

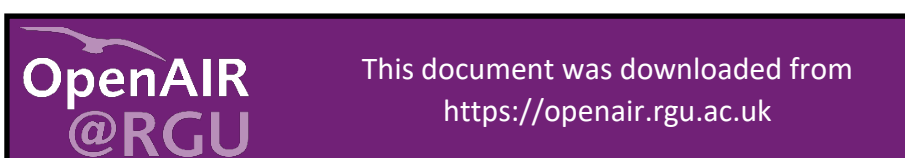
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What are the unmet supportive care needs of people affected by cancer: an umbrella systematic review.

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Supplementary materials are appended after the main text of this document.



Abstract

Objective

The aim of this umbrella systematic review was to critically synthesise unmet supportive care needs of people affected by cancer.

Data sources

The Joanna Briggs Institute (JBI) umbrella review method provided an overall examination of the body of evidence that was available in relation to the unmet supportive care needs among people living with cancer. All qualitative, quantitative, and mixed methods reviews were included irrespective of review design. Electronic databases were searched using a wide range of search terms. All records were managed using the software package Endnote X21 and uploaded to Covidence systematic review software. Duplication of records were removed. A pre-selection eligibility criterion was applied to all records. Data extraction, methodological quality assessment was conducted independently by two reviewers and a meta-level narrative synthesis conducted.

Conclusion

A total 30 systematic reviews were included representing a total of 666 publications globally. Irrespective of the type of cancer there were many commonalities in relation to the reported experiences of unmet supportive care needs which therefore enables the development of targeted future clinical trials, clinical guidelines, and policy contribution. In descending order of frequency, the highest unmet supportive care needs were related to psychological/emotional (30/30), health system/information (29/30), interpersonal/intimacy (21/30), social (20/30), physical (19/30), family (18/30), practical (16/30), daily living (10/30), spiritual needs (8/30), patient-clinician communication (8/30) and cognitive needs (5/30).

Implications for Nursing Practice:

This umbrella review has underscored fundamental shortcomings in care delivery irrespective of the patient population and the type of cancer. People with cancer are continually reporting that their needs are not being met across many supportive care domains. It is time for change within the health care system and to full leverage multidisciplinary person-centred models of care to optimise recovery and survivorship experiences. In the meantime, policy makers and cancer care clinicians are encouraged to reflect on these findings to address individualised care needs.

Keywords: cancer care, unmet supportive care needs, umbrella review, needs, oncology nursing

1. Introduction

Cancer is the second leading cause of death internationally ¹. Worldwide cancer data identifies that there were 18.1 million new cancer cases, and 9.6 million cancer deaths that occurred in 2018 ².

Globally, the burden of cancer represents significant challenges for healthcare systems across the entire cancer care continuum ³. The impact of cancer and associated treatments can have a significant negative impact on an individual's physical, psychological, social and spiritual well-being, including economic implications ⁴. Evidence has identified a relationship between reduced quality of life and unmet supportive care needs experienced by people affected by cancer ⁵. Supportive care is defined as a person-centred approach to the provision of the necessary services for those living with or affected by cancer ^{6,7}. This approach aims to meet their informational, spiritual, psychological, social, or physical needs during diagnosis, treatment or follow-up phases, including issues of health promotion and prevention, survivorship, palliation and bereavement ^{6,7}. There is growing evidence identifying that unmet supportive care needs are associated with reduced psycho-social outcomes across a range of tumour patient populations groups including: mixed ⁵, breast ⁸, oesophageal ⁹, prostate ¹⁰, haematological ¹¹, myeloma ¹², including informal caregivers ¹³. Unmet supportive care needs are modifiable factors that should be targeted through well-designed, adequately powered clinical trials to improve psychosocial well-being among people affected by cancer.

