"I'm just in the shadow to keep an eye" - an investigation to understand need for support in family members of people having chemotherapy

Executive Summary

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Prof. Emma Ream
Ms Jenny Finnegan-John
Ms Rebecca Foster
Mrs Ginny Fuller
Ms Catherine Oakley
Prof. Alison Richardson

Members of Research Team

- Jennifer Finnegan-John, Research Associate, King's College, London
- Rebecca Foster, Research Fellow, University of Southampton
- Ginny Fuller, User Representative
- Gwen Harlow, User Representative
- Elaine Lennan, Consultant Chemotherapy Nurse, University Hospital Southampton NHS Foundation Trust
- Catherine Oakley, NIHR Doctoral Research Fellow, King's College, London
- Emma Ream, Professor of Supportive Cancer Care, King's College, London
- Alison Richardson, Clinical Professor of Cancer Nursing and End of Life Care, University of Southampton and University Hospital Southampton NHS Foundation Trust
- Rebecca Verity, NIHR Doctoral Research Fellow, King's College, London
- Members of Carer Reference Group

For further information about this study please contact

Professor Emma Ream
Professor of Supportive Cancer Care
Florence Nightingale School of Nursing & Midwifery
King's College London
James Clark Maxwell Building
Waterloo Road
London
SE1 8WA

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Executive summary

Project Summary

The purpose of this research was to provide new understanding of the experiences and needs of family members supporting a person through a course of chemotherapy and to determine how advice and support should best be provided to them by healthcare professionals throughout the process.

Background

More than 320,000 people are diagnosed with cancer annually in the UK. The illness impacts profoundly on patients and their family and friends – referred to here as informal carers. Informal carers' own wellbeing (physical and emotional) can be affected through the role they play in supporting patients. Their anxieties can be exacerbated by the requirement for patients to have chemotherapy. Family members are important for health professionals during chemotherapy – carers are relied upon to alert them if the patient becomes unwell. They also provide patients with emotional, practical and physical support. Despite this, it appears that demands on informal carers, and their associated needs, are often overlooked by formal providers of care. Previous research has been conducted into the needs of carers while patients undergo chemotherapy. However, this has not drilled down into how carers' needs change over time, nor has it identified suitable interventions to address gaps in information and support.

Aims

This study therefore aimed to:

1. Describe the experiences of family members supporting relatives through chemotherapy
2. Conceptualise their evolving need for information and support
3. Examine factors that impact their confidence in supporting a patient
4. Identify feasible and acceptable interventions to be tested in the future.

Design and methods

The study comprised qualitative research conducted in two phases which ran between April 1st 2011 and May 31st 2012 in two sites: London and Southampton. The first phase was a longitudinal study which consisted of semi-structured interviews with family members at three points during the course of the patient's chemotherapy. These were carried out at the beginning, mid-point and end of treatment. These interviews provided insights into the implications of being a carer over time and assessed what affected carers' confidence throughout that journey.

The second phase of the study involved six focus groups: three groups with carers and three with healthcare professionals. These groups sought to validate the findings and conclusions drawn from the first phase. The groups also aimed to reach consensus on priorities and recommendations for future carer support. These groups also sought to compare carer and healthcare professionals' perspectives on priorities and create achievable targets for the provision of increased support.

Phase one

Sample and sampling

The study aimed to recruit 25 carers. Family members of patients having cisplatin-based treatment were specifically sought – this treatment has high toxicity and could therefore give insight into how carers manage difficult side effects.

Patients about to commence their first course of chemotherapy were approached for consent to recruit a family member considered most helpful and supportive in their everyday life.

The research used quota sampling to obtain a broad sample with diverse experiences. Participants were grouped according to gender, age and relationship to the patient and samples came from within each of these groups.

