

Palliative social media

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ABSTRACT

The uses of social media have become ubiquitous in contemporary society at an astonishingly fast-paced rate. The internet and in particular platforms such as Facebook, Twitter and YouTube are now part of most people's vocabulary and are starting to replace many face-to-face interactions. The online world, in particular, is alive with discussions, comments and anecdotes about the topics of illness, disease, hospitals, death and dying. The topic of death and dying had in the not too distant past been seen as taboo, but willingness and need to talk openly about it appears to be on the increase. In parallel to this, many public awareness campaigns are highlighting society's need to be more prepared for dying and death. This will have a significant impact on the way terminally ill patients and their families approach the last years, months and weeks of their lives and how they might expect palliative health and social care professionals working with them through these difficult periods to interact with them. We pay particular attention to the areas of digital posterity creation and memorialisation within the wider holistic context of end-of-life care.

INTRODUCTION

In July 2013, 58 million tweets were being posted daily.¹ Topics and stories on social media microblog sites like Facebook and Twitter are wide-ranging, but often discussions centre on healthcare, illness and how the vulnerable are treated in society. Here, we focus on how the subject of death and dying has influenced the world of microblogging, how it is fast becoming a focus of research, and discuss how this may impact on the professional lives of palliative care workers, in particular around the area of digital legacy building for people approaching death. We also provide a brief overview of what else social media can provide for palliative care and bereavement workers, in terms of information provision, discussion forums, feedback, opinion gathering, areas of controversy, representing organisations and research.

Much has already been said in other articles about the dangers of social media microblogs to the healthcare professional, and both the UK's General Medical Council and the British Medical Association have issued statements urging caution.^{2,3} But the debates on social media sites on topics such as death and dying are intensifying. Staff in healthcare settings have in the past been seen as reluctant to broach the topic of death and dying in the eyes of their patients.^{4,5} And our societal attitudes support this; there still exists a contemporaneous phenomenon of striving toward the youthful, healthy body, and that anything related to death and disease is viewed with a degree of shame and embarrassment, and is even hidden away.⁶ In some cultures, talking about dying and death itself is unacceptable, disrespectful, even seen as bad luck or, worse still, may be perceived as bringing death about sooner.⁷

Conversely, the rise of microblogging websites has not just seen the general public, but also some healthcare professionals themselves turn this taboo on its head and take to the public forum, for instance, in the debate about the use of the Liverpool Care Pathway for end of life care in the UK.^{8,9} Palliative healthcare professionals are openly debating present day topics,^{10–13} particularly on sites like Twitter.¹⁴ Social media provide an option for fast track information, for example, feeding live palliative care conference information and other activities in real time to many people across the world.¹⁵ As an example, typing #eapc or #eapcresearchcongress into the Twitter search engine can provide feedback from the most recent European Association for Palliative Care conference attendees and organisers.

Some argue that the risks of being active in blogs and online should not prevent doctors and nurses representing their views on matters pertaining to medicine in the social media setting. Having palliative care doctors, nurses and



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allied healthcare professionals online may be a good counterbalance to nonsense science, erroneous media health scares and may contribute to ethical debates that have previously been one-sided, especially surrounding the topic of death and dying. Of those professionals who are actively engaged with the online microblogging community, some choose to debate openly disclosing their full names, while others have used assumed identities such as 'The Medical Registrar'¹⁶ and the 'Palliative Medicine Registrar'¹⁷ on Facebook. Dr Margaret McCartney, a Glasgow GP and Twitter user, reflects that 'hiding behind an assumed name may seem to offer more possibilities for edgier disclosures, however write under your own name, and you are ensuring transparency as well as a conscious check of willingness to stand by what you've written. Social media enable doctors to stand up for good medicine, democratically and instantly.'¹⁸ The quick, instant access to all these debates, the immediacy of publication of both actions and reactions carry many allures but also dangers to those passionate about palliative healthcare matters.

An emerging field of research

The emergence of a newer area of focus, that of analysing trends in social media vis-à-vis end of life care, appears to have been embraced by researchers in anthropology, social sciences, death studies and computer sciences and it is likely that medicine in general and palliative care in particular will follow suit. As an example within the field of medical research, Greene *et al*¹⁹ used social media searches to qualitatively evaluate the content of communication in Facebook communities dedicated to diabetes.