A considerable number of systematic reviews have been conducted to understand the experience of unmet supportive care needs among people affected by cancer. Despite the many systematic reviews conducted on the topic, the evidence is yet to be pooled for the purpose of informing future clinical trials, clinical guidelines, and policies to address what matters most to patients and their loved ones. Therefore, the aim of this study was to present an umbrella review to summarise, appraise its quality, and combine relevant data to provide clinical decision-makers with the evidence that they need for targeted intervention development to improve psychosocial outcomes for people living with cancer. Umbrella reviews enable a systematic approach to appraise the evidence on an entire topic across many meta-analyses in relation to addressing the following research questions:

- 1)** What are the unmet supportive care needs of people affected by cancer?
- 2)** What are the most frequently reported domains in unmet supportive care needs?

2. Material and methods

2.1 Study Design

The Joanna Briggs Institute (JBI) umbrella review method ¹⁴ provided an overall examination of the body of evidence that was available in relation to the unmet supportive care needs among people living with cancer. The key features of this review design were that it: 1) compiled evidence from multiple research syntheses that were qualitative and/or quantitative in nature; 2) included reviews

that were based upon empirical studies rather than theoretical speculations or opinions; and 3) summarised evidence from existing reviews without re-synthesis of the primary studies. This review has been reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement guidelines (see **Supplementary Table 1** for completed checklist)

15.

2.2 Types of Participants

This umbrella review included multiple participants with diverse clinical and demographic characteristics across the entire cancer care continuum. The primary inclusion was being affected by cancer which included patients, partners and their family caregivers. All stages of disease and treatment modalities were included.

2.3 Types of reviews

All qualitative, quantitative and mixed methods reviews (systematic review, meta-analysis, narrative review, descriptive review, scoping review, qualitative review, realist review, critical review, literature review, mixed methods reviews, qualitative evidence synthesis, rapid review, review of reviews, and umbrella reviews) were included irrespective of review design. Reviews were excluded if at a minimum they did not describe the search strategy, inclusion criteria and quality assessment methods. All commentaries, editorials and reviews where unmet supportive care needs were not the primary aim/research question for the review were excluded. Systematic reviews only published in English were included. Reviews not based on primary empirical studies were excluded.

2.4 Phenomena of Interest/Outcomes

The phenomena of interest for this review was the experience of unmet supportive care needs. Supportive care is broadly defined as the necessary cancer services for those affected by cancer to meet their person-centred physical, psychological, social, informational, spiritual and practical needs during diagnosis, treatment and follow-up phases, encompassing issues of survivorship, palliative care and bereavement^{6,7}. The primary outcome of this umbrella review was related to unmet supportive care needs (e.g. the Supportive Care Needs Survey¹⁶ and qualitative experiences) informed by the definition of supportive care^{6,7}.

2.5 Context setting

The context included diverse geographical locations, wide range of cultural factors and different health care settings (acute, primary and community health care).

2.6 Search strategy

The search strategy was based on the SPIDER model¹⁷ (see **Supplementary Table 2**). The SPIDER model is a tool developed for qualitative research questions and consisted of five domains of interest, namely:

- Sample (S): People affected by cancer.
- Phenomena of Interest (PI): Unmet supportive care needs.
- Design (D): All qualitative, quantitative, and mixed methods reviews.
- Evaluation (E): -.
- Research (R): Systematic reviews.

In this context “evaluation” was not applied in the string due to the nature of the umbrella study. A comprehensive search was conducted in Medline, CINAHL, and PsycINFO from inception to July 2022. The search terms included variations of the MeSH terms or keywords to increase the sensitivity and inclusiveness of the searches. All records were managed using the software package Endnote X21 and uploaded to Covidence systematic review software. Duplication of records were removed. A pre-selection eligibility criterion was applied to all records.

2.7 Systematic review selection

The publications (titles and abstracts) were double screened independently by two authors to promote consistency and reliability in the application of the eligibility criteria. All articles that met the inclusion criteria were retrieved in full-text. Full-text articles were double screened with any disagreements resolved by discussion. One reviewer extracted data from the final sample of systematic reviews and were all quality checked by a second author using pre-determined data extraction tables.

2.8 Critical appraisal systematic reviews and research synthesis

Systematic reviews that were eligible for inclusion were assessed for methodological quality (critical appraisal) using the JBI tool¹⁸. Each criterion was scored as being met, not met, unclear or not applicable.

