# Work and Cancer Survivors

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*Work we know is both a burden and a need, both a curse and a blessing. But work is an extension of personality. It is an achievement. It is one of the ways a person defines himself or herself, measures his work and his humanity.*

–Peter Drucker

# Foreword

During the past decade, there has been a dramatic shift in the focus of cancer outcomes research. Five-year survival rates are no longer the gold standard; many cancers have become like other chronic diseases, where prolonged survival is common, even with repeated relapses. Success is more appropriately measured in terms of quality of life, not mortality. For most adults, work is an essential component of daily life in the developed world, a key facet of participation in society. Thus, the focus of this book is timely, and crucial, as providers and patients begin to think more broadly about life after treatment.

What can cancer researchers learn from those of us who have been studying return to work and disability prevention in musculoskeletal disorders? We bring a long tradition of theoretical and scientific development. Purely biomedical models have given way to a broader biopsychosocial view. Specific diagnoses and purely clinical measures fail to explain much of the variance in return to work outcomes. Disability is a separate condition, where motivation, skills, attitudes and outlook, employer-employee communication, accommodations, and other psychosocial factors are the primary outcome determinants. Medical interventions, at least at this point, appear to have relatively little impact compared to approaches that pursue a multidisciplinary and integrated approach, focused on case-specific barriers to return to work.

There is good evidence for efforts to improve employer responses, address patient fears and concerns, support employer-employee problem-solving about work modification, and facilitate provider-employer communication. Current investigations are now seeking to measure and predict future work capacity, avoid disability recurrence and exacerbation of symptoms by work demands and exposures, and support more effective accommodations in the workplace. These perspectives appear common to both cancer and musculoskeletal disorders. This book provides cancer researchers and practitioners with a concise, focused overview of theoretical developments and research results in our field, as well as excellent suggestions about how these results can be adapted to improve outcomes for cancer survivors.

The second half of the book addresses several challenges that may be more unique to cancer survivors. Childhood cancer treatment disrupts normal early work experiences and often leaves survivors with one or more chronic illnesses.

Without extra support, childhood cancer can result in the inability to progress in vocational development. Residual cognitive and emotional limitations, especially in persons surviving Central Nervous System tumors but other cancers as well, may not be readily obvious, but can profoundly impact work ability. Decision-making about post-treatment return to work may be challenging as well, depending on the specific cultural, legislative, benefits, and vocational milieu. Cancer-specific fears and prejudices, and reluctance of supervisors and employees to discuss the work implications of cancer, can create barriers to problem-solving. Cancer is also an illness that involves the entire family, and thus can have a significant impact on the work ability of more than just the survivor. Although rehabilitation and work reintegration services have been specifically developed for individuals with musculoskeletal, psychiatric and cardiac conditions, similar services are just now emerging for cancer survivors. Many disability compensation systems still operate on an antiquated assumption that a cancer diagnosis is equivalent to permanent and total disability.

It is in this context that this book makes a particularly important contribution. Dr. Feuerstein has done a superb job in bringing together leading researchers in cancer survivorship to present the current state of knowledge about factors affecting return to work, how return to work outcomes can be measured, and new approaches that are being developed in order to help survivors achieve their maximum potential. It represents the next logical step in the development of this field following the Institute of Medicine report. The material is authoritative, challenging, forward-looking, and well-referenced. Hopefully, this book will stimulate a new generation of researchers and will motivate practitioners to think more carefully about how they can not only treat, and often cure cancer, but also make a significant contribution to the quality of life in their patients. Significant progress in return to work in the area of work-related musculoskeletal disorders in the last few decades is very encouraging, and suggests that similar progress is just around the corner in cancer research.

Worcester, MA Glenn Pransky

# Preface

Why this book?

I am now a six year survivor of a malignant brain tumor. Just a few years ago, this would be unthinkable. Due to the very skillful management of this brain tumor by many, I am able to work. I actively manage symptoms and stay on top of my health, but this tumor can reoccur at any time. I do not take this second chance at life lightly.

I am grateful to be alive and for the wherewithal to pull this book together. The MRIs of my brain that I receive, now twice a year, indicate that the area in my cerebellum where the tumor was remains relatively tumor free, except for some dormant abnormal cells at the margins of the radiation field. Despite or because of this outcome, I am left with problems that I did not have before. . . episodic fatigue, "subtle" cognitive problems, blurred vision, hearing loss, and prolonged reactions to stress to name but a few. I know full well that I am a survivor of a major brain tumor. I know that brain radiation is related to residual neurosensory and cognitive problems. I am acutely aware that age can interact with these changes or even account for many of them, but all my problems as they relate to work occurred during or after treatment of my tumor. It is very clear that these symptoms impact my ability to work the way I had prior to my diagnosis and treatment.

I am also well aware there are many "survivors" that are much worse off and many who did not survive. I have had excellent heath care, great advice, and I have read almost everything that might even be remotely helpful. I have also tried many "workarounds" and accommodations and attempted to maintain a sense of "realistic optimism" needed for such resilience [1]. This is not a simple process. Despite all this information and support, I must work long hours to stay on top of work that would have taken me half the time to complete before my cancer. Clearly, this is my choice. I could have retired or slowed down, but I am now focused on a new mission in life. . . to help other cancer survivors.