But there is a larger, more established body of research on digital death and dying in the field of social sciences. Searching the social sciences literature with keywords such as '(after-)death', 'memorializing', 'grieving', 'hybridization', 'publics', 'rituals' and 'historicization' revealed a number of discussion, opinion and research articles surrounding digital death and dying. Research, in particular, focuses strongly on online memorial sites and in particular looks at the content of what is written there and how people grieve online, but concludes that analyses of practices on how the 'digital self' is managed after death have only just begun.²⁰

Professor Daniel Miller, an anthropologist, is conducting research on end of life care practices in relation to new media and this is a 3-year project extending to 2015.²¹ This research illustrates both positive and negative aspects of social media use in this population, as reported by hospice staff. One example cited a story about a death being relayed on Facebook before most relatives had been informed by more appropriate channels. More positively, social media were seen to lead to an avoidance of isolation for those individuals who were undergoing chemotherapy. Being susceptible to infection made it more difficult to socialise with

friends or family in person, so social media microblogs became particularly valuable as a way of avoiding isolation and staying in touch.

The broader context of social media and end-of-life care and communication is examined extensively by Carla Sofka *et al*^{22 23} who argue that we have always employed the latest advances in our approaches to death and dying and grieving and that this significantly impacts on how society organises behaviours around dying and death.

In the field of death studies, Walter *et al*²⁴ provide an analysis of contemporary trends in online practices related to death and dying and find that they may affect funerals, as well as grief and memorialisation, inheritance and even archaeology. Social network sites have to some extent brought grieving and dying out of the private domain into the everyday life of the online world. They also open up another aspect of digital death, that of *posterity creation*.

Posterity in the digital realm?

The psychologist Roy Baumeister has argued that the length of time most of us might expect to be remembered for is a maximum of 70 years, pointing out that

Box 1 Example of a memorial virtual candle website service taken from Walser Funeral Home website, found as the top Google search result when researching memorial candles³⁰

Light a Memorial Candle

The Memorial Candle Program has been designed to help offset the costs associated with hosting this tribute website in perpetuity. Through the lighting of a memorial candle, your thoughtful gesture will be recorded in the Book of Memories and the proceeds will go directly towards helping ensure that the family and friends of [insert deceased person's name] can continue to memorialize, re-visit, interact with each other and enhance this tribute for future generations.

Thank you.

Payment Information

- ☐ Cheque
- ☐ PayPal
- ☒ Credit Card

You may write a check to cover the cost of lighting a virtual candle in remembrance of your loved one. In order to prevent fraudulent lighting, please know that if your cheque is not received within 14 days, your memorial candle will no longer be lit.

- ☐ \$10.00—1 Month
- ☐ \$20.00—1 Year
- ☒ \$50.00—Permanent

not many people can name their great-grandparents.²⁵ The philosopher Stephen Cave, in his book *Immortality*, has described the phenomenon of symbolic reproduction and posterity within online social networking contexts.²⁶ To this effect, David Giles, a psychologist, has called physical aspects of posterity creation, such as statues, records, diaries and images of individuals past and present, a 'reproduction of the self'.²⁷ Once merely the jealously guarded domain of royalty, conquerors and politicians, we have today myriad opportunities to symbolically reproduce our own selves, for example via photos, videos and blogs, and for these reproductions to remain present and accessible while our bodily selves have disintegrated.²⁸ The current explosion of digitalised social media is perhaps the greatest opening of the cultural world since printing presses started rolling in the 15th century. Individuals' personalised spaces created and shared within the digital space are now the norm, and may be of great significance to those who remain once the page's owner has died. Creating this form of online diary and making it available for posterity can therefore be an incredibly powerful and meaningful

way of expression for those still living but faced with death.

