

**Results** Hospice healthcare professionals highlighted challenges when providing palliative care to individuals from minority ethnic communities, particularly language barriers. Minority ethnic communities in South Wales appeared uninformed about local palliative care services and the keyworker implemented a range of initiatives to raise awareness and widen hospice referral routes. Additionally, the keyworker supported healthcare professionals when caring for people from minority ethnic communities, for example meeting religious needs at the end-of-life.

Looking ahead, hospice staff are keen to increase their understanding of different ethnic groups and cultures, while the keyworker hopes to work with community healthcare teams to improve referral rates to the hospice.

**Conclusions and application** The evaluation has demonstrated the progress made by the keyworker to engage minority ethnic communities and support hospice staff to holistically care for people from different ethnic groups.

The keyworker role appears, at this early stage in the project, to be an excellent way of engaging minority ethnic communities and improving access to palliative care services.

#### P166 WHEN ENGLISH ISN'T YOUR FIRST LANGUAGE: SUPPORTING DEAF PEOPLE IN END OF LIFE CARE

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Identified as a significant public health issue, hearing loss affects more than 10 million people in the UK. This figure is expected to rise to 14.5 million by 2031 [1] and the WHO anticipates that adult onset hearing loss will be amongst the top ten health problems\* in the UK by 2030 [2]. Approximately 50,000 people use British Sign Language (BSL) as their first or preferred language [3].

It is thought that of those dying each year in England and Wales, more than 70,000 will be deaf or hard of hearing and it is reported that there is 'little deaf awareness within the world of palliative care' [4].

Low deaf awareness amongst health staff and insufficient communication support means that people with hearing loss can find health services difficult and frustrating to use and family members may be inappropriately used as interpreters.

Access to end of life care can be impeded by communication difficulties and low health literacy. Research suggests that people who are deaf may have limited understanding of their choices for end of life care [5]. Pain and symptom management can be key issues [6] and a literature review indicates that there is little information available in BSL to help people find out about hospice care.

We discuss barriers to communication, impacts of a lack of deaf awareness, outline ways in which hospice care professionals can support people who are deaf and present a new BSL hospice care information resource.

#### P167 AN EXPLORATION OF END OF LIFE CARE NEEDS OF PEOPLE WITH INTELLECTUAL DISABILITIES: DEVELOPING A MODEL OF SERVICE DELIVERY

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**Background** People with intellectual disabilities are living longer and suffering from the same life limiting illness as general population. The changing needs and care demands of this group force service providers and professionals to better equip themselves to respond and attend to the specific health needs of this group. In the caring process service providers often forget to hear, listen to and include the voices of this vulnerable population which can lead to people with intellectual disabilities receiving inconsistent and inappropriate end-of-life care.

**Aim** To explore the end-of-life care needs of people with intellectual disabilities and develop a model of service delivery.

**Objectives** 1. To explore attitudes, perceptions and preferences of people with intellectual disabilities about end-of-life care. 2. To explore perceptions and experiences of family members of people with intellectual disabilities about end-of-life care needs of people with intellectual disabilities. 3. To develop a model of service delivery for people with intellectual disabilities at the end of life.

**Methodology** The study was conducted in an intellectual disability service that provide residential and community service to adult with intellectual disabilities. Constructivist version of Grounded Theory Methodology was adopted. Ethical permission was obtained from the academic institution and service to carry out the study. All consenting participants (17) were interviewed between 45-60 minutes. Data were analysed using Constant comparative method.

**Findings** The data revealed how the participants wanted to be cared at the time of dying and after death. The participants' main concerns are revealed from the data are *Holism* and *Familiarism* which explain the care needs at the time of dying and *Respectivism* which explains the care requirement after death. A core category of *Continuum and Ultimatum* was constructed.

**Conclusion and Implication** The findings from this study will help to develop a model of service to meet the needs of people with intellectual disabilities at the end of life.

#### P168 LEARNING DISABILITIES AND PALLIATIVE CARE: BUILDING BRIDGES – SUPPORTING CARE

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Palliative care for people with learning disabilities (PWLD) is often complex but it is vital that these challenges are faced. It is also important to recognise that life limiting illness is more prevalent in the learning disability population and that PWLD die on average 25 years younger than the general population<sup>1-2</sup>. Increasing numbers of PWLD are living at both ends of the age spectrum with co-morbid conditions and complex health needs and there is a growing need for palliative care provision.