2.9 Data extraction

Data extraction was carried out by three reviewers and cross-referenced by two reviewers using templates guided by JBI¹⁴. Key information was extracted from each systematic review which included: (1) citation details; (2) objectives of the included review; (3) type of review; (4) participant details; (5) setting and context; (6) number of databases sourced and searched; (7) date range of database searching; (8) publication date range of studies included in the review; (9) number of studies, types of studies and country of origin of studies included in each review; (10) instruments used to appraise the primary studies and the rating of their quality; (11) outcomes reported that are

relevant to the umbrella review question; (12) method of synthesis/analysis employed to synthesise the evidence; and (13) comments or notes the umbrella review authors may have regarding any included study.

2.10 Data synthesis

There were no meta-analyses conducted across the included reviews. Therefore, a meta-level narrative synthesis of the findings across the included reviews was structured around: 1) the type of reviews (qualitative or quantitative); 2) target populations characteristics; and 3) outcomes related to unmet supportive care needs. Specifically, this involved data reduction (subgroup classification by domain of unmet need, with results tabulated), data comparison (identifying patterns and themes through clustering and counting and making contrasts and comparisons) and conclusion drawing and verification (synthesis of subgroup analysis to inform a comprehensive understanding of the topic, verified with the primary source data for accuracy).

3. Findings

Figure 1 presents the PRISMA flowchart of the literature search and selection process. 30 systematic reviews that met the inclusion criteria and underwent full data extraction and quality assessment.

The results of the quality assessment are presented in **Table 1**.

3.1 Systematic review characteristics

The included 30 systematic reviews represented a total number of $n = 612$ publications which were conducted in a range of countries (see **Figure 2**). The original studies were largely dominated by United State of America (USA) $n = 146$, Australia $n = 99$, United Kingdom (UK) $n = 70$, and Canada $n = 55$, indicating a lack of research with non-WEIRD (Westernised, Educated, Industrialised, Rich, Democratic) populations¹⁹. The types of studies included across the 30 systematic reviews were: qualitative $n = 206$; cross-sectional quantitative studies $n = 360$; longitudinal quantitative studies $n = 22$; narrative review $n = 1$; mixed methods $n = 19$; case control study $n = 2$; and feasibility randomised controlled trial (RCT) $n = 2$. The included systematic reviews represented a total of 123,411 participants affected by a range of different cancers; see **Table 2** (see **Supplementary Table 3** for an in-depth overview of the included systematic reviews).

3.2 Frequency of unmet supportive care

The systematic reviews represented diverse patient populations affected by cancer that included: Arab survivors²⁰; Australian survivors²¹; Chinese survivors²²; people living in urban and rural areas²³; lesbian, gay and bisexual people²⁴; older people affected by cancer²⁵; younger people^{26,27}; male partners of women affected by a gynaecological cancer²⁸; and people affected by: gynaecological²⁹, melanoma³⁰, thyroid³¹, prostate³²⁻³⁴, colon/rectum³⁵, cervical³⁶, lung³⁷, kidney⁵⁷, testicular⁵⁸,

brain metastases³⁸, high grade glioma³⁹, young people with brain cancer⁴⁰, oral⁴¹, advanced cancer^{42,43}, bladder⁴⁴, penile⁷, chemotherapy induced alopecia⁶ and mixed cancers⁴⁵. However, irrespective of the cancer patient population group there were many commonalities in relation to the reported experiences of unmet supportive care needs which therefore enables the development of targeted future clinical trials, clinical guidelines and policy contribution (see **Table 3**). In descending order of frequency, the highest unmet supportive care needs were related to psychological/emotional (30/30), health system/information (29/30), interpersonal/intimacy (21/30), social (20/30), physical (19/30), family (18/30), practical (16/30), daily living (10/30), spiritual needs (8/30), patient-clinician communication (8/30) and cognitive needs (5/30). (see supplementary Table 4).

