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TITLE

Identifying the most prevalent unmet needs of cancer survivors in Australia: a systematic review

RUNNING TITLE

Unmet needs of Australian cancer survivors

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

ABSTRACT

Understanding the unmet needs of cancer survivors is crucial to inform health service planning and optimise survivorship care. This systematic review sought to identify the most prevalent unmet needs of cancer survivors in Australia, and to determine personal, disease and treatment-related variables correlated with unmet needs. Seventeen studies were included in the review. Substantial heterogeneity across the included studies precluded statistical pooling of the data; narrative synthesis and vote counting were used to synthesise results. Unmet needs were ranked by the number of endorsements (n) each item received. The most frequently reported unmet needs of Australian cancer survivors are for help with psychosocial issues, including fear of cancer recurrence (n=14; 14-42%), uncertainty about the future (n=9; 12-26%), worry about partners, friends and families (n=8; 12-26%), help to reduce stress (n=8; 12-34%) and sexual changes (n=7; 11-29%). Survivors also needed more help with physical issues including fatigue (n=7; 10-27%), and usual activities (n=6; 13-27%), and expressed supportive care unmet needs, including for affordable hospital car parking (n=7; 12-26%), information about available services (n=7; 11-33%) and peer support (n=6; 13-26%). Anxiety, depression and lower overall and physical quality of life were significantly correlated with greater unmet needs, as were younger age and more advanced disease.

KEYWORDS

Australia; Health Services Needs and Demand; Neoplasms; Review; Survivorship

INTRODUCTION

Cancer is the leading cause of disease burden in Australia.[1] An estimated 1.1 million people are currently living with or beyond a diagnosis of cancer in Australia, and this number is expected to increase to 1.9 million by 2040.[2] Due to advances in cancer detection and treatment, 68% of Australians with cancer may expect to live five years or more after diagnosis.[3]

While many people live well after cancer treatment, others may experience a broad range of physical, psychological, social and financial issues that impact upon their quality of life (QoL).[4,5] These include long-term and late effects arising from treatment, physical impairments and activity limitations, lifestyle adjustments, altered relationships and caring arrangements, and impacts on work or education. These issues place substantial burden upon individuals with cancer, their families and carers, upon the broader community through loss of participation and productivity,[6] and upon health services and systems as they strive to meet the needs of the growing cancer survivor population.[7]

It is a current national imperative to consider how we provide survivorship care to improve patient and health system outcomes through delivery of effective, efficient and sustainable models. Cancer Australia has recently released its position statement ‘Principles of cancer survivorship’, which advocates for person-centred care that is tailored to individual circumstances and needs, assessment of needs over time, and support for living well.[8] Similar recommendations have been made by Cancer Council[9] and the Clinical Oncological Society of Australia,[10] however current care is not meeting these standards.

The shift towards person-centred care relies on assessing and responding to the self-reported needs of patients. Assessment of unmet needs goes beyond measuring the symptoms and issues that people experience by directly capturing those issues that people need more help for, as well as providing a measure of the magnitude of that need. A growing body of evidence demonstrates that identifying and attending to the needs of cancer survivors may improve health outcomes, QoL, and satisfaction with care.[11,12] Previous systematic reviews have not focused on the unmet needs of people in the survivorship phase, and included unmet needs of people who are newly diagnosed, on treatment or those at the end-of-life, which are likely to differ from the needs of cancer survivors,[13,14] or focused on specific cancer types.[15] If we are to address the current inadequacies in care for cancer survivors in Australia, it is necessary to articulate the gaps between the needs of cancer survivors and current service provision. We therefore undertook a systematic review to determine the most commonly reported unmet needs of Australian cancer survivors.

The primary aim of this systematic review was to identify the unmet needs of cancer survivors in Australia. Specifically, we wanted to answer the question: What are the most prevalent unmet needs reported by cancer survivors in Australia? The secondary aim was to identify demographic, disease or treatment-related predictors of unmet need.

METHODS

Inclusion criteria

Studies were eligible for inclusion in the review if:

Participants: Studies included adult (aged ≥18 years) survivors of any type of cancer. Survivors were defined as people who had completed primary treatment for their cancer with curative intent; studies were only included if more than 75% of participants met this definition. Studies focusing on the needs of people undergoing active treatment, or people at the end-of-life, were excluded.

Setting: Studies were conducted in Australia and published in English.

Outcomes: Studies used quantitative measures, either validated tools or study specific-measures, to assess the prevalence of unmet needs. Studies that reported on the experience of issues or concerns (e.g. issues with fatigue) in the absence of defining an unmet need for help with the issue were excluded.