There are many cancer survivors who similarly work at jobs with residual problems from cancer or its treatment. Also, there are many survivors of cancer who are not aware of or who cannot gain access to the opportunities that are available to optimize their ability to work. As more of us diagnosed with cancer live through the primary treatment of cancer (definition of survivor in this book), returning to as "normal" a life as possible becomes an important goal.

Work becomes a priority. The information in this book was written to help make this outcome a reality despite the symptom burden and societal barriers we may face. However, when it comes to this aspect of recovery, we must recognize that work is not always a realistic outcome. It is critical to consider each survivor's specific health, economic, and social situation in relation to work.

Returning to work is one of those aspects of life that many consider to signal a degree of normalcy and control during a period when most things are chaotic. As mentioned above, not all cancer patients can or desire to return to work during or following the diagnosis of and treatment for cancer. Some decide that it is now time to pursue another course in one's life that does not involve work. If financially feasible, some decide it is now time to retire from work altogether. Still others believe that although they want or need to work for fulfillment and/or income, they just can't make it through a full day given low energy levels, confusion, pain, or some other residual effect of the cancer and/or its treatment. Others are uncomfortable or fearful with the way they might be perceived, either appearance-wise or functionally. Some older cancer survivors who were working prior to diagnosis may desire or financially need to return to work following the bulk of treatment if possible. This group will grow in significant numbers over the next few decades as the cohort of baby boomers move into the ranks of older adults [2] and the retirement age continues to inch upward [3]. There are also those survivors who are at their peak working age [3] who desire and need to work in order to continue to provide a viable income for themselves and their family or, in the US, to make certain health care coverage is available.

Even over the past decade, much has changed regarding how we handle cancer in the workplace. Our cultural expectations have shifted along with the specificity and reduced intrusiveness of various treatments. Knowledge regarding factors related to work disability in general, and innovative approaches to assisting those with chronic illness and functional limitations, return and remain at work, have also greatly evolved over the past decade or so. Perhaps most importantly in terms of defining cancer survivorship as a public health concern is the escalation in the prevalence of survivors of many types of cancers [4]. These trends clearly justify the need for a compendium that provides a comprehensive consideration of work in cancer survivorship. This volume provides the reader with an integrated review of work in cancer survivors from research, practice, and policy perspectives. The widely publicized contribution by the Institute of Medicine [5] sensitized many to the concern of employment among cancer survivors and raised our awareness of this problem. The present volume expands that effort and addresses in more detail the epidemiology, current thinking regarding work and work disability, factors that can impact work in cancer survivors, and intervention options. Legal and policy related matters are also addressed and a global perspective is provided.

The focus we took

Topics covered in the chapters of this book were chosen to provide the reader with a perspective on work and the cancer survivor that has not been

available in the past. In section I, chapters help define several dimensions of work and cancer. Chapter 1 covers the emerging findings of relevance to the epidemiology of cancer survivorship and work to help set the stage for addressing the many dimensions of the problem covered in subsequent chapters. In chapter 2, economists known for their work on the economics of work disability related to musculoskeletal disorders provide a detailed analysis of the economic burden of cancer survivorship and work in the US. As these authors conclude, the economic burden related to cancer survivorship and work (inability to work and lost productivity) in the US alone is staggering. Work and cancer survivorship appears to be one of those world-wide public health problems that has simply been under the radar for years. While the number of cancer survivors has increased considerably [6], the economic impact of work and survivorship has been an almost unspoken consequence of the war on cancer [7–9]. It is hoped that such analyses as found in Chapter 2 will fuel efforts to better understand the many facets of this problem, improve interventions, as well as facilitate the development of evidence based policy to reduce its impact on the lives of many.

Chapter 3 shifts our attention to another aspect of burden, the perceptions of both employers and employees in relation to work and returning to work. Given the concerns of both parties it is not surprising that cancer survivors in the US workforce have more disputes related to early termination and terms and conditions such as equivalent benefits and promotions than employees with other types of impairments [10]. Clearly, not all is well at work.

Section II covers some of the basic considerations that shall guide us when it comes to work and chronic illness. I thought that readers should hear the perspective of a surgeon who made a total shift in his orientation to patients when he took a critical look at the impact of his surgery on work outcomes. Chapter 4 provides a perspective on cancer and work from an orthopedic surgeon who is now focused on an interdisciplinary approach to work disability rather than tracking down the biological root of the "problem." The author presents his persistent efforts at achieving ideal surgical outcomes or the "perfect fusion" only to observe that despite this, the approach did not have much effect on the "functional outcomes" of patients he saw, which seems somehow to be related to other non-surgical matters. He describes his own experience with the purely surgical approach to back pain and work disability that motivated him to develop and investigate innovative multidisciplinary treatments that have focused on a broader approach to the management of work disability and functional restoration. This chapter is a poignant illustration as to why it is so useful to address a broader concept of work disability as we consider the optimal approach to work reentry and work optimization in cancer survivors. We cannot simply focus on physical impairments as the exclusive factor contributing to work disability. For certain, there is a need to identify and improve the management of long-term and late health effects and their contribution to work disability in cancer survivors. However, we must also consider several

