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Review

Long-term survivors of adult cancers and uptake of primary health services: A systematic review

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ABSTRACT

Aim: The aim of this paper is to systematically review the literature on the use of primary and community care services by long-term survivors of adult cancers.
Methods: We conducted a systematic search of eight databases and considered papers looking at primary care aspects of surviving cancer at least 3 years past diagnosis.
Results: Ten eligible papers in four categories: consultation rates in primary care, cancer screening, use of preventative services and chronic disease management. There was no conclusive evidence that cancer survivors have increased rates of consultation in primary care. The studies reported that cancer screening is well managed in survivors. Preventative and chronic care is worse in long-term colorectal cancer survivors compared with long-term breast cancer survivors and controls.
Conclusion: We found little research, especially outside the United States, relating to the care of long-term cancer survivors in primary care. Future work should examine screening for treatment-specific sequelae and the quality of care for co-morbid disease.

1. Introduction

Due to improvements in the detection and treatment, more people are surviving cancer for many years after diagnosis. Recent statistics indicate that survivors of adult cancer live longer in a cancer-free period; in the UK, 5 and 10 year survival for three of the commonest cancers – breast, colorectal and prostate – has increased steadily since the 1970s.[1] Latest estimates indicate that 65% of all people diagnosed with cancer will live for at least 5 years.[2] The majority of cancer survivors are over 65 years of age, and if current demographic estimates are correct, by 2050 the number of people aged 65 and over diagnosed with cancer will double.[3] The health care needs of this ageing and increasing population are, therefore, becoming increasingly relevant.

Long-term survivors of adult cancer, just like the general population, need to manage their health by participating in preventative care and screening. Cancer survivors, however, have unique health needs as a result of living through cancer and its treatment. The late-effects of radiotherapy and chemotherapy are increasingly well documented, and many survivors face the risk of recurrence and second primary neoplasms.[4–10] The risk of adverse health can potentially be reduced through the uptake of preventative services. Cancer survivors, therefore, have a great need for community-based screening and preventative services to manage late-effects

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of treatment along with concurrent co-morbidities. Long-term survivors of adult cancer are also likely to access primary care services for care of chronic conditions as well as health promotion and disease prevention services.[11]

Much of previous research on cancer survivors has concentrated on the survivors of childhood and young adult cancer.[12] We have conducted a systematic review of the literature to look at primary care and community based aspects of care for the survivors of cancer diagnosed in adulthood. Specifically, we looked at the uptake of screening, preventative services and the standards of care for cancer-related health needs and co-morbidities. This work aims to provide background data to inform further research in this area with a view of improving the care of long-term survivors of adult cancers.

2. Patients and methods

2.1. Literature search

We searched eight electronic databases (MEDLINE, EMBASE, CINAHL, BNI, PsycInfo, HMIC, SSCI and Cochrane databases) from 1990 to February 2007, using search terms relating to survivorship in combination with cancer, family practice, community health care and long-term care (see Appendix A for an example of the Medline search). Two reviewers (NFK and PWR) screened titles and abstracts of all papers in the initial search and excluded citations which did not meet the inclusion criteria. Disagreements at this stage were resolved through discussion. One reviewer (NFK) independently assessed the retrieved full-text papers for relevance and inclusion, and examined the reference lists of all included papers for additional papers. Trials registered on the Office for Cancer Survivorship (OCS) and International Cancer Research Portfolio (only trials listed under ‘patient care and survivorship issues’) websites were checked for relevance.

2.2. Inclusion and exclusion criteria

Our definition of a long-term survivor was a person who had survived at least 3 years from diagnosis, as the majority of patients have completed active treatment (radiotherapy, chemotherapy or surgery) by this time point. Thus, we included studies which focused on the use of primary care services amongst survivors 3 years or more from diagnosis of an adult cancer. Papers written in English and non-English languages were considered for inclusion. We excluded papers based in secondary care, or which looked at the end-of-life care, survivors of childhood cancers, quality of life measures and research specifically on the families of cancer survivors. Papers were excluded if more than 50% of the participants in the study were less than 3 years from initial diagnosis, and authors were contacted for missing information on the length of survival.

