FAMILY CARERS’ EXPERIENCES DURING THE END OF LIFE CARE IN A RESOURCE POOR SETTING

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Background Palliative and end of life care is an international issue but is receiving very little formal attention in Sub-Saharan Africa in general and Nigeria in particular, there is inadequate information and lack of accessibility to care. Research to inform adequate end of life care in Africa is at an early stage and many research areas need to be explored. Previous studies were carried out in western countries, but the information is culturally in-congruent and not transferable to poor resource context like Nigeria. This means that the information exists but not necessarily be helpful because of the cultural sensitivity, values, and beliefs attached to end of life care in Nigeria and other Sub-Saharan African countries. The study explored the experiences of family carers during the end of life care.

Method An ethnographic case study approach was used to explore family carers’ experiences during the end of life care in the medical unit of a Nigerian University Teaching hospital. Interviews and participant observations were used as the tools for data collection.

Results Fourteen family carers were interviewed separately, and each interview was preceded by a week of observations. Preliminary analysis identified five overarching themes: Challenges/barriers to end of life care, Family carers experiences, Educational needs and support, Family carers roles and Family carers perception about end of life care.

Conclusion Majority of the family carers described their end of life care experiences as unpleasant, there was lack of support generally and a wide communication gap between carers and healthcare professionals. The study generates evidence-based clinical and health services data to inform policy, practice and future research. At the same time to ensure that end of life care services provision in Nigeria is effective, appropriate, ethical and culturally competent.

COMMUNICATION AND ADVANCED CARE PLANNING IN A GENERAL PRACTICE SETTING

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Aims To investigate the effective undertaking and recording of end of life conversations within a busy urban general practice. These included important areas such as physical, psychological, social, spiritual and financial concerns as well as DNAR decisions and preferred place of care.

Methods Utilising EMIS database, all deaths between the 1st January 2016 and 31st December 2016 of patients registered at Newington Road Surgery, Ramsgate were identified. The electronic notes and records were accessed and reviewed. A total of 63 deaths were recorded.

Results In 54% of deaths in the practice, end of life discussions would have been appropriate because of evidence of general decline, end stage cancer or frailty. Despite this only 38% of these patients had end of life discussions.

Out of these discussions 62% focused on physical symptoms with only 38% recording psychological, social, financial or spiritual discussions.

Most surprisingly only 9% of patients had a saved and accessible care plan and none of those plans recorded had any information regarding patient’s preferred place of care, preferred place of death or an escalation plan regarding hospital admissions.

Conclusions This project concluded that many factors are involved when contributing to discussions held by GPs towards the end of patient’s lives. These included time pressures and the need for additional input from hospital, oncology and palliative care teams.

However, this project highlighted the importance in identifying patients towards the end of their life in the community.
THE COST OF A NIGHT NURSING SERVICE AT RENNIE GROVE HOSPICE CARE, AND THE TOTAL COMMUNITY COST OF CARE AT HOME COMPARED TO AN ADMISSION TO HOSPITAL


Background Rennie Grove (RG) runs a 24/7 Hospice at Home service. An independent study calculated the cost of a visit and the total community cost of home care, including all health care professional (HCP), carer, and family member visits.

Methods Over a period of 145 days, 550 calls and 335 visits made to the night team were recorded, averaging 3.79 per night. The salary cost per hour for each nurse, plus organisational add on costs, were calculated. To derive a total community cost, 35 families, able to consent, kept a diary for up to two-weeks, recording all HCP, carer and family support visits and duration of each visit. 17 diaries were returned. Descriptive analysis was used with the Statistical Package for the Social Sciences (SPSS v22). Costs were taken for HCPs and social care services from the PSSRU data 2015/2016.

Results Average length of the diaries was 10.4 days. For 3.79 visits per night the cost per visit was £195 (RG nurses travel in pairs). 17 patient diaries covered 177 days and showed a range of visits and complexity of care. RG staff provided 19% of the care at a cost of £3,295; district nurses 13%, cost £2,005; formal carers 55% at a cost of £1,344. 23 GP visits comprised 4% of visits but 15% of total costs. MacMillan/Marie Curie nurses accounted for just 2% of visits but 19% of cost as they stayed overnight. The cost of 177 days of care for 17 patients was £11,814; i.e. £66.7 per day as care was not needed every day of each diary period.

Conclusions The cost of home care seems acceptable, compared to the national average cost of a day in an inpatient specialist palliative care bed at £397-£400 (Data.Gov.UK, 2015).