other factors that can influence the ability to return and/or maintain an active work life. In short, we need a comprehensive perspective on work disability. An example of this perspective, one from someone who has focused on recovery of function from purely a biomedical perspective for years, should provide readers a reminder of the importance of an integrated approach to understanding and managing the many challenges discussed in this book. Finally, while the evidence-based developments in cancer survivorship and work will inform us as to which factors and what interventions can improve outcomes in this area, many of the work disability models that have been created for other illnesses can serve as a guiding light.

Chapter 5 provides an in-depth view of what many cancer survivors experience psychologically when faced with challenges returning to or remaining in the workplace. This level of understanding provides the reader with a deeper understanding of just what work means to many cancer survivors. This perspective argues for the need to avoid superficial or generic band-aid solutions for this problem.

Section III reviews factors that can impact return to work, work retention, and work productivity. The challenges at work experienced by survivors can perhaps be better understood from the perspective of the meaning that work has for cancer survivors. Chapter 6 covers fatigue and pain and relates these symptoms to work function. The suggestion that the areas of human factors and ergonomics can inform us of the complexities involved in work, analysis techniques, and ways to improve the human-work interface as it relates to cancer survivors is also highlighted. Chapter 7 reviews what is known presently about cognitive limitations and its rehabilitation. This is a challenging concern of cancer survivors in the workplace. The special situation related to employment and adolescent/young cancer survivors, some who are childhood cancer survivors, is comprehensively covered in Chapter 8. This age group of survivors have experienced unique challenges related to developing careers, obtaining initial employment, shifting work places, and maintaining employment. While it is apparent that much needs to be changed to provide opportunities to this group, lessons learned with existing research in this group, particularly around late effects, can also inform us regarding symptoms and work in adult cancer survivors. While efforts have been initiated to minimize and even eliminate many of the long-term and late effects [11], it is well known among cancer survivors and some clinicians that survivors experience long-term or residual symptoms for life [12]. A greater understanding of how these symptoms impact work provides a foundation for future research, development, evaluation, and implementation of innovative interventions and policy.

Section IV includes chapters related to primary and secondary prevention of work disability in cancer survivors. The approaches included in this section involve physician practices at the front line of care, rehabilitation, accommodations at the workplace, and legal and policy related efforts to improve work outcomes. As Chapter 9 indicates, while there are simple actions providers can implement to assist in the work reentry process, very little of this information

is readily available and, as such, cancer survivors receive only modest help related to work. Since cancer survivors have several opportunities to interface with health care providers, a serious consideration of just how physicians can help facilitate return to work and work retention (rather than simply indicating "when you are 'ready' to return, you can go back to work") is provided in this chapter. Chapter 9 covers research and practice related to the provision of information related to work in cancer survivors that can be directly used by primary care and occupational physicians. Attention to this element of recovery doesn't often require much beyond information and can be simple to implement, but it also has the potential to greatly impact the recovery of cancer survivors.

Chapter 10 addresses rehabilitation in the context of work. The approaches discussed consider the application of common models of disability in efforts to rehabilitate cancer survivors who are experiencing pain, fatigue, physical limitations, and/or emotional distress that can interfere with work. In the U.S. and other countries, when the cancer survivor returns to work with a documented disability that is secondary to the cancer diagnosis and/or treatment, they are entitled to reasonable accommodations (U.S.: workplace with 15 or more employees). Chapter 11 covers workplace accommodation. This approach to optimizing work in affected workers is very promising. At this point, many accommodations for cancer survivors typically do not include specific approaches to mitigate many of the concerns raised in previous chapters. This chapter provides a comprehensive consideration of options that have been used in general and to some extent in cancer survivors. Chapter 12, the final chapter in this section, addresses legal concerns that are relevant to cancer survivors in the workplace and their families. These regulations were developed to help facilitate positive outcomes regarding work and illness in general, and are applicable to cancer survivors when a limitation in function necessitates some type of employer response. Of course, the spirit of the law is often as important as the law itself. Just because a regulation exists does not mean all parties adhere to it. Also different stakeholders in this process may have different goals when considering returning to work or retaining those who are survivors of cancer. Chapter 12 provides a critical review of these laws and areas where reform can be fine-tuned and policy implemented to make these types of efforts more effective as primary prevention evidenced based policy.

Section V discusses the international perspectives of cancer survivorship and work and provides a review of both the emerging international literature in this area as well as specific programs designed to aid cancer survivors in matters related to work. It is well recognized that work disability is a global public health concern [13]. Research and interventions specific to many other countries especially the lower income countries that are becoming global partners in manufacturing, agriculture, computer-related communications, and other commercial areas need to be included in this effort. This is a first attempt to document what has transpired in certain countries

where information was available. Specifically, we are seeing work coming out of the UK, the Netherlands, Denmark, Sweden, Canada, Australia, and the US, but we need information as to the status of work and cancer survivors in other countries as well. This became very clear when producing this book.

