



Employment following cancer diagnosis

A narrative summary of the evidence

June 2009



UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

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Table of Contents

Preamble	5
1. Employment and cancer research and policy in Scotland	6
2. Methods	16
3. Overview of the evidence	18
4. Employment status	22
5. Experience in the workplace	28
6. Re-evaluating Work	30
7. Partners and carers in the workplace	32
8. Implications for workplace rehabilitation	35
9. Conclusions	39
Appendix A : Review Tables	42
Appendix B : Search strategy: electronic databases	96
References	98
Reader Information	116

Preamble

The Scottish Government in *Better Cancer Care: An Action Plan* identifies returning to work for people diagnosed with cancer as a major concern. It reports that the Scottish Centre for Healthy Working Lives (SCHWL) will bring a national perspective to initiatives designed to support people with cancer back into work. The Cancer Care Research Centre (CCRC), University of Stirling, was commissioned by SCHWL to conduct a review of literature. The objectives of this review are to:

1. Identity key literature about employment and cancer
2. Categorise the literature under key topics
3. Summarise key findings and conclusions of this literature
4. Identify gaps in research evidence

1. Employment and cancer research and policy in Scotland

Key points

- Approximately 27,000 people each year receive a cancer diagnosis in Scotland. Some of them are in paid employment when they are diagnosed.
- Supporting people living with cancer to remain in, or return to, work following diagnosis is a key UK policy priority.
- The Scottish government has responsibility for the health and well-being of people living with and beyond cancer. However, some of the legal requirements and guidance relating to employment and welfare is mandated by Westminster.
- Despite changes in the law aimed at protecting workers with cancer from unfair treatment, employers are still discriminating against people with cancer rather than making adjustments that could keep them in work.
- Macmillan Cancer Support, Breast Cancer Care and Scottish Centre for Healthy Working Lives have been supporting research and developing guidance and services to support people with cancer in the workplace.
- There is a lack of systematic and depth evidence about employment and cancer in a UK context.

Given improvements in cancer survival (Verdecchia et al. 2007) the number of people of working age living with cancer in Europe is likely to increase. In the UK, approximately

500,000 people under the age of 65 have been diagnosed with cancer at some point in their working lives (Cancer Backup 2006). Approximately 27,000 people each year receive a cancer diagnosis in Scotland (ISD Scotland 2007). The prevalence of cancer in the Scottish population is 0.4% of men and 0.5% of women aged under 45 and 2.2% of men and 4.3% of women aged 45-64 (ISD Scotland 2007). On average, a patient in the UK has a 46.2% chance of being alive 10 years after diagnosis compared with 23.6% 30 years ago. The overall 5 year survival rate is now 49.6%; the sharpest rise in overall survival occurring in the last 10 years (Corner 2009).

There is recognition that in the context of employment and cancer, there is a strong link between (fluctuating) employment markets and disability benefits rolls. Economic downturns as experienced in the 1990's (and the current economic recession) result in an increase in disability benefit rolls. In adverse economic climates, those with disability or with long term illness find difficulty in finding suitable employment (Beatty et al. 2004; Bell et al. 2004; Burchardt 2003; McVicar 2008).

Trends in health improvement, including cancer survival, are argued to have contributed to the increase in disability claimants. The numbers of those who are survivors/living with cancer has increased with consequent rise in numbers of individuals seeking or required to seek employment opportunities, or return to work (Bell et al. 2004; McVicar 2008). Institutional discrimination and lack of knowledge continue to be recognised as key features of failure of duty by employers to make 'reasonable adjustments' or provide opportunities for those with disability seeking employment or to return to or resume work.

In 2005, the Disability Rights Commission (DRC) (now the Equality and Human Rights Commission) published a briefing paper aimed at people with cancer, Multiple Sclerosis and HIV (Disability Rights Commission 2006). This paper was designed to give basic ideas regarding protection against direct discrimination and less favourable treatment while in employment. However, despite changes in the law aimed at protecting workers with cancer from unfair treatment, a 2006 survey by DRC has revealed that employers are, for example, discriminating against women with breast cancer rather than making adjustments that could keep them in work (Disability Rights Commission 2006).

Before the legal change, employers could dismiss workers with cancer or long-term health

conditions on the assumption that their condition could affect their ability to carry out normal activities. However, an amendment to the Disability Discrimination Act (DDA) 1995 meant that from December 2005, people with these conditions received legal protection from the point of diagnosis.

The Act was amended in 2005 to give legal rights to people with cancer as soon as they have been diagnosed. These important legal rights apply to workplaces in Scotland. Employers are required to make reasonable adjustments to help people at work. An employee should not be treated less favourably than colleagues because of their cancer or for any reason relating to their cancer, nor should they be subject to harassment. Despite this, the Disability Rights Commission helpline figures since 2005 show that the Commission has taken on average 2 calls per week from women with breast cancer complaining of unfair treatment at work (Disability Rights Commission 2006).

In October, 2006 Cancerbackup, working with Macmillan Cancer Support and in partnership with the Chartered Institute of Personnel and Development (CIPD) and the Working with Cancer group, published research accompanied by new guidance to address lack of support for employees affected by cancer (Cancer Backup 2006). This research and guidance reveals that more than 1 in 5 employers (22%) are not aware that the Disability Discrimination Act now classes cancer as a disability and that more than 40% of employers do not provide any support or information to employees with cancer, despite the fact that the illness casts its shadow on the vast majority of workplaces. Practical guidance is offered to help employers manage the estimated 90,000 people of working age who receive a cancer diagnosis each year. Key findings include:

- Nearly 73% of employers do not have a formal policy in place for managing employees affected by cancer
- Only a third of organisations ensure relevant staff have a good understanding of cancer and the impact of treatment
- Just under a half of organisations provide support
- Under a third of organisations track whether an employee returns to work
- Few employers provide counselling

- Nearly 50% of employers purchase private health cover but only 9% assess suitability for cancer-related cover

Social Security policy reform as integrated in the Employment Act 2008 presents further challenges for service users and service providers. The Employment and Support Allowance (ESA) for people with a disability or long term conditions (such as cancer) specified in the Employment Act 2008 relates specifically to service users, their families, carers and advisors. Return to work and/or engaging in work have become conditional in benefit entitlement for individuals deemed to be 'capable'. In relation to work, the provisions of ESA include a statutory 'work capability' assessment phase of 13 weeks and income means testing. Importantly, a work-focused health-related assessment is included in the work capability assessment. ESA may vary during the period of assessment dependent upon if the individual is determined to require support or to be capable of moving towards work. Barriers to movement towards work and 'work-related activity support' needs are identified in the final phase of the process (Green et al. 2007; McVicar 2008).

While Employment and Support Allowance has not yet been evaluated, disability rolls continue to increase and the drive to reduce those claiming benefit and back in work has not been achieved (Grover et al. 2007). McVicar (2008) identifies that 'those with impaired health find themselves at the back of the job queue' and goes on to note that employers identify disadvantages to, or have negative perceptions of, potential productivity. Despite being found capable of work, many individuals may be unable to find suitable employment and continue to require benefits. Individuals with health issues may also be 'casualties' by means of employment redundancy in economic down turns (Beatty et al. 2002; Burchardt 2003)

In 2008, Macmillan Cancer Support and the Department of Health launched the National Cancer Survivorship Initiative (NCSI). In 2009, NCSI commissioned Breakthrough Breast Cancer, Roy Castle Lung Foundation, Prostate Cancer Charity and Bowel Cancer UK to map the 'survivorship journey' and identify gaps in evidence for breast, lung, prostate and colorectal cancer respectively. These charities identified that there is a lack of information about returning to work and information for employers.

The Scottish government is committed to supporting people with cancer in paid employment. Better Cancer Care: An Action Plan (Cancer Backup 2006; Scottish Government 2008) sets

out cancer as a national clinical priority for NHS Scotland. It recognises that rehabilitation and support services are necessary following treatment completion. Self management of the condition, sustaining employment and access to welfare benefits are highlighted in particular. Under the direction of the Scottish Cancer Taskforce, a working group on 'Living with cancer' has been established to maintain a national focus on issues of concern for people living with cancer and identify requirements for further research.

The Scottish government has responsibility for, and is already taking steps to improve the health and well-being of people living with and beyond cancer. The NHS, local authority, with support from the voluntary sector, provides and delivers services to meet the needs of people living with and beyond cancer under Scottish government direction. However, some of the legal requirements and guidance relating to employment and welfare is mandated by Westminster.

The Black Report (Black 2008) for instance, set the direction of travel for health and employment policy for the whole of Britain. It represents a move away from understandings of health and well-being as a medical issue alone. It rolls out a vision of a new approach to health and work. That is, individuals have a fundamental personal responsibility to maintain their own health and employers must work alongside this to change the nature of the modern workplace. This new vision aims to change perceptions of fitness for work and tackle, for example, stigma around ill-health, the assumption that work impedes recovery, the assumption that people should be 100% fit to attend work and, relatedly, changing the focus from what people cannot do to what they can.

Current UK initiatives supporting people with cancer include:

Scottish Centre for Healthy Working Lives

The Scottish Centre for Healthy Working Lives (SCHWL) was established to help employers, employees and partner agencies to come together to create a much healthier and motivated workforce. As part of this initiative, the SCHWL offers a vocational rehabilitation service, with the aim of benefiting both individuals and employers alike. Vocational Rehabilitation grew out of efforts to rehabilitate people with disabilities. However, today it encompasses the provision of assistance to a much broader group, including people with

physical health problems and mental health problems. Early in 2007, the (then) Scottish Executive published Co-ordinated, integrated and fit for purpose: A Delivery Framework for Adult Rehabilitation in Scotland (Scottish Executive 2007). The Framework sets out how provisions for VR in Scotland should operate. It defines VR as:

“... a process that enables people with functional, psychological, developmental, cognitive and emotional impairments or health conditions to overcome barriers to accessing, maintaining or returning to employment or other useful occupation.”

(pg 32)

The focus of VR is to help people retain or regain the ability to participate in work, rather than to treat any illness or injury itself. It is well recognized that, as well as providing economic benefits, engagement in work or other meaningful and valued activity has health benefits for the individual, and can aid recovery from physical or mental health problems.

The Scottish Centre for Healthy Working Lives and NHS Tayside has recently established a pilot project within Dundee Community Health Partnership to improve access to vocational rehabilitation in Dundee. The services provided within this project are aimed at small and medium sized enterprises (of less than 250 employees) and where there is no occupational support available. A specialist VR team has been established and tasked with providing fast-track care and services to employees who may be about to take sick leave. It also supports those who are currently off work and in need of VR services and support, with the goal of allowing them to return to work as soon as is practical. Similar Working Health Services have been introduced into NHS Borders and NHS Lothian. The main focus of these Services are musculo-skeletal disorders and mild to moderate mental health conditions. Additionally, but less frequently, a range of occupational health conditions, including skin, respiratory and audiology present. SCHWL is currently in discussion with Macmillan Cancer Support to develop services to support people with cancer remain in or return to work.

Macmillan Cancer Support: Working through cancer

Macmillan Cancer Support is championing fairer treatment of people affected by cancer in the workplace. Macmillan Cancer Support provides information and support for employees, offering ideas on how to cope at work plus information for when people affected by cancer

are thinking of giving up work. Macmillan Cancer Support also provides information for managers. These initiatives include information and advice for managers to help them deal with an employee (or their close family member) in 'Working through cancer: a guide for managers'. Resources also include a booklet and a DVD. The DVD consists of five different 'workplace' scenarios examining cancer-related issues in the workplace such as 'breaking the news' and 'confidentiality'. Macmillan Cancer Support also provides workplace policies for people affected by cancer and carers for organisations to adopt to ensure that employees get the right support when returning to work after a cancer diagnosis. Macmillan Cancer Support has called for the Department for Work and Pensions to work with them to ensure that Jobcentre Plus employment services are able to cater for the specific needs of people with cancer.

The Macmillan Manchester Research Unit (MMRU) has investigated the impact of cancer on people's working lives in England (Amir et al. 2007). A postal survey was conducted of people with cancer in North and West England from June 2002 through December 2002. Aged between 18 and 55 years, respondents had received a primary diagnosis of cancer and were in paid employment at the time of diagnosis. The study found that the median length of sickness absence was less than 6 months and longer in the most economically deprived quintile. One fifth of those who returned to work reported deterioration in job satisfaction and career prospects. While a high proportion of respondents managed to return to their place of work, 20% were not able to do so. Longer duration of sick leave absence was associated with more difficulties in returning to work. Despite the fact that males were more likely than females to take no sick leave, they were more likely to take longer periods of absence when they did (18 months and over). People on lower incomes were more likely to take longer sick leave. However, those on the lowest incomes were slightly more likely to take no sick leave at all, which might be explained by strong financial pressures to get back to work as soon as possible. Getting back to work soon after treatment was seen as part of re-establishing a normal way of life for the majority of people in the study, or a therapeutic process and this was a strong incentive for them. However, this eagerness to return to work could create problems in going back too soon. Financial pressures were a strong factor in driving people back to work, which is especially important given the extra costs during treatment over a long period (e.g. car parking charges and travel costs). This was more strongly felt by people who had less entitlement to sick pay from their employers, and who were off work for more than twelve months. The next phase of this research programme is to explore the views and experiences of line managers and occupational health practitioners,

with the ultimate aim of developing and testing an effective model for supporting people with cancer to return to work.

Breast Cancer Care

Each year more than 44,000 women are diagnosed with breast cancer, and it is estimated that more than 24,000 of these will be of working age. The impact of managing the side effects of treatment alongside the pressure of work can cause untold anxiety and financial strain to those diagnosed with breast cancer. 422 people replied to Breast Cancer Care's employment questionnaire between February and April 2006 (i.e. after DDA changes) (Breast Cancer Care 2008a). It showed that the majority of people with breast cancer were not aware of their employment rights once diagnosed. 61% of respondents to the charity's survey said they were not aware that the Disability Discrimination Act (DDA) offers specific rights and protection – despite the fact that it was extended in 2005 to give everyone with cancer legal protection from discrimination in the workplace. An on-line poll of 108 respondents in 2008 showed that awareness of employment rights under the DDA was still low, with 68 % not aware of their employment rights under the act.

In June 2008, Breast Cancer Care launched its employment initiative - EMPLOY Charter⁵ – to help breast cancer patients understand their employment rights and to offer guidance for employers on how to support employees diagnosed with the illness. This initiative reflects separate research (Simm et al. 2007) included in the government's recently published Cancer Reform Strategy (Department of Health 2007), that while 80 % of employers are aware of the Act, less than a fifth knows that cancer is classed as a disability.

In addition to research conducted by Macmillan Cancer Support and Breast Cancer Care, there have been only a handful of UK studies that have investigated employment and cancer. In Scotland, a recent qualitative study of people's experiences within the first year following cancer diagnosis (Forbat et al. 2009; Hubbard et al. 2008) highlights that:

- The impact of stopping work during the onset of a life-threatening illness such as cancer can come as a shock to people who have always been in paid employment.
- Health professionals can encourage people with cancer to realise that they

may be able to continue in paid employment despite the illness. They can play a role in allaying the 'guilt' that some people with cancer experience when taking sick leave.

- Alongside physical reasons for not being at work, for example being in pain, people also require time to recuperate and adjust to the life-changing impact of cancer. This is because cancer is more than a disease entity; it is life-changing.
- Some people with cancer imagined how colleagues would relate to them in their current physical state, and cited this as a reason for not wishing to be at work.
- Senior managers and Human Resources influence people's experience of cancer in and out of the workplace. They can facilitate people's access to sick pay through clear communication, signal that the priority is the patient's health and well-being, and ease a successful return to work.
- Work colleagues can relate to people with cancer in a positive manner by explicitly showing that they care about the patient's health and well-being and by helping them to manage the impact of cancer on their ability to do the job.
- Not all people with cancer return to work following a cancer diagnosis. Two main reasons for not returning are that the person is too ill or the person is nearing the age of retirement. Irrespective of the reason, the transition out of work leads individuals to re-negotiate their relationship to paid employment.
- The role that partners play in a patient's care can be restricted unless the partner's employer facilitates this caring role by enabling them to have time away from work. Permitting absence from work to care varies from workplace to workplace and is an area of negotiation because policy and procedures are not always in place or clearly understood.