2.3. Data abstraction and quality scoring

Two investigators (NFK and PWR) independently reviewed articles meeting the inclusion criteria and abstracted relevant data on to a standardised data extraction form. The same investigators appraised the quality of the papers using checklists developed by Goldsmith and colleagues[13] incorporating the following quality guidelines: Critical Appraisal Skills Programme (CASP),[14] Scottish Intercollegiate Guidelines Network (SIGN)[15] and the New Zealand Guidelines Group.[16] A third reviewer (AW) resolved any uncertainties on the main outcomes and quality scoring.

3. Results

We identified 1986 papers from the initial database searching, of which we retained 239 potentially relevant papers following abstract review. Of these 239 papers, 229 were excluded as they did not meet the criteria of the review (see Fig. 1). The remainder of the papers ($n = 10$) were assessed for quality and included in the review. See Table 1 for a summary of study methodology and quality scoring. The results are grouped and presented in four main components: consultation rates in primary care, cancer screening, uptake of preventative services and chronic disease management.

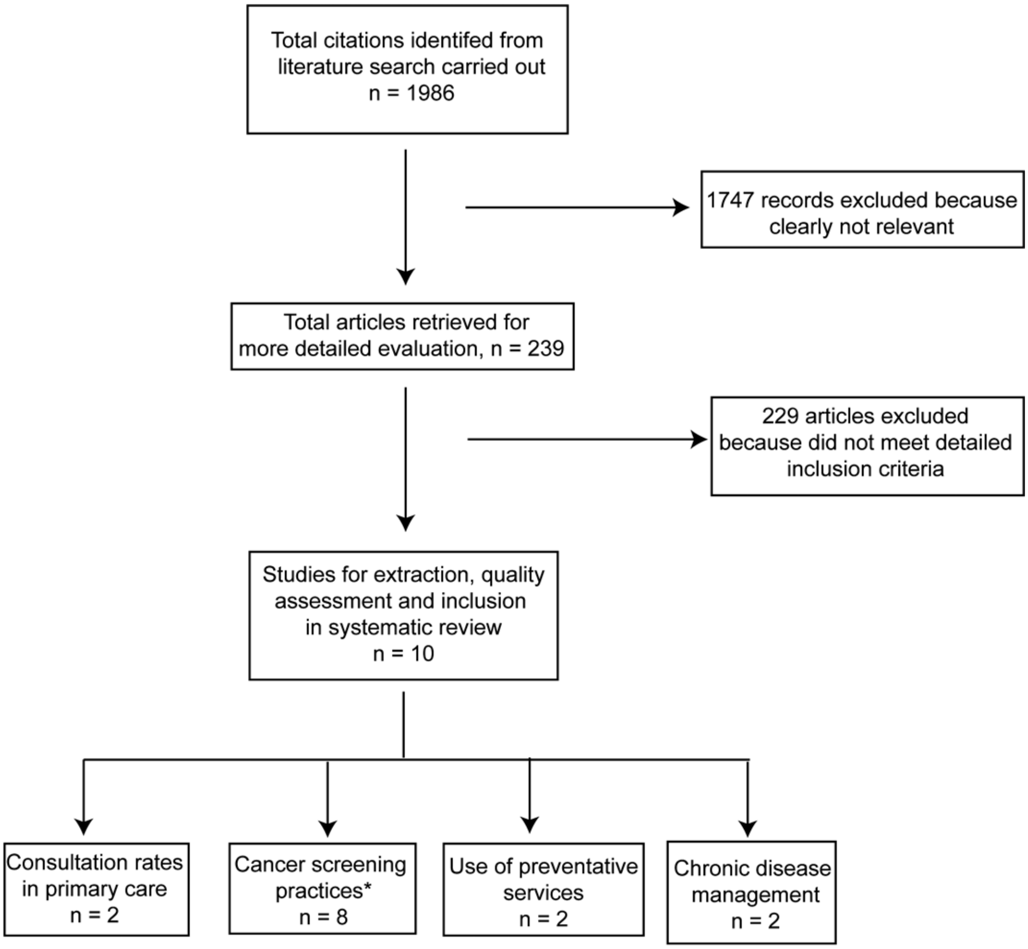
3.1. Consultation rates in primary care

Only two papers discuss consultation rates in primary care in long-term survivors of adult cancer following discharge from secondary care.[17,18] The first study, of Hodgkin’s disease survivors in France, showed that survivors made at least one more visit to their GP over a 6-month period than controls (83% versus 69%, $p = 0.013$). Survivors also had a slight increase in the number of visits to a general practitioner, with a mean number of 2.9 visits compared with 2.1 visits for controls ($p = 0.05$).[18] The second study, based in the UK, involved a voluntary discharge scheme from an oncology follow-up clinic. Of 65 patients, 41 (63%) accepted discharge and had a non-significant increase in primary care consultation after 12 months. However, the patients who were more anxious refused discharge from secondary care; 22% of patients accepting discharge had Hospital Anxiety and Depression Scale (HADS) anxiety scores of 8 points or more compared with 56% of those refusing discharge.

3.2. Cancer screening practices

In total, seven papers describe mammography use by survivors of adult cancer (Table 2). Three studies found that survivors were significantly more likely to follow US Preventative Services Task Force (USPSTF) guidelines on mammography than non-cancer survivor controls.[19–21] Additionally, two papers examined the adherence to USPSTF mammography recommendations in long-term survivors without comparison to controls.[22,23] These papers showed that breast cancer survivors had a higher rate of adherence to guidelines than Hodgkin’s disease (HD) survivors, however, the breast cancer survivors were all at least 50-years-old and therefore, in the recommended age group for mammography, whereas half of the HD survivors were under 40.