This project recognises the need for education and the development of robust partnerships which lead to collaborative working, to ensure that PWLD will experience equity in accessing palliative care services.

The aim of the project, funded through Help the Hospices and the Scottish Government, is to bring the two specialities of Palliative Care and Learning Disabilities with Greater Glasgow & Clyde together using a practice development approach. This will provide support to staff in the provision of best quality care for people with Learning Disabilities who have palliative care needs.

## Abstracts

Links have been made at both local and strategic levels within both learning disability and specialist palliative care services. All 9 learning disability teams and 6 hospices within NHS GG&C have access to this project.

Strategically the project sits within the current learning disability strategy and although all 6 hospices are independent in their delivery of care, Chief Executives have demonstrated their commitment to the project.

All education events are evaluated and the evaluations have been extremely positive, with staff suggesting that the education provided will have a direct impact on their professional development and provision of best quality patient care for PWLD.

PWLD are at the heart of this project with the ultimate aim being to improve their care.

### P169 REACHING MORE PEOPLE AT THE END OF LIFE THROUGH DIGITAL COMMUNICATION

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End of Life care is arguably both a public health and diagnosis specific concern. Those living and dying from life threatening illness access support and care from formal (e.g. health and social care) and informal (e.g. community, friends and family) networks. The last few years has seen an explosion in social media and new communication technologies in the informal arena. As hospices face the challenge of extending their reach and realigning their existing resources, researching new ways to support patients and their families is key.

A 3 year collaborative study between Professor Daniel Miller (Department of Anthropology, University College London) and Kimberley McLaughlin, Director of Supportive Care (Hospice of St Francis) focuses on the hospice, patients and those living in the community.

#### Aims

- To understand the impact and future potential of new communication technologies e.g. webcam, social networking sites and smart phones.
- To gain the widest and deepest understanding of the role of these technologies in all aspects of communication between people in end of life situations, their carers, family and friends.
- To research issues including privacy, feelings of security and vulnerability, loneliness, boredom, memorialisation and sense of connexion with others.
- To explore the relationship between any sense of loss of communicative capacity for persons and simultaneously a gain in communicative capacity as a result of new technologies.
- To understand the use of communication technologies and health care professionals/hospice staff.

#### This research will

- Advance the body of knowledge regarding the use of social media in end of life care as well as researching in sensitive areas.
- Provide guidance in the use of social media in end of life care.
- Facilitate communication between end of life individuals who remain in their home and with carers, friends

and families both during this period and following upon their death.

### P170 DIGITAL LIFE, DIGITAL DEATH – AN APP TO FILL THE GAP

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**Context** The crisis of illness provokes people to review their life, dwell on regrets and unfinished business, think about bucket lists and maybe their funeral.

This critical time however is dominated by treatment, panic and anxiety, and these important tasks are often neglected and delayed.

Lawyer, Victoria Moore and business partner Morag Cormack have designed a simple, elegant iPhone App to digitally capture life's special moments, in the midst of life, long before an illness takes hold.

Victoria was inspired to create the *Legacy Organiser* App after completing her will – she felt there was so much more to record than simply 'who gets what'!

**The Legacy Organiser App allows you to:**

- Save photos for your 'life album'
- Choose music to create the 'soundtrack of your life'
- Create a 'bucket list'
- Record your life lessons, your biggest regret, your best kiss!
- The 'farewell and will' section lets you record funeral wishes

**Palliative Potential** This innovative app provides opportunities for those in the palliative phase to:

- Use as a therapeutic digital tool to provoke new conversations
  - 'Tell me about that regret', 'talk me through your bucket list'
  - 'Have you thought about how you might celebrate your life?'
- Use as an advance care planning platform to capture wishes, not simply about funerals but about preferences for future care.
- Create a generativity document (Chochinov Dignity Therapy)
- Carry choices around with them - mobile phones allow instant access and sharing of key preferences with others

#### Next steps

1. Therapeutic pilot with 10 patients
  - download App to patients iPhone
  - demonstrate potential
  - homework to complete a section eg bucket list
  - review together at next clinic.

*First impressions* – patients love it, provoking different conversations!

2. Evaluation questionnaire currently in design.
3. Co-create new sections to support advance care planning eg care preferences, with App inventor Victoria Moore