

Conclusion This survey demonstrates hospices to be interested and active in facilitating social support. It is possible that increasingly diverse approaches used in practice may improve issues regarding access to and awareness of hospice care. More work is needed to share best practice, document outcomes, and consider cost-effectiveness.

0-22 HOLISTIC (HOSPICE-LED INNOVATIONS STUDY TO IMPROVE CARE)

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10.1136/bmjspcare-2018-hospiceabs.22

Background A current concern is the number of people dying in hospital who have no medical need, or wish, to be there (Marie Curie Cancer Care, 2012). 72% of people would prefer to die at home (ComRes, 2014), yet just 25% do so, with 50% dying in hospital (Gomes, Calanzani, Higginson, 2011). Instinctively, hospice-led initiatives play an important role in minimising inappropriate hospital usage at the end of life, but there is a lack of robust data.

Aim To establish the impact of different hospice led innovations on a) reducing the number of hospital bed days during the last 90 days of life, b) place of death and other secondary outcome measures: the number of emergency and inpatient admissions and discharges to a hospice in the last 90 days of life.

Method Mixed methods study with a quantitative quasi-experimental longitudinal design employing a 'difference of difference' analysis of HES data to assess the impact on hospital utilisation in the last 90 days of life. Any encountered differences are compared to control cohorts. Stakeholders were qualitatively interviewed through open-ended, semi-structured and structured interviews followed by narrative, framework and content analysis respectively.

Results Quantitative: ongoing, however, we anticipate data showing a reduction in the number of hospital beds days, in the last 90 days of life, within the locality of the intervention hospice. Qualitative: interviewed 188 people, including 24 patients and carers, across 27 interventions at 25 sites providing 31 recurrent topics of which the five most relatively frequent were the process of development, collaboration, the intervention group, staff roles and professional culture.

Conclusions Qualitative evaluation of these innovations shows benefit to the patient experience and factors critical to success and replicability. Quantitative data will show the impact on NHS resources, and together the findings will enable better evidence-based commissioning, supporting service redesign at a local level. Final report due Sept. 2018.

Parallel session 7: Engaging patients and the wider public

0-23 PATIENT AND PUBLIC INVOLVEMENT (PPI) CONTRIBUTIONS TO PALLIATIVE CARE RESEARCH

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10.1136/bmjspcare-2018-hospiceabs.23

Background Patient and public involvement (PPI) is an established component of high quality palliative care research. The way patients and public are involved in research differs between and across research studies, however the range of contributions and different models of working are not well documented in palliative care.

Aim The aim is to document the range and scope of activities of a service user advisory panel – the Palliative Care Studies Advisory Group (PCSAG), established at The University of Sheffield in 2009.

Methods A narrative summary of PPI activities, documenting the range and scope of contributions to research over the nine years since the PCSAG was established.

Results Since they were established the group have contributed to 34 research projects and funding applications in the area of palliative and end of life care. These have ranged from substantial multi-million pound international research studies to PhD studies and student projects. In the main, researchers attended facilitated group discussions to request advice on aspects of their research projects, however, other models of working have emerged in more recent years. These include group members sitting on project steering committees as co-applicants, contributing to data analysis and presenting at conferences, and developing on-line methods of providing PPI input.

Discussion The Palliative Care Studies Advisory Group have made a substantial contribution to palliative and end of life care research. The scope and depth of PPI involvement has increased over the years, as researchers and service users have gained confidence in working together. Models of co-working which involve service users as co-applicants have more recently become commonplace as the PPI movement has become more embedded in research. However, little guidance is available to support researchers working with service users in palliative and end of life care, and further research could address this gap.

0-24 END OF LIFE CARE AND DECISION MAKING: PUBLIC KNOWLEDGE, NEEDS AND PREFERENCES IN WALES

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10.1136/bmjspcare-2018-hospiceabs.24

Introduction A prudent approach to provide quality end of life care (EoLC) advocates for active participations of the patients in designing the service (Wynne, n.d.). Patients and carers demand for improvements in decision-making at the EoLC (Sinuff *et al*, 2015). But there is a lack of evidence on understanding of people's attitudes towards EoLC and shared decision-making (Hajizadeh, Uhler, Herman, *et al.*, 2016).

Aim To increase understanding of people's views, feelings and preferences around EoLC and decision making.

Method An online survey was conducted using an electronic survey tool. Descriptive statistics and thematic analysis were used to perform data analysis.