Cancer screening in survivors comprises routine follow-up for recurrence and second cancers. The final two papers considering breast screening examined the use of mammography in survivors of any adult cancer, with or without excluding



*Where papers addressed more than one question, they have been included in each relevant table/grouping.

Fig. 1 – Flowchart of search results.

breast cancer survivors to control this effect. Even with breast cancer survivors excluded, all survivors adhered better than controls to mammography.[21] Conversely, Mayer and colleagues report that after excluding breast cancer survivors, women over 40 were not more likely to have had a mammogram compared with controls.[24]

Five studies discuss Papanicolaou (pap) screening test for cervical cancer (Table 3). Three papers found that cancer survivors were significantly more likely to adhere to pap test guidelines than controls.[19–21] However, once survivors of cervical cancer were excluded from analyses, the significant association was lost in two papers.[21,24] Colorectal cancer survivors received significantly less pap testing than controls.[25]

Two studies show that survivors of adult cancer are more likely to have a PSA test[19,21] (Table 3). Trask and colleagues repeat the analysis after excluding prostate cancers survivors and show that the survivors are still more likely to have a PSA test.[21] However, Mayer and colleagues report that after excluding prostate cancer survivors, survivors were not more likely to ever have had a PSA test.[24]

Three papers describe screening for colorectal cancer[20,21,24] (Table 3). All the survivors of adult cancer were more likely to undergo colorectal cancer screening, even after conducting analyses after excluding survivors of colorectal cancer.

Female breast cancer survivors were more likely to have a mammogram if it was physician recommended or if their original cancer was picked up by a mammogram.[22] Participation in the health care system was also an important predictor of screening uptake; consulting a gynaecologist or a primary care physician was the strongest predictor of having a mammogram .[26] Patients not seen by an oncologist were less likely to undergo colonoscopies and mammographies.[20,25]

3.3. *Delivery of preventative health services and chronic disease management*

We defined preventative health services as non-cancer-related screening and disease prevention. Two papers examined the receipt of preventative health services, including flu vaccine, lipid testing, bone densitometry and eye exam by long-term survivors of adult cancer[20,25] (Tables 4 and 5). Breast cancer survivors received better care compared with non-survivor controls, conversely, colorectal cancer survivors received worse care compared with controls. Colorectal cancer survivors also received less chronic disease

