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Survivorship burden for individuals, households and society: Estimates and methodology

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ABSTRACT

With more and more individuals surviving cancer it is important to estimate the economic burden survivorship places on these individuals, and also on their friends, family, carers and the wider society. This paper provides a review of current estimates of the cost of living with and surviving cancer. Few studies have provided an all-encompassing estimate of the burden. A range of methodologies to estimate the direct health care costs, direct non-health care costs, productivity loss and informal care costs of surviving cancer are described. Additionally an often overlooked burden that on survivors' and caregivers' quality of life is also discussed. This paper hopes to encourage more research on the economic burden of cancer survivorship to aid policy makers in their resource allocation decisions and help establish an ongoing research agenda.

1. Introduction

Cancer survivorship has been described as a pandemic of treatment success [1]. The increasing number of treatments and interventions available for previously untreatable cancers and the improving success rate of treatments due to targeted therapies coupled with increased uptake of and improvements in early detection means the number of cancer survivors is growing. Thus the accumulative burden of cancer has shifted from the narrow active treatment phase to include the medical and non-medical issues across the treatment and post-treatment spectrum.

While a substantial proportion of costs are incurred immediately following diagnosis the long-term burden is not insignificant. There may be additional ongoing health care costs, social care costs and personal financial issues. Much of this might be magnified given the considerable unmet needs of cancer survivors [2]. In order to address this issue it is important to provide evidence to both health care professionals and policy makers on the economic burden of survivorship. This paper contributes to this by undertaking a targeted review of the current evidence and presenting the necessary methodologies to generate additional evidence.

The paper proceeds as follows. First it is necessary to define survivors and survivorship. Additionally we provide a definition of economic burden. We then review a number of estimates of the burden, and present methodology and methods to inform future estimates of the burden.

1.1. Cancer survivorship and survivors

The term cancer survivorship refers to the period of the cancer trajectory between primary treatment and cancer recurrence or end of life [3]. Survivorship represents an intermediate point of the so-called 'cancer control continuum', a simplified representation of the cancer experience used since the mid-1970s to describe the phases of cancer care from prevention to end-of-life.

While the definition of cancer survivorship is fairly well established, views differ regarding the population of individuals with a history of cancer to which the term 'survivors' applies. Advocacy groups and health policy organisations have promoted broad definitions of the term to encourage an improvement in the quality of care provided to people living with cancer. The National Coalition for Cancer Survivorship (NCCS) in the United States uses the term survivor for all individuals diagnosed with cancer, but also for their family, friends and caregivers [4]. The definition used by the National Cancer Survivorship Initiative (NCSI), a UK partnership between the Department of Health and the charity Macmillan Cancer Support, includes individuals with active cancer, who are undergoing treatment, in remission or that have been cured [5].

From a clinical point of view, cancer survivors are typically identified as individuals who have been disease free for a minimum of five years, when the risk of recurrence is lower [6]. However, Khan, Rose and Evans [7] argue that it is difficult to determine the optimal time threshold that qualifies cancer survivors as such. End of active treatment for example may not be the appropriate cut-off date because

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patient care may continue with long-term treatments like hormone therapy. Five years after diagnosis may be the appropriate threshold for cancers characterised by higher survival rates, but inappropriate for aggressive cancers where patients die approximately one year after diagnosis. In the latter example, a patient overcoming the first year after diagnosis may already be considered a survivor.

Coupled with the definition of cancer survivor is also the acceptability of the term. Empirical evidence in the US has found that some former cancer patients do not like being labelled as survivors for fear of recurrence [8], for not identifying with the heroic connotation of the term [8], or for associating it with a traumatic experience such as victims of violent crimes [9]. Other perspectives oppose a definition of survivor that focuses only on length of life after cancer, arguing that quality of life is also important [10].

Views differ around necessity of a universal definition of ‘cancer survivors’. A universally agreed definition could foster the improvement of the type of survivorship-specific care offered to patients [11]. Other researchers believe that ‘distasteful’ labelling to patients should be avoided and that a universal definition is unlikely to suit all patients because cancer is too heterogeneous of a disease [7]. However, operational definitions are necessary to move forward policy positions and the provision of care and support for survivors, therefore in our discussion of the economic burden of survivorship we focus on survival post-primary treatment, i.e. the longer term costs and consequences. When presenting estimates from previous studies that use the term ‘survivor’ we acknowledge that the definition may differ.