3.2 Unmet supportive care needs

Psychological/emotional needs

Psychological and emotional unmet needs were reported across all the included systematic reviews, which underscores fundamental shortcomings in care delivery irrespective of the patient population and the type of cancer. Evidence identified that the experience of unmet supportive care needs was negatively correlated with quality of life and positively correlated with experiences of anxiety and depression^{20-23,26,34,41,45}. Existing systematic reviews identified frequent experiences of depression, sadness, guilt, helplessness, losing one's sense of identity, isolation, fear of the cancer spreading and developing other types of cancer, worries about loved ones, which lasted from diagnosis, post-treatment and into survivorship^{6,7,23-26,29,30,32-39,41,43,44}. Patients described the need for assessment of their psychological well-being to enable timely access for support which was unavailable to them within existing services among people affected by gynaecological²⁹, oral⁴¹, colon³⁵, bladder⁴⁴, brain³⁸, melanoma³⁰, thyroid³¹, prostate³² cancers, adolescents and young adults^{26,27}, those living in rural locations²³ and individuals living with advanced cancer⁴². The important need for psychological support was also expressed by partners^{28,38,39} and family caregivers^{40,43}. Noteworthy, one review identified that men affected by penile cancer reported that they had major depression, suffered subsequent alcohol misuse, with suicidal tendencies and had no support or referrals provided to them – a significant problem with service design and delivery⁷.

Health system/informational needs

The second largest unmet area for people affected by cancer was related to informational needs about cancer, treatments, symptoms, self-management advice and support, healthcare system navigation and care coordination^{6,7,20,25-27,30-36,38,39,42-45}, including information about complementary and alternative therapies^{21,36}, which arguably feeds into psychological distress and unmet

psychological needs (i.e., anxiety, frustration, anger). Patients wanted ongoing contact with healthcare professionals within the system to develop shared plans of care which were person-centred^{24,39}. Specifically, women living with gynaecological cancer expressed that they needed to know how to self-care for symptoms (pain, lymphedema, fatigue, nausea and vomiting, daily care activities)²⁹ whereas their partners, expressed frustration with healthcare providers because they were rarely given information on how to cope with sexual complications as a couple²⁸. Adolescents and young adults needed information specifically related to issues around fertility preservation, changes in appearances, education and finances, that was age-appropriate to them^{26,27}. For individuals living in remote and rural areas it was important that they were provided with all the necessary information before they travelled, which necessitated the need for remote support to provide clarifications and answer questions at home²³. People who identified as sexual or gender minority groups expressed concerns that the information was not tailored to them which resulted in a sense of isolation in which they were left to self-care and self-educate themselves, with little written information or support from healthcare professionals²⁴. Evidence identified that those living with a life-limiting cancer (advanced cancer) expressed the need for information and access to palliative care services who could supported end-of-life discussions within the multidisciplinary team³⁷⁻³⁹.

Interpersonal/intimacy needs

Both men and women expressed a range of unmet needs related to a lack of information and opportunity for discussion with healthcare professionals about adjusting to changes in sexuality, altered body image and sexual dysfunction^{6,7,34-36,41,43-45}, again likely causing psychological distress. Specifically, women affected by pelvic cancers expressed the requirement for discussions with healthcare professionals about fertility, sexual intercourse, managing vaginal changes, changes in sensation and coping with premature menopause and reduced libido^{29,36,44}. Partners of women affected by gynaecological cancer expressed fear of vaginal bleeding, cancer recurrence and transmission if sexual activity restarted, which were important issues that were seldom discussed with them²⁸. Similarly, partners of people affected by brain metastases expressed that their highest unmet needs were related to relationship problems, a lack of intimacy and no opportunity of emotional expression³⁸, which are linked to psychological wellbeing⁴⁶. Some cultures²⁰ and minority sexual and gender groups²⁴ were reluctant to discuss issues related to sexual well-being, sexuality and relationships; therefore, healthcare professionals should be sensitive to this potential barrier to ensure timely support and intervention within a non-judgemental discourse. For men affected by cancer, concerns were related to the quality of erections, early ejaculation, dyspareunia,

a disconnect between sensory self and physical self and a lack of support or information related to interventions available ^{7,25,34,44}, which can lead to experiences of low self-esteem and depression⁴⁷.