Results 2210 people (Age: Mean \pm SD; 55 \pm 14 years) participated in the survey, 43% of those were members of the public, 29% were patients/carers, and 23% were health professionals. 49% of respondents thought that available EoLC and palliative care was inadequate and only 31% believed that people could access these facilities. More than 60%

people did not know if cultural/religious/ spiritual needs were met during EoLC. 58% believed that end of life care for older people should have equal priority for the NHS. 43% of respondents did not know where to get the support if someone close to him/her were to die. Only 41% believed that people could take part in decision-making around EoLC though 85% of respondents felt confident to get involved in EoLC decision-making. 82% thought that their preference should take priority over wishes of others, 61% considered that involving others in the EoLC decision making of using life-supporting technology would place extra burden on them whereas 27% considered that this would limit their privacy.

Conclusions Understanding public attitudes is essential to understanding changing contexts of care. Developing a need-based EoLC model will be innovative and enhances an effective service delivery.

0-25 LIGHTS, CAMERA, ACTION – THE STORY BEHIND THE SCENES OF ‘THE HOSPICE’

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10.1136/bmjspcare-2018-hospiceabs.25

Background Promoting the work of hospices is challenging, partly due to the nature of society’s taboos around death and dying (Dying Matters Coalition, 2016). One TV company approached hospices to offer a ground-breaking opportunity of developing a documentary. 17 hospices were contacted prior to shooting a short ‘taster’ film, which was used to commission a full 13 week series.

Aims

- Open up public dialogue on end of life
- Celebrate the work of hospices
- Showcase all aspects of hospice care, across all ages
- Increase hospices’ profile on a local, regional and national level.

Methods Both the Head of Communications and Head of Quality and Clinical Governance were dedicated to the project during filming, ensuring continuity for the crew and hospice team. Staff engagement was crucial. Weekly planning across clinical and communications teams ensured a full range of stories were identified and handled sensitively. The crew followed patients, families, staff and volunteers within the hospice, care homes and the community. A communications and press plan, alongside the TV channel and partners, focused on local, regional and national levels, and a multi-channel communications approach maximised on and offline, with a dedicated Just Giving page. Regular staff briefings were essential as part of communications risk management to ensure careful messaging and timing.

Results

- Millions of people reached nationally
- Extensive press coverage – Daily Mail, Sunday Express, Metro
- Outdoor billboards in prominent positions
- Viewing figures of 30 k in the first weeks. Aim to reach 100 k

- Significant increase in traffic to hospice website and social media, including Facebook and six-fold increase in Twitter followers within three weeks
- Increased dialogue with supporters and peers; increased staff engagement and morale
- Greater engagement and networking with new influential audiences
- No complaints or negative publicity.

Conclusion The TV series is the most significant opening up of the hospice sector in recent years.

Poster presentations

Bereavement, loss and grief

P-1 BEREAVEMENT CAFÉ: MORE WITH LESS IN BEREAVEMENT SUPPORT

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10.1136/bmjspcare-2018-hospiceabs.26

Background Bereavement support is well-established within palliative care. The need for good quality bereavement support is exponential but the ability of hospices to address this need is limited. The Commission into the Future of Hospice Care identified the need to develop collaborative partnerships in order to extend hospice care (Calanzani, Higginson & Gomes, 2013). Partnering with volunteer community/faith groups suggests an opportunity to extend bereavement support beyond what a hospice might hope to achieve alone. It also furthers the goal of building compassionate communities (Kellehear, 2005).

Aim To extend the hospice’s bereavement support to more people across its care area by building a network of collaborative partnerships between the hospice and community/faith groups.

Methods Three community/faith groups expressed interest in providing bereavement support by setting up a Bereavement Café. Each group provided a venue, volunteers to staff the Bereavement Café and modest refreshments. The hospice provided a two-day training course, publicity materials, guidance on setting up and running the Café and ongoing support and mentoring through the first year.

Results Initial meetings were held in March 2016 and a two-day training course delivered in June. The first two Cafés opened on a once-monthly basis in October 2016. The Cafés open at different times on different days of the week for up to 90 min. They welcome any bereaved person (regardless of previous hospice involvement). Average attendance is 4–8 people per session. The hospice provides regular supervision for Café volunteers through a debrief when the Café has closed. The partnerships require no financial commitment from the community/faith groups.

Conclusions Currently, five Cafés are operating, with five more planned in 2018. The model has proved replicable and sustainable and is achieving the hospice’s ambition of expanding its bereavement support to more people across its area of care.