). #Stupidcancer: Exploring a typology of summary
- National Institute for Health and Care Excellence (2017). End of life care for infants, children and young people. Retrieved 13th October 2017, from https://www.nice.org.uk/guidance/qs160
- Ventola, C. L. (2014). Social media and health care professionals: benefits, risks, and best practices. Pharmacy and Therapeutics. 39 (7). 491.