



The financial impact of a cancer diagnosis

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irish cancer society

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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.*

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