

Rejected words: Palliative, Holistic, Specialist, Rehabilitative, Care in the last days

Conclusion Phyllis Tuckwell Hospice Care provides supportive and end of life care for patients and families living with a terminal illness.

P-215 PATIENTS' UNDERSTANDING OF TERMINOLOGY USED IN PALLIATIVE CARE SERVICES

¹Abi Ponnampalam, ²Nicola Holtom, ²Sanda Hlaing. ¹Garden House Hospice, Letchworth Garden City, UK; ²Norfolk and Norwich University Hospital, Norwich, UK

10.1136/bmjspcare-2016-001245.236

Background Good communication stipulates that we avoid using jargon. However patients' understanding of terms such as 'specialist palliative care nurse' and 'Macmillan nurse' seems variable. We are often asked by patients who are already known to a palliative care specialist nurse, whether they could also see a Macmillan nurse.

In addition, as palliative care evolves and the role of hospices has changed to include complex symptom control, the subsequent name change to 'Specialist Palliative Care Unit' seems logical. However patients' understanding of this seems variable.

Aim To establish the understanding patients have of the terms commonly used in palliative care and ascertain whether the terms we take for granted cause any confusion.

Methods Qualitative semi structured interviews with 20 participants attending palliative care outpatient clinics. Participants had a range of life-limiting conditions and prognoses. Patients new to the service and those already known were sampled to identify any difference in their understanding. Interviews were recorded and transcripts were analysed using the principles of thematic analysis.

Results Only four patients were able to identify that the roles of specialist palliative care nurses (SPCN) and Macmillan Nurses were similar. Four patients felt that the SPCN was the same as the cancer specialist nurse. Five patients specifically mentioned the Macmillan nurse being available to provide hands on basic nursing and overnight care.

All participants identified end-of-life care with the term hospice. More than half did not know what a Specialist Palliative Care Unit entailed. Almost a third thought it was the same as the acute oncology ward or chemo/radiotherapy unit. Only three patients expressed their understanding of the two providing a similar role.

Conclusion There seems to be a real discrepancy between what is meant by these terms used commonly in practice and what is actually understood by patients. This raises serious issues which would benefit from further study

P-216 INTERVAL

Steven Eastwood, Peter Gilliam. *Earl Mountbatten Hospice, Newport, UK*

10.1136/bmjspcare-2016-001245.237

Introduction Non-fiction filming involving death and dying has taboo status in terms of what western society can and cannot sanction. Made over the course of 12 months through close engagement with individuals experiencing and witnessing death and dying, our film consists of long sequences showing the

people, environments and activities in and around the hospice, exploring what happens at the end of a person's life.

The project Upon filming it became clear that the hospice acts as the beating heart at the centre of the island, with its community team operating as an artery system, extending out to every part of the land. In many ways this is a palliative island, a place where dying is visible. With this notion of an island as ecology, one that is familiar with end of life, the filmmaker began to notice complex and coexistent movements and practices associated with dying. Filming with people in family homes and on the ward during the last weeks of life unfolded to include the very intimate moment of the instant of death. Filming also extended out into the landscape, taking in chemotherapy, bereavement seminars, pathology lab activity, but also ferry crossings, druid death ceremonies, and palliative care given to ageing big cats at the zoo.

The project attempts to engender a space where the phenomenon and phenomena of dying and death can be given an image. This reflects changing attitudes in palliative care and society around the visibility of death and dying. Navigating this difficult ethical territory involved adopting a way of seeing, and being with, the terminally ill person that has some confederacy with the practices of the palliative care professional. What emerges is a slow cinema description of the temporality of dying, an image of care and attentiveness and the very natural process of death.

P-217 COMMUNICATION PASSPORT PROJECT

¹Ruth Butcher, ¹Leanna Tuffin, ¹Natasha Harding, ¹Liz Lewington, ²Sophie Dziwinski. ¹Jessie May, Bristol, Great Britain; ²Roald Dahl; ³Burdett Trust

10.1136/bmjspcare-2016-001245.238

Jessie May is a charity-run organisation who provides specialist care and support through a team of children's nurses and nursery nurses in partnership with families and other agencies to deliver respite and palliative care service in the comfort of the families own home to children and young people with life limiting conditions.

The Departments of Health and Education (2015) define children with complex and continuing health care needs as individuals with prolonged chronic conditions which have an adverse effect upon a child's development and welfare. Many of the children with long term life-limiting illness or disabilities may have impaired communication (Teare, 2009).

However Hewitt-Taylor (2008) suggests that communication difficulties may not arise because of the child's inability to understand, but occurs through inability to make themselves understood by others. Children with complex needs communicate about the same things as the other children, for example their feelings, needs, likes and dislikes (Mencap, 2010). The Convention on the Rights of a Child (2014), specifically states that each and every child has a right to be listened to. Jessie May has recognised the possible barriers for some of the children that we care for being heard and listened to due to communication barriers. This problem is something that communication passports address.