Social needs

Social unmet needs were identified across 18 of the included systematic reviews. Young people affected by cancer ^{26,27,40}, individuals living with melanoma ³⁰, colon and/or rectum ³⁵, prostate ^{32,33}, malignant glioma ³⁹ and thyroid cancers ³¹, individuals who belonged to a minority sexual or gender group ²⁴, and family caregivers ^{20,40} all expressed the need for peer support and connecting to others who shared a similar experience. Other social needs related to planning ahead and knowing the proximity to bathrooms to prevent stoma related embarrassment in social situations ^{35,44} and for men experiencing urinary dysfunction ^{7,34}; needs that could be better supported through coordinated multidisciplinary care. For people affected by lung ³⁷, bladder ⁴⁴, and penile cancer ⁷, as well as those affected by chemotherapy induced alopecia ⁶ and immigrant patients ²² expressed issues with stigma, loneliness, social isolation and feelings of abandonment from society, which can lead to depression⁴⁸. The need to belong and feel included is a fundamental human motivation⁴⁹. For women affected by cervical cancer they expressed compromised social desirability due to concerns of unpleasant body odour being noticed by others ³⁶. Specifically, for young people affected by brain cancer they experienced impairment in social functioning (avoiding social situations), social isolation and difficulties re-integrating into society because of problems with impaired physical fitness and cognitive function which reduced the opportunity to participating in sports and hobbies ⁴⁰. Partners and caregivers also expressed social needs because of feelings of isolation and a diminished participation in social activities because of the impact of cancer ⁴³.

Physical needs

People affected by various types of cancer experienced a range of distressing physical concerns which were poorly managed and negatively impacted on mood, daily activities, and quality of life ^{6,7,22,25,27,30,34-38,40-45}. Among Arab people affected by cancer prominent physical issues related to constipation, vomiting, chest pain and heaviness, fatigue, muscular tightness, hair and weight loss ²⁰. These are concerns that could be prevented or minimised through referrals to appropriate health professionals within the multidisciplinary team such as dietitians. Gynaecological cancer survivors expressed concerns related to pain in the groins and legs due to lymphoedema which were often long-lasting several years after initial cancer treatment ²⁹. People affected by cancer in remote and rural areas often reported more severe symptoms compared to those in urban areas ²³.

Family related needs

Family related concerns were commonly identified. Many patients across the reviews described concerns about being a burden on other family members ^{20,23,35-38,44}. This sense of burden also was

experience by young people who were concerned about protecting their partners and parents²⁷, and concerns around family members inheriting aggressive cancer genes³⁶. Caregivers expressed concerns related to their own sleep disturbance, anxiety, and financial constraints, as well as, how to provide good care to their loved ones^{20,22,43,44}, with these unmet needs potentially leading to burnout⁵⁰ and caregivers experiencing mental health difficulties. Caregivers needed help in how to reduced their loved ones distress and supporting decisions in a context of uncertainty of living with cancer^{22,29,34,40} and worry of cancer progression^{38,39}. Informal family caregivers also expressed the need for timely and individualised information to support them in the transition in their caregiver role, and to support them in preparing for financial loss due to family income^{39,40}. People affected by cancer⁶, and parents of children with cancer, expressed concerns for other siblings in the family who may feel alone and were provided with less time and attention⁴⁰.

Practical needs

For young people affected by cancer they needed practical help with access to facilities for recreation, relaxation and studying, including considerations for a young person's schedule for (sleep, wake times and visiting hours)^{26,27}. Patients living in remote and rural areas also had specific practical needs related to the financial implications of travel, and the challenges of organising financial reimbursement²³. Patients living in geographical regions such as United States of America and Australia were more likely to comment on rural contexts than other European countries. Partners of women affected by gynaecological cancer also reported problems with the financial burden of outright medical expenses further compounded by reduced family incomes²⁸. Similarly, financial issues caused concern for people affected by colon and/or rectum³⁵, prostate³⁴ and bladder cancer⁴⁴. Patients articulated problems daily grappling with the experience of using a stoma/urostomy bag^{35,44}, and associated side effects to maintain lifestyle modifications (due to cancer and treatment), with little support³⁵. Issues that could managed if appropriate multidisciplinary care was accessible. Other practical issues for patients included where to source containment pads for urinary incontinence³⁴, stoma supplies⁴⁴, and other self-care aids^{6,7} among patients who experienced life-changing side-effects from cancer treatment. For other patients, practical considerations were important including affordable and convenient parking when attending hospital appointments^{24,34-37,39}. For those with life-limiting cancers practical help was needed for funeral arrangements and making a will/advanced directive³⁷.