Other UK cancer-specific studies highlight factors that influence return-to-work decisions, including:

- The importance of workplace support and advice and recognition of how the cancer experience affects the quality of work life and the adaptations required; the importance of improvement in work-related advice from health and social care professionals (Kennedy et al. 2007)
- The increased expenditure and employment impact faced by parents of children with cancer (Eiser 1998; Eiser et al. 2006).
- The significance of a longitudinal perspective. For example, one study (Rogers et al. 2002) highlights poor employment outcomes and quality of life in patients 5-10 years after primary surgery for oral and oropharyngeal squamous cell cancer.

However, there is a lack of systematic and depth evidence about employment and cancer in a UK context and in this review we summarise findings from research conducted in other parts of the world. The evidence was identified and summarised using methods that we describe in the following section. This body of evidence provides intelligence about employment and cancer. However, we are mindful of – and highlight - limitations for generalising about experiences of employment and cancer between countries that have different legal, employment and health and social care systems. There remains a need for more UK based research on employment and cancer, which can be used to inform policy and practice in this area. This review does not report on the relationship between the environment and the workplace as causal factors for cancer. Instead, we summarise evidence about people's experiences of employment following cancer diagnosis.

2. Methods

This report comprises a narrative summary of employment and cancer literature. A narrative summary involves the selection, chronicling and ordering of evidence to produce an account of the evidence and includes commentary or interpretation. As detailed below, this technique can be combined with systematic techniques for the searching and appraisal of the literature (Dixon-Woods 2004). This review was conducted in four stages: searching, screening, data extraction and synthesis.

Searching

Systematic searches of the electronic databases Medline, OVID and MED were conducted in December 2007 and repeated in March 2009 to identify further publications since 2007. The database Medline was chosen for instance, because it is the US National Library of Medicine's premier bibliographic database covering the fields of medicine and nursing. The searches combined the following key-word medical subject headings: cancer, illness, chronic illness; chronic disease; employment, work, occupation; occupational health and rehabilitation. A full list of electronic databases searched and examples of search strategies used can be found in Appendix B.

Screening

Articles about employment and cancer were included in the review if they were written in English language and published from 1984-2009.

Data extraction and analysis

All abstracts were assessed by researchers and selected for review according to inclusion/exclusion criteria and the full texts of these abstracts were retrieved. All selected papers were read by NI and GH. A thematic analytical approach was adopted, which involves identifying prominent or recurrent themes in the literature and summarising the findings

of the different studies under thematic headings. Summary tables providing descriptions of the key points and themes, can then be produced (Mays et al. 2001). For this review, data was extracted from the included studies on methods, sample, demographic and clinical information about study participants, key findings/author conclusions and author recommendations for policy/continuing service development and future research. Data extraction tables can be found in Appendix A. It should be noted that while no detailed and systematic quality assessment was carried out on any of the included studies, commentary has been included below referring to sometimes weak methodological and design criteria.

Synthesis

The studies included in this review were heterogeneous in terms of research design and methodology, sample size and outcome measures. Hence, we have not synthesised the results quantitatively for example, by conducting a meta-analysis. Instead, we present a summary of the evidence in thematic and narrative form.

3. Overview of the evidence

Key points

- 124 articles were found about employment and cancer.
- Whilst the majority of articles studied people with a cancer diagnosis, 16 also reported either directly or indirectly on the experiences of partners.
- 81% of articles were published in 2000 or later.
- Most studies do not incorporate a longitudinal and prospective approach in this field, thereby limiting our understanding of survivorship and more long term employment experiences.
- Few studies had age and sex-matched control groups. Yet, studies using a group of cancer-free referents make it possible to separate cancer specific effects from those resulting from other factors for example, approaching retirement age and thereby control for potential confounders.

124 articles were found about employment and cancer. The type of articles is indicated in the table below:

Table 1: Type of articles

Type of article	Number
Research articles (qualitative and quantitative design)	82
Commentaries (media), journal/magazine reviews/opinion pieces	21
Policy response/initiatives	5
Economic reviews	2
Literature reviews and summaries (non-systematic)	11
Systematic literature reviews	3

Of the 82 research articles reporting study results, most research had been conducted in the United States. 29 were articles published from studies carried out in the United States, 11 articles from studies conducted in the UK, followed by 11 in Canada, 8 in Sweden and 4 in Norway. The remainder explore employment and cancer in New Zealand, Denmark, Netherlands, China, Singapore, Korea and Finland. 29 articles included people with different types of cancer, 41 included only single cancer sites, for example, 20 research articles focused on women with breast cancer. Whilst the majority of articles studied people with a cancer diagnosis, 16 also reported either directly or indirectly on the experiences of partners. 8 studies included a general population-matched control group to compare and explore trends. The studies included in the review were mostly relatively recent, with 81% published in 2000 or later.

Table 2: Date of Publication of the studies (N=124)

Date of publication	Studies N
1985-1994	4
1995-1999	16
2000-2005	40
2005-2009	64

However, few studies pay limited attention to:

- The effect of differing cancer sites
- The effects of differing job types
- The effects of time since diagnosis

A number of studies are weakened by a 'snapshot' approach towards the employment experiences of people affected by cancer. Most studies do not incorporate a longitudinal and prospective approach in this field, thereby limiting our understanding of survivorship and more long term employment experiences. For example, one study (Gudbergsson 2008a; Gudbergsson 2008b) identified that the job strain of cancer survivors did not differ in any work relevant way from the control group in the study. However, the authors noted that fully understanding the job strain of cancer survivors may require a longer follow-up study to confirm findings from the data as experiences may change over time. Likewise, another study (Henley et al. 2005) of women with breast cancer found few women reported a negative work impact. However, the authors acknowledged study limitations, for example, that temporary changes in employment patterns and difficulties close to the time of treatment may not have been captured using a retrospective study design. A disadvantage of retrospective studies that investigate experiences of employment during the longer period of cancer survivorship, is the demands for extended recall over a period of time can be problematic and may skew results (Short et al. 2008).

Research is also often impeded by:

- Weak research designs including lack of validated and standardised measures and a haphazard measurement of work outcomes (Spelten et al. 2003). Many studies continue to use solely descriptive or univariate analysis and lack a strong, theoretical foundation (Myers et al. 1999).
- Stronger studies included a population comparison group. Few studies that we identified (N=8) had age and sex-matched control groups. The information highlighted, therefore, is not compared and matched against general, country-specific population employment trends and patterns.

In short, studies using a group of cancer free referents make it possible to separate cancer specific effects from those resulting from other factors for example, approaching retirement age and thereby control for potential confounders. More longitudinal data, using larger sample sizes and multivariate analysis continues to be required to effectively explore the full

economic and employment burden of cancer alongside the quality of life domains affected by treatment. This approach would ensure that vocational rehabilitation programmes are developed that maximise rehabilitation outcomes.

Through the sections below, we present a narrative summary of the findings of the included studies. The Data Extraction Tables found in Appendix A are sectioned via qualitative research; quantitative research; commentaries; policy responses and initiatives, economic reviews; literature reviews and summaries, systematic reviews and field commentaries. In the sections of this report, we present a narrative synthesis, broken into the following thematic areas:

- Employment status
- Experience in the workplace
- Re-evaluating work
- Partners and carers in the workplace
- Implications for workplace rehabilitation

4. Employment status

Key points

- Employment status changes for some people following cancer diagnosis. Employment status is defined as: being in paid employment or not, leaving paid employment, changing jobs, decline in earnings, and sickness absence.
- Changing employment status following cancer diagnosis varies by clinical (cancer site, time since diagnosis, symptoms) and demographic (occupation, gender, education) factors.

Employment status changes for some people following cancer diagnosis. Employment status is defined as:

- Being in paid employment or not
- Leaving paid employment
- Changing jobs
- Decline in earnings
- Sickness absence

Different studies provide different evidence so it is not possible to present a general figure showing the number of people following cancer diagnosis who leave paid employment,

change jobs or experience a decline in earnings. Instead, we report study findings separately:

Being in paid employment or not

People living with cancer in Finland have a 9% lower probability of being in paid employment than the cancer-free population (Taskila-Abbrandt et al. 2004). A US 1996 telephone poll of 500 people affected by cancer employed at the time of their treatment and 100 co-workers and supervisors of people affected by cancer found that workers with cancer are fired or laid off at five times the rate of other workers (Amgen and Working Women Magazine 1996). The poll also found that 31% of supervisors thought employees affected by cancer should be replaced and 14% of cancer survivors expected their supervisors to have them replaced.

A US 1997 survey of 662 employed adult female and male Americans (not all people affected by cancer) found that 18% believed people being treated for cancer are incapable of working because of the side-effects of treatment; 27% felt they would have to 'pick up the slack' for a co-worker with cancer; 14% felt that a co-worker with cancer could not do their job as well as before they were diagnosed and 42% believed a co-worker with cancer would have special needs and requirements (National Coalition for Cancer Survivorship and Amgen 1997).

Leaving paid employment

One US study identified that 13% of people living with cancer quit working within 4 years of diagnosis and over 50% quit within the first year (Short et al. 2005). This study cautions against focusing solely on immediate return to work and reintegration after treatment because it ignores the experience of those who quit working at a later stage. This underlines the importance of developing both short and long term strategies in the workplace for people living with cancer. Choi (et al. 2007) report 53% lost their job after acute treatment and during the subsequent 24 months of follow up in Korea.

Changing jobs

Thirty-eight percent of people who were diagnosed with cancer when in paid employment changed jobs after cancer treatments in China, mostly due to discomfort caused by

treatment and also changes in appearance and perceived value at work (Liu 2008). Of those who changed jobs, 55% were blue-collar, 28% white-collar and 7% self-employed. In Korea, Choi (et al. 2007) also reports 23% of people with cancer were redeployed or reemployed. The risk of job loss was more common amongst older, less educated, lower income, non-sedentary people with cancer.

Decline in earnings

In one Norwegian study, cancer diagnosis was associated with a 12% decline in earnings overall (Syse et al. 2008). In this study, earnings decline was strongly associated with lower educational level, illustrating an association between education and the impact of cancer on employment. Modifications in employment status were experienced such as reduced work hours or lower-wage jobs.

Sickness absence

People following cancer diagnosis experience sickness absence from work. A 12 month prospective cohort study in the Netherlands (Spelten et al. 2003) revealed that after 6 months 24% had returned to work; after 12 months, 50% had returned to work; after 18 months, 64% of people had returned to work.

Changing employment status following cancer diagnosis varies by clinical and demographic factors. Clinical factors include cancer site, time since diagnosis and symptoms:

Cancer site

Research suggests that employment status varies by cancer site. One Korean study investigating experiences of liver, stomach and colorectal cancer found that people with liver cancer were most likely to lose their job, followed by people with stomach cancer and then people with colorectal cancer. (Choi et al. 2007). Several studies highlight people with lung cancer have difficulty working or are least likely to be employed and experience disruptions in day to day activity compared with other workers without cancer (Sarna 1994; Sarna 1995; Taskila-Abbrandt et al. 2004). Compared with people with other types of cancer, one study (de Boer et al. 2009) found that unemployment was higher in people with breast cancer, as well as people with gastrointestinal cancer and cancers of female reproductive organs compared with blood cancers, testicular cancer and prostate cancer. Compared

with people with other types of cancer, one study (Short et al. 2005; Short et al. 2006; Short et al. 2008) reports that people diagnosed with cancer of the central nervous system, head and neck, and Stage IV blood and lymph malignancies had the highest adjusted risk of disability or quitting work.

Time since diagnosis

Although there is a paucity of evidence, research suggests that employment status changes over time. A US study, interviewed 1433 people with cancer from 1 year to nearly 5 years after diagnosis (Lindsay 2005). One in five people with cancer reported cancer-related disabilities at follow up. A projected 13% of all people with cancer had quit working for cancer-related reasons within 4 years of diagnosis. More than half of them quit working after the first year, when three-quarters of those who stopped for treatment returned to work.

Symptoms

Physical limitation is a significant correlate of not working. In a Finnish study (Taskila et al. 2007a) 26% of people affected by cancer reported that their physical work ability had deteriorated and 19% that their mental ability had deteriorated owing to cancer diagnosis and treatment. Some studies show poor cognitive function and difficulties managing fatigue (Amir 2008; Pryce et al. 2007). In one systematic and univariate analysis (Spelten et al. 2003) fatigue at 6 months predicted a longer sick leave. A further related study (de Boer et al. 2009) indicated that fatigue was only a predictive factor of return-to-work in the univariate analysis but not in the more recent study adopting multivariate analysis, which included work ability. In this study, work ability and fatigue were correlated. Other studies have also found that fatigue influences conditions of employment and productiveness (Hoffman 2007) underlining the need for strategies in place to enable employers and employees to best manage cancer-related fatigue in the workplace. Conditions and contracts of employment, alongside the physical limitations experienced directly in the workplace must be successfully managed. For people affected by cancer, successfully managing the physical symptoms of illness and treatment alongside work is not an easy task and one which is aided by good workplace support. A study of people with head and neck cancer (Terrell et al. 1998) found difficulties of fatigue, speech difficulties and disfigurement, all of which potentially interfere with ability to work and require specific work-based solutions to minimize impact. 34% of people with head and neck cancer ceased working as a result

of disability.

Demographic factors that impact on employment status include type of occupation, gender, and education.

Occupation

Research suggests that blue-collar and lower paid workers are more likely to change employment status following cancer diagnosis. One Korean study (Choi et al. 2007) highlights 35.8% of employed patients changed jobs after cancer treatments, mostly due to discomfort caused by treatment and also changes in appearance and perceived value at work. Of those who changed jobs, 55.5% were blue-collar, 28% white-collar and 7% self-employed. One study (Drolet et al. 2005a) notes that female blue-collar union members in Canada were more likely to take time off compared to non-blue-collar union members. Similarly, Choi (et2007) highlights the risk of job loss was more common amongst older, less educated, lower-income and those in non-sedentary occupations in Korea. Bouknight (2006) highlights the combination of lower annual income, lower educational attainment and blue-collar work are strong factors influencing a lower likelihood of a return to work after cancer in the US. In a breast cancer study (Lauzier et al. 2008), 90% of women with breast cancer in Canada had relatively long full-time absence from work, resulting in a major source of wage loss. These women were more likely to be lower educated, self-employed, with shorter job tenure and/or part-time working status, thereby increasing employment impact.

Gender

There are few studies that have examined the relationship between gender and employment for people with cancer. In the UK, (Amir et al. 2007) found that males were less likely to take sick leave than females but when they did, they took longer periods of absence.

Education

In a Finnish study (Taskila et al. 2006), those with higher educational attainment received more support from Occupational Health. However, it was those with less education and lower occupational status that had the greater need for support. Likewise, (Syse) (et al. 2008) reports earning decline as strongly associated with educational level in Norway.

This study highlights the negative experiences of those with less education and holding lower-waged jobs, illustrating a social class gradient within experiences of cancer and employment that must be addressed.

5. Experience in the workplace

Key points

- While some workplace experiences following cancer diagnosis can be positive, many people report negative experiences. These include denial of promotion; fear of dismissal; employer reprisal and actual dismissal, a reduction in previous work role, 'smothering' by co-workers, accompanied by hostility, mimicry, jokes and snide remarks.
- The need for both employer and co-worker education and support remains paramount.

Few studies have explored people's experiences within the workplace. Of the handful that did, many changes reported by people with cancer about their employment experiences are negative. People with cancer report: the denial of promotion, fear of dismissal, employer reprisal and actual dismissal (Geddes 1995; Main et al. 2005; Schultz et al. 2002) A 2002 US study (Schultz et al. 2002) of 4364 long term cancer survivors (living and diagnosed with cancer for at least 5 years and aged 18-63 years) found that 7.3% of cancer survivors experienced job discrimination and 10% indicated they had been fired or forced to quit. Other people affected by cancer have reported a reduction in previous work role for example, less assignments (Geddes 1995; Stewart 2001). Stewart (2001) reports that participants in this study identified that disclosure sometimes results in negative work and insurance experiences.

Muzzin (1994) explored how stigma affects social participation in the workplace in Canada, revealing how a number of respondents described 'smothering' by co-workers, accompanied by hostility, mimicry, jokes and snide remarks. Significantly, employers and co-workers often equate a cancer diagnosis with decreased ability or death (Messner et al. 2001). Highlighting the workplace experiences of people affected by cancer illustrates the importance of workplace education about cancer and the importance of workplace support.