It will therefore be possible for our great-grandchildren to click on our social media microblog site timelines, and get an impression of our entire lives. This has led to social media sites creating settings and rules for what happens to the pages of the deceased.²⁹ A 'Memorial Page' function has been available for Facebook users who have died for some time now. These facilities are called online 'memorialisation services', and can be microblog site specific, or even extended to the entire internet. In fact, some companies now offer a digital legacy service, with photos, videos, blogs and status updates from the past collected from the entirety of the internet and transmitted to electronic devices in a real, physical gravestone, whence it is beamed to passers-by.²⁶ Such phenomena may become the norm, and we may soon be less surprised to see them in our everyday (working) lives. For example, palliative care and other healthcare staff may be asked to contribute to lighting virtual candles online, with sites offering services as described in box 1. This will, naturally, bring with it discussions

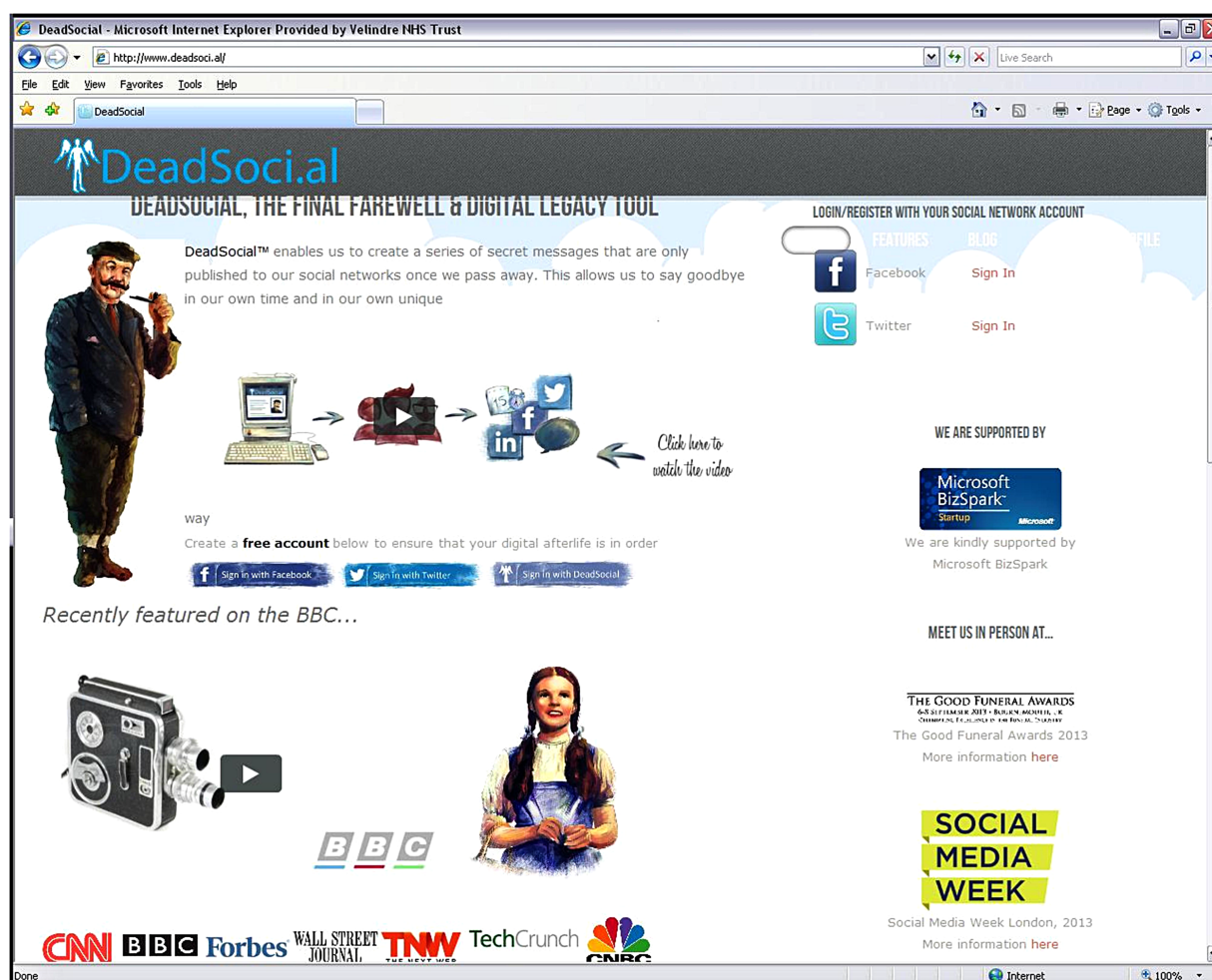


Figure 1 DeadSocial website where users can prime their Facebook and Twitter accounts to post future status updates after they have died.