Daily living needs

Patients living in remote and rural areas experienced challenges with functioning and self-managing side-effects from treatment and cancer with little support from healthcare professionals²³. For partners they had to change their daily routines from being a husband and father, to caregiver and

income-generator²⁸. Many patients needed help with daily living needs because of severe fatigue which limited their ability to tend to the normal living routines^{21,22,25,34,42,43,45} and would have benefited from timely access to healthcare professionals³⁶, including out-of-hour access to support³⁷. For young people affected by brain cancer they experienced living challenges everyday related to reading, managing finances and self-managing medications because of long lasting impairment on physical health (including issues of poor mobility, hearing and/or vision problems, poor physical fitness, hair loss, weight issues and scars)⁴⁰.

Spiritual needs

People affected by various cancers provided insight into their spiritual needs for those diagnosed with lung³⁷, prostate³⁴, penile⁷, melanoma³⁰, people affected by chemotherapy induced alopecia cancer⁶, patients and caregivers of high-grade glioma³⁹, patient and caregivers of people with advanced cancer⁴³ and partners of women affected by gynaecological cancer²⁸. Many people affected by cancer were distressed by the fear of the unknown^{30,34,37,43} and end-of-life with a reported sense of “death anxiety”^{34,39,43}, with both of these associated with poor mental health outcomes⁵¹. Often the spiritual needs and existential concerns of patients and their families were not discussed with a qualified healthcare professional³⁹. Evidence identified that patients perceived that obstacles with healthcare professionals were related to their lack of skill, time and confidence to have confronting conversations to explore and meet spiritual care needs³⁹. Other patients described a sense of losing their faith due to cancer⁷. Whereas, for others patients⁶ and for their partners²⁸ they gained internal strength from being close to nature and their used faith and prayer as a coping mechanism.

Patient-clinician communication needs

It was important to people affected by cancer that the consultations with their healthcare professionals provided the needed information about cancer, treatment effectiveness and how to manage symptoms, which was not always achieved well in practice^{6,7,20,36,37,44}. Written information needed to be in a format that was easy to comprehend and available in non-English speaking languages²⁰, this was particularly relevant when patients perceived that their doctor did not take time and care to overcome language barriers with them²⁰. In particular, young people affected by cancer emphasised the importance that their healthcare professional must demonstrated empathy, trust and use active listening skills during information exchanges with them²⁶. The qualities of having a trusted clinician were also vital to adults affected by cancer to facilitate an open and safe dialogue for issues that patients were embarrassed or reticent to discuss^{6,7,36,37}. Patients reported dissatisfaction with the explanations of test results and a lack of upfront discussion about the impact

that treatment can have on sexuality and function^{7,34,36,44}. Patients also expressed distress about a lack of continuity of care and suboptimal care co-ordination^{7,34}.

Cognitive needs

Patients reported issues with cognitive function, such as, forgetfulness, poor cognition and confusion that affected their quality of life and was not always acknowledged or discussed with their healthcare professionals^{6,34,37}. Cognitive needs among young people affected by brain cancer were described as an invisible effect; therefore, timely support was not always provided to them⁴⁰.

Cognitive decline affected the young person's ability to self-care, make friends and reach developmental milestones and educational attainment⁴⁰. Importantly, evidence underscored that educational providers were not tailored to meet the unique learning, teaching and assessment needs of young children affected by brain cancer⁴⁰.

