

The physical and practical problems experienced by cancer survivors: a rapid review and synthesis of the literature

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Abstract

Purpose: A rapid and comprehensive review to identify what is known and not known about the physical and practical problems faced by adult cancer survivors.

Methods: A systematic literature review process was used. This focused on published reviews to enable a fast but rigorous identification of both the gaps and well researched areas within survivorship.

Results: The search identified 5121 reviews, of which 42 were screened and 9 met the quality and inclusion criteria. 6 looked at mixed disease groups, and 3 were disease-specific (ovarian, prostate and testicular cancers). The majority of papers focused on physical well being (n=6) with the remaining papers focusing on practical well being (employment and finance). The quality of the reviews was variable (ranging from weak to good). Gaps identified include sexual function, lower limb lymphoedema, peripheral neuropathy, bladder and GI problems, hormonal sequelae,

older cancer survivors, work impact of cancer and context-specific unmet supportive care needs. The review found a lack of standardised nomenclature for survivorship and methodological limitations.

Conclusions: Four main gaps in knowledge relating to the practical and physical problems associated with cancer survivorship have been identified. These are key symptoms, employment, unmet supportive care needs and older cancer survivors, and should be addressed by future research and systematic literature reviews. Work is also needed to address the nomenclature of survivorship and to improve the methodology of research into cancer survivors (including standardised measures, theoretical frameworks, longitudinal design, inclusion of older survivors and age-matched controls for comparison). The review highlighted the need for better research within the identified areas in order to improve the experiences of cancer survivors.

Keywords

Cancer survivor, adult, well being, physical, practical, review

Introduction:

Approximately two million people across the United Kingdom live with a diagnosis of cancer. Of these, 1.24 million had an initial cancer diagnosis more than five years ago (Maddams et al, 2008). Worldwide, 24.6 million people were diagnosed with cancer in the last five years and it is expected that 50% of these will live at least five years (CRUK, 2008). With the increasing incidence of cancer and the improvement in treatment and prognosis leading to better survival rates, it is anticipated that the number of cancer survivors is likely to grow by 3% per year (Maddams et al, 2008).

The term *cancer survivor* as way of describing those who are living with and beyond cancer has emerged relatively recently. There is currently no clear and universally accepted definition of what cancer survivor means and it often used to refer to people at any point on the cancer trajectory from diagnosis to end of life. Thus it can include those who are living with cancer and those who have had cancer in the past (Richardson et al., 2009).

It is increasingly recognised that the impact of cancer does not end after treatment and that current approaches fail to address the full range of physical, psychological, social, spiritual and financial needs that cancer survivors may have after treatment (Feuerstein, 2007). The Health and Well Being Survey (Macmillan, 2008) found that

cancer survivors reported poorer health and well being than the general population. As a result of cancer and its treatment, survivors are often left with the physical reminders such as pain, fatigue, sterility and loss of sexual function. Indeed, the aftermath of treatment has been described as worse than the disease itself (Doyle, 2008). A recent study of 1,152 people with breast, colorectal and gynaecological cancers found that 30% reported more than five moderate or severe unmet needs at the end of treatment. For 60% of these individuals the needs remained six months later (Armes et al, 2009).

Cancer survivors also experience issues relating to practical well-being, which encompasses employment and finance. In the UK it is estimated that there are 700,000 people of working age who have had cancer diagnosis (ONS, 2003). Many of these feel that they need to return to work when they feel fit and ready (Amir et al, 2007); however, a meta-analysis (de Boer et al. 2009) which compared cancer survivors to people with no cancer, found that cancer survivors are 1.37 times (95% CI; 1.21-1.55) more likely to be unemployed than those without cancer. Furthermore, many people affected by cancer report some degree of economic hardship resulting from loss of income and extra costs incurred due to cancer (Lauzier et al, 2008).

Given the survival rates and the physical and practical costs to cancer survivors, the UK's Cancer Reform Strategy (DoH, 2007) identified a need to shift care towards personalised assessment, care planning and self-management, supported with information on the consequences of cancer and its treatment. This will necessitate a shift from viewing cancer as an acute illness to a greater focus on cancer as a chronic illness, with a view to maximising health and well being after treatment.

The survivorship field is in its infancy and the complex array of potential risks, target problems and potential long term outcomes which individual survivors experience are just beginning to be explored and understood (Feuerstein, 2007). In the UK, the National Cancer Survivorship Initiative (NCSI) was established following the publication of the Cancer Reform Strategy (DOH, 2007) in order to consider approaches to survivorship care and how these can best be tailored to meet individuals' needs. The NCSI aims, by 2012, to have taken steps to ensure that

cancer survivors get the care and support necessary to enable them to lead as healthy and active a life as possible, for as long as possible.

