Oral presentations

Free papers 1–3 | Bereavement

1 LOSS OF RELATIONSHIP: A QUALITATIVE STUDY OF FAMILIES AND CAREGIVERS AFTER HOME-BASED PALLIATIVE CARE ENDS

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Background Home-based palliative care is care of the patient in the comfort of their own home, while doctors and other healthcare providers make visits as required. Family involvement naturally cultivates a relationship between healthcare providers and the family. Once the patient dies and care ends, this relationship is abruptly terminated, which may be challenging to both parties. This study explored healthcare providers' and family members' thoughts regarding the loss of relationship following home-palliative care, how to mitigate this loss, and their opinions on a system that allows for contact post patient death.

Methods Perceptions of 63 participants (32 healthcare providers and 31 family members) were explored using semi-structured interviews and qualitative research methodology, around three months after patient death. Healthcare providers were interviewed primarily at a home-based palliative physician group (TLCPC), and at two hospitals, while family members were recruited from the deceased patients of TLCPC physicians.

Results Six overarching themes emerged:

- Caregivers and families have a mutual appreciation and recognition of the intimacy of home-palliative care;
- both parties expressed awareness and dissatisfaction with the abrupt ending of relationship;
- open and clear communication with healthcare providers is beneficial to family members, especially after patient death;
- healthcare providers discern the insufficiency of resources and gap in transition to bereavement services for grieving families;
- a proposed system to mitigate loss of relationship has multiple perceived benefits;
- logistical challenges and boundary issues for a system raise concern in healthcare providers.

Conclusions The findings obtained in this study provide recognition of how caregivers and families perceive the dynamics of home-palliative care, and their thoughts regarding the loss of relationship. Overall, families and healthcare providers do not like this halt in contact, and recognise the potential benefits of an approach that would allow for communication going forward.

2 THE ROLE OF PRIMARY CARE IN PROVIDING BEREAVEMENT SUPPORT: PERSPECTIVES FROM A COMMUNITY SAMPLE

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Background Around 5 00 000 people die in England and Wales each year, leaving approximately 2 million people experiencing close bereavement. Around 15% will develop a complex grief reaction requiring specialist support. GPs are often the first point of contact in the health services for bereavement support: GP consultations increase after a loss. GPs therefore have a central role in providing bereavement support and in identifying those at higher risk. Experiences and perceptions of primary care bereavement support are not well defined.

Methods Sixty three recently bereaved people were recruited via Registry Officers at the death registration appointment. A sub-sample of 14 participated in in-depth interviews within five months of bereavement, exploring their perceptions and experiences of primary care bereavement support. Audio recordings were transcribed verbatim, and analysed using a framework approach.

Results The nature of grief varied across the sample, shaped by prior losses, relationship with the deceased, and presence of sequential losses. GP support was one aspect of a broader picture of support provision. Barriers and facilitators of the use of primary care for bereavement support included: difficulty with securing appointments, prior relationships with the GP, the appropriateness of accessing general practice for a non-physical complaint, and expectations of how the GP might help. These served to either encourage or discourage potential help-seeking in bereavement. When the bereaved were registered at a different GP practice from one that had provided consistent GP palliative care for the deceased, bereavement care was particularly difficult.

Discussion Understanding bereaved peoples' perceptions of the role of the GP and the wider primary care team as a source of bereavement support, and the factors encouraging or discouraging such help-seeking in bereavement can enable primary care to optimise the provision of person-centred bereavement support.

3 A STUDY ON THE MEDIUM-TERM EFFECTIVENESS OF A COMMUNITY BASED BEREAVEMENT PROGRAMME FOR VULNERABLE CHILDREN AND YOUNG PEOPLE

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Background Utilising the knowledge derived from Attachment theory, Growing Around Grief theory and Continuing Bonds theory, Winston's Wish supports children and young people (CYP) to rebuild their lives after a death in the family. This study investigated the medium-term effectiveness of SWITCH, a programme supported by the Big Lottery, for CYP aged 8–14 years who were at increased risk of truancy or antisocial behaviour.

Methods The study explored whether tailored psychotherapeutic support after the death of a parent, grandparent or sibling can enhance CYP's psychological, social and educational functioning. Data was collected at either home or school settings across three points in time: initial attendance (baseline), one month after the end of support and six months afterwards. Participants (n=108) completed the Strengths and Difficulties Questionnaire (SDQ), which enhances the identification of children at risk of developing mental health problems.