Search strategy

Databases were searched as follows. PubMed: ("Neoplasms"[Mesh] OR cancer[ti]) AND ("Survivors"[Mesh:NoExp] OR survivor*) AND ("Health Services Needs and Demand"[Mesh:NoExp] OR need OR needs) AND Australia; 349 results on 7/5/2018. PsycINFO: (cancer.mp. or exp Neoplasms/) AND (exp SURVIVORS/ or survivor*.mp.) AND (exp Needs/ or exp Health Service Needs/ or unmet need.mp.); limit to journal articles only; 177 results on 7/5/2018. Google Scholar was searched using keywords only on 7/5/2018, results were sorted by relevance, and the first 100 results were screened. Reference lists of included papers were screened for additional relevant literature.

Study Selection

Complete search results were imported into EndNote and duplicates identified and removed. Studies were screened by title and abstract before retrieval and screening of the full texts of potentially eligible studies. Study selection was performed by one reviewer (KL) and included studies confirmed by the review team.

Quality assessment

The quality of all eligible studies was assessed using the Centre for Evidence-Based Management Critical Appraisal Checklist for Cross-Sectional Study.[16] Studies that met six or more out of 11 quality criteria were included in the review.

Data extraction

Basic study data were extracted, including participant characteristics and measures used to assess unmet needs. Studies varied in their reporting of the prevalence of unmet needs. Most studies reported ‘top ten’ or ‘top five’ lists of most frequently endorsed unmet needs. Unmet needs data were extracted if 10% or more of study participants reported any level of unmet need with that item.

Data synthesis

Substantial clinical, methodological and statistical heterogeneity across the included studies precluded statistical pooling of the data. Main differences were in study populations, which varied by cancer type, time since diagnosis, age and gender, and in data collection measures used. A narrative synthesis of the extracted data was therefore conducted.

Top unmet needs: The purpose of the synthesis was to develop a short and accessible evidence-based list of the most frequently reported unmet needs of Australian cancer survivors. To enable synthesis of the data, like items from different measures of unmet need were consolidated. For example 'dealing with fears about the cancer spreading' (from the Survivors' Unmet Needs Survey (SUNS)[17]), 'I need help to manage my concerns about the cancer coming back' (from the Cancer Survivors Unmet Needs measure (CaSUN)[18]), 'fear about the cancer spreading' (from the Supportive Care Needs Survey – Short Form 34 (SCNS-SF34)[19]) and 'managing concerns about cancer returning' (study-specific measure[20]) were grouped into one item labelled 'fear of cancer progression and recurrence'. Similarly, like items within scales were consolidated. For example, 'changes in sexual relationships' and 'changes in sexual feelings' from the SCNS-SF34 were both consolidated into one item 'changes in sexual relationships and sexual feelings'. The combination and consolidation of items was discussed and agreed upon by the review team. The number of times each item was endorsed as an unmet need by more than 10% of participants in included studies was tabulated to generate a list of the most frequently reported unmet needs. Items were further classified into domains of psychosocial, physical and supportive care.

Correlates of unmet needs: To enable identification of correlates, the analysis focused on a sub-set of papers that explored relationships between a range of variables (typically demographic, disease or treatment-related), and overall unmet needs. We excluded from our analysis data exploring correlates with specific items of unmet needs or domains of unmet needs. Vote counting was used to synthesise correlation data.[21] Any statistically significant correlations between any variable and increased unmet needs were extracted and presented in a table, with each statistically significant correlation contributing one 'vote'.

RESULTS

Study selection

The search returned 606 unique articles that were screened by title and abstract (Figure 1). Of these, 573 were excluded, leaving 33 for full-text examination. Fifteen studies were excluded at this stage for not meeting the review criteria (i.e. not reporting quantitative data of unmet needs and not including participants who had completed treatment), and one study[22] was excluded to avoid double-counting of unmet needs, as the same sample was described in a separate publication (Appendix I).[23] Ultimately, 17 studies were included in the review.

Characteristics of included studies

Fifteen cross sectional studies and two longitudinal studies were included in the review (Table 1). All studies were published from 2007, with fourteen studies published within the last 10 years. In keeping with the inclusion criteria, all studies were conducted in Australia, and participants varied in cancer type, time since diagnosis, and age. Six studies included participants with various cancer types,[18,20,24-27] one study compared breast and brain cancer survivors,[28] and other studies focused on single types of cancer, including gynaecological (four studies),[29-32] haematological (two studies)[22,23,33] and one study each for breast,[34] endometrial,[35] prostate[36] and testicular[37] cancer. Studies with multiple cancer types presented combined data, with the exception of the study comparing breast and brain cancer.[28] Here, data were presented separately for each population, and this study therefore contributed two sets of data, one each for the top unmet needs of breast and brain cancer survivors. Studies used a range of validated and study-specific measures of unmet needs, with the most common being the CaSUN (nine studies[18,28,30-35,37]) and the SCNS-SF34 (five studies[24-26,29,36]) (Table 2). All studies were deemed to be appropriately conducted and of sufficient quality to be included in the review (Appendix II).