In order to identify key areas for future research into cancer survivorship the NCSI commissioned research to identify what is known and not known about the health and well being and care needs of cancer survivors. This paper reports the findings of the rapid and comprehensive scoping and synthesis of the research evidence into the physical and practical aspects of health and well being for cancer survivors and identifies priority areas for further research.

Aim

Aim

The aim was to undertake a rapid and comprehensive review of the literature to identify what is known and not known about the physical and practical problems faced by adult cancer survivors. This will identify areas that should be addressed by future research.

Scope

The scope of this review was the consequences of cancer on well being, focusing on physical (e.g. symptoms) and practical (employment and finance) problems. As part of the NCSI review a separate rapid review of the psychological and social problems faced by cancer survivors was also carried out using the same search method. A precise phase-based conceptual framework was adopted in order to focus the review based on a framework proposed by Feuerstein (2007). This identifies 6 phases of survivorship: diagnosis, treatment, acute, subacute, chronic/long term and end of life. The focus of the NCSI on care and support from the end of primary treatment onwards signified that the review limited itself to the acute, sub acute (although in practice the boundary between the latter is often unclear) and long term phases, to which was added a fourth 'disease free' phase (Table 1).

[insert table 1]

Materials and Methods:

A systematic literature review process was adopted for the rapid review. The principles of systematic review that were retained included identifying search engines, generating inclusion and exclusion criteria that assess for relevance and quality and assessing abstracts independently. However, it differed from a traditional systematic review in that only published review articles were examined. This approach was selected as it was deemed cohesive with a fast but rigorous identification of both the gaps and well researched areas within survivorship, enabling the swift identification of clear areas for future research. This style of literature review permits a preliminary assessment of potentially relevant literature, its scope, quality and size, and is an essential preparatory step before conducting a systematic review (Centre for Reviews and Dissemination, 2001).

Quality was assessed using a 7-item checklist informed by the Critical Appraisal Skills Programme (CASP) (Oxman et al, 1994), with a maximum possible score of 7. A data extraction sheet was used to document the findings from included literature reviews. 20% of all full papers were extracted and systematically summarized by both reviewers in order to verify good agreement.

Search methods

The electronic databases searched during June-August 2009 were Medline, BNI (British Nursing Index), CINAHL (Cumulative Index to Nursing & Allied Health Literature), EMBASE, Psycinfo, Web of Science, Pubmed and Cochrane

Search Strategy

The search strategy was developed based on a combination of keyword and expert search strings with input from medical librarians. The search strategy for Medline was as follows (1) exp Neoplasms, (2) cancer\$, (3) tumo?r\$, (4) malignan\$, (5) neoplas\$, (6) oncolog*, (7) carcin\$, (8) 6 or 4 or 1 or 3 or 7 or 2 or 5, (9) Physical Fitness/ or Physical Exertion/, (10) physical, (11) 9 or 10, (12) well being, (13) income/ or occupations/ or poverty/ or social change/ or social class/ or social conditions/, (14) financ\$, (15) employ, (16) Work, (17) income/ or pensions/ or "salaries and fringe benefits"/, (18) 13 or 14 or 15 or 16 or 17, (19) 8 and 11, (20). 8 and 12, (21). 8 and 18, (22) 19 or 20 or 21 with limitations. A comprehensive search string is included in the appendix.

Review Identification

The bibliographic details, keywords, abstracts and website address (where available) of all identified titles were imported into the software program Reference Manager 11.0 and combined into one database. Duplicated papers were removed. The title and abstract of each article were read by two reviewers (SB and ZS) and potentially relevant studies were independently selected for review by using the inclusion/exclusion criteria. Inclusion criteria included review papers published between 2000 and 2009 (permitting the inclusion of evidence from primary data studies published before 2000), all cancers, and patients diagnosed ≥ 18 years. Exclusion criteria included childhood and adolescent cancers, papers reporting only biomedical data, review papers other than research literature reviews, and papers in a language other than English.

Potentially relevant papers were read and summarized systematically using the data extraction sheet and assessed in terms of inclusion/exclusion criteria and methodological quality. They were then organised into categories, according to the focus of the review, the key findings, the limitations and recommendations of the review. Each of the papers was awarded a quality score (maximum score of 7) as a broad indication of quality. A review paper was included if it achieved a score of >2 . Any disagreements were resolved by discussion and the involvement of a third researcher (ZA).

Results

5121 potentially relevant papers were identified, from which 42 non-duplicate abstracts met the inclusion criteria and the full papers were screened using the extraction sheet. Of these, nine papers met the quality and inclusion criteria and merited inclusion in the review (Fig. 1).