Results The cause of death for the vast majority of families was accident or illness. Death of a father was experienced by 41% of CYP. Six months after the end of support, improvements were shown for the following areas: peer relationship difficulties, emotional difficulties, behavioural difficulties, overall stress and impact of difficulties on the child's life.

Conclusions CYP with multiple needs who were supported through this programme experienced fewer mental health difficulties in the medium-term. Tailored psychosocial support can promote adaptive developmental outcomes after bereavement and it can be particularly helpful for CYP who face school or social adjustment difficulties.

Free papers 4–6 | End of life care in hospitals

4 BUILDING ON THE BEST QUALITY IMPROVEMENT PROGRAMME – SUPPORTING IMPROVEMENTS IN END OF LIFE CARE IN ACUTE HOSPITALS

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Background Building on the best (Botb), a 24 month partnership quality improvement (QI) programme delivered by Hospice UK aims to improve the quality of end of life care in acute hospitals. The programme design uses a collaborative methodology with flexibility for teams to work in alignment with local priorities.

Methods Four Improvement areas were prioritised for the collaborative by a clinical reference group: outpatient setting, communication of transfer, shared decision making, pain and symptom management. Teams received structured improvement coaching, monthly Webex, and the development of a community of practice. In addition to headline outcome and process measures, key outputs include teams' improvement case studies sharing impact and learning.

Results Botb currently encompasses 13 Trusts across England and Scotland. The collaborative has had 9 face to face community of practice learning events plus 18 monthly webinars. An example case study from Guy's and St Thomas' outlines testing on an acute admissions ward of a symptom observation chart and care planning guide for dying patients. A working group including the clinical lead and matron for acute medicine identified alignment of a local priority with Botb. Staff surveys and clinical audit demonstrated a positive impact on care planning and delivery. A positive feedback loop strengthened staff pride in the work of the ward. Success was boosted by a focus on influencing culture and delivery of flexible on the job education. These staff will now champion and support roll out within elderly care wards. The materials have been shared within the community of practice.

Conclusions Building on the best programme collaborative enables improvements by embedding systematic QI change methodology, supporting a mature community of practice to democratise knowledge and deliver results within complex systems by peer to peer learning.

5 IMPROVING CARE FOR PATIENTS WHO HAVE CLINICAL UNCERTAINTY OF RECOVERY: THE LENS OF ACUTE ADMISSIONS

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10.1136/bmjspcare-2018-ASPabstracts.5

Background Acute Trusts are an important provider of care for patients who may be in their last months of life; emergency admission may indicate underlying clinical decline. Acute admission processes are not generally designed to manage care for this group.

Wirral University Teaching Hospitals NHS Foundation Trust participated in an ECIP-funded End of Life Care Project in 2016/2017 to improve quality of care for this group of patients.

Method An acute physician and a consultant in palliative medicine reviewed 26 deceased patient records using a method designed to uncover clinical system issues and to create a 'common language' between the specialities. This review included focus on patients with clinical uncertainty of recovery. An acute and an elderly care physician carried out 'Plan Do Study Act' tests of change using the AMBER care bundle in the AMU and an elderly care ward for a total of 26 patients.

Results Qualitatively, the review showed that doctors struggled to recognise patients at risk of dying and viewed palliation as an 'all or nothing' approach to care. Tests of change showed an improvement from 75% to 100% recognition of expected deaths; 15% to 42% awareness of what is important to the patient; 53% to 78% preferred place of care recorded; 85% record of what family feels is important. 96% of patients had ceilings of treatment documented. 62% of patients were discharged.

Discussion The numbers are small. Qualitative feedback is initial conversations in AMU set the scene for the whole admission. Feedback was positive however time implications at the 'front door' can present a challenge. Redesign of the process to 'protect' time may be required.

Conclusions This is an important topic. Early recognition of clinical uncertainty, honest conversations can set the scene for the whole admission potentially resulting in improved patient and staff experience.

6 END OF LIFE CARE ON ACUTE HOSPITAL WARDS: THE IMPORTANCE OF DIALOGUE AND DECISION MAKING

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10.1136/bmjspcare-2018-ASPabstracts.6

Background shared decision-making (SDM) has been recommended as the gold standard for decision making in end of life care when decisions may be complex and involve multiple possible courses of action. The perspectives of patients, relatives and staff members about decision making at the end of life on hospital wards have been little researched in reaching this recommendation. This presentation analyses the practice