27

IMPLEMENTING AND SUSTAINING THE DELIVERY OF QUALITY END-OF-LIFE CARE IN CARE HOMES: THE IMPORTANCE OF PAYING ATTENTION TO THREE LAYERS OF LEARNING

Julie Kinley, Jo Hockley. *St Christopher's, The University of Edinburgh*

10.1136/bmjspcare-2018-ASPabstracts.27

Background Implementation of organisational change is recognised to be challenging. This is particularly true in a care home where organisational, financial and care barriers are known to exist. Early research demonstrated that education in palliative care alone did not achieve organisational change. Recently, 'high facilitation' of end-of-life care programmes, alongside a multi-layered approach to learning, has been identified as a research-based model to support organisational change in this setting. With growing numbers of people dying in care homes providing care to meet this need is now essential.

Methods A Care Home Project Team (CHPT) was commissioned to deliver an end-of-life care programme within nursing care homes (NCHs) in 2008. The CHPT provides 'face to face' high facilitation to NCHs to implement and then sustain the programme in practice. Both implementation and sustainability is based on facilitating individual learning (a single person), organisational learning (the NCH staff and external professionals) and appreciative learning systems (learning across NCHs).

Results All 74 NCHs and all commissioners have remained engaged with the programme. Currently 27 NCHs are implementing and 45 sustaining an end-of-life care programme (the remaining two NCHs have closed). Monthly audit data show clear improvement with 75% residents dying in the 74 NCHs in 2015/2016 compared to 57% in the 19 NCHs at the outset in 2007/8. Over time the delivery of this initiative has varied; from a practice development model, to one incorporating clinical care: vocational qualifications and more recently piloting the use of information technology. What has remained core within the sustainability initiative is the multi-layered approach to learning regardless of its format.

Conclusion Within a NCH the on-going provision of multi-layered learning offers the potential to develop and sustain the delivery of high quality end-of-life care that is now required within this care setting.

Poster presentations

Bereavement | Posters 1–2

1

A NOVEL RECRUITMENT METHOD FOR A STUDY OF RECENTLY BEREAVED PEOPLE IN THE COMMUNITY

Pia Thiemann, Rhiannon Newman, Brooke Swash, Annabel Price, Derek Fraser, Stephen Barclay. *Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK*

10.1136/bmjspcare-2018-ASPabstracts.28

Background NICE guidelines state that 'everyone should be given bereavement support according to their needs and preferences'. The few existing studies on the bereaved persons perspective of Primary Care bereavement support are often limited by recruitment biases, low participant numbers and

recall bias. We assessed the feasibility and acceptability of a new recruitment method for recently bereaved people in the community.

Methods Recently bereaved people were invited to take part in a questionnaire study when registering a death. Registry Officers handed out study packs over a 12 week period. On receipt of reply slip indicating interest in participation, participants were sent further study information and after 6 weeks a postal questionnaire concerning bereavement support. Questionnaires could also be completed online. Qualitative interviews with a subsample of Registry Officers (n=6) and bereaved people (n=14) investigated their views of the recruitment approach.

Results Between 25/07/2016 and 14/10/2016, 1726 deaths were registered and 1069 study packs were distributed: 72 reply slips and 6 online-questionnaires were returned (response rate 7%). Over 50% of reply slips were returned within a week of registering the death. The questionnaire response rate was 83% (60/72). Interviews highlighted that the bereaved and Registry Officers felt comfortable with the study recruitment approach. Data on reasons for refusal, collected from Registry Officers and reply slips declining participation did not reveal ethical concerns or distress caused by the recruitment approach.

Conclusions The response rate was lower than previous bereavement studies, possibly related to the early timing of recruitment. Nevertheless, novel data were obtained from early in bereavement and the recruitment timing was found to be acceptable by all consulted participants. We conclude that a sensitive recruitment approach even shortly after the death can be acceptable to the (newly) bereaved, although the low response rate calls into question the feasibility of the Registry Officers approach.

2

BEREAVEMENT SUPPORT AND CHILDREN'S WELL-BEING

Kalliopi Selioti. *Winston's Wish*

10.1136/bmjspcare-2018-ASPabstracts.29

Background According to the Childhood Bereavement Network, a parent of children under 18 dies every 22 min in the UK. This kind of loss is particularly painful and it seems to play a vital role in educational underachievement, truancy, concentration difficulties, social problems and mental health difficulties. Winston's Wish supports children to recognise, understand and manage their feelings and behaviours in relation to their grief. With an onus on rigorous evaluation of a specific project with the Big Lottery, this study examined the outcomes of bereavement support for children and young people one month after the end of the intervention.

Methods The study explored if a brief support intervention after a death in the family can have immediate positive effects on children's well-being. Data was provided before the intervention and one month after its completion. Participants (n=156) completed the Strengths and Difficulties Questionnaire (SDQ).

Results The most common cause of death was accident or illness (94%). A comparison of the pre- and post-intervention scores showed a reduction for children's peer relationship difficulties, emotional difficulties, overall stress, behavioural difficulties and impact of difficulties on the child's life.

Conclusions Constructive change was reported for all the areas measured. The study showed that when needed, bereavement interventions may have direct positive effects for children. It is important that every bereaved child has access to support as and when they need it.

