The financial impact of a cancer diagnosis

Linda Sharp
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National
Cancer
Registry
Ireland

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Summary

Introduction

The costs to the health services of the diagnosis and treatment of cancer are substantial. These costs have increased over the past decades and are expected to rise further in coming years with population ageing and advances in treatment. However, the economic burden of cancer does not fall only on the health services, but also on patients, their families, and society as a whole. Until recently, little has been known about the costs incurred by cancer patients and their families.

This project set out to answer the following questions:

- What are the main elements of additional cost (medical and non-medical) incurred by cancer patients and their families?
- How much additional expense do patients incur as a result of their diagnosis with cancer?
- What impact does cancer have on income (e.g. lost pay, availability of sick pay, access to benefits)?
- What proportion of patients (a) incur additional costs or (b) experience financial difficulties as a result of their cancer diagnosis?
- Are particular groups of patients more vulnerable to incurring additional costs or financial difficulties as a result of having cancer?
- What are the consequences of the additional expenses, and any changes in income, for patients and their families?

Methods

The project focussed on breast, prostate and lung cancer. The research was in three stages and used complementary qualitative and quantitative methods. Stage one involved in-depth, face-to-face, interviews with key informants, namely 21 hospital-based Oncology Social Workers, based in 11 hospitals. Stage two involved in-depth, face-to-face, interviews with 20 cancer patients who had experienced additional costs, or financial difficulties, as a result of being diagnosed with cancer (11 with breast, five with prostate and four with lung cancer, from eight hospitals). Stage three involved a large postal survey of cancer patients. 1,373 patients diagnosed with breast or prostate cancer in the previous 6-24 months, or with lung cancer in the previous 3-21 months, were identified from the records of the National Cancer Registry and invited to complete the survey; 740 (54%) participated.
This triangulation of methods generated rich data and enabled in-depth analysis.

Key findings

Most patients and families incur additional costs as a result of a cancer diagnosis. These can include direct medical costs such as those associated with seeing consultants, GPs, or allied health professionals, and those associated with buying medications to help alleviate the symptoms of cancer and the side-effects of treatment. In addition, the majority of patients have out-of-pocket expenses in relation to travelling to hospital appointments. Increased utility bills are also common because patients undergoing treatment, or recuperating from surgery, are at home more often than before diagnosis. For some patients and families, the additional costs incurred can be substantial.

The majority of cancer patients who are working need to take time off around diagnosis and during treatment and a substantial proportion do not receive any sick pay from their employer. This means that household income decreases for many patients and their families. In addition, the process of obtaining medical cards, and HSE and social welfare payments, can be complex and demanding for patients, and may involve a long wait.

The combination of this reduction in income with the additional costs has wide-ranging consequences for cancer patients and their families. Some have to use savings and some borrow money from financial institutions, friends, family, or employers. Some have more difficulties in meeting financial commitments, such as mortgage payments. Some have to reduce general household spending, as well as spending on "extras" like clothes, holidays and leisure activities. Overall, the household's ability to make ends meet is more difficult for a substantial proportion of patients (increased financial stress). Many also experience increased worries about their household's financial situation (financial strain). This increased financial stress and strain is associated with a greater likelihood of experiencing depression, anxiety or emotional stress.

Patients in every socio-demographic group can be vulnerable to experiencing financial difficulties as a result of a cancer diagnosis, and their vulnerability is a function both of their own financial and employment circumstances and the support available to them from those around them (e.g. family and friends). Some groups of cancer patients appear particularly vulnerable to the adverse financial effects of a cancer diagnosis, in particular those with dependants and those who are working at the time of diagnosis. This can mean that, for example, the self-employed may decide to keep working, or return to work, during treatment, on financial grounds. Patients, and their families, who live in remote areas may experience particular difficulties due to having to travel long distances for treatment.

Conclusions and recommendations

This research has revealed - for the first time in Ireland - the significant financial impact that a diagnosis of cancer can have for patients and their families. The findings of this research are relevant, and have implications for, a range of groups and organisations including - perhaps most importantly - those who plan and provide cancer and health services in Ireland.

The conclusions, and recommendations which follow from these, fall into four main areas.

Costs associated with cancer care

- Many cancer patients incur out-of-pocket costs in visiting their GP or hospital doctors.
- Many patients pay for prescription and over-the-counter medicines, which they need to support their treatment.
- Treatment-related travel and transport costs can be a major burden for patients.

Recommendations

1. *Great attention needs to be given to alleviating the financial costs of undergoing cancer treatment.*
2. *Specific initiatives are needed to minimise the cost of travel.*

Work issues

- Most cancer patients who are working at the time of their diagnosis experience a drop in income. The self-employed can be particularly badly affected.
- Employers' sick pay provision is very variable and policies are often unclear to staff, causing worry and confusion.
- Patients have many other concerns around employment, including anxiety about returning to work, and worries about their ability to do the same work post-treatment.

Recommendations

3. *The self-employed should be encouraged to take out permanent health insurance and income protection.*
4. *Employers should be encouraged to be more supportive of staff affected by cancer, and to be clearer about their staff policies and provisions.*

Medical cards, HSE and social welfare payments, and financial advice

- Patients with cancer can find it difficult to get information on availability, eligibility and the application process for medical cards. This also applies to HSE and social welfare payments.
- Patients experience major variations in the time taken to process applications, entitlement to medical cards, medical card reviews, and funding awarded to help with the costs of wigs. In consequence, decision-making around applications can appear arbitrary.

Recommendations

5. *Improved information about medical cards and HSE and social welfare payments should be made available to cancer patients.*
6. *In view of the rapid course of the disease in many cases, applications from cancer patients for medical cards and other benefits should be fast-tracked.*

Overall financial impact of cancer

- The impact of extra costs, sometimes exacerbated by decreased income, means that cancer patients can have difficulty paying household bills and mortgages. This results in increased levels of financial stress and strain.

Recommendations

7. *Hospital-based financial advice services for cancer patients should be established.*

Foreword

For a long time the Irish Cancer Society has been aware that, for many people, a cancer diagnosis has not only been a health and psychological burden, but also a considerable financial burden. In the last ten years the Society has seen a doubling in demand for financial assistance paying out €3.5 million in grants in the last five years alone. In 2009 the number of people seeking financial help increased by 20%.

Until now, the financial burden of a cancer diagnosis has not been measured or quantified and therefore, the Society could not be sure that its response was the best one to meet the needs of the many patients who turn to us for help. This study provides vital and timely information for the Society and for all those who support cancer patients, as well as representing an important contribution to our understanding of the full burden of cancer on patients and their families.

The Society now has key information for policy-makers who play a central role in designing services which are responsive to the needs of cancer patients. The current economic and financial crisis must not be allowed to get in the way of ensuring that cancer patients get the help they need. In that regard, speedy and easy access to a medical card and where necessary, to supplementary welfare, for a cancer patient should be immediately made available as one way to ensure that financial worries do not increase the emotional stress experienced by patients.

It is notable that every social group is vulnerable to the financial burden of a cancer diagnosis but some groups are more exposed, including those at work and supporting a household and the self-employed. The Society believes measures can and must be taken to support these patients in a timely and effective manner, to ensure that the burden they carry due to their illness is lessened.

The Society welcomes this report and wishes to acknowledge all those who have contributed to its publication. In particular we thank those patients who participated and those Oncology Social Workers whose contribution to this study was invaluable. Finally, we wish to thank the National Cancer Registry for completing an excellent study on our behalf.

Bill McCabe
Chairman, Irish Cancer Society

Foreword

At a time of fundamental reconfiguration of our cancer services this report, focussed on the impact which a diagnosis of cancer has on the individual patient and their wider family, is particularly welcome. The need for an ever increasing patient focus in the ways in which we plan and deliver our health services has been stressed in the National Cancer Control Strategy and the Health Strategy, Quality and Fairness. In striving for higher quality and efficiency in our cancer services, we must never lose sight of the cost of cancer to the individual, be these costs physical, psychological or economic. As a society our overall response to cancer must seek to respond to all of these needs.

This report focusses on the financial and economic costs of cancer to patients and their families in Ireland. It provides a detailed picture of the financial impact that cancer has, in terms of out of pocket costs for healthcare, related outgoings (such as costs of travel to hospital appointments) and effects on employment and income. It also describes the financial, and some of the emotional, consequences of these extra costs on patients and their families. The report describes some of the actions which could be taken to alleviate this impact.

On behalf of the National Cancer Registry Board we appreciate the involvement of the Irish Cancer Society in this work.

Tony O'Brien
Chair, National Cancer Registry Board

Contents

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Linda Sharp and Aileen Timmons

Chapter 1 Introduction

1.1 Background

One in three people will be diagnosed with cancer at some point in their lifetime. In Ireland this translates into almost 23,000 individuals diagnosed with a new invasive cancer each year (National Cancer Registry, 2009). Cancer incidence is expected to increase by 45% between 2010 and 2020, and by 110% between 2010 and 2030 (National Cancer Registry, 2008) mainly due to population ageing. In Ireland, as in other countries, survival from cancer is increasing slowly, but steadily (Comber & Walsh, 2008). Altogether this means that there are increasing numbers of people living with cancer in Ireland. Estimates from the National Cancer Registry Ireland (NCRI) suggest that there are more than 134,000 people living with a diagnosis of cancer in Ireland, 59,500 men and 75,000 women.

There is growing awareness that cancer can have a major financial impact on newly diagnosed patients, those living with the disease, and their families. Indeed, it has been claimed that almost all families confronted with a diagnosis of cancer have financial issues or economic losses of some kind (Berkman & Sampson, 1993; Gordon et al., 2007). Cancer patients are more likely to report financial difficulties than persons without cancer (Arndt et al., 2004; Arndt et al., 2005). In several small studies, conducted in diverse locations, between 11% and 16% of patients considered themselves to have major financial difficulties due to a cancer diagnosis (Bruera et al., 1990; Martinson et al., 1993; Karesen & Langmark, 2000). However, it appears that in addition to the group who experience severe financial problems, there is a more general and widespread issue of patients incurring additional expenses as a result of cancer. These out-of-pocket costs are varied and might include: expenses directly due to treatment (e.g. doctors fees); expenses related to treatment (e.g. travel costs, prescription medication, wigs); or more general expenses that are a result of having cancer (e.g. new clothes due to weight fluctuations, different food or nutritional supplements due to the effects of chemotherapy, home or childcare)(Moore, 1999; Pearce et al., 2001; Longo et al., 2007). In addition, some patients may experience a drop in income due to time away from work because of the cancer or its treatment (Bennett et al., 2008; Lauzier et al., 2008). It has been suggested that particular sub-groups of patients (e.g. those with a lower income; Arozullah et al., 2004; Langa et al., 2004) may be particularly vulnerable to the adverse financial and economic effects of cancer.

A few studies have described the financial consequences of cancer for patients and their families, which include a reduction in total household earnings due to family adjustments for the disease (Chirikos et al., 2002), having to cut-back on "extras" such as social expenditure or holidays (Cohn et al., 2003), and having to borrow money (Dockerty et al., 2003). In terms of non-financial consequences, the additional expenditure may cause financial worries or stress and lead to psychological and emotional problems (Chapple et al., 2004). Indeed, in a study by Macmillan Cancer Support in the UK, many patients claimed that financial concerns were second only to pain as a cause of stress (Quinn, 2002).

There have, however, been relatively few studies of the costs incurred by those affected with cancer and many that have been done have some limitation. Some used data routinely collected for other purposes to make estimates and inferences about the financial and economic impact of cancer on patients (for example, Yabroff et al., 2005; Hassett et al. 2009). Some imputed aspects of costs (e.g. travel costs based on mileage; Longo et al., 2007). Some focussed on a single dimension of costs (e.g. patients' time costs associated with treatment, non-medical costs, transport, medications, impact on earnings)(Houts et al., 1984; Allirajah et al., 2005; Owusu-Barnaby et al., 2006; Yabroff et al., 2007; Syse et al., 2008; Schrag et al., 2009). However, the financial impact of cancer is likely to be multidimensional; for example, patients may incur costs associated with treatment while, at the same time, losing income through being away from work to undergo treatment. Some studies were small in size, focussed on patients with a single cancer, or used a methodology that makes it difficult to assess the extent to which the results are affected by bias. Finally, the financial consequences of cancer for patients are likely to be dependant on the health and social welfare setting in which the patients live - therefore it is not clear how relevant the findings of studies from other settings (e.g. the UK or USA) are to Ireland.

1.2 Financial impact of cancer for patients in Ireland

The Irish Cancer Society (ICS) offer a welfare grant scheme which provides assistance to individuals who have financial difficulties following a cancer diagnosis.[a] These grants are for amounts up to €1000 and are intended to meet a specific financial burden that arises exclusively out of a cancer diagnosis. Typically grants are awarded for one or more specified purposes, such as costs of travel to treatment appointments, fuel costs, cost of a wig, costs of home modifications, etc.

The Society noticed that demand for these grants appeared to be increasing. However, it was impossible to know whether this was due to increasing awareness of the scheme or increasing hardship amongst the patient population. There was no other evidence to draw on as regards the financial impact of cancer in Ireland - nothing is known about the type and magnitude of costs incurred by patients, which patients are affected, and the consequences for patients and their families in Ireland. This, and the evidence accumulating from other countries, provided the rationale for the project.

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[a] For more information about this scheme and the application process, see the website of the Irish Cancer Society (http://www.cancer.ie/nursing/finance.php).

The Society asked the National Cancer Registry (NCRI) to conduct a research project investigating the financial impact of cancer for patients and their families in Ireland. This report is the result of that research.

1.3 Project aim and research questions

The aim of the project was to identify and describe the financial costs and consequences of cancer for patients and their families in Ireland.

The project set out to answer the following questions:

- What are the main elements of additional cost (medical and non-medical) incurred by cancer patients and their families?
- How much additional expense do patients incur as a result of their diagnosis with cancer?
- What impact does cancer have on income (e.g. lost pay, availability of sick pay, access to benefits)?
- What proportion of patients (a) incur additional costs or (b) experience financial difficulties as a result of their cancer diagnosis?
- Are particular groups of patients more vulnerable to incurring additional costs or financial difficulties as a result of having cancer?
- What are the consequences of the additional expenses, and any changes in income, for patients and their families?

1.4 Structure of the report

The project adopted both qualitative and quantitative approaches (i.e. semi-structured, in-depth interviews and a questionnaire survey) to investigate the financial impact of cancer and the methodology is described in detail in chapter 2. Chapter 3 includes the results of the qualitative interviews. The results of the quantitative survey are contained in chapter 4. The results and their implications are discussed in chapter 5, and chapter 6 summarised the findings of the study and presents the overall conclusions and recommendations.

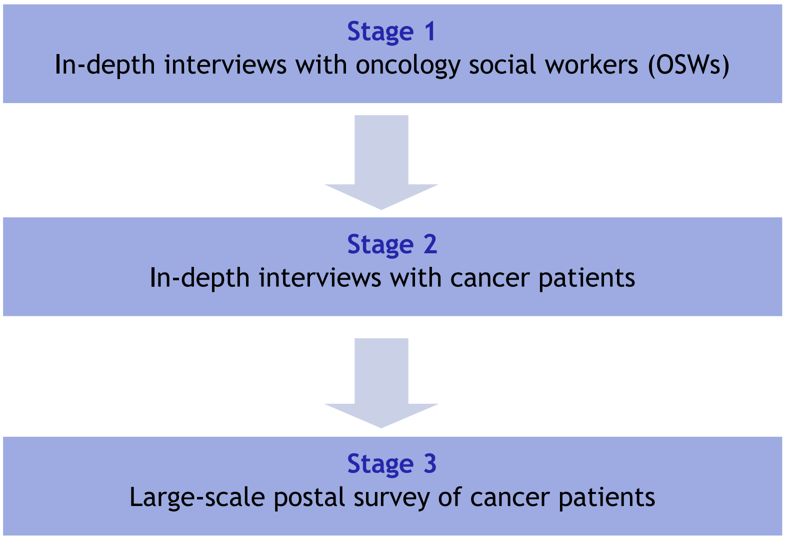
A summary of the healthcare and social welfare system in Ireland is provided in Appendix 1. Appendix 2 contains an analysis of welfare grants awarded by the Irish Cancer Society in 2006.

Chapter 2 Methods

2.1 Overview of the project design

The project employed complementary qualitative and quantitative methods. Qualitative methods - specifically in-depth, face-to-face, semi-structured interviews with key informants and cancer patients - were used to identify the full range of additional costs/expenses incurred and to explore the consequences of these for patients and their families. Quantitative methods - specifically a postal survey of cancer patients - were used to describe the "big picture" in terms of assessing the financial impact across the population of cancer patients in Ireland. This triangulation of methods generated richness in data and enabled in-depth analysis.

Figure 2.1 Stages of the project



The project fieldwork was conducted in three stages (figure 2.1). Stage 1 involved in-depth interviews with key informants, namely oncology social workers (OSWs). Oncology social workers are based in several of the larger hospitals across the country. Although it is not part of their formal remit to deal with financial problems experienced by cancer patients, they often advise and assist patients in relation to financial matters. In particular, an oncology social worker is one of the healthcare professionals who can make an application on behalf of a patient to the Irish Cancer Society for a welfare grant. It was considered, therefore, that oncology social workers would have a good overview of the range of expenses incurred by patients in different financial situations, as well as the consequences of these, and therefore would be suitable key informants. Stage 2 involved in-depth interviews with cancer patients[b] who had experienced additional costs, or financial difficulties, as a result of being diagnosed with cancer. These interviews concentrated on patients' personal experiences and provided greater insight into the consequences of any increase in expenses and/or any change in income experienced directly as a result of the cancer diagnosis. Analysis of both sets of interviews allowed us to develop a questionnaire for a large-scale postal survey of cancer patients in Ireland (stage 3). The survey allowed us to quantify the proportions of patients who incurred additional expenses and the amounts incurred and to identify which sub-groups of patients were most likely to experience additional costs or financial difficulties.

2.2 Costs and consequences

The project focussed on costs incurred by individuals living with cancer, typically those experienced around the time of diagnosis and initial treatment and soon afterwards. Costs specifically associated with palliative care were not investigated.

Three categories of costs were considered (Adis Data Information BV, 2005):

- **direct medical costs** - which are costs associated directly with a healthcare intervention. In this category, we included costs of treatment or follow-up appointments with healthcare professionals, costs of supportive medications, etc;
- **direct non-medical costs** - which are costs associated with the provision of medical services. We included out-of-pocket expenses related to treatment (e.g. travel and parking costs associated with hospital appointments) and other associated issues (e.g. household utility bills).
- **indirect (non-medical) costs** - which are costs associated with reduced productivity due to illness. We assessed these in terms of time off work and decreased income.

The consequences of these direct and indirect costs for patients and their families may be wide ranging. Some, such as emotional or psychological effects, could form the focus of a study on their own. The main focus of this study in terms of assessing consequences was the overall financial impact of cancer on the patient's household. Although emotional and other issues were raised by cancer patients in interviews for example, these were not followed-up or discussed in great detail, so as to limit the burden on participants. The survey also concentrated primarily on financial consequences, although a brief assessment of negative emotional states was also included.

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[b] Individuals who have been diagnosed with cancer at some point in their life may use a variety of terms to refer to themselves, such as "cancer patient", "cancer survivor", "a person living with cancer", "a person who had cancer (in the past)", etc. In this report, we have used the term "cancer patient" to refer to anyone who has had cancer, irrespective of how long ago the individual concerned was diagnosed or treated.

2.3 Cancer sites included in the study

The study focussed on cancers of the breast[c] and prostate (the most commonly diagnosed tumours in females and males respectively) and lung (the third most common cancer in both sexes).[d] The numbers of new cases of breast, prostate and lung cancer diagnosed each year in Ireland are shown in table 2.1 (National Cancer Registry Ireland, 2009; http://www.ncri.ie).

In addition to their frequency, the reasons for selecting these cancers were: (a) they permit the investigation of sex-specific issues, as well as a comparison of the sexes; (b) the treatment patterns differ, and so patients may have experienced different treatment-related expenses; (c) the average age at diagnosis ranges from 59 years for breast cancer, to 70-72 for lung cancer and 73 for prostate cancer, so employment/work-related issues may be more of less important for different cancers; (d) the relationship with social class varies (e.g. lung cancer incidence is strongly inversely related to social class, while breast and prostate cancer risk is higher among the higher social classes). We considered that including these three cancers would help capture the entire picture with regard to the costs and consequences of cancers in adults in Ireland.

Table 2.1 Average annual number of new cases of breast, lung and prostate cancer diagnosed in Ireland in 2005-2007

Cancer site	*Males*	*Females*
Breast	-	2,315
Prostate	2,462	-
Lung	1,068	742

Source: National Cancer Registry Ireland (www.ncri.ie)

2.4 Ethical approval

The study received ethical approval from the following committees:

- Beaumont Hospital Ethics (Medical Research) Committee
- Clinical Ethics Committee of the Bon Secours Health System (Dublin, Cork, Galway, and Tralee)
- Ethics Research Committee at the Mid-Western Regional Hospital, Limerick

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[c] Although breast cancer can occur in men, it is very rare, and the study was limited to breast cancer in women.

[d] Colorectal cancer is the second most common cancer in both sexes. Patient costs associated with treatment for colorectal cancer are being investigated in a related project being conducted by the NCRI, therefore colorectal cancer was not included in the current study.

- Galway Research Ethics Committee (site specific approval for University College Hospital Galway, Merlin Park, and The Galway Clinic)
- Letterkenny General Hospital Ethics Committee
- Mayo General Hospital Research Ethics Committee
- Research Ethics Committee, Health Service Executive, South Eastern Area
- St James Hospital/The Adelaide & Meath Hospital incorporating the national Children's Hospital Research Ethics Committee
- St Luke's Hospital Research Management Committee
- St Vincent's Healthcare Group Ethics and Medical Research Committee
- The Clinical Research Ethics Committee of the Cork Teaching Hospitals

2.5 Pilot work: analysis of Irish Cancer Society welfare grants

To obtain an initial picture of the nature of financial difficulties among cancer patients and their families, the welfare grants awarded by the Irish Cancer Society were analysed. The analysis related to 2006, the most recent complete year at the time the current project began. Full results of the analysis are included in Appendix 2.

Briefly, a total of €429,511 was awarded by the ICS in the form of grants to 717 individuals in 2006. The median amount awarded was €600. Grants may be awarded for more than one purpose. Almost half (49%) of awards were intended to help cover the costs of travel, generally to hospital appointments, with a further 8% for related accommodation and subsistence costs. Just over one fifth (21%) of awards were intended to help with difficulties in paying household bills, and a further 9% were contributions towards the cost of personal care items, such as wigs or hairpieces. 17% of awards were related to loss of earnings. A few awards were made in relation to respite care, convalescence care, assistance around the home or with children, and household modifications. Two particular issues were suggested from the analysis of the awards made to patients with breast, prostate, lung or colorectal cancer: (1) the time between applying for, and receiving, social welfare benefits may be a time of financial difficulties for some patients; and (2) those with dependants aged under 18 may have particular financial difficulties.

2.6 Methods of the in-depth interviews

2.6.1 Stage 1: Interviews with key informants

All practicing oncology social workers were invited to take part in an in-depth interview on the topic of financial difficulties experienced by cancer patients. Only the few oncology social workers who did not see patients with breast, prostate or lung cancer were ineligible.

Interviews were conducted by a single researcher (the study coordinator (AT)) and took, on average, between 60 and 90 minutes. All except one was carried out face-to-face at the respondent's place of work; the other interview was carried out by telephone. All participants provided informed consent and, before the interview started, were given assurances of confidentiality. With the permission of the interviewees, interviews were audio-recorded. One interview was transcribed by hand during the interview at the request of the interviewee.

Interviews were semi-structured around a topic guide. The topic guide helped to ensure systematic coverage of key areas across interviews but was used flexibly to allow respondents to discuss the topics in a natural way and to facilitate appropriate probing. The topic guide was developed from a review of the literature, the results of the analysis of the Irish Cancer Society welfare grants scheme (see Section 2.5 and Appendix 2), and brainstorming sessions. Interviewees were asked about: direct extra costs (medical and non-medical) due to cancer which patients experienced; the impact of a cancer diagnosis on work and income for patients and family members; and the impact of both any extra expenses and/or any change in income on family budgets. Interviewees were also asked about which groups of patients, if any, they considered to be especially vulnerable to experiencing cancer-related financial difficulties and for suggestions to improve the system and help alleviate hardship among patients and families. They were invited to discuss any other issues they thought pertinent or relevant. Interviewees were *not* asked to discuss particular "cases" or reveal names or other identifying information about particular patients or families. The topic guide was able to evolve to some extent from one interview to the next i.e. if new themes/issues were raised in one interview, these could be followed-up in later interviews.

Twenty-one oncology social workers were interviewed during February and March 2007. The original intention was to stop recruiting social workers when no new information or themes were being raised in interviews. However, because of the small number of social workers working in oncology departments in Ireland and the high level of interest in the study, it was decided to include all eligible social workers who wanted to be interviewed. This allowed us to achieve a very detailed and comprehensive picture of the financial burden of cancer on patients in Ireland. The 21 social workers interviewed were based in 11 hospitals across the country, including large and smaller hospitals, those in urban and more rural areas, and those that were near and far from centres where radiotherapy was available. They had varying levels of experience; while some had been practicing in social work for more than 10 years, others were more recently qualified. In addition, some had also worked in settings outside oncology.

2.6.2 Stage 2: Interviews with cancer patients

This stage of the project focussed on patients and/or families who had experienced financial difficulties or incurred additional costs as a result of their cancer diagnosis. In this context "financial difficulties" was self-defined by the patient or family member. Patients potentially eligible to participate in the study were identified by oncology health professionals (oncology social workers, clinical nurse specialists in oncology, breast care nurses, urology nurse specialists, and other health professionals based in cancer centres) in eight hospitals throughout Ireland. In some centres, the medical teams displayed study posters and leaflets in patient waiting areas and patients who had incurred extra costs or experienced financial difficulties as a result of having cancer were invited to contact the research team directly. In other centres, the healthcare professionals told patients about the study, asked them if they would be willing to take part, and passed the details of those who agreed on to the research team. The study co-ordinator then contacted the patients to arrange a suitable time and location for the interview.

Interviews were semi-structured around a topic guide, which was developed from the results of the analysis of the interviews with oncology social workers, a review of the literature, analysis of the Irish Cancer Society welfare grant scheme, and a brainstorming session with members of a cancer support group. As with the social worker interviews, the topic guide was used as a prompt to ensure that key areas were covered, but was applied flexibly so that topic and issues were discussed as and when respondents raised them. Although the topic areas were similar to the social worker interviews, in these interviews the focus was on the *personal experience* of the respondent and their family. Interviewees were asked about the direct medical and non-medical costs they had incurred because of their cancer; the impact their cancer diagnosis had on work and income; and the impact of both any extra expenses and/or any change in income on their family budget and other aspects of their life. Interviewees were also invited to make suggestions on how the system might be improved to avoid future patients experiencing similar difficulties and to raise any other issues they felt were important. As with the social worker interviews, if a new topic was raised in one interview, it could be added to the topic guide for discussion in later interviews. During the interview, some information was sought on patients' socio-demographic characteristics and circumstances (e.g. age, sex, area of residence, family size, dependants, employment status, health insurance).