Discussion

This umbrella review has identified key areas that need urgent attention within international health systems. Psychological and emotional needs were identified by this study to be the highest reported shortcoming in fundamental care within their own domain and cutting across other areas of unmet needs. Lack of support has been identified to lead to a decrease in quality of life and increase in depression and anxiety among people affected by cancer. Second to this is the lack of information provided to people with cancer during their care pathways. People with cancer and their families reported having difficulties with understanding their diagnosis, treatments, symptoms and self-management advice. They also report that cancer coordination is sub-optimal, with a large gap identified in their ability to navigate the health systems to access the information they require. Although the classification of domains for supportive care needs is well established, what has been identified through this umbrella review is that unmet psychological needs appear to tie most of the domains together, with impacts of unmet physical, family, social, interpersonal, daily living, spiritual, and cognitive all potentially leading to poorer mental health overall. Cancer treatment should take a holistic approach examining all aspects of a person's life, as anyone of those unmet needs could potentially cause a deterioration in mental health, which in turn may influence physical health and recovery, with research identifying the reciprocal influences of mental and physical health on each other⁵².

The unmet needs for people living in rural and remote areas was specifically highlighted in this umbrella review including health system/informational needs, physical needs, practical needs and daily living needs. For people living with cancer telehealth services, which have significantly increased during the COVID-19 pandemic⁵³, may offer a potential solution⁵⁴. Telehealth services can be as effective as in-person consultations⁵⁵, transcend geographical barriers and offer, potential

financial, access, monitoring and in-home advantages⁵⁶. As such, telehealth could offer cancer patients in rural or remote areas, as well as vulnerable persons who find it challenging to travel, increased access to multiple healthcare professionals and could be considered as a targeted intervention towards addressing unmet supportive care needs.

This umbrella review has also identified the need for improved trust, empathy and safe health services; timely individualised multidisciplinary care; communication (written and verbal) with an emphasis on active listening; and the co-ordination of client-centred services across the continuum of care. A greater emphasis on patient and family centred interprofessional education for health professionals working in oncology (supporting the education and training of values/ethics, professional roles and responsibilities, communication and teamwork) may be warranted⁵⁷.

Limitations

While this umbrella review was comprehensive there are some limitations. Reviews that were published in non-English were not assessed, which may in some part reduce some of the generalisability of the findings to non-English speaking cultures. Further to this point, as identified in the review characteristics, most of the research was conducted on WEIRD populations and therefore potentially lacks a cross-cultural perspective¹⁹. In particular, there was a lack of research in non-Westernised, Educated, Industrialised, Rich, Democratic populations, and therefore the findings of this review maybe not be clinically transferable to low-medium income countries. For example, the unmet needs in the poorest parts of South America or Saharan Africa are likely different from each and Westernised countries, such as the US, UK, and Australia. Furthermore, we were not able to discern cultural differences across countries in relation to patients expectations of health professionals in relation to supportive care service provision. Additionally, it was not possible to identify the trajectory of unmet supportive care needs across the cancer care continuum (at the point of diagnosis, treatment, post-treatment, survivorship, end-of-life and bereavement). Although the views of lesbian, gay, and bisexual people were examined in one systematic review and meta-synthesis²⁴, there was an underrepresentation of sexual and gender minorities, which may lead to heteronormative approaches in addressing unmet needs of cancer patients. Future research should aim to determine the unmet needs of patients with cancer in poorer and un-industrialised countries, as well as other minority groups (e.g., sexual and gender diverse populations, indigenous populations).

Clinical implications/conclusion

This umbrella review has identified important areas of need for cancer survivors undertaking their health care journey. Given that all reviews have identified that psychological and emotional needs are not being met within the health system, urgent change is required. People with cancer are have

reported that their needs are not being met across many domains as identified in this study. Cancer specialist nurses are conduits for change and can provide sound leadership in developing clinical service innovations. Supportive care is a modifiable factor and nurses can use patient reported outcomes to tactfully identify areas of care which are most concerning/distressing to the individuals and their loved ones and use that information to develop a shared supported self-management care plan. Globally, in cancer communities it is now time for change across the health system to support people with cancer undertaking this debilitating journey so that people living with cancer are supported and empowered to lead a life with renewed physical and psychological energy and with the self-management skills needed for a healthy and successful survivorship experience. Future research should consider identifying a clear pathway forward for clinicians working with cancer survivors so that the supportive care needs of patients are being met.

