Oral presentations

Parallel session 1: Making a difference: volunteers, research, outcomes, and magical care

0-1 DEVELOPING A 'VOICE FOR VOLUNTEERING' – THE EAPC MADRID CHARTER ON VOLUNTEERING

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Background The perception of hospice and palliative care (HPC) volunteers as willing amateurs, peripheral to the multi-disciplinary team overlooks the importance and complexity of their work in delivering truly holistic care. This project, led by the European Association for Palliative Care (EAPC) Task Force on Volunteering aimed to develop a volunteering charter.

Aims The aims were to develop a Charter to:

- Promote the successful development of volunteering.
- Recognise volunteering as a third resource.
- Promote research and best practice models.

Methods Information was initially collected during an international HPC volunteering symposium in Prague in 2013. Further feedback on draft versions was gathered at international congresses in (Vienna & Copenhagen, 2015; Dublin, 2016). Additionally, email consultation took place with researchers, volunteers, staff, and EAPC Board members. Thirteen countries (Australia, Austria, Belgium, Croatia, Germany, Hungary, Ireland, Italy, The Netherlands, Poland, Portugal, Romania, and UK) took part in the consultation process.

Results Consensus was reached and a Charter developed with goals for individuals, organisations and national organisations, focused on four key themes:

- 1) Recognise the important role of volunteers in the total care of patients and their families, and in sustaining HPC services.
- 2) Promote volunteering in support of patients and their families.
- 3) Ensure effective management of volunteering, including clearly defined policy on roles, careful recruitment, selection, training and development.
- 4) Ensure effective support for hospice and palliative care volunteering at organisational, local and national levels.

The Charter was adopted by the EAPC Board and launched as an official EAPC Charter at the EAPC World Congress in Madrid in 2017.

Conclusions This project was successful in creating a Charter with a consensus about the importance and place of volunteering in HPC. This next stage is to evaluate the implementation and impact of the Charter over the next two years.

0-2 THE IMPLEMENTATION OF OACC IN A HOSPICE SETTING

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10.1136/bmjspcare-2017-hospice.2

Background Outcome measurement plays a pivotal role in enhancing the quality, efficiency and availability of palliative care services. The Outcome Assessment and Complexity Collaborative (OACC) is a validated suite of outcome measures that is aimed to measure, demonstrate, and improve care for patients and families.

Aim To implement the OACC Suite of Outcome Measures to all clinical services within Saint Francis Hospice (SFH).

Method The implementation of the project went through several stages using Kotter's (2012) eight step model of change. A Steering Group was established to provide leadership and oversee the implementation of the project. A strategy, vision, and purpose for implementation were devised in consultation with the Steering Group. The strategy, vision, and purpose were communicated to all clinical services using a variety of methods. A project lead from each service was appointed to facilitate the process within their service area. Training for all clinical staff was provided throughout the process. Feedback on implementation strategy, and availability of staff and IT support were sought throughout the process.

Results Multiple barriers were experienced and successfully addressed by the Steering Group and project leads. OACC was successfully implemented into the organisation over a period of six months. Short term achievements were identified and shared with teams.

Conclusion Barriers can be encountered when implementing outcome measures within a clinical setting. However, by displaying effective leadership and reinforcing the change throughout the process of the project implementation, the OACC suite of measures are now being successfully embedded within the organisation. Ultimately this will enhance the quality, efficiency and availability of our service for patients and their families.

0-3 PALLIATIVE CARE RESEARCH IN SCOTLAND 2006–2015: A SCOPING REVIEW

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10.1136/bmjspcare-2017-hospice.3

Background The Scottish Government set out its five year vision to improve palliative care in its Strategic Framework for Action 2016–2021. This includes a commitment to evidence-based knowledge exchange across Scotland. A comprehensive scoping review of Scottish palliative care research was considered an important first step.

Aims

- to identify all Scottish palliative care research published from 2006 to 2015.
- to map key thematic areas relevant to clinical practice, service development and policy.

Methods Palliative care research involving at least one co-author from a Scottish institution was eligible for inclusion. Five databases were searched with relevant MeSH terms and keywords. Additional papers were added following consultation with members of the Scottish Research Forum for palliative and end-of-life care. Initially 1919 papers were screened; 496 underwent full text review.

Results 308 papers were retained in the final set. Methodologically, 33% were quantitative, 29% were qualitative, 14%

were reviews and 25% were other designs including mixed methods. Just over 70% were descriptive studies, and 10% were interventions or feasibility studies. Twelve RCTs were identified. 58 papers were concerned with palliative care for people with conditions other than cancer. Key areas of research were experiences or needs (23%), services and settings (23%), physical symptoms (22%) and psychological or psychosocial concerns (16%). Few papers focused on out-of-hours care, health economics or ehealth.