The interviews

The interviews in phase one were semi-structured – allowing carers to tell their stories in detail and focus on what they wanted to discuss. The first interview involved discussion of carer information needs and support at the start of chemotherapy. The interview at the mid-point focused on symptoms or problems and their management. The final end of treatment interview looked at how the impact of the treatment had altered over time and how carers accessed support for themselves.

Analysis

Data were analysed in two ways. First, through looking at the interviews on a line by line basis and adding up the time carers spent discussing different issues. The second depth approach was through Framework Analysis. Here a framework was devised from recurrent themes in the interviews. Within this, changes in experiences and perceptions over time were compared, both within an individual's journey and between carers.

Phase two

Sample and sampling

Family members were selected purposively primarily from those that completed the interviews in phase one and were willing to participate. Health professionals were selected from a range of medical, nursing and allied health professional groups.

The focus groups

Each focus group addressed the same guiding question: '*As a carer supports their friend/relative through chemotherapy, what help and information would increase their confidence?*'

The research team also created eleven statements on themes drawn from the phase one research. In groups, participants were asked to rank and rate these themes. The groups drew on a method called nominal group technique in attempt to reach consensus on recommendations for future needs.

Analysis

The data drawn from these groups were analysed with descriptive statistical analysis.

Findings

Phase one findings

Interviews were conducted with a diverse sample of 25 carers. Notably a third of carers recruited to the study were male – something lacking in prior research in this area. Most carers were the spouse or partner of the patient.

Findings differed between those carers supporting patients though a course of chemotherapy with curative intent, versus those in support of someone having palliative treatment. Although their stories often reflected common themes, there were crucial differences in outlook and experience:

- Carers of patients having curative treatment experienced considerable distress at the outset of treatment that appeared to continue throughout. At the root of this anxiety was fear of recurrence and concern as to whether the cancer could be cured.
- Carers of those having palliative treatment typically saw chemotherapy in a positive light; this was something offering hope for the patient's wellbeing. Their anxiety was focused on how they would manage the patient's decline.

Carers' confidence in managing their responsibilities was affected by:

- Where they were in the process: confidence developed from the beginning to mid-point of treatment. Carers of those having curative treatment came to view chemotherapy as part of a routine which helped them deal with it.
- Developing a familiarity with the hospital environment; relationships with the healthcare staff and knowledge of the treatment processes.
- Having the right contact numbers for acute oncology and out of hours support.
- Knowing when to call for help. This was sometimes unclear and an area of concern.
- Knowing how to interpret, manage and alleviate less tangible symptoms such as fatigue and weakness.
- Having needs met and questions answered when deciding to ask for help from professionals.

Carers felt the personal impact of treatment most keenly:

- With its impact on daily life: on limiting social arrangements or needing to take on chores or activities usually carried out by the patient. The impact of this was strongest at the outset of treatment.
- With the challenge of work. Over half of those interviewed were working. Employers were varied in their support for carers who needed to take time off for hospital appointments. For some carers it was difficult to deal with conflicting demands.
- With increased physical pressure: stress caused physical symptoms for some. Other carers with existing health issues felt limited in how much they could do.
- With the all-consuming nature of the patient's disease and treatment. Some carers felt their identity was compromised as cancer took over. Carers compared their role to the pressure and demands of a job.

Financial concerns were a consistent worry:

- Anxiety about lost income, travel expenses to appointments, unpaid bills and mounting debt recurred throughout the treatment journey.

Relationships were impacted by cancer and chemotherapy:

- With some carers there was evidence of some positive changes by the mid-point of treatment as it brought people together and strengthened relationships.
- For others there was strain and distance from their partner.
- In curative treatment cases, carers were more likely to express resentment and anger towards the patient. This was prevalent around the mid-point of treatment. Carers detailed points in the cycle where they felt patients should be able to do more for themselves; but often didn't.
- Relationships with friends (socially) or with other family members were seen to be neglected as treatment took over. Other people seemed to find it difficult discussing the disease and its treatment.