The most prevalent unmet needs of cancer survivors in Australia

Extracted data showed a total of 71 items of unmet need reported by at least 10% of participants using all unmet needs measures from included studies. These were amalgamated into 44 overall items of unmet need based on consolidation of like items from each separate measure (Appendix III). Items were ranked based on the number of endorsements each item received (denoted by n), and then by the higher proportion in the prevalence range of survivors experiencing that unmet need. Based on this rubric, the most frequently reported unmet needs identified by cancer survivors in Australia were defined (Table 3).

Overall, the top four unmet needs reported by Australian cancer survivors were within the psychosocial domain. The most frequently endorsed unmet need was for help with fear of cancer recurrence and progression, endorsed 14 times (n=14), and reported by 14-42% of participants across the included studies. Up to 26% of participants reported unmet needs for help to cope with uncertainty about the future (n=9), which included not being able to set future goals or make long-term plans, and need for help to reduce stress was reported by up to 34% of participants (n=8). Between 12-26% reported unmet needs related to the worries and emotions of partners, family members and friends (n=8), including support partners and family members, and between 11-29% of survivors had unmet needs for help with changes to sexual feelings and relationships (n=7).

Other unmet needs were within supportive care and physical domains. Survivors reported unmet needs for information about available supportive services (n=7; 11-33%) and for affordable car parking when attending hospital appointments (n=7; 12-26%). Other unmet needs within the supportive care domain were access and information about complementary and alternative therapies (n=6; 17-31%), knowing that HCPs communicated to coordinate care (n=6; 15-31%) and peer support (n=6; 13-26%). Unmet needs for help with physical consequences of cancer pertained to fatigue (n=7; 10-27%) and limitations in carrying out usual activities (n=6; 13-27%).

Correlates with unmet needs

The data from six studies[27,30,32,34,35,37] was examined to identify relationships between various factors with overall unmet needs (rather than with unmet needs items or domains) (Table 4). There was substantial variation in the measurement of predictors of unmet needs. Studies assessed different patient, disease and treatment-related variables and also used different measures for similar variables (for example using the Functional Assessment of Cancer Therapy (FACT) or SF-36 as measures of QoL). Three studies reported on correlates with overall unmet needs,[27,30,34] one study on strength of unmet needs,[32] one study on both overall number and strength of unmet needs in separate analyses,[37] and one study on predictors of reporting at least one unmet need.[35] Due to these differences, vote counting was used to display the presence of a statistically significant correlation between any variable and unmet needs as assessed in the papers.

Correlations between unmet needs (any definition) and psychosocial issues with anxiety,[27,30,32,34,35,37] depression,[30,32,35,37] low mental QoL[30,37] and post-traumatic stress disorder[30,32] were found. People who were younger,[35,37] with lower physical QoL[35,37] (measured using the FACT physical wellbeing scale and SF-36 physical component score) and lower overall QoL[32,37] (FACT-G and SF-36) had greater unmet needs in two studies, and more advanced disease was correlated with greater unmet needs in two studies.[30,35]

DISCUSSION

This systematic review demonstrates that substantial proportions of Australian cancer survivors are living with unmet needs for help to deal with cancer and its consequences. The most common domain of unmet need is for help with psychosocial issues including fear of cancer recurrence, uncertainty about the future, stress reduction and worry about family, friends and partners. Our findings are consistent with an earlier review (current to 2006) reporting common unmet needs of people with cancer.[14]

A challenge for our health services and systems is how to best care for the cancer survivor population and meet the unmet needs described in this review. Promising work is being conducted both locally and internationally that may contribute to addressing the most commonly reported unmet needs. For example, interventions have been developed to address the specific needs of fear of cancer recurrence (Conquer Fear[38]) and sexual needs (the Rekindle study[39]). Additionally, the government-led Victorian Cancer Survivorship Program has funded multiple projects since 2011 to develop, implement and evaluate interventions aiming to improve the organisation of survivorship care, and the wellbeing of cancer survivors.[40] Projects thus far have addressed issues with fear of recurrence, cognitive impairment, sleep, fatigue, and help with diet and exercise, to name a few. Barriers remain regarding sustainability of such programs beyond the initial funding periods.

This quantitative review shows agreement with qualitative data identifying commonly reported needs of dealing with fatigue, fear of cancer recurrence and changes to physical ability.[41] Qualitative enquiry also reveals other unmet needs not typically assessed in quantitative studies, such as help with anxiety about leaving the hospital system and help with specific symptom items, thus it is possible that existing quantitative measures may not comprehensively address the unmet needs of people after cancer treatment. Making needs assessment part of routine care is likely to increase identification of unmet needs and concerns that patients require help with; however it is imperative that needs assessments are undertaken using tools that are responsive to the full suite of issues patients experience, while recognising that embedding needs assessment in clinical practice may be more feasible with a shorter measure.