In Section VI, the final section of this book, I focus on the future. Many cancer survivors return to work and experience few problems. This book is focused on the challenges faced by those who experience work related problems, aiding heath care providers responsible for caring for them, and fostering an understanding and response at both an individual and societal level. The book addresses the basic question... how do we improve the working lives of cancer survivors and meet the needs of employers? I certainly don't profess to have the answer, but after carefully considering the information in the chapters of this book, experiencing this challenge myself as a cancer survivor, and thinking about the area of work disability for 25 years, I do have some perspective on the problem. In this final section, I consider many of the challenges covered in this book from research, practice, and policy perspectives in order to help readers integrate these areas. In this final section, I also have provided an example of the process of evidence-based policy development for those who may not be familiar with it. In order to provide a perspective on this process, not often made explicit, it is hoped that those involved in cancer survivorship and work will use this information to help transfer evidence to policy.

Each chapter in this book is written by experts in specific disciplines that can impact the working lives of cancer survivors. The reader is provided with basic evidence and thoughtful reflections in the areas of epidemiology, economics, theories of work disability, and theory and practice of work disability prevention and management. This information can impact return to work and/or work optimization in cancer survivors. The topics covered in this book will be of interest to those involved in improving efforts to assist cancer survivors with problems related to work. It should also prove useful to those involved in redesigning policies or modifying existing ones based on economic, workplace, cultural forces, and new knowledge. While we must remember that not all cancer survivors experience challenges with work, for those who do it is no longer acceptable to simply ignore this important aspect of survival.

Note: Cancer survivorship and work is an emerging area. The relevant literature is not vast. As such, authors of certain chapters cited similar studies at times. During editing, every attempt was made to reduce redundancies. However, similar citations were retained in several chapters to highlight a point in that specific chapter.

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Work is one of those aspects of life that can stabilize the other dimensions of one's existence even during a major crisis such as cancer. When this pillar of normalcy cracks, crumbles or even collapses, life can change for the worse. Efforts to understand the importance of work in cancer survivorship, how to manage and ideally prevent the many problems that can impact work and efforts to help cancer survivors maximize work productivity is what this book is all about.

First I want to thank the many authors of this volume. Their commitment to the deadline and their unwavering willingness to provide overviews of critical information and new insights has made working with them an absolute pleasure. This group of authors represent experts in many disciplines related to health, disability, and work. As with most complex phenomena, an interdisciplinary focus is needed to truly address the multiple factors and rehabilitation strategies that can impact cancer survivors and work. These individuals are very experienced in their respective fields and the information they provide should inform your efforts in the laboratory, clinic, workplace, and policy arenas.

My family (Shelley, Sara, Andrew, Erica, Umang, Kiren, Maya, David and my mother Shirley), my primary source of support, need to be thanked. Their love and continuous encouragement is so important to me. They do wonder about all the time I spend on the computer on my new "mission" (i.e., cancer survivorship)! Despite their warnings, their love and support inspire me to keep going. I also would like to acknowledge my long standing colleagues at USUHS who have endured my reentry into the workplace and long-term adjustment following the diagnosis of my brain tumor: Neil Grunberg, PhD, David Krantz, PhD, Tracy Sbrocco, PhD, and Corinne Simmons. Their professional and personal interactions over these trying years mean a lot to me. My relationships with them have helped me gain a much better perspective on my cancer survivorship. They have truly helped me optimize my work experience. I also wish to thank my dear friend and colleague Glenn Pransky, MD, MOccH who has been my cheerleader and personal interpreter of all the medical and work-related concerns I have shared with him since my diagnosis. Glenn, you will never know how much you have helped me over the years.

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# Section I
# Defining the Problem

# Chapter 1
# Epidemiology

**David Neary**

## Introduction

The number of cancer survivors around the world is increasing due to continuing improvements in diagnosis and treatment that are allowing more people to hopefully lead full and happy lives. Both now and in the future, millions of people who would previously have died because of cancer are going to survive and a sizeable proportion of them are going to want, and be able, to return to their working lives. Cancer survivorship is a potentially broad concept [1] that can include individuals who have been diagnosed but not yet started treatment to people who have completed their treatment and have been disease-free for five or more years. For the purposes of this chapter, the focus will be on survivors after they have completed their primary treatment.

The impact of cancer on survivors and their working lives is complex and dependent on a large number of factors that provide challenges to individual survivors, their families, work organisations, and the social welfare provisions of societies around the world. We are only beginning to address and understand them. The focus of this chapter will be on paid work, indeed usually on paid employment in the market economy, but it is important to acknowledge that a cancer diagnosis will have a considerable impact on the vast amount of unpaid work that necessarily takes place in all societies. This unpaid work, such as the care giving in households that is often performed by women, is the vital aspect of societies with a market economy but has yet to be systematically researched.