6. Re-evaluating Work

Key points

- The experience of cancer often effects a re-prioritisation in life and may undermine identity and normalcy.
- The importance of work may often be re-evaluated.
- While work can sometimes be devalued, emphasis is often placed on the benefits of the working experience.

Only a few studies explored the relationship between cancer, employment and identity. Work identity is important to self-concept and self-esteem. While survival rates are increasing, cancer remains a life-threatening illness that encourages individuals to reassess the basis of their identity. According to Peteet (Peteet 2000), unanticipated changes in employment can trigger a disturbing exacerbation of this process, undermining identity and normalcy.

People affected by cancer may re-evaluate their relationship to work and question its priority, worth and relevance against the resultant stress of ill-health. In one Canadian study (Stewart 2001), over 40% felt cancer had altered their priorities at work. In another Canadian study some people affected by cancer described re-prioritising life, reducing the significance of work and underling the positive benefits of leaving work (Drolet et al. 2005b).

In Amir's study (2008), forty-one people of working age were purposively selected from the North Western Cancer Intelligence service and interviewed by telephone to describe their experiences returning to work following diagnosis and treatment. The results indicated the importance of return to work from diagnosis and through treatment which was then followed by a reassessment of work-life balance when people recovered from primary treatment and were back in employment. A quest for normality and financial pressures combined to form the principle motivation to get back to work.

Work can also be considered as part of the therapeutic healing process; as relief of boredom and distraction and as providing a source of focus, energy, structure routine and social support and as reaffirming a sense of achievement and personal validation (Ferrel et al. 2003; Forbat et al. 2009).

7. Partners and carers in the workplace

Key points

- Work often has to be juggled with care. Demographic changes mean that 3 in 5 people will become carers at some stage in their lives.
- The peak age for caring is 45-64; so many working carers will have significant skills and experience, which may be lost to a workplace unless they are supported.
- Substantial care needs create economic and psychosocial burdens.
- Many carers of people affected by cancer face indirect work costs such as job loss and payment for carer support.

Most of the articles that we found focus primarily on the experiences of people affected by cancer in the workplace. However, the significance of caring for someone affected by cancer was a factor present in some of the articles. The impact of caring for a person affected by cancer can often be neglected as a primary focus within the literature yet substantial care needs create economic and psychosocial burdens and additional care and rehabilitation services may be required (Emanuel et al. 2000). Caring also has a significant impact in the workplace and takes a prominent place in this review to highlight carers' employment impact and requirements for workplace support.

In general, combining paid work and caring can be stressful. Caring has an impact on absenteeism and a large number of carers give up work to care. Many other carers have

to combine caring with employment, exposing the vulnerability of the working family caregiver (Burns et al. 2004). Given demographic concerns over an ageing population, the demand for formal and informal care may increase and generate further support requirements (Arksey et al. 2008).

A further more general picture of the demands upon carers has been highlighted throughout the 2009 Carers Week (Carers Week 2009). The results of the 2008 Carers Week survey of 1,997 carers throughout the UK highlights the effects that caring can have, especially regarding health, relationships, career and finances. 3 out of 5 (60%) of carers who are also in paid employment said they have used part of their annual leave simply to allow them to devote more time to their role as carer. One fifth of those questioned (67%) said they had used more than 10 days of their holiday allocation to provide further care.

Focusing directly on the impact of caring for partners and carers of someone affected by cancer, a longitudinal observational study (Burns et al. 2004) explored levels of knowledge and support awareness. Carers gave an average of between 10 – 30 hours caring on a monthly basis. This study concluded carers were less aware of available health and community support services and had little knowledge of support available.

A New Zealand study (McKechnie et al. 2007) explores the dying experience and sense of uncertainty for people affected by cancer. In terms of their roles and responsibilities in relation to employment, all the people affected by cancer in this study had to resign from their jobs sooner than expected due to the effects the treatment regime was having on them. For carers and partners, many had to change jobs or take leave to be available to take over household responsibilities. Through the collation of economic data examining the costs of toxicity among a cohort of women receiving chemotherapy for ovarian cancer, Calhoun (et al. 2001) illustrate the indirect work costs that many carers must negotiate, including work loss and payment for carer support.

Preliminary results from an ongoing three-year study, which is being conducted by the Gender, Culture and Health Research Unit at the University of Western Sydney (McKewen 2006) and co-funded by the Australian Research Council and Cancer Council NSW, show that female carers of people with cancer experience higher rates of distress, have more unmet needs and a greater burden of care than males. The majority of female carers who took part in the study gave accounts of being positioned by others, or by themselves, as natural

all encompassing expert carers with an unquestioned competence and little instruction or support. This resulted in experiences of over-responsibility and self-sacrifice. Women reported having no freedom and no time for themselves with the caring role taking up 24 hours a day, seven days a week and requiring their own self care to be sacrificed. Women also revealed they often felt isolated and were expected to cope on their own, often combining both caring and work requirements and faced the risk of greater emotional distress amid increased care demands.

Rose (1998) in an earlier UK study of the experiences of carers of terminally ill people with cancer, concluded that health and social care professionals must work with the family unit living through cancer to provide suitable help and support. The competing demands faced by carers of people affected by cancer underlines the need for information, home respite, employment advice, financial assistance and emotional and occupational support (Verbeek et al. 2003) to support carers and partners of people affected by cancer to manage these competing demands. In relation to employment support, this can include, for example, offering flexible working; special leave options; line manager and team member support; access to relevant information and advice; confidential support and work buddies (Macmillan Cancer Support 2009)

8. Implications for workplace rehabilitation

Key points

Implications for work rehabilitation include:

- Educating employers and co-workers about the realities of people affected by cancer and how well they can perform in the workplace.
- Partnership working and communication amongst health and social care professionals to increase professional knowledge of work-related difficulties.
- Continuing education for people affected by cancer concerning workplace exit as well as workplace re-entry.
- The related development of effective workplace planning, including systematic return-to-work plans and flexible working arrangements.

In 1999, a Canadian Study (Maunsell et al. 1999) explored experiences of women who had returned to work after experiencing breast cancer. This study highlighted both old and new areas of concern, illuminating the slow pace of change in this field. Many of the same difficulties experienced by people with cancer in the past, are still prevalent today.

This systematic review of literature up to 2009 also highlights similar areas of concern. However, in the UK, moves forward are being made. The Black Report, published in 2008, highlights the need to change perceptions of fitness for work, concurrently tackling the stigma around ill-health and disability, encouraging employers to work alongside the report to change the nature of the workplace in Britain.

In a recent UK study, significant return-to-work barriers continue to be highlighted (Amir 2008) and the importance of developing joint-working across all sectors is underlined. A

questionnaire exploring opinions of Occupational Health Professionals (OHPs) regarding supporting people affected by cancer back to work was posted to all members of the UK Society of Occupational Medicine (Amir 2008). Responses suggested the need to institute information resources on cancer and work for OHPs and developing communication skills training. Most respondents (n=797) felt managers treated referral to occupational health differently for employees with cancer compared with management referral for employees with other diagnoses, with 45% of respondents indicating that referral may take place too late to be effective in securing a return to work. A significant lack of understanding of the information requirements of employers and the role of occupational health by treating doctors was identified. From this study alone, significant issues are identified in relation to the experience of cancer and work place return.

Several of the articles that we found offer recommendations for service provision and workplace rehabilitation. These are summarised under the following categories: Education and Communication and Workplace planning: vocational rehabilitation.

Education and Communication

The importance of educating employers, employees and co-workers about the realities of how well people affected by cancer generally perform and the productivity of people affected by cancer, both during and after acute treatment (Schultz et al. 2002) is prominent in the literature. Further, the literature also highlights a lack of awareness of the impact of different cancer sites and related interference with ability to work (de Boer et al. 2009; Short et al. 2008). Employers should be aware of the differing and sometimes more acute needs immediately after return to work (Bradley 2006).

The need for further education for social and health care professionals in relation to the employment needs and requirements of people affected by cancer is highlighted. Clinicians should consider and enquire about the economic well-being of the individual with cancer and have direct input into the establishment of rehabilitation plans, making workplace well-being a primary focus of treatment and recovery (Chirikos et al. 2002b). This requires extended health and social care professional knowledge of work-related difficulties and employment regulations alongside increased referral to psychosocial clinicians (Petee 2000).

Continuing education and preparation for people affected by cancer should include preparation for workplace exit, as well as workplace re-entry (Bradley 2006). Social and healthcare professionals should provide more continuity of care and be aware of the extent of the negative effect on wage losses and on families and this should be explicitly discussed early in the treatment programme (Lauzier et al. 2008; Verbeek et al. 2003).

Enhanced education in workplace settings for both employers and co-workers creates a supportive work environment, leading to better communication and strong employer-employee relationships (Bouknight 2006). A Finnish study (Taskila-Abbrandt et al. 2004) found that co-worker support reduced the risk of impaired work ability, particularly amongst women. Education and communication are necessarily related to the development of effective workplace planning and support for people affected by cancer and would include, for example, information regarding patients' physical capacities and the daily demands likely to be faced once the patient returns to work (Satariano et al. 1996) and career education and counselling for people affected by cancer (Schultz et al. 2002).

Workplace Planning: vocational rehabilitation

The lack of effective 'return to work' plans, including timely and appropriate advice from both employers and health and social care professionals (Spelten et al. 2003) is a strong finding within this review. A number of articles illustrated that the lack of effective workplace planning increases worker reluctance to request or apply for work adjustments (Allen et al. 2003; Amir et al. 2007; Amir 2008; Baanders et al. 2001).

While no firm suggestions for the development of specific delivery models are outlined, clear recommendations are made. A number of commentators argue there is a need for support services to work with people affected by cancer and health providers together to establish a health workplace (Bradley 2006; Nachreiner et al. 2007) and more systematic 'return to work' schemes (Taskila et al. 2007a). For example, flexible working arrangements should be supported by clinicians (Chirikos et al. 2002b; Chirikos et al. 2002a) and employers should make the required adjustments. Job flexibility (Nachreiner et al. 2007) could also include, for example, a partial (initial) return to work to help those with reduced ability to stay in physically demanding occupations (Josephson et al. 2008).

Patient perceptions of work can change after illness. If vocational rehabilitation is to be successful, then changing these perceptions needs to be included in planning occupational rehabilitation (Marhold et al. 2002; Maunsell et al. 1999; Maunsell et al. 2004). To achieve this success, vocational rehabilitation schemes and programmes must be multi-disciplinary enough to offer the required support (Taskila et al. 2006), underlining the importance of partnership working between health services and local authorities and the integration of health and social services required to foster effective employment practice.

9. Conclusions

For this narrative summary, 124 studies were located. These included qualitative and quantitative research articles; economic reviews; non-systematic literature reviews and summaries; systematic reviews; policy responses/initiatives and commentaries, media reviews and opinion pieces. These articles covered a wide range of contexts and populations in relation to employment and cancer.

This narrative summary represents the selection, chronicling and ordering of evidence to produce an account of the evidence and includes commentary and interpretation, a technique that can be successfully combined with systematic techniques for the searching and appraisal of the literature (Dixon-Woods 2004). Given the heterogeneity in terms of contexts, populations, outcome measures and tools, follow-up times and data analysis methods, this narrative summary can only be provisional and advisory in nature. We remain mindful of the limitations generalising about experiences of employment and cancer between countries that have different legal, employment and health and social care systems.

However, this is both a limitation and strength of this summary. This is one of the few studies to review and summarise in detail the experience of people affected by cancer returning to work. While the studies reviewed are heterogeneous in nature, this is also beneficial. This study highlights similar findings across countries and confirms earlier research illustrating the difficulties of negotiating financial pressures to return to work, little or poorly effective social and healthcare professional advice and the subsequent difficulties faced in returning to the workforce itself. One limitation of this study is the missing views of those people

who did not return to work after diagnosis. Two main reasons for not returning to work are that the person is too ill or the person is nearing retirement. Irrespective of the reason, the transition out of work leads individuals to renegotiate their relationship to paid employment. Further research in this field would enhance our understanding of the difficulties returning to employment for people affected by cancer.

This summary highlights that, despite changes in the law and wider initiatives aimed at protecting workers affected by cancer from unfair treatment, employers are still discriminating against people with cancer rather than making the necessary adjustments that could keep them well supported in work.

This summary acknowledges the changing employment status for some people following cancer diagnosis and how this is variable by clinical and demographic factors. While some workplace experiences may be positive following cancer diagnosis, many are negative, highlighting the need for increased employer and co-worker education. People affected by cancer may re-evaluate their relationship to work and question its priority, worth and relevance. Effective support in the workplace remains paramount for successful transition and workplace rehabilitation.

While we have focused primarily on the experiences of people affected by cancer in the workplace, this summary also illustrates the substantial care needs of people affected by cancer and the economic and psychosocial burdens upon partners and carers. Many carers and partners of people affected by cancer must manage competing demands and may also require flexible employment support.

Improvement in the rate of return to work after cancer is likely to require improvement and change across a number of critical areas. Partnership working between local authorities and health boards remains central as does multidisciplinary support and knowledge sharing between health and social care professionals. For example, clarification of the clinical role in work related advice is yet to become clear. Workplace well-being should also be a primary focus of treatment and recovery. We summarise the recommendations for service provision and rehabilitation under the following categories: Education and Communication and Workplace Planning. Effective education, for employees affected by cancer, their co-workers

and employers creates a more effective and supportive environment and one that begins to alleviate the difficulties faced returning to work. Effective education ensures effective workplace planning and builds a framework of support within the working environment. If workplace planning is to be effective vocational rehabilitations schemes and programmes must be multi-disciplinary enough to offer the required support. An effective framework of support must lead to successful workplace rehabilitation. There is legislation, policy and guidance; what we need is implementation.