While needs and unmet needs assessment measures have been used for research and health service planning, the clinical utility of such measures is not clear.[42] The two most commonly used measures of unmet needs in the Australian literature included in this review are the CaSUN and the SCNS-SF34. Both measures were developed in Australia and validated with Australian cancer populations, however the SCNS-SF34 is not specific to the survivorship phase and includes items about treatment.[19] While each measure is relatively comprehensive, covering 35 and 34 items across five domains respectively, there are several issues experienced by Australian cancer survivors that are not included in these measures. For example, cognitive issues are often experienced by cancer survivors,[43] however neither the CaSUN nor the SCNS-SF34 contains items specifically regarding unmet needs for help with memory or concentration. Studies that did ask about cognitive issues found substantial levels of unmet need amongst participants. The SUNS has an item ‘Coping with having a bad memory or lack of focus’ which was endorsed by 14-16% of participants in the two studies that used this measure.[22,23] Additionally, the Cancer Needs Questionnaire for Young People (CNQ-YP) has an item about help with focusing on tasks and remembering things, which was endorsed by 36% of participants in the one study that used it, rendering this item the top unmet need reported by young people in that study.[27]

Unmet needs assessment may be complemented by assessment of other patient-reported outcomes (PROs), such as the experience of specific symptoms, quality of life issues and psychosocial distress. Anxiety was found to be associated with unmet needs across all studies, depression was associated with unmet needs in four studies, and low physical and mental QoL were also associated with greater unmet needs. These findings provide support for processes to identify such issues in oncology settings in addition to performing needs assessments to inform clinical encounters.[44] Two notable initiatives underway in New South Wales are examining online assessment of PROs, linking to clinical management pathways; the Patient-Reported Outcome Measures for Personalised Treatment and Care (PROMPT-Care)[45] study assessing the feasibility and acceptability of PROs (including needs assessment, symptoms and distress) for cancer patients either during or following treatment, and the Anxiety and Depression Pathway Program (ADAPT) specifically investigating screening for anxiety and depression in cancer patients using an online patient portal.[46] International studies evaluating routine PRO collection have demonstrated a range of benefits for both patients and health systems, including improved communication between patients and their treating team,[44,47-50] increased identification and management of symptoms,[44,49,51] increased health-related QoL,[48,50,51] increased patient satisfaction[44] and reduced emergency department utilisation.[51] Wider adoption of similar approaches may improve symptom and issue identification, facilitate greater access to available resources, and improve patient outcomes.

Limitations

Findings of this review must be considered in light of several limitations. Firstly, available data are limited by the measures used to assess unmet needs. It may be useful for future studies to utilise more comprehensive measures and to specifically ask about unmet needs for problems commonly experienced after cancer treatment, including, for example, problems with cognitive issues, fatigue or sleep. A further limitation is that the review does not include a proportionate distribution of cancer types in Australia. Six studies included various cancer types, however 10 studies focused on one type of cancer only, potentially shifting the results in favour of unmet needs specific to survivors of these cancer types. We acknowledge that different groups which are not represented in this review will likely have different unmet needs that warrant exploration. For example, needs may differ for Aboriginal and Torres Strait Islander people and other cultural groups, and people who identify as sexually or gender diverse. Further research using appropriate and sensitive measures (such as the Supportive Cancer Care Needs Assessment Tool for Indigenous People (SCNAT-IP)[52]) to ascertain the unmet needs of discrete populations may facilitate development and delivery of person-centred care that may more adequately meet specific requirements. In terms of the conduct of the review, study selection and quality appraisal were conducted primarily by one reviewer; although all aspects of the review were discussed and agreed upon by the review team, this may have led to studies being missed or reduced the reliability of quality assessment. Finally, studies included in this narrative review were equally weighted regardless of sample size; smaller studies tended to report higher prevalence of unmet needs, and this should be considered when interpreting prevalence ranges.

CONCLUSION

Substantial numbers of Australian cancer survivors have needs across psychosocial, physical and supportive care domains, with the most frequently reported unmet needs being fear of recurrence, uncertainty about the future, reducing stress and worry about family and friends. People experiencing anxiety, depression, post-traumatic stress disorder and low mental and physical QoL may be at particular risk of having needs for further care and support that are not being recognised or provided for. These findings support the implementation of comprehensive routine patient needs assessment in oncology settings, and may be useful in informing priority areas for developing interventions that may support survivors of cancer in Australia.

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49. Ristevski E, Regan M, Jones R, Breen S, Batson A, McGrail MR. Cancer patient and clinician acceptability and feasibility of a supportive care screening and referral process. *Health Expect* 2015; **18**(3): 406-18.

50. Velikova G, Booth L, Smith AB*, et al.* Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol* 2004; **22**(4): 714-24.

51. Basch E, Deal AM, Kris MG*, et al.* Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *J Clin Oncol* 2016; **34**(6): 557-65.

52. Garvey G, Beesley VL, Janda M*, et al.* Psychometric properties of an Australian supportive care needs assessment tool for Indigenous patients with cancer. *Cancer* 2015; **121**(17): 3018-26.

