

referrals, access to services (including self-referral), referral criteria and waiting times.

Results Responses were gained from 26 services. Twelve offered Bereavement specific services and eight of these were hospices. From the total responses, only 47% of services that GPs had referred to offered Bereavement specific support. Three of the hospices only accepted referrals if the person had a prior connection to the hospice but most services had no specific criteria apart from age restrictions (i.e. they offered support to adults only). All services accepted self-referrals (except for children where consent was required) or from a healthcare professional including GPs. Number of referrals to each service in 2018 varied widely from 81 to 1522. Waiting time on average was 50 days.

Conclusions This evaluation mapped community Bereavement support services in the North East of England. It will be essential to ensure referrers develop knowledge of who, when, and how to refer to Bereavement services going forward

Caregivers and the family | posters 2 – 5

2 CAREGIVER BURDEN AND HEALTH STATUS PERCEPTION OF FAMILY CAREGIVERS OF PATIENTS RECEIVING PALLIATIVE CARE AT HOME

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10.1136/spcare-2020-PCC.23

Introduction The aim of this study was to explore the repercussions associated with caregiving of patients who receive palliative care at home due to an oncological disease through the assessment of the health status self-perception in the last year, the presence of anxiety and depressive symptoms and the assessment of caregiving burden.

Method Design: Descriptive, cross-sectional study. Sample: family caregivers of patients with oncological disease who are under the follow-up of a home palliative care program hospital-based. Period: July 2015 and December 2016. Analysis: descriptive statistics. Questionnaires: Goldberg anxiety and depression scale; Zarit Caregiver Overload Scale in reduced version

Results 80 family caregivers were included in the study. 56 (70%) were women and 24 (30%) men, with a mean age of 61.75 years (SD=12.98). 52.5% of the family caregivers assessed negatively affect their health status in the last year (regular, bad or very bad) while 47.5% valued it positively (good or very good). 48 caregivers presented symptoms of possible anxiety diagnosis, and 36 caregivers symptoms of possible diagnosis of depression.

The risk of claudication due to caregiver's burden was assessed in 57 caregivers. The average score was 14.95 on the Zarit Scale (short version). 16 caregivers (20%) presented claudication risk criteria. The results showed a significant positive association between age ($r=0.316$; $p=0.008$), anxiety symptoms ($r=0.333$; $p=0.005$), care overload ($r=0.277$; $p=0.037$) and the worst health status perception.

Conclusion In the sample studied, the family members who take care presented a worse perception of their health status, higher levels of anxiety and a greater perception of care overload.

3 PALLIATIVE CARE AT HOME IN PATIENTS WITH ONCOLOGICAL DISEASES: TRENDS IN CHARACTERISTICS AND CIRCUMSTANCES OF THE PRIMARY FAMILY CAREGIVER

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10.1136/spcare-2020-PCC.24

Introduction This study aims to describe the characteristics and circumstances related to caregiving at home of family caregivers of people receiving palliative care at home due to cancer disease.

Method Design: Descriptive, cross-sectional study. Sample: family caregivers of people in follow-up in the home care program. Period: July/2015 to December/2016. Variables: sociodemographic data, characteristics of the role of caregiver as previous experience caring, reasons for caring, living together, simultaneous care of other people, care environment preferences, perception of the relationship, time and hours assuming care.

Results The sample was made up of a total of 80 relatives, 56 (70%) were women and 24 (30%) men, with a mean age of 61.75 years (SD=12.98). 55.7% of them had primary education, 45% were a pensioner followed by 23.8% who said they were working. The degree of kinship was spouse/partner (48.8%) followed by daughter (42.5%). 92.5% of caregivers identified themselves as primary caregivers while 7.5% were sole caregivers. In most cases (76.3%) they resided at the same address. In 30% of cases, caregivers also treated other dependents besides the patient. The main reasons for caregiving described were: own initiative (47.5%) and feeling obligated (36.3%). For 40% of the caregivers it was the first experience of caring. The average time caring was 12.98 months (SD=21.41), the average of hours caring per week 38.29 (SD=20.66). 53.8% of caregivers described their relationship with the patient as very intimate, however 25% of them identified that the relationship had worsened.

Conclusions In home palliative care scenarios, knowing the circumstances of caregivers and caregiving environment could contribute to recognize and support family caregiving.

4 AN EVALUATION OF THE AVAILABILITY OF INFORMATION ACCESSIBLE FOR EMERGENCY SITUATIONS WITHIN THE PATIENT POPULATION OF A PALLIATIVE CARE SERVICE

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10.1136/spcare-2020-PCC.25

Background In an emergency, medical professionals need urgent access to patient information. Patients can share information via the Message in a Bottle (MIAB) scheme or via the 'emergency contacts' feature on their smartphone.

Objectives The first objective was to find out if patients receiving specialist palliative care use the MIAB scheme, or their smartphones, to store and share health information. The second objective was to increase the use of these methods to share information. The third objective was to make the use of these methods' routine, beyond the end of this project.