Appendix A : Review Tables

Data Extraction Tables

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
Qualitative				
(Allen et al. 2003) AUS	Individual in-depth interviews; n=13 (1 cancer)	Exploring transition from health to illness and illness disclosure in workplace	In general ill-health concealment frequently and spontaneously used in the workplace. Despite Disability Legislation, discrimination in employment remains a real concern for people with a disability.	Vocational rehabilitation professionals required to provide a return-to-work plan; developing a disclosure plan; empowering social skills training helping clients deal with employers
(Arksey et al. 2008) UK	Qualitative interviews n= 80 carers (purposive sampling) with >20hrs caring per week.	Exploring carers' decision-making around work and care	Population ageing is a global phenomenon and may lead to increased demands for formal and informal care.	Support requirements for increased formal and informal care demands
(Brobäck et al. 2003) SWE	Phenomenological, qualitative interviews (25-60 minutes) n=6 carers	Exploring next of kin experience palliative care of relatives at home;	Broader focus on palliative care but raises employment issues for next of kin/carers. Feelings of insufficiency and uncertainty; lack of control.	Support services/initiatives should extend provision to include next of kin: information; teaching specific skills and techniques; increasing personal empowerment.
(Carpenter et al. 1999) USA	Qualitative, semi-structured interviews; age 35+. First time breast cancer diagnosis; disease free at least 2 months after end primary treatment; <55 months post diagnosis	Describing differences in self-transformation among breast cancer survivors; associated factors and relationship to self-esteem and well-being.	Positive transformation began with increased self-awareness; Breast cancer 'sparked a coming of age' leading to life review; new life understanding used to make changes in lives, such as relationships to work.	n/a
(Ferrel et al. 2003) USA	Ethnographic qualitative examination of correspondence to newsletter by women with ovarian cancer 1994 – 2000; n=74 (21,806 letters cards and emails)	Exploring needs and social well-being of women with ovarian cancer.	Significant number reported having to take time off work due to treatments; expressed urgency to return to work quickly; return to work = regaining normalcy, validation, sense of achievement, return to role as employee, reducing economic burden	HCPs should address social issues that affect women with ovarian cancer throughout the disease trajectory as these significantly impact QOL.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Geddes 1995) USA	Case study to illustrate policies that support US Disability Act of 1990. n=1 female employee >50yrs	Exploring employee difficulties faced when rescheduling work to facilitate medical care	Patient had to stay in work (health insurance); age an issue (>50 in tight job market); poor employer attitude; fear of reprisals; lesser assignments, less stimulating work; high cost of litigation; abandonment by friends, colleagues; innuendos by management and others; negative impact on career; physical impact of stress.	"...no laws against bad management" Highlights legal questions concerning employee/supervisor/ employer legal and moral responsibilities.
(Kennedy et al. 2007) UK	Qualitative (interviews and focus groups) n=19 Mean age 52.6 years	Exploring factors that influence return to work decisions and how the cancer experience affects the individual's quality of work life.	Factors influencing return to work: financial; normality/distraction/ social network/emotional health; responsibility/loyalty; health professional advice (when discussed). Experience of work: concerns about reduced capability; expectation from employers – no long term understanding; ongoing appointments; job changing; dealing with physical effects and work impact; Support at work: minority negative reactions and support; support changing over time. Poor adjustment strategies in place Attitudes about work: changed; re-evaluation; questioning relevance; less ambitious; resisting stress; 2/3 respondents experienced financial problems; little health professional advice re work issues; many could return to work but some difficulty adjusting to changed performance; minority negative; wide diversity re capacity to offer flexible arrangements; some employers unaware of services and support available.	Need for support, advice and accommodations from various directions: improvement in work-related advice and information from HCPs; employers to provide reasonable support and accommodation.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Lauzier et al. 2005) CAN	Purposive sample; n=26 female non-metastatic cancer and primary carers; thematic content analysis of focus groups (3 x patients, 3 x carers)	Exploring economic burden of breast cancer from perspective of women and their carers	Costs due in part to no pay insurance: patient's wage losses affect whole family finances: some patients stopped work permanently or reduced hours. Increased worry. All patients stopped work completely once or twice for 2 days to > 1 y. Length of absence and working conditions (e.g. insurance, sick leave) seen as 2 factors contributing most to extent of wage losses. Some patients used paid sick leave, annual leave, accumulated overtime or promised to pay back time by working unpaid later. Self-employed had to use savings; No insurance led to continued working despite ill-health; unrecoverable wage losses; use of personal savings. Carers: no wage losses but paid sick leave and loss of annual leave.	Economic dimensions of cancer may contribute to the global burden of disease.
(Main et al. 2005) USA	Qualitative interview n=28, 21-66 yrs; 12 stratification groups, diagnosed within previous 24-36 months	Quality of work life; factors influencing decisions about work	Diverse patterns of work return and work change. Work influences: financial; feeling fit; positive, healthy distraction; accomplishment and self-worth; fear of sacking; minority HCP advice; family/friends encouragement; social support. Employer accommodation: many supportive (flexible working). Treatment effects: fatigue; mental and cognitive health; work and emotions; changing motivations; increased tolerance; adjustment and stress avoidance; work an important contributor to QoL; added sense of meaning and accomplishment at a time when cancer made meaning important; importance of distraction.	Acknowledging complexity (different cancer diagnoses) of measuring employment outcomes and range of adaptations made to improve quality of work life. Additional research needed to identify prognostic factors that can guide clinical or workplace efforts to restore cancer survivors to their desired level of work function and economic productivity.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Mathieson et al. 1995) CAN	Purposive sampling various cancer sites and stages; n=27 (11 male, 26 female) mean age 47.5 – 26-77 years, 6-60 months post diagnosis) interviews followed by 10 2nd interviews exploring questions arising. Grounded theory; semi-structured interviews/ narratives/ self descriptions	To frame living with cancer in context of identity-alteration	Employment problems: identity threat.	Importance of understanding identity. Identity is discovered over time: in illness it is bounded by bodily and social limitations.
(Maunsell et al. 1999) CAN	Qualitative Unstructured thematic interviews; n=13 breast cancer survivors in paid employment at diagnosis and returned to work; variable socio-demographic and medical characteristics	Exploring work experience after breast cancer	Health professionals not discussing employment-related issues: apprehension returning to work – fear of job loss/change; /less input/disappointing colleagues; unwanted changes after treatment e.g. demotion, task modifications, poorer relationships; employer doubting capacity/ability; physical impact/capacity for work decreased; new areas of concern: health professionals telephoning at work; underlined importance of period around the end of sick leave and return to work : need for support; dealing with ongoing physical impact; women: changed attitude to work.	Slow pace/lack of change. Recurrent problems being identified and akin to problems underlined 20 years previously
(McGrath et al. 1999) AUS	Qualitative structured in depth interviews (media self-selected)with n=24 women with breast cancer and service providers	Post-diagnosis support needs of women with breast cancer in remotest and rural Queensland to evaluate service gaps	Return to work: therapeutic measure. Majority non-supportive workplace, sometimes non-supportive colleagues; work relationships dwindled as employment ceased (n=2); Impact in rural communities.	Need innovative solutions to problems faced by rural cancer sufferers.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(McKechnie et al. 2007) NZL	Phenomenological, thematic and interpretive analysis. Semi-structured face-to-face interviews n=7 women with terminal cancer 6 months – 4 years post-diagnosis	Exploring narratives of lived experience of palliative care, images of embodiment and the ways these might inform those involved in palliative care	Patients left jobs early due to nature of treatment, unpredictability of symptoms; changed household roles and responsibilities. Approach of 'social death' as they withdrew from employment and social responsibilities;	n/a
(Rasmussen et al. 2008) DEN	Ethnographic study : participant observation and interviews; purposive sample 23 cancer survivors (10 male, 13 female) interviewed after stay in cancer rehabilitation centre and 18 months later (2 deceased, n=11).	Analysing the meaning of paid work/working life for cancer survivors of various diagnoses and changes in this meaning over time.	Return/attempt to return to work seen as process that starts when patients leave work at cancer diagnosis or treatment. Long process. Work regarded as natural part of everyday-life-structures, creates order/normality/satisfaction. Inability to work leads to loss of identity (disruption). Most see work as a goal, part of identity. Side effects affect work psychologically and physically. If unable to work, finding activities that recreate a structured everyday, makes the self feel valued and significant, creates a new identity; 3 themes emerged: (1) disruption of work and working life, (2) re-establishing work and working life, (3) everyday-life without work and working life. Biographical disruption - cancer means a final disruption re work, patients need to create a recognisable everyday-life after this disruption.	Further research exploring the processes of both returning and not returning to work; explore the interaction between psychological and physical symptoms.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Reynolds et al. 2006) UK	Interpretative phenomenological analysis of 1–2 hour interviews. 3 case studies, 2 female breast cancer, 1 male stomach and lung cancer; age 47-59yrs; white; postgraduate education	Understanding why some people with cancer take up art as a leisure activity; how it might support identity maintenance and reconstruction in daily life.	Positive identity through engaging in art as leisure activity; strengthens personal and social identity, helps resist being dominated by cancer label, promotes relationships; prove oneself, take up new challenges. Importance of meaningful activity as well as cognitive and emotional support; powerful role in maintaining familiar, positive personal and social identities in cancer (e.g. links to previous employed identity as teacher), and providing a coping resource.	Implications for professionals working with cancer patients: counselling and support: explore personally meaningful activities to maintain/ develop positive identity and provide coping resource
(Rose 1998) UK	Phenomenological descriptive analysis - unstructured interviews/ telephone conversation/written statement. N=21 carers of cancer patients with poor prognosis or deceased/other	Describe, analyse and interpret experiences of informal carers of terminally ill cancer patients related to time	Many carers combine caring and employment. Hidden demands on employed carer's time and coping skills: high stress. Employed carers need help to plan their time effectively, come to terms with own perceptions about past, present and future.	HCPs working with families living through terminal illness need to assess each family individually and provide suitable help and support.
(Swanberg 2006) USA	Semi structured interviews n=30 informal caregivers, content analysis	Identifying workplace factors that inhibit or facilitate ability of informal carers of cancer patients to provide care	Job demands have direct impact on carers' capacity to care. Cancer = complex and changeable needs. Changing day to day status: stress, ambiguity. More information required re courses of care-giving for carers; Social service agencies could assist carers negotiate the demands of work and home.	More carer-directed services required, for example, courses in care-giving for carers.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Winterling et al. 2004) SWE	Phenomenographic interviews n=14 patients (7 male, 7 female, age 52-80 years, recently diagnosed with advanced gastrointestinal cancer and their partners 43-83 yrs (interviewed separately)	Describing perceptions of changes in life in patients recently diagnosed with an advanced gastrointestinal cancer and in their spouses.	Negative physical/psychological impact: despair and uncertainty. Household role change. Several ways of coping including "one shouldn't complain" (patients) and hope (spouses). Other coping mechanisms: reconciliation, avoidance, preparation for death, seeking support and isolation. There are differences in way patients and spouses experience similar substantial changes in lives close to diagnosis of an advanced cancer	HCPs have responsibility to create atmosphere where patients and carers can express despair, existential concerns, discuss symptoms and prognosis to lessen uncertainty
Quantitative				
(Amir et al. 2007) UK	Postal survey all cancer patients registered NW England June 2002-December 2002; age 18-55; primary diagnosis of cancer and paid employment. N=267; response rate 50%	Evaluating return to paid work after cancer in England.	20% respondents not able to return to work; duration of sick leave absence associated with most difficulties in returning to work; males more likely than females to take no sick leave, but likely to take longer sick leave (≥ 18 months) when they did; length of sick leave greatest in most economically deprived group and in those survivors of cancer diagnosis and treatment who did not receive surgery.	Incidence of cancer is age-related, resulting in a vulnerable group of older people with non-professional occupations. Can assume return to work for this group is more difficult and less successful than previously reported. Research required: if return to work is a goal, legal protection and employer practices and procedures must be improved

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Arrossi et al. 2007) ARG	Cross-sectional survey n=120 new cervical cancer patients	Measuring socio-economic impact of cervical cancer borne by patients and families	45% households reported reduction in work hours; 28% reported work disruption; 39% reported loss of family income; 37% reported reduction in food consumption; in 28% households children missed school days; Socio-economic impact considerable and negative consequences on treatment compliance. Effective social support systems for cancer patients should be implemented. For almost half patients, at least two households were involved in arrangements to provide caregiving and face socio-economic impact of the disease.	Burden of cancer not restricted to the individual – disease effects borne by the close social network: 'Medical poverty trap'. Action needed to minimise impact of disease on patients and families. Mechanisms required to protect patients from loss of income; increase social protection.
(Baanders et al. 2001) NDR	Longitudinal panel study postal questionnaires and follow up response. 1998-2000; recruitment via 56 general practices >15, diagnosed with long-lasting or non-curable illness. N=2487 start, ending with n=65 <65 yrs and employed	Quantifying the presence of work adjustments among chronically ill workers	Chronically ill may not be fully aware of possibilities and/or procedures of applying for work adjustments. Need for more adequate information, e.g. job counsellors. Due to negative image of illness, workers may be reluctant to request adjustment. Limited presence of work adjustments may also be attributable to employer negligence. Information should be particularly directed at older workers with lower or vocational education, with physically demanding jobs and frequent hindrance from their symptoms, who encounter problems at work owing to physical disabilities, concentration deficits and transportation problems.	Dutch policy priority given to workplace adjustments but study reveals only used by limited number of working persons with chronic illness; need further implementation of work adjustments and encouraging working people to make use of these adjustments. Also limited take-up of workplace adjustments may be due to employer negligence. Policy need to develop disease-generic measures.
(Bergman 1987) SWE	3 prospective randomized chemotherapeutic trials (also referred to as retrospective). N=91 70yrs and under	Estimating what proportion of SCLC patients regain ability to work during or after chemotherapy, duration of working periods and factors influencing vocational rehabilitation	Stage of disease at diagnosis significantly correlated with return to work. Easier to return to 'light' work than 'heavy'.	n/a

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(Boman et al. 2004) SWE	Cross-sectional case control. N=30 young adult survivors of childhood cancer compared with control and general population norms	Evaluating long-term social effect of illness and its treatment on young adult cancer survivors	Social, vocational and educational adjustment of relapse-free survivors appears moderately, if at all, negatively affected by illness and treatment history. However, treatment intensity and particularly survivors coping with their illness experience may influence ability to achieve long-term social goals; Tendencies include: delayed autonomy in relation to their family; tendency for less frequently entering or later entry into long-term partner relationships; relative hesitation in adopting plans for future; tendency to months seldom proceed to higher education.	Special attention should be given to matters concerning education and partner relationships at long-term follow up of paediatric cancer patients.
(Bouknight 2006) USA	Telephone interviews 12 and 18 months after diagnosis, prospective, longitudinal study. N=416 employed women, 30-64yrs, employed.	Identifying correlates of return to work for employed breast cancer survivors: focus on employers role	Factors influencing lower likelihood of return to work: lower annual income, lower educational attainment, blue-collar, advanced tumour state, heavy lifting required, perceived employer discrimination. College graduation, sick leave, white-collar, perceived employer accommodation increases likelihood of work return; Employers have pivotal role in breast cancer patients' successful return to work. Perceived willingness of employer to accommodate workers' illness and treatment needs is important factor in work return. Women reporting work discrimination significantly less likely to return to work at 12 months. Older patients less likely to return to work at 18 months.	A supportive work environment facilitates a return to work. Further research required to assess patient and employer understanding of workplace accommodation and to assess accuracy of patient reports.

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(Bradley et al. 2002) (2 x 2002 studies) USA	1992 Health and Retirement Study; probit regression; cohort interviewed 51-61	Effect of breast cancer on women's labour supply	Probability of breast cancer survivors working is 10 percentage points less than for women without cancer. Among women who work, breast cancer survivors work approximately three more hours per week than women who do not have cancer. No evidence results attributable to selection bias; For some women, breast cancer = economic hardship due to leaving employment. For women who survive and remain working, study failed to show a negative effect on hours of work associated with breast cancer. Possibility morbidity associated with certain types and stages of breast cancer and its treatment does not interfere with work.	n/a
(Bradley et al. 2005a) USA	Structured telephone interview (patients); longitudinal cohort study; n=445 30-64 yrs	Examining consequences of breast cancer for women's labour market participation through 6 months post-diagnosis	Average weekly working reduced by up to 7-18hr (18%-28%) dependent on cancer type/staging; Women with local stage cancer were 24 percentage points less likely to be employed 6 months on; women with regional/distant stage cancer 39 percentage points less likely to be employed 6 months on; results twice as strong for African-American women.	Need for preparation for some level of economic loss and to increase awareness amongst cancer patients that employers are required to accommodate

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(Bradley 2006) USA	Telephone interview (paid) 6 months post diagnosis; n=444 female, n=267 male, 30-64 years breast or prostate cancer	To better understand how cancer treatment affects patient's employment – e.g. number of days missed work	52% of patients who received chemo quit work. Of rest, average days missed (44.5) for breast cancer patients increased with progressive cancer severity; likewise prostate (27). Leaves of absence statistically significant. During months following treatment, patients need on average one full month away from work. Those in poor health quit work altogether and therefore excluded from sample.	Need for cancer specific Vocational Rehabilitation Programs aimed at minimising impact of treatment. Health professional skills development – awareness of employment impact may also benefit patients and their physicians deciding between different treatment options
(Bradley et al. 2005b) USA	Prospective, population-based, longitudinal cohort study	Exploring how prostate cancer and treatment affect men's employment status	10% less likely to be working 6 months after diagnosis. At 12 months post diagnosis, likelihood of employment not significantly different. Some patients reported that cancer and its treatment interfered with their ability to perform physical and cognitive tasks (26%); Despite return to work rates, 6-12 month absence from work may cause serious financial burden. Those remaining employed after 12 months were not able to perform specific job tasks because they had been treated for cancer. Early detection and treatment has positive implications for mortality, but may inflict morbidity at least in months after treatment – that will interfere with patients' ability to work. Patients need to be aware of this and potential work disruption within first 12 months, alongside awareness that after 12 months situation will improve.	The impact of prostate cancer treatment on patients' ability to work can be incorporated into patient and physician decisions regarding treatment.