The included review papers mostly examined multiple disease groups ($n=6$), with the remaining three papers looking at the survivors of ovarian, prostate and testicular cancer. Only one review focused specifically on female survivors, two on male survivors and six looked at a mixed population. In terms of the physical or practical well being focus; three reviews focused on general symptoms associated with

cancer survivorship, two on fatigue, two on employment, one on sexual functioning and one on unmet supportive care needs. Quality scores varied; 5 reviews scored $\leq 4/7$ (weak to moderate/weak), and four scored $\geq 5/7$ (moderate/good to good). Only two reviews met the full quality criteria (7/7). There was a lack of standardised nomenclature varied greatly across the reviews and the phase was often unclear. A summary of the characteristics of each of the 9 review papers is provided in Table 2.

Three themes were identified through broad thematic analysis and are presented below:

1. On-going physical symptoms experienced by cancer survivors;
2. Functional Impairment, defined as the Individual's loss of the ability or capacity to perform his/her day-to-day activities;
3. Factors affecting the needs and experiences of cancer survivors.

On-going physical symptoms

The review identified pain, fatigue, peripheral neuropathy, lymphoedema, gastrointestinal problems, sleep disturbance, bladder dysfunction and menopause as physical symptoms experienced by cancer survivors.

1. Pain

There is moderate amount of literature on pain, mainly related to fatigue (Visovsky & Schneider, 2003; Servaes et al., 2002). The systematic reviews indicate that pain is a problem for many cancer survivors and, specifically, that chronic pain is more prevalent in breast cancer survivors than it is in the general population. Some cancer treatments may cause pain. Radiotherapy and younger age are found to be predictors. It was suggested that future research on pain should prioritise sequelae prevention.

2. Fatigue

There is strong evidence that cancer survivors experience fatigue during and soon after treatment, with the majority of studies finding that fatigue is an important problem for approximately one-third of cancer survivors. There is only modest evidence illustrating the manifestation of fatigue in the longer term and whether fatigue affects cancer survivors in a different way than the general population (Avis &

Demling, 2008; Lockwood-Rayermann, 2006; Visovsky & Schneider, 2003; Servaet et al., 2002; Spelten et al., 2002). Fatigue is found to be associated with pain, sleep disturbance, menopausal symptoms anxiety and depression and physical activity/physical functioning. Higher levels of fatigue affect quality of life, functional status and symptom management.

It is hard to draw conclusions about the relationships between fatigue and disease- and treatment-related characteristics, because these relationships are seldom properly investigated. Most evidence relates to disease-free women with breast and ovarian cancer and survivors of Hodgkin lymphoma. Further work is needed in post-treatment populations using longitudinal studies (to indicate factors correlated with the initiation or persistence of fatigue) which utilise reliable and valid multi-dimensional fatigue instruments and include control groups.

3. Peripheral neuropathy

Peripheral neuropathy is rarely studied in relation to cancer survivors and there is limited evidence on the incidence and course of this symptom. It is currently known to be chemotherapy-induced and is associated with platinum-based chemotherapy and taxanes (Lockwood-Rayermann, 2006).

4. Lymphoedema

Lower-limb lymphoedema is reported to be a problem for breast and gynaecological cancer survivors, however, little conclusive research was found. There was a call for more clinical trials to determine what interventions can improve this problem, and more systematic surveillance for its early detection (Lockwood-Rayermann, 2006).

5. Gastro-intestinal problems/ eating changes

Evidence about eating changes and gastro-intestinal (GI) problems is prominent with ovarian and prostate cancer survivors (Lockwood-Rayermann, 2006; Eton & Lepore, 2002). Appetite changes, alterations in taste and bowel problems are linked to treatment and are more likely to occur after treatment. The review identified the need to explore survivors' experiences with weight problems, particularly the emergent area of weight gain, and also to develop interventions to support survivors coping with these problems.

6. Sleep disturbance

Insomnia and night sweats are commonly reported by breast cancer and mixed cancer survivors, however the causes of these problems have not been extensively investigated (Visovsky & Schneider, 2003). It is documented that they might be related to anxiety, fear and uncertainty for the future. The recommendation is that future work should look at the causes of sleep problems experienced by the cancer survivors as well as the potential interrelationship between sleep disturbance and cancer related fatigue, which is currently unclear.

7. Bladder dysfunction

Little evidence exists on bladder and urinary problems of cancer survivors (Lockwood-Rayermann, 2006; Eton & Lepore, 2002). The existing evidence is focused on ovarian and prostate cancer survivors. More studies are needed to clarify the trajectory of this problem before bladder symptom management is recommended.

8. Menopause

Menopausal problems are documented by cancer survivors and are linked to the severity of fatigue (Lockwood-Rayermann, 2006). However, well designed evidence is limited. There is clearly more research needed to understand the severity and sequelae of this phenomenon.

Functional impairment

The reviewed literature identified the impact of cancer on individuals' ability to perform activities of daily living, particularly in relation to physical function, sexual function, cognitive dysfunction and the ability to work.