Interviews were conducted by a single researcher (the study coordinator (AT)), were face-to-face, took place in a hospital or at a cancer centre and were, as far as possible, scheduled to coincide with a patient appointment or visit so that patients would not have any additional travel costs associated with taking part in the study.

Table 2.2 Characteristics of patients interviewed	
Cancer site	breast: 11 prostate: 5 lung: 4
Age	less than 50 years: 7 50-59 years: 8 60-69 years: 4 70 and older: 1
Sex	female: 14 male: 6
Area of residence	urban[1]: 10 rural: 10
Medical card	at time of diagnosis: 3 obtained after diagnosis: 13 no medical card: 4[2]
Private health insurance at diagnosis	yes: 8 no: 12[3]
Status in household - main earner	yes: 10 no: 10
Employment status at diagnosis	working: 14[4] temporarily laid-off: 1 on maternity leave: 1 on national training scheme: 1 retired: 3
Received sick-pay from employer	yes: 7 no/not applicable: 13
Dependants[5]	yes: 7 no: 13
Marital status	married: 10 single: 4 single mother: 4 widow(er): 1 separated: 1

[1] "urban" includes those resident in cities, "rural" includes all other patients; [2] one patient didn't apply for a medical card, one had army medical care, one was not eligible for a medical card, and one obtained a medical card at a later stage following recurrence; [3] one patient had free medical care provided through the army; [4] none of the interviewees were self-employed; [5] school age children living at home

All participants provided written informed consent. Before the interview started, participants were given assurances of confidentiality and reminded that participation was voluntary and they could change their mind about taking part at any time, or refuse to answer particular questions. Interviews lasted between 45 minutes and 1 hour on average. With the permission of the interviewee, interviews were audio-recorded. One interview was only partly recorded (because of technical difficulties) but was immediately transcribed from memory by the interviewer.

Recruitment to the study ceased once new themes/issues stopped emerging. Twenty patients were interviewed during August and September 2007. The characteristics of the participants are summarised in table 2.2.

2.6.3 Analysis

Each interview was transcribed verbatim and anonymised to ensure confidentiality by removing any details that might identify the social workers or any patient or family. The accuracy of the transcription was verified against the audio-recordings. The set of social worker interviews and the set of patient interviews were analysed separately. A thematic approach was used for the analysis (Pope et al., 2000; Malterud, 2001). The analysis was ongoing and iterative, such that analysis of early interviews informed the content of future interviews to ensure sufficient depth was reached. Transcripts were read and re-read by the interviewer to obtain an overall picture and familiarity with the data. The interviewer and another researcher independently reviewed and coded transcripts of the first few interviews. They then discussed the coding to arrive at a consensus. This process helps ensure validity of coding categories and analytic rigour. The codes were combined into families by the interviewer. The codes were then applied to the rest of the interviews, with the code lists allowed to refine and develop as interviews and the analysis progressed. Descriptive accounts were then prepared, enabling the identification of the major themes and sub-themes. Atlas.ti software (Murh, 1997) was used to facilitate coding as well as to link codes/families/themes across interviews and to consider each theme in the context of the interview set.

Since common themes arose in the social worker and patient interviews, the results of the two sets of interviews have been presented together. Where a theme only arose or was more strongly emphasised in the social worker interviews or in the patient interviews, this has been made clear in the text.

2.7 Methods of the questionnaire survey

Stage three of the project involved a large-scale questionnaire survey of patients with breast, lung and prostate cancer in Ireland. In order that a representative picture of the financial burden of cancer in the patient population in Ireland could be obtained, the survey was not limited to those patients who had incurred financial problems or additional expenses as a result of their cancer: all patients who fulfilled the eligibility criteria could take part (Section 2.7.2).

2.7.1 Questionnaire development and content

The results of the pilot work and the qualitative analysis were used to develop a questionnaire to quantify the financial impact of a cancer diagnosis for patients with a diagnosis of breast, lung, and prostate cancer in Ireland. A self-completion, postal questionnaire was developed. Topics for inclusion in the questionnaire were identified from stages one and two of the project and included:

(a) what expenses patients had had because of their cancer diagnosis (including cost of consultant and GP visits, treatment-related travel costs, hospital parking, prescription medications, clothing and wigs, dietary supplements, home-help, childcare, etc.) and an estimate of how much was incurred;
(b) whether spending on household bills (e.g. heating, telephone, food) had changed since the cancer diagnosis;
(c) whether patients had to take time off work because of the cancer diagnosis and if so, if sick pay was provided; whether family members had to take time off work; and any changes in household income following diagnosis;
(d) whether HSE or social welfare payments or other sources of financial help were obtained following the cancer diagnosis;
(e) financial consequences, including whether savings were used, or money borrowed; ability to meet mortgage or personal loan payments; whether household spending on regular (e.g. nights out, take-away food) or other (e.g. leisure activities, holidays) items was reduced because of cost.

Most of the questions were closed, with respondents invited to tick one or more response options. A few comment boxes were provided for respondents to add more detail on specific issues (e.g. "other" items of additional expenditure incurred). The questionnaire also included one general question on the impact of the cancer diagnosis on average household spending, responses to which were a 5-level Likert-type scale ("increased a lot" to "decreased a lot"). Two general questions were included assessing the overall financial impact of cancer. Following Francoeur (2005), we sought to distinguish (a) objective financial *stress*, which results from all medical and non-medical events that are financial stressors for the household, and (b) subjective financial *strain*, which is an individual's subjective, reactionary, perception of financial distress experienced. Thus, financial stress was assessed in terms of the impact of the cancer diagnosis on the household's ability to make ends meet, and financial strain in terms of how the respondent had felt about their household's financial situation since their cancer diagnosis. Reponses to both of these were on 7-level Likert-type scales, ranging from "much more difficult"/"very concerned" to "much less difficult"/"much less concerned". The short version (21 questions) of the Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995) was used to assess negative emotional states (i.e. depression, anxiety, stress) in the week prior to completing the questionnaire. Detailed information was also collected on socio-demographic characteristics (e.g. age, sex, marital status, dependants, health insurance status, medical card status, whether claiming social welfare payments at diagnosis).

Because of the sensitive nature of the topic, and in order to encourage response, questionnaires were completely anonymous (i.e. they did not include identifying details or a study identification number and completed questionnaires could not be linked back to patient details held by the National Cancer Registry). In addition, a carer or family member (proxy) could complete a questionnaire on the patient's behalf if this was preferred/considered more appropriate by the individuals concerned.

The draft questionnaire was pre-tested in five cancer patients, following EORTC guidelines (Blazeby et al., 2002), to assess presentation, acceptability, ease of understanding, face validity, etc. The questionnaire required little modification prior to use.

The final questionnaire included 23 pages, contained 102 questions (not all of which were relevant to each participant) plus the DASS, and took around 30 minutes to complete.

A copy of the questionnaire is available from the authors on request.

2.7.2 Subjects and recruitment

A population-based sample of cancer survivors was selected from the database of the National Cancer Registry in March 2008. Patients were eligible if they had been diagnosed with a primary breast or prostate cancer between six months and two years previously, or with a primary lung cancer between three months and 21 months previously. This time interval was chosen to ensure that patients had incurred most of the costs associated with their initial treatment by the time they completed the questionnaire, while being close enough in time for them to have a detailed recollection of the individual components of these costs. We included lung cancer patients from three months post-diagnosis in recognition of the short survival for this cancer. Patients had to have been diagnosed or treated at one of the hospitals from which ethical approval had been obtained (Section 2.4). The treating consultant(s) for each patient was identified. Consultants were asked to review the details for each patient and confirm that they were still alive, were aware that they had cancer, and that there was no other reason why it would be inappropriate to approach them regarding the study (e.g. if the patient had dementia or was terminally ill). If the patient fulfilled these eligibility criteria, s/he was approached and invited to take part in the study. If the patient did not fulfil the criteria, or the consultant did not reply, the patient was not contacted.

Table 2.3 Hospitals from which patients were invited to take part in the survey: numbers of consultants who collaborated with the study, and numbers of patients invited to take part

	No. of consultants	*No. of breast cancers*	*No. of lung cancers*	*No. of prostate cancers*
Public hospitals/mixed public-private				
Beaumont Hospital, Dublin	3	54	1	20
St James's Hospital, Dublin	2	-	5	57
St Luke's Hospital, Dublin	1	-	-	5
St Vincent's University Hospital, Dublin	2	-	10	55
Cork University Hospital, Cork	3	172	22	-
Mercy University Hospital, Cork	1	-	-	147
South Infirmary-Victoria Hospital, Cork	1	135	-	-
Letterkenny General Hospital, Co. Donegal	1	75	15	2
Mayo General Hospital, Co. Mayo	1	106	-	-
St John's Hospital, Limerick	1	38	-	-
Mid-Western Regional Hospital, Limerick	3	65	4	-
Tralee General Hospital, Co. Kerry	1	-	-	10
University College Hospital Galway	3	125	-	-
Wexford General Hospital, Co. Wexford	1	21	2	1
Private hospitals				
Bon Secours Hospital, Galway	2	38	-	16
Bon Secours Hospital, Cork	3	27	-	54
Bon Secours Hospital, Tralee	1	-	-	91
Total	28[1]	856	59	458

[1] Some consultants held appointments at more than one hospital.

Since pre-contact has been shown to increase questionnaire response rates (Edwards et al., 2005), each patient who remained eligible was sent a pre-contact letter by the research team, describing the study and letting them know that they would soon receive a questionnaire. Approximately two weeks later, each patient was sent the questionnaire and asked to complete it and return it in the enclosed reply-paid envelope. If no response was received, up to two reminder letters were sent, at fortnightly intervals. To optimise response rates (Sharp et al., 2006), an Irish Cancer Society-branded pen was enclosed with the questionnaire (the pen provided contact details for the ICS cancer helpline).

The survey took place between June and October 2008. 1,373 patients, treated by 28 consultants at 17 hospitals throughout Ireland (table 2.3), were invited to take part. Breast cancer patients (n=856) had been seen by 13 consultants at 11 hospitals; prostate cancer patients (n=458) had been seen by 11 consultants at 11 hospitals and lung cancer patients (n=59) had been seen by 9 consultants at 7 hospitals.[e]

2.7.3 Analysis

Completed questionnaires were entered into a custom-written database. After data checking, the analysis was undertaken in Stata 10.0 (StataCorp, 2008), using standard descriptive methods. If respondents did not answer a particular question about costs incurred, it was assumed that they had not incurred costs in relation to that item (e.g. GP visits). Where appropriate Likert-type response scales were collapsed into three groups in the analysis (e.g. increased, stayed same, decreased). The DASS was scored using the standard scoring template and participants were classified on each of the three subscales (depression, anxiety, stress) as "normal", "mild", "moderate", "severe" or "extremely severe" (Lovibond & Lovibond, 1995). In the analysis, these categories were combined into three groups: normal, mild/moderate, severe/extremely severe (labelled "severe" in chapter 4). Associations between DASS outcomes and (1) financial stress (household ability to make ends meet) and (2) financial strain (feelings about household financial situation) were assessed using chi-square tests. The response rate and characteristics of respondents are summarised in chapter 4.

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[e] Some consultants (e.g. medical oncologists) treated patients with more than one type of cancer.

Chapter 3 Results of the in-depth interviews

Key findings

- Cancer patients can incur a range of medically-related expenses as a result of their cancer and its treatment. These include hospital bills (for tests, procedures, in-patient stays and consultant visits), costs of visiting their GP and costs of supportive medications. Some patients need convalescence stays, counselling or other therapies or interventions (e.g. manual lymph drainage) and incur costs in relation to these.

- The costs associated with travelling to hospital appointments are a substantial additional concern for cancer patients. Patients who live in rural areas, in particular, can have long and complicated trips to and from hospital for treatment, and managing these complex journeys can be a source of worry. Family members may also be out of pocket through accompanying patients to hospital or visiting them during treatment. Related expenses include the costs of meals and overnight accommodation during radiotherapy treatment.

- Increases in household bills may be experienced by patients undergoing, or recuperating from, treatment. Patients can be worried about how they will pay high heating and telephone bills.

- Patients may experience other out-of-pocket expenses as a result of their condition including the costs of wigs and hairpieces, new clothes and childcare.

- Most cancer patients need to take time off work during treatment and some suffer a substantial fall in their income, due to the discretionary nature of sick pay. Financial and other pressures can make patients feel they need to return to work as soon as possible.

- With regard to applications for medical cards and HSE and social welfare payments, patients and oncology social workers described a lack of information for potential applicants, confusion about eligibility, and a complex, slow and difficult application process.

- The combination of decreased income and extra costs can have wide-ranging consequences for cancer patients and their families. These include financial worries, juggling money to avoid getting into debt, having to budget very carefully, cutting back on food shopping, buying second-hand clothes and not going on holiday. Patients who have savings may find that they need to use these to help meet additional cancer-related costs. Some patients borrow money.

- Family, friends, neighbours and work colleagues are an important source of both financial and practical support (such as lifts to hospital appointments, help around the home, or childcare) for cancer patients.

- Individuals falling into almost any socio-demographic group can be vulnerable to experiencing financial difficulties as a result of cancer, depending on their particular circumstances and the formal and informal support which they have available.

- A range of suggestions were made by Oncology Social Workers and cancer patients about possible improvements to the health and social welfare systems and services that could help alleviate the adverse financial impact of cancer on patients and their families.

> ***“And it’s at a time in your life when you are most vulnerable. It's at a time of your life where worry should be, if possible, taken off you. Even if it's only for a short period of time*** *(pause)* ***the time of your treatment is a time when you most need to have your mind focussed. And your mind needs to be focussed on making yourself better, not worrying about the finances.”***
>
> **- cancer patient PT16**

> ***“I suppose when you get sick first and mortality is kind of staring you in the face, you don’t think about money. And then as you go along I suppose things are going ok. You know, you feel things are getting better*** *(pause)* ***you start thinking about money then, that’s what I’m saying, you know. It hits like, you know.”***
>
> **- cancer patient PT03**

This chapter contains the results of the in-depth interviews with oncology social workers and cancer patients. The results of both sets of interviews are presented together in the form of main themes and sub-themes. Quotes from participants are used throughout the chapter to illustrate patients' experiences.

3.1 Main themes

The main themes which emerged from the in-depth interviews are summarised in table 3.1. The chapter section where each theme is described in more detail is indicated in parentheses.

Table 3.1 Major themes identified from the qualitative interviews
Additional expenses – medically-related (3.2) and non-medical (3.3)
Income, work and benefits (3.4)
Savings, borrowing and support (3.5)
Medical cards and HSE and social welfare payments (3.6)
Overall financial impact on patients and their families (3.7)
Vulnerable patients (3.8)
Interviewees’ suggestions (3.9)

3.2 Additional expenses: medically-related

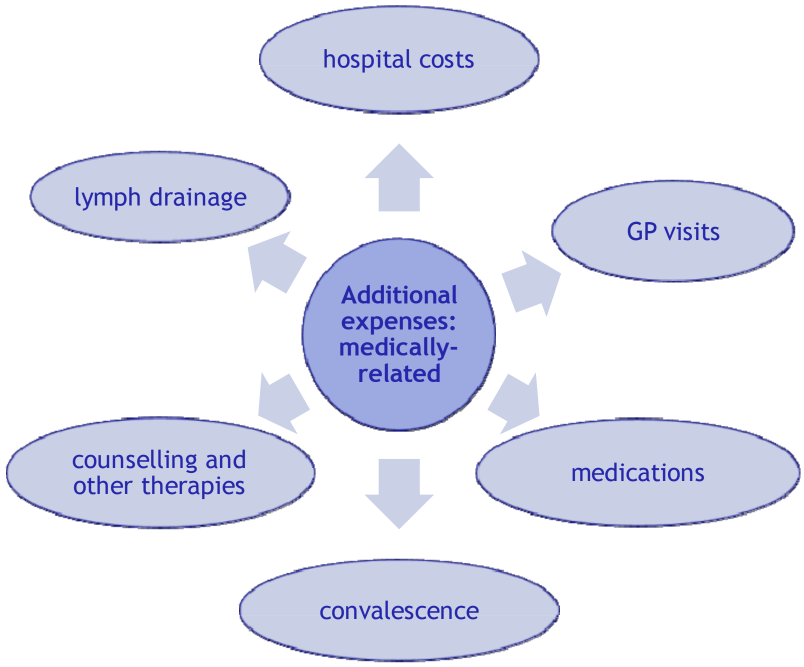
Figure 3.1 summarises the sub-themes which fell under the heading for medically-related additional expenses.

3.2.1 Hospital costs

Oncology social workers described how the costs of care in the public system (Appendix 1) can constitute a substantial expense for patients who do not have a medical card, or are waiting to have a medical card application assessed. They can find it hard to meet these costs. One social worker described meeting families and thinking:

> *“this family, they are not going to cope, it [hospital bills while waiting for medical card] is actually pushing them over the edge and it's that one thing.”*
>
> - oncology social worker OSW12

Figure 3.1 Sub-themes relating to medically-related additional expenses



Patients who have private health insurance can experience additional costs for tests or appointments not covered by their policy. Some patients described how their hospital costs were covered, but that they needed to pay to see consultants in their private rooms; typically this can cost between €100 and €150 per visit. Other patients had the costs of their chemotherapy met by their insurance, but had to pay for the cost of the blood tests required prior to a chemotherapy session.

Patients without a medical card sometimes also have to pay substantial amounts for procedures. For example, one spoke of having to pay for a breast ultrasound examination at a cost of €80. Another described having to pay for more than one PET scan, each of which had "*cost a bomb*" (PT06). Costs such as these were incurred both by private and public patients, since private insurance policies may not cover these costs and patients who are mainly accessing care through the public system may decide to have procedures done privately.

Sometimes patients can find hospital costs a heavy burden, especially if they are accompanied by other expenses. For example, one patient spoke about having spent €900 on hospital costs, plus €85 a month for medications under the drug repayment scheme (see below). Patients also described the speed with which bills can accumulate. For example, in one two week period just before Christmas, one interviewee paid €270 in oncologist and radiotherapist bills plus €500 for a hairpiece.

3.2.2 GP visits

Social workers spoke about how patients can incur significant costs associated with additional visits to their GP because of their cancer. These usually relate to the side-effects of treatment, and are either because patients are worried or because they live a long way from the treating hospital and have been advised to see their GP about follow-up of side-effects. One social worker described the situation for patients as follows:

> *"And so if you don't have some kind of coverage for that [GP visits] either, you're sitting at home panicking [because] you can't afford to go the GP or you're going and you're spending all of this money (…) that you really can't afford and (pause) that €50 comes out of your grocery bill this week (pause). And maybe the year before that you hadn't gone to the GP in a year and half (…) because you've never been sick. So it's like, it's really new expenses that come up for people".*
>
> - oncology social worker OSW09

3.2.3 Supportive medications

Social workers considered that one of the first worries for cancer patients relates to the cost of the medications that they need, particularly those required to manage pain or offset the side-effects of chemotherapy. Some of these can be obtained on prescription and others are bought over-the-counter. In terms of prescribed medications, even patients participating in the drugs payment scheme (Appendix 1) can find the costs (€85 per month at the time of the interviews[f]) significant, especially if they come on top of other medical or non-medical additional expenses.

> *"They're told they're on this, this, and this medication and all you're thinking of is - how much is this going to cost? And I know there is the drug payment scheme (…) but that's €85 you still have to pay (…) it sounds little but it can be a lot sometimes for people to be paying."*
>
> - oncology social worker OSW21

3.2.4 Convalescence

Some patients, generally those who are elderly or live alone, or whose spouse is unable to care for them, require a convalescent stay, usually in a nursing home, after leaving hospital following surgery. Typically the costs of convalescence are not fully covered by private health insurance and the additional out-of-pocket expense can be substantial (e.g. up to €400 per week).

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[f] This has subsequently increased to €120 per month.

3.2.5 Counselling and other therapies

Some patients may require counselling sessions to help them deal with having cancer, and this can be a substantial out-of-pocket expense. One patient described being fortunate enough to receive counselling sessions free of charge through a cancer support group and described this as:

"absolutely a life saver. I was in a desperate state and if that facility [counselling] was not available I would have had to pay for it."

- cancer patient PT02

Other types of therapy and support can result in further costs for patients. For example, after she was diagnosed with bone metastases, one patient arranged play therapy for her son as this helped him cope. She felt she was fortunate to receive charitable funding to pay for the therapy, otherwise the cost would have been substantial.

3.2.6 Lymph drainage

Patients with breast cancer may develop lymphoedema (an accumulation of lymph which causes swelling) following surgery or radiotherapy, which can be painful and make it difficult to move the affected arm. The condition can be managed through manual lymph drainage, which involves specialised massage along with skin care, compression therapy and special exercises. Patients described difficulties in accessing HSE-provided manual lymph drainage services, which made them feel that they had little option but to pay for treatment privately. For example, one patient spoke about paying for manual lymph drainage in a private hospital at a cost of €55 per session.

3.3 Additional expenses: non-medical

The sub-themes relating to additional non-medical expenses incurred by cancer patients are shown in figure 3.2.

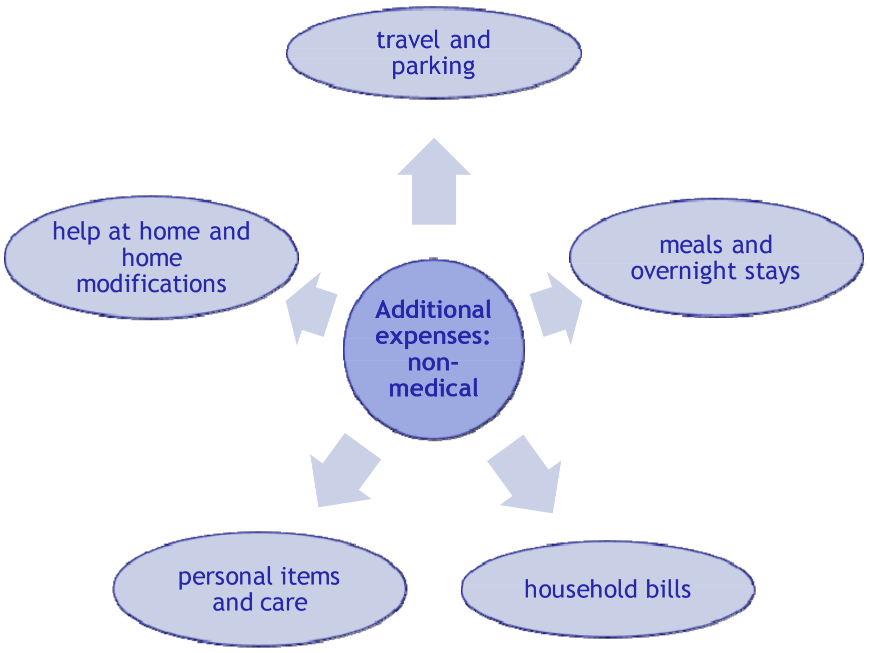
3.3.1 Travel and parking for hospital appointments

"I would say the next biggest one [issue] to the medical card is often the travelling".

- oncology social worker OSW13

All of the social workers spoke about the extra expenses associated with travelling to hospital appointments. This included public transport fares, taxi fares, and petrol costs. Because of the specialised and multi-modal nature of cancer treatment, many patients repeatedly travel long distances for treatment, and incur substantial costs each time.

Figure 3.2 Sub-themes relating to non-medical additional expenses



Patients in rural areas described long and - if they did not have access to a private car, or live close to public transport - complicated journeys to hospital. For example, one patient said that she often had to wait all day for a train home in the evening even if her hospital appointment was early in the day. Even for those living and being treated in a city, such as Dublin, the trip to the hospital may take a long time. Patients often spoke about having to take two buses, or a bus and a train, to and from hospital. As well as the expense incurred, patients - especially those in rural areas - found managing these complex journeys a source of worry. They were concerned, for example, about whether someone would be able to pick them up at the train station or bus stop.

"So basically I just had to look for lifts here and there. And my son wasn't at home for some of the time. If he was at home he would bring me. And then I would walk down to the train (…) and have my treatment and then walk back in the evening. (…) I had an extra worry. How will I get up there on Monday for my treatment? How will I get home?"

- cancer patient resident in a rural area PT14

"To get here it takes two [buses]. And then when I was going to the other hospital, which I still am, I took the little bus and the train."

- cancer patient resident in the same city as treating hospital PT21

There are often practical issues associated with travel for cancer patients which can result in additional out-of-pocket expenses. Because they may be very ill, and treatment can result in side-effects (e.g. fatigue, nausea, diarrhoea), patients often find it impossible to travel by public transport or free hospital transport services (i.e. buses) even if these are available. They are forced instead to opt for more expensive travel options, especially for the homeward journey after treatment, such as taxis. Some patients are not allowed to drive because of side-effects of treatment, and have to rely on others to drive them to the hospital. Patients spoke about feeling that they should pay for petrol and lunch if someone provided a lift.

> *"When I came up I would have to stay all day in the city. Because the train comes up at eight and it doesn't leave until five. So you're here all day. So you need something to eat."*
>
> \- cancer patient resident in a rural area PT14

> *"The travelling in and out of the hospital can be very expensive. (…) A lot of patients would come in by bus maybe, but then after the chemotherapy they might have to go in a taxi home."*
>
> \- oncology social worker OSW20

For those travelling by private car, the cost of parking at the hospital can be a considerable expense (e.g. €2 per hour, €13 per day). Both social workers and patients stressed that cancer patients may be parked at the hospital for several hours while having chemotherapy or waiting for an x-ray result, for example; even attending for a simple blood test may involve parking for more than an hour or two.

A few hospitals provide cancer patients with a disc which entitles them to free parking. Some have designated free parking spaces for chemotherapy or radiotherapy patients, and others offer subsidised parking rates. However, patients spoke about there being insufficient designated spaces for all those attending, or not being aware that these were available until late in their treatment. Social workers described how not all cancer patients were offered subsidised parking, and patients said that the costs could still be considerable. For example, one man described paying a subsidised parking fee of €12 per visit but noted that:

> *"[Paying €12 for hospital parking] can be a lot out of [an income of] €185 per week."*
>
> \- cancer patient PT20

Interviews revealed a particular issue relating to blood tests required prior to chemotherapy; these may entail an additional trip and further expense before each chemotherapy session. For example, one patient described how she had to make a round trip of 130 miles to the hospital for blood tests the day before each chemotherapy treatment (in addition to the journey to receive the chemotherapy).

Travel and parking costs were not limited to patients themselves. Family members visiting patients also incurred these expenses.

3.3.2 Meals and overnight accommodation

Another notable out-of-pocket expense associated with attending hospital appointments is meals, for both the cancer patient and anyone who accompanies them. These costs were an issue for those who had to travel some distance, or for some time, to get to hospital. Some spoke about how, if they were feeling well enough, they would prepare a packed lunch in order to reduce costs.