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(Buckwalter et al. 2007) USA	Prospective, observational outcomes study; N=666 patients with carcinomas of the head and neck, between 1998-2004	Evaluating patients' reported reasons for discontinuing employment following treatment for head and neck cancer	38.1% discontinued work because of their cancer and treatment. 90.1% of these rated fatigue as the highest contributing factor; followed by speech difficulties; eating, pain or discomfort and appearance. 40.7% of patients who discontinued work returned to work within 1 yr of treatment; Identifying factors (fatigue, speech difficulties. Eating, pain or discomfort and appearance) associated with the decision to discontinue work is a first step in providing focused solutions to minimize disability. Fatigue, for example, may be more amenable to early intervention and other deficits may respond well to treatment.	Identifying factors (fatigue, speech difficulties. Eating, pain or discomfort and appearance) associated with the decision to discontinue work is a first step in providing focused solutions to minimize disability.
(Burns et al. 2004) AUS	Longitudinal, observational study, 1996-2003; Matched sample 129 patient-carer pairs where both completed baseline questionnaire and 87 pairs who completed the follow-up at week 12	Examining patient awareness of availability of health and community support services	In relation to employment, almost 1/3rd of carers (29%) had stopped work to care, of whom half were able to take special leave. Substantial commitments: more than 80% of carers had given an average of over 10 hours weekly in the past month, majority invested more than 30 hours; Employment status was most important factor associated with carer knowledge. Retired carers more knowledgeable. 30% had stopped work to care and many spent long hours providing assistance.	Finding that those who were retired were more likely to be aware of range of services emphasises vulnerability of working family carer: may have multiple needs and competing role claims and need further attention, including more research and more effective targeting of existing services. Important subgroup: young unmarried carers showed low recognition of available services. Patients and families need timely assistance in planning care.
(Calhoun et al. 2001) USA	Collation of economic data	Evaluating the feasibility of obtaining detailed information on direct and indirect costs of toxicity amongst a cohort of women receiving chemotherapy for ovarian cancer	Indirect costs relating to patient and caregiver work loss and payments for caregiver support were substantial.	Highlight awareness of indirect costs of work loss

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(Chen et al. 2006) SING	Questionnaire; N=32 cancer survivors; n=30 non-cancer survivors	Exploring attitudes to cancer survivors	Both cancer survivors and members of public reported cancer misconceptions; While members of public had positive attitudes towards cancer survivors, most said they would not employ them and they didn't deserve equal opportunity at work. Public misconceptions based on sparse facts. These misconceptions might hinder cancer survivors' re-assimilation into society and specifically the workforce.	Require: correction of misconceptions through cancer education. Identify methods of rehabilitation to allow cancer survivors to return to the workforce, thereby changing behaviour of cancer survivors and public attitudes towards them.
(Chirikos et al. 2002a) USA	Face-to-face structured interview, 50-60 mins, including index of general health perceptions and SF-36 used to score physical, mental and social functioning. N=105 women diagnosed breast cancer 5 years previously and age-matched group of women without breast cancer n=105	Exploring the long-lasting (at least 5 years) and continuing economic consequences of breast cancer.	Economic toll for long-term survivors; survivors working at time of diagnosis = significantly larger reductions in annual market earnings arising from reduced work effort as opposed to reduced pay. Changes in total household earnings also lower for survivors, suggesting family adjustment to the disease.	Clinicians and policy makers must seek ways to minimize the indirect economic losses attributable to breast cancer. Clinicians already inquiring about mood disorders, anxiety but should also inquire about economic well-being of patient and family establish effective rehabilitation plan. practitioner-backed requests for flexi-time; job re-assignment or other work-related accommodation required.

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(Choi et al. 2007) KOR	Prospective cohort study; questionnaire examining employment status and its associated factors: completed every 3 months for 24 months. N=305 male diagnosed with stomach, liver or colorectal	Investigating impact of cancer diagnosis on employment status and identifying relevant associated factors/economic burden diagnosis	53% lost job during 24 months follow up: liver patients most likely, followed by stomach, colorectal; at 24 months follow up, 23% redeployed or reemployed; job loss associated with years of education, job characteristics and disease stage and cancer site; risk of job loss more common amongst older, less educated, lower income, non-sedentary patients; more significant amongst those with advanced or terminal illness; change of employment common; early retirement common; Little information on employment changes of cancer patients and factors that relate to these changes. Study highlights need to reduce unnecessary work cessation and increase rate of employment for cancer survivors.	Need for policy support but must also take into consideration country specific employment laws. More protective laws mean cancer patients tend to remain employed and remain productive. Work-related issues dependent on nature of social security system and many other social and cultural factors. Korea – National Health Insurance – decisions to return to work may be influenced by level of state support (and private health payments required).
(de Boer et al. 2000) NDR	Homogenous patient sample: (resected only; excl adjuvant therapy; Jan 1993 to May 1996. QoL assessed via mail questionnaires (SF-36 subscales); SPSS analysis. N=100 May 1998, follow up 43 surviving, 8 excluded with secondary or recurrent	Assessing QoL in long term survivors (2 years) of oesophageal carcinoma	Before operation, 22 patients retired and 13 in paid employment. At time of survey, 2 patients unable to continue working, 2 retired. 9 continued working (3 with reduced hours); 10 incurred additional expenses; If patients were employed before operation, the majority of cancer-free patients resumed occupational activity.	Further longitudinal research needed to investigate the course of long-term QoL of these patients.

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<p>(de Boer et al. 2009) NDR</p>	<p>Meta-analysis: systematic literature search (1966 – 2008) association of unemployment with cancer type, country of origin, average age at diagnosis and background unemployment rate. Pooled relative risks: 26 articles describing 36 studies – analyses of results included 20,366 cancer survivors and 157,603 healthy controls. 16 USA studies, 15 from Europe, 5 from other countries.</p>	<p>Assessing association of cancer survivorship with unemployment compared with healthy controls.</p>	<p>Cancer survivors 1.37 times more likely to be unemployed than healthy controls (33.8% vs 15.2%). Unemployment higher in breast cancer survivors compared to control participants (35.6% vs 31.7%), as well as in gastrointestinal cancer survivors (48.8% vs 33.4%), and cancers of female reproductive organs (49.1% vs 38.3). Unemployment rates not higher for survivors of blood cancers compared to controls (30.6% vs 23.7%), prostate cancers (39.4% vs 27.1%) or testicular cancer (18.5% vs 18.1%). For USA survivors, unemployment risk 1.5 times higher compared to survivors in Europe. After adjustment for diagnosis, age, and background unemployment rate, this risk disappeared; Limitations - quality of included studies varied depending on study design and objectives, or unemployment rates were secondary outcomes, not all studies had age- and sex-matched control group. Mechanisms that may explain higher unemployment rates among cancer survivors: i) survivors may be less available for labour market; (ii) health is important determinant of labour participation and for patients more often than controls, reasons for unemployment were physical limitations, cancer-related symptoms or both; (iii) relative risk of receiving disability benefit or being disabled for work was almost 3 times higher for survivors compared to controls, so the mechanism behind higher unemployment rate among survivors likely to be a higher disability rate.</p>	<p>Employment outcomes can be improved by treatment innovations and clinical and support services for better symptom management, rehabilitation and accommodation for disabilities; workplace interventions needed, aimed at accomplishing workplace accommodations and paid sick leave during treatment.</p>

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(Herrera et al. 2007) USA	Questionnaires, phone contact and chart review. N=170 survivors(initial group n=1085)		Not fully relevant: study based on treatment impacts and likelihood of being able to work: Patient with potentially cured AML likely to be able to return to work.	n/a
(Drolet et al. 2005b) CAN	Population-based retrospective cohort study. Telephone interview 3 years after diagnosis. Working women < 60 when first treated for cancer. N=646 survivors	Exploring factors increasing likelihood of not working among breast cancer survivors compared with women in general population over 3 year period after diagnosis. Identifying and comparing characteristics that increase likelihood of not working.	Slightly more survivors not working 3 yrs after diagnosis compared with cancer free referents. After 3 yrs, survivors valued work less. Age and union membership increased likelihood of not working; income level influenced likelihood of not working; survivors who attached less value to work at interview than pre-diagnosis still significantly more likely to have stopped working at interview compared to those reporting increased value. Breast cancer survivors likely to stop working within 3 yrs are women who may believe that advantages of work no longer outweigh disadvantages; A slightly higher proportion of women reduce work after breast cancer. Characteristics of these: older age, low income and being faced with any new cancer event during follow up. Cancer survivors possibly reprioritize their lives. Study caution: women assessed at end of follow up when already stopped working. Emerging belief: some survivors find benefit from leaving work – can be seen also as a positive experience.	Survivors reducing work may be a negative outcome from a societal viewpoint, it may be less so for survivors if congruent with their values and the possible reordering of their priorities.

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(Drolet et al. 2005a) CAN	Telephone interview breast cancer 3 yrs after 1st diagnosis; n = 646.	Examining work absences of 4 weeks or more among women who had breast cancer during the first 3 years and compared with women with no breast cancer	1 year after diagnosis, 85% absent from work 4 weeks or more compared with 18% healthy women. By 3rd year, disease free women not absent more than women in comparison group, unless new cancer event experienced; Most women with breast cancer took time off work (6months on average) after diagnosis. 3 yrs after diagnosis, not absent from work more often or for longer periods of time than other working women. New cancer events = more absence. Women union members and blue-collar more likely to be absent. Being able to take time off not an option equally available to all – e.g. s/e women or non-union members. For 74% of survivors, absence duration exceeded 15 week federal employment insurance available during short bouts of illness.	Reporting work absences
(Eiser et al. 2006) UK	Questionnaires, descriptive statistics; n=145	Investigating impact/costs of caring for child with cancer	Parents faced increased expenditure (e.g. treatment centre travel costs); many gave up/reduced outside employment to care. Fewer fathers than mothers had changed work since diagnosis; more mothers than fathers took unpaid leave; Financial problems faced because legislation prevents benefits being claimed for first 3 months of a child's illness and this associated with further financial problems.	Benefits backdated only to point at which claim made = families do not recoup all their costs. Need to waive 84 day wait period for children undergoing chemotherapy radiotherapy; introduction of weekly bridging payments with DLA claim being assessed.

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(Emanuel et al. 2000) USA	Face to face interviews of terminally ill patients and their carers; using survey with 135 questions (patients) and 118 questions (carer). N=988 terminally ill patients and 893 carers, drawn from 4 census regions of 50 US states	Understanding economic and other burdens of terminal illness for patients and carers and identifying ameliorating interventions	Costs of illness and medical care causes economic hardship for patient and family. Many families had to take out loans or sell assets or take on an additional job to pay healthcare costs. Terminally ill patients with physical symptoms experience substantial care requirements and, in turn, economic and other burdens; Substantial care needs create economic and psychosocial burden; empathetic physicians who list can reduce some of the burdens.	Increased training for physicians and increase in provision of additional care services, without increasing patients' and families expenses.
(Feuerstein et al. 2007) USA	Web-based questionnaire measuring anxiety and depression, problem-solving, fatigue, cognitive function, job related questions, health behaviours and work limitations; N=95 (working adults with malignant brain tumour) and n = 131 (non-cancer comparison)	Determining association of symptom burden to work limitation among working survivors of malignant brain tumours	Those working with diagnosis of malignant brain tumours, average of 3.8 yrs since diagnosis, experiencing greater levels of work limitations than comparison group. Higher levels of fatigue, depressive and anxiety-related symptoms, cognitive limitations and difficulties problems-solving. Less physical activity, poorer sleep. Did not differ from comparison group in terms of association of these factors on work limitations: factors above were found to contribute independently to work limitations. Despite higher levels of burden, poorer health behaviours and negative problem solving coping style, modifiable behaviours account for most of variance in work limitations for both groups e.g. fatigue across control and survivor groups.	n/a

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(Gaugler et al. 2005) USA	Correlational, cross-sectional (in-person or phone interviews); various indicators and measures, multivariate regression; 233 primary carers of people with cancer (130 from city+ suburb+ impoverished rural site and 103 from mostly inner city site in SE USA)	To identify predictors of various aspects of emotional distress in cancer caregivers.	Care recipient work status one of a number of variables significantly assoc with role overload, role captivity (unwanted participation in a particular role) or loss of intimate exchange; employed care recipients more likely to have carers indicate role captivity; Suggests demands of informal cancer care together with other life course roles inc fulltime employment for younger caregivers can exacerbate feelings of exhaustion, fatigue and overload; work requirements make carers feel trapped in care responsibilities, particularly for families with fewer economic resources.	Underserved families may face particular challenges providing informal care due to difficulties of securing long-term, sufficient employment; need to refine existing models of carer stress to tackle this
(Gaugler et al. 2008) USA	Correlational, cross-sectional survey (detailed interviews, bivariate and multivariable analyses of various indicators and measures); 183 primary informal carers of people with cancer (pooled from 2 samples, baseline data from more recent study): female employed (n=72); female unemployed (n=60), male employed (n=31), male unemployed n=20	Examining association of employment status and gender in family cancer caregivers' reports of stress and well-being	Women and some men who worked tended to be younger, more highly educated, and cared for persons who were younger. Regardless of employment status women carers of people with cancer more likely to indicate and perform IADL-types of tasks than men who work; Women carers faced with employment seem particularly at risk for emotional distress and greater perceived care demands. Socialized, gendered nature of women's household labour roles emerge more strongly in context of informal long-term care	Identifying cancer carers at risk based on work, gender, or other contextual variables may inform development and targeting of clinical interventions for this population.

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(Greenwald et al. 1989) USA	Retrospective cancer-specific cohort; face-to-face interviews with various measures, multiple regression analysis. NB did not equate specific cancer to work variables; Patients within 1y diagnosis- full/ or p/t work pre- diagnosis or at interview N=247 (120 lung, 7 pancreas, 86 prostate, 34 cervical, mean ages 57, 55, 63 and 42 yrs respectively)	Identifying factors affecting ability of people with recent cancer diagnoses to remain employed and retain pre-morbid levels of work performance.	Physical factors related to disease are strongest predictor of work disability in persons with recent cancer history. Those doing physical work more likely to sustain work disability, those with high time discretion more likely to remain employed and work at prior levels. Physical demands of work: 48% employed at interview working shorter hours, 25% doing only light work and 16% doing part of job at home. Social background seems to have little influence on work disability; Work disability predicted by physical demands of work (negative) and discretion over hours worked and how much work would be done (positive). Life-threat nature of cancer may encourage some to leave/reduce work. Increasing flexibility of working hours and work pace could help some people with cancer histories remain in workforce.	Desirable to increase public work rehab programmes. NB – this paper published before USA Disability Act 1990
(Grunfeld et al. 2004) CAN	Semi-quantitative longitudinal comparative; cohort followed until death of patient or study end at 3 y; Various questionnaires comparisons: start of palliative period v. end of palliative period; start of palliative period v. beginning of terminal period; 89 carers of women with advanced breast cancer (55% male, 52% spouse or partner, mean age 53y)	Prospectively examining psychosocial, occupational and economic impact of caring for a person with a terminal illness	5% carers quit job or declined advance due to care responsibilities; 69% of employed reported some form of adverse impact on work; 77% reported missing work in terminal period (decline in patient's functional status, need for appointments, interrupting phone calls); increased inability to work regular hours and increased hours of work lost; use of special leave/ holidays to fulfil care-giving responsibilities; Carers bore economic and occupational burdens as well as psychological morbidity. Perceived burden is the strongest predictor of carer anxiety and depression.	Findings emphasise importance of implementing Canadian Senate recommendation for income security and job protection for family members caring for dying relatives and other reports that recognise need for policy addressing growing impact of drug costs

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(Gudbergsson 2006) NOR	Questionnaire n=852 cancer survivors; n= 1548 controls; n=317 women; n=279 men	Exploring living conditions in disease free cancer survivors participating in the workforce across Nordic states	The proportion of cancer survivors active at work almost same as that for the matched controls without cancer. But, study demonstrates work participation in cancer survivors is associated with significantly poorer mental and physical work capacity compared to controls. Raises questions whether survivors will be able to keep their jobs to retirement age; Optimism re return to work experience but possible future impact re long-term work experience	Pension contribution impact. Need for health professionals to focus on long-term issues during follow up programs
(Gudbergsson et al. 2007) NOR	Retrospective cross-sectional matched (on age, sex and dwelling place) case control - self-completion questionnaire; Employed cancer survivors: 208 breast and 209 testicular/ prostate diagnosed 1-5y before study and tumour-free vs 417 employed controls	Exploring job strain in primary-treated cancer survivors in work compared to matched population controls	Job strain of cancer survivors in sample did not differ in any work relevant way from their controls; survivorship status not significantly associated with job strain. No significant difference in work situation for younger and older survivors; Longer follow-up required to establish data stability.	
(Guidry et al. 1998) USA	593 breast, colon, cervical, prostate, lymphoma patients (diagnosed 1989-1993, 65.2% response; age range 17-91; % in employment not given)	Determining work barriers to treatment of cancer patients	Those in ethnic minorities were more than twice as likely to report being denied insurance cover. Indirect costs such as wage loss for sick time more problematic for ethnic minority groupings.	Cancer HCPs need to be aware of non-clinical financial factors impinging on treatment.
(Hounshell et al. 2001) USA	Survey on employment, insurance, finances and lifestyle; n=31, 24-73 yrs, median 49	Effects of cancer on aspects of lifestyle	Not wholly focused on employment – only 1 of 4 issues. Concludes cancer survivors may experience difficulty remaining in employment.	General study