Table 1 – Study characteristics

Authors	Country	Study design	Type of cancer	Length of survival	Number of participants	Response rate/follow-up	Quality score
Chait et al.[17]	UK	Questionnaire survey	Mixed	All over 5 years post-diagnosis	41 patients	88% and 95% response rates to the 4 and 12 month Q	+
Joly et al.[18]	France	Retrospective case–control	Hodgkin's disease	Average 10 years post-diagnosis	93 survivors, 186 controls	91% for cases, 66% for controls	++
Andersen and Urban[22]	USA	Cross-sectional interview	Breast	All more than 3 years, 87% more than 5 years post-diagnosis	351 women interviewed, 248 interviews analysed	83% participated, 59% analysed	++
Doubeni et al.[26]	USA	Retrospective cohort in HMO Administrative Data project	Breast	83.8% followed up for 3 years	797 women at start of cohort	262 women followed up for 5 years, 33% follow-up	++
Bloom et al.[23]	USA	Randomised control study	Hodgkin's disease	All more than 3 years, 75% more than 11 years post-diagnosis	157 women	85% completed the post-test six months after the intervention	++
Bellizzi et al.[19]	USA	Retrospective case–control using NHIS survey data	Mixed	60.9% more than 5 years post-diagnosis	7384 survivors and 121,347 controls from 1998, 1999, 2000 and 2001 NHIS surveys	Response rates 74%, 69.2%, 72.1% and 73.8% for each year respectively	++
Earle et al.[20]	USA	Retrospective case–control using SEER /Medicare data	Breast	All at least 5 years post-diagnosis	5965 survivors, 6062 controls	93.7%	++
Earle and Neville[25]	USA	Retrospective case–control using SEER/Medicare data	Colorectal	All at least 5 years post-diagnosis	14,884 survivors, 16,659 controls	79.6%	++
Mayer et al.[24]	USA	Retrospective case–control using NCI HINTS data	Mixed	Average 11.9 years post-diagnosis	619 survivors, 2141 controls	Overall response of 32.6%	++
Trask et al.[21]	USA	Retrospective case–control using NHIS data	Mixed	All at least 5 years post-diagnosis	2151 survivors, 30195 controls from NHIS 2000	88.9% response to NHIS 2000	++

Table 2 – Mammography

	Outcomes	
	Mammogram	Predictors of screening
Andersen and Urban[22]	70% of women were adhering to guidelines	Physician recommendation or if the original breast cancer was picked up by mammogram
Doubeni et al.[26]	80% of women had a mammogram in year 1, dropped to 63% in year 5	Visit to a gynaecologist (odds ratio (OR) = 3.5, 95% CI 2.55–4.79) or a primary care physician (OR = 2.2, 95% CI 1.73–2.82)
Bloom et al.[23]	36% of women were adhering to guidelines (pre-intervention)	–
Bellizzi et al.[19]	Survivors were 34% more likely than non-survivors to adhere to guidelines (95% CI 1.18–1.51)	–
Earle et al.[20]	Survivors were more likely than non-survivors to receive screening (74% of survivors compared to 41% of controls $p < 0.001$)	Breast cancer survivors not seeing an oncologist were significantly less likely to be undergoing surveillance mammography
Mayer et al.[24]	Excluding breast cancer survivors, female cancer survivors were not significantly more likely than non-survivors to ever have had a mammogram (OR 1.83, 95% CI 0.82–4.05) [a]	–
Trask et al.[21]	Survivors were more likely to follow guidelines than non-survivors (OR = 1.8 95% CI 1.5–2.1, OR = 1.5 95% CI 1.3–1.9 if breast cancer survivors excluded)	–

a Although there was not a significant difference in the rates of screening between survivors and non-survivors, both groups in this study met or exceeded American Cancer Society guidelines for screening.

management (eye exam in diabetics, diabetes monitoring, angina follow-up, heart failure and COPD follow-up and lipid testing in angina patients) than controls.[25] In contrast, diabetic breast cancer survivors received more lipid testing than controls, but no other indicators of chronic disease care were investigated.[20]

