

Marjorie Simpson New Researchers Award 2011

Current Research Study

Title: Preparing and meeting the needs of family and friends who support people having chemotherapy.

Background

Chemotherapy treatments are toxic, diverse and complex, and often scheduled over weeks or months with some maintenance therapies lasting years (Colbourne, 2008). The number of cancer patients that received chemotherapy in the UK increased by 40% from 2003-2007; 65,000 courses of chemotherapy are currently administered to cancer patients annually (NCAG, 2009). In addition to greater provision of chemotherapy, there has been a shift in how chemotherapy is administered with a steady decline in inpatient treatment in favour of outpatient treatments (NCAG, 2009). A positive aspect of this shift is that patients benefit from chemotherapy, whilst remaining at home. However, the downside is that patients, experience debilitating side-effects and potentially life-threatening complications whilst having limited contact with chemotherapy health professionals. They usually only see them when being administered treatment. Thus, family/friends (informal carers) are assuming increasing responsibility for the complex care of patients receiving chemotherapy.

It is vital that healthcare professionals prepare and facilitate patients' informal carers in monitoring and managing side effects, and providing emotional support. However, there is little evidence to suggest how best to do this. This PhD study aims to develop, following the Medical Research Council (MRC, 2008) framework for complex interventions, an intervention that will address the needs for information and support in this often overlooked group of informal carers that provide important support to patients receiving chemotherapy. Specifically the research aims to:

1. Describe how health professionals prepare and support informal carers in the chemotherapy outpatient setting.
2. Identify informal carers' perceived needs for role preparation and support, establish how and where these are fulfilled and determine needs that are not met
3. Identify health professionals' perceptions of informal carers' needs, how they perceive they are and should be addressed and their perceptions of barriers to informal carers being adequately prepared for their role.
4. Develop with health professionals and informal carers an intervention to prepare informal carers for, and sustain them in, their role of supporting patients receiving chemotherapy.
5. Conduct a pilot study to assess the feasibility and acceptability of, and to refine, the intervention.
6. Identify the training/education needed by health professionals to deliver the intervention to informal carers.

Plan of Investigation

The MRC framework (2008) for developing complex interventions provides the foundations for the proposed study design. This framework is ideal for guiding the development of a multi-faceted and

complex supportive intervention for informal carers of chemotherapy patients. Further, it allows a degree of flexibility when developing an intervention. This is important when it is difficult to define its exact components (Campbell et al, 2000).

There are a number of iterative phases to the MRC framework (2008). The initial pre-clinical phase, a systematic literature review, is in progress. This aims to appraise current evidence on interventions for informal carers supporting people with cancer. As yet, no research has reported on an intervention for carers in the chemotherapy setting. Findings from this systematic review will underpin phases 1 (the modelling phase) and 2 (the exploratory pilot stage) of the proposed study.

The modelling phase is predominately concerned with defining the components of the intervention (Campbell et al, 2000) and will meet the first four objectives of the study. Data collection and analysis will be iterative, occurring simultaneously throughout the modelling phase of the study (MRC, 2008). Data will be collected via a number of methods including participant observation within the chemotherapy treatment setting; interviewing 25 informal carers and 25 health professionals. Groups of informal carers and health professionals will then contribute in workshops. They will consider the findings from the observation and interviewing. They will help identify an intervention package that will meet the needs of informal carers.

In the piloting phase, the intervention will be tested in an exploratory pilot study to explore whether it is feasible and acceptable. It is not possible at this stage to state precisely what form this complex intervention will take or how it will be delivered. It is envisaged that it will have assessment, educational, information and service related components. The prototype carer intervention will be delivered to approximately 25 informal carers prior to the first treatment cycle. The findings of this study will underpin a larger scale post-doctoral randomised control trial.

Supporting Statement

I would like to attend the RCN Annual International Nursing Research Conference because I have recently registered for my PhD studies and would value the opportunity to network, learn from and share experiences with other experienced researchers in nursing. I recognise undertaking study at doctorate level is not just about undertaking a research project, it provides a training platform to become an independent researcher in the future.

There is a need to undertake robust research that improves and evaluates the evidence base for nursing interventions. I am committed to a nursing career within which I will rigorously conduct robust research to inform and evaluate nurse-led interventions. My proposed doctoral study will enable me to develop skills in the development and evaluation of complex interventions. In the future I aim to build a programme of research focussing on the support of patients and informal carers during chemotherapy and supporting health professionals to develop and improve care in this setting.

Colleagues who have attended this conference in previous years have informed me that it is a vibrant and informative event. I would value listening to nationally and internationally recognised nursing research leaders presenting their work. I would also value the opportunity to present the findings from a small preliminary mixed methods study. This research underpins my proposed PhD study it would therefore, be useful to receive valuable feedback and constructive criticism. This study, funded by the Christine Hewson Memorial Foundation, explored the information and support needs of family members of people having chemotherapy (Ream et al, 2010). Findings indicated that there is a need for interventions that support this often overlooked group of informal carers that provide important support to patients receiving chemotherapy.

(281 words)

References

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