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(Insinga 2005) USA	Analytic framework: estimate of annual productivity costs due to cervical cancer; Annual number of cervical cancer deaths and labour force participation rates	Estimating annual productivity costs due to cervical cancer	Despite availability of cervical cancer screening, it is evident that a substantial health and economic impact associated with cervical cancer mortality still remains. Few prior analyses estimating productivity loss associated with cervical cancer in US; Annual productivity loss for cervical cancer substantially larger than previously estimated. Overall, estimated that > 5 billion dollars in direct and indirect costs are incurred in prevention, diagnosis and treatment of cervical cancer in US each year, including lost production.	
(Janda et al. 2004) AUS	Retrospective cohort; semi-quantitative, descriptive - semi-structured interviews to describe QOL generally and specifically to vulvar cancer; 15 patients treated for vulvar cancer, 2 weeks – 39 months since surgery; mean age 68.8 (52-85) years	Developing vulva cancer-specific QOL subscale for the Functional Assessment of Cancer—General (FACT-G) questionnaire	4 patients returned to employment after treatment (some were just 2 weeks post surgery and only 4 were employed at time of interview); all reported work-related problems, including reductions in physical strengths and problems with sitting and driving; Lymphoedema of legs can influence patient's ability to work; patients required more info on their condition and treatment so that they could cope	Increased work-related advice required
(Jansson et al. 2004) NDR	Population-based case-control study; n=1438	Examining whether stressful working conditions might be involved in aetiology of oesophageal and gastric cardia cancers	Work related stress does not seem to be of importance in aetiology. However, the interaction of a stressful work environment and the individual's responses to it may be associated with a moderately increased risk of these cancer types.	Further studies required regarding increased workplace cancer risk

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(Johannesen et al. 2007) NOR	Statistical analysis of data from Norwegian Cancer Registry and Registry of causes of death and Norwegian Social Insurance Scheme; Children with a haematological malignancy N = 1042 and children with a primary CNS tumour N = 1208 diagnosed between Jan 1, 1970 and Dec 31,1997	Investigating prevalence of patients with childhood cancer compared to general population to assess working ability, yearly income and need for health benefits in survivors at least 5y after treatment (CNS or haem malignancies)	High degree long-term morbidity in CNS patients. Yearly income and working ability especially low for survivors of childhood CNS cancer (CNS patients particularly at risk for educational deficits). High proportion of CNS survivors unemployed though rate among HM only slightly above general population.	Clinicians should inquire about the economic well-being of patient and family and encourage referrals for assistance.
(Johansson et al. 2002) SWE	Sample of working patients from larger prospective longitudinal multi-centre randomised trial (self-assessed questionnaire of social factors, 4 alternatives re work return); 270 breast cancer patients working at baseline – 12, 18, 24 and 36 months follow-up (focus on 24 months on) [limitation = small sample size and number of patients not returned to work was small].	Investigating association of socio-economic and treatment-related factors with returning to work among pre-menopausal women	At 12 months, 52 (21%) had not yet returned to work; at 24 months, recur-free patients = 222 and 35 (16%) still not returned to work; at 36 months, recur-free patients = 204, 29 (14%) not back at work. Total stay out of labour market was 1,044 months between 12 and 36 months after baseline. Of those 35 at 24 months, 30 were on sick-list, 4 early retired and 1 begun to study. Chemo/nodal status negatively associated with work status. Reasons for not able to work as before = working environment, and/or nature of work, and physical exhaustion and deterioration after illness and treatment; Working environment and/or nature of work precluded return to work in women who had had treatment for breast cancer; also physical exhaustion and deterioration after cancer and treatment	More longitudinal research to assess social factors such as vocational motivation, income and vocational rehab needed to distinguish between factors associated/not associated with problems in work return in breast cancer patients, to find methods of reducing exclusion from labour market.

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<p>(Lauzier et al. 2008) CAN</p>	<p>Prospective cohort of patients n=459 working women of sample n=962 eligible with early-stage breast cancer – 3 telephone interviews over 1st year and analysis of wage losses. analytic approach (cost identification); first treated between Jan 1 – Dec 23, 2003</p>	<p>Estimating wage losses for patients over 1st 12 months after diagnosis; personal, disease, treatment and job factors assoc with losses; effects of losses on family's finances</p>	<p>Working women lost 27% of projected usual annual wages after compensation taken into account; higher % lost wages was significantly associated with lower education level, living ≥50 km from hospital where surgery performed, lower social support, invasive disease, having had chemotherapy, self-employment, shorter tenure in job and part-time work. Few women reported change for worse in financial ability to meet basic needs but those who lost ≥33% usual income more likely to report lack of funds for necessities; 90% of women had relatively long full-time absence from work; this likely represents the major source of their wage losses. Financial hardship after breast cancer multifactorial and factors may interrelate in complex ways to produce wage losses e.g. chemotherapy + RT strongly assoc with higher of annual salary lost → longer absence + reduced compensation; self-employed, lower education, shorter job tenure and part-time women may have more limited access to sick insurance etc = higher loss.</p>	<p>HCPs should be aware of extent of negative effect of wage losses on working women and families. Work absence and possible financial results should be explicitly discussed by HCP with patient early in treatment trajectory. Acknowledged different and longer interviews required to assess effects on income of self-employed or seasonal workers.</p>

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(Lee et al. 2008) KOR	Comparative cross-sectional questionnaire study; n=408 stomach cancer survivors 21-36 months post diagnosis and n=994 general population	Comparing employment status and work-related difficulties of stomach cancer survivors vs general population	Nonworking significantly higher in stomach cancer survivors (46.6%) than general population (36.5%); 24% male and 48% female survivors decreased working hours; patients had more fatigue in performing work, reduced work-related ability compared to members of general population; non-working associated with poorer ECOG Performance Status and total gastrectomy; older age and being female were common correlates of post-cancer work stopping; Physical limitation was main correlate of not working. Correlation with older age may reflect that cancer occurred at time of life when patients already thinking about retirement and greater physical limitations increased tendency to stop work; re being female - women had more cancer-related disabilities than men. More females decreased work hours - women value work less than men due to family commitments or not being main earner? Further research required.	Further research required
(Lindqvist et al. 2005) SWE	Statistical analysis of data from National Cancer Register, National Social Insurance Board and National Hospital Discharge Register; n=1834 all women diagnosed with breast cancer, 2000 aged 18-64 (mean 51.8years); measure sick leave days after discharge in year after surgery	Investigating how differences in shift from in-patient to day surgery and reduced hospital stay affect sick-leave period for female breast cancer surgery patients	Type of employment (employed vs self-employed) was controlled for. Patients with breast-conserving surgery had 54.7d shorter sick-leave than those with more invasive surgery; day-surgery patients had 24.3d shorter sick-leave than patients on overnight care; median length of hospital stay results suggested hospitals with short or long length of stays were associated with longer sick-leaves;	

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(Liu 2008) CHI	Retrospective cross-sectional, systematic sampling; questionnaire. N=97 head and neck cancer survivors (25% response rate); 88 male, 9 female, mean age 50.9 years	Assessing changed working status between pre-surgery and study time of head and neck patients after tumour excision and micro-reconstructive surgery	29 (35.8%) of employed patients changed jobs after cancer treatments, mostly due to discomfort caused by treatment (n=15); others due to changes in appearance and value (n=5), retirement (n=4), national economic downturn (n=3), no answer (n = 2). Of those who changed jobs, 55% (n=16) were blue-collar, 28% (n=8) were white-collar, 7% (n=2) were self-employed; Patients employed at pre-op had higher satisfaction with personal appearance than non-employed; blue-collar workers – significantly higher satisfaction with personal appearance than self-employed.	Include job rehabilitation and body image into daily care of head and neck patients e.g. teach how to use cosmetics. Strategies to decrease cancer-related symptoms and manage fatigue and maintain continuity of care could help head and neck patients return to former jobs more easily.
(Longo et al. 2006) CAN	Prospective cohort, self-administered questionnaire (83.6% response rate); n=282 (74 breast, 70 colorectal, 68 lung, 70 prostate), active cancer treatment, 149 male; 132 female, mean age 61.2 (26-87 years); 154 patients: 98 recruited consecutively from 3 rehab clinics and 56 from a register at a National Insurance Authority on persons who were on sick leave (81% female, 19% male, mean age 45 y); 73% in permanent work, 4% in part-time and 23% unemployed	Determining financial and family resources burden associated with cancer treatment	Of patients that had worked in past 30 d, mean lost time from work = 12.6 d. 38% of patients that took time off work did so without pay. 35.6% of patients required others to take time from work (mean no days lost from work in previous 30 d for these carers = 7); crude estimate of lost income: patients and family lost average \$101/day work missed; Working carers may lose one third working days in any given month to assist in pt care, especially if pt care needed at home Problem where cancer resembles chronic condition, i.e. long term, so patients likely to exceed allocated public funding limits in Ontario. Demographics – authors suggest some cancers that tend to have younger population are more likely to have uninsured/ underinsured individuals	Current demand for supportive services may exceed supply, and gap in level of support services going to fall onto the carers. Research suggests gap significant. Boundaries of health care spill over into or influenced by other welfare programs e.g. income replacement.

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(Marhold et al. 2002) SWE	Prospective cohort, self-administered questionnaire (Obstacles to Return-to-Work Questionnaire (ORQ)) validated concurrently by completion of 4 other scales – MPI, CSQ, BDI and DRI	Develop and evaluate predictive ability of a questionnaire based on results of epidemiological studies re psychosocial and physical risk factors for pain and disability in workplace.	Factor analyses reduced ORQ to 55 items in 9 subscales. Subscales 'Perceived prognosis of work return (best predictor)', 'Social support at work', 'Physical workload and harmfulness', 'Depression', and 'Pain intensity' could predict sick leave significantly and correctly classified 79% of patients. But NB – this was a chronic population – no mention of cancer; Patients' perceptions and beliefs about work and returning to work may be significant hindrance for actual recovery.	Future research: investigate if ORQ can be used in planning occupational rehabilitation.
(Maunsell et al. 2004) CAN	Telephone interviews 3 years after diagnosis. Population-based retrospective cohort study; n=646 breast cancer survivors, n=890 control group, <60 years	Assessing discrimination at work as a result of breast cancer	Majority of breast cancer survivors still employed 3 years after diagnosis. Negative effects (being fired or leaving work) rare. No evidence to support idea that women who had disease recurrence experienced discrimination. Decisions to stop work were women's decisions and not via workplace pressure. Older women did not retire earlier because of disease – may reflect fact cancer occurred late and already thinking about retirement; Little evidence of discrimination and this helpful for women considering returning to work after breast cancer. Survivors attached less value to work after cancer – treatment itself not affecting work decisions but changed perception of work	Useful information for health professionals counselling women

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(McCarthy et al. 2000) USA	Retrospective interview and chart abstraction data (from larger study) collected at several time points; 316 metastatic colon cancer and 747 lung cancer patients (and identified surrogates) enrolled in larger study (Surrogate interviews within 4-10 wks of patients death to ascertain financial impact)	Characterising dying experience of patients with cancer over last 6 months of life	During last 6 months of life, patients and families had significant financial burdens due to end of life care; by time of death, >40% surrogates reported family member had to quit work to care for patient; Findings highlight important opportunities to improve quality of care at end of life for patients dying with cancer	
(Poirier 2006) USA	Prospective, longitudinal – Revised Piper Fatigue Scale, Brief Fatigue Inventory and single item subscale to gauge fatigue; 77 patients receiving RT to breast, chest, head and neck, pelvis, prostate	Examining relationship among sick leave benefits, employment patterns, individual characteristics and fatigue in patients receiving RT	Side-effects, education, living situation, age, treatment site and work associated with fatigue along RT trajectory. Participants who were working at end of RT had lower fatigue scores than those not. Availability of sick leave benefits associated with employment patterns during treatment; Fatigue most common of RT side-effects; exacerbated by working during treatment; current sick leave policies do not support patients' needs to adjust work due to side-effects e.g. fatigue; management of side-effects may help patients stay in workforce during treatment.	Oncology nurses need to take active role in policies re employment issues and symptom management for patients undergoing treatment.
(Yeung et al. 1999) UK	Retrospective, cross-sectional (cf 25 patients in prospective similar cohort) self-completion UW-QOL, EORTC QOQ-C30 and EORTC HandN35 questionnaires; 38 patients (of 48 sent questionnaire) treated by primary surgery for oral and oropharyngeal cancer 1987-1992; 35 male 23 female; mean age at op 58 (22-81)yrs;	Describe QOL in patients 5-10y after primary surgery for oral and oropharyngeal squamous cell cancer and compare to cohort treated at same unit one year after surgery	Survivors had poor employment outcomes in UW-QOL domains (but NB due to retirement in many patients, most of whom said retirement not related to cancer treatment); None in relation to employment	n/a

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(Sanchez et al. 2004) USA	Survey and univariate logic regression; N=250 colorectal cancer survivors	Describing the return to work experiences of colorectal cancer survivors. The ability to return to work has been linked with survival therefore understanding barriers to returning to work critical	Of 200 survivors employed prior to diagnosis, 89% returned to work and 80% reported current employment at least 5 yrs after diagnosis. 60% remained at their pre-cancer place of work. Factors influencing delayed return to work (≥ 60 days): older 50-59; female; non-white; had a partner; had completed less than 4 years of college. Survivors who got chemotherapy were 3 times more likely to delay their return to work. Survivors in blue-collar or service occupations and those employed less than 20 hours per week more likely to delay returning to work; Within this sample, a disease related factor (chemotherapy) appeared to have a greater impact on predicting work delay than person or work related factors. Consequences of work delay can be far reaching – e.g. insurance benefits. Surgery did not contribute to work delay.	If work delay related to chemotherapy, oncologists and primary care providers can identify and modify problem situations with a focus on minimizing side-effects.
(Sarna et al. 2002) USA	Self-report questionnaires; multivariate regression methods; n=142	Exploring QoL and recovery after cancer through the perspective of long-term survivors of lung cancer	In comparison with other workers, lung cancer survivors have difficulty working and disruptions in day-to-day activity,	

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(Satariano et al. 1996) USA	Retrospective cross-sectional, questionnaire by interview 95% face-to-face, 5% by phone; 296 employed women age 40-84, 2-4 months after diagnosis with breast cancer (212 had returned to work, 84 on medical leave at time of interview)	Examining factors associated with returning to work after diagnosis of breast cancer	Black women twice as likely to be on medical leave 3 months after diagnosis; later breast cancer stage more likely to be on leave 3 months after diagnosis; after more analysis, these factors reduce and 3 factors significantly associated with being on leave from work 3 months after diagnosis: need for assistance with transport; limitations in upper-body strength; employment in jobs requiring at least some physical activity; Return to work after breast cancer affected by functional status, need for transport and physical job demands. Black/white differences seem partly due to differences in reduced upper-body strength and in demands of everyday life.	Breast cancer rehab should address physical capacity and daily demands likely to be faced once patient returns to work. Future studies: larger numbers of employed women; address characteristics and physical demands of specific jobs, racial and socioeconomic differences inc family supports available to different ethnic groups
(Schultz et al. 2002) USA	Survey; n=4364 long term cancer survivors (living and diagnosed with cancer for at least 5 years); 18-63 years	Survey results of cancer survivors responding to questions on ability to work, job discrimination and quality of life	Analysis of variance indicates significant effect for age, cancer type, and whether or not the participant was working; 7.3% indicated had experienced job discrimination 10 participants indicated they had been fired or forced to quit jobs as a result of cancer diagnosis and treatment; 4 denied promotion; 7 denied employment; 5 denied health insurance; 1 employer unsympathetic and resistant to job adjustment because of chronic fatigue. 8.5% unable to work (influenced by cancer type). Impact on society, other than economic is little understood.	OH Nurses in a unique position to intervene re work re-entry – experience coordinating and liaising. Education of employees and co-workers about the realities of how well cancer survivors generally perform. Career counselling for cancer survivors

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(Sherwood et al. 2008) USA	Cross-sectional, descriptive, 45–60min structured tel interviews with carers-IADL scale; NPI-Q'aire; CES-D scale; CRA scale; Caregiver Mastery scale; N=95 carers initially (used for descriptive analysis); 74% female (70); med age 51.4y; Missing data gave N=80 (Multivariate analysis of tel interviews); med time since diagnosis 19(2–216)months.	Identifying variables associated with employment and lost hours from work for caregivers of persons with cancer (primary malignant brain tumour)	58% (N=61) carers employed full or part time-21 lost work hours due to care (of these, 33% lost insurance/retirement benefits); 59% patients unemployed due to tumour; of 56 patients who changed job due to tumour, 25% retired, 32% quit, 29% took paid leave, and 14% took unpaid leave; Age significant: older carers less likely to be employed than younger; trend for more employment if patients care needs (IADLs) less. Employment not significantly related to: patients ability to do ADLs, neuropsychological function, or employment status; carer gender, relationship to patient, children in home, carers' depressive symptoms, burden, mastery, or no of secondary caregivers	Interventions to assist carers keep employment should target carers of those with limited physical function; and include strategies to coordinate care to assist with activities of daily living.
(Short et al. 2005) USA	Telephone interviews from 1 year to nearly 5 years after diagnosis; n=1433	Employment pathways in a large cohort of adult cancer survivors	13% survivors quit working within 4 years of diagnosis; over 50% quit within 1st year; cancer survival has long-term effects on employment; Focusing on return to work and reintegration after treatment ignores survivors who quit working at a later stage of survivorship; need to focus on long-term needs and possibility long-term discrimination – physical impact over time can be severe	Need to prioritise efforts to develop effective treatments with fewer negative consequences for survivors; also could help target clinical and psychosocial services that address threats to their employment = both short and long term challenges identified.

