Who cares? A prospective study to develop an alert system for informal carers

Katherine Knighting, Barbara Jack, Brenda Roe, Mary O’Brien, Mike Nolan, Mari Lloyd-Williams, Kirsty Pine

Background
Informal family carers have vital roles caring for patients with cancer and advanced progressive illness, especially during the final year of life, which can incur an increasing burden compromising their physical and psychological health. Understanding how to prevent these stresses is vital to meeting the increasing demands for home-based care and to prevent inappropriate hospital admission of patients.

This study has four phases involving carers, health and social care professionals, and an expert panel. The study will culminate in the development and evaluation of an alert thermometer to assess carers’ needs. The thermometer will act as an alert indicator to the increasing burden experienced by carers in order to trigger referral of carers to appropriate support or services.

Research Question
What do carers of patients with cancer and advanced progressive illness find burdensome during the final year of life; how might this be alleviated by the adoption of an alert system and the subsequent provision of appropriate support?

Carer Eligibility
1) 18 years or over
2) Carers of patients with cancer and other advanced progressive illnesses who are identified as approaching the end of life will be recruited through the Supportive Care Register (SCR)/Gold Standards Framework (GSF) administered through GP practices.

Method
Three focus groups and five interviews with 22 carers

Conclusions
All the carers were interested in having a regular assessment with the alert thermometer to identify increasing burden and prevent self-neglect.

Topics suggested for inclusion on the alert thermometer were: access to information and support, financial advice and support, respite care, carer’s own health and social needs, and the need for assessment prior to loss of a loved one with planned bereavement support where needed.

The interview study will continue until June 2012 when an on-line questionnaire will be administered to health and social care professionals for them to rank the main topics identified by carers.

Emerging Themes
Perceived benefit of using a regular carer alert system to identify problems before they become too much

Fear of: Being ill as a carer
What will happen to a loved one when the carer is no longer there
How the carer will cope with bereavement

Lack of time or support to:
- Be able to attend any support groups or carer control events
- To attend to own health needs or appointments
- As a person

Lack of any regular alert system or brief assessment focused on carers needs:
- As a carer &
- As a person

Lack of information and access to:
- Services
- Healthcare teams
- Financial advice & support

Contact details: katherine.knighting@edgehill.ac.uk Edge Hill University, Faculty of Health and Social Care, Ormskirk, L39 4QP, Tel 01695 650768.