1. Physical function

Impairment in physical function has been commonly researched as a secondary symptom associated with fatigue or other symptoms. Several of the studies on female survivors found an association between a decline in physical function and a decline in quality of life (QoL), indicating that physical function can be a useful measure of QoL (Avis & Demling, 2008; Visovsky & Schneider, 2003; Eton & Lepore, 2002). There was a correlation between age and physical (and sexual) function, with older cancer survivors found to have more co-morbidities and poorer function than

non-cancer survivors (Avis & Demling, 2008). The review concluded that more work is needed on the late effects of cancer and the development of interventions to prevent loss of physical function with age.

The review found great variability with regards to the quality of research, in particular:

- No consideration was given to different co-morbidities and their interaction.
- Most studies did not report effect sizes (particularly important in those studies which determined statistical significance with large sample sizes).
- Studies comparing older and younger cancer survivors did not take into account treatment characteristics (beyond type of surgery or adjuvant therapy). To understand the impact of age on cancer survivorship, it is important to control for type of treatment received.
- Long term survivorship studies which included older adults did not include a comparison group of similarly aged individuals without a history of cancer.

2. Sexual function

The review found evidence that cancer and its different forms of treatment can have consequences for a person's sexual function leading to loss of desire, erectile disorder, orgasmic dysfunction, and decrease in sexual activity (Harrison et al., 2009; Avis & Demling, 2008; Lockwood-Rayermann, 2006; Eton & Lepore, 2002; Jonker-Pool et al., 2001). This issue has been most studied with survivors of ovarian, testicular, prostate, bladder and cervical cancer, however better understanding is needed about those most at risk, how best to assess patients and the impact of experiencing a disruption in sexual function. There is modest evidence to suggest that symptoms accompanying treatment-induced menopause are distressing.

Quality issues related to the research including lack of information on the relationship between follow-up periods and sexual function; variation in the number of variables and treatments, which make it difficult to assess the effects of specific treatments on physiological morbidity; and difficulties in comparing outcomes due to the variety of research methods.

3. Cognitive dysfunction

There is some limited evidence that cognitive dysfunction occurs as a consequence of cancer treatment ('chemobrain') and affects quality of life, but much of the evidence is limited to women with ovarian cancer (Lockwood-Rayermann, 2006). More understanding of the incidence, course and effect of alterations in cognitive function in cancer survivors is needed.

4. The ability to work

There is good evidence that cancer survivors are more likely to be employed than the general population and we have a reasonable understanding about the issues and problems associated with return to work for cancer survivors. Survivors of breast, GI and female reproductive cancers and disabled cancer survivors are at higher risk of unemployment. There is good evidence that those who have head and neck cancer, do a job that involves manual labour and perceive their work environment to be unsupportive are less likely to result to work. (Spelten et al. 2002).

More research is needed into the effect of different types of cancer treatment, different types of cancer and other socio-economic, cultural, and geographical factors on return to work. Future research should use large patient samples, matched control groups and standardised measures.

Factors affecting the needs and experiences of cancer survivors

A review by Harrison et al. (2009) looked at the prevalence of unmet supportive care needs at different time points along the cancer trajectory. The review identified that unmet needs were those associated with activities of daily living (ADL), economic needs, physical needs, supportive care needs and sexuality. Unmet needs were found to be greater in women, low income earners, those with low educational status, those living in remote or rural areas, those under the age of 45 and those not in remission or advanced disease.

The review identified discrepancies in the length of time from treatment completion which makes it difficult to generalise the results. It highlighted the need for well

designed prospective studies using standardised measures and reporting techniques.

Discussion

The aim of this rapid and systematic review of the literature was to identify what is known and not known about the physical and practical problems faced by adult cancer survivors. The review identified that there is evidence of survivorship research being undertaken, although the scope and focus of the research is limited and methodological limitations abound. The areas where we have some knowledge on the physical and practical well being of cancer survivors (Table 3) was dominated by symptoms or issues associated with symptomatology, particularly peripheral neuropathy, fatigue, pain, lymphoedema, bladder dysfunction, GI problems, eating problem, sexual problems, menopausal problems, sleep, cognitive dysfunction and physical function. Despite the number of studies already undertaken (93 studies in total reported in 6 reviews) these were all identified as key issues linked to the well being of cancer survivors and areas where research is still required.

Key symptoms requiring future research included:

- i) Sexual function: there is good evidence of the prevalence of problems (possibly allied with body image) reported within testicular, prostate ovarian and mixed cancer survivor populations. More research is needed into the experiences of patients and to explore the impact of different treatments on physiological sexual morbidity.
- ii) Lymphoedema: More research is required into lower-limb lymphoedema within the ovarian cancer population.
- iii) Hormonal sequelae: such as effects of treatment-related menopause.
- iv) Peripheral neuropathy: identified as a key finding within the ovarian cancer survivor population which requires more investigation.
- v) Bladder & GI problems: These were particularly highlighted within prostate and ovarian cancer survivor populations and more research is needed into symptom management and the impact on QoL.
- vi) Fatigue: identified as a common complaint which has been well researched, albeit within a focus on the disease free breast-cancer population. Clarity is

needed about the relationship between fatigue and pain, insomnia and menopausal symptoms.

