

Family members' experiences and concerns as loved ones undergo chemotherapy treatment for cancer

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Introduction

Imagine hearing that one of our family or someone we dearly love has just been given a diagnosis of colorectal cancer, has to undergo major surgery and then at minimum, a six month course of chemotherapy. These are stories doctors relate to patients and their families every day. However, when it comes to us personally, when we are that family member sitting in that chair in the doctor's office with a loved one, and, hearing those words, we are shocked to the core. Our lives as well as theirs, will change forever, and whether we know it or not we (family members) are the most important people for that patient to help them get through this most difficult life-threatening experience. So the question is — how would we face it? How would we deal with it and, what would it be like for us as family members to care for, help and support a loved one who is on one of the most challenging journey's of their lives? This study aims at looking at some of these issues from the family members' perspective with a view to identifying family members' experiences and concerns in this cancer type context.

Background

Recent changes in healthcare management generally, and in cancer care in particular, indicate a major shift in the clinical management of cancer from hospitals and healthcare professionals (HCPs) to patients and their families. Several factors have contributed to this shift; shorter hospital stays, the global shortage of nurses, decreased financial resources and increased emphasis on outpatient treatment. One of these changes is in the administration of chemotherapy, whereby a patient receives treatment in the outpatient (chemotherapy) unit but is not admitted overnight. Prior to this patients receiving chemotherapy were treated as in-patients in hospitals. This change in practice then has shifted the responsibility for clinical management of cancer from hospitals to patients and their families.

Colorectal cancer (CRC) is cancer of the colon and is second only to lung cancer as a cause of cancer death in Ireland. Next to non-melanoma skin cancer, CRC is the second highest registered cancer in Ireland affecting both males and females (National Cancer Registry, Ireland (NCRI) 2006). Following a diagnosis of CRC various treatments or a combination of treatments are proposed. For example, treatment may begin with surgery followed by a course of chemotherapy. According to the NCRI (2006) almost 40% of patients with CRC are now being treated with chemotherapy.

Chemotherapy however, can present many undesired side-effects. Patients can experience symptoms such as nausea, vomiting, diarrhoea, anorexia, fatigue, alopecia, poor sleep, pain and forgetfulness. While many patients cope well, high proportions develop significant psychosocial distress, anxiety, depression and/or hopelessness.

With the administration of chemotherapy now in chemotherapy units, coupled with more aggressive treatment regimes, patients and family members are more likely to encounter side-effects of chemotherapy at home where there is limited access to oncology nursing or medical specialists. In these situations, the side-effects of chemotherapy may exacerbate patients' suffering and trauma and burden of care for family members. In addition, research indicates that family members often misconstrue the side-effects of chemotherapy as evidence that the cancer illness is worsening, and this increases their fears in relation to the future of their loved one.

In summary, the management and treatment of CRC is changing. Many family members are now caring for patients, who attend chemotherapy units, in their own homes. While this might be welcomed, the many side effects caused by chemotherapy can be particularly worrying for both patients and their families. Chemotherapy units are relatively new to Ireland and a review of the literature highlights a paucity of research on family members of patients with cancer who are attending chemotherapy units. The aim of this study therefore is to explore family members' experiences as loved ones undergo chemotherapy treatment for colorectal cancer and to develop a theory of their resolution processes.

Method

In order to examine these issues, family members of patients with colorectal cancer who, had undergone surgery and are now undergoing chemotherapy, are being interviewed, in order to understand their experiences and concerns. In addition, the strategies family members use to resolve these issues are being explored in order to capture how family members manage the difficulties and personal challenges of caring for a loved one with cancer.

Family members are being asked to tell their story, to reflect on their experiences of what it has been like for them from when they first heard about their loved one's diagnosis of

cancer to where they are presently. During the initial interviews family members' stories were listened to without interruption except to clarify or give more detail on some spoken issues. However, as interviews continue and as some issues are being repeated by family members, then these issues are explored in more depth to see how family members resolve some of these concerns.

This study is currently ongoing. However, some of the findings emerging from the interviews with family members include: managing uncertainty, guarding emotions, monitoring patient deterioration, distancing from outsiders and keeping routines.

As interviews continue each interview is compared to the next interview to identify what are the commonalities and what are the differences with family members' experiences and concerns. Family members' main concerns along with how they resolve these concerns will be explored examined and then developed into a theory.

Conclusion

The outcomes of this study will be particularly relevant to a number of people. It is envisaged that findings from this study will provide oncology healthcare professionals with a clearer understanding of family members' experiences and concerns during the chemotherapy treatment stages of CRC. This knowledge and understanding will help healthcare professionals to be more sensitive to family members needs and how best to support them as individuals and as families.

Additionally, it is envisaged that the findings will help to establish better support structures that give family members a voice firstly, in relation to having access to oncology healthcare professionals, secondly to receiving cancer related information from healthcare professionals. Thirdly, findings will contribute to establishing best practice guidelines for involving family members in the care of patients with cancer. These structures could be viewed as recognising the rights of family members to have information and support from healthcare professionals thus enabling them to provide better care and outcomes for loved ones with cancer. Finally, these structures would give oncology healthcare professionals a practical workable approach to guide support structures for family members.

Similar to establishing best practice guidelines for oncology healthcare professionals, it is expected that the findings from this study will influence policy makers to establish best practice policies and guidelines as to how best to support family members during the chemotherapy stages of cancer treatment. In doing so, the operationalisation process could be made more visible to those healthcare professionals who practice in cancer care contexts and who are responsible for rolling out these policies.

Given the lack of research on family members' experiences and concerns in the chemotherapy stages of patients' treatment, data generated by this study will significantly impact on

healthcare professionals and family members and thereby will impact on the wider public. It is hoped that the findings will help to increase the public trust of the healthcare system at a time when trust in the cancer care programme has received much criticism in Irish media news and political fora. Establishing policies that are open and transparent, that aim to improve patient outcomes, and support family members; family members and healthcare professionals will help to rebuild this public trust by responding to the needs and concerns of family members of patients with cancer who are at the core of patient care management. This is all the more critical at a time when there are limited resources.

Finally, family members can have a significant impact, both on costs to the healthcare system and to patient outcomes, but this will only be realised if more attention is given to responding to their needs in the cancer-chemotherapy care context.

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