Figure 1. Study selection flow diagram

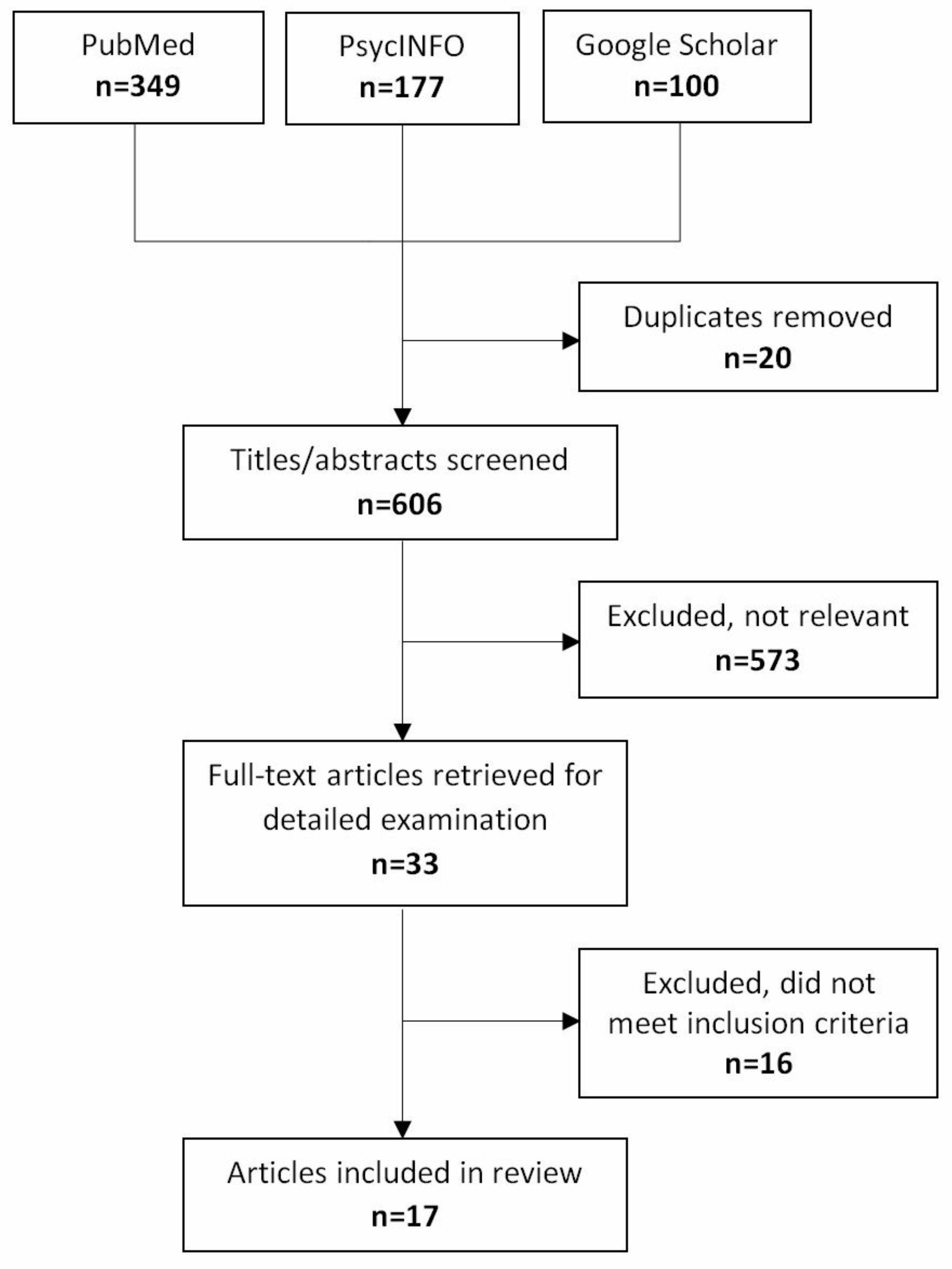

Table 1. Characteristics of included studies

Reference; study type	Cancer type	Participant characteristics	Unmet needs assessment
Amataya et al 2014[28]; cross sectional	Breast and brain	Breast cancer: 85 participants, mean age 57 years, median time since diagnosis 2.2 years; Brain cancer: 106 participants, mean age 51 years, median time since diagnosis 2.1 years	CaSUN
Beesley et al 2008[29]; cross sectional	Gynaecological	802 participants, aged 18-70+ years (no mean given)	SCNS-SF34
Boyes et al 2012[24]; cross sectional	Prostate, melanoma, breast, blood, colorectal, lung, head and neck	1323 participants, median age 63 years	SCNS-SF34
Butow et al 2012[20]; cross sectional	12 most common cancers	319 Anglo-Australian born participants, 277 immigrant participants, aged 18-80, 1-6 years post-diagnosis	Study-specific (including SCNS and CaSUN items)
Hall et al 2012[25]; cross sectional	Any	58 young adults aged 18-40 years, 6-7 months post-diagnosis; 58 matched older adults aged 64+ years	SCNS-SF34
Hall et al 2015[23]; cross sectional	Haemotological	715 participants, aged 18–80 years (61% aged 50–69 years at diagnosis)	SUNS
Hodgkinson et al 2007a[18]; cross sectional	Any	353 participants, aged ≥18 years, ≥1 year post-diagnosis	CaSUN
Hodgkinson et al 2007b[34]; cross sectional	Breast	117 participants, aged 32–88 years (mean age 61 years)	CaSUN
Hodgkinson et al 2007c[30]; cross sectional	Gynaecological	199 participants, aged 28–89 years (mean age 59.1 years)	CaSUN
Hyde et al 2012[36]; cross sectional	Prostate	333 participants, ≤12 months post-diagnosis	SCNS-SF34
Lobb et al 2009[33]; cross sectional	Haematological	66 participants, aged 24–82 years (mean age 54 years), completed treatment with curative intent or in substantial remission	CaSUN
McDowell et al 2010[26]; longitudinal	Any	439 participants, majority (79%) post-treatment, average time 49 weeks post-treatment	SCNS
Millar et al 2010[27]; cross sectional	Any	22 young adults, aged 18-25 years, 1-5 years post-treatment	CNQ-YP (plus 24 study-specific items)
Rowlands et al 2015[35]; longitudinal	Endometrial	629 participants, aged 18–79 years (55% aged 50–65 years at diagnosis)	CaSUN
Smith et al 2013[37]; cross sectional	Testicular	244 participants, aged 21–68 years (mean age 38.3 years); no evidence of cancer recurrence	CaSUN
Stafford et al 2011[31]; cross sectional	Gynaecological	176 participants, aged 19–88 years (mean age 58.4 years)	CaSUN
Urbaniec et al 2011[32]; cross sectional	Gynaecological	45 participants, ≥1 year post-diagnosis	CaSUN

Table 2. Measures of unmet needs used in included studies

Measure	Items	Domains	No. studies and references
CaSUN (Cancer Survivors Unmet Needs)	35 items across 5 domains assessing need for help (N/A or none, met, weak, moderate, strong) in last month	Information needs and medical care issues, quality of life, emotional and relationship issues, life perspective, positive changes	9 [18,28,30-35,37]