A literature review identified three pieces of research, Millar (2007), Sanderson (2003) and Bell, (2012), all have similar findings that suggest there are significant benefits to using communication passports, and we aim to conduct a study on communication passports to ensure that we produce a passport that is relevant to the service that we provide.

P-218 ORANGELINE

Jane Frame. *Saint Francis Hospice, Romford, UK*

10.1136/bmjspcare-2016-001245.239

Background We will be launching a new non-clinical telephone helpline formally in September 2016. The Big Lottery (BIG) agreed to fund this exciting new project for three years and this innovative and much needed service will be branded as 'Orangeline'.

Aim We are mindful that there are some people with life limiting illnesses, and their friends and carers, who are living in an isolated world with little communication outside of their immediate circle, some are totally alone. Orangeline will give people a link into Saint Francis Hospice for support and friendship and the opportunity to be signposted to our services such as occupational therapy, complementary therapy and our bereavement services.

Method Our Orangeline service will be centrally based within the day therapy unit and will be managed by two members of staff and a team of volunteers within our Quality and Care Directorate. Orangeline will operate later into the evening and weekends, these are times when people living or not coping well alone are at their most vulnerable, how lovely will it be to have a friendly caring voice on the end of the telephone, or even better to come into see us for lunch on a Sunday and meet new friends. We have so many great ideas and would welcome the opportunity of sharing the success of this new project at the Hospice UK conference in November.

Results Our aim for this service will be the catalyst for reaching out to people already known to us and many more out in the community who aren't. We believe it will be the start of something BIG. As the project rolls out we will concentrate resources on evaluating outcomes, and assessing the benefits to people's health, wellbeing and recovery.

P-219 DOES ENGAGING WITH SOCIAL MEDIA BENEFITS HOSPICES? CASE STUDY ANALYSIS OF SOCIAL MEDIA PRESENCE OF FOUR UK HOSPICES

¹Munikumar Ramasamy Venkatasalu, ²Sivakumar Subramaniam. ¹Universiti Brunei Darussalam, Gadong, Brunei Darussalam; ²Ellenor Lions Hospice, Northfleet, Kent, UK

10.1136/bmjspcare-2016-001245.240

Background Emerging evidences suggest that use of social media helps to share information and resources and reach intended and 'beyond' audiences with quick and fast manner. Currently, hospices around the UK and the world actively engage with social media with different purposes. Yet, little is reported around the role of social media and its benefits for hospices.

Aim To investigate the use, engagement and the reach-out of social media among four hospices in the UK.

Methods A qualitative case study approach was adopted; studying purposeful sampling of four social media engaged hospices within UK. Data collection used multiple methods to collect publicly available data that include feeds, comments, shares, tweets, status updates from two online social networking sites namely Facebook and Twitter of selected hospices. Using Nivio10[®], a thematic analysis was undertaken.

Results Analysis of data found that all the hospices were actively engaged mainly in four different activities; fundraising, sharing best clinical practices, promoting educational activities, and advertng jobs. Hospices also involved in community outreach

activities by celebrating local events and cultural and religious celebrations.

Conclusion Findings indicate that engagement with social media enable hospices to remain in 'core businesses' of 'running with local support'. Yet, hospices could be more explicit in sharing about how well it benefits for patients and carers that could enable access to hospice services across the diverse population by sharing stories of hospice patients and relatives' experiences.

P-220 DEATH AND GRIEF ONLINE: THE OPPORTUNITIES AND CHALLENGES OF INCORPORATING DIGITAL LEGACIES INTO PALLIATIVE CARE IN HOSPICE SETTINGS

¹Jacklyn Pollock, ²Thomas Calvard. ¹St Columba's Hospice, Edinburgh, UK; ²University of Edinburgh, UK

10.1136/bmjspcare-2016-001245.241

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 2098, for instance, dead Facebook users will outnumber living ones (Newsweek, 2016), 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 parties, 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 frameworks to improve care, and the ethical challenges of using new technologies to engage the highly sensitive, taboo subjects of dying and death.

P-221 WORKING WITH HOSPICES TO ENSURE PATIENTS' DIGITAL LEGACY WISHES ARE ADHERED TO

^{1,2}James Norris, ^{3,4}Mark Taubert. ¹Digital Legacy Association, London, UK; ²DeadSocial; ³NHS UK; ⁴Velindre Centre, Cardiff

10.1136/bmjspcare-2016-001245.242

The Digital Legacy Association (DLA) was launched at last year's Hospice UK conference. Their work is focused on raising awareness and improving processes in areas relating to death and the internet.