Caregivers and the family | Posters 3–7

3 THE ACCEPTABILITY OF HAVING CONVERSATIONS ABOUT POOR PROGNOSIS WITH THE PATIENT WITH FRAILTY OR DEMENTIA AND THEIR RELATIVES

Kate Davies, Charlie Beard, Colette M Reid. *University Hospitals Bristol*

10.1136/bmjspcare-2018-ASFPabstracts.30

Objective In an attempt to address the findings of the CQC report ‘A different ending – addressing inequalities in end of life care’, we interviewed family members of patients on Care of the Elderly wards in our trust. Our aim was to ascertain their views about hearing prognostic information.

Method We interviewed family members who had told ward staff they were happy to speak to us. We used vignettes to aid discussion and explained we did not know the details of any ward patients. We wrote copious notes which were then analysed to produce a summary of participants’ views, supported by verbatim quotes.

Results We spoke to 9 relatives (three wives, three siblings, two sons and one son-in-law) and one patient. Key themes identified were: families welcome prognostic information since it allows them to feel prepared and prioritise their time – some would feel relieved to hear that time could be short; relatives have strong feelings about the appropriateness of medical treatments and do not always hope for active treatment, but are mostly guided by medical staff; given the choice relatives would wish the patient to be given the opportunity to receive end of life care at home.

Conclusions Relatives (and one patient) told us they would welcome a pro active approach to the recognition of a patient approaching the end of life. They would also wish information regarding prognosis to be shared with the GP, even if it was not information the patients themselves wished to have. No funding was obtained for this study.

4 WELLBEING OF INFORMAL CAREGIVERS

Ee Jane Lim, Seng Beng Tan, Andrew Yeoh, Ai Xin Cheah, Chooi Lin Doong, Ee Chin Loh, Chee Loong Lam. *Royal Berkshire NHS Foundation Trust, University Malaya Medical Centre*

10.1136/bmjspcare-2018-ASFPabstracts.31

Background Informal (unpaid) caregivers provide care that goes beyond customary and normative support, and endure ‘silent suffering’ often unrecognised by healthcare providers. Understanding factors that contribute to the wellbeing of informal caregivers can further the capacity of healthcare workers to promote caregivers’ wellbeing.

Methods We performed a qualitative study of semi-structured face-to-face interviews in Malaysia. Transcripts were read repeatedly for familiarisation, followed by coding and thematic analysis. NVivo11 software was used to analyse data.

Results The five main themes shown to promote the wellbeing of informal caregivers are: acceptance, appreciation, hope, happiness and support.

- Finding acceptance mirrors the seven stages of grief – shock, denial, anger, bargaining, depression, testing and acceptance – and seems to be born out of having no other choice. This lack of choice is rationalised in three non-mutually exclusive ways: understanding that death is an inevitability of life, trust in the sovereignty of a higher power or god, and seeing death as the ultimate freedom from suffering.
- Caregivers were appreciative of healthcare providers, the time they had with their loved ones, the opportunity to give back to their loved ones, and were also grateful to god. Of note, skills traditionally seen as ‘soft’ by medical practitioners, were most appreciated – professionalism, providing education, responsiveness to requests and humanity.
- The hope seen in preserving wellbeing is built on having accepted their situation and shapes hope for realistic goals. Without acceptance, unrealistic hope would only frustrate and be detrimental to their wellbeing.
- Happiness is protective against negative rumination and is derived from the patients themselves, relationships and moments of respite.
- Support systems comprised spiritual or religious groups, family and friends, each catering to slightly different needs.

Conclusion Awareness of these five factors that promote caregiver wellbeing should inform clinical practice and holistic care.

5 ‘HAVE YOU GOT THE DRUGS?’ A SURVEY OF CUSTOMERS ACCESSING PALLIATIVE MEDICINES FROM COMMUNITY PHARMACIES IN SHEFFIELD

Elizabeth Miller, Julie D Morgan, Alison Blenkinsopp. *Sheffield Teaching Hospitals NHS Foundation Trust, University of Bradford*

10.1136/bmjspcare-2018-ASFPabstracts.32

Background Prompt availability of Palliative Medicines (PMs) towards the end of life supports symptom management however little is known about patients’ and carers’ experience in accessing PMs from community pharmacies.

Aim To investigate urgency, availability and referral pathways for accessing PMs according to community pharmacy customers.

Methods A customer survey was developed based on the Community Pharmacy Patient Questionnaire (CPPQ) and piloted in one pharmacy and a hospice day unit. The survey collected non-confidential information on pharmacy usage, whether prescription items were urgent, available and other descriptive data. Pharmacy staff from a purposive sample of five pharmacies in Sheffield, including two participating in a Locally Commissioned Service (LCS) providing access to PMs, distributed the survey to customers collecting PMs between May-October 2016. Survey data were analysed using SPSS v23. Ethical approval was obtained from the University of Bradford.

Results Surveys were completed for 73.3% (55/75) patients with PM prescriptions. Non-completion related to care home and home delivery prescriptions. 21.8% (12/55) of customers were referred to the pharmacy by a healthcare professional. For 20% (11/55) of customers at least one PM was not