surrounding privacy and appropriateness and may cause considerable disagreement within families of people who have passed away. Some may wish for content to remain online, while others may wish for it to be removed entirely.

There are also digital social media developments that extend beyond a person's natural death. Preparing in advance what gets posted after death is now possible via websites like DeadSocial³¹ (see figure 1). The site helps Facebook and Twitter users prepare items to be posted at specific future dates and can help send (preprepared) messages to loved ones, for example, on their birthdays well into the future.

#Social media history?

Questions arise from the many facets of social media impacting on end of life care. Are palliative care services ready for all of this? Do health and social care professionals working in the specialty know how to respond when someone asks them whether their personal online page will remain visible forever after they die? And if not, do they know how to respond or who to ask for advice on this? Do palliative care specific medical, nursing and/or family support worker notes need a section entitled 'Social Media History' in a similar way that we frequently focus on people's spiritual background? Could this, in fact, be part of the spirituality assessment, given the importance this has on peoples' legacies and memories, in a similar way to memory boxes? Beverly Smith in a case report argues that because a palliative care team guides patients and family members through the grieving process and its accompanying pitfalls, social media use should not necessarily be seen as separate within the context of holistic care.³²

Another case report in *Palliative Medicine* describes a young patient with pontine glioblastoma multiforme who used social media as a form of expressing his grief and his emotions and took some comfort in being able to do so. Staff at the hospice where he was being treated were aware of his blog, and were given an insight into his thoughts at each stage of his illness.³³ We need to be aware that both patients and their families and friends may be reviewing services online, and may have a wide reach and local readership (see box 2).

In the USA, a well-known radio show host called Scott Simon tweeted from a Chicago hospital room; his mother had entered the ICU there, following surgery. She died during that admission, at the age of 84. In the week before her death, Simon began live-tweeting his mother's final days to almost 1.3 million followers from her hospital room.³⁴ There was an extraordinary response to Simon's tweets, ranging from members of the public to the media. This highlighted to many that there appears to be a huge need for Americans to find ways to integrate death and mourning into their lives, a need met by

Box 2 Case example—online blog review of palliative services

Patients and carers who are avid smart phone, laptop or tablet computer users may be reviewing your service provision in real time, perhaps even while you are speaking to them. One of the authors was surprised one day when an elderly, previously confused and unwell ward patient produced a smart phone and announced she was going to give the hospice and its staff a glowing review on her Twitter feed. But what does a service do if it hears of a complaint that has been made on a public website or microblog, rather than on one of the neat, paper forms made available in the outpatient or inpatient departments? Many hospices now have their own Facebook and Twitter pages (eg, <http://www.facebook.com/MarieCurieWales>), which allow local communities to interact.

Presumably, there will be a lot of positive feedback, but interspersed within may be aggrieved patients, relatives and friends who may vent anger or frustration in this kind of domain. It is important to define how individual services may wish to respond to this novel form of complaint or grievance.

social media feeds such as Scott Simon's. Microblogs are changing the way people are mourning across the planet by creating a public space for it.

Pandora's box?

While it is tempting to not open the potential Pandora's box that the questions raised above bring with them, it is worth staying abreast of ongoing social media developments as much as possible. We simply cannot feign ignorance about all matters to do with the internet, as many patients and their friends and families will see this as important legacy building, and will also expect us to be able to communicate with them appropriately. In the same way that years ago we would not have turned anyone away asking to create a memory box for their family and children once they are gone, we now cannot ignore the fact that end-of-life matters have taken a significant shift into the online world, and that increasingly we will be set difficult, sometimes ethically dubious challenges. The young, terminally ill Dr Kate Granger's Twitter feed has and is being viewed by the public, the media and the healthcare profession with avid interest, and has started a debate about 'deathbed tweets'.^{35 36} In Germany, the blog of the now deceased author Wolfgang Herrndorf attracted a large amount of attention and discussion.³⁷ Some further examples of where to start looking up current blogs, trends and discussions are provided in box 3.

