



**Florence Nightingale School of Nursing & Midwifery
King's College London**

**Enhancing the role of carers in the outpatient
chemotherapy setting: a participatory action research
project**

Executive Summary

August 2013

**Professor Emma Ream
Dr Vicki Tsianakas
Ms Rebecca Verity
Ms Catherine Oakley
Mr Trevor Murrells
Professor Glenn Robert
Professor Alison Richardson**

Membership of Research Team

Professor Emma Ream, Department of Supportive Cancer Care, Florence Nightingale School of Nursing and Midwifery, Kings College London

Dr Vicki Tsianakas, Department of Supportive Cancer Care, Florence Nightingale School of Nursing and Midwifery, Kings College London

Rebecca Verity, Department of Supportive Cancer Care, Florence Nightingale School of Nursing and Midwifery, Kings College London

Catherine Oakley, Department of Supportive Cancer Care, Florence Nightingale School of Nursing and Midwifery, Kings College London

Trevor Murrells, National Nursing Research Unit, Florence Nightingale School of Nursing and Midwifery, Kings College London

Professor Glenn Robert, National Nursing Research Unit, Florence Nightingale School of Nursing and Midwifery, Kings College London

Professor Alison Richardson, Faculty of Health Sciences, University of Southampton and University Hospital Southampton NHS Foundation Trust

Acknowledgments

This study was undertaken at the chemotherapy unit at Guy's and St Thomas' NHS Foundation Trust. The research was made possible through a grant from Dimbleby Cancer Care and the generosity of carers who participated in the study in various ways through sharing their stories, and through both developing and testing the intervention. Without their support this research would not have been possible. We would like to acknowledge the support of nurses at the chemotherapy unit at Guys' and St Thomas' NHS Foundation Trust and thank them for their much valued assistance with recruitment and facilitation of the carer support sessions and to other staff members who contributed to the 'Take Care' support package. In particular, we would like to thank Mairead Griffin, Head of Nursing and Lead Cancer Nurse and Michael Flynn, Chemotherapy Nurse Consultant for their continued support. We also thank Catherine Dale, Programme Manager for patient centred care, King's Health Partners for facilitating the co-design events for carers and staff and for providing group facilitation training to nurses for this study. Finally, to our carer advisory group- Sue Berry, Ginny Fuller and John Bather- who were consulted on all aspects of the study.

Background

Chemotherapy is a common treatment for patients with cancer, with around 65,000 courses administered each year in the UK (NCAG, 2009). Many of these treatments are initiated in outpatient departments. When chemotherapy is given on a day case basis the onus for managing symptoms and alerting health professionals to concerning side effects falls on patients and carers. The supportive role undertaken by carers is crucial but their contribution to patient safety and wellbeing can go unrecognised. Some carers report being dissatisfied with aspects of the chemotherapy service (Isaksen et al, 2003), feeling overly anxious and concerned and state their own needs for support and information are rarely met. There is an urgent need to develop resources to support carers of people undergoing chemotherapy.

Aims

The study aimed to use a participatory action research approach to develop an intervention for carers in the chemotherapy outpatient setting and then test it.

Methods

The study employed a 3-phase mixed methods research design. Phases I and II addressed the development of the intervention and used a particular action research approach - Experience Based Co-Design (EBCD) - in the process. Data collection for Phase I comprised 20 hours of non-participant observation, 20 semi-structured interviews with staff members and 20 filmed narrative-based interviews with carers. Carers of patients having treatment for four common cancers (breast, lung, colorectal and upper gastro-intestinal [GI]) were invited to participate. Based on these findings, healthcare professionals and carers were given the opportunity in Phase II to collectively model (or co-design) an intervention for carers supporting someone through chemotherapy. The process of co-designing the intervention involved two facilitated feedback events where findings from Phase I were fed back to (1) healthcare professionals (HCPs) involved in phase I and (2) carers interviewed in phase I. Following these was a third event referred to as a 'co-design event' that was attended by both carers and HCPs where the elements of the intervention were designed

and refined. The aim of these events was for carers and HCPs to review the themes arising from observation and interview data and work together to design an intervention – a carer support package that was to be delivered as patients started chemotherapy.

