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Viral- International online peer support & learning in palliative care

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Aims: In Wales, the Advance & Future Care Planning (AFCP) strategic group oversees the national direction for advance care planning. The aim is to establish a peer-supported campaign to effectively inform people about AFCP. The group includes patient representation and has had a strong focus on promoting person-centred AFCP via new media.

Methods: Several social media campaigns, for instance #TalkCPR, #FutureCarePlanning & #WhatMattersMost, have been led & co-directed by technology-savvy patients & carers. YouTube videos on the complexities of resuscitation & AFCP education have been co-created by patients. Apps, websites, YouTube channels & hashtags were created including https://advancecareplan.org.uk, www.wales/nhs.uk/DNACPR, #TalkCPR & http://talkcpr.com. Patient groups helped write scripts for explanatory videos. A national conference in 2019 further helped to set direction. Resources have been accessed over a million times, including countries like Lesotho.

Results: The online content has had a worldwide reach & highlighted Welsh advance care planning materials. As an example, a patient wrote about the resources on a medical journal site, "Twitter helped me decide that I'm not for resuscitation" in the BMJ 'What your patient is thinking' series. The article was downloaded over 10,000 times, with readership breakdown of 61% members of public, 29% practitioners, 8% scientists & 1% journalists.

Conclusion: Our patient & carer representatives have stated that by connecting to others in similar situations, including via social media, they found solace & felt less alone. The discussions between patients, carers & bereaved next-of-kin on Twitter that are associated with our Welsh campaign's hashtags, have made for sometimes challenging but valuable learning. Peer-support in the online world of social media is real & at present it is uncharted new territory. Moral & ethical challenges on how to recruit into, establish & maintain peer-support structures are discussed.

Summary:

Peer support in social media campaigns

The Advance and Future Care Planning (AFCP) strategic group oversee the national direction of advance care planning for Wales. This is supported with oversight from the Deputy Chief Medical Officer for Wales.

Its goal is to inform the public about preparing for decision making during serious illness and nearing the end of life. Patients are represented on the group, which has promoted person-centred AFCP via new media since 2015.

In 2019 a national conference helped to set direction, with significant input and feedback from patient and carer representatives, including individuals with dementia.

Technology-savvy patients and caregivers have led and conducted several social media campaigns, such as #TalkCPR, #FutureCarePlanning, #WhatMattersMost. [1 2]

Patients have co-created YouTube videos on the complexities of cardiopulmonary resuscitation and education on AFCP. Apps, websites, YouTube channels and hashtags have been created such as AdvanceCarePlan.org.uk, Wales/nhs.uk/DNACPR, #TalkCPR, and TalkCPR.com.

Highlighting Welsh advance care planning materials, the online content has been used globally. Participants in countries as remote as Lesotho, have accessed resources over a million times.

A patient wrote, "Twitter helped me decide that I'm not for resuscitation" in the British Medical Journal series entitled What Your Patient is Thinking, on the back of the Welsh #TalkCPR hashtag campaign. The article was downloaded over 10,000 times. Sixty-one percent of readers were from the public, 29% practitioners, 8% scientists, and 1% journalists. [3]

Patients and caregivers have stated that by connecting to others in similar situations, including via social media, they have found solace and felt less alone.

Tweets between patients, caregivers, and bereaved next of kin associated with the Welsh campaign's hashtags have allowed for sometimes challenging but valuable learning, in an area with many differing viewpoints. Though uncharted territory, peer support via social media has been established. Moral and ethical challenges include recruitment and the establishment and maintenance of peer support structures. Next steps will involve promoting information about patient-led advance decisions to refuse treatment, out-of-hours care provision [4] and how to appoint a lasting power of attorney.

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[3] Cass, K, Taubert, M. 2018. Twitter helped me decide that I'm not for resuscitation. BMJ 2018; 362 doi: https://doi.org/10.1136/bmj.k2784 (Published 05 September 2018) 10.1136/bmj.k2784

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