Box 3 Palliative social media examples—where to get started on information feeds and blogs

- ▶ The Association for Palliative Medicine (APM) on Facebook and Twitter: <https://twitter.com/apmposttweets> www.facebook.com/apmnews
- ▶ Vital Options Channel on Youtube (run by Selma Schimmel a cancer survivor, this channel provides viewers with videos specific to palliative care and oncology): <http://www.youtube.com/user/vitaloptions>
- ▶ The Palliative Medicine Registrar and the Medical Registrar on Facebook: <https://www.facebook.com/Palliation> <https://www.facebook.com/medicalreg>
- ▶ Tumblr's Pallimed Blog: <http://pallimedblog.tumblr.com/>
- ▶ The European Association for Palliative Care: <https://twitter.com/EAPCONlus>
- ▶ Twitter page BMJ Supportive and Palliative Care: https://twitter.com/BMJ_SPCare
- ▶ LinkedIn Profile for St Michael's Hospice Hereford: <http://uk.linkedin.com/pub/st-michael-s-hospice/4b/1b3/220>
- ▶ Pinterest's 'What is Hospice and Palliative Care?' pinboard: <http://www.pinterest.com/nhpco/what-is-hospice-palliative-care/>
- ▶ Twitter page Dying Matters Charity: <https://twitter.com/DyingMatters>
- ▶ Twitter page "I support the Liverpool Care Pathway": <https://twitter.com/isupportthelcp>
- ▶ Twitter page "LCP: Pathway to Death": <https://twitter.com/Pathway2Death>
- ▶ Google+ page "PalDaily": <https://plus.google.com/communities/106953647341937978973#%2BPalDaily/posts>
- ▶ Slideshare site: "The Adoption of Palliative Care" (Presentation): <http://www.slideshare.net/jmckeever/palliative-care-28850899>
- ▶ Twitter page Dr. Kate Granger, Registrar in Elderly Care : <https://twitter.com/GrangerKate>
- ▶ Twitter page Mr. Tony Nicklinson (this blog is being continued by Mr. Nicklinson's daughters) <https://twitter.com/TonyNicklinson>
- ▶ Researchgate: Journal of Social Work In End Of Life Care: http://www.researchgate.net/journal/1552-4264_Journal_of_Social_Work_in_End-of-Life_Palliative_Care

It is vital that palliative care workers are aware of the potential benefits and harm that the world of social media can have in the death and dying 'arena'. This article can only discuss some of the ramifications and permutations of events that occur online, but our aim was to provide an overview of some of the current and possible future developments, in particular surrounding digital legacy building and memorialisation. Social media have the potential to cause significant harm and breakdown in the stressful

environment that surrounds the death of a family member. But while they are sometimes criticised for lacking emotional depth, those professionals working with grieving people may see them as a potential further option to use as a means of communication and follow-up, in addition to the more traditional ways of support. The ethical questions remain as do the questions of appropriateness and will need a very individualised approach. However, in a growing internet family with 'mass collaboration' these questions are likely to be raised with increasing frequency and in more local situations, so we all need to be prepared to enable the best advice and service to our patients.

CONCLUSIONS

Social media are agents of change and have transformed our society and the way we interact with each other. This is most evident in the private sphere, but patients may not want to exclude the end of their life from these activities, and will want to carry this on in their social activities. They may expect some interaction with healthcare professionals and institutions like hospices and palliative care services as well. For palliative care, there are inherent challenges with the use of social media, but also major opportunities. What we need is a careful discussion about their limits and limitations, but also an open mind towards the social change they are bringing, and how we in palliative care want to fit in. Feel free to 'retweet', 'favourite', 'share', 'like', 'dislike' or 'pin' this article and its linked editorial by Dr. Kate Granger³⁸ deep into the blogosphere.

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