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Primary care palliative and supportive care services: Experiences and perceptions of patients with advanced progressive disease and their informal carers

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Inclusion criteria

Sample

Aims

Macmillan Nurse

District Nursing

Health care assistants

Admin staff

Hospice assistants

Home:

Team:

Participants decide whether or not to participate.

participating in the research. The researcher will then make contact to discuss the research further before potential participants decide whether or not to participate.

Participants to be recruited via the clinicians involved in their care. Potential participants will be given an information pack regarding the research, and will be asked to return a reply slip for further information if they are interested in participating in the research. The researcher will then make contact to discuss the research further before potential participants decide whether or not to participate.

Sample to be purposive. With a mix of disease, age and sex.

Data will be analysed using the Template Analysis approach.

Potential primary care contacts for patients with advanced, progressive disease with palliative and supportive care needs and their informal carers.

To increase understanding of the experiences and perceptions of patients with advanced progressive disease, and their informal carers of receiving support from multiple primary care palliative and supportive care services.

To explore how different care environments affect primary care contacts from a patient and informal carer perspective.

Method

Example Pictor diagram done by a district nurse describing a case study of a patient with COPD in the last hours of life, and receiving care in the home environment.

Palliative care can be defined as the active, holistic care of patients with advanced progressive illness, and incorporates symptom management with psychological, social and spiritual care (WHO, 1990). Palliative care is for patients in the advanced stages of illness.

Supportive care follows people throughout the process of their disease, from pre-diagnosis, treatment, cure, continuing illness, death and into bereavement. The aim of supportive care is to maximise benefits of treatment and help people to live as well as possible with a disease (NCHSPCS, 2002).

The majority of palliative/supportive care is delivered in primary care, and up to 90% of people spend most of their last year of life at home (Aoun et al, 2005).

Palliative services were initially only available for cancer sufferers, however recent policy proclaims that palliative and supportive care services should be available to all, regardless of diagnosis (DoH, 2008) and a plethora of services now exist to meet these needs.

This research will take a interpretive phenomenological methodology to explore the experience of receiving these services from the perspectives of patients and their informal carers,