The 3 reviews on practical problems associated with the well being of cancer survivors reported on 28 studies; focusing on finances (2 studies), employment (12 studies) and unmet supportive care needs (14 studies). In terms of unmet needs, despite the relatively high number of studies in this area, there remains a lack of evidence on the information and follow up needs of cancer survivors.

There was evidence of a link between unemployment and cancer and an association between unemployment, increasing age and disability. Three gaps relating to employment and requiring future research were identified:

- i) The work impact of cancer.
- ii) Identifying prognostic factors and vulnerable subgroups for unemployment.
- iii) Distinguishing between the disease/treatment-related, work-related and person-related factors associated with unemployment.

The final identified gap concerned work within the older cancer survivor population. Recommendations were made about the need for research which includes age groupings (young-old and old-old), comparisons with age-matched non-cancer controls (to understand the impact of cancer) and assessments of physical and mental health function at baseline (to enable an assessment of changes due to treatment). Particular research focus should be given to:

- i) Co-morbidities: more evidence is required on the interaction between a cancer diagnosis and existing co-morbidities.
- ii) Risk: research needs to be undertaken to identify subgroups of older survivors at greatest risk.

Limitations and recommendations

This review was commissioned by the NCSI as a scoping review rather than a comprehensive systematic review. Relevant and potentially important findings published from primary research papers outside the time frame of the review may have been excluded from this literature review. Consequently in making

recommendations for future research it is important to acknowledge that a review of reviews can only provide information on existing research and identified gaps in the literature, and may introduce bias towards certain types of research. For example qualitative studies are often less represented in literature reviews (Pearson, 2004). Alongside the identified gaps are the unidentified research gaps comprising areas which have not yet been explored or where a review has not been undertaken to date, and these may emerge as more research is undertaken within the area of cancer survivorship.

The scoping review can be as good as the quality of the reviews on which it is based. Taking into account that six reviews scoring $\leq 2/7$ were excluded based on their quality (Figure 1), it may be that high quality primary papers were also excluded. However, the review also identified many methodological challenges that should be addressed in future research. The quality of studies in the included reviews varied greatly, with many reviews citing the need for improvement. In particular they recommended that future research should comprise context specific, longitudinal, well designed prospective studies, using standardised reporting methods and measures, theoretical frameworks, and age-matched controls for comparison. Future studies should also consider the bio-psychological aspect of symptoms and avoid limiting the focus of research to biological-medical factors. Nomenclature was also a problem which requires standardisation. Most studies did not provide a clear definition of survivorship and, when survivor was defined, it was far broader than the Feuerstein (2007) model, encompassing active treatment and long-term disease-free survival.

