Abstract
One implication of social media is that when we die, we live on to an extent through our online presence and digital footprint or legacy. By 2008, for instance, dead Facebook users will outnumber living ones (Newsweek, 2015), effectively making the website into the largest graveyard in the world, albeit in digital form. The terminally ill, as well as their families and friends, can use these internet pages in various ways, as a legacy, tribute and memorial for addressing loss and bereavement.

In recent years, various enterprises, services, and associations have sprung up (e.g. Dead Social, the Digital Beyond, Final Road Map, and The Digital Legacy Association) with powerful implications for linking interactive digital tools like social media and blogging to the work of palliative healthcare professionals. Longer lifespans combined with widespread technological trends are inevitably reshaping experiences and perceptions of death and grief – with compelling questions for how palliative care can use such trends to improve its practices. Depending on how they are used, digital assets and legacies may help support people’s coping and grieving processes, or they may have more negative effects, inhibiting acceptance and prolonging more dysfunctional responses to grief and loss.

Through research into the development of the Digital Legacy movement, and an ongoing programme of semi-structured interviews with hospice staff, technological innovators, patients and bereaved families, this paper is aimed at critically assessing how effective palliative care might be delivered through various digital legacy services. Implications and conclusions are drawn for finding out and addressing the needs of patients and grieving relatives through online media, integrating digital legacies with existing palliative frame-works to improve care, and the ethical challenges of using new technologies to engage the highly sensitive, taboo subjects of dying and death.

"What is a digital legacy? Simply put, your digital legacy is the online presence you leave behind when you pass away. This includes social media profiles, e-mail and online shopping accounts and libraries of digital music or photos."

Soga.co.uk, 2015

"The internet is the biggest and most ‘disruptive’ force since the industrial revolution. As a result, society is spending an ever increasing amount of time online. This has led to a range of benefits whilst changing the way in which society mourns and remembers the deceased into posterity."

Digitallegacyassociation.org, 2016

Company Name | Founded | Service Offered
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DeadSocial | 2012 | Digital Social provides a range of free tools. It provides advice and encourages you to be actively involved in planning your digital legacy.
DigitalBeyond | 2010 | 2010
FinalRoadMap | 2014 | 2014
Celebrated.com | 2012 | Afterward is marketed as an online secure tool which will allow you to leave messages to be accessed after your death.
Celebrated.com | 2009 | By 2065, people with Facebook profiles that have died, than there will be of living account holders!
Celebrated.com | 2009 | Nearly 55% of people have not written a will!
Celebrated.com | 2009 | Nearly 90% of people have made no plans for their social media accounts after death!

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Dying, like living is multi-dimensional. The Biopsychosocial model of health incorporates 3 domains. Physical, Social and Emotional.

When caring for the dying patient, Spirituality is often considered an extra domain to be included. Spirituality has been proven as so significant so this domain has been included in the adapted model below.

Government statistics report that in 2015 87.9% of adults in the UK had recently (in the last 3 months) used the internet, compared with 86.2% in 2015.

Ofcom has conducted a ‘Media use and attitude’ survey for 10 years. In 2015, nearly 2000 adults aged 16 and above, spent nearly 10 hours (9 hours 53 minutes) a day online in some capacity. This could be interpreted as people spending nearly half their days living online.

The adapted model below shows the biopsychosocial model with added dimensions. The original model encompassing 3 domains: Physical, Social and Emotional. In the model below, Spiritual and Digital have been added.

The digital domain surrounds the other domains as it encompasses all other domains in some aspect.

Physical: 3 million fitness bands (An activity tracker is a device or application for monitoring and tracking fitness-related metrics such as distance walked or run, calorie consumption, and in some cases heartbeat and quality of sleep.) were sold in Britain in 2015. Many people track their physical activity digitally via apps.

In 2010, 84% of teens used the internet to get health information. Internet search giant Google has even introduced a symptom tracker.

Social: Social is probably the biggest dimension reflected online. In June 2016, 1.13 billion people worldwide logged on to Facebook

Emotional: The search term ‘emotional health and wellbeing online’ returned 30,700 000 results. Many mental health charities have an online presence as it may be easier for some people to access due to barriers in going to a health centre. Having access to information, or even a support forum online can really empower some people.

Spirituality: Many patients have spiritual needs related to illness that could affect mental health, but go unmet. Religion is one aspect of spirituality. The search term ‘Online Churches UK’ displayed 15,400 results. It is evident that online groups, social media and web pages can be important to some people and their spirituality needs.

Medical: The internet is the biggest and most ‘disruptive’ force since the industrial revolution. As a result, society is spending an ever increasing amount of time online. This has led to a range of benefits whilst changing the way in which society mourns and remembers the deceased into posterity."

Digitallegacyassociation.org, 2016