Table 3 – Pap smear, PSA testing and colorectal screening

	Outcomes		
	PSA	Colorectal screening	Pap smear/cervical screen
Bellizzi et al.[19]	Survivors were 32% more likely than non-survivors to adhere to guidelines (95% CI 1.21–1.52)	–	Survivors were 36% more likely than non-survivors to adhere to guidelines (95% CI 1.10–1.57)
Mayer et al.[24]	Excluding prostate cancer survivors, male cancer survivors were not significantly more likely than non-survivors to ever have had a PSA test (OR 1.13, 95% CI 0.39–3.3)[a]	Excluding CRC survivors, cancer survivors were significantly more likely than non-survivors to ever have had CRC screening (OR 2.03, 95% CI 1.29–3.2)	Excluding cervical cancer survivors, female cancer survivors over 21 were not significantly more likely than non-survivors to ever have had a pap smear (OR 1.85, 95% CI 0.48–7.16)[a]
Trask et al.[21]	Survivors were more likely than non-survivors to have a PSA (OR = 2.48, 95% CI 2.04–3.0, OR = 1.59, 95% CI 1.23–2.0 if prostate survivors excluded)	Survivors were more likely than non-survivors to have a colon screening exam (OR = 2.16, 95% CI 1.9–2.5 OR = 1.9, 95% CI 1.6–2.4 if CRC survivors excluded)	Survivors were more likely than controls to have a pap smear (OR = 1.28, 95% CI 1.08–1.5, not significant when cervical survivors excluded)
Earle et al.[20]	–	Survivors were more likely than non-survivors to receive colon exam (17% of survivors versus 14% of non-survivors, $p = 0.0001$)	Survivors were more likely than non-survivors to receive cervical screening (31% of survivors versus 27% of non-survivors $p < 0.0001$)
Earle and Neville[25]	–	–	Survivors were less likely than non-survivors to receive cervical screen (17.8% of survivors versus 21.9% of non-survivors, $p < 0.001$)

PSA, prostate specific antigen; CRC, colorectal screening.
a Although there was not a significant difference in the rates of screening between survivors and non-survivors, both groups in this study met or exceeded American Cancer Society guidelines for screening.

Table 4 – Use of preventative health services

	Outcomes				
	Flu vaccine	Lipid testing	Bone densitometry	Eye exam	Predictors of screening
Earle et al.[20]	65% of survivors versus 58% of non-survivors received vaccine over 1 year ($p < 0.0001$)	48% of survivors versus 43% of non-survivors received test over 1 year ($p < 0.0001$)	8.3% of survivors versus 6.8% of non-survivors over 1 year ($p = 0.001$)	–	Patients with higher SES, not African-American, decreasing age, living in an urban area or receiving care in a teaching hospital were more likely to receive preventative services. Those seeing a PCP were more likely to receive all other preventative services (except bone densitometry). Patients who saw both oncologists and PCPs received the highest rates of preventative services
Earle and Neville[25]	53.2% of survivors versus 55.4% of non-survivors ($p < 0.001$)	36.5% of survivors versus 39.4% of non-survivors ($p < 0.001$)	4.2% of female survivors versus 5.7% of non-survivors ($p < 0.001$)	47.4% of survivors versus 50.6% of non-survivors ($p < 0.001$)	Patients seen only by a PCP were more likely to receive flu vaccine and bone densitometry

SES, socioeconomic status; PCP, primary care physician.

Patients seeing a primary care physician or oncologist were more likely to receive necessary and preventative care. On the other hand, being African–American, lower socio-economic status, older age and living in a rural area were associated with lower receipt of preventative and chronic disease management.[20,25]

4. Discussion

4.1. *Main findings*

We have conducted a systematic review that has investigated four aspects of care for survivors of adult cancer managed outside of hospital: consultation rates in primary care, uptake of screening, use of preventative services and chronic disease management. Much of the research comes from the United States from secondary analyses of large datasets.

Only two papers describe consultation rates in primary care in long-term survivors of adult cancer, and the results are inconclusive. However, cancer patients may have differing levels of anxiety and preferences about how their discharge from secondary care should be managed.[27,28] Patient choice should be a component of deciding when and how to discharge patients from secondary care and in planning their follow-up care.