Radiotherapy is often delivered five days a week over several weeks. For some radiotherapy patients, particularly those living in rural areas or those receiving treatment in another city, overnight accommodation was a significant extra cost. Although some patients stayed with relatives whenever possible, others described paying for overnight accommodation during their treatment weeks.

A small number of hospitals have limited overnight accommodation which is provided free of charge to patients and accompanying family members. Patients who had been able to take advantage of this facility were very grateful, both because of the cost savings and because it allowed them to meet other cancer patients informally. As one patient observed:

"It's a lifeline for me now because I have met lovely people up there. So we try and keep in contact."

- cancer patient PT14

In contrast, it was sometimes upsetting for patients who had had to pay for accommodation themselves to find out that others had been provided with free accommodation.

3.3.3 Household bills

Interviewees described how heating bills can increase following a cancer diagnosis. The social workers considered that the rise in heating costs is one of the biggest expenses incurred by many patients. Patients described feeling the cold more as a result of having had chemotherapy or radiotherapy, because they had lost weight or because they were less active and more tired while recuperating from surgery. In addition, those who had stopped working were at home more.

"Then you have the worry of will I be cut off? You shouldn't have that worry. You know, you just shouldn't have that worry."

- cancer patient PT14

The extra cost of fuel bills was a source of worry for patients, even amongst those who felt they had been budgeting or managing quite well. Difficulties in paying, or arrears, were common, especially amongst those diagnosed or treated in the winter months. Some of the patients said that they did not put the heating on as often as they would like. One patient described how she would put on the heating, but:

"Because I'm so cold now. You know what I mean. And I paid €20 off the ESB [electricity] every week. So that I wouldn't (…) have a big bill. Because (…) the bills [were] coming in and they'd be in and around €350 to €400."

- cancer patient PT19

"you would find you're watching it [the heating] then. You're putting it on and you're saying - it's on there now. [In] half an hour I will turn it off (…) for a while."

- cancer patient PT08

Others described wearing more clothes to try to keep warm rather than putting the heating on.

Interviewees also discussed increases in telephone bills (for both landlines and mobile phones) as a result of having cancer. This is partly because patients may be at home more during the day, but mainly because they use the phone to let friends and relatives know how they are and to make arrangements regarding hospital appointments. Keeping in touch with family and friends was an important source of support for patients. For example, one interviewee living in a rural area described how the telephone was a "*lifeline*" (PT14) for her since her diagnosis with cancer. Some patients had problems in paying their landline or mobile phone bills.

"The big thing is transport and your phone (pause) well, my phone is my lifeline you know. And then you're afraid to use the phone, the cost of the phone you know."

- cancer patient PT14

3.3.4 Personal items and personal care

3.3.4.1 Wigs, hairpieces and head coverings

The issue of wigs and hairpieces to cover treatment-related hair loss was a major issue for patients. While some patients may get financial assistance from Community Care to help pay for these (Appendix 1), out-of-pocket expenses in relation to buying wigs and hairpieces are common and the amounts incurred can be substantial (e.g. several hundred euro). The psychological effects of hair loss on body image was raised by interviewees, as was the importance of being able to buy a wig that did not look like a wig. As one social worker said:

"The last thing a woman wants is a wig (…) that stands out as being a wig."

- oncology social worker OSW21

Bandanas or caps are sometimes preferred, or required to keep the head warm at night. Patients described having to pay for these themselves. Sometimes patients need these items but cannot afford them.

3.3.4.2 Prosthesis bras

The cost of bras can be an issue for women with breast cancer who have a prosthesis. Some spoke about getting one or two bras free following surgery, but said that they had had to buy additional bras at a cost of up to €60 each.

3.3.4.3 Weight changes, clothes and healthy eating

The nature of cancer is that it is often accompanied by loss of weight, which can be regained following treatment. Patients and social workers spoke about having the expense of buying new clothes at different times so that patients had some clothes that fitted them at each stage of cancer diagnosis and treatment.

Some patients said that they had tried to eat more healthily while they were undergoing treatment, and spoke about how this had added to their costs.

"I probably changed my diet a bit. I (…) always had looked at the kind of organic stuff but now I'd use all organic and that. That is more expensive."

- cancer patient PT15

3.3.5 Childcare, other help at home and house modifications

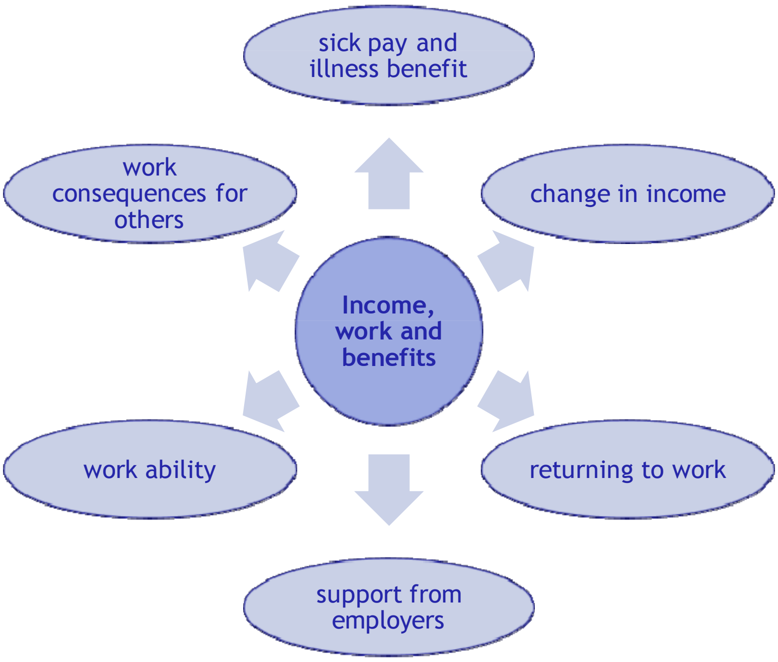
Some patients or families with young children incur childcare costs (e.g. a babysitter or crèche) while one or both parents are attending treatment appointments. This can place a particular burden on lone parents or families who do not have family or friends living nearby. Other patients require help around the home when they are recuperating, and pay to obtain this from a private organisation or individual.

Social workers spoke about the patchy nature of, and waiting lists for, community services which should - theoretically - be available to provide some support for (some) cancer patients who have a medical card (such as homehelp). They stated that these limitations forced patients to have to pay for services privately.

Some patients need to make modifications to their home after they have cancer so that the layout is more suitable for their levels of mobility following treatment (e.g. move bathrooms or bedrooms downstairs, or install a stairlift), but the cost of this can be high and the waiting times for those who apply for a grant (Appendix 1) may be long. For example, one interviewee with lung cancer had applied for a grant to fund a downstairs bathroom, but had waited a very long time for her application to be processed because of the waiting time for an assessment by a community occupational therapist. She described how she really needed a stairlift in the meantime, but had not obtained one as the cost was prohibitive (approximately €5000) and there was no financial assistance available.

3.4 Income, work and benefits

Figure 3.3 Sub-themes relating to work, benefits and income



Most cancer patients are not able to continue to work during their illness and need to take some sick leave. In the initial stages after diagnosis, some patients will continue to work, but they usually have to stop when treatment starts, particularly chemotherapy. Occasionally patients will be well enough to work for a few hours, or at home, or between courses of treatment, but whether this is possible depends on the flexibility of their employer. Figure 3.3 shows the sub-themes relating to work, benefits and income which emerged from the analysis of the interviews.

"With chemotherapy or radiotherapy (pause) [patients] have to take a break [from work] for a few months. Also, they are more vulnerable to infection and more tired during chemotherapy. (pause) In exceptional cases some patients do go back to work to balance the family situation. There are two aspects to this, one is financial and the other is to get back to ordinary life."

- oncology social worker OSW20

3.4.1 Sick pay and illness benefit

The discretionary nature of sick pay (see Appendix 1 for more details) was talked about by all of the social workers. This was demonstrated in the varied experiences of the patients interviewed. For example, one patient received full salary for six months and half pay for a further six; another received full salary for 15 months taken over a four year period, with full pay provided for some months at a time and no pay between times; several received a basic salary which did not include additional amounts they would usually receive for working nights or weekends, or undertaking specific duties; and several others received no sick pay from their employers.

Sometimes patients on sick leave were unsure how long their employers would continue to provide sick pay, and at what level. They were also unsure about when they would be able to return to work, and so were worried about how they would manage when the sick pay ceased, even if they received illness benefit.

Patients who were not eligible for illness benefit (Appendix 1) were an especially vulnerable group. For example, one patient spoke of having no work income or sick pay and the pressure that this put on her. The social workers described how self-employed people - many of whom may not be eligible for illness benefit or means-tested disability allowance - sometimes try to continue to work between treatments, even if only on a part-time basis, if and when they are able. They also spoke about the complex process and long waiting times involved in trying to obtain means-tested financial help (such as disability allowance or supplemental welfare allowance) for patients who are judged to be ineligible for illness benefit (benefits are discussed further in Section 3.5).

3.4.2 Change in income

"My income is nearly sliced in half. God almighty, its sliced in half."

- cancer patient PT21

All except one of the patients who had been working at the time of their diagnosis experienced a decrease in income when they stopped working during their illness and treatment, even if they were receiving sick pay or illness benefit. The amount by which income fell depended on patient (and family) circumstances, but several spoke of the decrease as being "*huge*" (PT18). The drop in income was also repeatedly highlighted by the social workers as a significant problem for patients, resulting in changes in family lifestyle and a range of other consequences (see section 3.7).

3.4.3 Returning to work

"When I had my lung removed I went back to work too quick. (…) I needed the money because I wasn't getting any sickness benefit. I was getting nothing off the State (…)."

- cancer patient PT07

The drop in income made patients anxious to return to work at the end of their treatment. However, some patients were surprised that they felt so tired from treatment that they were physically unable to restart work as soon as treatment finished. One patient described having returned to work soon after surgery because she had no income and was not entitled to any HSE payments; she felt subsequently that she had returned too soon and had struggled to work.

As well as financial pressures to return to work, there are pressures from employers. The social workers considered that some patients felt under pressure to return to work before they were ready, while others were afraid that they would lose their jobs if they took too much sick leave.

3.4.4 Support from employers

An understanding employer can help a patient cope financially by allowing them to work shorter or flexible hours or to take paid leave (e.g. annual leave), during their illness and treatment. This was spoken of by the social workers and illustrated in the patients experiences. For example, one patient described how his employer had let him take some time off every working day for several weeks to attend the local hospital for radiotherapy. He felt fortunate that he had been able to come to this accommodation and had not had to travel to another city for treatment, which would have required him to take sick leave:

> *"And if I had to go to city 2 or city 1 to do that [radiotherapy], it would have entailed my whole day gone. It would have entailed me not being able to work (…) where I do work in [name of business] (…). I dread and fear to think the affect that that would have had on me, myself, financially and on my family (…). Because I don't think that the company I work for would pay me eight weeks wages. And I wouldn't have been able to work."*
>
> - cancer patient PT16

Some patients described how their employers had given them a loan because they did not receive sick pay or were not eligible for illness benefit; other patients spoke about how, if this had been available, it would have helped them financially. However, those who had received a loan found that paying it back could bring its own problems (Section 3.5.2).

3.4.5 Work ability

Cancer can impact on patients' ability to work and the tasks that they can undertake. This was particularly the case for women with breast cancer who developed lymphoedema and whose job pre-diagnosis had entailed any kind of manual activity or heavy lifting (e.g. chef, hairdresser, etc). They spoke of how the lymphoedema restricted the kind of work they could do to some extent, depending on which arm was affected. They felt that they would not be physically able to do the same job in the future. One male interviewee who was experiencing side-effects of surgery had similar concerns.

Patients considered that it would be psychologically difficult if they had to look for other types of work after their illness and treatment, especially since they would have been out of the workforce for some time.

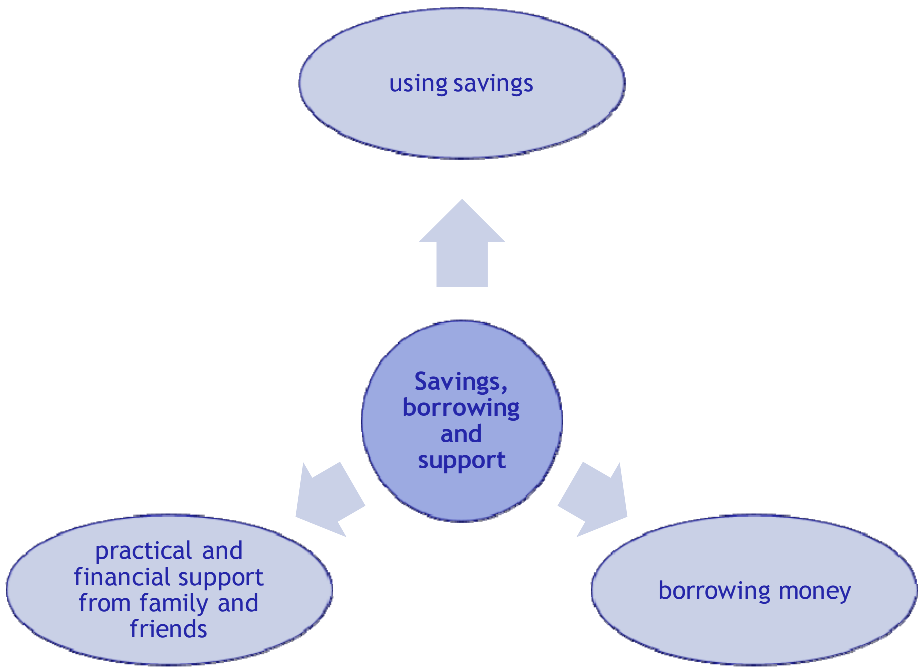
3.4.6 Work consequences for family members/friends

Cancer can also have consequences for the working life of family members. Social workers described how the second breadwinner in the family often has to take time off, or reduce hours, to accompany a cancer patient to hospital for treatment or to help to look after them while they are ill or recuperating. This was confirmed in the experiences of patients. For example, one patient described how she had lost her own income due to stopping work because of her illness, and her self-employed husband had also taken a lot of unpaid time away from work to take her to hospital appointments. In addition, for patients with children, the unaffected parent may have to take time off to look after the children.

In some circumstances, the impact may be wider than the immediate family. One interviewee - a single mother - described how a friend had used up most of his annual leave to drive her to treatment appointments and help with childcare.

3.5 Savings, borrowing money and support

Figure 3.4 Sub-themes relating to savings, borrowing money and support



Using savings, borrowing money and support from family and friends was a theme which emerged from the interviews with the patients, rather than those with the social workers. The related sub-themes are summarised in figure 3.4.

3.5.1 Use of savings

> *"Since I haven't been working and just depending on the one wage, all we're doing every week is dipping into savings. So my savings now are down to zero at the moment. Because you find (…) even to go grocery shopping I go to take the money out (…) because like one wage you can't (pause) we have three kids, you know what I mean."*
>
> \- cancer patient PT08

Patients spoke about having to use some or all of their savings to cover cancer-related costs. Even those who did not have a lot of savings described having to dip into them. Several participants spoke about having to use their savings to pay for repeated travelling up and down the country for treatment (e.g. radiotherapy). Using savings to pay household bills was commonly mentioned, with some patients concerned about the consequences of not being able to pay bills. Savings were also used to cover the costs of necessities, such as grocery shopping or clothes.

"Any money I had saved is gone now. (…) We said if we didn't have [some savings] we would be in a dire situation now. Because the bills are mounting (…). And if we weren't able to pay for those we would be in a bad situation now."

- cancer patient PT08

Participants described having worked hard to save during their lives (e.g. for retirement), or having budgeted carefully for particular things (e.g. their children's education), but now finding that they had to use their savings to meet costs associated with having cancer. Among those who were not working because they were undergoing treatment, concerns were expressed about not being able to replace savings that had been spent, or to continue saving for the future.

"I would have been a person that would have been saving for my retirement. And I had to stop all that because I couldn't afford to. I knew that I was cutting down my money if I wasn't getting a pay cheque and that I couldn't afford to keep doing them so they all had to be stopped."

- cancer patient PT04

"And you're not replacing it. You know, you're dipping in and you're not saying, well sure I'll get a weeks wages next week I can replace that. You're replacing nothing. And that's (…) that is frightening, you know."

- cancer patient PT21

Among the few who had not had to use their savings, one interviewee anticipated that she would be likely to have to do this in the future. Only one interviewee who had been working at the time of diagnosis had not used her savings, but her circumstances were such that she did not have dependants, had good levels of sick pay, had insurance to cover mortgage payments, and did not have to travel for treatment. Another interviewee who was retired had a wife who was still working and had not had to use savings.

3.5.2 Borrowing money

"I hated asking my family for money (…) but they offered (…). I just had to take it in the end (…). And as my husband says we don't know when we can pay it back. At the moment (…) they're saying "we don't want it back". But you don't want to be in that position either."

- cancer patient PT03

Interviewees described borrowing money from a variety of sources including the credit union and employers. Most had received some financial help from family and friends to varying degrees. For example, one interviewee said that he was lucky that his family and friends were "*giving you the few bob here and there*" (PT20) when he needed it (e.g. his mother bought him some clothes and a friend paid for his car insurance), another interviewee with school-age children said that her sister had paid for her grocery shopping on a few occasions, others said that family members had helped with the costs of buying a wig. Sometimes the borrowing was prompted by a specific event, such as Christmas. Patients expressed worries about their ability to repay money borrowed from parents or other family members.

Some patients had been given money by family members but did not describe this as borrowing.

Those who had been loaned money by their employers had either found it difficult to pay back when they had returned to work or were concerned about how quickly they were going to be able to get back to work to pay back the loan.

The difficulty of being in a position of having to ask for financial help from family or friends or employers was discussed, especially if help was needed over a prolonged period of time. For example, one interviewee didn't want her family to think that she was "*leeching off (pause) begging off them*" (PT19). Several interviewees emphasised that they had been offered financial help, rather than having sought it. This was consistent with comments from the social workers, who noted:

"Everyone likes to have their financial independence."

- oncology social worker OSW04

"[Patients are] proud and they're not going to even allow anyone to think that I can't survive."

– oncology social worker OSW06

3.5.3 Practical and financial support from family and friends

As well as financial assistance, patients receive many other types of support from families and friends. All of the patients interviewed said that they had received some practical help from their extended family, friends and neighbours, and this significantly reduced the potential costs for some patients. Family and friends took annual leave from work to take interviewees to hospital appointments and helped with driving and petrol costs. They also helped with childminding, housework, cooking meals and shopping. For some older interviewees, neighbours helped with lifting and practical matters around the home. In some cases extended families were able to provide overnight accommodation when interviewees had to travel for treatment. Work colleagues of one interviewee made a collection to provide financial help.

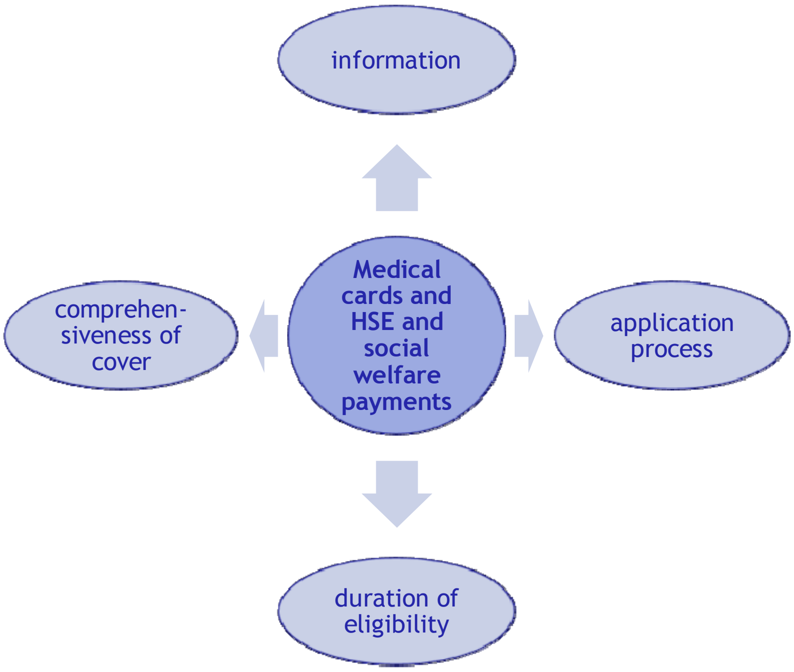
Those who have a supportive family felt fortunate. The security of knowing that family members were supportive was commonly spoken about. It was felt that most cancer patients "*probably had to depend on family support*" (PT03), but whether this was "right" was questioned. Patients felt that they did not necessarily want to be in a position where they were so reliant on help (whether financial or practical) from family and friends. It was not always easy for them to ask for this help, or to accept it.

"I suppose I'm lucky to have such a supporting family. But should you have to rely on your family?"

- cancer patient PT03

3.6 Medical cards and HSE and social welfare payments

Figure 3.5 Sub-themes relating to medical cards and HSE and social welfare payments



The sub-themes relating to medical cards and HSE and social welfare payments which emerged from the interviews are shown in figure 3.5.

3.6.1 Information

There was a strong feeling that there was insufficient information available to patients about medical cards and HSE or other social welfare payments (Appendix 1). Some patients found it difficult to find out what they were entitled to; getting the appropriate information was particularly challenging when patients were feeling ill or unwell because of the cancer and its treatment. Sometimes patients were quite advanced through treatment before discovering that they would have been entitled to a medical card. In contrast, others described having been given information and application forms by oncology social workers, other healthcare professionals or other patients soon after their diagnosis.

There were various myths and misunderstandings surrounding medical cards, both among patients and healthcare professionals. For example, some patients had thought that they would be automatically entitled to a medical card because they had been diagnosed with a serious illness. This was confirmed by the social workers who reported that patients had often been told this by other health professionals, or other patients. There were also beliefs that applications for a card are processed quicker in some parts of the country than in others. For example, one patient expressed the view:

"In Dublin once you are diagnosed (pause) you get it [a medical card] immediately."

- cancer patient PT03

3.6.2 Application process

"It [a medical card] wasn't easy to get. There was a lot of running around but eventually I got it."

- cancer patient PT02

"To be honest with you I had a battle [to get a medical card]."

- cancer patient PT03

Some of the patients found the application process for a medical card arduous and some had a long wait before they were issued with a card. It was thought that making an application was difficult for someone who is ill with cancer and who might be recuperating from surgery. For example, patients described how difficult it was to go to the GP, then to the health centre, soon after surgery, when they were still sore and tired.

The application forms were considered to be complex and even experienced oncology social workers said that they could find them difficult to complete[g]. Patients need to collate detailed financial information and this could be especially challenging around the time of a cancer diagnosis and treatment. Any missing information could result in a delay in the application being assessed and approved. Patients could not understand why it took so long to process applications. One patient described repeatedly telephoning to find out about the progress of her application. Others spoke about the time during which they were waiting to hear the outcome of their application as a period of worry about ability to cope financially. Overall, the application process could be stressful. The process made some patients feel as if they were begging.

"Well, [applying for a medical card] it's like begging really."

- cancer patient PT13

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[g] Oncology social workers sometimes assist patients in completing medical card application forms, although this is not formally part of their role or remit.

Social workers spoke repeatedly about the discretionary nature of the system and the inconsistencies that this resulted in. Decisions could appear entirely arbitrary and the social workers considered that the outcome of an application often depended entirely on which individual community welfare officer was involved. Social workers felt that the particular circumstances (e.g. different types of treatment, often involving extensive travel) and expenses incurred by cancer patients (e.g. increased heating bills) were not recognised or appreciated in the application process or the social welfare system overall.

Some patients, however, had more positive experiences in applying for a medical card. This tended to be those who were assisted by oncology social workers in making the application and/or who found the community welfare officer helpful. Some of the patients were grateful for the flexibility and discretionary element in the social welfare system, as it meant that they were given help (e.g. a medical card, rent allowance, or an HSE emergency payment) on medical and/or hardship grounds although they would not have satisfied the means test requirements.

3.6.3 Duration of eligibility

It was felt important that a medical card, if issued, continue throughout ongoing treatment. One woman described her worry that, having been prescribed morphine and other pain medicine, she would have difficulty paying for these when her medical card expired. Both patients and social workers spoke about patients being issued a card for a limited period (e.g. three, six or 12 months) and having to reapply, and the uncertainties around this process.

3.6.4 Comprehensiveness of cover

Patients described how a range of medical items that they had required as a result of their illness and treatment were not covered, or only covered in part, by the medical card. Examples commonly cited included pain relief medicines and mouthwashes, which were needed during chemotherapy. For women with breast cancer, while the costs of one bra and prosthesis were covered for card holders, if they needed another bra, interviewees had to meet the cost themselves.

Social workers stressed that the medical card can provide a gateway by which cancer patients are able to access other community-based services, such as home help or occupational therapy, therefore making the issue of access to medical cards even more important.

The specific issue of wigs was raised frequently. Both social workers and patients said that the amount available from Community Care, and the frequency of payments (e.g. a single payment, or two payments) varies across the country, and often did not fully cover the cost of a wig. If the amount was provided in two payments, patients sometimes had to ask the company providing the wig if they would let them have the wig at the time of the first payment, with the second payment to follow later. Sometimes patients had to pay for a wig upfront because they felt they could not wait until the cheque came in.

"The wig she has now, it's just like real hair. It's beautiful and it's given her an awful lot more confidence."

- oncology social worker OSW21

"But it was a horrible wig (pause). If you had more money you could get a nicer wig. Money again (…) you know."

- cancer patient PT14

The social workers emphasized the huge implications of hair loss both physically and psychologically for patients with cancer, and how it was important that patients had access to good wigs and hairpieces. Patients often described how the total amount provided was insufficient to fully cover the cost of an acceptable wig: if they wanted a nicer wig, they had to meet the additional costs themselves. It was often family members who paid the extra amount needed for a patient to be able to buy an acceptable wig.

3.7 Overall financial impact on patients and their families

"I had to cut back on everything. Groceries, everything. Had to really, really say well, do we need that? And (…) plan meals and how to make up meals out of everything."

- cancer patient PT18

This was a theme which emerged very strongly from the patient interviews as they described their experiences.

Interviewees repeatedly described being concerned or worried about their financial situation following diagnosis and during treatment. The combination of decreased income and extra costs had wide-ranging consequences, but the extent of these depended on individual circumstances. Only two interviewees were not concerned about their financial situation, and this was because of their particular circumstances (one was already retired and their spouse was still working full-time, and the other had good sick-pay and insurance cover for her mortgage).

The period after diagnosis was a time of particular financial struggle for some of the patient interviewees, especially those who were waiting for medical card applications or illness benefit/allowance applications to be processed. Others found it more difficult to cope financially as time passed and this was especially the case for those who had had to use their savings.

“Now, I mean financially (…) I’m in terrible state really (…) even with your €186 a week (…). There’s no possible way to survive on that really.”

- cancer patient PT13

“It's just the money doesn’t go far really. Because of this [cancer] now, I’m absolutely broke at the moment.”