Conclusion The findings reveal a considerable increase in palliative care research over the last decade when compared with 44 papers identified in a similar Scottish review in 2006 and 151 papers identified in a review of Irish palliative care research in 2013. The new Scottish Research Forum for palliative and end-of-life care is now engaging with clinicians, service managers and policy-makers to facilitate understanding, use and dissemination of key implications for education, service innovation, policy and practice.

0-4 MARRIED JUST IN TIME: MEANING AND MAGIC OF WEDDINGS IN A TERTIARY CANCER CENTRE

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10.1136/bmjspcare-2017-hospice.4

Background Discovering what matters to people when they are dying may highlight a relationship that needs formalising in the last weeks of life. Hospices have become expert at high speed last-minute weddings. But surprisingly, many weddings also take place in a tertiary cancer hospital. Over a period of nine months the palliative care team supported six weddings in the hospital. These were expertly supported by the nursing, catering, facilities and chaplaincy team, and were a well-kept secret, apart from one which made it onto national news, as the patient was a well-known journalist.

Method A retrospective analysis of notes of patients who were married in the hospital, to discover who initiated the conversation about goals of care, about marriage, documentation about the relationship and the wedding plans, whether the patient left hospital after the ceremony and where possible, the meaning of the wedding to the couple or the bereaved widow or widower.

Findings and Discussion The hospital weddings were organised superbly, always spiritual, a mixture of joy and sadness, hard to bear but with no regrets for those who lived on. The ceremonies seemed to be for love, deepening connexion, rather than financial security. In fact one new wife inherited all her partner's debts by marrying him! Half were new relationships, with previous marriages behind them, and half were partnerships of many years, that seemed important to formalise. Only one out of six patients left the hospital, and one patient died within minutes of the wedding which was shocking for all. The purchase of the rings was a particularly symbolic gesture. Wedding outfits varied from borrowed gowns from local bridal shops, to blue hospital scrubs! Jan, widow of Colin said, 'I wanted to be a widow, not someone whose partner had died.'⁷ Further qualitative research is planned with the bereaved partners.

Parallel session 2: What can we learn from young people and prisons?

0-5 EMPTY SHADOWS: A FILM MADE BY YOUNG PEOPLE TO DEMYSTIFY DEATH AND DYING AND TO PROMOTE HOSPICE WORK

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10.1136/bmjspcare-2017-hospice.5

An increased understanding of death within the younger generation is crucial to the demystifying of hospice work. A more balanced and healthier view of death, dying and bereavement has been encouraged through joint working between the hospice and a local grammar school. Fifteen Year 10 pupils visited the hospice as part of their Drama GCSE; they had a formal talk on hospice work, met with a bereaved person and asked questions regarding the family's experience. A comprehensive tour of the building gave them insight into the work undertaken and of the environment. They developed a piece of live theatre called Empty Shadows which was then filmed. This film was created by the students and was filmed within the hospice itself. Pupils sensitively used the gardens, reception area, the in-patient unit and other hospice areas to act out the story. The 50 min film explores themes experienced by pupils whilst visiting the hospice: breaking bad news, how children understand and relate to the death of a loved one, creation of a memory box, writing letters to those who are being left behind, the importance of honesty and trust, the impact of bereavement on men, funerals, bereavement theories and the importance of support within schools and the work place. The film created from this innovative project will be used by the hospice's Family Support Team to further their work with schools and colleges. They will use the resource to enable a more balanced and healthier view of death, dying and bereavement. The film is to be shown at the Worcestershire Palliative Care Conference in July 2017. Following the film, pupils and hospice staff will answer questions, encouraging and empowering professionals to work with young people to demystify death and dying and to promote hospice work.

0-6 SCHOOL IS THE LINK FOR CHILDREN FACING LOSS

Marilyn Dyas. *Trinity Hospice, Blackpool, UK*

10.1136/bmjspcare-2017-hospice.6

Background As an adult and children's hospice we support children (4–18 years) and their siblings through our bereavement and pre-bereavement services. We provide counselling and therapeutic groups for all types of bereavement, and counselling for children living with progressive ill-health. Supporting the Government's agenda (Department for Education, 2016) to see all schools providing access to counselling, our unique schools link service was developed to support more children, and expanded to cover any significant loss, not just bereavement. Our paid coordinator supports 74 schools by