This chapter sets the scene by providing a brief overview of the scale of cancer survivorship on a global and regional scale by presenting data on the incidence, mortality, and prevalence of cancer. Although there are severe limitations in the existing data, it is important to grasp the contemporary

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position and to consider the future trends in cancer incidence. This is followed by a brief history of research in the area of cancer survivorship and work from the pioneering work in the USA in the 1970s to an outline of two reviews published in recent years. Although there are limitations to research in this area, there follows a thematic review of the growing literature on this topic to provide a summary of the state of knowledge. Finally, the gaps in our knowledge are briefly presented to provide possible avenues for future research.

## The Scale of Cancer Survivorship

At a global level, the incidence of 26 cancers in 2002 was estimated at 10.9 million new cases by the GLOBOCAN series of the International Agency for Research on Cancer. The incidence of cancer is age-related with older people, for example those over the age of 65, are far more likely to receive a cancer diagnosis than younger people. In terms of incidence by site, lung cancer was the most common with 1.35 million new cases, followed by breast cancer with 1.15 million cases and colorectal cancer with 1.02 million people diagnosed. In terms of mortality, lung cancer was also the most common cause of death with 1.18 million cases followed by cancer of the stomach with 700,000 and of the liver with 598,000 [2] (Table 1.1).

In terms of prevalence (number of people alive with cancer at a particular point in time) there is no clear agreement on how this should be defined. For statistical purposes, survival up to five years after diagnosis is a widely used benchmark because of its association with cure and long-term survivorship. According to this measure there were an estimated 24.6 million people living with cancer in 2002. The most prevalent sites were breast with just over 4.4 million survivors followed by colorectal with 2.83 million and prostate with 2.4 million (Table 1.2).

Globally, the incidence of cancer is higher in the developed world, due mainly to demographic and lifestyle factors, although the developing world is experiencing an increase in cancer incidence. Survival rates are higher in economically developed regions than in the developing world although Eastern Europe is an exception [2] and there are a large range of variations within developed areas such as Western Europe [3] and the USA [4]. It is important to recognise that the figures from GLOBOCAN are estimates that are based on a mixture of actual data, extrapolations from limited samples, and informed guesses, but they are the most reliable available information. Looking to the future, the scale of global cancer incidence is forecast to increase from approximately 10 million cases in 2000 to about 15 million in 2020 due to demography, the level of tobacco consumption, and other risk factors [5]. Looking even further ahead, it has been estimated that the incidence of cancer could approach 70 million new cases by 2050 [6].

**Table 1.1** Global incidence and mortality by gender and cancer site, 2002

| | Incidence | | Mortality | |
|---|---|---|---|---|
| | Males | Females | Males | Females |
| | Cases | Cases | Cases | Cases |
| Oral cavity | 175,916 | 98,373 | 80,736 | 46,723 |
| Nasopharynx | 55,796 | 24,247 | 34,913 | 15,419 |
| Other pharynx | 106,219 | 24,077 | 67,964 | 16,029 |
| Esophagus | 315,394 | 146,723 | 261,162 | 124,730 |
| Stomach | 603,419 | 330,518 | 446,052 | 254,297 |
| Colon/rectum | 550,465 | 472,687 | 278,446 | 250,532 |
| Liver | 442,119 | 184,043 | 416,882 | 181,439 |
| Pancreas | 124,841 | 107,465 | 119,544 | 107,479 |
| Larynx | 139,230 | 20,011 | 78,629 | 11,327 |
| Lung | 965,241 | 386,891 | 848,132 | 330,786 |
| Melanoma of skin | 79,043 | 81,134 | 21,952 | 18,829 |
| Breast | – | 1,151,298 | – | 410,712 |
| Cervix uteri | – | 493,243 | – | 273,505 |
| Corpus uteri | – | 198,783 | – | 50,327 |
| Ovary | – | 204,499 | – | 124,860 |
| Prostate | 679,023 | – | 221,002 | – |
| Testis | 48,613 | – | 8,878 | – |
| Kidney | 139,223 | 79,257 | 62,696 | 39,199 |
| Bladder | 273,858 | 82,699 | 108,310 | 36,699 |
| Brain, nervous system | 108,221 | 81,264 | 80,034 | 61,616 |
| Thyroid | 37,424 | 103,589 | 11,297 | 24,078 |
| Non-Hodgkin lymphoma | 175,123 | 125,448 | 98,865 | 72,955 |
| Hodgkin disease | 38,218 | 24,111 | 14,460 | 8,352 |
| Multiple myeloma | 46,512 | 39,192 | 32,696 | 29,839 |
| Leukaemia | 171,037 | 129,485 | 125,142 | 97,364 |
| All sites but skin | 5,801,839 | 5,060,657 | 3,795,991 | 2,927,896 |

Adapted with permission from Parkin et al., Global Cancer Statistics, 2002, Table 1