SCNS-SF34 (Supportive Care Needs Survey – Short Form 34)	34 items across 5 domains assessing need for help (N/A, none, low, moderate, high)	Physical and daily living, psychological, sexuality, patient care and support, health system and information	5 [24-26,29,36]
SUNS (Survivor Unmet Needs Survey)	89 items in 5 subscales on 5-point scale (no unmet need to very high unmet need) in the last month	Emotional health, access and continuity of care, relationships, financial concerns, information	1 [23]
CNQ-YP (Cancer Needs Questionnaire for Young People)	108 items in 7 domains on 4-point scale (no, low, moderate, high) with 24 additional study-specific questions for young people	Structure of care, process of care, relationships, information, daily living, emotional/ psychological, school/ occupational	1 [27]
Study-specific (some items from CaSUN and SCNS)	Used 10 items from SCNS and 4 items from CaSUN with 14 additional study-specific questions for immigrants	Information/support, physical, sexual, future needs	1 [20]

Table 3. Top unmet needs of cancer survivors in Australia

Unmet Need	Domain	No. of endorsements	Prevalence range	References
Fear of cancer recurrence and progression	Psychosocial	14	14% - 42%	18,20,24-26,28-34,37
Feeling uncertain about the future	Psychosocial	9	12% - 26%	23-26,28-31
Help to reduce stress	Psychosocial	8	12% - 34%	18,23,28,30,31,33,37
Worry about partners, family and friends	Psychosocial	8	12% - 26%	24-26,28,29,33,36
Information about support services	Supportive care	7	11% – 33%	20,27,31-34
Changes in sexual relationships and sexual feelings	Psychosocial	7	11% – 29%	20,24,36,37
Affordable hospital car parking	Supportive care	7	12% - 26%	24-26,28,29,33,36
Help with feeling tired/lack of energy	Physical	7	10% - 27%	20,23-26,29,36
Access to complementary and alternative therapy	Supportive care	6	17% - 31%	28,30,31,33,34
Knowing that HCPs communicate to coordinate care	Supportive care	6	15% - 31%	18,28,31-34
Not being able to do usual things	Physical	6	13% - 27%	20,23,24,26,29,36
Needing to talk to other people who have experienced cancer	Supportive care	6	13% - 26%	23,28,30,32,33,37

Table 4. Correlates with greater unmet needs

Factors	No. reporting statistically significant correlation with ↑unmet need	References
Demographic		
Younger age	++	35,37
Higher education level	+	35
Employed	+	35
Current smoker	+	35
Comorbidities	+	37
Psychosocial		
Anxiety	++++++	27,30,32,34,35,37
Depression	++++	30,32,35,37
Lower mental QoL (SF12-MCS, SF-36 MCS)	++	30,37
PTSD	++	30,32
Lower optimism	+	32
Stress	+	37
Self-blame	+	32
Less social support	+	35
Physical		
Lower physical QoL (FACT PWB, SF-36 PCS)	++	35,37
Lower overall QoL (FACT, SF-36)	++	32,37
Disease/treatment related		
More advanced disease	++	30,35
>15 lymph nodes removed	+	35
Adjuvant treatment	+	35
Lymphedema	+	35