Phase III of the study aimed to test and evaluate the carer support package developed in Phase II through a small randomised feasibility trial. Carers (N= 47) of people having chemotherapy to treat breast, lung, colorectal or upper GI cancer were recruited. Trial participants had made no contribution to earlier phases of the study. Questionnaires were completed by carers at baseline (after patients' pre-chemotherapy nursing consultation and prior to randomisation) and follow-up (one month after baseline). Outcomes selected to measure the impact of the intervention included knowledge of chemotherapy and its side effects (series of 100 mm visual analogue scales), information needs (Supportive Care Needs Survey for Partners and Carers [SCNS-P&C44]), experience of care (investigator-designed tool), perceived confidence in supporting friend/relative, tool based on Schwarzer & Fuchs (1996), and emotional wellbeing (GHQ-12).

Finally, two focus groups were conducted at the end of the study- one with carers and the other with HCPs. These explored the feasibility and acceptability of the intervention.

All phases of the study were undertaken in a chemotherapy day unit of a large teaching hospital in London.

Findings

Phase I

Carers were observed adopting different roles throughout the chemotherapy process and included: the 'emotional' supporter; the 'advocate'; the 'practical' carer; the 'uncomfortable' carer; the 'protector'; and the 'excluded' carer. Three factors appeared to influence carer involvement in the chemotherapy process: the patient-carer relationship; gender; and the degree to which health care professionals (HCPs) involved carers.

Many carers were observed to be struggling with their situation, as much of the information and support provided by HCPs was patient-centred and failed to address carer's needs.

Carers were given the opportunity to tell their story about supporting someone through chemotherapy. Analysis identified 12 key 'touchpoints' or 'key' moments that shaped their experience which fell within six broad themes:

- Finding out about chemotherapy: feeling shocked and uncertain about the future, feeling reassured before chemotherapy treatment begins, being aware of symptoms and side-effects
- Carers' concerns about chemotherapy: concerns about the benefits of chemotherapy
- What is it like being a carer?: feeling anxious, isolated and helpless, putting on a 'happy face', providing physical support
- Managing life as carer: balancing carers' own life with supporting the patient
- Interactions with HCPs and need for carer support: feeling part of the process, lack of emotional support for carers
- Improving support during chemotherapy: need for carer-specific information, support from other carers

HCPs were interviewed about their perceptions and experiences of providing support to carers in the chemotherapy outpatient setting. The key findings revealed that:

- Carers are distressed and are impacted emotionally by patients' needs for chemotherapy and the support they need to provide
- Carers adopt many different roles when supporting someone through chemotherapy: providing physical, emotional and practical support, being a 'second pair of ears' during consultations and providing a realistic view of patients' experiences
- There are six types of carer personas: the 'assertive' carer, 'passive' carer, 'over-protective' carer, 'uncomfortable' carer, 'demanding' carer and 'excluded' carer
- Several factors influence carer involvement in the chemotherapy process: carers' relationships with their families, carers relationships with HCPs, gender, psychological resilience, work and family commitments and length and stage of treatment

- Carer interventions in the chemotherapy outpatient setting are warranted. The carer should be recognised, acknowledged and prepared for their role.
- Barriers to offering interventions include: focus on patient or obviously vulnerable carers, time, busyness and a lack of resources, lack of confidence and skills among HCPs to deal with carers, carers not seeking support themselves and HCPs dealing with difficult carers

Phase II

At the co-design event, carers and HCPs identified the following factors as important for carers during chemotherapy and it was agreed these should provide the framework for any carer intervention:

- Having preparatory information
- Being provided with practical tips about how to support someone through chemotherapy whilst balancing daily life
- Being acknowledged as having an important role to play in supporting someone through chemotherapy
- Knowing that their feelings, concerns and experiences are normal and shared by others
- Having freedom/ time/ opportunity to ask questions of a HCP

The intervention was developed and refined in collaboration with both participating HCPs and carers and the project steering group. The intervention package - known as 'Take Care'- comprised: a supportive/educative DVD, accompanying leaflet and 1-hour group consultation facilitated by a chemotherapy nurse. The support package was delivered in one-off consultations by one of two chemotherapy nurses trained in group facilitation. It was provided to groups of no more than 5 carers. Sessions were usually run on a Thursday between 11-12pm, although on two occasions they were run on different days to accommodate carers' schedules. The chemotherapy nurses delivering the intervention were known as 'carer support nurses'; they delivered the intervention on alternate weeks.