**Table 1.2** Prevalence of cancer survivors by site (selected)

| | Males (000s) | Females (000s) | Total (000s) |
|---|---|---|---|
| Breast | – | 4,408 | 4,408 |
| Colon/Rectum | 1,515 | 1,315 | 2,830 |
| Prostate | 2,369 | – | 2,369 |
| Stomach | 951 | 522 | 1,473 |
| Cervix uteri | – | 1410 | 1,410 |
| Lung | 939 | 423 | 1,362 |
| Bladder | 860 | 250 | 1,110 |
| Corpus uteri | – | 775 | 775 |
| Non-Hodgkin | 427 | 324 | 751 |
| Lymphoma | 467 | 274 | 741 |
| Oral cavity | | | |

Adapted with permission from Parkin et al., Global Cancer Statistics, 2002, Figure 3

At a regional level in the developed world, there are slightly more reliable statistics from cancer registry data across Europe and the USA. Across 39 European states there were an estimated 3,191,600 new cases diagnosed in 2006 with breast cancer being the most common with 429,900 people, followed by colorectal (412,900) and lung cancer (386,300). In terms of mortality, lung (334,800), colorectal (207,400), breast (131,900), and stomach cancer (118,200) were the most common causes of death from cancer across Europe [3]. In the USA, an estimated 1,437,180 new cancer cases are forecast for 2008 along with 565,650 deaths as mortality rates continue to decline [4]. The overall survival rate for people under the age of 65, a proxy for working age adults, was 70.6% and was 77.2% for people under the age of 45 who could be considered to be in the prime of their working lives [7]. There are no accurate and reliable statistics published for the incidence, mortality, and prevalence of cancer among people in employment at either a global or regional level although it is apparent from the data that we currently have that returning to paid work and remaining at work is a concern for millions of cancer survivors now and their numbers are certain to increase in the future.

## The Impact of Cancer on Paid Work

### *The American Pioneers*

The impact of cancer on paid work has been an issue for research since at least 1973, when Robert McKenna in his capacity as President of the American Cancer Society, declared that enabling a cancer patient to return to work after treatment was a joint responsibility of all society [8]. Following McKenna's initial work, Frances Feldman conducted three studies in California that examined the experiences of white and blue-collar workers and young people that were published in 1976 [9], 1978 [10], and 1980 [11]. All three studies showed high rates of returning to work after cancer but highlighted two main categories of difficulties for cancer survivors. The first set of difficulties related to disease and treatment-related issues, such as fatigue and loss of strength, while the second set of difficulties revolved around the workplace and included issues with health insurance and the attitudes of co-workers and managers leading to job discrimination. This work in the USA set the template for research on this topic although these issues were shaped by a social welfare system which provided sharp incentives for cancer patients to return to work as quickly as possible due to a lack of financial protection and a pivotal relationship between employment and health insurance [12]. It is therefore vital that the position of cancer survivors in relation to paid work is seen in the wider context of the prevailing social welfare arrangements for access to health care, financial protection due to ill health through disability benefits, or retirement

provision and the legal framework for protection from discrimination in the workplace. These provisions vary considerably across countries and an acknowledgement of these differences is essential if we are to more fully understand cancer survivorship and paid work.

## *The Literature Reviews of Studies*

With improvements in diagnosis and treatment leading to higher survival rates in most of the developed world in the 1990s, there was increased interest in the issues around cancer survivors returning to paid work. This led to a review by Spelten and colleagues [13] that covered 14 studies conducted between 1985 and 1999 on this topic. Spelten and colleagues adopted a systematic approach for their review based on the World Health Organisation's disability model that categorised issues into work-related, disease- or treatment-related, and person-related factors. The results of this review indicated that a positive attitude from co-workers and having discretion over the amount of work or the number of work hours appeared to facilitate individuals returning to work. However, most work-related factors, such as physically demanding manual labour and the pace of work, were also a hindrance to returning to work. The evidence relating to disease and treatment-related factors found that only the number of months since the end of treatment was positively associated with returning to work. There were mixed results for factors such as disease stage and cancer site although survivors of testicular cancer reported relatively few difficulties compared to people with other cancer types. For person-related factors, mobilising social support appeared to help people to return to work but for other factors such as age and education the results were either mixed or negative. Overall, Spelten and colleagues were critical of the return to work research of this period both in terms of its quantity and quality. The 14 studies all suffered from methodological weaknesses such as small samples, non-standardised study-specific research instruments, cross-sectional rather than longitudinal design, and a lack of statistical testing of results. In their view, what was needed for future research was a prospective design with a distinction between work-related, disease- and treatment-related, and person-related factors. This would also require standardised measures to allow for more reliable and valid assessment of variables and the development of a model of the factors and inter-relationships that affect return to work behaviour. Finally, they called for cancer registries to record more information on the working status of patients so that the prevalence of cancer in the working population could be accurately measured.