FACT: Functional Assessment of Cancer Therapy; MCS: Mental Component Score; PWB: Physical Wellbeing subscale; PCS: Physical Component Score

Appendix I: Table of excluded studies

	Reference	Reason for exclusion
1	Beesley, V. L., B. M. Smithers, P. O'Rourke, M. Janda, K. Khosrotehrani, and A. C. Green. 2017. 'Variations in supportive care needs of patients after diagnosis of localised cutaneous melanoma: a 2-year follow-up study', Support Care Cancer, 25: 93-102.	Not exclusively disease-free (includes participants with recurrence), and presents very limited data of unmet needs.
2	Bell, M. L., P. N. Butow, and D. Goldstein. 2013. 'Informatively missing quality of life and unmet needs sex data for immigrant and Anglo-Australian cancer patients and survivors', Qual Life Res, 22: 2757-60.	Did not present data of the prevalence of unmet needs in the sample.
3	Clinton-McHarg, T., M. Carey, R. Sanson-Fisher, C. D'Este and A. Shakeshaft (2012). "Preliminary development and psychometric evaluation of an unmet needs measure for adolescents and young adults with cancer: the Cancer Needs Questionnaire - Young People (CNQ-YP)." Health Qual Life Outcomes 10: 13.	Did not present data of the prevalence of unmet needs in the sample; sample not disease-free.
4	DiSipio, T., S. Hayes, B. Newman and M. Janda (2009). "What determines the health-related quality of life among regional and rural breast cancer survivors?" Aust N Z J Public Health 33(6): 534-539.	Included mean scores of health service needs, no prevalence data of unmet needs.
5	Fletcher, C., I. Flight, J. Chapman, K. Fennell and C. Wilson (2017). "The information needs of adult cancer survivors across the cancer continuum: A scoping review." Patient Education and Counseling 100(3): 383-410.	Unable to directly extract data from review; used to source references.
6	Garvey, G., V. L. Beesley, M. Janda, P. K. O'Rourke, V. Y. He, A. L. Hawkes, J. K. Elston, A. C. Green, J. Cunningham, and P. C. Valery. 2015. 'Psychometric properties of an Australian supportive care needs assessment tool for Indigenous patients with cancer', Cancer, 121: 3018-26.	Not exclusively cancer survivors.
7	Hall, Alix, H. Campbell, Rob Sanson-Fisher, Marita Lynagh, Catherine d'Este, Robin Burkhalter, and Mariko Carey. 2013. 'Unmet needs of Australian and Canadian haematological cancer survivors: A cross-sectional international comparative study', Psychooncology, 22: 2032-38.	Same sample and data as Hall et al 2015.
8	Jabbour, J., C. Milross, P. Sundaresan, A. Ebrahimi, H. L. Shepherd, H. M. Dhillon, G. Morgan, B. Ashford, M. Abdul-Razak, E. Wong, M. Veness, C. E. Palme, C. Froggatt, R. Cohen, R. Ekmejian, J. Tay, D. Roshan and J. R. Clark (2017). "Education and support needs in patients with head and neck cancer: A multi-institutional survey." Cancer 123(11): 1949-1957.	Not clear of time since treatment and if participants were disease-free.
9	Li, J. and A. Girgis (2006). "Supportive Care Needs: Are Patients with Lung Cancer A Neglected Population?" Psycho-Oncology 15(6): 509-516.	Patients on treatment, not survivors.
10	Lynagh, M. C., A. Williamson, K. Bradstock, S. Campbell, M. Carey, C. Paul, F. Tzelepis and R. Sanson-Fisher (2018). "A national study of the unmet needs of support persons of haematological cancer survivors in rural and urban areas of Australia." Support Care Cancer 26(6): 1967-1977.	No data on cancer survivors, rather unmet needs of their support persons.
11	McGrane, J., P. Butow, M. Sze, M. Eisenbruch, D. Goldstein and M. King (2014). "Assessing the invariance of a culturally competent multi-lingual unmet needs survey for immigrant and Australian-born cancer patients: A Rasch analysis." Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation 23(10): 2819-2830.	Did not present data of the prevalence of unmet needs in the sample.
12	Oberoi, D., V. White, J. Seymour, H. Prince, S. Harrison, M. Jefford, I. Winship, D. Hill, D. Bolton, A. Kay, J. Millar, N. W. Doo and G. Giles (2017). "The course of anxiety, depression and unmet needs in survivors of diffuse large B cell lymphoma and multiple myeloma in the early survivorship period." Journal of Cancer Survivorship 11(3): 329-338.	Mixed sample of patients on treatment at two different time points, not clear if participants are disease free. Looks at unmet needs domains only.