- cancer patient PT08

Those who were receiving sick pay from their employers spoke about being concerned about how they would manage financially when this ceased. Some of those on illness benefit, disability allowance, or supplementary welfare allowance reported struggling financially and experiencing difficulties in managing on the amount provided (€186 per week at the time of the interviews). This became more difficult the longer they were out of, or away from, work.

Difficulties in managing the household budget or weekly spending were commonly described. Participants described "scraping by" each month and constantly juggling money to avoid getting into debt. Those who had a mortgage said that this was a priority but that meeting the payments was a worry. In some cases interviewees were considering deferring mortgage payments or making other arrangements. Participants had to budget and spend more carefully than before they had cancer.

“Robbing Peter to pay Paul. I feel like (…) this is terrible. I hate feeling like this.”

- cancer patient PT19

“You couldn’t go to the supermarket without a list, because you couldn’t pick up [things]. You could if you wanted to go into debt, but I was reared [differently].”

- cancer patient PT17

“But I find I’m like somebody mean. You know everything is down to "how much?" How much is that now? How much is this? Or if my husband had to do something or go somewhere you’re going "how much will that cost you now?" And you’re sounding very kind of petty but you’re watching everything. Whereas before I never had that problem, you know.”

- cancer patient PT08

Patients gave many examples of ways in which their weekly/monthly spending had been cut back. These included: cutting back on weekly food shopping, putting off food shopping for a few days and trying to make their groceries last longer, cutting back on new clothes, or buying second-hand clothes, not going on holiday, not going out socially and not going to the hairdresser. Some described skimping on items they needed because of the cancer (e.g. wigs or bandanas to cover hair loss) because of the cost.

"(…) I'd find that some days even my little girl (…) she was three the other day (pause) [says] Mum, the fridge is bare, are you going to go shopping? You feel bad then and you have to go."

- cancer patient PT08

"I had to cut down on clothes (…). I just like to buy something, well say if I was going to a wedding or if I was going (…) out for a night. And I had to start going to the secondhand shops."

- cancer patient PT17

"I did have to do without myself."

- single mother with cancer PT14

Some patients who had children described going without themselves so that their children could have what they needed. Others talked about how they had had to cut back on spending on children (e.g. classes after school).

Large one-off expenses, either personal or household-related, were a particular problem - both for those solely reliant on illness benefit and for those with some other income.

"We went to a wedding earlier in the year. It took us three months to save enough, just to not (…) be embarrassed at the wedding."

- cancer patient PT19

Social workers spoke about the need for respite breaks for patients and family members, but said that there was often no money for this once bills were paid.

"When you are on the very basic social welfare it's difficult to (…) buy anything new."

- oncology social worker OSW16

"People often need a weekend away. There is no room for any kind of break like that when you're on your basic [social welfare payment]."

- oncology social worker OSW16

3.8 Vulnerable patients

It was apparent from the interviews that individuals in almost any socio-demographic group could be vulnerable to experiencing financial difficulties, depending on their particular circumstances and the level of support available to them, both formal (e.g. through social welfare, employers) and informal (e.g. through family and friends). However, certain groups had particular financial concerns relating to their specific circumstances: these included those with children, living in rural or remote areas, and other groups described below.

3.8.1 Patients with children

In both the social worker and patient interviews, patients who had young children were identified as being a vulnerable group financially. Difficulties can arise because either the affected parent was the main earner in the family, or the unaffected parent has to take time off work (perhaps unpaid) to help with childcare. Lone parents with cancer could be especially vulnerable, as they do not have the income of a spouse/partner to rely upon or a spouse/partner to help with childcare.

3.8.2 Patients living in remote areas

Those living in remote areas were particularly vulnerable to difficulties related to travelling to hospital appointments. As well as the issue of cost (discussed above), additional challenges for those in rural areas described by oncology social workers and patients themselves included: infrequent public transport services; difficulties in getting to public transport stops; and limited availability of alternatives (e.g. taxis). For example, one lone parent described needing to get two buses and a train to the hospital; she lived nine miles from the nearest bus stop, and there were only two trains a day, so even a brief appointment involved an entire day trip. Another interviewee described how she had chosen to have chemotherapy in a different hospital to the one originally intended, because of the inconvenience and cost associated with getting to the original hospital. Patients who had family or friends who could help with transport were less vulnerable.

The costs of meals and overnight stays were also a heavier burden for those in more remote areas. Costs incurred by visitors were emphasized. The point was made that travel costs for patients and family members often come out of the same household budget, placing a multiple burden on families in remote areas.

3.8.3 Self-employed patients

Self-employed patients were considered by social workers to be potentially vulnerable financially, since they may not have sufficient social insurance contributions for entitlement to illness benefit and may not be eligible for means-tested payments. An example of this was provided in one of the patient interviews:

"The really annoying part (…) is that for ten years I was considered self-employed. And all I was doing was sub contracting. Like I didn't have a big business or anything. I was one little tradesman running around working on me own. Probably working five or six hours a day and paying all this PRSI in and other stuff. And when it came to me needing something, it's just a blank no."

- cancer patient PT20

3.8.4 Younger patients

Younger patients (especially those with young children) who may have a significant drop in income during the time of cancer treatment and recuperation, but still have to meet mortgage payments, were viewed as financially vulnerable by social workers. A patient described the way in which she had coped with this issue:

> *"The big thing was (…) when I knew I was going to be coming off pay. What to do about my mortgage, and my car payments. So I arranged with the bank to freeze them for three months."*
>
> - cancer patient PT04

3.8.5 Patients on a low income or state benefits

Based on their experience, social workers thought that patients on a low income prior to diagnosis, and with little by way of savings, were potentially vulnerable to cancer-related financial difficulties. Social workers also expressed the view that while those on state benefits at the time of diagnosis do not experience a drop in income, they can have more difficulties with meeting additional costs, such as travel costs, or increased heating bills, because of their limited financial resources.

3.8.6 Elderly patients

In the opinion of social workers, some elderly patients were vulnerable to financial problems as a result of extra cancer-related costs and limited financial resources (e.g. state pension). Those living alone, without much support from family or friends, can be an especially vulnerable group. On the other hand, social workers pointed out that some patients over 70, who have a medical card and are treated as an inpatient, have no additional costs, and indeed, may have lower living expenses during treatment.

3.8.7 Foreign nationals

Social workers raised concerns about the financial burden on foreign nationals resident in Ireland who are diagnosed with cancer. Some of these individuals may not have been in Ireland long enough to establish habitual residency, and may have to pay for treatment. Since none of the cancer patients interviewed in the study were foreign nationals, we were unable to gauge the impact of cancer from the perspective of members of this group.

3.9 Interviewees' suggestions

Interviewees provided many suggestions about how the system could be improved to alleviate the financial stress and strain on cancer patients and their families. These are summarized below.

3.9.1 Travel and hospital parking

- Provide free parking for oncology or radiotherapy patients in all relevant hospitals.
- Provide food vouchers to cover the costs of meals for those with a long traveling distance or time.

3.9.2 Financial support and advice

- Have a financial service/advisor located in each hospital that/who could provide advice on financial issues related to a cancer diagnosis, including applying for benefits, allowances and medical cards, dealing with debt, reclaiming tax, and other financial issues. Oncology social workers suggested that a designated community welfare officer be assigned to each hospital. Patients suggested that it would be helpful to have a general financial advice service in the hospital. Both groups stressed that it is essential that the advisors have an in-depth understanding of cancer, its treatment, and the specific challenges it poses for patients and families.
- Increase the number of hospitals in which oncology social workers are located, and the number of oncology social workers, so that more patients can be seen.
- Provide information about financial support, services, advice and assistance to cancer patients soon after diagnosis, perhaps at the same time as they receive information about their treatment plan.

3.9.3 Medical cards and medications

- Provide automatic entitlement to a medical card for all cancer patients.
- Increase means-test income limits specifically for cancer patients, so that a greater proportion of patients are automatically entitled to a medical card.
- Streamline the application process so that it is simpler and more direct (e.g. community welfare officers could be based in hospitals at specific times and review patients' applications in a "one-stop shop").
- Improve the system so that there is prompt review of applications and issue of cards (e.g. fast-track system for cancer patients).
- Issue a single medical card to cover entire duration of cancer treatment/illness.
- Improve understanding of cancer among community welfare officers by, for example, providing training on cancer, its treatment, and implications for patients and families;

or have designated community welfare officers, who have an understanding of cancer, deal with all applications from cancer patients.

- Add cancer to the list of long-term illnesses for the duration of treatment, so that patients can obtain required drugs, medicines and appliances free-of-charge.

3.9.4 Benefits, allowances and financial assistance

- Provide an extra allowance, in addition to illness benefit, in recognition of the additional expenses incurred by cancer patients.
- Extend eligibility criteria for existing allowances (e.g. fuel allowance, diet supplement, etc.) to accommodate cancer patients who have extra costs in these areas.
- Extend the Community Care scheme to fully cover the cost of a high-quality wig for every patient who needs one.
- Establish a fund in hospital oncology departments (from central resources), to which patients could apply for financial assistance (e.g. with travel costs, or other expenses).

3.9.5 Community services and other support

- Extend, and reduce geographical variation in, the provision of community-based home help services, so that cancer patients can obtain support when needed.
- Establish services (or extend existing services) to provide counseling free of charge to cancer patients who require it.

Chapter 4 Results of the questionnaire survey

Key findings

- Almost half (45%) of cancer patients had paid fees for a consultation with a hospital clinician. More than one third (36%) had incurred costs for seeing a GP. The average amount spent was €465 on consultant fees and €250 on GPs fees. Almost one in 10 (9%) patients had paid for physiotherapy, 6% for counselling and 2% for other therapies, spending on average €300-€400 on each form of therapy. 15% had spent money on complementary therapies.

- 29% of patients had incurred costs for prescription medications (on average €300) and 39% for over-the-counter medicines (€100 on average). 13% had paid for dietary supplements.

- Among women with breast cancer, 40% had incurred costs for wigs or hairpieces, spending on average €400, and 5% had paid for manual lymph drainage.

- Almost eight in every 10 (79%) cancer patients had costs in relation to transport to hospital appointments. 72% paid for travel and 52% for parking. On average, these amounted to €360 and €75 respectively. The percentage with travel expenses fell with increasing patient age.

- Of those who were working at the time of diagnosis, 83% took some time off. This figure was higher among those working for an employer (87%) than the self-employed (65%). Of those who took time off, half received some sick pay - 63% of those working for an employer and 5% of the self-employed.

- Almost one quarter of patients (23%) had claimed a new HSE or social welfare payment because of their cancer diagnosis. 38% had obtained a medical card following diagnosis.

- Almost one third (30%) reported that their household income had decreased since their cancer diagnosis. This percentage was higher among women, younger patients, those who were working at diagnosis and those with dependants.

- Household spending had increased as a result of the cancer diagnosis for almost half (47%) of patients - for 34% it had increased a little and for 13% it had increased a lot.

- Almost six in every 10 patients (58%) experienced an increase in their household bills as a result of their cancer diagnosis. This percentage was higher among women and younger patients. 44% had increased heating bills, 42% increased telephone bills, and 29% increased food bills

- Of those who had had some savings at the time of diagnosis, 55% had to use some or all of these because of the cancer. Those who were younger patients, working at the time of diagnosis, had dependants, or did not have private health insurance were more likely to have to use their savings. 11% had to borrow money.

- 45% of those who had a mortgage reported that it was more difficult to meet the payments since their cancer diagnosis. Of those who had personal loans, 57% indicated that paying these was more difficult. The percentage finding it more difficult to make mortgage or loan payments was higher among younger and self-employed patients.

- One fifth of patients (20%) had reduced spending on regular items such as new clothes, nights out and take-away meals because of cost. 19% had reduced spending on holidays and 12% had reduced spending on leisure activities.

- Almost half (48%) of patients reported that the financial stress on their household had increased since their cancer diagnosis. The percentage who reported that cancer had made it more difficult for their household to make ends meet was higher among those who were younger, working at diagnosis, or with dependants. Financial stress was not related to pre-diagnosis household income.

- In terms of financial strain, slightly less than one third (31%) of patients indicated that they were more worried about their household's financial situation since their diagnosis with cancer. The percentage who reported increased financial strain was higher in younger patients, those who were working at diagnosis, and those with dependants. It was not associated with pre-diagnosis household income.

- Financial stress (household ability to make ends meet) and financial strain (feelings about overall financial situation) were significantly associated with the prevalence of depression, stress and anxiety. The frequency of mild, moderate or severe negative emotional states was consistently higher among those who reported increased financial stress and increased financial strain since diagnosis, compared to other groups.

This chapter contains the results of the questionnaire survey. The initial sections describe the response rate and the characteristics of the respondents. Later sections deal broadly with

- **additional costs/outgoings** due to the cancer diagnosis (essentially the extra costs, split into medical or health-related expenditure, treatment-associated costs, and household and personal expenditure);
- **household income** (including employment and benefits) and the impact of cancer on this; and
- **consequences** of increased outgoings and reduced income (including effects on savings, borrowings and loans, spending, overall financial strain, stress and psychosocial impact)

4.1 Response rate

Seven hundred and forty (54%) of the 1,373 patients invited to take part in the survey returned a completed questionnaire. The questionnaire response rate was highest for those with breast cancer (58%), slightly lower for prostate cancer (47%) and lower again for lung cancer (32%). The response rate was slightly higher for patients diagnosed in 2007 (52%) compared to those diagnosed in 2006 (45%). The response rate decreased steadily with increasing age. Of those aged 50 or younger at diagnosis, 59% participated; among those aged 50-59, 60-69, 70-79 and 80 and older the response rate was 55%, 47%, 36% and 24% respectively.

Although it was not possible to collect comprehensive data on reasons for non-participation, some information was available from individuals who contacted the research team. Several patients indicated that they had not had any extra expenses as a result of their cancer diagnosis,[h] and therefore did not wish to take part; some said that they considered that their cancer was "in the past", and they did not wish to look back now that they had completed treatment; and others stated that it was too difficult psychologically or emotionally to recall the time when they were diagnosed and treated. For several other patients, family members informed us that they had recently died.

4.2 Characteristics of survey participants

Clinical and socio-demographic characteristics of survey participants are summarised in table 4.1.

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[h] These were typically older patients who had a medical card and whose family members had driven them to their hospital appointments.

Table 4.1 Characteristics of survey participants

Characteristic		*No.(%) of respondents*
Cancer site	Breast	495 (67%)
	Prostate	216 (29%)
	Lung	19 (3%)
	Not reported	10 (1%)
Age	<50 years	163 (22%)
	50-59 years	198 (27%)
	60-69 years	173(23%)
	70 and older	119 (16%)
	Not reported	87 (12%)
Marital status	Married or living as married	535 (73%)
	Single, widowed, or divorced	192 (26%)
	Not reported	13 (2%)
Educational level completed	Primary school	156 (21%)
	Secondary school to junior certificate	181 (25%)
	Secondary school to leaving certificate	187 (25%)
	Third level or post-graduate	195 (26%)
	Not reported	21 (3%)
Child or adult dependants[1]	Yes	319 (43%)
	No	403 (55%)
	Not reported	18 (2%)
Employment status at diagnosis	In paid employment	275 (37%)
	Self-employed	89 (12%)
	Retired	174 (24%)
	Not in paid employment[2]	185 (25%)
	Not reported	17 (3%)
Social welfare/HSE payments at diagnosis	Yes	175 (24%)
	No	528 (71%)
	Not reported	37 (5%)
Medical card	Yes, held at diagnosis	269 (36%)
	Yes, obtained following diagnosis	282 (38%)
	No	180 (24%)
	Not reported	9 (1%)
Private health insurance at diagnosis	Yes	464 (63%)
	No	264 (36%)
	Not reported	12 (2%)

[1] children under 18 living at home or adult dependants; [2] includes those who described themselves an unemployed, looking after the family or home, or unable to work due to permanent sickness or disability

Of the 740 questionnaires, 685 (93%) had been completed by the cancer patient themselves, and 55 (7%) by a proxy respondent, generally the spouse or son or daughter of the cancer patient[i]. 495 (67%) of the questionnaires related to individuals who had had breast cancer (table 1), 216 (29%) to those who had had prostate cancer and 19 (3%) to those who had had lung cancer; the site of cancer was not reported on 10 (1%) questionnaires. Approximately three-quarters (76%) of the patients had undergone surgery for cancer, two-thirds had had radiotherapy, 41% had had chemotherapy and 39% had received hormone therapy.

Reflecting the cancer site distribution, just over two-thirds of participants were female (68%) and slightly less than one third were male (31%); the remaining nine (1%) did not report their gender. For the 19 respondents with lung cancer, 13 (68%) were male and six (32%) were female. Slightly over 12% of respondents did not report their date of birth; among those who did, the median age was 58 years. 43% of those with lung cancer were aged 70 and older, compared to 25% with prostate cancer, and 14% with breast cancer. None of the lung cancer patients were under 50, compared to 3% with prostate cancer and 35% with breast cancer.

Just over 70% reported that they were married (n=511) or lived as married with a partner (n=24), while 26% reported their status as single (n=75), divorced (n=37) or widowed (n=80). 22% of respondents had one or more children aged 18 or under living at home. Nearly one third (29%) had dependants over the age of 18. Combining these, 43% had child or adult dependants. This varied by cancer site, with 47% of those with breast cancer having dependants, compared to 39% with prostate cancer and 33% with lung cancer.

98% of participants reported their ethnic group as white. 93% reported their nationality as Irish. In terms of the highest level of education achieved, just over one fifth of participants (21%) had completed primary level education, 25% had completed secondary school to inter or junior certificate level, 25% had completed the leaving certificate and 26% had completed third level education. At the time of diagnosis with cancer, 37% were in paid employment and a further 12% were self-employed. One quarter were retired and a further quarter were not in paid employment, mainly describing themselves as looking after the family (n=133), or away from work because of sickness (n=30). As would be expected, employment status varied by age and cancer site. Among those under 60, 59% were in paid employment at the time of diagnosis, 13% were self-employed, 24% were not in paid employment, and 3% were retired. The figures for those aged 60 and older were: paid employment, 13%; self-employed, 10%; not in paid employment, 25%; and, retired, 49%. Among women with breast cancer, 42% were in paid employment and a further 8% were

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[i] Proxy respondents were asked to answer the survey questions from the perspective of the individual with cancer. The analyses in this chapter include the questionnaires from proxy respondents.

self-employed; for prostate cancer, 28% were in paid employment and 22% were self-employed; and for lung cancer, 21% were in paid employment and none were self-employed.

One quarter of respondents were in receipt of social welfare or HSE payments (Appendix 1) at the time of diagnosis (including unemployment benefit/allowance, illness benefit, disability allowance, rent allowance, old age pension etc). Of the 637 participants who reported their household annual income, one quarter fell in each of the following categories: less than €18,720, €18,720-€27,635, €27,636-€41,600, more than €41,600.

Just over one third of respondents (36%) had had a medical card immediately before they were diagnosed with cancer, and a further 38% obtained one following diagnosis. Reflecting the entitlements in the system at the time the study was conducted (Appendix 1), 96% of those aged 70 and older had a medical card at diagnosis and all but one of the remainder obtained one following diagnosis. The youngest subjects were least likely to have a medical card at diagnosis, and most likely to obtain one afterwards. Almost two-thirds (63%) of those under 50 obtained a medical card following diagnosis, and 18% had one at diagnosis; among those aged 50-59 years, the comparable figures were 43% and 18%; and among those aged 60-69 they were 39% and 30% respectively. Thus, the percentages without a medical card were: <50, 19%; 50-59, 39%; 60-69, 31%.

Slightly more than one third of respondents (37%) reported that they were already using the Drugs Payment Scheme (Appendix 1) at the time they were diagnosed with cancer. Almost two-thirds (63%) had private health insurance at the time of diagnosis. This figure was slightly lower (57%) in those aged 70 and older, compared to younger subjects; among those under 70, there was little variation in the percentage with health insurance by age. Of those who had private health insurance, 23% also had a medical card at diagnosis, and 43% obtained a medical card following diagnosis; of those who did not have private health insurance, 61% had a medical card at diagnosis, and 31% obtained one following diagnosis.

4.3 Medical, health and treatment-related costs

4.3.1 *Medical care and related costs*

4.3.1.1 Costs of seeing consultants, GPs and allied health professionals

Table 4.2 summarises participants' responses in relation to costs associated with visits to doctors and other allied health professionals. These figures do not include patients who had had their costs fully reimbursed or covered from some source (e.g. private health insurance or medical card); they therefore reflect those who incurred direct out-of-pocket expenses.

Table 4.2 Medical and health-related costs incurred by participants[1]: number (%) of respondents who had incurred costs, and median amount paid

Category of expenditure	*No. (%) of respondents who had incurred costs[2]*	*Median amount*
Costs of visits to clinicians and allied health professionals		
Visits to hospital consultant(s)	333 (45%)	€465
GP visits	267 (36%)	€250
Physiotherapy	63 (9%)	€320
Counselling	43 (6%)	€360
Other therapies[3]	14 (2%)	€400
Medications		
Prescription medicines	218 (29%)	€300
Over-the-counter medicines	289 (39%)	€100
Other items		
Complementary therapies	113 (15%)	€300
Dietary supplements	95 (13%)	€200
Convalescent stay	10 (1%)	-[4]

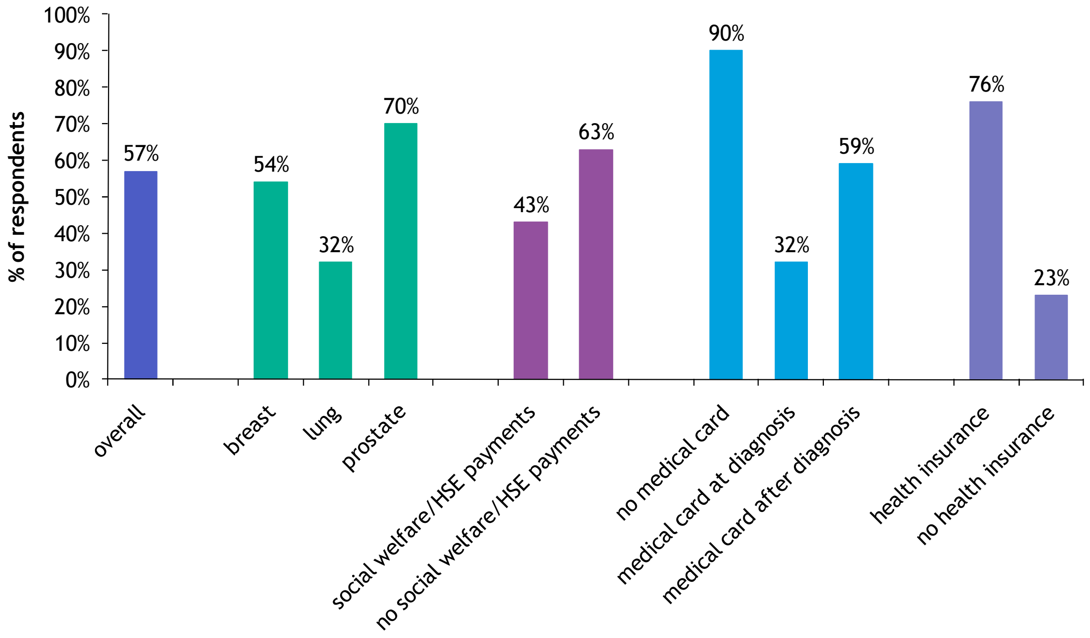
[1] all costs relate to direct out-of-pocket expenses (i.e. costs which were not covered by medical card or private health insurance); [2] % of all 740 respondents; [3] such as occupational therapy; [4] see text for weekly amounts

Almost half (45%) of respondents had incurred costs in relation to seeing hospital consultants regarding their cancer diagnosis and treatment. The average amount spent was €465. One quarter of those who had incurred costs spent more than €800. The percentage that had costs in relation to hospital consultants was higher among prostate cancer patients (61%), than among those with breast (39%) or lung (21%) cancer. Two-thirds of those with private health insurance had some out-of-pocket expenses for seeing consultants, compared to 11% without health insurance. Of those who did not have a medical card, 69% incurred consultant fees, compared to 46% who obtained a medical card following diagnosis. Among those who had a medical card at diagnosis, just under one third (28%) had paid to see a consultant.

More than one third (36%) of cancer patients had paid a fee to see a GP following their cancer diagnosis. The median cost incurred was €250 with one in four of those who had incurred costs spending at least €400. The percentage that had paid GP fees was higher among those with prostate (51%) than breast (31%) or lung (16%) cancer. Almost half of patients (48%) with private health insurance paid to see a GP, compared to 16% without insurance. Of those without a medical card, 78% incurred costs associated with seeing a GP, compared to 12% who had a medical card at diagnosis and 32% who obtained a medical card following diagnosis.

Almost 10% of respondents had paid for physiotherapy, 6% for counselling and 2% for other therapies as a result of their cancer diagnosis. The median amount spent on each of these was between €300 and €400. One quarter of those who had incurred costs for physiotherapy spent more than €500; for one quarter of those who had spent money on counselling, this had cost more than €900; and for one quarter of those who had paid for other therapies, the cost incurred was more than €960.

Figure 4.1 Percentage of respondents who reported that they had incurred costs in relation to visits to clinicians or allied health professionals,[1] by selected patient characteristics



[1] costs not covered by medical card or private health insurance for visits to consultants or GPs, or for physiotherapy, counselling or other therapies (e.g. occupational therapy)

Combining GP and consultant visits, physiotherapy, counselling and other therapies, 57% of respondents had incurred costs in relation to one or more of these. This percentage varied by cancer site, and patients' medical card, health insurance status and social welfare status. More men with prostate cancer (70%) had spent money on visits to clinicians or allied health professionals, than women with breast cancer (54%), or those with lung cancer (32%; figure 4.1). Among those without a medical card, 90% had costs in relation to visits to clinicians or allied health professionals, compared to 32% who had a medical card at the time of cancer diagnosis, and 59% who obtained a medical card after diagnosis. The percentage was higher among those who had private health insurance (76%) than those who did not (23%). Those who were on social welfare or HSE benefits at the time of diagnosis were less likely to incur costs in relation to visits to clinicians and allied health professionals than those who were not (43% and 63% respectively).

4.3.1.2 Costs of supportive medications

In terms of supportive medicines, 29% had incurred costs for prescription items as a result of their cancer (table 4.1). These individuals each spent on average €300 on prescription items, with one in four incurring a cost of at least €700. Among those who did not have a medical card either at diagnosis or afterwards, almost two-thirds (64%) had spent money on prescribed drugs or medications.

Almost four in 10 cancer patients (39%) had paid for over-the-counter medicines that they needed to help with cancer symptoms or side-effects of treatment (e.g. mouthwashes, creams), spending an average amount of €100 per person. One quarter incurred costs of €200 or more on over-the-counter items.

4.3.1.3 Other medical and health-related costs

As a result of their cancer or its treatment, 15% of patients had spent money on alternative or complementary therapies, such as acupuncture or reflexology. These patients reported spending, on average, €300 on such therapies. One in four patients who incurred costs for complementary therapies spent at least €600.

