

Dimbleby Marie Curie Cancer Care Research Fund - Project Grant

Project details

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A retrospective national cohort study of the demographic characteristics, health outcomes and health service use of cohabittees living with terminally ill patients with cancer, chronic obstructive pulmonary disease and dementia

Duration of project: 12 months

Start date: June 2012 (TBC)

Budget: £59,000 (TBC)

Abstract

The UK population is ageing and many more people will die from diseases involving a long decline, such as chronic obstructive pulmonary disease (lung disease), dementia or cancer. People with these conditions require increasing support from their family and friends. Very little is known about the age, gender and circumstances (demographics) and patterns of health and illness of these unpaid carers. Many people who care for someone dying from a progressive disease may not identify themselves as a "carer" yet they provide considerable emotional and practical support. The stress and burden of caring may lead to them developing their own physical or mental health problems.

There have been concerns that there is worse access to good quality end of life care for people dying with non-cancer diagnoses including dementia and COPD; we do not know whether this has a further impact on the health of carers.

We aim to undertake a large national study to describe the 1) characteristics, 2) physical and psychological health outcomes and 3) service use of people living in a two adult household with someone dying with cancer, dementia or COPD. We will study two time periods; six months before and the year after death. By focusing on cohabittees of a person dying from a progressive disease, we overcome the barrier that many carers do not identify themselves in this role or are not recognised to be carers by health or social services.

The UK health improvement network database (THIN) covers 500 GP practices, over 9 million patients. The data base anonymously records the characteristics, medical history, prescriptions and health service use of patients. It provides many years of follow up, and therefore, is a rich source of information. We will identify people who have died of life limiting illnesses (cancer, dementia, lung disease) in a two adult household. We will then be able to study their cohabittees (gender, ethnicity, level of deprivation in the area they live in, service use) and track their health (including diabetes, heart attacks and mental health) before and after the death of the terminally ill person. Our study will also give information on differences in health in the cohabittees depending on the whether the terminally ill patient suffered from cancer, dementia or lung disease.

This information on the health and well being of people who are caring for a dying person can help us better target ways of helping them.