

CORD

Pro-active follow up in primary care from early in the cancer trajectory: the introduction of a framework developed by service users

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Summary

This study is testing the feasibility of anticipatory care for people with cancer in primary care from immediately after diagnosis. The study pilots a care framework generated by people affected by cancer to help primary care clinicians provide on-going holistic care, and will inform Macmillan if GP-based anticipatory care from diagnosis is feasible and appreciated by patients.

Background

There are currently 2 million people living with cancer and this number is predicted to increase to four million by 2030. Cancer is now considered as a chronic condition, which people live with and only rarely die from. There is little research available which tests a primary care model of supporting this growing population.

This study builds on previous pilot work undertaken by the research team, in which a care framework was generated by people affected by cancer and implemented in a variety of different ways in five general practices in Scotland (1,2). This research showed that patients highly value pro-active care led by a key health professional, and they wanted this from when they were diagnosed with cancer, and not just at a later stages. In the UK, the Gold Standards Framework (an evidence-informed approach to optimising the care for patients nearing the end of life delivered by generalist providers) is used routinely but only in the later stages of cancer care to improve co-ordination in the community.

The aim of this research is therefore to assess the feasibility, advantages and disadvantages and cost of active follow-up of patients in primary care from immediately (within four weeks) after initial cancer treatment in GP practices in Scotland and England.

Specifically, the study seeks to:

- Implement and evaluate a pro-active approach to the co-ordination of cancer in primary care in all patients who have cancer from the completion of initial cancer treatment onwards.
- Assess the acceptability and evaluate the use of a cancer ongoing review document with patients, their relatives, and professionals.
- Incorporate, monitor and evaluate the use of the Macmillan suggested Quality and Outcomes Framework cancer care template.
- Establish an evidence-base to guide cancer survivor follow-up nationally and future QoF developments.

Findings

The records of 107 patients who had completed CORDs were drawn from 13 practices. Each of these was examined whilst 45 interviews were conducted

with patients (n=16 in which the family carer attended in four cases), and health care professionals (n=29). CORDs were started for 54% of people with a new diagnosis of cancer, and generally usually used only once (range 1 to 9 times), but when used prompted clear and often graphic documentation of multi-dimensional needs and patient's understanding. GPs felt it helped to structure consultations and ensure discussion of psychosocial aspects of care, but the CORD had to be better integrated in the GP practice IT systems, ideally with computerised prompts to use it in place. Few discussed the review openly with patients, and the CORD was often completed after the consultation. Patient and carers valued ongoing care and support from within primary care, which was seen to provide holistic care and foster effective relationships.

The CORD is unobtrusive, promoting continuity of care and holism. This CORD and process is fit for purpose but needs to be integrated within GP and community nursing computing and reporting and reimbursement systems. Rather than a single "cancer care review" as currently featured in the Quality and Outcomes Framework (QOF), most patients would benefit from an offer of ongoing pro-active care after an initial review. A care framework similar to other chronic illnesses such as diabetes, which uses templates which are flagged up for review at agreed intervals, is possible in primary care. This would require patients to be aware that they may seek advice at any time for their symptoms alongside liaison between primary and secondary care. Most aspects needed for holistic cancer care are already integrated in cancer templates in UK primary care systems, but are underutilised.

Why is this work important?

This work will give us a better understanding of how people diagnosed with cancer wish to be supported in primary care. The findings may be used to devise tailored, personalised care and support services to improving the quality of care and hence life for cancer survivors. The findings could yield evidence sufficient to lead to the introduction, possibly through the Quality and Outcomes Framework, of a care framework akin to other chronic illnesses such as COPD and Diabetes that will improve the continuity of care and possibly extend the care of all people living with cancer. Such care starting from the end of the initial treatment has the potential to make a difference to the lives of all cancer survivors, from very early in their illness, especially if they have progressive disease. It thus has the potential to improve the experience of everyone in the UK who gets cancer.

Publications

Murray SA, Boyd K, Campbell C, Cormie P, Thomas K, Weller D, Kendall M. Implementing a service users' framework for cancer in primary care: an action research study. *Family Practice*. 2008. 25(2):78-85.

Kendall M, Boyd K, Campbell C, Cormie P, Fife S, Thomas K, Weller D, Murray SA. How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers. *Family Practice*. 2006. 23:644-650.

Papers have been submitted to two peer-reviewed journals for academic dissemination.