A slightly smaller percentage of patients (13%) had had out-of-pocket expenses for dietary supplements that they had needed because of their cancer diagnosis or treatment. The average amount spent was €200, with one quarter spending €500 or more.

Sixty individuals had a convalescent stay following diagnosis and 10 (1% of survey respondents) reported that they had incurred some expenses in relation to this which were not covered by a medical card or private health insurance. Three subjects reported paying up to €230 per week, three reported paying €400-€500 per week, and four reported paying €750-€800 per week for the cost of their convalescent stay.

4.3.1.4 Costs of wigs, hairpieces and lymph drainage

Some expenses are specific to the type of cancer and treatment that a patient receives. Among women with breast cancer, 40% stated that they had had out-of-pocket expenses relating to the purchase of wigs or hairpieces due to treatment-associated hair loss (table 4.3). This percentage does not include those who had the cost of a wig covered by another source, such as a payment from Community Care (Appendix 1). The average amount spent was €400. One in four women who had outgoings for wigs or hairpieces spent more than €500.

One in twenty women with breast cancer had had to pay for manual lymph drainage. The average out-of-pocket expenditure was €140.

Table 4.3 Other health-related costs incurred by participants with breast cancer[1]: number (%) of respondents who had incurred costs, and median amount paid

Category of expenditure	*No. (%) of respondents who had incurred costs[2]*	*Median amount*
Lymph drainage	25 (5%)	€140
Wigs and/or hairpieces	200 (40%)	€400

[1] all costs relate to direct out-of-pocket expenses (i.e. costs which were not covered by medical card, private health insurance, or HSE payments); [2] % of 495 respondents with breast cancer

4.3.1.5 Other costs

Almost one quarter of respondents (n=181; 24%) reported that they had had other extra costs because of their cancer diagnosis which were not covered by a medical card or health insurance. Extra costs were incurred for a range of items including some relating to medical tests (e.g. ultrasound examinations, MRIs, x-rays), some associated with personal and family care (e.g. incontinence pads, nursing home care for dependant spouse) and other miscellaneous items (e.g. lost deposit for cancelled holiday).

4.3.2 Costs related to cancer treatment

More than seven in every 10 respondents reported that they had had travelling expenses associated with their cancer treatment appointments (table 4.4). The average amount spent was €360, with one in four spending €785 or more.

Just over half of patients (52%) indicated that they had paid for parking when at hospital for cancer treatment. On average, respondents spent €76 on parking fees. One in four reported out-of-pocket expenses of more than €160 for parking alone.

Taking travel and parking expenses together, almost eight in every 10 cancer patients (79%) had costs in relation to attending cancer treatment appointments. The percentage who had had travelling or parking expenses decreased with increasing age: 91% in those aged under 50, 84% in the 50-59 age group, 76% in the 60-69 age group and 68% in those aged 70 and older. A slightly lower percentage of those who were single, widowed or divorced (71%) had travelling or parking expenses than those who were married or living as married (83%). The percentage who incurred such expenses was also slightly lower among those who had a medical card at the time of diagnosis (69%) than among those who obtained a medical card following diagnosis (88%) and those who did not have a medical card (81%).

Fifty patients (7%) reported that they had had to pay for overnight accommodation when they had received treatment. The average among those who reported the amount they had spent was €200, with one in four spending at least €500.

Table 4.4 Costs related to cancer treatment[1]: number (%) of respondents who had incurred costs, and median amount paid

Category of expenditure	*No. (%) of respondents who had incurred costs[2]*	*Median amount*
Travel	535 (72%)	€360[3]
Parking	384 (52%)	€76[4]
Overnight accommodation	50 (7%)	€200[5]

[1] all costs relate to direct out-of-pocket expenses (i.e. costs which were not reimbursed from any source); [2] % of all 740 respondents; [3] based on 486 respondents for whom it was possible to compute a total amount spent on travel (the remaining respondents reported a cost per trip, but did not report number of trips); [4] based on 292 respondents who reported the amount spent on parking; [5] based on 43 respondents who reported the amount spent on overnight accommodation

4.3.3 Assistance with medical, health and treatment-related costs

Fifty-six respondents (8%) reported that they had had some financial assistance to help them meet medical or treatment-related costs. Of these, 26 had received help from family (n=22), friends (n=2) or work colleagues (n=2); 10 from a charity; 10 from the HSE via a community welfare officer; three from a hospital cancer fund; and two from a critical illness or other insurance policy. Several received assistance with meeting costs of travel (n=19) or overnight accommodation (n=6) associated with treatment; others had help with costs of meals, bills, clothes, wigs, and counselling.

4.4 Employment, benefits and household income

4.4.1 Employment and cancer patients

Of the 364 patients who were working immediately before they were diagnosed with cancer, 83% took some time off following diagnosis. This percentage was higher among those who were working for an employer (87%) than among those who were self-employed (65%).

Of those who did not take time off work, 31% reported that finances had affected their decision on whether or not to take time off work. This percentage rose to 46% among those who were self-employed. These figures should be interpreted with caution as they are based on small numbers of individuals.

Of those who took time off, 50% received some sick-pay. This figure was 63% among those who had been working for an employer. Among those who were self-employed, 5% received sick-pay.

77% of those who took time off had either returned to work (61%) or planned to return (17%) at the time they completed the questionnaire. Of these individuals, two-thirds reported that finances had affected their decision to return to work. The percentage who had returned to work was higher among those who were self-employed (70%) than those who worked for an employer (60%).

4.4.2 Employment and family members

16% of respondents reported that someone else in their family or household had had to make some change to their working pattern (e.g. time off, changed hours, changed shifts, etc) because of the cancer diagnosis. This percentage was higher among those with child or adult dependants (24%) and higher still among those with children under 18 living at home (30%).

Among the family members who had changed their working pattern, 54% had decreased, and 20% had increased, their working hours. More than half (58%) indicated that the individual had had a drop in pay; pay for 10% had increased.

4.4.3 New social welfare/HSE payments

Almost one quarter (23%) of respondents reported that they had claimed a new social welfare or HSE payment because of their cancer diagnosis. The largest group had claimed illness benefit, with others claiming disability allowance, invalidity pension, old-age pension, and a range of other payments (e.g. widows pension, farm assistance, carer's allowance, etc).

The percentage claiming new payments or benefits was similar among those who were already in receipt of social welfare or HSE payments at the time of diagnosis and those who were not. It was higher among younger than older patients (<50: 39% claimed new payment(s); 50-59 years: 33%; 60-69 years: 12%; 70 and older: 6%). A higher proportion of those with child or adult dependants claimed new payments than those without (30% vs 18%). Among those who were in paid employment at diagnosis 44% claimed new payments, compared to 9% of those who were self-employed, 4% of those who were retired, and 17% of those who were not in paid employment.

Table 4.5 Respondents' experiences of finding out about and applying for new social welfare/HSE payments; number (%) of respondents[1]

Experience	*Getting information*	*Making an application*
Very easy	46 (27%)	49 (23%)
Quite easy	71 (42%)	76 (45%)
Quite difficult	22 (13%)	20 (12%)
Very difficult	13 (8%)	11 (7%)
Not reported	17 (10%)	23 (14%)

[1] % of those who had claimed new payments

Table 4.5 summarises how respondents rated the experience of getting information about entitlements and making the application for a new payment. Most respondents found it quite or very easy to get information or applying. Slightly more than one fifth of those who had claimed new payments reported that it was quite or very difficult to get information about entitlements. Similarly, just fewer than 20% in total found the application process difficult, with 7% stating that it was very difficult.

4.4.4 Household income

When asked about what had happened to their total household income since their diagnosis with cancer, 30% of respondents reported that it had decreased, 59% reported that it had not changed, and 11% reported that it had increased[j].

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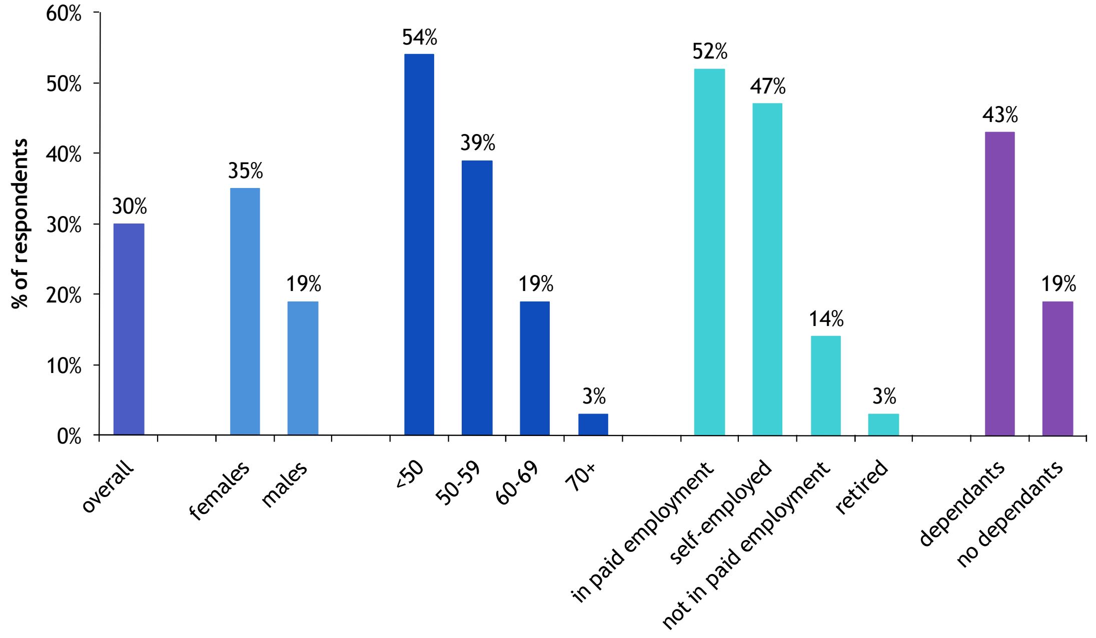
[j] The level of missing data was higher for this question that most other questions. The figures in this section exclude the 98 respondents who declined to answer this question.

Figure 4.2 Percentage of respondents[1] who reported that their household income had decreased since their cancer diagnosis, by selected patient characteristics



[1] based on 642 respondents in total

The percentage who reported that their total household income had decreased was higher among women, those who were younger at diagnosis and those who were in work at diagnosis (figure 4.2). Those with dependants were more likely to report a decrease in household income than those without (figure 4.2). In particular, more than half (53%) of those with children aged under 18 living at home said that their income had fallen since their cancer diagnosis. Those who were on social welfare payments at the time of diagnosis were less likely (19%) than those who were not (33%) to report a decrease in income.

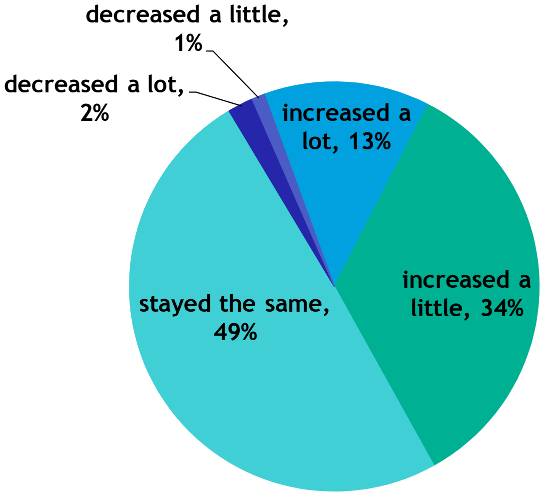
4.5 Household spending

4.5.1 Overall household spending

Figure 4.3 indicates the effect of cancer on average day-to-day spending in participants' households. Half of respondents indicated that household spending had not changed as a result of the cancer diagnosis, and 3% that spending had decreased. The remaining 47% reported that spending had increased as a result of the cancer diagnosis; for 34% spending had increased a little and for 13% it had increased a lot.

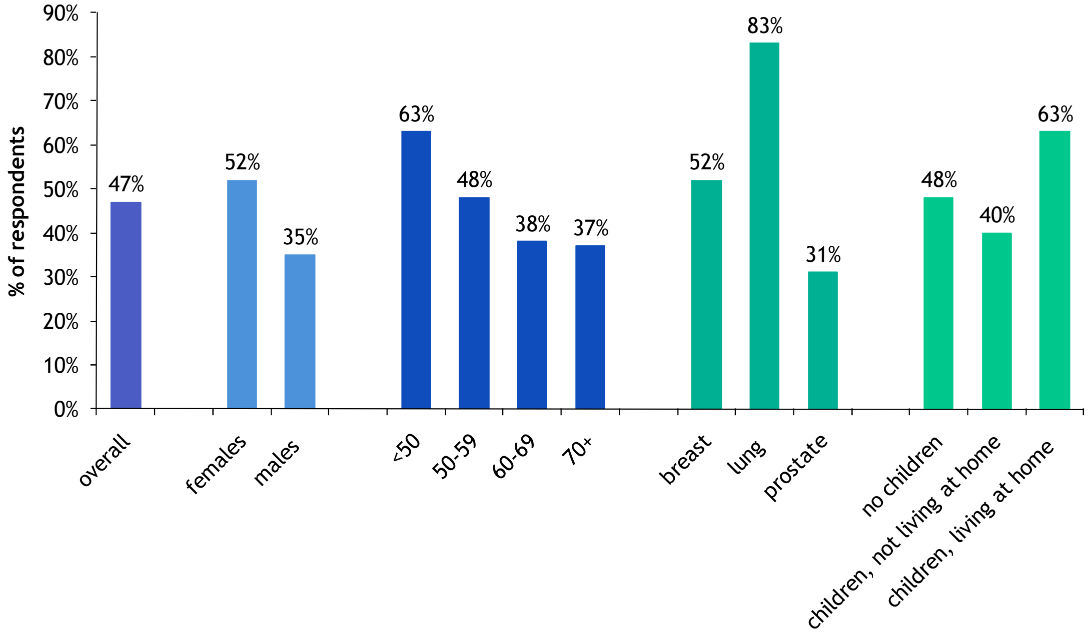
More female than male respondents reported that household spending had increased since their cancer diagnosis (figure 4.4). More than 80% of lung cancer patients reported increased household spending, compared to half of those with breast and one third with prostate cancer, but this figure needs to be interpreted with care as only 19 patients with lung cancer responded to the survey. The percentage reporting an increase was higher among younger than older patients, especially those aged under 50 at diagnosis (63% reported an increase). Those with children under 18 living at home were more likely to report increased spending than those who had either no children or whose children did not live at home. Almost three-quarters (72%) of lone parents reported increased household spending but, as with lung cancer, this figure is based on relatively few individuals (n=18). Increased household spending was more common among those in paid employment (55%), and those not in paid employment (53%), than among the self-employed (43%) and retired (32%).

Figure 4.3 Effect of cancer diagnosis on household spending[1]: % of respondents



[1] % of 712 respondents who completed the question

Figure 4.4 Percentage of respondents[1] who reported that their average household spending had increased because of their cancer diagnosis, by socio-demographic characteristics



[1] based on 712 respondents

4.5.2 Household bills

Almost six in every 10 respondents (58%) indicated that spending on household bills (heating, telephone, food, rent or other bills) had increased to some extent since their cancer diagnosis. The percentages who reported increased spending on heating, telephone and food bills specifically are shown in table 4.6. More than 40% of patients reported that they had had increased spending on heating and telephone bills, and almost one third had increased food bills.

Table 4.6 Spending on household bills since cancer diagnosis: numbers (%) of respondents who reported increased spending[1], by type of bill

Type of bill	*Increased spending*
Heating	297 (44%)
Telephone	280 (42%)
Food	190 (29%)

[1] % of respondents who answered the question and to whom the question was applicable (n=678, 662, 660 for heating, telephone and food bills respectively)

A much higher percentage of female respondents (67%), than males (38%) reported that spending on household bills had increased since their cancer diagnosis. Consistent with this, an increase in household bills was more commonly reported by those with lung cancer (72%) and women with breast cancer (66%), than men with prostate cancer (32%). The percentage reporting increased spending on bills was also higher among younger than older patients (<50: 80%; 50-59: 55%; 60-69: 49%; 70+: 49%). Those with dependants reported increased bills more often than those without dependants (64% vs 53%). Retired individuals were least likely to say that their household bills had risen (45%, compared to 65% in paid-employment, 53% of the self-employed, and 61% of those not in paid employment).

4.5.3 Other household and family-related out-of-pocket expenses

Three hundred and three respondents told us that their weight had changed as a result of developing cancer or its treatment. Of these, 80% had had to buy new clothes.

Of those respondents who had one or more children under 18 living at home (n=165), 15% had had to spend money on childcare as a result of their cancer diagnosis.

Slightly less than 10% of respondents had incurred out-of-pocket expenses to obtain help around the home because of their cancer. The percentage was higher for female (14%) than male patients (1%) and among younger (<60: 14%) than older (60 or older: 5%) patients.

Just over 1% of respondents reported having had to spend money on nursing care as a result of being diagnosed with cancer.

One in twenty cancer patients had had to make a modification to their home because of their cancer diagnosis. One third of these respondents had incurred costs associated with making the modifications; the amount spent ranged between €500 and €10,000.

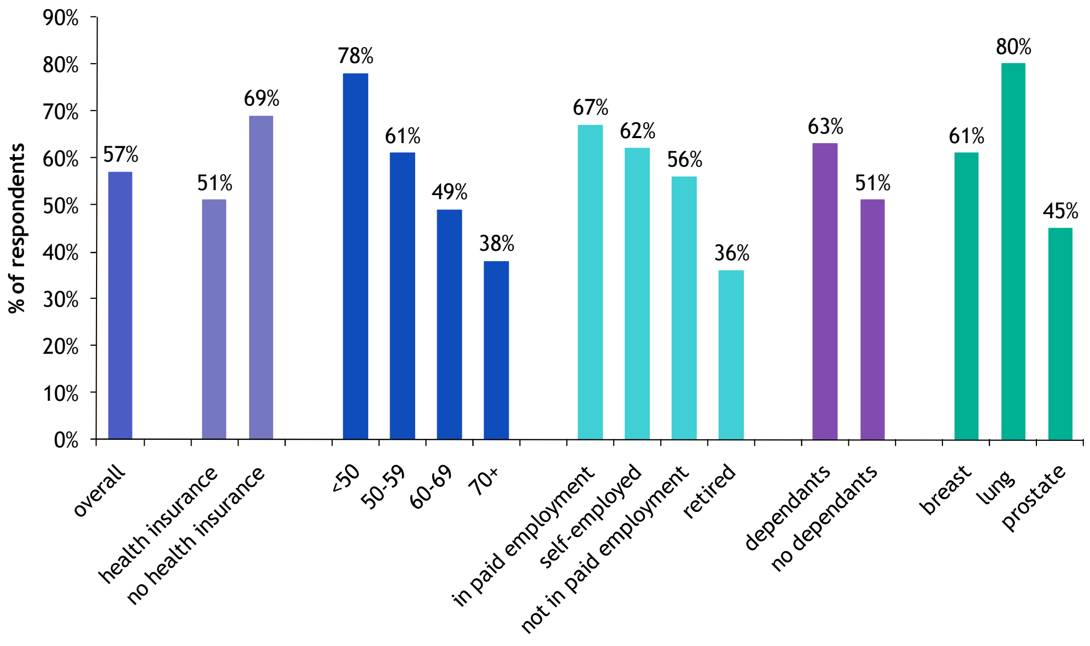
4.6 Financial consequences

4.6.1 Savings

Five hundred and thirty-nine respondents reported that they had had some savings at the time of their cancer diagnosis. Of these, a total of 57% reported that they had had to use some (50%) or all (7%) of their savings because of their cancer diagnosis.

Among those who had savings, the proportion that had had to use some or all of these because of their cancer diagnosis was higher among younger patients and those who had been working at the time of diagnosis (figure 4.5). More patients with lung cancer (80%) or breast cancer (61%) had to use their savings compared to those with prostate cancer (45%), reflecting the association with age and employment status. Patients who did not have private health insurance were more likely to report using their savings (figure 4.5). Similarly, those who obtained a medical card following diagnosis were more likely to use savings (69%), compared to those who had a medical card at diagnosis (54%) and those who did not have or obtain one (41%). Almost two-thirds of those with dependants had to use savings compared to half without dependants (figure 4.5). In particular, almost all lone parents (92%) had had to use some or all of their savings, but this figure should be interpreted with caution since it is based on only 12 lone parents who had savings.

Figure 4.5 Percentage of respondents[1] who reported that they had had to use some of all of their savings because of their cancer diagnosis, by socio-demographic characteristics



[1] based on 539 respondents who had savings

4.6.2 Borrowing

11% (n=84) of respondents reported that they had had to borrow money because of their cancer diagnosis. 8% had borrowed from a bank or credit union, 5% from family or friends, and 2% on credit cards.

The percentage who had had to borrow money was higher among: females (13%) than males (8%); younger than older patients (<50: 21%; 50-59: 15%; 60-69: 5%; 70+: 3%); those who were single, widowed or divorced (15%) compared to those who were married or living as married (10%); and those who did not have private health insurance (17%) compared to those who did (8%).

4.6.3 Reductions in household spending on specific items

Some patients indicated that, since their cancer diagnosis, they had had to reduce or give up spending on particular items because of the cost (table 4.7). These included holidays (spending on holidays was reduced or given up by one fifth of respondents) and leisure activities (spending cut by 12% of respondents). One fifth of respondents indicated that they had had to cut the amount they spent on other items that would, in the past, have been a regular part of their household budget, such as new clothes, nights out, and take-away meals.

Unsurprisingly the percentages who reported that they had reduced or given up spending were higher among patients who stated that their household income had fallen since their cancer diagnosis. Among those whose income had decreased, 49% cut spending on regular items, 30% cut spending on leisure activities and 46% cut spending on holidays.

When asked about anything that they, or their family, had needed but decided to forgo because of cost, respondents listed short breaks, homehelp, home repairs/maintenance and upgrading their car.

Table 4.7 Cuts in household spending because of cost, since cancer diagnosis: numbers (%) of respondents[1] by type of expenditure

Type of expenditure	*Spending reduced or given up*
Regular items (e.g. new clothes, nights out, take-away meals, etc)	149 (20%)
Leisure activities	86 (12%)
Holidays	142 (19%)

[1] % of all 740 respondents

4.6.4 Ability to meet mortgage and loan payments

Two hundred and six participants had a mortgage at the time of diagnosis with cancer. Of these, 45% reported that it had become more difficult to pay their mortgage since their cancer diagnosis; 46% stated that it was no more or less difficult and 8% reported that it was less difficult.

When asked about the extent to which their ability to meet mortgage payments had changed, 20% reported that it was a little more difficult, 18% that it was more difficult and 5% that it was much more difficult.

Among those who had a mortgage, patients under 50 were more likely than older patients to indicate that they were finding it harder to pay: 54% of those aged under 50 compared to 33% and 35% of those aged 50-59 and 60-69 respectively (no-one aged 70 or older had a mortgage). The frequency was higher among self-employed (52%) patients, than among those who were working for an employer (45%), retired (17%) or not in paid employment (38%).

Other types of personal loans were held by 203 respondents at the time of diagnosis with cancer. Almost 6 in every 10 who had a loan (58%) stated that it was more difficult to meet loan payments since they had been diagnosed. This was much more difficult for 8% of respondents, more difficult for 19% and a little more difficult for 20%. Paying personal loans was less difficult for 5% of respondents and no more or less difficult for 37%.

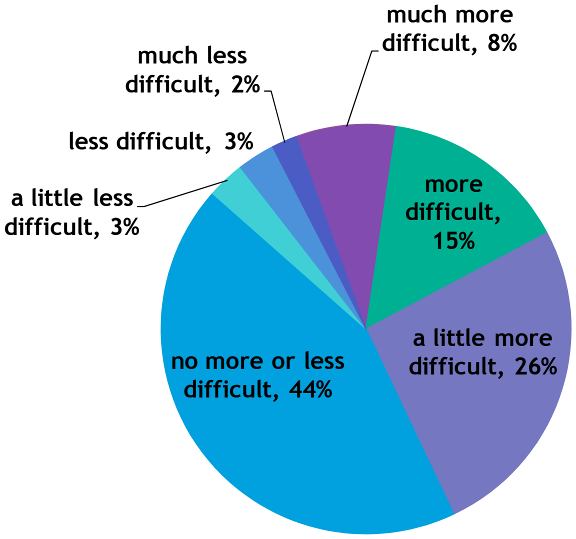
As with mortgages, among those who had personal loans, the percentage having more difficulty in meeting payments was higher among patients under 50 (63%) and those who were self-employed (86%).

4.6.5 Overall financial stress

Almost half of respondents (48%) reported that financial stress on their household had increased since the cancer diagnosis - it was more difficult, to some extent, for their household to make ends meet (figure 4.6). For 8%, cancer had made their household's ability to make ends meet much more difficult, while it was more difficult for 15% and a little more difficult for 26%. A further 44% stated that their household's ability to make ends meet had not changed, and the remaining 8% indicated that it had improved.