A second review by Steiner and colleagues [14] published in 2004 used six methodological criteria to evaluate studies of the impact of cancer on paid work. The first criteria for inclusion began with enrolment of a population-based

sample of cancer survivors from a cancer registry to help avoid selection bias. Second, a longitudinal assessment of a cohort of cancer survivors beginning diagnosis and initial treatment as soon as possible in order to assess both the short- and long-term impact of cancer on work would be ideal. Third, there should be scope for comparisons between cancer survivors and a cohort of people without cancer so that the impact of cancer can be distinguished from other factors such as age, other health conditions and the overall state of the labour market. The fourth criteria included a detailed assessment of work intensity, role, and content in order to measure the complex and varied nature of paid work. Simply reporting the proportion of survivors who return to some type of paid work is a single measure that tells us nothing about the amount of work or the cognitive and physical demands placed upon survivors. Fifth, moderators of work return and work function such as cancer site, treatment modalities, individual characteristics such as age, co-morbidities, family structure, and the availability of health insurance, all might be included. Finally, the sample size of any study should be sufficient to allow multivariate analysis and have a sufficient number of survivors for a range of sub-groups such as gender, cancer site or stage, and ethnicity. Steiner and colleagues identified 18 studies that were published between 1975 and 2003 that met at least one of the necessary criteria. Seven studies had been published since 1999, the end point for Spelten and colleagues' review, indicating the increasing interest in this area of research.

There was not a single study that met all of the outlined criteria and only four that satisfied even four of them, indicating the methodological limitations of knowledge in this area. Of these four studies [15–18], three were from the United States (two used data from Detroit) and one was from the Netherlands but each had relatively small sample sizes ranging from 235 to 296 survivors. The findings from these studies are difficult to summarise because they used different sets of measures but physical symptoms were important predictors of work return and work function. It was also found that functional limitations and cancer site were also consistently predictive of subsequent work outcomes. Steiner and colleagues were similarly critical of the methodological quality of the research in this area and outlined the research needs according to the six criteria. They also suggested a conceptual model to guide future research by providing a comprehensive assessment of the influences on work after cancer (Fig. 1.1).

Steiner and colleagues also called for practical work-related interventions to be developed and evaluated so that optimal work outcomes could be achieved for cancer survivors. From a wider social and economic perspective, an optimal work outcome may well involve returning to work but future research should take into account the possibility that for some individuals this will not be the case. Cancer and paid work must be assessed in the context of individual's priorities and values rather than relying on social or economic metrics.

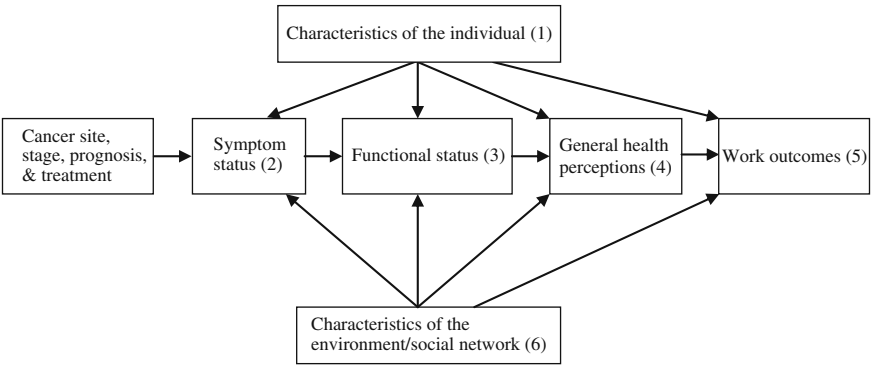


**Fig. 1.1** Relationship between cancer, quality of life, and work outcomes
(1) Socio-demographic characteristics, personal goals and values, baseline physical and mental co-morbidities, and perceived importance of work.
(2) Examples include presence or absence of fatigue, pain, and dyspnea.
(3) Includes presence or absence of various physical and mental health limitations.
(4) Includes self-rating of overall health, among other self-perceptions.
(5) Includes working, work intensity, changes to job schedule and work status, work role and content including change in employer, work type, productivity, job satisfaction, value of work, and ability to change job.
(6) Includes social support, presence or absence of dependents, and need to maintain health insurance.
Source: Steiner et al., 2004.

## A Thematic Review of the Literature

There should be no doubt that there are important methodological limitations in the research on cancer and paid work. However, despite these limitations there are a number of important themes that have emerged from this growing body of work. The aim here is to offer an accessible summary of the state of knowledge in this area for a wide range of readers by providing a thematic overview rather than repeating the reviewing exercises that have been outlined.