This review suggests that cancer screening is generally well managed through normal channels and is adequate amongst survivors of adult cancer in the United States. This result is not surprising amongst survivors of cancer for which the screening test was designed; for instance, prostate cancer survivors are likely to have more PSA testing as the screening test comprises routine follow-up for early detection of cancer recurrence. However, in one paper, when the relevant survivors of the cancer were removed from analyses, uptake of screening was neither significantly higher nor lower than matched controls. Cancer survivors are at a higher risk of developing a second primary cancer and once a patient has survived cancer both the physician and the patient should be more vigilant in screening for other cancers. The reviewed papers do not clarify the driving factors behind these practices, and how patient's health-seeking behaviour, physician-directed routine screening or recommended follow-up for recurrence affect the rates of screening. Targeting patients has the potential to improve the uptake of screening; the trial by Bloom and colleagues describes a telephone intervention that significantly increased the rates of mammography in Hodgkin's disease survivors.[23] Furthermore, visits to a primary care physician or oncologist were also correlated with higher rates of screening.[20,25,26] A better understanding of these factors will identify which areas should be targeted to increase the rates of screening in cancer survivors.

Cancer survivors are also at risk of developing long-term sequelae. One of the challenges will lie in recognising which late-effects need to be monitored for each survivor, as these will vary depending on the site of the disease and the treatment.[29] The American Society of Clinical Oncology (ASCO) recently reviewed the evidence on late-effects in cancer survivors and confirmed the higher incidence of cardiac and pulmonary dysfunction in some long-term survivors.[30] The ASCO panel highlights the need for large randomised control trials to identify treatment-related effects, and long-term prospective studies to determine the efficacy of screening for late-effects in cancer survivors. It is unknown from the studies reviewed in this paper whether any specific surveillance for late-effects of treatment is being carried out. Future research should work towards developing evidence-based guidelines for screening and appropriate use of services for late-effects of cancer and its treatment.

Table 5 – Chronic disease management

	Outcomes							
	Diabetes			Heart disease				
	Lipid testing in diabetics	Eye exam in diabetics	Visit every 6 months for diabetes monitoring	Visit every 6 months for angina follow-up	Visits every 6 months for heart failure	Lipid testing in angina pts	COPD	Predictors of receiving necessary care
Earle et al.[20]	60% of survivors versus 50% of non-survivors ($p < 0.05$)	–	–	–	–	–	–	–
Earle and Neville[25]	–	27.2% of survivors versus 30.1% of non-survivors ($p = 0.01$)	93.2% of survivors versus 94.5% of non-survivors ($p = 0.03$)	94.1% of survivors versus 96.3% of non-survivors ($p < 0.01$)	87.5% of survivors versus 94.1% of non-survivors ($p < 0.001$)	64.3% of survivors versus 69.1% of non-survivors ($p = 0.01$)	90.6% of survivors versus 93.3% of non-survivors ($p < 0.001$)	Being African–American, older or not regularly seeing a PCP or oncologist was associated with receiving less necessary care. Having a higher SES, care in a teaching hospital, more co-morbidities, seeing a PCP only or a PCP/oncologist was associated with receiving more necessary care

COPD, chronic obstructive pulmonary disease; SES, socioeconomic status; PCP, primary care physician.

Only two papers looked at preventative and chronic disease management in cancer survivors. Non-cancer co-morbid conditions are highly correlated with health-related quality of life, indicating that chronic disease management is an important issue for older survivors.[31] However, our review shows that, compared with the general population, long-term survivors of adult cancer may not receive the same quality of care for co-morbid conditions. It is possible that primary care physicians treat cancer survivors differently, and focus on cancer-related care at the expense of non-cancer health needs. It is also unclear why there are differences between the care of colorectal and breast cancer survivors, however, these may be due to patient characteristics such as gender, education and age or health-seeking behaviour.

