Abstracts

Aim To ensure appropriate community-based support for those recently bereaved, a large care provider in the West Midlands has established a team of Bereavement Visitors. The 20-strong team offer emotional support, provide information, education and coping strategies to bereaved relatives either on site/in the community. They also run individual and group therapy sessions to support those adjusting to the loss of a loved one.

Results Last year 241 people used the service, citing a range of benefits. In June 2018 the scheme was awarded the Queen’s Award for Voluntary Service. This poster explores the drivers for the programme, discusses how volunteers are recruited, trained and supported and considers the impact and outcomes of the programme from a range of perspectives.

P-11 RECRUITMENT OF BEREAVEMENT SERVICES USERS VIA HOSPICES: REFLECTIONS FROM THE BEREAVEMENT STUDY

1Mirella Longo, 1Hannah Scott, 1Kathy Seddon, 1Jim Fitzgibbon, 1Fiona Morgan, 2Sara Pickett, 2Anthony Byrne, 2Stephanie Sivel, 1Annmarie Nelson, 1Emily Harrop, 1Marie Curie Palliative Care Research Centre, Cardiff, UK; 3Swansea Centre for Health Economics, Swansea, UK

10.1136/bmjspcare-2018-hospiceabs.36

Background The quality of the recruitment process has a fundamental influence on the potential value of research outputs. The bereavement study aimed to develop a set of core outcomes specific to bereavement support services for bereaved adults. A consensus methodology involving all the key stakeholders (including service users) was used to address the research questions. Nine hospices in the UK were approached to facilitate recruitment of study participants. We report on the recruitment of service users.

Methods Service users were asked to answer to a two-round DELPHI questionnaire (Hasson, Keeney & McKenna, 2000). Past service users could not be contacted because hospices would not normally retain the details of the people who have left their services. We relied on hospice staff who regularly saw bereavement support service users to identify users who were on their way to recovery and were able to reflect on the outcomes that were important when assessing the value of the service they received. Hospices were given two months to carry out recruitment.

Results Hospice-based health professionals helped us refine inclusion and exclusion criteria, time from loss was not an inclusion/exclusion criteria. Some of the hospices had lower recruitment rates mainly due to the tight time schedule set for inclusion/exclusion criteria. Some of the hospices had lower inclusion and exclusion criteria, time from loss was not an exclusion criteria. Results to facilitate recruitment of study participants. We report on the recruitment of service users.

Conclusions Hospice staff played an important role in supporting the recruitment of bereavement service users, but researchers need to allow enough time for efficient recruitment. Earlier engagement allowed active influence over the recruitment process. Hospital ‘internal’ readiness to recruit is an important factor. Both the literature (Bentley & O’Connor, 2015; Akard, Gilmer, Miller et al., 2014) and practice suggest that bereavement study participants are themselves the best judges on when to participate in research studies and time from loss is not an important inclusion/exclusion criteria.

P-12 PUBLIC INVOLVEMENT (PI) IN A STUDY OF BEREAVEMENT SUPPORT SERVICES FOR ADULTS

1Kathy Seddon, 1Jim Fitzgibbon, 1Barbara Harrington, 1Fiona Morgan, 1Hannah Scott, 1Stephanie Sivel, 2Sara Pickett, 1Mirella Longo, 1Anthony Byrne, 1Annmarie Nelson, 1Emily Harrop, 1Marie Curie Research Centre, Cardiff, UK; 3Swansea Centre for Health Economics, Swansea, UK

10.1136/bmjspcare-2018-hospiceabs.37

Introduction Bereaved adults may develop complicated grief reactions associated with mental and physical health problems and good support services are vital. This research included a systematic review and the development of a core outcome set for bereavement support service research in palliative care. The collaborative relationship (PI) with the Research Partners (RPs) was fully planned and then documented through reflective logs. PI was central to this research.

Aim To detail the RPs’ contribution to this study.

Methodology RPs helped refine the research question. Following this a study protocol was agreed that set out the steps needed to ensure that: (1) Research design and methods used were appropriate for bereaved adults; (2) All documentation and outputs were accessible to ‘lay’ readers; (3) RPs ‘experience based’ expertise was embedded in ongoing planning, outputs and ongoing research design; (4) The experience for RPs was worthwhile leading to new skills and knowledge detailed in the reflective logs. Reflective log sheets were used to capture how well this was achieved. Researchers and RPs completed these independently. Their reflections were shared at quarterly meetings and used to inform each stage of the research.

Results The reflective logs confirmed that steps 1 to 5 were carried out. RP inputs achieved the planned impact (e.g. the questionnaires held hardly any missing data, reflecting content and face-validity). Enhancement of the bereavement research through planned, documented RP collaboration was thus confirmed.

Conclusion Well-planned and documented PI can enhance the quality of health care research. Researchers felt that the solid collaboration with the research partner broadened their perspective and signalled a clear departure from a simple tick-box exercise. Research Partners confirmed the rich learning gained through participation.