Phase III

Forty-seven carers were recruited over 4 months between the 16th July 2012 and 2nd November 2012 to the randomised feasibility trial. The estimated recruitment rate of 10 patient/carer dyads per month proved feasible. Carer characteristics were evenly distributed across the two study arms; a diverse group of carers were recruited. Randomisation appeared acceptable as carers agreed to participate and did not decline upon learning that participation required random allocation.

The majority of carers who received the 'Take Care' support package reported that they expected it to provide them with knowledge, understanding and confidence in supporting someone through chemotherapy. Nineteen out of 21 carers said the intervention met their expectations. Carers were asked to reflect on the most helpful aspect of the 'Take care' intervention. Their responses were grouped into 3 themes: information and awareness, reassurance and support, and validation of the carer role.

In post-intervention focus group discussions, carers who received the 'Take Care' intervention reported being informed of symptoms and side effects and felt empowered, confident and reassured throughout the chemotherapy process as a result of receiving the intervention. Carers felt the group consultations worked particularly well. They thought the intervention should be offered as early as possible to carers, possibly at the pre-chemotherapy consultation.

Focus group discussions with HCPs revealed that they perceived the main impact of the package was to empower carers and increase their confidence, knowledge and awareness. They affirmed that the package was a source of support to carers that helped reduce anxiety about the chemotherapy process. The legitimisation of the carer role was also highlighted. HCPs were satisfied with the components of the 'Take care' support package and considered the DVD and leaflet to be a complementary package. They valued the carer consultations as a useful forum at which carers could receive information and address concerns. HCPs agreed that the intervention should be delivered to carers at the pre-chemotherapy

consultation but felt it should be followed-up to ensure carers' needs were continuing to be met at later stages.

Data from the outcome measures pre and post intervention revealed the intervention 1) significantly enhanced carers' knowledge of chemotherapy; 2) significantly reduced unmet needs for information and support, and 3) significantly enhanced experience of, and satisfaction with care. However, it appeared to have limited impact on carers' confidence in caring for patients and appeared not to impact on their emotional wellbeing.

Discussion

Previous studies have investigated the needs, challenges and impact of supporting a friend or relative through cancer and its treatment. Our study contributes to this body of literature; it is the first to investigate in detail the process of supporting carers of people having chemotherapy and to develop an intervention for, and test the feasibility of an intervention for this group of carers. Our study also provided HCPs perspectives regarding the drivers and barriers to providing support to carers. In addition, through observing carers' interactions and behaviours on the chemotherapy unit and during scheduled consultations, we were able to understand first-hand the roles and behaviours adopted by carers and the context in which these are enacted. Further, we were able to understand the factors influencing carer involvement in the chemotherapy process such as specific patient-carer relationships, gender differences and the degree to which HCPs involved carers. The similarities between observational data, carer interview data and HCP interview data suggest an understanding among HCPs of the needs of carers and the impact on carers of supporting someone through chemotherapy. This awareness may have impacted the positive way HCPs responded to developing the intervention and implementing it in practice.

The purpose of the feasibility trial was to determine whether the intervention was appropriate for further testing and to assess the parameters needed in this case. The outcome measures selected for the feasibility study were those expected to most effectively and accurately capture the effects of the intervention. The intervention appeared acceptable to both carers and HCPs and several outcome measures indicated improvements associated with it. The intervention group reported significantly greater knowledge of

chemotherapy side-effects and their management than the control. They also recorded fewer unmet needs for information. Confidence in caring for patients was higher in the intervention group on completing the study than the control but this failed to reach significance. This may have resulted from: the feasibility study being underpowered (as would be expected given its scale and scope); the scale used to measure confidence in caring being insufficiently sensitive; or the timing of the follow-up questionnaires being unsuitable. Arguably one month may have been an insufficient time period for carers to have developed confidence in their role.

The initial recruitment estimate proved feasible, approximately 10 patient/carer dyads per month (including drop-outs and refusals). Randomisation appeared to be acceptable as carers agreed to participate and did not decline upon learning that participation required random allocation.