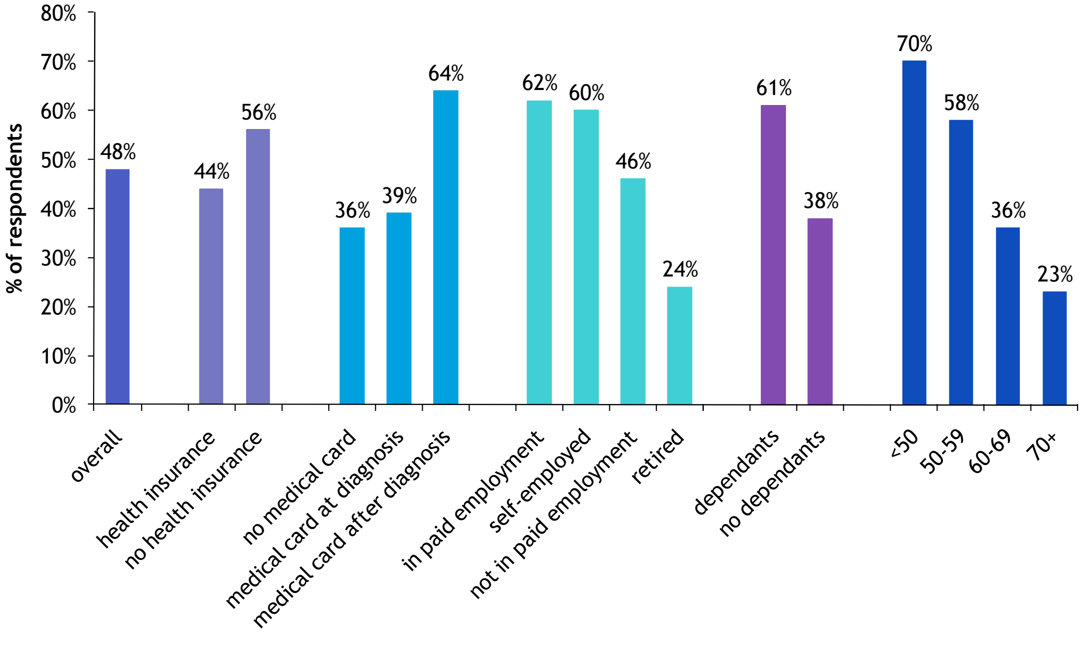
Just over half (51%) of female patients reported increased financial stress, compared to 42% of males. Greater difficulty in making ends meet was more commonly reported by patients with lung cancer (68%), than those with breast (51%) or prostate (40%) cancer; once again, this needs to be interpreted with care because of the small number of respondents with lung cancer. The percentage reporting increased financial stress was higher among younger than older patients, and among those who were employed or self-employed at diagnosis than among other groups (figure 4.7). It was also higher among those with dependants, than those without. Among those with children under 18 living at home, 69% reported that financial strain had increased. In particular, 88% of lone parents were experiencing more

Figure 4.6 Financial stress - effect of cancer diagnosis on household's ability to make ends meet[1]: % of respondents



[1] % of 716 respondents who completed the question

Figure 4.7 Financial stress - percentage of respondents[1] who reported that the cancer diagnosis had made it more difficult for their household to make ends meet, by socio-demographic characteristics



[1] based on 716 respondents

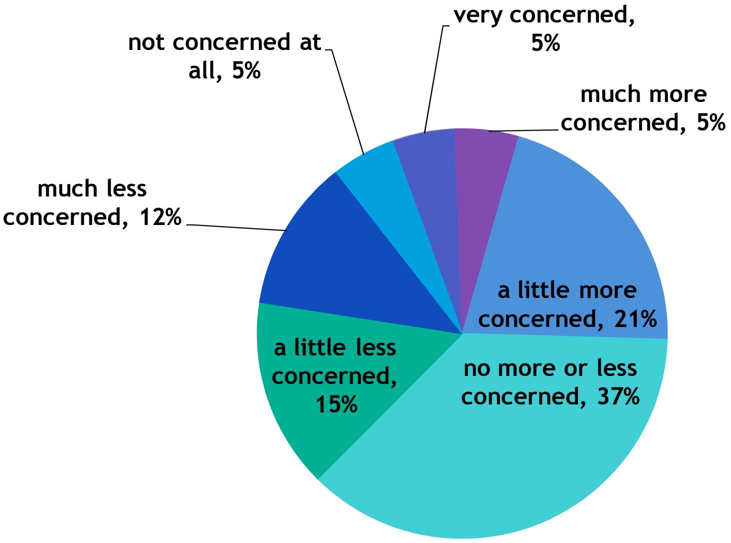
difficulty in making ends meet but, as before, this figure should be interpreted with caution as there were few lone parents in the study. Those who did not have private health insurance, and those who obtained a medical card following diagnosis, were more likely to report increased financial stress since the cancer diagnosis (figure 4.7). There was no significant association between financial stress and quartiles of pre-diagnosis household income.

4.6.6 Overall financial strain

When asked to indicate their feelings about their household's financial situation since the cancer diagnosis (financial strain), 32% of patients responded that they were less concerned, 37% that they were no more or less concerned, and 31% that they were more concerned (figure 4.8). In terms of the extent of financial strain experienced by patients, 5% reported that they were very concerned about their household's financial situation, 5% that they were much more concerned, and 21% that they were a little more concerned.

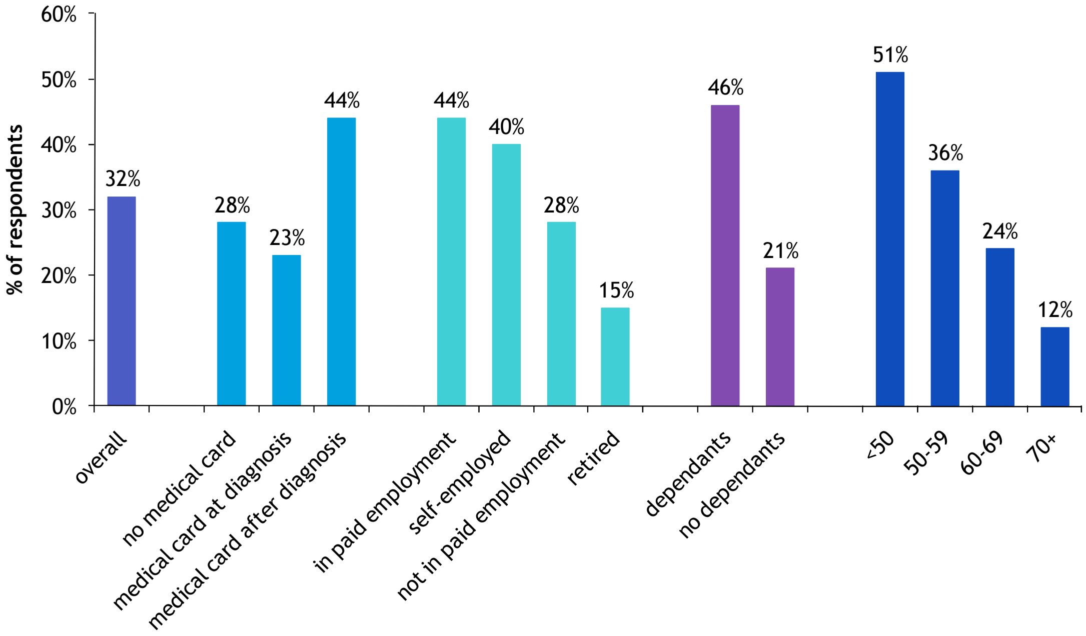
The distribution of financial strain varied according to the patient's age, employment status, medical card status, and whether or not they had dependants (figure 4.9). Almost half of those with dependants (46%) reported that they were more concerned about their financial situation since their cancer diagnosis, compared to one fifth (21%) without dependants. The percentage reporting increased financial strain declined with increasing age. It was higher among those who were working (employed or self-employed) at diagnosis. Increased financial strain was more frequently reported by those who had obtained a medical card following diagnosis (44%), than by those who had one at diagnosis (23%), and those who did not have one at all (28%). Increased financial strain was somewhat less common among those with prostate (29%) and breast (33%) cancer, than among those with lung cancer (42%), but this figure is based on just 19 respondents with lung cancer. There was no significant association between financial strain and quartiles of pre-diagnosis household income.

Figure 4.8 Financial strain - feelings about household's financial situation since cancer diagnosis[1]: % of respondents



[1] % of 718 respondents who completed the question

Figure 4.9 Financial strain - percentage of respondents[1] who reported that they were more concerned about their household's financial situation since the cancer diagnosis, by socio-demographic characteristics



[1] based on 718 respondents

4.7 Emotional outcomes

4.7.1 Financial stress and depression, emotional stress and anxiety

Figure 4.10 shows the relationship between financial stress (household ability to make ends meet since the cancer diagnosis) and emotional state at the time the questionnaire was completed. There was a significant association between financial stress and depression (X^2_4=56.37, p<0.001), stress (X^2_4=55.93, p<0.001) and anxiety (X^2_4=40.23, p<0.001). The prevalence of depression, stress and anxiety was higher among those who reported that it was more difficult to make ends meet, than among those who reported less difficulty or no change in ability to make ends meet. If only severe emotional outcomes are considered, the prevalence was again consistently higher among those who had greater financial stress (i.e. more difficulty making ends meet) than other groups.

In terms of depression, just over half of those who found it more difficult to make ends meet had mild, moderate or severe depression, compared to 33% of those who found making ends meet less difficult, and 24% of those who reported no change. Among those who had more difficulty making ends meet, more than three times as many patients scored in the severe depression range than among other groups (27% vs 6-8%).

A similar pattern was seen for emotional stress. Among those who had more difficulty making ends meet, half had mild, moderate or severe emotional stress, compared to 21% of those who reported no change and 29% of those who reported less difficulty. In addition, the frequency of severe emotional stress was more than twice as high among the group with more difficulty making ends meet (22%) compared to other groups (6-9%).

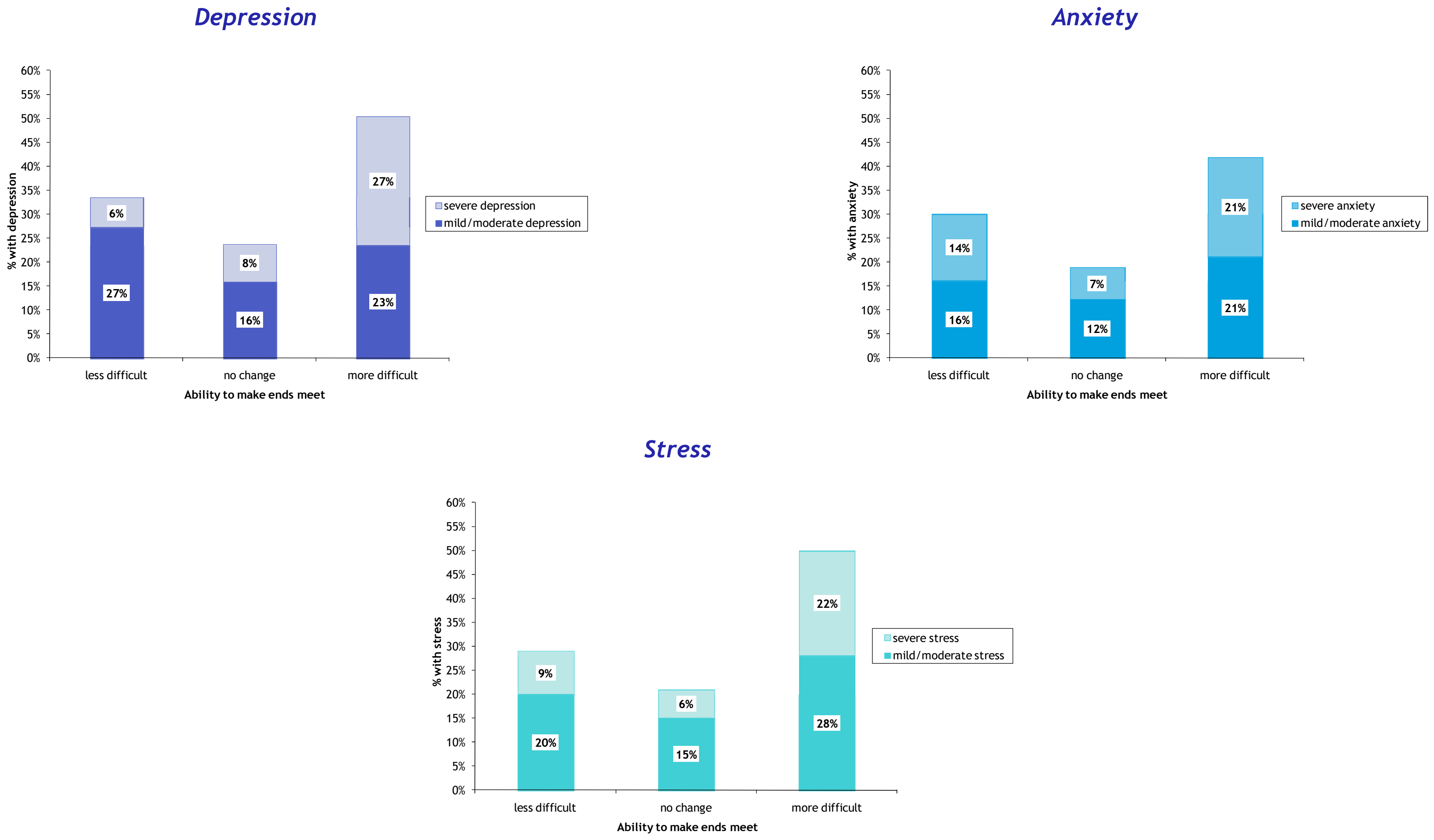
Anxiety was slightly less frequent in all groups than depression and emotional stress. More than four in every 10 patients who had more difficulty making ends meet had mild, moderate or severe anxiety; among those who reported no change or less difficulty making ends meet, the frequency was 19% and 29% respectively.

4.7.2 Financial strain and depression, emotional stress and anxiety

There was a significant association between financial strain (feelings about overall financial situation since the cancer diagnosis) and depression (X^2_4=52.44, p<0.001), emotional stress (X^2_4=51.18, p<0.001) and anxiety (X^2_4=37.96, p<0.001). The prevalence of negative emotional states was consistently higher among patients who reported that they were more concerned about their household's financial situation than among those who reported that they were less concerned, or no more or less concerned (figure 4.11).

Among those who were more concerned about their household's financial situation, more than half (52%) scored in the range for mild, moderate or severe depression, compared to 25% who reported no change and 39% who reported that they were less concerned. The pattern for mild, moderate or severe stress was similar: 51% among those who were more concerned compared to 21% in those who were no more or less concerned and 36% in those who were less concerned. A less pronounced difference between the groups was seen for anxiety; the frequencies with mild, moderate or severe anxiety were 44%, 18% and 34% for those who were more concerned, no more or less concerned, and less concerned respectively. In addition, the frequency of severe depression, severe emotional stress, or severe anxiety was consistently higher among those who were more concerned (i.e. had increased financial strain) than among other groups.

Figure 4.10 Emotional outcomes and financial stress[1]: % of respondents with mild, moderate or severe depression, stress or anxiety



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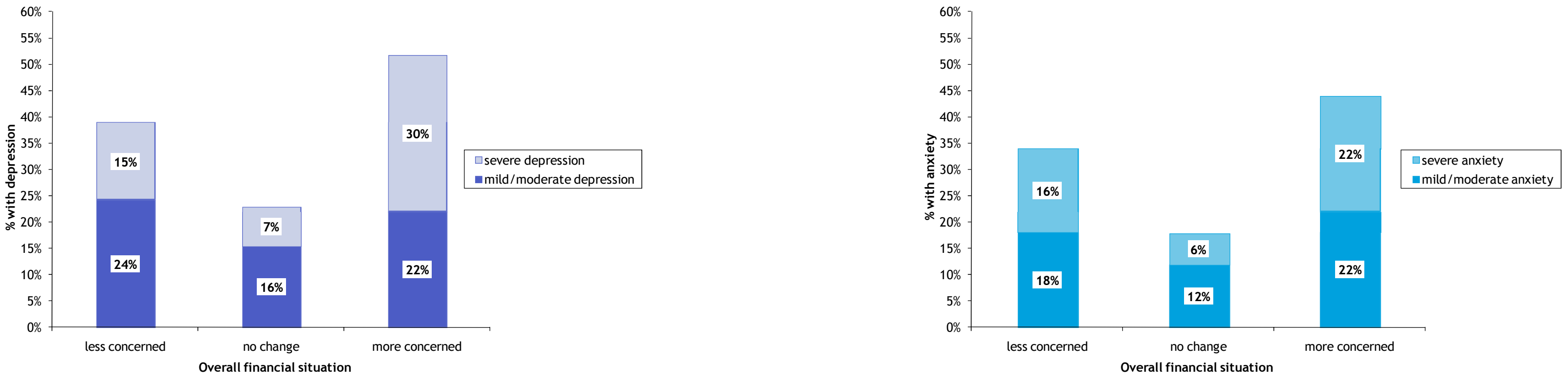
[1] based on respondents who completed all items on DASS and financial stress question (depression: n=628; stress: n=622; anxiety: n=621)

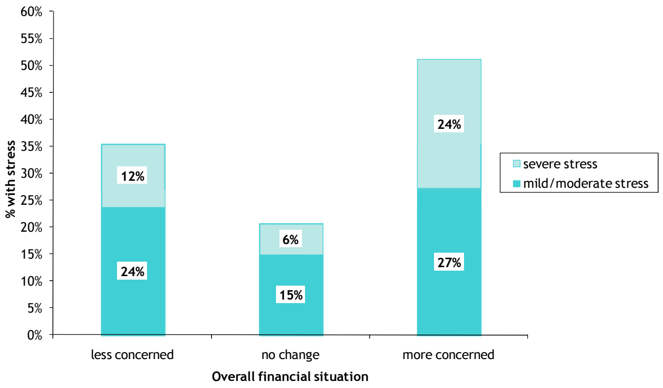
Figure 4.11 Emotional outcomes and financial strain[1]: % of respondents with mild, moderate or severe depression, stress or anxiety



Depression

Anxiety

Stress



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[1] based on respondents who completed all items on DASS and financial strain question (depression: n=628; stress: n=623; anxiety: n=624)

Chapter 5 Discussion

5.1 Financial and economic impact of cancer on the health care system, patients and their families and society

The costs to the health system for the diagnosis, treatment and follow-up of cancer patients are substantial. Although no data are currently available for Ireland, figures from the USA illustrate the burden of cancer on the health system. In 2004 in the USA, an estimated $72 billion was spent on cancer treatment, just under 5% of the total US spending on medical treatment (National Cancer Institute, 2005). In addition, it had been estimated that the cost of treating cancer in the USA rose by 75% during 1995-2004 (National Cancer Institute, 2005). This increase is a result of advances in diagnostic methods and surgical techniques and innovations in pharmaceutical therapies. For example, during 1991 to 2002, the cost of treating patients with one of the four most common types of cancer - breast, lung, prostate, or colorectal - grew steadily as a result of more widespread use of chemotherapy, and the introduction of new and more expensive chemotherapeutic agents and the emergence of more effective multidrug chemotherapy regimes (Warren et al., 2008). The development and dissemination of newer forms of treatment, such as the biological agents or targeted therapies now used to treat a range of cancers (see, for example, Tappenden et al., 2007; Di Cosimo et al., 2008; Bastien et al., 2009; Quintas-Cardama & O'Brien, 2009) is expected to further increase the costs of cancer to the health care system.

This report has revealed, for the first time in Ireland, that it is not only the health care system which bears the costs of cancer. Additional costs are incurred by patients and their families. These costs include out-of-pocket expenses associated with paying for medical care (costs which are recognised by the health care system) and also costs for associated items, such a travel to treatment appointments (costs which are hidden from the health care system). Patients and their families also incur indirect costs due to the impact of cancer on work. The majority of patients (83% of those in work at the time of diagnosis, in this study), and sometimes also family members, need to take time off work during cancer treatment and follow-up. A proportion will never return to the workforce (Amir et al., 2007; Bradley CJ et al., 2007). As well as substantial loss of earnings for patients and family members, this results in lost productivity, the cost of which is borne by employers and society as a whole (Fryback & Craig, 2004). Considering that there are almost 23,000 new cases of cancer diagnosed each year in Ireland (National Cancer Registry, 2009), this suggests that the burden of cancer on employers and society is substantial.

5.2 Frequency, level and multi-dimensional nature of the financial impact of cancer on patients, and interpreting study findings

Three of the most important findings of the research in this report concern the frequency, level and multi-dimensional nature of the financial impact of cancer on patients in Ireland.

The results of the survey suggest that most cancer patients in Ireland incur some direct out-of-pocket costs as a result of their cancer diagnosis, whether in relation to medical costs, travel costs, increased household expenditure, or a combination of these. Eight in every 10 patients reported that they had incurred costs for travel or parking associated with attending hospital appointments; nearly six in every 10 had paid for visits to consultants or their GP, or for other therapies; four in every 10 had paid for over-the-counter medications that they needed because of the cancer; six in every 10 reported an increase in household bills; and nearly half of patients stated that their household spending had increased as a result of having cancer. Coupled with the proportion who reported a drop in income due to having cancer (30%), it is clear that being diagnosed with cancer has some kind of financial consequences for the majority of patients in Ireland.

Some particular items of cancer-related expenditure were less commonly reported by survey participants (e.g. physiotherapy, 9% of patients; counselling, 6%; dietary supplements, 13%; help at home, 9%). However, if these frequencies apply to all cancer patients in Ireland, the absolute number of individuals who need to find extra money from their household budget, savings, or elsewhere, for these, and other such, items is substantial.

The survey results also illustrated the magnitude of the financial burden on patients. For most items, the levels of expenditure reported were not trivial. For example, the average (median) amount spent on travel was €360, on wigs or hairpieces was €400, and on GP visits was €250. Since patients were asked to disregard any costs which where covered by medical cards, private health insurance or other payments (e.g. from the HSE), these amounts represent direct out-of-pocket costs. In addition, as is common with cost data, the distribution of the reported amounts was skewed with a proportion of respondents reporting much higher expenditure; this latter point is worth remembering when considering the burden on patients.

Taking the findings from the qualitative and quantitative research together, this study also clearly demonstrates the multi-dimensional nature of the financial burden that cancer can impose on patients. Patients can incur extra costs associated with the disease and its management *and* a rise in household bills and other items of household expenditure *and* a drop in income. It is most likely the combination of these factors that leads to a substantial proportion of patients describing themselves as suffering increased financial stress or strain as a result of cancer.

Following from this, it is clear that considering only a single aspect of this array of financial and economic impacts is likely to under-estimate the overall extent of the financial burden of cancer on patients. Moreover, there is an important issue in terms of interpreting the findings in relation to particular elements of extra expenses (e.g. out-of-pocket expenses for supportive medications or travel) in the current study, and in other studies. It is tempting to look at the average amounts incurred by patients on, for example, travel, and consider that these are not so large, especially if they are (like travel costs) incurred over a period of a few months. But it needs to be remembered that costs are rarely isolated. It is likely that patients will have a range of other costs or expenses due to the cancer, and each particular element of costs should always be interpreted in the context of this bigger picture.

5.3 Implications and relevance

It is clear that the results of this research are relevant to, and have implications for, a range of groups, and organisations in Ireland. These include: (1) cancer patients and their families; (2) cancer support groups; (3) health care professionals, including clinicians, cancer nurses, allied health professionals, and oncology social workers; (4) those who work in the social welfare system; (5) employers and employing organisations; (6) those who make decisions about the provision of cancer services (both direct clinical care and support services); and (7) those who make health and social welfare policy in Ireland. The relevance and implications of particular issues for particular groups and organisations is discussed further below.

5.4 Specific issues of importance in Ireland

Many of the financial issues which were identified in the current study - in particular the types of additional costs incurred - have also been reported in studies in other countries. The relative importance of the different types of costs is dependant on the health care system of the country in which the study was conducted. For example, in systems where there is little publicly-provided health care (e.g. in the USA), medical care costs are high and dominate patients' out-of-pocket expenses (Arozullah et al., 2004; Chang et al., 2004; Hensley et al., 2005; Bradley S et al., 2007; Gordon et al., 2007); these costs are relatively less important, and other out-of-pocket expenses more important, in countries with greater levels of public health care, such as Ireland. The social welfare and legal context is also important, and influences the relative importance of issues such as lost income. The actual amounts spent by patients are not generally comparable from study to study, since they depend on the cost of specific items in particular countries, and when the study was conducted.

Several issues which were of particular importance in Ireland are discussed in more detail below, and recommendations are made for selected areas where action is needed.

5.4.1 Costs of seeing consultants, GPs and other allied health professionals

It was striking that in Ireland, which has a public health care system which all residents are entitled to access, many cancer patients incurred expenses in relation to seeing consultants, GPs or other allied health professionals. Even among those who had a medical card at the time of diagnosis, one third reported that they had experienced costs for some aspect of their cancer-related medical care. This probably reveals something about the ways in which patients access hospital services in Ireland, specifically switching between public and private care at different points in their treatment. In addition, for those with private health insurance, it probably reflects the type of cover held and what tests, procedures and treatments are reimbursed either partially or fully (e.g. whether, or the extent to which, outpatient procedures, such as diagnostic radiology, are included in a specific plan); there are a variety of plans on the market with varying levels of cover. It may also point to perceived deficiencies or limitations by cancer patients in public provision of allied health services (such as physiotherapy and counselling), leading to a "need" to purchase these services privately. For example, psycho-oncology services, which provide patients with access to counselling and other psychological services, have developed over recent years in several hospitals (International Psycho-oncology Society, 2006) and were seen as a core part of the managed cancer control networks recommended in the National Cancer Strategy (National Cancer Forum, 2006). As yet, however, such services are not universally available across the public system. The National Cancer Control Programme (NCCP) intends that support services, including psychotherapy and occupational therapy, will be provided at each designated cancer centre (Health Service Executive, 2009); these provisions should provide support for future cancer patients in dealing with the wider impact of cancer on their lives.

Recommendation

1. *Great attention needs to be given to alleviating the financial costs of undergoing cancer treatment.*

5.4.2 Travel and related issues

Treatment-related travel and associated matters emerged strongly, from both the social worker and patient interviews, as a vitally important issue for patients, and this was borne out in the survey. It is possible that the proportion of survey respondents who reported that they had had travel costs (79%) is a under-estimate, since we know that some patients did not consider that *they* had had travel costs if someone else (e.g. a child) drove them to the hospital. Because the questionnaire was anonymous, we did not have precise information on where patients lived and where they were treated, so were not able to investigate associations between distance to hospital and travel costs, or whether travel costs were greater for patients in rural areas. The burden of travel costs is particularly striking given that individuals aged 66 and older are entitled to use public transport free of charge (Appendix 1).

The issue of the cost incurred by patients (and family members; see Section 5.5) travelling to cancer treatment centres is not one that is specific to Ireland. It is, in part, a function of the changing nature of cancer treatment over the past two or three decades. Internationally there has been increasing centralisation and specialisation of cancer services, together with therapeutic advances which offer more opportunities to treat those who would simply have had best supportive care in the past, and changes in how treatment is delivered, with more provided in an out-patient setting. Because of the side-effects of cancer treatment, patients can find it distressing or difficult to travel by public or hospital transport services, even if these are available, making them very reliant on private cars, taxis, etc. Research from the UK and other countries has highlighted the costs of travel and related expenses (e.g. meals) experienced by patients and their families (Houts et al, 1984; Cohn et al., 2003; Lauzier et al., 2003; Allirajah et al., 2005; Heath et al., 2006; Owusu-Barnaby et al., 2006; Longo et al., 2007). For example, a study by MacMillan Cancer Support in the UK, published in 2006, found that 70% of patients faced extra costs in getting to their treatment and the average overall cost of travel and parking per patient was £325[k] (Owusu-Barnaby et al., 2006). The results of the current study are broadly consistent with these findings. However, the research in the UK was conducted *after* the re-organisation of cancer services which centralised care, whereas our research was done before the thrust towards centralisation that is underway under the NCCP (Health Service Executive, 2009). In addition, there are particular challenges in Ireland (e.g. relatively large proportion of the population living outside urban centres, limitations in public transport services in many areas, limited provision of hospital transportation). Altogether, this makes it possible that service re-organisation will further exacerbate the issue of travel costs for patients and their families.

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[k] Equivalent to approximately €475 at the exchange rate around the time the research was conducted.

Recommendation

2. Specific initiatives are needed to minimise the cost of travel.

The out-of-pocket expenses incurred by patients are not the only concern relating to travel. Qualitative research in Scotland suggests that various aspects of treatment-related travel and transport are associated with cancer-related fatigue and anxiety (Hubbard et al., 2006). There is also the possibility that travel costs, or other travel-related issues, such as transportation difficulties or being away from social support networks, might impact on clinicians' treatment decision-making, or patients' compliance with treatment (Payne et al., 2000). Some studies in the USA have suggested that problems with transportation may lead some patients to forgo treatment (Goodwin et al., 1993; Guidry et al., 1997). In the UK, one study found that patients living longer distances from specialist centres were less likely to receive surgery, chemotherapy or radiotherapy (Jones et al., 2008). In contrast, another UK study found that travel time did not significantly affect uptake of radiotherapy (Cosford et al., 1997), but all patients lived within one hour of the centre: this would be unusual in Ireland.