P-13 A PILOT STUDY: EXPLORING FAMILY BEREAVEMENT EXPERIENCES WHEN A MEMBER OF THE FAMILY HAS DEMENTIA

1Nikki Archer, 2Alison Poole, 1St Giles Hospice, Lichfield, UK; 2Keele University, Keele, UK

10.1136/bmjspcare-2018-hospiceabs.38

Bereavement support for families is an integrated and essential component of palliative care (Hudson, Hall, Boughey et al., 2017), although a growing evidence base for the provision of services exists (National Bereavement Alliance, 2017), the need to broaden our understanding to reflect broader family and sociological perspectives has been identified (Stroebe & Schut, 2015). Despite the growing incidence of dementia (Alzheimer’s Society, 2017), little is known about the bereavement experiences of people with dementia (PWD), (Watanabe & Suwa, 2017).
Pilot studies guide the development of research plans to ensure that the methods and ideas which are being proposed will work in practice (Kim, 2010). This pilot study was undertaken to explore the feasibility of a proposed Doctorate study designed to answer the research question: ‘What is the family expérience of bereavement when a family member has dementia and what might this mean for the provision of support?’ using constructivist grounded theory (Charmaz, 2014).

The pilot explored the family bereavement experience from the perspective of one family member and focused on the use of unstructured interviews and research diaries as tools for quality data collection, and a process of data analysis involving process coding and memo writing (Saldaña, 2016).

Tentative theoretical understanding of the data emerged including:

- Experiencing a spiritual dimension
- Being a bereaved carer
- Family functioning
- Relationship between bereavement and dementia.

These early findings will be integrated into the main study through the constant comparison process consistent with grounded theory methodology (Charmaz, 2014; Urquhart, 2013).

Carrying out and reflecting on the pilot highlighted several issues including the researchers’ role within the interview and data analysis process, the design and use of a diary for data collection and the ethical dilemma of involving or excluding people with dementia within the study. Learning from this pilot will help shape future study plans.

Communication, voices and stories

P-14 EXPLORATION OF SUPPORT WORKERS’ AND VOLUNTEERS’ INITIATION OF QUALITY OF LIFE CONVERSATIONS

Sharan Watson, Alison Hembrow. University of Derby, Derby, UK; Treetops Hospice Care, Derby, UK

Background Through being a pilot site for NHS England exploring Personal Health Budgets (PHBs) in end of life care, Treetops Hospice Care became aware that there needed to be more focus on conversations around what was important to patients. There appeared to be barriers around developing these conversations, possible reasons were lack of healthcare professionals’ time and clarity as to whose role it was. Resulting from this highlighted need, Treetops Hospice Care and the University of Derby are undertaking a research project to explore the outcomes of developing support workers and volunteers in initiating conversations around quality of life. Policy drivers have acknowledged that there is a much greater need and demand for person-centred care than professionals in health and social care can meet (Health Education England, Skills for Health & Skills for Care, 2017). This follows the principles of a ‘public health’ approach to end of life care, and a ‘de-professionalisation’ of supportive care, involving volunteers and support staff engaging in these conversations, could result in being able to include more individuals (Abel & Kellehear, 2016).

Aims Exploring participants’ involvement and perceptions of patient-centred conversations to improve end of life care experiences.

Methods/conclusion Qualitative interviewing will be undertaken before and after a new educational training approach is delivered, along with a pre and post Likert evaluation tool capturing self-perceived confidence and competence. The new approach will focus around the mnemonic L.I.S.T.E.N (developed by Treetops Hospice Care) supporting these conversations around preferences and wishes, within a person-centred approach.

We anticipate that with the appropriate support and training, unregistered healthcare professionals/volunteers feel more enabled in having these conversations, empowering them to offer more timely conversation opportunities with palliative care patients. Resulting outcomes will inform future training.

P-15 BESPOKE HOSPITAL DISCHARGE SUMMARY GUIDES COMMUNICATION OF PATIENT PREFERENCES AT END OF LIFE

Jean Potter, Liz Bunker, Eleni Baldwin, Marc Magee. The Hillingdon Hospital NHS Foundation Trust, London, UK

Introduction Identification of patients approaching end of life, and advance care planning (ACP) with them, can improve patient outcomes and reduce hospital deaths.

Methods The essential items that should be included in any initial ACP discussions were agreed by a working group (COTE doctor, palliative care doctor and nurse, GP and Patient in Partnership Group). Some items were mandatory and some dynamic. Items included:

1. Dropdown menu: prognostication (based on SPICT)
2. Yes/No: elements of discussions had, e.g. regarding prognostication, resuscitation status during stay, Preferred Place of Care, Preferred Place of Death
3. Free text: e.g. ceilings of care.
4. These items were added to the usual hospital discharge summary template (EPRO) by the Trust’s IT department.

Results The new ACP template improves frequency of documentation in discharge summaries from baseline of: resuscitation status (10% to 100%) information regarding prognostication (0% to 100%) and any mention of patient preferences for care (8%–100%).

Conclusion Specific items added to the hospital discharge summary at no extra cost improves ACP information sharing from secondary to primary care. Staff fed back that the ACP discharge summary fields were easy to use. The teams continue to engage with the process as they see improved cross