In future, research efforts must be made to maximise response and minimise attrition by offering the intervention at times that would accommodate carers who worked full time or had other daytime responsibilities. Both carers and HCPs advocated delivering the intervention as early as possible in the chemotherapy process. There was consensus that the chemotherapy consultation may be the most appropriate time to offer the intervention. However, participants stressed that it should also be available at other times to ensure carers who do not attend the patient's consultation could still access it.

All participants valued the complementary components of the 'Take Care package: DVD, leaflet and consultation with the carer support nurse. The group consultation was appreciated by carers as it provided them opportunity to share experiences, exchange information, support others and be supported by HCPs. Carers expressed a preference for group over one-to-one consultations; they valued the group dynamic, highlighting the importance of the 'relational' aspects of care. Spending time with carer support nurses helped carers establish rapport and relationships with HCPS and enabled them to address concerns. Further it legitimised their carer role. This would suggest that future delivery of the intervention should incorporate group rather than individual carer consultations with a support nurse. Apart from the economic benefits of group-delivered interventions, they are effective in reducing psychological and emotional consequences of cancer, and often yield

better coping outcomes than those using other methods of delivery (Northouse, 2010). Carer support nurses concurred that the group dynamic was important; their skills in facilitating group discussion were clearly important. However, most chemotherapy nurses are not trained in group facilitation and it is important that they receive adequate training prior to delivering interventions such as 'Take Care'.

Traditionally, EBCD has been used to improve patient experience by deliberately drawing out the subjective, personal feelings of service users, carers and staff to identify 'touchpoints' - key moments that shape a person's overall experience. This leads to a co-design process where priority areas for service improvement are identified. Whilst these elements of EBCD were applied in this study, the co-design process was adapted in this study to explicitly fashion a supportive/educative intervention for carers. This is the first time that EBCD has been used in this way. Our study results indicate that EBCD is a valuable tool for developing specific interventions for health service users. Second, unlike conventional use of EBCD, this study determined in advance that the intervention to be would incorporate a DVD; additional materials (in this case the accompanying leaflet and support nurse consultation) were identified and developed through the co-design process. A film was considered a practical and economical way of conveying consistently important information to carers. We do not know whether carers would have selected the creation of a DVD as a component of the intervention had they been given the option of identifying their own priorities for improving their experiences (although the level of carer engagement through the co-design process suggests this was felt to be an important aspect). As is usual with EBCD, one joint co-design event was incorporated into Phase II. However, additional follow-up co-design meetings would have benefitted particularly during the initial phases of the intervention's development to facilitate the co-refining (rather than co-designing) of the emerging intervention. Indeed, one participant commented during the focus groups at the end of the study on the potential benefits of having more co-design meetings during the development of the DVD. Due to time constraints this was not possible.

Conclusions

This study developed an intervention to support carers of people commencing chemotherapy and undertook preliminary testing of it through a feasibility trial. The intervention proved acceptable to carers and healthcare professionals and demonstrates considerable promise and utility in practice. The findings of this study suggest the intervention warrants further evaluation within the context of a fully powered RCT to determine effectiveness and cost effectiveness. EBCD provides a powerful approach to developing interventions that are grounded in the issues that people experience and has the benefit, through the very nature of the co-design process, of expediting the implementation of research into practice.

Recommendations

Results of the study suggest that:

1. An adequately powered multi-site RCT is conducted to determine the effectiveness and cost effectiveness of the intervention.
2. Researchers consider using EBCD methods to develop user-centred interventions that have salience for both the client group and those involved in delivery. This may have value for future intervention development.
3. Awareness should be raised among HCPs about the role they play in influencing carer involvement during chemotherapy. HCPs need to actively seek to involve carers and to attend to their needs in the chemotherapy outpatient setting, ensuring carers are made to feel part of the process.
4. There is an urgent need for training within chemotherapy teams to generate awareness about the role they play in supporting and referring carers to existing services and to build a skill set among nurses to provide carers with support.
5. Carers' needs for information and support, and their ability to support someone through chemotherapy, should be assessed prior to patients beginning treatment with onward referral for psychological, financial and practical support if required.
6. Chemotherapy services need to think about providing opportunities for carers to come together in groups, to gain access to both information and peer support.