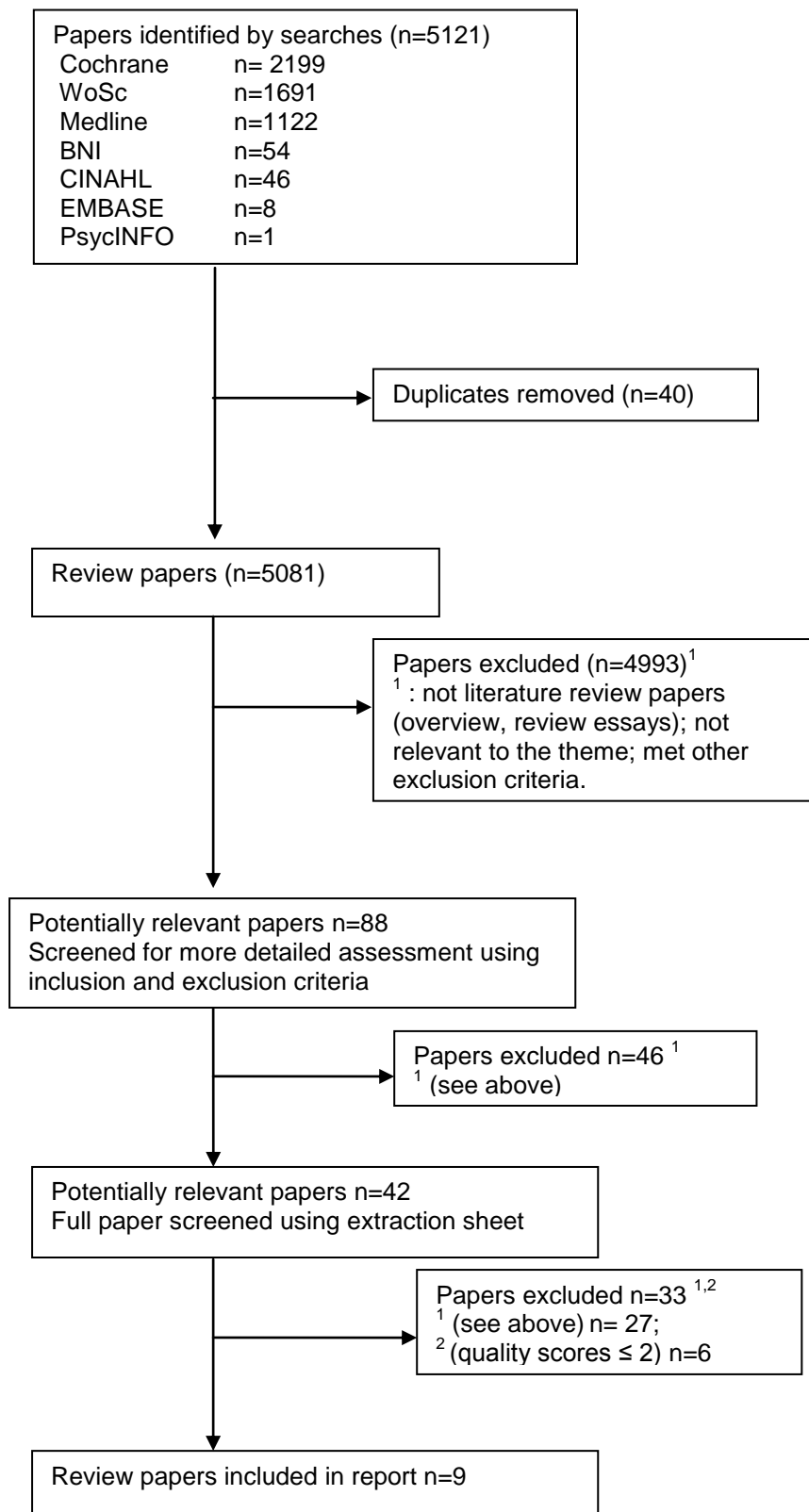
This review identified four key gaps in the research into the physical and practical well being of cancer survivors. It indicates that future work in this area should initially concentrate on key symptoms, employment, unmet supportive care needs and older cancer survivors. In order to establish the precise nature of research in these areas we recommend systematic reviews and, where possible, meta-analyses are first undertaken. Overall, there needs to be more research of better quality into the needs and experiences of cancer survivors in order to lead to the development of appropriate interventions and solutions to survivorship challenges.

Table 1 Description of phases for survivorship to be included in the review

Phase	Description
3. Acute	Covering the immediate period following primary treatment and then <i>'going home / follow up treatment'</i> . This stage overlaps with <i>'treatment'</i> but specifically covers long term treatment out of hospital, e.g. tamoxifen for breast cancer. This stage may be short or non-existent if the treatment is uncomplicated.
4. Sub acute	Covering <i>'living with the consequences of cancer'</i> , this is a term used in many diseases / illnesses to refer to that time directly after initial treatment when there is an expectation that health and function will begin to stabilise
5. Long term	Also covering <i>'living with the consequences of cancer'</i> and encompassing the initial aspects of <i>'if cancer comes back'</i> prior to diagnosis again. Not every cancer survivor experiences problems but they go into this stage some time after acute and sub-acute stages with around a third to a half of all survivors experiencing problems. Some cancer survivors continue to experience problems for years covering a varying burden of symptoms and functional changes.
6. Disease free	Added to the original model to specifically recognise that for those for whom treatment is successful and uncomplicated in terms of side effects and long term late effects that the 'end stage' can be long term disease free survival.

Source: modified from Feuerstein (2007)

