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.

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

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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

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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

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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