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(Spelten et al. 2003) NDR	Prospective inception cohort study with 12 months of follow up; n=235 patients with primary diagnosis of cancer. Rate of return to work measured at 6, 12 and 18 months	Exploring return to work and impact of cancer-related symptoms (fatigue)	At 6 months, 24% had returned to work; at 12 months = 50%; 18 months 64%. Fatigue levels at 6 months after the start of sick leave predicted the return to work at 18 months following the first day of sick leave; Findings in line with previous research that established importance of fatigue and physical workload, in addition to diagnosis and treatment, but study also showed that cancer-related symptoms highly correlated. Return to work also dependent on nature of social security system and many other social and cultural factors.	To better predict problems encountered, more knowledge is required about the return to work process in general.
(Stewart 2001) CAN	Mail survey; 500 questionnaires distributed and 378 (75.6%) returned n=378	Determining experience of breast cancer survivors re the impact of cancer on confidentiality, work and insurance	Over 70% disclosed their diagnosis to friends, children, siblings, partners; over 50% disclosed to work colleagues and supervisors. Over 40% felt cancer had altered their priorities or progress at work. 5% afraid to change jobs in case they became ill again. Disclosure sometimes resulted in negative work and insurance experiences Difficulty in obtaining life insurance problem for 17.9% of all women; Systemic issues probably affected the over 12% of women who felt unable to fulfil their work and career potential, made a career change, decided to retire early, or were afraid to change jobs in case they were sick. Most employers do not realise that over half of all cancer patients will survive over 5 years, that cancer is not contagious and that survivors of cancer have the same productivity as other workers.	Health professionals and cancer survivors should engage in education about the potential positive and negative effects of disclosure and advocacy against cancer-based work and insurance discrimination

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(Syse et al. 2008) NOR	Logistic regression modelling; Norwegian register data of entire population (2001): 567,000 men and 549,300 women 40–59 yrs old, 34,000 of whom diagnosed with cancer.	Exploring extent to which Norwegian cancer survivors stay allied to working life compared with cancer-free population and quantify cancer-associated earning declines.	Cancer diagnosis strongly associated with not being employed. Cancer associated with 12% decline in earnings overall. Leukaemia, lymphomas, lung, brain, bone, colorectal and head-and neck cancer caused largest reductions in employment and earnings. Earning declines strongly associated with educational level; Cancer survivors less likely to be employed than cancer-free population and assume modifications in their employment such as reduced work-hours or lower-wage jobs that result in reduced earnings. A social class gradient also found.	The social class gradient must be tackled to assist appropriate interventions from welfare bodies.
(Taskila et al. 2006) FIN	Mailed questionnaire using SFSS; n=64- breast, lymphoma, testicular and prostate, aged 25-57	Exploring importance of social support from work life	Survivors received most support from co-workers; they hoped for more support from OH personnel. People with different diagnosis received unequal amounts of support from co-workers and supervisors. People who had chemotherapy received more support than people who had other treatments. Those with more education received more support from OH. Difference observed between manual and non-manual workers; Few comparative studies about the impact of cancer type on social support. Men with less education and lower occupational status had greater need for support – those in better occupations/ positions, higher education are in better health and experience less work-related stress than those in lower positions.	Cancer survivors' social support from their work place and especially from OH personnel inadequate. Difficult (e.g. costs) for workplaces to establish OH teams that are multi-disciplinary enough to offer required support. Quality and quantity of occupational health support variable across workplaces. OH has important role to play in evaluating working conditions and survivor coping – need early assessment, intervention, rehabilitation. More research needed.

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<p>(Taskila et al. 2007b) FIN</p>	<p>Questionnaires QPSNordic; N=591 survivors, n-751 referents prostate, testicular, breast and lymphoma</p>	<p>Studying work ability of cancer survivors, whether perception cancer impaired work ability and which disease factors, socio-demographic and social factors had an impact on work ability</p>	<p>Mean values for perceived current work ability of employed cancer survivors with good prognosis and their referents were nearly same. In both groups, higher education = better work ability. Older age, several diseases or injuries lowered work ability. Male referents who got more support had better work ability; women getting support from a supervisor increased work ability in both status groups. Unlike other studies, strength of this study = inclusion of a reference group. Cancer survivors having had chemotherapy and other injuries or diseases most likely to report impaired work ability; Cancer survivors' return to work strongly dependent on type of cancer and treatment received (e.g. chemo). Support from co-workers found to reduce risk of impaired work ability among women, but association not found among men – women seek support more widely, larger social networks. Age associated with impaired physical and mental work ability among women, whereas among men, age did not increase risk of impairment. Seemed no essential difference in current work ability between cancer survivors who had a good prognosis and remained in work life, and cancer-free referents. But many survivors did experience impaired work ability due to their illness.</p>	<p>More attention should be paid to treatment-related factors, as well as social factors at work, as these play an important role in the work ability of cancer survivors and their continuance in work life.</p>

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<p>(Taskila-Abbrandt et al. 2004) FIN</p>	<p>Statistical analyses using Finnish Cancer Registry; N=12542 in final data set (including referent group)</p>	<p>Exploring effect of cancer diagnosis on employment according to education, occupation, cancer-type, age, gender, cancer type</p>	<p>Education and occupation modified effect of cancer on employment. Other variables did not have such modifying effects. Probability of being employed was lowest among cancer survivors who had only primary education – 19% less likely to be employed. Probability of employment was low among people with leukaemia, stomach and cancer of the nervous system; Cancer survivors are in employment almost as much as general population – only 9% lower employment rate. However, differences in employment rates between educational and occupational classes and between cancer types. Previously shown lower socioeconomic status associated with higher mortality risk among cancer patients. This study, higher education status = more likely employment and less likely early retirement. Industries associated with lower rate of return: fishing, agriculture, transport, mining, forestry and communication. More likely that less educated are working in more physically demanding jobs. NB when there is an oversupply of the workforce it is less likely that people with a history of cancer will be employed. Prognosis has an impact on ability to return to work. Variable by cancer type and difficulty of fatigue.</p>	<p>Cancer diagnosis does not automatically lead to unemployment or early retirement, but has an impact on work continuance. Previous studies highlight lack of knowledge, fear amongst work mates. More research required on the return to work process; to clarify both environmental and personal factors that predict the successful return to work of cancer survivors.</p>

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(van den et al. 2005) NDR	Multicentre, randomized clinical trial; N=1530, SPSS multivariate analysis	Describing results of diagnosis and treatment of rectal cancer for paid and unpaid labour over time and to identify associated socio-demographic-, treatment-, and QoL-related factors .	Treatment related variables not only affected paid labour resumption by reduced quality of life, but also not being able to return to work may affect quality of life; Diagnosis and treatment of rectal cancer may affect paid and unpaid labour. Multiple other socio-demographic-related and quality of life variables also associated with resumption of paid labour, indicating that different factors contribute and may interact in the decision to resume paid labour.	Interventions focused on promoting paid labour participation in patients who have been treated for rectal cancer should be tailored to the specific characteristics and needs of those patients.
Reviews, commentaries, summaries and policy briefings				
(Carmichael et al. 2003)	Commentary drawing from GHS survey data on commitment	Investigating costs borne by male and female carers in terms of foregone employment opportunities	Not cancer specific. However, data illustrates the direct impact of informal care commitments on labour supply; co-efficients imply a wage reduction of around 18% for males caring for 10 or more hours a week while the wage reduction for a comparable female carer is just under 9% and underlines the economic factors that play a part in caring; Negative influence of informal care on labour supply. For women, due to combined lower ability to earn and direct substitution effect. For males, the lower probability of employment is due entirely to the indirect effect of lower ability to earn.	Policy direction towards respite care, carer-friendly employment practices and additional (non means-tested) financial support would be of particular benefit.

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(Amir et al. 2008) UK	Mixed method; N=384 GP's (out of 500); n=284 patients (out of 523)	Exploring return to work after cancer	<p>Methodological problems comparing studies. Cancer diagnosis – negative impact on labour market position; consequent effect on household income and welfare; effect of impact varies by cancer site and influenced by treatment modality; age; occupation, work role etc. Many labour market effects transient but are permanent for a significant minority. Permanent effects: include retirement, disability or limitations in workplace e.g. fatigue and loss of concentration. Males less likely to take sick leave than females but when they did = longer periods of absence. Good relationship with employer a major influence on work return; Work can provide a structured routine to people's lives, valuable social support from colleagues and was of therapeutic value: a major goal for many. Number of issues need to be considered for further exploration and research: role played by employers and line managers in assisting people with cancer diagnosis back into workplace is important in supporting and sustaining a successful return to the workplace. Lack of advice from clinicians appears widespread. Duration of sick leave absence associated with more difficulties returning to work. Employer-employee relationship – critical sustaining return to work. Study limitation: does not reflect experiences of those who didn't return to work. Limitation: recall difficulty.</p>	<p>Highlights need for research on workplace accommodations (the physical workplace); the content of work; The role of co-workers, supervisors and OH; need for medical advice; Gap in the literature re examining the role of employers, supervisors/ managers and co-workers in the return to work process. As the state pension age gradually increases, more likely that people of certain age (50's and 60's) will have be diagnosed and expect to return to work/receive support. Need for more advice and support being made available to people with a cancer diagnosis and their employers and managers in order to improve the management of long-term sick leave and the process of returning to work. Improved role of cancer clinicians and physicians; implications for HR, OH and line managers; flexible working.</p>

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(Anon 2008) UK	CareandHealth consensus statement, National Director for Health and Work, Dame Carol Black		Evidence shows returning to work is usually good for health and recovery. In signing the consensus statement medical profession acknowledges this and agrees to act on it.	Government aim and focus to work with healthcare professionals to help prevent people from sliding out of work onto Incapacity benefit as well as getting those isolated from world of work back into employment. GP focus.
(Anon 1998) USA	News piece		1997 survey shows 87% of those surveyed recognised the emotional importance of work. However, 18% believe people being treated for cancer are incapable of working because of side effects from treatment; 27% feel they have to 'pick up the slack'; 14% feel a co-worker with cancer cannot do their job as well as before they were diagnosed; 42% believe a co-worker with cancer would have special needs and require special arrangements; 41% would worry about their job if diagnosed; 59% would tell supervisors but only 38% would tell their peers; 20% would not tell anyone at their workplace. 1996 Survey (telephone) of 500 cancer survivors: 81% said job helped them maintain emotional stability; 40% missed fewer than 5 days a month as a result of treatment; 33% supervisors felt survivor could not handle their job; only 19% of workers thought this; 31% of supervisors thought employee should be replaced; only 19% of workers felt so. Workers with cancer are laid off at 5 times the rate; 6% had a family member lose their job due to absences to care for survivor	n/a

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(Barnes et al. 2008) UK	Article reconfiguring the meaning of work for disabled people	Arguing a social model analysis of the oppression of disabled people is long overdue	Consensus that paid employment is central to social inclusion. Marginalisation of disabled from the labour market a major factor in their exclusion → promotion of the rights of people with impairments; Reformulation of the concept of work forms an integral part of the philosophy of independent living.	n/a
(Elliot 2008) UK	News commentary	News commentary	Breast cancer survivor: returned to work, small company, no advice, limited support → clinical depression. Fatigue a huge problem but felt unable to rest. No employer information, advice, support.	Employer education required as long term survival rates increasing.
(Berkman et al. 1993) USA	Article reviewing psychosocial effects of cancer economics on patients and their families		If financial needs are not met, the patient's treatment, overall functioning and quality of life may be compromised. Unmet financial need may inhibit the treatment regimen, making cancer more costly in the long run; Financial burden greater for lower income patients and also more likely to be diagnosed with cancer. Disadvantaged have lower survival rates. Cancer diagnosis can also drive many middle class families into poverty – loss of income and depletion of assets. Financial strain a significant, negative effect on family's emotional status. Insurance: applying for new or additional insurance problematic. Retaining insurance benefits problematic.	Need to ensure cancer prevention, detection, treatment and rehabilitation services are accessible and available to all who need them.

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(Berthoud 2008) UK	Article exploring disability employment penalties in Britain; a large scale and detailed survey of disabled people for a discussion of their employment outcomes.	Proposing a new view of disability. Exposing lack of detailed understanding of the relationship between disability and employment	Disability a complex construct that can be measured and analysed. Employment rate of disabled people varies according to the type of impairment reported and experienced. A severely disabled person with adverse conditions and impairments was much more likely to have a job if she/he had good education and lived in a prosperous area than if she/he had minimal education and lived in a depressed area.	n/a
(Black 2008) UK	Review	Review of the health of Britain's working age population	Work good for health. Correlation between lower parental income and poor health in children. Costs of ill-health to the taxpayer significant. New approach to health and well-being required – not just a medical issue. Need to change perceptions of fitness for work; e.g. tackle stigma around ill-health and disability; that work impedes recovery; that need to be 100%; switch focus from what people can do instead of what they can't; Pathways to Work – limited effect – need integration of providers; Employer information and support; need clear workplace plans, clear standards of practice and formal accreditation of all providers. Focus on educating next generation to understand the benefits of a life in work.	Rolling out vision of a new approach to health and work in Britain. Individuals have a fundamental personal responsibility to maintain their own health. Employers must work alongside this to change the nature of the modern workplace in Britain. Trade Unions to champion health and well-being in the workplace. Promotion of case-managed multidisciplinary support

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(Breast Cancer Care 2008b) UK	The Employ Charter: Information for Employers: Breast Cancer	Breast Cancer Care's guide to best practice in the workplace	Responsibilities under disability discrimination law: Illegal to discriminate against employee with cancer; employees protected against being harassed; employees should be able to raise a complaint; employers must make reasonable adjustments; money entitlements; off work time	n/a
(Breast Cancer Care 2008c) UK	The Employ Charter: Information for Employers: Breast Cancer; based on 2006 survey n=417	Breast Cancer Care's guide to best practice in the workplace: policy briefing	Low awareness of rights for cancer patients under the DDA. Wide range of individual experiences – e.g. time off work; 62% said employers supportive during treatment; 57% said employer supportive after treatment. Lack of regular employer/ employee dialogue; On the whole, employers supportive. However, a few respondents reported good practice measures (regular meetings, phased return to work, work adjustments – despite the fact that some of these measures could often be regarded as legal duties under UK disability discrimination law.	Breast cancer patients should be signposted to sources of employment-related and financial information and support; by breast cancer nurses or other HCPs. UK governments and departments should work together to raise awareness of the DDA among employers and cancer patients.