Figure 1: Summary flowchart of the literature search



Author	Cancer site	Gender	Focus of review	Summary	Comments
Avis & Demling (2008)	Mixed	Mixed	General symptoms of the older cancer survivors	Review of 8 papers (2002-2007) on physical functioning of older cancer survivors. <ul style="list-style-type: none"> Suggests that cancer survivors have more co-morbidities and poorer functioning (i.e. sexual problems and fatigue) than non-cancer survivors. 	Weak review: scoring 3/7 <ul style="list-style-type: none"> Highlights the importance of studying the late effects of cancer and developing interventions to prevent loss of functioning with age.
De Boer et al. (2009)	Mixed	Mixed	Unemployment	Meta-analysis of 26 papers, describing 36 studies, from 1996 to 2008. Comparison of cancer survivors and people with no cancer which found: <ul style="list-style-type: none"> Cancer survivors 1.37 times more likely to be unemployed. Higher relative risk of unemployment due to disability from cancer. Survivors of breast cancer, gastrointestinal cancers, and female reproductive cancers especially likely to be unemployed. 	Good review: scoring 7/7 <ul style="list-style-type: none"> Highlights that a number of prognostic variables associated with whether survivors return to work have not been examined, including socio-economic factors, cultural factors and geographical factors. Need better estimates of the unemployment risk to enhance the identification of prognostic factors and vulnerable subgroups for unemployment.
Eton & Lepore (2002)	Prostate	Male	Health Related QoL and general symptoms	Review of 32 papers from 1992 to 2002. Focus on physical and psychosocial consequences of prostate cancer and its treatment, specifically: <ul style="list-style-type: none"> Disease specific sequelae of prostate cancer; namely urinary, sexual and bowel functioning outcomes. Evidence on health related quality of life. Evidence from comparison groups, longitudinal studies and cross sectional studies. Issues for men with localised prostate cancer.. 	Weak review: scoring 3/7 <ul style="list-style-type: none"> Suggests that there is research into consequences of disease/treatment Data in relation to QoL and well being are sparse. Need to start assessments early as currently they tend to occur years post treatment.
Harrison et al. (2009)	Mixed	Mixed	Unmet supportive care needs	Review of 14 papers from 1950 to 2006 focusing on the prevalence of unmet needs at different time points of the cancer trajectory. <ul style="list-style-type: none"> Unmet needs associated with activities of daily living, economic, physical, supportive care and sexuality. Unmet needs greater in women, low income 	Moderate/good review: scoring 6/7 Results difficult to generalise due to discrepancies in length of time since completion of treatment between studies.

				earners, low educational status, those living in remote or rural areas, those under the age of 45 and those not in remission or advanced disease.	
Jonker-Pool et al. (2001)	Testicular	Male	Sexual functioning	<p>Review of 36 papers from 1975 to 2000.</p> <p>Identified the following symptoms:</p> <ul style="list-style-type: none"> • Loss of desire. • Erectile disorder • Orgasmic dysfunction • Ejaculation disorder • Decrease in sexual activity • General sexual dysfunction. 	<p>Moderate/weak review: scoring 4/7</p> <ul style="list-style-type: none"> • Wide variation of variables and treatments made it difficult to assess the effects of specific treatment on the physiological morbidity. • Comparison of outcomes hindered by the wide variation of different research methods. • Papers reviewed failed to show a clear relationship between follow-up periods and sexual functions.
Lockwood-Rayermann (2006)	Ovarian	Female	General symptoms	<p>Review of 32 papers from 1983 to 2005. Focus on general symptoms for women post treatment</p> <p>Identified:</p> <ul style="list-style-type: none"> • Gastro Intestinal (GI)-related symptoms (i.e. constipation and diarrhoea). • Bladder/kidney dysfunction. • Lymphoedema. • Peripheral neuropathy. • Cognitive dysfunction. • Fatigue. • Body image. • Sexuality (particularly symptoms directly related to alterations in the reproductive duct). <p>Several studies suggest that the symptoms experienced by female survivors can directly affect their quality of life and represent a useful measure of QOL: e.g. a decline in QOL is concomitant with a decline in physical functioning.</p>	<p>Weak review: scoring 3/7</p> <ul style="list-style-type: none"> • Only 5 papers clearly addressed long-term survivorship <p>Gaps identified include:</p> <ul style="list-style-type: none"> • Lower limb lymphoedema. • Incidence and course of peripheral neuropathy. • Cognitive dysfunction related to treatment (outside of those in relation to breast cancer). • Effects of treatment-related menopause and other hormonal sequelae have had limited study. • Neurotoxicity. • Bladder symptom management. • Sexuality. • Cancer fatalism, post traumatic stress syndrome.
Servaes et al., (2002)	Mixed	Mixed	Fatigue	<p>Review of 16 papers from 1980 to 2001.</p> <ul style="list-style-type: none"> • Fatigue is mostly studied during active treatment for cancer, and is an important problem during this 	<p>Good review: scoring 7/7</p> <ul style="list-style-type: none"> • Fatigue is a problem for approx 1/3 of cancer survivors.