The end of treatment brought new concerns:

- Carers felt that the effect of stress and anxiety were cumulative and were unsure how to manage on-going worry.
- Carers' emotions were heightened at this transitional phase. Indeed, for those looking after palliative patients, the end of treatment was approached with trepidation.
- Carers felt anxious about what would happen next and what the future would hold. The challenge of living with and beyond cancer was evident among carers as well as patients.
- For others the end of treatment was an opportunity to reflect and consider future priorities.

Caring is an individual journey:

- Across all stages of the treatment trajectory, carers' experiences were varied – patients had different symptoms and needs and carers had different conflicting responsibilities and personal issues.

Phase two findings

Fifteen carers contributed across three focus groups – the majority were female. Twenty-five healthcare professionals took part in the three other groups. Within these, the largest participating professional group was nurses.

Focus group participants discussed the statements created from phase one of the research and discussed any additions to that list.

Rating the statements

They were then asked to rate the statements from 0 for 'No Importance' to 10 for 'Significant Importance'. The scores were summed and standardised and healthcare professional and carer scores compared.

There was clear consensus (equal or over 90%) on the importance of the following:

- carers should be given practical advice about how the side effects of chemotherapy can be managed;
- carers should be given details of sources of information for financial, emotional and practical support;
- carers should be clearly informed about how to access out of hours chemotherapy services and what to expect from them.

Informal carers as a group ascribed importance to the following statements, which suggest a need for direct and open relationships with healthcare teams:

- carers should be given information about diagnosis and prognosis in lay language that is easily understood;
- carers should be given specific information about their caring role and the impact it might have on their lives;
- carers should have an option to discuss their friend's/relative's chemotherapy with a health professional without them being present.

However, this was not echoed by the health professionals who placed more importance on directing carers to other sources of information and support. For example, they suggested it was relatively important that carers were given guidance on recommended web information (this was later ranked by carers as the least important statement).

Ranking the statements

The groups were then asked to rank the statements in order of importance to identify the most salient issues. Answers were looked at in two ways:

- frequency of ranking for a statement within the Top 5 list;
- frequency a statement was placed as number 1 (of most importance).

When 65% or more of the sample ranked a statement as top five importance, consensus was considered to have been reached. This consensus was reached on the same statements rated as important above: managing chemotherapy side effects, having clear information on out of hours services and giving information on sources of support. When assessed however, this agreement was felt to be dominated by the over-representation of healthcare professionals across the sample – and the consensus between those professionals. Looking at the way carers ranked the statements there was much greater variation. In fact, amongst carers only one statement reached 65% consensus; that carers 'should be given information about diagnosis and prognosis in lay language that is easily understood.' This statement was also ranked by carers as the most important overall. When it came to the health professionals, however, they again placed most importance on giving carers practical information about managing the side effects of chemotherapy, rather than interacting with the carers' individual information needs.

Discussion

The study revealed that carers of those having chemotherapy can feel confident supporting patients at home in both symptom management and accessing help from professionals if and when the patient becomes unwell. This ability to access help is very important for patient safety.

This confidence is upheld when carers have the right numbers to call for acute or out of hours support; when they are clear on the issues that warrant calling; and when they have their concerns dealt with appropriately. Their confidence increased when they gained familiarity with the hospital environment and built up relationships with practitioners.

The study also highlights carers' unmet emotional needs. These relate to fears over the patient's health declining. For some, these concerns start early on and persist throughout treatment. While patients' emotional needs have been previously identified, this research exposes carers' needs which are not routinely addressed in either primary or secondary care.

The research shows how carers are struggling to manage financial worries, work commitments and their everyday lives and this is affecting both their mental and physical health.

In addition to this, cancer diagnosis and treatment affects carer/patient relationships. For some, lack of knowledge about the effect of treatment – especially on a patient's energy levels and fatigue – means that their expectation about what the patient can do is mismatched with reality. This can lead to resentment and anger that arguably will be fuelled by carers' own tiredness, emotional fragility and the existential distress that a cancer diagnosis can generate.