Methods We asked patients attending Y Bwythn Newydd to complete a simple questionnaire about how they store and share information about their health in case of an emergency. We gave a Lions' tub to those patients that did not have one, explaining that the scheme provided information about their diagnosis, next of kin information, and any advanced care decisions such as preferred place of care/death. We taught patients how to use the 'emergency contacts' feature on their smartphone.

Results 31 patients completed the questionnaire. Only one of the patients was already using a MIAB. 28 MIAB tubs were handed out over four weeks. 29 out of 31 patients thought the scheme was a good idea. Nine out of 31 patients had a smart phone, of which four had set up the 'emergency contacts' feature.

Conclusions This project increased the use of the Message in a Bottle scheme, and the 'emergency contacts' smartphone feature. We have demonstrated how to increase the use of these methods of sharing emergency information. Advance care planning with simple interventions such helps empower patients and their families by ensuring their wishes are fulfilled at the end of life. More research is needed to further evaluate the impact of such interventions.

5 THE DIFFICULTIES FACED BY FAMILY CAREGIVERS WHEN HOME IS THE PREFERRED PLACE OF DEATH

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10.1136/spcare-2020-PCC.26

Background Eighty per cent of people in the UK state they would prefer to die at home. A 'good death' is a key objective of palliative care and a comfortable death improves wellbeing among the bereaved. This study was designed to take a deep-dive into the service experiences of a new Hospice@Home service, with the overall aim of ascertaining the human stories behind Hospice@Home helping people to achieve their preferred place of death.

Methods We collected 45 narratives from bereaved caregivers whose family member had received Hospice@Home in the weeks prior to their death. We used the Trajectory Touchpoint Technique (TTT), a rich pictures methodology that enables the collection of deep and rich data. The TTT encourages people to talk about their whole Hospice@Home journey in 5 stages: pre-arrival, arrival, clinical care and support, comfort, discharge and aftercare. Narratives were recorded and transcribed verbatim before being subjected to thematic analysis.

Results We found multiple problems. A lack of awareness and understanding of hospice help among both families and some referring clinicians delays access. Even when offered, resistance comes from a reluctance to allow 'strangers' into their homes, a hesitancy to hand over the care of their loved ones, and/or a disinclination to use the service due to not feeling entitled. These barriers persist despite many families being in crisis. Certainly, we found Hospice@Home positively impacts quality of life and quality of death for patients. However, families were unable to equate their experiences with a positive impact on their own quality of life, resulting in many re-thinking their own place of death preferences.

Conclusions There are major gaps in care provision, particularly notable in the wider healthcare system, including GPs, Pharmacies, access to equipment, and private care providers.

Dementia | poster 6

6 MAPPING THE TRAJECTORY OF THE LAST 12 MONTHS OF LIFE OF PEOPLE WITH DEMENTIA: THE ROLE OF SPECIALIST PALLIATIVE CARE

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10.1136/spcare-2020-PCC.27

Background Dementia is now one of the top five underlying causes of death. There are concerns about the quality of care and barriers to the provision of quality end of life care for people with dementia, meaning they may not have access to specialist palliative care (SPC) or adequate symptom control.

Aim To map the last 12 months of life for people with dementia; the role of SPC

Method Retrospective, mixed method study reviewing clinical records of decedent patients and narrative interviews of the carer/next of kin.

Results Of 34 carers approached, 15 consented to being interviewed (44% response).

2 typical trajectories were identified: 'A revolving door' recurrent acute events and crises, with regular attendance at accident and emergency (A&E) and changes in care setting; and 'gentle fading', minimal health or social care intervention required).

13 patients had at least 1 visit to the A&E department (range 1–6) but recurrent attendance was common. There was limited evidence of ACP and DNACPR was predominantly completed in the final days of life.

12 of the patients were referred to SPC. Median time from referral to death was 10 days: input included non-complex end of life symptom control, ACP, education and support of care home staff and family support.

Place of death was care home (5), hospital (6), hospice (2) and home (2). 7 died in their usual place of care.

Conclusion SPC has a role in the last 12 months of life for people with dementia but late referral limits the efficacy of SPC intervention. Local initiatives are needed for health and social care to work together with SPC to look at optimising care for people with dementia earlier in the illness trajectory.

Education and training | posters 7 – 45

7 OUTSIDE THE MARGINS: PALLIATIVE AND END-OF-LIFE CARE EDUCATION FOR HOMELESS SUPPORT SERVICES

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10.1136/spcare-2020-PCC.28

Background The CQC report 'A different ending: addressing inequalities in end of life care' highlighted homeless people with end of life care needs experience considerable barriers accessing palliative care. Mary Stevens Hospice developed a workshop for hostel workers, West Midlands Police, and Dudley Metropolitan, focused on palliative and end of life