### *Most Cancer Survivors Are Able to Return to Work*

Numerous studies conducted since the year 2000 have shown high return to work rates for cancer survivors. From the United States, Bradley and Bednarek [15] found that 67% of the 141 cancer survivors in their sample from metropolitan Detroit who were employed at the time of their diagnosis were still in full time employment some five to seven years later. Their results suggested that there was good reason to be optimistic about the ability of cancer survivors to return and thrive in the labour market. Short and colleagues' [19] study in

Pennsylvania and Maryland found that the return to work rate for 1433 survivors increased from 43% between diagnosis and five months, to 73% after six to eleven months, to 84% after thirty-six to forty-seven months. Once again, these results suggest that there are grounds to be optimistic about the ability of survivors to return to work. Bouknight and colleagues' [20] study of breast cancer survivors in Detroit also found a high rate of returning to work with only 18% not working twelve months after diagnosis which can be considered as encouraging. Sanchez and colleagues [21], in their study of colorectal survivors in Los Angeles, found that 89% returned to work and 80% of this group were still working five years later. In Quebec, Canada, Maunsell and colleagues' [22] study of breast cancer survivors found that 21% of them were not working three years after diagnosis compared to 15% of a comparable cancer-free sample of women. Once again, this provides solid evidence that most breast cancer survivors are able to return to work. Spelten and colleagues [18], in their study in the Netherlands, also found an upward trend in the proportion of survivors who were able to return to work from 25% at six months after diagnosis to 64% at 18 months. In their study in Norway, Gudbergsson and colleagues [23] found no significant differences in the labour market position of 430 breast, prostate, and testicular cancer survivors and an appropriate control group. Across numerous advanced industrial countries around the world there is every reason to be optimistic about the ability of cancer survivors to recover and return to work.

## *The Importance of Cancer Site to Return to Work*

The term cancer describes a heterogeneous group of diagnoses with a variety of treatment regimes and a range of prognoses in terms of survival rates. So while there are good grounds to be more optimistic now than in the past about cancer survivors being able to return to work, there are significant variations by cancer site. This variation has been known to be an important factor in returning to work since the pioneering research of Feldman [9–11] in the late 1970s. The extent of the variation varies between studies, but one of the largest samples to measure this variation was Taskila-Abrandt and colleagues' [24] study of all working age cancer survivors in Finland known to be alive on December 31st 1997. Overall, they found that 50% of cancer survivors were employed compared to 55% of appropriately age and gender-matched referents. However, there was considerable variation between different sites with lung, multiple myeloma, and cancer of the nervous system survivors having a much lower likelihood of being employed. Encouragingly, the most prevalent cancer sites – breast, female and male genital organs, and urinary – had employment rates that were only slightly below the norm for the referents (Table 1.3).

It is likely that there will continue to be considerable variation in the ability of survivors to return to work because of the differing prognoses and cancer

**Table 1.3** Employment of cancer survivors with age and gender matched referents

| | Number | % of cancer survivors employed | % of referents employed | Relative risk |
|---|---|---|---|---|
| All cancer sites | 46,312 | 50 | 55 | 0.91 (0.90–0.92) |
| Head & neck | 1,823 | 43 | 51 | 0.80 (0.74–0.86) |
| Digestive organs | 4,051 | 45 | 50 | 0.90 (0.85–0.94) |
| Female genital organs | 5,105 | 48 | 52 | 0.93 (0.89–0.97) |
| Urinary & male genital organs | 4,558 | 44 | 48 | 0.92 (0.88–0.96) |
| Skin | 3,997 | 60 | 56 | 1.07 (1.03–1.11) |
| Sarcomas | 1,122 | 52 | 59 | 0.87 (0.81–0.94) |
| Lymphomas | 3,791 | 51 | 59 | 0.87 (0.83–0.90) |
| Lung | 934 | 29 | 46 | 0.63 (0.56–0.71) |
| Breast | 13,086 | 54 | 56 | 0.96 (0.94–0.98) |
| Nervous system | 3,667 | 43 | 60 | 0.72 (0.69–0.75) |
| Thyroid gland | 2,840 | 63 | 64 | 0.99 (0.95–1.02) |
| Multiple myeloma | 269 | 32 | 48 | 0.67 (0.54–0.83) |

Source: Taskila-Abrandt et al., 2005

survivorship challenges for different forms of cancer. However, for the vast majority of people who receive a cancer diagnosis during their working lives, there is still hope and evidence that they could return to work.

## *The Impact of Treatment and Symptom Burden Matters*

Treatment for cancer varies according to the site and stage of the disease and may involve surgery, chemotherapy, radiotherapy, and hormone treatment either singly or in combination. The impact of treatment on an individual's health can be significant as it can induce fatigue and a range of other physical symptoms such as nausea and sleep disturbance. Diagnosis and treatment can also influence an individual's mental well-being by inducing anxiety or depression and there can also be effects on a person's cognitive ability and therefore their ability to function in the workplace at the same level prior to their diagnosis. The treatment regime that patients undergo and the ensuing symptoms that survivors endure play an important part in individuals feeling able to return to work.

Satariano and DeLorenze [17], in their study of women with breast cancer, found that limitations in upper body strength and fatigue were important factors that inhibited survivors' ability to return to work. Spelten and colleagues [18] explored a range of cancer/treatment-related factors, such as sleep problems and physical complaints, in their prospective study in the Netherlands and came to the view that it was difficult to disentangle the relationship between these individual factors and returning to work. The more general complaint of fatigue, a component of many cancer/treatment-related symptoms, provided a more suitable concept to address as they found that the risk of staying off work