The second phase of research may shed some light on the gap between carers' confidence supporting patients at home, and their stress in relation to the process. Carers emphasised the need for an ongoing dialogue with health professionals together with more specific information on the patient's diagnosis and prognosis. Healthcare professionals put less focus on engaging with carers, especially when the patient is not present. The research opened up a gap between what carers want and what healthcare professionals are able to provide in terms of specific advice and meeting carers' needs. Future research could tackle health professionals' attitudes in this area.

This research suggests that carers are heavily impacted by the demands of ambulatory chemotherapy and that their own physical and mental health can be compromised as a result. Carers' needs should be addressed to avoid placing further stress on both carers and the NHS itself.

Recommendations for research

Research should:

- Explore more fully the work involved for informal carers in supporting patients through the chemotherapy process and develop, implement and evaluate a minimally disruptive approach to care with the aim of reducing the burden of treatment on informal carers.
- Compare and contrast informal carers experiences and needs though execution of a large, longitudinal survey
- Explore the nature of and dynamics in family relationships over time through longitudinal qualitative studies incorporating samples of both patients and informal carers.
- Explore experiences and needs of informal carers from black and minority ethnic groups.
- Deepen understanding of the perspective of healthcare professionals regarding issues, concerns, challenges and solutions to supporting informal carers better in the chemotherapy setting.
- Develop and evaluate educational interventions for carers that aim to prepare informal carers' better for supporting patients through chemotherapy.

Recommendations for practice

- **Issue**: The impact of caring for someone receiving chemotherapy varies considerably and can result in widely varying needs that are not always consistently met by health professionals
- **Recommendation:** Health professionals need to become more aware of the experiences of carers and how they can potentially differ according to the type of treatment a person is receiving (curative or palliative) and the impact this can have and seek out opportunities to talk to carers about their own needs
- **Issue:** Some carers remain unclear about who to contact should the patient become unwell
- **Recommendation:** Specific information resources need to be developed and systems introduced to ensure carers are routinely given an explanation about whom to contact and in what circumstances and when this might be important
- **Issue:** As patients become unwell as a consequence of chemotherapy some carers had little confidence about what to do in these circumstances
- **Recommendation:** Health professionals should routinely assess and re-assess carers' confidence to support a person who is having chemotherapy. Informational resources should be developed to prepare and support them in this role.
- **Issue**: Some carers don't feel included by health professionals in the care planning process and lack information about treatment and its likely outcome
- **Recommendation:** Carers should be routinely encouraged to attend the hospital and be introduced to the health professionals involved in a patient's care, and with the patient's permission provided with an opportunity to hear about what treatment will involve and the outcome being worked towards. Health professionals should make time to establish a relationship with both the patient and carer and actively seek to involve them in the chemotherapy process.

- **Issue**: Carers often express a desire to speak to health professional on their own without the patient present but this opportunity is often not afforded them
- **Recommendation:** There should be opportunities made available for carers to discuss their own needs and concerns with health professionals and have any questions they have answered
- **Issue:** A significant number of carers experience emotional distress and the timing and pattern of this can differ according to whether patients are receiving curative or palliative treatment
- **Issue:** Some carers report experiencing significant financial hardship as a result of their caring role
- **Issue:** Being a carer for someone having chemotherapy can result in a considerable amount of 'work' and the impact this has on carers is often not acknowledged by health professionals
- **Issue:** The experience of chemotherapy can place a significant strain on family relationships, and partners sometimes expressed a sense of frustration with their partners and had not appreciated how difficult the whole experience would be
- **Recommendations:** Informal carers' needs for information and support should be assessed prior to a patient starting treatment and needs revisited as treatment progresses. In particular the need for emotional, financial and practical support should be addressed and information made available and onward referrals made as necessary. Explanations about the physical and emotional impact of chemotherapy on the patient may help mitigate feelings of frustration and misunderstanding between family members