				<p>period.</p> <ul style="list-style-type: none"> • Studies focusing on fatigue in disease-free cancer patients, although less prominent, also indicated that fatigue is an important complaint in this time period (for approx 1/3 of cancer survivors). • Comparison of cancer patients with healthy control subjects shows that cancer patients report more frequent and severe fatigue than healthy controls. • Fatigue was also found to be related to anxiety and depression, sleep quality, and a few physical variables (pain, dyspnoea, menopausal symptoms and physical activity/ physical functioning). 	<ul style="list-style-type: none"> • Difficult to draw conclusions about relationships between fatigue, disease and treatment-related characteristics as they are seldom investigated. • Studies of off-treatment fatigue mainly focus on disease free breast cancer patients.
Spelten et al. (2002)	Mixed	Mixed	Return to work	<p>Review of 14 papers from 1985 to 1999.</p> <ul style="list-style-type: none"> • Factors negatively associated with the return to work include <ul style="list-style-type: none"> • Non-supportive work environment. • Manual labour. • Fatigue. • Head & neck cancer. • Those survivors returning to work report problems associated with leaving the workforce: <ul style="list-style-type: none"> • Health & life insurance problems. • Lack of understanding from co-workers. 	<p>Moderate review: scoring 5/7</p> <ul style="list-style-type: none"> • Lack of systematic research into the return to work of cancer patients. <p>Gaps include:</p> <ul style="list-style-type: none"> • Prevalence of cancer in the working population. • Effect of cancer site. • Impact of the most common types of treatment. • Differences in job type, (beyond distinction between manual and non-manual labour).
Visovsky & Schneider (2003)	Mixed	Mixed	Fatigue and menopausal symptoms	<p>Review of 94 papers from 1983 to 2003</p> <ul style="list-style-type: none"> • Cancer-related fatigue continues after completion of cancer treatment. • Higher level of fatigue affects quality of life, functional status and symptom management. • Fatigue associated with pain, sleeping disturbances and menopausal symptoms. 	<p>Weak review: scoring 3/7</p> <ul style="list-style-type: none"> • Need to clarify link between fatigue, pain, sleep disturbances and menopausal symptoms in cancer survivors. • Evidence needed about severity of fatigue across types of illness.

Table 2: Summary of review papers on the physical and practical well being of cancer survivors

Identified issues	Amount of research	Scope	What is known
<u>Physical problems</u>			
Peripheral Neuropathy	3 studies	Ovarian cancer	<ul style="list-style-type: none"> A problem in 57-92% of patients treated with cisplatin and 60% treated with taxanes
Fatigue	10 studies	Ovarian cancer, Hodgkin's disease, breast cancer & mixed cancers	<ul style="list-style-type: none"> Fatigue mostly studied during the active treatment for cancer although evidence that cancer related fatigue continues after the cancer treatment is completed. Problem for 1/3 cancer survivors, and may affect their QoL, functional status and symptom management.
Pain	8 studies	Mixed cancers	<ul style="list-style-type: none"> Pain, fatigue and mood state are interrelated and affect the QoL in the physical domains of an individual's life. High levels interfere with mood and the ability to function Disturbs sleep, leading to increased fatigue.
Lymphoedema	3 studies	Ovarian cancer	<ul style="list-style-type: none"> Lymphoedema has been considered as a problem, but little conclusive research was found
Bladder dysfunction	4 studies	Ovarian & prostate cancer	<ul style="list-style-type: none"> Bladder dysfunction problems and damage to the kidneys may cause electrolyte imbalance
GI problems	9 studies	Ovarian & prostate cancer	<ul style="list-style-type: none"> Bowel problems linked to the treatment and are more likely to occur post treatment (especially after radiotherapy.)
Eating problems	2 studies	Ovarian cancer	<ul style="list-style-type: none"> Appetite changes and alterations in taste identified
Sexual problems	36 studies	Ovarian, testicular & mixed cancers	<ul style="list-style-type: none"> Include loss of desire, erectile disorder, orgasmic dysfunction, ejaculation disorder, decrease in sexual activity and general sexual dysfunction
Menopausal problems	2 studies	Mixed cancers	<ul style="list-style-type: none"> Menopausal symptoms linked to severity of fatigue

Sleep	6 studies	Breast & mixed cancers	<ul style="list-style-type: none"> • Causes of sleep problems have not been extensively investigated • May be linked to anxiety, fear, tension and uncertainty for the future. • Inactive patients experience insomnia • Breast cancer patients who become menopausal may experience night sweats
Cognitive dysfunction	2 studies	Ovarian cancers	<ul style="list-style-type: none"> • New phenomenon, which requires further investigation
Physical function	8 studies	Mixed cancers	<ul style="list-style-type: none"> • Cancer affects physical function more than psychological function in older cancer survivors (due to co-morbidities and poorer function at baseline)
<u>Practical problems</u>			
Employment	12 studies	Mixed cancers	<ul style="list-style-type: none"> • Cancer survivors are 1.37 times more likely to be unemployed. • Survivors of breast, GI and female reproductive cancers especially likely to be unemployed • Non-supportive work environment, manual labour, fatigue and having head and neck cancer found to be negatively associated with return to work
Finances	2 studies	Mixed cancers	<ul style="list-style-type: none"> • 5-13% of cancer survivors noted unmet needs in the financial domain of their life
Unmet supportive care needs	14 studies	Mixed cancers	<ul style="list-style-type: none"> • Identified around the cancer survivors' ADL's, economic, physical, supportive care and sexuality domains. • Greater in women, low income earners, low educational status, those living in remote or rural areas, those under the age of 45 and those not in remission or advanced disease

Table 3: What is known about the practical and physical well being of cancer survivors

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