It seems clear that the issue of patient travel, and related issues (e.g. costs, access to appropriate modes of transport, need for overnight accommodation, meals, arrangements for family members) should be a central consideration in the re-organisation of cancer services in Ireland. Plans under the NCCP to offer some out-patient treatment (such as some types of chemotherapy) in outreach clinics located in local hospitals, organised in liaison with a designated cancer centre, suggest that these issues are being recognised. Moreover, the introduction of a NCCP-funded scheme to provide assistance with transportation costs for patients attending designated cancer centres is to be welcomed. This scheme, known as *Travel2Care*, is being implemented on a phased basis consistent with the transfer of cancer services to the designated cancer centres. Initially, individuals diagnosed with breast cancer were entitled to claim financial support for travel costs related to diagnosis and treatment. The scheme will extend to patients with other types of cancer as services are transferred to the relevant designated centres.[l] The scheme is being facilitated by the Irish Cancer Society and more information can be found on their website (Irish Cancer Society, 2010a). Further roll-out of the Irish Cancer Society *Care to Drive* volunteer driving service for cancer patients (Irish Cancer Society, 2010b)[m] also has the potential to help alleviate the difficulties patients experience in travelling by public or

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[l] At the end of 2009, the Travel2Care scheme was extended to lung and prostate cancers, and it is anticipated that more cancer sites will be eligible in 2010. See the Irish Cancer Society website for updates: www.cancer.ie.

[m] The Care to Drive scheme has been piloted in St Vincent's University Hospital, Dublin. As of 1st March 2010, the Irish Cancer Society intends to roll out the scheme nationwide. See the Society website for more details: www.cancer.ie.

hospital transport. There are, in addition, a range of actions that individual hospitals might consider to help alleviate the burden on patients, such as offering, or extending, subsidized parking schemes for oncology or radiotherapy patients, and/or providing meal vouchers for those required to spend a long time on day wards.

It will be important to monitor the impact on patients of the re-organization of cancer services under the NCCP. Travel-related areas that might be explored include: (1) the financial and emotional burden of travelling long distances from home for treatment; and (2) whether the distance that a patient lives from a designated cancer centre affects clinicians' treatment recommendations or patients' treatment decisions or compliance.

5.4.3 Household bills

Another factor which emerged very strongly from both the qualitative and quantitative aspects of the study concerned household bills, and specifically patients' beliefs that their spending on heating, telephone and food had increased as a result of their cancer diagnosis. Since the study was cross-sectional and did not involve a comparison group without cancer, it is impossible to disentangle the effects of general rises in the cost of utilities and food over time from those specifically due to the cancer. Nonetheless, the fact that patients *perceived* that their household bills had increased as a result of having cancer is important. The possible explanations offered for this in patients' stories (e.g. spending more time at home; feeling cold and/or unwell following treatment; needing to telephone hospital(s)/doctors(s); keeping in touch with family and friends) suggests that the finding is real. Moreover, our observations are supported by evidence from some small studies from Australia and the USA, which reported increased spending on telephone and food bills following a cancer diagnosis (Moore, 1999; Arozullah et al., 2004; Langa et al., 2004). The higher cost of food and utilities in Ireland than in some other countries, notably the UK (Forfas, 2008), suggest that increases in household bills may be a particular burden for cancer patients in Ireland.

In the UK, Macmillan Cancer Support reported that paying heating bills is the biggest money worry for two-thirds of those with financial difficulties due to their cancer (Macmillan Cancer Support, 2008). This is compatible with evidence from our in-depth interviews, during which patients spoke about worries about paying large heating bills and described not having the heating on as often as they would like because of concerns about the cost. In addition, in further analysis of the current survey data, there were significant associations between increased household bills and financial stress and strain. The frequencies of those reporting increased financial strain or stress were higher among those who reported that spending on household bills had increased since their cancer diagnosis. These observations illustrate the wide-ranging consequences that additional outgoings on utility and other household bills can have for cancer patients.

5.4.4 Employment issues

There is a growing body of literature on the effects of cancer on employment. A proportion of patients are absent from work during treatment and others may work shorter hours (Drolet et al., 2005; Bradley et al., 2005; Bradley et al., 2006; Bradley CJ et al., 2007). In addition, although rates of return to work post-treatment are high (Spelten et al., 2002; Bouknight et al., 2006; Amir et al., 2007; Taskila & Lindbohm, 2007; Hassett et al., 2009), cancer survivors have an increased risk of unemployment compared to those without cancer (Maunsell et al. 2004; Yabroff et al., 2004; Taskila-Abrant et al., 2005; Carlsen et al., 2008; Park et al., 2008; de Boer et al., 2009). A proportion also experience a drop in income post-diagnosis, even after taking compensatory benefits and allowances into account (Bennett et al., 2008; Lauzier et al., 2008; Rayce et al., 2008; Syse et al., 2008). Our findings - that more than four in every five cancer patients who are working at the time of diagnosis take some time off, and those who are working are more likely to experience a drop in household income than those who are not - reveal the situation for the first time in Ireland.

Studies from the USA, Canada and Australia point to the impact that the healthcare and social welfare system can have on patients' decisions about work (Drolet et al., 2005; Bradley CJ et al., 2007; Gordon et al., 2008). The synthesis of our survey findings suggests two important issues in this regard in Ireland: firstly, that the availability of sick pay is a key influence on patterns of workforce participation among cancer patients in Ireland; and secondly, that those who are self-employed may have to make decisions about continuing, or returning, to work on financial, rather than health/medical, grounds.

Recommendation

3. *The self-employed should be encouraged to take out permanent health insurance and income protection.*

A further issue relating to sick-pay emerged from patient interviews. It was apparent that patients are often unclear about the sick pay provision offered by their employers, even when they are currently on sick leave. This implies that there is a lack of communication between employers and employees. A similar observation was made in a recent survey of employing organisations in the UK; this study found that while many organisations aim to be supportive of employees with cancer, the employees may not be adequately informed about the services and supports available from their employer (Grunfeld et al., 2008).

For cancer survivors, returning to the workplace is a key step on the path to recovery, representing a measure of control over the illness and an objective measure of life quality; it restores a sense of normalcy, enhances self-esteem and offers social and financial support (Maunsell et al., 1999; Peteet, 2000; Sanchez et al., 2004). On the other hand, departure from the workforce by cancer survivors has wide-ranging economic implications, impacting not only survivors and their families but also the labour market, employers and society as a whole (Steiner et al., 2004; Spelten et al., 2002). As was evident in our interviews, and has been reported elsewhere (Bouknight et al., 2006; Pryce et al., 2007; Taskila & Lindbohm, 2007; Amir et al., 2008), supportive or accommodating employers, and good employer-employee relationships, can help patients either continue to work during treatment, or return to work as soon as possible following treatment. In contrast, negative attitudes by employers, or a lack of information on services and supports offered to patients by employers, may hinder return to work (Bouknight et al., 2006; Grunfeld et al., 2008). Overall, these observations suggest that finding ways to enhance employer-employee communication would be likely to bring about benefits for both cancer patients and those who employ them.

Recommendation

4. *Employers should be encouraged to be more supportive of staff affected by cancer, and to be clearer about their staff policies and provisions.*

5.4.5 Hair loss and financial help with wigs and other head coverings

It has been clearly shown that cancer patients consider alopecia to be one of the most - if not the most - important side-effect of chemotherapy (Lindley et al., 1999; Boehmke & Dickerson, 2005; Mulders et al., 2008). Even if patients know that hair loss is temporary, they perceive it to be a burden (Mols et al., 2009). It can impact strongly on body image and is associated with a range of negative quality-of-life and psychosocial consequences including distress, anxiety, depression, and a reduced sense of well-being (Hesketh et al, 2004). Moreover, there is some evidence to suggest that the fear of hair loss may impact upon patients' preferences or decisions regarding cancer treatment (Fallowfield et al., 2004; Hesketh et al., 2004). This evidence demonstrates why it is so important that patients are able to obtain high quality hairpieces, wigs and other head coverings, such as turbans or bandanas. However, our interviews with patients and social workers revealed that this can be a major problem. Although financial assistance is available for wigs for those with medical cards, and the costs of wigs may be included in some private health insurance policies, the amount awarded or reimbursed may be insufficient to cover the cost of a high quality wig that looks like the patient's own hair. This was reflected in the patient survey where 40% of the women with breast cancer told us that they had had to spend money (on average €400) on wigs or hairpieces. In interviews, some patients described how there could be a time lag between when they lost their hair and when funding came through for the cost of a wig. In addition, some patients told us that they had not been able to afford to buy a suitable wig or other head coverings. Because of the range of potential consequences of hair loss, this is an area which requires attention.

5.4.6 Supportive medications

Medications and related items (e.g. dietary supplements) required because of cancer or its treatment were an important source of additional expense for cancer patients in Ireland. Although 36% of survey respondents had a medical card and 37% were using the drugs payment scheme at diagnosis, three in every 10 patients were out of pocket for prescription medicines, four in 10 spent money on over-the-counter items, and more than one in 10 purchased dietary supplements. The amounts spent were not trivial, amounting to several hundred euro on average. Although a medical card provides assistance for patients as regards prescribed items, it does not necessarily cover all of the medications or dietary supplements which are recommended to help alleviate treatment side-effects.

In a large-scale, wide-ranging, survey like ours it was not possible to ask respondents to provide details about specific medications, drugs, or supplements they used. It is likely that many of these supportive medications are to alleviate side-effects of chemotherapy, but little more than this is known. In order to develop strategies to minimise the financial burden on patients, further research is needed to clarify what supportive medications cancer patients in Ireland are commonly prescribed, which ones they purchase over the counter, what stage(s) in their disease and treatment process they generally use these medications, and how long use lasts.

Recent research in the USA has reported that one in every 10 colorectal cancer patients was very worried about paying for supportive prescribed medications, and one in five had adopted more than one money saving strategy, such as not taking medicines as often as recommended (Dana-Farber Cancer Institute, 2009; Schrag et al., 2009). This is consistent with a small study in the UK which showed that 15% of breast cancer patients had decided not to get a prescription dispensed because of the cost[n] (Breast Cancer Care, 2006). In our study, although we did not address these issues specifically, the social workers described how patients can be very worried about how they are going to afford to pay for medications. The US investigators observed that this is an issue of which oncologists should be mindful, and recommended doctor-patient communication about this topic to help alleviate anxiety and identify strategies to minimize the cost burden (Dana-Farber Cancer Institute, 2009). We agree with this. In addition, since this issue has the potential to impact

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[n] At the time the study was conducted, prescription charges paid by patients were limited to approximately £6.50 per item.

on both patients' quality of care and quality-of-life, further research would be valuable in clarifying: (1) the extent to which cancer patients in Ireland are worried about meeting costs of supportive medications (prescribed or over-the-counter); (2) whether patients have adopted coping strategies to help meet costs, and (3) the awareness of oncology teams about this matter.

5.4.7 Medical cards, HSE and social welfare payments and financial advice

Our survey found that almost four in every 10 cancer patients who had not had a medical card prior to diagnosis obtained one some time after diagnosis; many of these probably did not formally fulfil the mean-testing requirements, but were awarded the card on medical grounds and/or because of hardship. While this figure is encouraging and suggests that a large proportion of cancer patients has some protection and assistance in terms of costs of medical treatment and supportive medications, it was clear from the in-depth interviews that the process for obtaining a medical card is not without problems. Oncology social workers - who give patients advice regarding entitlements - strongly emphasised that the application process was complex (for them and for patients), evaluation of applications could be slow and the outcome of applications appeared to be inconsistent across the country. Social workers also described how, in their view, some of those reviewing applications did not have an appreciation of the particular circumstances and challenges experienced by cancer patients. Patients reiterated these concerns and also spoke about the difficulties in getting information about entitlements and their "battle" to get a medical card. It is clear from these findings that both social workers and patients would welcome some consideration of ways to: (1) routinely provide patients with clear, understandable, information about medical cards soon after diagnosis; (2) streamline and speed-up the application and review process; and (3) ensure greater consistency in which cancer patients are awarded or refused a medical card.

Patients expressed similar concerns about the process of finding out about and applying for other social welfare and HSE payments. Ireland is not unique in this. Many of the issues which arose in our interviews echoed findings from a qualitative study of lung cancer patients' perceptions of access to financial benefits in the UK (Chapple et al., 2004). In that study patients reported that they found it hard to get information on entitlements, that claim forms were complicated, and that they had to "struggle" to obtain what they were entitled to. "Struggling" with the benefits systems also emerged as a fundamental theme from a recent qualitative synthesis of social support services for people with cancer in the UK (Wilson & Amir, 2008) and complex application forms and a lack of understanding of cancer symptoms and treatment by those assessing application were also identified as problems in a study of benefits advisors by Macmillan Cancer Support (Macmillan Cancer Relief, 2005).

Recommendations

5. *Improved information about medical cards and HSE and social welfare payments should be made available to cancer patients.*
6. *In view of the rapid course of the disease in many cases, applications from cancer patients for medical cards and other benefits should be fast-tracked.*

In our survey, those who had claimed a new social welfare or HSE benefit or payment since their cancer diagnosis were reasonably positive in their ratings of access to information and ease of the application process. This finding is likely to be, in part, a consequence of the way in which the questions were constructed. Only those who had been successful in obtaining new payments or benefits were invited to respond to the questions on access to information and the application process; anyone who was entitled to benefits or payments but was either unaware of this, or had found the application process so difficult that they did not apply, were not asked to complete these questions.

There is widespread evidence from Europe and north America of under-claiming of social welfare benefits by those who are entitled to them (Hoskins and Carter, 2000; Hernanz et al., 2004; Gray et al., 2008). It appears that those most in need of financial benefits may be least likely to obtain them (Toeg et al., 2003). In terms of cancer, an assessment in the UK published in 2004 estimated that more than £120 million in two specific benefits to which cancer patients would have been automatically entitled went unclaimed (Tunnage et al., 2004; Macmillan Cancer Relief, 2004). Although we are not aware of data for Ireland on uptake of benefits, it seems likely that some cancer patients who would be eligible for benefits are not claiming them. The reasons for under-claiming are diverse. As well as a lack of awareness of entitlements by patients and difficulty with the application process (which, as described above, emerged as issues in our interviews), the reasons for under-claiming include patients' fear of stigmatisation and, from the perspective of health professionals, limited knowledge, a lack of time to discuss benefits with patients, and in relation to benefits to which patients with terminal cancer would be entitled, reluctance to discuss prognosis (Chapple et al., 2004; Martin, 2004). For example, as an illustration of the potential magnitude of the issue of under-claiming, a UK report described how more than three quarters of terminally ill patients were not provided with information on financial benefits to which they would have been entitled by the NHS or others, and that more that half of those not provided with information would have welcomed it (House of Commons Public Accounts Committee, 2006).

The provision of information is likely to be key in improving cancer patients' experiences of the benefits system and increasing their uptake of social welfare entitlements. A recent systematic review concluded that providing welfare rights advice in healthcare settings leads to financial gains for recipients of the advice (Adams et al., 2006). For example, in the UK, MacMillian Cancer Support established a network of financial advisors to work in partnership with the Citizen Advice Bureau and NHS to assist patients to establish entitlements and gain access to payments. By May 2009, in Scotland, this scheme had assisted around 16,000 people in obtaining payments totalling more than £42 million (The Herald, 2009).

At the moment in Ireland oncology social workers play an important role in providing cancer patients with advice and assistance regarding social welfare benefits, medical cards, etc, although this is not necessarily their responsibility. The number of oncology social workers is limited and even in hospitals in which there are oncology social workers, not all patients have the opportunity to see them; this is an important limitation in current services. It is evident from our study that many cancer patients could benefit from a service which provided more *general* financial advice and information (on issues such as claiming tax, dealing with debt, coping with a reduced income, options for addressing problems in meeting mortgage and loan payments, as well as benefits and medical card entitlements); this is clearly not the responsibility of oncology social workers. When we asked interviewees what they would like to see, the oncology social workers suggested that there should be a community welfare officer located in hospitals to provide advice about medical cards and social welfare payments, and patients suggested that a general financial advisor associated with the hospital would be helpful. Both sets of interviewees emphasized that, irrespective of *how* financial advice was provided, whoever delivered it needed to have an in-depth appreciation of the specific needs and circumstances of cancer patients. The reorganisation of cancer services in Ireland provides an opportunity to address the issues of who should have responsibility for providing financial advice for patients and where any service enhancements should be located and how they should be delivered.

Recommendation

7. *Hospital-based financial advice services for cancer patients should be established.*

5.5 Consequences of the increased financial burden for patients

As was evident from both the in-depth interviews and the survey, the increased cancer-related financial expenditure among patients in Ireland is extensive and wide-ranging. In common with two studies of families affected by paediatric cancer (Cohn et al., 2003; Dockerty et al., 2003) and another of women with breast or ovarian cancer (Sherwood et al., 2008a), we found that some patients borrow money to help them meet extra cancer-related costs, and others cut back on household expenditure on items such as holidays, or social or leisure activities. In our survey, we estimated that one in 10 patients borrow money. Based on how patients spoke about borrowing in interviews (e.g. they often did not perceive family members offering them money as borrowing) we consider that this is likely to be an under-estimate.

We also observed that cancer has a major impact on patients' savings, and their ability to meet obligations in terms of mortgages and other personal loans. The stress and worries that this can cause was clear from the qualitative work. Others studies have described how additional costs can be a source of worry for patients (Lauzier et al., 2005). Indeed, a study from the UK found that many patients claimed that financial concerns are second only to pain as a cause of stress (Quinn, 2002).

The high proportions of our study population who reported increased financial stress or strain as a result of their cancer diagnosis were striking (for 48% of patients cancer had made it more difficult for their household to make ends meet; 32% were more concerned about their household's financial situation). Intriguingly, almost one third reported that they were less concerned about their household's financial situation since the cancer diagnosis. This may be because some patients feel that they have to give all their energy and attention to dealing with the cancer and its treatment (Lauzier et al., 2005), or because having cancer leads them to readjust their personal priorities (Komura & Hegarty, 2006), with finances becoming less important.

Studies in the USA, Austria and Israel have shown positive associations between economic concerns or financial problems (usually pre-diagnosis), and levels of psychological distress and frequencies of depression and anxiety in cancer patients (Baider et al., 2003; Golden-Kreutz & Andersen, 2004; Ell et al., 2008). We also found strong associations between reporting of financial stress or strain *as a consequence of a cancer diagnosis* and depression, anxiety and emotional stress. Our analyses are cross-sectional (and, therefore, it is impossible to know, for example, whether the depression preceded or followed the financial strain), so some care must be taken in their interpretation. Having said this, the high frequency of depression, anxiety and emotional stress observed in the study population, the strength of the associations with financial stress and strain, and the compatibility with previous evidence, suggest that these findings should not be disregarded; they suggest an important area that urgently requires further investigation. They also provide a further reason for taking initiatives to alleviate the financial burden that cancer places on patients and their families.

5.6 Which patients are most vulnerable?

The findings from the survey data relating to associations between patients' socio-demographic characteristics and financial outcomes suggested some subgroups of patients who might be particularly vulnerable to different aspects of the financial costs and consequences of cancer. These findings should be interpreted with some care, since the analyses were univariate (i.e. they only considered the effect of one socio-demographic variable at a time) and the socio-demographic variables are inter-related (e.g. cancer site is related to gender and age; age is related to employment status and having dependant children). Thus we cannot always be sure that the group most likely to experience some particular type of costs are, for example, patients with breast cancer, rather than younger women with cancer. In addition, while these analyses give some idea of the most vulnerable sub-groups, the in-depth patient interviews suggest that the issue is more complex. From these interviews, it was clear that people in almost any socio-demographic subgroup could be vulnerable to financial difficulties following a diagnosis of cancer, and their vulnerability is a function both of their own financial and employment circumstances and the support available to them from those around them (e.g. family and friends). This means that it is important that we do not assume that particular types of patients are automatically not likely to suffer negative financial effects of cancer.

Bearing these caveats in mind, many of the findings from the survey suggest that younger patients - particularly those of working age and those with children at home or other dependants - may be most likely to experience an adverse financial impact of cancer. This illustrates the importance of a drop in income coupled with increased outgoings in influencing a family's financial situation. In this study most of the patients of working age were women with breast cancer. Women are less likely to be the main earner in families, and having a husband/partner who continues to provide the greater part of the household income may cushion the family to some extent against the financial stress and strain of cancer. Because of this, it is possible that the overall proportion of younger patients who experience cancer-related financial stress or strain might be even higher than estimated in this study. Further investigation of patients with other types of cancer would be helpful to confirm this. The National Cancer Registry is undertaking a study of the economic impact of colorectal cancer which is likely to shed further light on this issue.

Two particular sub-groups of younger working-age patients emerged from the survey as potentially vulnerable to financial difficulties - lone parents and those who are self-employed. The specific issues relating to the self-employed are discussed in Section 5.4.4. Lone parents were more likely to report increased household spending as a result of having to use their savings, and to experience more difficulty in making ends meet. The information gathered in the in-depth interviews provides more details around these issues.

Lone parents were especially vulnerable to a drop in income, which may be because they do not have another income to rely upon, and may need to pay for childcare while they were undergoing treatment.

Two studies in the USA found that those with a low income spent a much greater proportion of their income on out-of-pocket healthcare expenditure (Arozullah et al., 2004; Langa et al., 2004) and a further study of paediatric cancer in Australia reported that low household income was associated with higher levels of post-diagnosis economic hardship (Heath et al., 2006). In contrast, a study from Canada observed that income was not a reliable predictor of high out-of-pocket costs (Longo et al., 2007). We found no significant associations between income and financial stress or strain. Moreover, we also found that those in receipt of social welfare payments at the time of diagnosis (a marker for lower income) were *less* likely to report increased financial stress or strain as a result of cancer than those who were not in receipt of social welfare payments. We can postulate several explanations for this finding. Firstly, a higher proportion of those receiving social welfare payments at diagnosis, than other patients, also had a medical card at diagnosis (66% vs 37%), which provides (some) protection from the costs of medical care and prescription medications. Secondly, although patients on social welfare benefits may have a lower income on average, their income is less likely to fall after diagnosis, and it may be that coping with the *change* in income is what induces financial stress and strain. Thirdly, patients on social welfare benefits probably have less capacity for increased expenditure, and so may simply not be able to consider paying for some of the cancer-related out-of-pocket expenses experienced by other patients. For example, 31% of those on social welfare payments incurred expenses in relation to over-the-counter medications, compared to 43% who were not on social welfare payments; this might suggest either, that some patients on social welfare require over-the-counter medications but simply can't afford to buy them, or that health professionals, sensitive to the financial circumstances of some patients on social welfare, do not recommend the medications.

From our survey, it appeared that older patients (those aged 70 or over) were - in general - less likely to be financially affected by cancer than younger patients. Similar to those on social welfare, older individuals are more likely to have a medical card[o] and to be retired and have a stable (albeit perhaps modest) income. They were also less likely to have a mortgage at the time of diagnosis (none of those aged 70 and older compared to 35% aged under 70) or personal loans (70 and older: 4%; under 70: 34%). However, in this study the majority of patients aged 70 and older were men with prostate cancer. Prostate cancer incidence is higher among more affluent socio-economic groups in Ireland and elsewhere (Liu et al., 2001; Rowan, 2007; Donnelly et al., 2009). This means that it is possible that

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[o] At the time the study was conducted, entitlement to a medical card was universal among those aged 70 and older.

our survey underestimated the levels of financial stress and strain among older cancer patients in general. Moreover, it was clear from the in-depth interviews, that some older patients may be particularly vulnerable to financial difficulties following a cancer diagnosis (e.g. those who live alone). Means-testing for medical cards among those aged 70 and older has recently been introduced (Citizens Information, 2009). This makes it imperative that the financial impact of cancer among older patients in Ireland should be monitored and/or re-evaluated in the future.

5.7 Impact on family members and friends

One effect of the transfer of cancer care from the inpatient to outpatient setting is that the burden of caring for patients is increasingly falling on family members (Hayman et al., 2001). In this regard, an important finding from both the in-depth interviews and the survey was that the financial impact of cancer is not limited to patients but also falls on family members.

Patients described in interviews how family members frequently accompanied them to outpatient appointments. Sometimes this was for emotional support, but other times it may have been because the patient required physical support or assistance or someone to drive them home following treatment. In addition patients noted that, if they were being treated as an inpatient, the financial impact of having to travel long distances for specialised treatment fell not only on them but also on family members who wanted to visit them. Research in the USA has revealed that the patient time costs associated with cancer treatment are substantial (Yabroff et al., 2007); for example, a session of chemotherapy may take almost an entire day when travel time, waiting time, and the time it takes to deliver treatment are considered. The current study suggests that there may also be substantial treatment-related time and travel costs incurred by family members.

We found that a proportion of family members had to make some change to their working pattern because of the cancer diagnosis. Although we did not gather detailed information on the changes made, other studies have shown that the effects of cancer caregiving on employment can include the carer cutting working hours, taking special leave or using holidays, having to quit work, or declining advancements to fulfil carer responsibilities (Grunfeld et al, 2004; Sherwood et al., 2008b). A study in Canada, for example, found that more than one third of patients required others to take time from work (Longo et al., 2006). Time away from work, and from other usual activities, represents an important economic impact of cancer both for family members and for society. A recent US study, based on a national survey of informal (i.e. unpaid) caregiving in the two years after a cancer diagnosis, estimated that on average caregivers (usually spouses, children, or siblings of the patient) provided care for 8.3 hours per day for 13.7 months (Yabroff & Kim, 2009). At 2006 wage rates, the authors estimated that the value of informal caregiver time was, on average, more than $47,000 per cancer patient.

Financial consequences are only one component of the burden on family caregivers. It is starting to become clear that carers can suffer from a range of adverse psychosocial effects, including increased anxiety, depression, psychological distress, and reduced quality-of-life (Cotrim & Pereira, 2008; Donnelly et al., 2008; Yun et al., 2005) and these effects may worsen as the patient's functional status declines (Grunfeld et al., 2004). As we have found for cancer patients, it is possible that financial and psychosocial affects may be linked among caregivers. For example, one small study has suggested that economic hardship is associated with depressive symptoms among cancer caregivers (Bradley et al., 2009). Carers are also likely to experience a variety of ongoing supportive care needs (Hogkinson et al., 2007), but what these needs are, and the extent to which they are being met (Schubart et al., 2008; Golant & Haskins, 2008), is not yet well understood. There is a real need to obtain a better understanding of the financial, economic, emotional, and other aspects of the burden on family carers of cancer patients in Ireland and elsewhere. This is essential to underpin the development of strategies to alleviate the burden that cancer places on caregivers.