13	Raupach, J. C., and J. E. Hiller. 2002. 'Information and support for women following the primary treatment of breast cancer', Health Expect, 5: 289-301.	Did not present data of the prevalence of unmet needs in the sample, rather number of respondents rating items of information as important and information sources.
14	Schofield, P., K. Gough, K. Lotfi-Jam, and S. Aranda. 2012. 'Validation of the Supportive Care Needs Survey-short form 34 with a simplified response format in men with prostate cancer', Psychooncology, 21: 1107-12.	No data on the prevalence of unmet needs.
15	Vardy, J. L. and H. M. Dhillon (2017). "Survivors of Cancer Need Support Managing Cancer-Related Cognitive Impairment." J Oncol Pract 13(12): 791-793.	Editorial, not research.
16.	Vetsch, Janine, Joanna E. Fardell, Claire E. Wakefield, Christina Signorelli, Gisela Michel, Jordana K. McLoone, Thomas Walwyn, Heather Tapp, Jo Truscott, and Richard J. Cohn. 2017. '"Forewarned and forearmed": Long-term childhood cancer survivors' and parents' information needs and implications for survivorship models of care', Patient Educ Couns, 100: 355-63.	Combined Australian and New Zealand data.

APPENDIX II: Critical appraisal

Study	Q1	Q2	Q3	Q4*	Q5	Q6	Q7	Q8	Q9	Q10	Q11*	TOTAL
Amatya et al 2014	Y	Y	Y	Y	Y	N	Y	Y	N	N	N	7
Beesley et al 2008	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	10
Boyes et al 2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Butow et al 2012	Y	Y	Y	Y	Y	N	N	U	Y	Y	Y	8
Hall et al 2012	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	9
Hall et al 2015	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	9
Hodgkinson et al 2007a	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	9
Hodgkinson et al 2007b	Y	Y	Y	Y	Y	N	Y	Y	Y	N	Y	9
Hodgkinson et al 2007c	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	10
Hyde et al 2012	Y	Y	N	Y	Y	N	N	Y	Y	Y	Y	8
Lobb et al 2009	Y	Y	Y	Y	Y	N	Y	Y	Y	N	Y	9
McDowell et al 2010	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	9
Millar et al 2010	Y	Y	Y	Y	Y	N	U	U	Y	N	N	6
Rowlands et al 2015	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	10
Smith et al 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Stafford et al 2011	Y	Y	Y	Y	Y	N	N	Y	N	N	N	6
Urbaniec et al 2011	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	9

Critical Appraisal Questions: Q1. Did the study address a clearly focused question / issue?; Q2. Is the research method (study design) appropriate for answering the research question?; Q3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described?; Q4. Did the way the sample was obtained seek to mitigate selection bias?*; Q5. Was the sample of subjects representative with regard to the population to which the findings will be referred?; Q6. Was the sample size based on pre-study considerations of statistical power?; Q7. Was a satisfactory response rate achieved?; Q8. Are the measurements (questionnaires) likely to be valid and reliable?; Q9. Was the statistical significance assessed?; Q10. Are confidence intervals given for the main results?; Q11. Were confounding factors identified and considered? (*Questions 4 and 11 were re-phrased to make a Y response positive; Question 12 was omitted)

APPENDIX III. Synthesis of the most frequently endorsed items of unmet need for cancer survivors in Australia

SCNS-SF34	Study specific	SUNS	CaSUN	CNQ-YP plus study specific	References endorsing	No.
Fear about the cancer spreading	Managing concerns about cancer returning	Dealing with fears about cancer spreading	I need help to manage my concerns about the cancer coming back		15,17,21-23,25-31,34	14
Uncertainty about the future		Dealing with not being able to set future goals or make long-term plans	I need help to try to make decisions about my life in the context of uncertainty		20-23,25-28	9
		Dealing with feeling stressed	I need help to reduce the stress in my life		15,20,25,27,28,30,34	8
Concerns about the worries of those close		Dealing with the emotional wellbeing of my family	I need to know how to support my partner and/or family AND I need emotional support to be provided to my family/friends		21-23,25,26,30,33	8
	Support services		I need an ongoing case manager to whom I can go to find out about services whenever they are needed	Information about support services and available help	17,24,28-31	7
Changes in sexual relationships AND Changes in sexual feelings	Changes in sexual relationships AND Changes in sexual feelings		I need help to address problems in my/our sex life		17,21,33,34	7
		Find car parking I can afford at the hospital	I need more accessible hospital parking		21-23,25,26,30,33	7
Lack of energy/tiredness		Dealing with feeling tired			17,20-23,26,33	7
			I need access to complementary or alterative therapy services		25,27,28,30,31	6
			I need to know that all my doctors talk to each other to coordinate my care		15,25,28-31	6
Not being able to do the things they used to	Unable to do usual things	Dealing with changes in my physical ability			17,20,21,23,26,33	6

		Finding someone to talk to who has been through a similar experience	I need to talk to others who have experienced cancer		20,25,27,29,30,34	6