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(Cancer Backup 2006) UK	Employer cancer guidelines, survey analysis; n=219 replies from organisations employing a total of more than 800,000 employees		73% of employers don't have formal policy in place for managing employees affected by cancer. 80% of respondents know DDA now classes cancer as a disability. But 20% employers remain unaware. Only one third organisations ensure relevant staff has good understanding of cancer and impact of treatment on an individual in workplace. Just under half organisations provide support. Under a 1/3 track whether employee returns to work; little emphasis on information and support; few provide counselling; nearly half employers purchase private health insurance for employees but only 9% assess suitability of this for cancer-related cover.	Employers should: Respect dignity and privacy; maintain employee involvement and engagement; ensure no financial detriment; provide employment benefits; adopt a flexible approach; provide access to development opportunities; provide information and support; support employee's team; time off for treatment; keeping in touch; line manager meetings. Also information for carers or family members affected by cancer, support, counselling, family and parental leave
(Carmichael 2008) News Week USA	Newsweek commentary		Exploring experiences of childhood cancer survivors; Childhood leukaemia survivors may be left with cognitive problems. Radiation and chemotherapy may stunt mental and physical development → some hide disabilities from potential employers; some admit to problems but don't try to explain them; specific job interview preparation required.	

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(Chirikos 2001) USA	Commentary/literature review: economic impact of growing population of breast cancer survivors; research review	Economic impact of breast cancer survivors.	Wider health literature = considerable evidence that individuals with chronic health conditions more likely to reduce work effort, earn less per hour when they do work and experience household changes in work. Little re cancer. Re breast cancer, available evidence not compelling one way or another → commentary setting up piece of research: exploring: long-term behaviour of survivor that bears on indirect economic consequences. Over time do women revert to pre-cancer patterns of work behaviour? Also little evidence to support prevailing idea that women with breast cancer involuntarily reduce work participation; Research not strong enough therefore cannot conjecture about current trends in morbidity/ disability losses. Current study aims to test relationships bearing on economic consequences of breast disease, particularly whether economic status of 5 year survivors of breast cancer over period since diagnosis in comparison with a matched control group. Does lengthening the period of breast cancer survival increase risk of adverse economic consequences? Also aim to disentangle effects of breast cancer from normal retirement processes (given average age of BC patients).	This is an ongoing study – only suggestions for policy relevance: to effectively explore full economic burden of cancer need long-term studies; new figures on economic losses are needed; the character of the losses may require new public sector efforts: flex-time; job reassignment; for example, medical social workers may help sustain work effort.

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(Cunningham et al. 2000) UK	Personnel review (of survey results)	N/A	Surveyed organisations found to place most reliance on making adjustments to working hours, providing transfers to other work and giving of light opportunities; more difficult to organise in smaller institutions. In contrast, far less emphasis placed on provision of occupational/ physical therapy, home employment and rehab. Few organisations used rehab and disability specialists to support return to work activities. Larger organisations = more extensive return to work policies.	Presence of return to work policies found to be associated with favourable trends in absence. Unions play significant role. Problem of organisational variation – requires research into the more effective options for each in this field. Nature of employer- worker relationships also underlined.
(Department of Health 2008) UK	Raising the Profile of Long Term Conditions Care. A Compendium of Information	N/A	Ageing population, number of people with long term conditions will grow; should be supported to make healthier lifestyle choices. People with limiting LTC less likely to be in work – being out of work detrimental to people's health → poor mental health and psychological distress; households containing someone with a LTC are more likely to have low incomes;	Ageing population, number of people with long term conditions will grow: policy response is required.
(Disability Rights Commission 2005) UK	Briefing paper aimed at people with cancer, MS or HIV	Paper designed to give a basic idea re DDA protection for these groups	Protection against direct discrimination; protection against less favourable treatment; employers must make 'reasonable' adjustments; protection from harassment and victimisation; equal service accessibility; equal access to insurance	As in key findings.
(Fallowfield 1995) UK	Editorial	N/A	Report meta-analysis of effects of psychosocial interventions in adults with cancer by Meyer and Mark (1995) Health Psychology 14: 101-108 (returning to work classified as positive functional adjustment)	Psychological interventions should be requirement for good cancer care and integral to every patient's management plan.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Feuerstein et al. 2006) USA	Published speech			Epidemiological studies on interactions and pathways among multiple risk factors and their relationship to work disability. RCTs to identify effective long-term interventions for work disability
(Feuerstein 2005) USA		Illustrating how knowledge and skills in area of musculoskeletal disorders and work disability can be brought to bear on understanding and then intervening in area of cancer survivorship and work	Cancer survivors = higher levels of lost productivity and higher levels of fair or poor health. Challenges of cancer patients returning and staying at work	n/a
(Haley 2003) USA	Review	Reviewing stressors of cancer caregiving and their potentially negative effects	Most older patients with cancer cared for by family member; secondary stressors include disruptions in schedules that may impact employment; caring for person ≥ 70 yr with cancer estimated @ 10h/week; Caring may take time away from employment	HCPs should educate in care management and availability of community resources, teach coping skills. Formal educational programs on cancer and caring
(Hanratty et al. 2007) UK	Systematic review; 24 papers from 21 studies in English between 1980 - 2006, 14 were cross-sectional.	Review evidence of financial stress and strain for people with terminal cancer and their carers, prevalence and identity consequences for health of patient or carer.	Little on employment per se; some USA studies mentioned taking on an extra job or giving up a job (range 10 to 40%); Emanuel et al. 2000, Slutsman et al. 2002, McCarthy et al. 2000, Covinsky et al. 1994, Welch et al. 2005, Tilden et al. 2004); USA studies mention specifically change in employment to cope with caregiving.	n/a

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Hoffman 2005) USA	Review (much of it related to legal system changes, new laws etc); 43 references	Reviewing how lives of cancer survivors at work have changed over past generation (last 30yrs) and how survivors preserve their legal and social gains and protect their rights to equal employment opportunities	One factor constant over past 30yrs - survivors want to and able to perform jobs and return to work after diagnosis though cancer treatment does limit ability of minority to work as they did pre-diagnosis. Most survivors work for financial benefit and also for health insurance, self-esteem and social support. Four Federal Laws provide some protection (Americans with Disabilities Act, Federal Rehabilitation Act, Family and Medical Leave Act and Employee Retirement and Income Security Act). Also State Employment Discrimination Laws and State Medical Leave Laws. Sections on genetic-based discrimination and on how to avoid employment discrimination (USA); 30yrs ago, most cancer resources directed towards medical treatment, few survivors had help finding/keeping job; now, laws and perceptions re living with and beyond cancer means job opportunities enhanced for survivors.	Advocacy resources should focus on enhancing survivors' QOL at work. From diagnosis on, survivors need team-based, long-term support in managing employment, including symptom management, physical and mental health rehab, legal rights and reasonable accommodations
(Institute of Medicine 2005) USA	Review of employment and health insurance concerns		20% of cancer survivors face work limitations 2-3 years after diagnosis. All at risk of experiencing subtle employment discrimination.	Employers should implement programs to assist cancer survivors. Public and private sponsors should support employer and public education about continuing productivity of cancer survivors

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Kam et al. 2002) USA	Discussion of Americans With Disabilities Act 1990 and review of guidance and website stories: un-sourced anecdotal evidence	Not apparent	Providing reasonable accommodation can provide a better working environment and provide tax incentives etc, the company and top management will get more respect and loyalty and providing accommodation will prevent companies being sued; Employers need to learn more about cancer and that accommodating employees is usually low cost and easy to put into practice. Suggests overall benefit greater than the cost.	n/a
(Mellette 1985) USA	Review: 18 references	Evaluate current status of employment of cancer patient.	Discrimination against cancer patient demonstrated; especially in hiring. Person treated for cancer may have unique problems resuming employment or starting new job. Employers have difficulty recognising variability in functional capacity and prognosis and often unaware of improved prognosis for many cancers. Patients need to adjust work schedule or need job training or vocational counselling; Efforts needed to educate employers and public to ensure rights of cancer patient recognised but HPs should not overemphasise potential problems to degree that increases patient fear and insecurity re employment. Insurance problems especially health insurance need major attention – high number of reported cancellations and changes in insurance benefits reported	In many US states, vocational rehabilitation agencies have increased interest in providing services to cancer patients. HPs need to provide info on employment resources available to patients

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Messner et al. 2001) USA	Commentary	N/A	Employers and co-workers continue to equate cancer diagnosis with decreased ability or death. Highlights key legislation/ protection resources on employment and discrimination and web sites;	HCPs can assist persons with cancer who wish to continue in the work force or to re-enter it by being well-informed about patient rights and resources available to them and advocate on their behalf.
(Myers et al. 1999) USA	Review of literature on physical and psychosocial correlates of head and neck cancer; Medline, Psychlit 1990-1996. Monthsst studies cross-sectional n=34 whereas one third are prospective. Majority of studies statistical analysis limited to univariate techniques; multivariate used in only 8 studies. Comparing with review done 10 years prior.	Literature review, focusing on quality of life issues, rehabilitation outcomes and changes in the literature from previous decade	In relation to employment and social functioning: social isolation. Because of cancer and treatment, some patients must discontinue their usual job, household and other activities: depression/facial disfigurement common – affects social participation; Importance of social support in recovery and rehabilitation widely reported – but significance increases with particular cancers (e.g. those visibly disfiguring). Little known about rehabilitation outcomes over time. Physical problems may decrease, but psychological problems (damage to body image and self-esteem) can worsen – affecting employment.	Still great variability and contradiction in results (small sample sizes and varying instruments); most studies still retrospective; many still only using descriptive or multivariate analysis; lack of theoretical basis. Need to: come to consensus and development and instruments to use; conduct more prospective studies to identify quality of life domains affected by treatment; larger sample sizes; multivariate analysis; develop programmes aimed at maximizing rehabilitation outcomes and evaluate these programmes with randomized designs.
(Naysmith 2009) SCOT	Newspaper report of opinions of cancer sufferers and head of Maggie's, Glasgow. Anecdotal.	N/A	Cancer sufferers struggle to get back to work; experiences of cancer patients in workplace can vary enormously; may have to opt for early retirement and feel robbed of the end of a career; financial results detrimental; a lot depends on line managers; phasing in is essential.	Steps to be taken by employer when worker falls ill: (i) employer-employee dialogue; (ii) clear information on financial entitlements; (iii) prejudice-free workplace; (iv) listen, understand employee's treatment plan and work decisions and accommodate employee; (v) flexible working arrangements, not annual leave for appointments; (vi) know responsibilities under disability law

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Petee 2000) USA	Commentary and perspective	Highlighting work-related sources of distress	Work is important to self concept and self esteem of growing % of population. Despite increasing survivorship, cancer remains a life-threatening illness that encourages individuals to reassess basis of their identity. Unanticipated changes in employment can trigger a disturbing exacerbation of this process. Cancer patients – disability undermines both identity and normalcy. Loss of normalcy, intactness and control. Return to work – reaffirming normalcy. Fairness at work important; Recognition of work related sources of distress has practical implications for clinicians and employers	Better screening of patients new to oncology setting to identify those who are struggling with work related issues of identity, normalcy and fairness. Extending health professional knowledge of work-related difficulties. Increased referral to psycho-social clinicians who can further assess need for specific interventions. Experienced clinicians = increased and more effective counselling.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
Practitioner Review (Eiser 1998) UK	Review	Reviewing the long term consequences of childhood cancer	Psychological consequences (may affect employment): impaired cognitive function but many children do recover and display academically as well as peers; more specific impaired neuro-psychological and social functioning; possible psychological and behavioural problems; employment problems but much research judges against gold standards of achievement; General reports of discrimination in work force and armed forces; ignorance and prejudice from career advisors → denial of opportunities to survivors; little realistic advice given about appropriate career opportunities. Current research gives little indication as to whether problems can be directly attributable to disease or treatment, or indirectly to social and family factors that have jeopardised child's chances of recovery. Advice about employment prospects and discrimination one of the main problems found.	Career advisors and counsellors must overcome prejudice and be more practical and realistic in their advice. Need for systematic investigation of long-term employment impact. Increased and better interventions and advice required. At present information too fragmentary → inability to make accurate predictions.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Rendle 1997) UK	Limited review of survivorship and psychosocial issues – tends to be older papers.	Reviewing literature of psychosocial issues re breast cancer survivors in relation to employment and social support	Specific breast cancer-related research needed and research re different types of work as many barriers re employment unidentified (but employer, other employees, age, physical barriers e.g. fatigue noted); relation of social support to significant other highlighted; Stigma/negative attitudes affect employment opportunities for cancer survivors. Employment is a vital component of many women's lives. Research suggests survivors rely on previous employers for employment. Support extremely important for all cancer patients.	Recommendations for nursing practice and research made; several now in practice
(Savage 2008) CAN	Press report of study of Lauzier and Maunsell 2008	N/A	N/A	None
(Schover 2004) USA	Editorial: notes re various studies, mostly Maunsell et al. 2004	N/A - Editorial	Maunsell's work shows women mention losing jobs, stigma in workplace, inability to meet physical demands of work. Other reports show breast cancer survivors only 10% less likely to be employed than similar women without BC; 80% of women initially employed and disease free at follow-up of ~6yrs were still working but women with physical blue-collar jobs may have more difficulty returning to work (Satariano and DeLorenze 1996); Reassured by comparable findings between Canada, where women's access to health care is independent of occupational status, and USA, where affordable private health insurance usually tied to a particular job.	n/a

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Spelten et al. 2002) NDR	Series of literature searches on return to work of cancer survivors, spanning 15 years; Studies had to focus on patient's perspective and had to include percentage of return to work or factors associated with return to work. 14 studies identified.	An overview of research into the return to work of cancer survivors, examining both the rate of return to work and factors impacting this return	1 study – 100% return to work rate because patients had to be back at work in order to qualify for study inclusion. 10 studies – rate of return ranged from 30 – 93% (mean return to work rate of 62%). Positive return rate? Associated with good co-worker and employer attitudes. Negative factors? Manual/physical labour requirements; Striking – wider variation in factors affecting return to work: work-related factors, disease/ treatment related factors and person-related factors combo. No clear trends emerging over 15 year review. However, supportive work environment facilitated return to work. Manual/ physical work negatively associated. Some cancers > difficulty e.g. head and neck. Socio-demographics (education, income, gender and marital status) not found to be negatively associated. Age hindrance? Results mixed.	Lack of systematic research. Poor theoretical frameworks. Little attention paid to effect of cancer site. Differences in job type not addressed. Studies need to adopt a longitudinal and prospective design, focusing on development of factors affecting work over time. Critical of methodological rigour and outlines 6 criteria for future studies.
(Steiner et al. 2004) USA	Systematic literature search. Adults >18. Excl adult survivors of childhood cancer. 6 methodologic criteria set to guide data abstraction.	Reviewing literature – existing rarely identifies targets for intervention and lacks rigorously tested intervention strategies	Research has been impeded by weak research designs, lack of validated and standardised measures, haphazard measurement of work outcomes; Work important to the individual, his/her family and social network, to employer and to society at large. Importance of designing interventions to restore the individual to optimal function.	We screen working-age people as a policy, but we do not understand entirely the outcomes of detection and treatment. Increasingly important to assess the impact of cancer diagnosis and treatment in broad personal and social context.

authors	study design and sample	study aim	key findings/author conclusions	author recommendations for policy/ services and research
(Talcott 2005) USA	Editorial reviewing research studies	Employment after therapy for localized prostate cancer	<p>Previous studies appear positive re employability but on closer inspection residual problems affect employment later. Those closer to retirement more likely to retire; many work fewer hours after diagnosis than before and report treatment-related symptoms that make them unable to work at former capacity. Burden of unemployment falls disproportionately on older, less educated men; Prostate cancer diagnosis affects employment.</p> <p>Refers to earlier hypertension study whereby men who became aware of hypertension subsequently doubled their medical absenteeism</p>	Should temper enthusiasm of those urging more energetic efforts to diagnose prostate cancer, at least until PSA screening is proven beneficial

Appendix B : Search strategy: electronic databases

Database	Total	Duplicates	Final Total	Notes
ASSIA: Applied Social Sciences Index and Abstracts, Social services Abstracts and Sociological Abstracts	888	48	840	All keywords
BNI	139	20	119	mp=keyword
exp =subject heading for BNI				
CINAHL	2178	157	2021	Searched in Abstract not keywords.
EMBASE	5099	1896	3203	All subject headings for EMBASE
MEDLINE	1708	238	1470	All MeSH terms for Medline
PSYCINFO	993	59	934	mp=keyword
exp=Subject heading				
WEB OF SCI	470	17	453	Topic
ALL DATABASES				
9040				

Then, duplicates removed from 'All Databases':

Total 9040

Duplicates 1336

FINAL TOTAL 7704

25th March 2009

All Keywords

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