Our research has also revealed that the direct and indirect economic effects of cancer can ripple out beyond the family unit. A proportion of cancer patients (particularly those with little family support and/or living alone) rely on friends for both practical and financial support. As far as we are aware, this is not something that has been previously reported and further examination of this issue is warranted.

5.8 Limitations of the research

This project concentrated on patients with breast, lung or prostate cancer. We have carried out in-depth interviews with patients with colorectal cancer and their family members in a related project. Similar themes emerged from these interviews as in the current study[p], suggesting that the results of the current study are likely to be broadly generalisable to patients with other cancers in Ireland, at least in terms of the *types* of costs and consequences experienced by patients and their families. For a specific cancer site, however, the percentages of patients incurring particular costs and lost income will depend to some extent on the age and sex profile of those affected (e.g. lost income will be relatively more important in cancers which affect a younger population; medical costs will be relatively less important in cancers which affect a mainly elderly population).

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[p] A survey of the costs incurred by colorectal cancer patients in Ireland is underway and will be reported in 2010.

The patients who participated in the interviews were self-selected on the basis that they defined themselves as having had additional costs or financial difficulties as a result of having cancer. Since this qualitative work was designed to obtain a broad understanding of the financial impact of cancer on patients and their families, care needs to be taken in making inferences from the findings. The examples given in the text are simply that - examples of patient experience: they are not intended to be representative of all patients. A similar caveat applies to the patient experiences described by the oncology social workers. It is noteworthy that the findings from the social worker and patient interviews were very similar in terms of the themes and sub-themes which emerged, although, as might have been expected, the social workers placed more emphasis on health service and welfare system issues than did patients.

Just over half of those invited to participate in the survey did so, which was high considering the sensitive and potentially intrusive nature of the topic. To minimise bias, we identified survey participants from the records of the National Cancer Registry (which are estimated to be at least 98% complete; National Cancer Registry, 2001) and asked all patients to respond whether they had incurred costs or not. It is possible that only those with extra expenses participated. If this were the case (and there is no particular evidence to suggest that it is so), the percentages of patients who incur additional costs are likely to be somewhat over-estimated. However, this would not change the primary conclusion of this research - that cancer can have significant financial impact on patients and their families in Ireland.

The survey was entirely reliant on patients' recollections of expenditure, which is, of course, potentially subject to errors in recall. However, this type of data is not available from any other source. Studies suggest that patients' recall of treatment details is reasonably accurate, at least up to three years after diagnosis (Maunsell et al., 2005; Phillips et al., 2005; Schootman et al., 2005; Oberst et al., 2009), which suggests that recall of financial outlays relating to treatment may be acceptably reliable. We deliberately did not ask patients to account for all possible items of cancer-related expenditure (e.g. the cost of each journey to hospital, amount of pre and post-diagnosis telephone bills) as we felt this would be too difficult to recall, would be overly intrusive and would be too burdensome. Instead we chose to focus on average amounts for key costs categories (e.g. medications, travel) and assessments of whether spending on other items had changed because of the cancer diagnosis (e.g. heating). Also, we took cognizance of the conclusions from a qualitative study of women with breast cancer in Canada, in which it was apparent that it was not the total economic or financial costs of cancer *per se* that were of prime concern to patients, but rather the *perception* of financial strain and coping with an unwanted change in circumstances (Lauzier et al., 2005). This is why we chose to assess overall financial stress and strain in terms of patients' own (1) assessment of the impact of the cancer diagnosis on their household's ability to make ends meet and (2) feelings about their household's financial situation since the cancer diagnosis.

Some types of costs were not examined in the project. For example, we did not consider patient time costs associated with treatment, which studies from the USA suggest are substantial (Yabroff et al., 2005; Yabroff et al., 2007). While wigs, hairpieces and other hair coverings were an important issue for the women with breast cancer in our study, these might not be so important for patients with other types of cancer which are either less likely to be treated with chemotherapy, or for which the usual chemotherapy regimes are rarely associated with hair loss. On the other hand, other costs might be relevant for patients with other types of cancer (e.g. colostomy or urostomy bags, and associated items, for those with colorectal and bladder cancer respectively).

Finally, the focus of our study was cancer in adults living with the disease. That is, we did not seek to specifically assess the financial impact of cancer in adults in the final stages of life. Although there has been little research on financial outgoings in the last six months of life, the available evidence suggests costs may be substantial (McCarthy et al., 2000). Further research exploring the end-of-life costs for cancer patients and their families would be of value, particularly since this is a time of change and expansion in the provision of palliative care services in Ireland (National Advisory Committee on Palliative Care, 2001). There is also a growing body of literature devoted to the financial impact on families of having a child with cancer and the long-term economic consequences for survivors of childhood cancer (see, for example, Crom et al., 1999; Cohn et al., 2003; Dockerty et al., 2003; Heath et al., 2006; Crom et al., 2007; Eiser & Upton, 2007). This literature suggests that it is likely that there are specific and acute financial and economic challenges for families affected by childhood cancer. As far as we are aware, these issues have not been examined in Ireland.

Chapter 6 Summary of key findings, conclusions and recommendations

6.1 Key findings

Most patients and families incur additional costs as a result of a cancer diagnosis. These can include direct medical costs such as those associated with seeing consultants, GPs, or allied health professionals, and those associated with buying medications to help alleviate the symptoms of cancer and the side-effects of treatment. In addition, the majority of patients have out-of-pocket expenses in relation to travelling to hospital appointments. Increased utility bills are also common because patients undergoing treatment, or recuperating from surgery, are at home more often than before diagnosis. For some patients and families, the additional costs incurred can be substantial.

The majority of cancer patients who are working need to take time off around diagnosis and during treatment and a substantial proportion do not receive any sick pay from their employer. This means that household income decreases for many patients and their families. In addition, the process of obtaining medical cards, and HSE and social welfare payments, can be complex and demanding for patients, and may involve a long wait.

The combination of this reduction in income with the additional costs has wide-ranging consequences for cancer patients and their families. Some have to use savings and some borrow money from financial institutions, friends, family or employers. Some have more difficulties in meeting financial commitments, such as mortgage payments. Some have to reduce general household spending, as well as spending on "extras" like clothes, holidays and leisure activities. Overall, the household's ability to make ends meet is more difficult for a substantial proportion of patients (increased financial stress). Many also experience increased worries about their household's financial situation (financial strain). This increased financial stress and strain is associated with a greater likelihood of experiencing depression, anxiety or emotional stress.

Patients in every socio-demographic group can be vulnerable to experiencing financial difficulties as a result of a cancer diagnosis, and their vulnerability is a function both of their own financial and employment circumstances, and the support available to them from those around them (e.g. family and friends). Some groups of cancer patients appear particularly vulnerable to the adverse financial effects of a cancer diagnosis, in particular those with dependants and those who are working at the time of diagnosis. This can mean that, for example, the self-employed may decide to keep working, or return to work, during treatment, on financial grounds. Patients, and their families, who live in remote areas may experience particular difficulties due to having to travel long distances for treatment.

6.2 Conclusions and recommendations

This research has revealed - for the first time in Ireland - the significant financial impact that a diagnosis of cancer can have for patients and their families. The findings of this research are relevant, and have implications for, a range of groups and organisations including - perhaps most importantly - those who plan and provide cancer and health services in Ireland.

The conclusions, and recommendations which follow from these, fall into four main areas.

Costs associated with cancer care

- Many cancer patients incur out-of-pocket costs in visiting their GP or hospital doctors.
- Many patients pay for prescription and over-the-counter medicines, which they need to support their treatment.
- Treatment-related travel and transport costs can be a major burden for patients.

Recommendations

1. *Great attention needs to be given to alleviating the financial costs of undergoing cancer treatment.*
2. *Specific initiatives are needed to minimise the cost of travel.*

Work issues

- Most cancer patients who are working at the time of their diagnosis experience a drop in income. The self-employed can be particularly badly affected.
- Employers' sick pay provision is very variable and policies are often unclear to staff, causing worry and confusion.
- Patients have many other concerns around employment, including anxiety about returning to work, and worries about their ability to do the same work post-treatment.

Recommendations

3. *The self-employed should be encouraged to take out permanent health insurance and income protection.*
4. *Employers should be encouraged to be more supportive of staff affected by cancer, and to be clearer about their staff policies and provisions.*

Medical cards, HSE and social welfare payments, and financial advice

- Patients with cancer can find it difficult to get information on availability, eligibility and the application process for medical cards. This also applies to HSE and social welfare payments.
- Patients experience major variations in the time taken to process applications, entitlement to medical cards, medical card reviews, and funding awarded to help with the costs of wigs. In consequence, decision-making around applications can appear arbitrary.

Recommendations

5. *Improved information about medical cards and HSE and social welfare payments should be made available to cancer patients.*
6. *In view of the rapid course of the disease in many cases, applications from cancer patients for medical cards and other benefits should be fast-tracked.*

Overall financial impact of cancer

- The impact of extra costs, sometimes exacerbated by decreased income, means that cancer patients can have difficulty paying household bills and mortgages. This results in increased levels of financial stress and strain.

Recommendations

7. *Hospital-based financial advice services for cancer patients should be established.*

Appendix 1 Health and social welfare system in Ireland

Health System

Ireland has a mixed public-private health care system. The Health Service Executive (HSE) is responsible for providing health care services and personal social services for all residents of Ireland. The National Hospitals Office, within the HSE, manages acute hospital services in 50 public and voluntary hospitals which have public beds. Voluntary hospitals are owned by private bodies, such as religious orders, or incorporated by charter or statue and run by boards appointed by the Minister for Health and Children, and most of their income comes directly from government. Most of the public and voluntary hospitals also offer private health care, and at any stage, patients can opt to transfer from public to private care. Private health care services are also available in entirely private hospitals/clinics.

All residents of Ireland are entitled to use the public health system. This provides for subsidized primary care services, hospital out-patient treatment, and in-patient treatment on a public ward in public and voluntary hospitals. Unless they have a medical card (see below), in the public system individuals generally have to pay a charge of approximately €60 to see a GP and - if not referred by a GP - to attend a hospital out-patient clinic or visit an Accident & Emergency department[q]. These fees usually have to be paid at the time of the appointment/visit. At the time the research was conducted, an overnight stay in a public hospital bed cost in the region of €60 per night, up to a maximum of €600 per year[r]. The HSE has the discretion to reduce or waive the charges entirely in cases of hardship. Higher rates apply for semi-private and private care in a public or voluntary hospital[s].

Private health insurance

Individuals may purchase private health insurance from one of a range of companies. Around 50% of the population (World Health Organisation, 2004) are believed to have private health insurance. This usually covers hospital in-patient care. Depending on the plan purchased, there may also be full or partial reimbursement of costs of day-case procedures, outpatient care (e.g. consultant fees, pathology, radiological investigations), GP visits, visits to allied health professionals (e.g. physiotherapy, counselling), convalescent care, and home care (e.g. nursing care at home). If particular procedures or treatments are not covered, individuals can either elect to be treated in the public system, or pay an additional fee.

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[q] The charge for attending an out-patient clinic or Accident & Emergency rose to €100 in January 2009.

[r] This has since risen to €75 per night, up to a maximum of €750 in any twelve consecutive months.

[s] See rate at http://www.citizensinformation.ie/categories/health/hospital-services/hospital_charges.

Medical cards and GP visit cards

GMS medical cards provide individuals with free access to services within the public health system. The costs of prescription drugs, medicines and appliances are also covered. Anyone over the age of 16 can apply for a medical card, and individuals can qualify in one of three categories:

- means-test: individuals (and their dependants) whose assessable income is within the financial guidelines set by the Department of Health & Children;
- undue hardship: individuals whose assessable income is over the financial guidelines, but for whom the HSE decides that the financial hardship of medical or other exceptional circumstances would cause undue hardship; and
- automatic entitlement: individuals who have automatic entitlement, under European Union or government schemes. At the time the research project was conducted, there was universal entitlement to medical cards for those aged 70 and older[t].

The fact that individuals can qualify under the category of undue hardship means that there is a discretionary element to the system. This can result in variations across the country in who is awarded, or refused, a medical card.

Applications for medical cards (and GP visit cards - see below) are assessed by an HSE designated officer; this is generally, but not always, a Community Welfare Officer (CWO). In 2007, just under 30% of the population had a medical card (Health Service Executive, 2008).

Those who do not qualify for a medical card may be eligible for a GP visit card, which covers the cost of GP visits; it does not cover prescription drugs, medicines and appliances. Applications for a GP visit card are also means-tested, with the income guidelines higher than for a medical card. In 2007, about 2% of the population had a GP visit card (Health Service Executive, 2008).

Prescribed medications and the drugs payment scheme

Unless they have a medical card, individuals normally pay the full costs of each prescribed drug, medicine or appliance. The drugs payment scheme is intended for those who do not have a medical card but regularly fill prescriptions. Individuals or families register with the scheme and obtain a card which, at the time the research project was conducted, limited their liability for prescribed items to a maximum of €85 per month[u].

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[t] Automatic entitlement to a medical card for those aged 70 and older began in mid-2001 and ceased from the start of 2009. Applications from this age group are now subject to a means-test.

[u] This amount has since increased to €120 per month.

People suffering from certain conditions (e.g. diabetes mellitus, epilepsy, cerebral palsy, cystic fibrosis, multiple sclerosis) may obtain drugs, medicines, and medical and surgical appliances for the treatment of that condition free of change under the long-term illness scheme.

Sick leave, sick pay and related benefits and allowances

There is no legislation on the issue of sick pay or sick leave, which means that policies on sick leave and sick pay are at the discretion of employers. If an employer does not provide sick pay, individuals can apply for illness benefit; entitlement to this depends on the individual having paid sufficient PRSI (social insurance) contributions. An individual who does not have sufficient contributions may apply for assessment by a CWO for eligibility for Basic Supplementary Welfare Allowance; this allowance can be paid while the individual is waiting for another social welfare payment. If an employer does provide sick pay, employees on sick leave will usually have to sign over any illness benefit to their employer.

Employees are entitled to time off work to attend hospital appointments, but are not automatically entitled to be paid for this time.

Benefits, allowances and other payments

The Department of Social and Family Affairs has responsibility for the provision of most social welfare payments including illness benefit, disability allowance, invalidity pension, carer's benefit, carer's allowance, and the old-age pension.

Some means-tested payments are provided by the HSE. These include:

- Supplementary welfare allowance scheme:
    - basic weekly payments, pending a primary social welfare claim;
    - weekly supplements (e.g. rent supplement, mortgage interest supplements, diet and heat supplements); and
    - exceptional needs payments, which are one-off payments for urgent/emergency situations. These payments may be awarded to cover costs of items such as exceptional domestic expenses (e.g. installation of a telephone), essential household items (e.g. heating oil), hospital clothing, travel for relatives and counselling;
- Mobility allowance, which provides a payment for individuals who have a disability and are unable to walk or use public transport and who would benefit from a change in surroundings;
- Motorised transport grant, which provides a payment for a disabled individual who either needs to buy a car, or modify a car or other vehicle.

The community care arm of the HSE may provide cancer patients with a payment towards the cost of a wig. The amount available varies across the country, and may or may not cover the full costs.

Local authorities offer disabled persons housing grants which provide for up to 75% of the costs of necessary house alterations.

Community services which may be relevant to individuals with cancer

Community care services are generally provided by the HSE, although this may be in conjunction with voluntary organisations. Entitlement to these services is not as clear cut as for hospital services. There are wide variations in the level of services available in different parts of the country and there may be waiting lists for particular services (Citizens Information Board, 2009).

Hospital transport services, which provide access to outpatient departments, and day hospitals and centres, are available on a varying basis throughout the country. If available, services will usually be free of charge to medical card holders; individuals without medical cards may (or may not) have to pay.

Physiotherapy services are usually provided at central locations in the community (rather than at individual's homes), and are free to medical card holders.

Occupational therapy services are available in most areas, and are generally free to medical card holders.

Respite care may be based in the community or an institution. In practice, it is provided to a varying degree at a number of locations around the country, in some cases by HSE and in others by voluntary organisations.

Although the HSE is not legally obliged to provide homehelp services, these are available in some areas, provided either by the HSE or through an arrangement with a voluntary organisation.

Free travel

Individuals aged 66 and over, and permanently resident in Ireland, are entitled to free travel on State public transport (bus, train, LUAS) and on services provided by a limited number of private bus operators. Individuals who have a free travel pass and are married or cohabiting are also entitled to a pass which allows the spouse/partner to accompany the individual free of charge.

Further information

More information on the HSE, organisation of health and social welfare services, and benefits and allowances can be found on the websites of the following organisations:

Citizens Information	http://www.citizensinformation.ie
Health Service Executive	http://www.hse.ie/eng/
Department of Social and Family Affairs	http://www.welfare.ie/EN/Pages/default.aspx

Appendix 2 Welfare grants awarded by the Irish Cancer Society in 2006

This appendix includes a review of all welfare grants awarded by the Irish Cancer Society in 2006. The aims of the review were to explore: (1) the types of expenses/costs incurred by cancer patients; and (2) the characteristics of patients who incur such costs.

Methods

Details were extracted from the information retained by the finance department of the ICS on each grant awarded in 2006. The details recorded included the date on which the request was received, the amount of the award, and the purpose (e.g. travel, heating costs). For each award made to an individual affected by one of the four most common cancers (breast, prostate, lung and colorectal), the letters of application were reviewed. Details were abstracted (where available) on the cancer type and status (whether the patient was terminal, undergoing palliative care, or had metastatic or advanced disease), age, marital status and whether the individual had children under the age of 18, and whether the individual or family were dependant on social welfare payments/benefits. Further relevant details were noted where available.

Results

Number of awards, timing and location of award recipients

Grants were awarded to 717 individuals in 2006. A further four awards were made but one individual did not cash the cheque as the funds were no longer required; the other three individuals had died by the time the award was made and the family returned the cheque.

In terms of the month during which applications were received by the ICS, this ranges from 34 in December to more than 70 in February, March, August and November.

Figure APP2.1 shows the number of grants made by the county of residence in which the recipient lived. Two hundred of the 717 (28%) grants were made to individuals living in the Dublin area, with a further 74 (10%) and 50 (7%) to Galway and Cork residents. Although awardees were spread across the country, the geographical distribution probably reflects, to some extent, the location of hospitals in which patients were treated and availability of/access to oncology social workers. Social workers play a major role in bringing the scheme to the attention of patients and assisting with preparing applications.

Figure APP2.1 Welfare grants awarded by county of residence of recipient, 2006

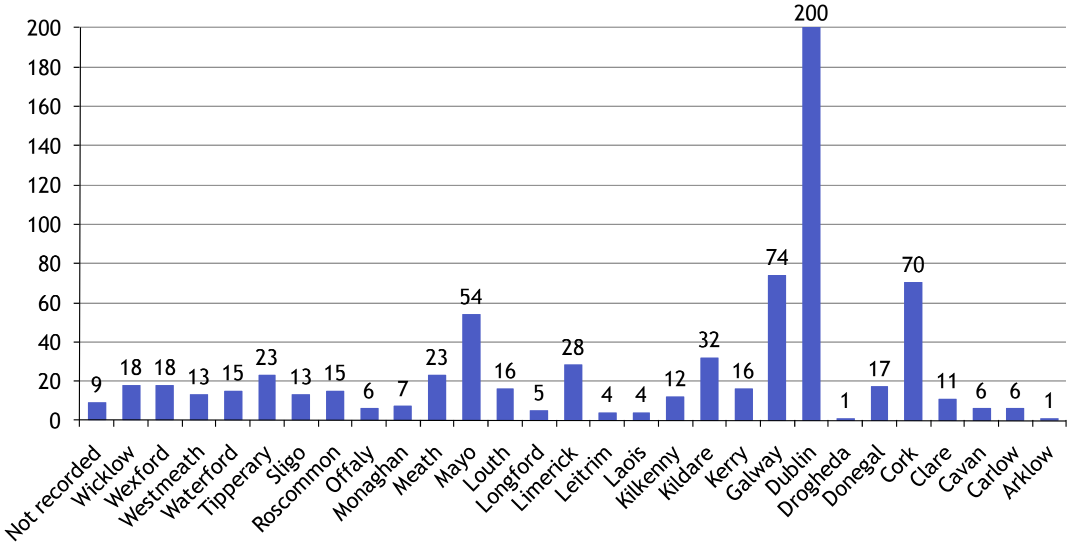

Table APP2.1 Amount awarded by purpose, and % of total amount

Purpose	*€*	*% of total amount*
Travel	150,167	*35.0*
Accommodation	20,190	*4.7*
Subsistence	3,910	*0.9*
Loss of earnings	66,055	*15.4*
Personal care	23,545	*5.5*
Household bills	68,545	*16.0*
Childcare	14,900	*3.5*
Homehelp	34,670	*8.1*
Home modifications	5,050	*1.2*
Other household costs	7,629	*1.8*
Respite	33,100	*7.7*
Convalescence	1,500	*0.3*
Other	250	*0.1*
Total	429,511	*100*

Amount and purpose of awards

The total amount paid out by the ICS was €429,511. Table APP2.1 shows the total amount awarded by purpose. Just over one third of the total amount was awarded to cover travel costs (€150,167; 35%), with a further 6% (€20,190 + €3,910) for related accommodation and subsistence expenses. Almost 16% of the total amount was awarded to cover loss of earnings (€66,055). A total of almost €70,000 (16%) was awarded to cover the costs of household bills. Most commonly individuals sought help with heating and phone bills, but a small number made applications because they had had difficulties with costs of food or mortgage payments. Help around the home, modifications to the home (e.g. installation of a shower or a stair lift) and other household costs (e.g. new bed, bed linen) accounted for a further 11% of the total amount awarded. Costs of childcare accounted for 3.5% of the total amount awarded. Payments to cover personal care costs (5.5% of total amount) were usually for wigs, but some payments were made for the purchase of new clothes, supportive care (e.g. physiotherapy, counselling) and appliances (e.g. voice aid, wheelchair). The category of respite covers items such as a weekend away, or a short holiday/break and almost 8% of the total amount awarded was for this purpose.

The average amount awarded to an individual was €600. Ninety three awards (13% of 717) were made for the full amount of €1000.

Table APP2.2: Number and % of awards by purpose[1]

Purpose	*No. of awards*	*% of awards*
Travel	348	*48.5*
Accommodation	45	*6.3*
Subsistence	11	*1.5*
Loss of earnings	119	*16.6*
Personal care	64	*8.9*
Household bills	151	*21.1*
Childcare	29	*4.0*
Homehelp	53	*7.4*
Home modifications	7	*1.0*
Other household costs	19	*2.6*
Respite	61	*8.5*
Convalescence	2	*0.3*
Other	1	*0.1*

[1] Categories not mutually exclusive, so total % does not sum to 100%. Awards made for multiple purposes are included in each relevant category.

Table APP2.2 shows the number of awards by the purpose of the award; grants may be provided for more than one purpose and each purpose is included in the table. Almost half (49%) of individuals received an award which was at least in part intended to cover the costs of travel. For just over one fifth of recipients (21%) the grant was provided because of difficulties in meeting the costs of household bills. 17% of individuals received a payment to help with loss of earnings. For just under 10% of individuals the award was intended to help meet costs of personal care items.

Awards to individuals affected by breast, prostate, lung or colorectal cancer

Ninety three (13%) of the welfare grants were made to individuals diagnosed with breast cancer (Table APP2.3); although the majority of these were female, applications were made by 3 men with the disease. Just over a quarter of those with breast cancer had either advanced or metastatic disease, or were in the terminal phase or receiving palliative care. Only 17 (2%) of the awards were made to men with prostate cancer (despite the fact that prostate cancer accounts for 16% of all invasive cancers in men in Ireland (www.ncri.ie)). Nearly one half of the men with prostate cancer had metastatic or terminal phase disease. 62 individuals with lung cancer (9% of the total) received grants; 38 of these were male and 24 female and overall 40% overall had advanced cancer. 50 individuals with colorectal cancer (34 men and 16 women) received an award, accounting for 7% of awards made. Just over 40% of those with colorectal cancer had metastatic or terminal disease. These percentages reflect an over-representation of metastatic and terminal patients compared to the distribution of newly diagnosed cancer patients.

For all four cancer sites, the median age at onset for grant recipients was lower than among all patients diagnosed with the particular type of cancer in Ireland. Breast cancer patients were on average younger (median 47 years) than those with colorectal (55 years), lung (59 years) or prostate (68 years) cancer. Almost 40% of those with breast cancer had children under 18, reflecting the younger age at presentation, compared to 28% with colorectal cancer, 21% with lung cancer and 6% with prostate cancer. Between 24% and 31% of the recipients were already in receipt of social welfare payments/benefits and a further 4-6% had applications for payments/benefits under assessment.

Table APP2.3 shows the purpose(s) of each payment made to the individuals with breast, prostate, lung or colorectal cancer. Breast cancer patients were more likely to seek help with costs of childcare than those with the other cancers; this reflects the lower average age at onset of breast cancer compared to the three other cancers and, possibly, that women bear the burden of childcare responsibilities. Loss of earnings was more commonly cited as a reason for which financial help was needed for those with breast and colorectal cancer. Once again this is likely to be a function of patient age at onset; patients with breast cancer more likely to be of working age. Awards for personal care costs were also more commonly made for those with breast cancer; these were mainly to cover the costs of wigs. Chemotherapy for the other cancers is unlikely to result in hair loss. Lung cancer patients were less likely to seek payment to cover costs associated with travel for treatment, probably reflecting the lower rates of treatment in this cancer than the others. The apparently relatively high proportion of recipients in receipt of social welfare payments suggests a subgroup that may be particularly vulnerable with regard to additional cancer-related costs.

Table APP2.3 Number and % of awards by purpose[1], for patients with breast, prostate, lung or colorectal cancer

	Breast		*Prostate*		*Lung*		*Colorectal*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Travel	43	*46.2*	8	*47.1*	19	*30.6*	21	*42.0*
Accommodation	2	*2.2*	2	*11.8*	2	*3.2*	7	*14.0*
Subsistence	2	*2.2*	0	*0.0*	0	*0.0*	0	*0.0*
Loss of earnings	17	*18.3*	2	*11.8*	6	*9.7*	11	*22.0*
Personal care	19	*20.4*	0	*0.0*	8	*12.9*	2	*4.0*
Household bills	19	*20.4*	4	*23.5*	17	*27.4*	11	*22.0*
Childcare	12	*12.9*	0	*0.0*	0	*0.0*	0	*0.0*
Homehelp	3	*3.2*	1	*5.9*	8	*12.9*	8	*16.0*
Home modifications	2	*2.2*	1	*5.9*	1	*1.6*	0	*0.0*
Other household costs	2	*2.2*	2	*11.8*	3	*4.8*	0	*0.0*
Respite	4	*4.3*	0	*0.0*	4	*6.5*	4	*8.0*
Convalescence	0	*0.0*	0	*0.0*	1	*1.6*	0	*0.0*
Other	0	*0.0*	0	*0.0*	0	*0.0*	0	*0.0*

[1] Categories not mutually exclusive, so total % does not sum to 100%. Awards made for multiple purposes are included in each relevant category.

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