Following hospital discharge, cancer survivors may be unaware of their heightened risk for cancer recurrence and late-effects of treatment. Additionally, patients may not know where to turn for help; a recent survey showed that more than a third of cancer survivors were unsure whether their primary care physician or specialist was responsible for their follow-up care.[32] A main recommendation of the Institutes of Medicine report, ‘From Cancer Patient to Cancer Survivor’ is to provide patients and primary care physicians with a ‘survivorship care plan’ when cancer patients are discharged from secondary care.[33] This plan details recommendations for receipt of cancer screening, monitoring for possible late-effects of treatment, along with other clinically relevant information. The survivorship plan, if implemented, will not only provide patients with the knowledge to reduce their risk of adverse health, but also will clarify which physician should take responsibility for the aspects of cancer and co-morbid disease care.[34]

4.2. *Limitations*

Paucity of the literature made it difficult to draw firm conclusions; very few of the papers gave results that were directly comparable. Data on the uptake of screening, preventative and chronic disease care is exclusively from US-based studies, and may not be generalisable due to differences in health care systems, access to health care and screening recommendations. Although we searched the published literature in several databases and trials listed on the OCS and ICRP websites we did not search for papers in conference proceedings, nor did we contact researchers for unpublished data. However, by using very broad search terms and two reviewers to independently assess records, fewer potentially relevant papers were excluded from the review.[35] Additionally, a librarian was involved in the early stages of the review to refine our search strategy.

4.3. *Conclusions*

The growing numbers of cancer survivors have specific health needs which need to be addressed for many years after diagnosis. Research into survivors of adult cancer is in its infancy. We found little research relating to the care of long-term cancer survivors in primary care, especially in terms of care of co-morbid conditions. Much of the current research on long-term survivors of adult cancer, especially that on screening behaviours, preventative health and chronic disease management, is based in the United States. Future research in this area should explore the health care of survivors of adult cancer in different health care settings, especially in Europe. This review has identified areas which need further description if we hope to understand the health care needs of these patients.

Conflict of interest statement

None declared.

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Appendix A

Medline search

Medline search		
#1	exp Neoplasms/(MeSH)	
#2	(cancer$ or neoplas$ or tumo?r$ or carcinoma$ or sarcoma$ or adenocarcinoma$ or adeno?carcinoma$ or adenoma$) in ti,ab	
#3	#1 or #2	Cancer
#4	Survivors/(MeSH)	
#5	Disease-free survival/(MeSH)	
#6	SEER programme/(MeSH)	
#7	survivor$ in mp	
#8	((history$ near3 (cancer$ or tumo?r$ or malignan$)) in ti,ab	
#9	(free of recurrence) in ti,ab	
#10	(SEER programme) in ti,ab	
#11	(Disease free or cancer free) in ti,ab	
#12	#4 or #5 or #6 or #7 or #8 or #9 or #10 or #11	Survivors
#13	Patient discharge/(MeSH)	

Appendix A – *continued*

#14	Continuity of patient care/(MeSH)	
#15	Long-term care/(MeSH)	
#16	exp Patient care planning/(MeSH)	
#17	After care/(MeSH)	
#18	(patient discharge or post?discharge or postdischarge or hospital discharge or continuity of care) in ti,ab	
#19	Palliative care/(MeSH)	
#20	exp Terminal care/(MeSH)	
#21	(palliative care or palli$ or terminal care or terminal disease or terminal or end of life or hospice).ti,ab	
#22	#14 or #15 or #16 or #17 or #18	
#23	#19 or #20 or #21	
#24	#22 not #23	Discharge of survivors to primary care
#25	Family Practice/(MeSH)	
#26	Primary Health Care/(MeSH)	
#27	Physicians, Family/(MeSH)	
#28	Nurse practitioners/(MeSH)	
#29	exp Community health services/(MeSH) without subheading hospice	
#30	(family pract$ or general pract$ or family phys$ or GP$ or primary care phys$ or PCP$ or primary care$ or primary health care) in mp	
#31	#25 or #26 or #27 or #28 or #29 or #30	Primary care
#32	#3 and #12 and #30	Primary care of survivors of cancer
#33	#3 and #24 and #31	Discharge of cancer patients to primary care

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