1.2. United Kingdom cancer survivors

In the United Kingdom, cancer incidence rates for all cancers combined have increased 12% since the early 1990s [12]. The latest available statistics on cancer survival in the United Kingdom (2010–11) show that survival for most cancers has doubled in the last 40 years and that 50% of individuals diagnosed with cancer survive for 10 years or more [13]. Maddams, Utley and Møller [14] estimate that two million cancer survivors live in the United Kingdom. Assuming that survival continues to grow at the current rate until 2040, the number of survivors is projected to increase at the approximate rate of one million per decade. The largest increase in survival is expected to occur among the elderly so that by 2040 77% of all cancer survivors will be aged 65 or above and around a quarter of the people aged 65 or older will be a cancer survivor [14]. Breast and colorectal cancer are estimated to contribute the largest proportion of survivors.¹

Odds of survival depend on the type of cancer and are highly variable. The most prevalent cancers that have shown the largest improvement in ten-year survival from 1971–72 to 2010–11 include prostate cancer (from 25% to 84%), breast cancer (from 40% to 78%) and bowel cancer (from 42% to 57%). These improvements in the UK are comparable to those in the United States where 10-year relative survival rates² for prostate, breast and colorectal cancer are respectively: 98%, 83% and 58% [15].

Notably the observed improvements in survival have led to cancer being described as a chronic disease rather than a life-threatening illness. Many cancers are responsible for long-term effects that can negatively impact the life of survivors. Examples of life impairing effects include lymphedema after breast cancer treatment, incontinence and erectile dysfunction as a result of prostate cancer treatment, and chronic diarrhoea for bowel cancer patients [15]. In addition, because cancer survivorship will grow particularly among the elderly, it will be necessary to consider the health and economic burden effect on cancer

¹ These estimates are based on the assumption that for all cancers incidence, survival and population demographics continue to change at current rates. Only the incidence rate for prostate cancer is assumed static.

² Relative survival rates are adjusted for life expectancy by age, race and sex.

Table 1
Cost components and associated payers.

	Cost Component	‘Payer’
Direct Costs	Medical costs for primary treatment and long-term care	Healthcare system/insurer
	Out of Pocket costs	Survivor (and family)
Indirect Costs	Productivity loss	Survivor (and family); Caregivers
	Informal caregiving costs	Caregivers
	HRQOL losses	Survivor; Caregiver

survivorship outcomes in combination with the comorbidities and multimorbidities experienced by older individuals [16–18].

2. Economic burden of cancer survivorship

The economic burden of disease is a measure reflecting the economic consequences of ill-health from a societal point of view. The burden of disease is estimated as the sum of the monetary value of resources used to treat the disease and the cost of the lost opportunities due to disease [19]. The former typically falls in the category of direct costs, while the latter into that of indirect costs. A taxonomy of the cost components associated with direct and indirect costs is presented in Table 1 along with the type of ‘payer’ who sustains the burden.

The cancer control continuum describes the cancer experience from cancer aetiology, prevention, early detection, diagnosis, treatment, survivorship to end-of-life care [20]. Along the cancer continuum, costs are expected to be highest immediately following diagnosis and at the end of life (see Fig. 1). Yabroff et al. [19] describe the evolution of the economic burden as a U-shaped curve, with varying width and height depending on the cancer site, stage at diagnosis and patient’s age. While burden may be at its lowest in the cancer trajectory during the ‘survivorship’ period, longer-term costs are likely to be substantial 1–5 years after diagnosis. Long-term economic burden from protracted poorer health outcomes may translate into both direct medical costs and indirect costs such as permanent productivity loss.

It is important to highlight that in addition to the monetary value of burden, burden can also be reflected in quality of life estimates, the Global Burden of Disease project is one example of this [23].

Below we present some estimates of the burden of survivorship. We particularly focus on the costs and losses incurred by individuals (cancer survivors) and their families – lost productivity, informal carer costs, out of pocket costs and quality of life impacts – as these are often overlooked.

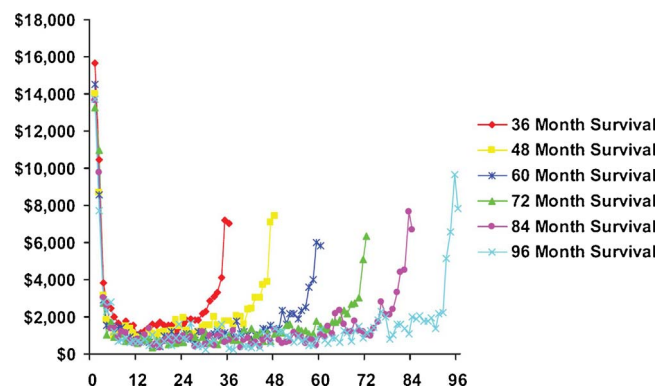


Fig. 1. Economic burden along the cancer control continuum. Source: Yabroff et al. [21]; adapted from Brown et al. [22].

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