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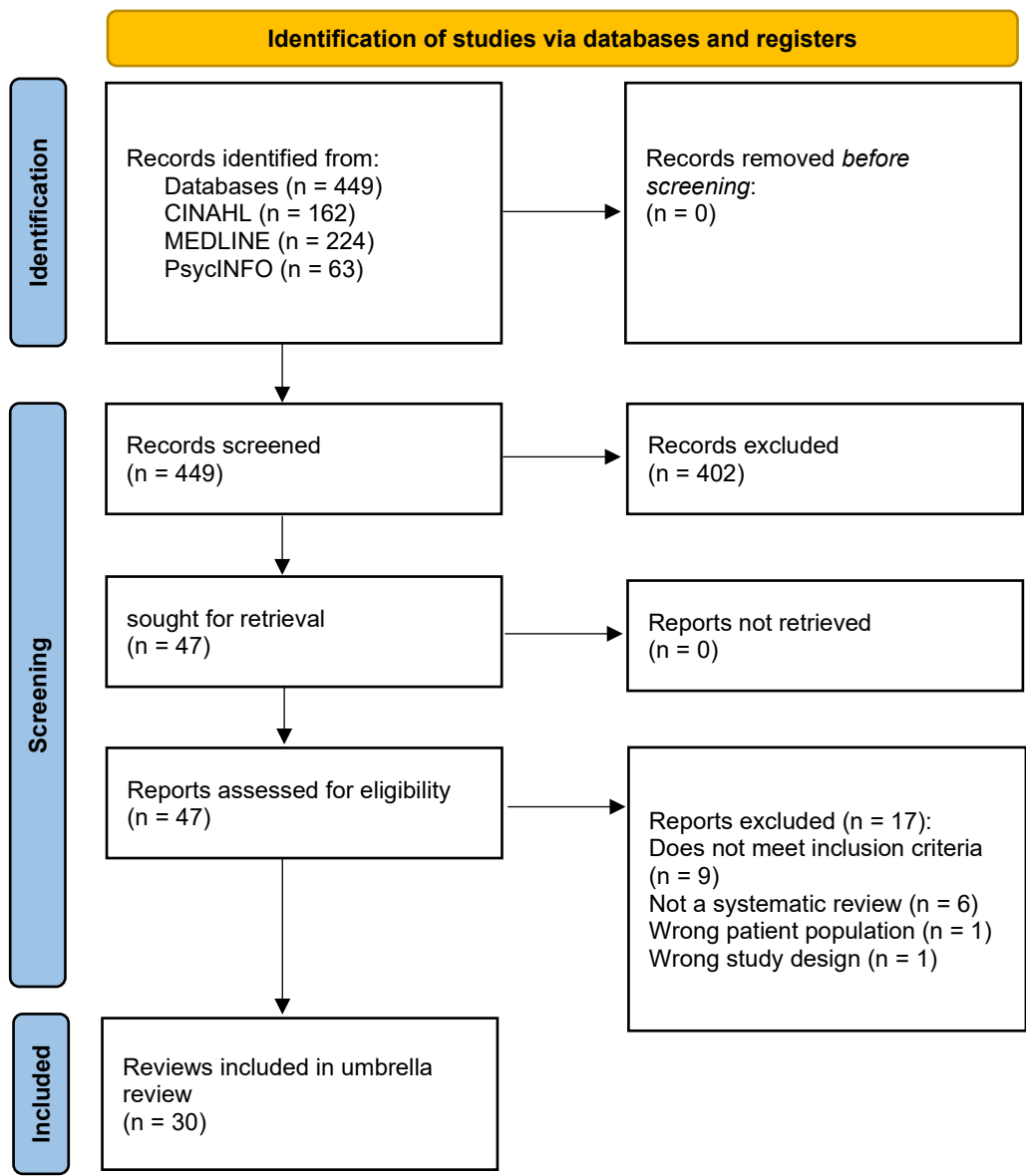


Figure 1. PRISMA 2020 flow diagram

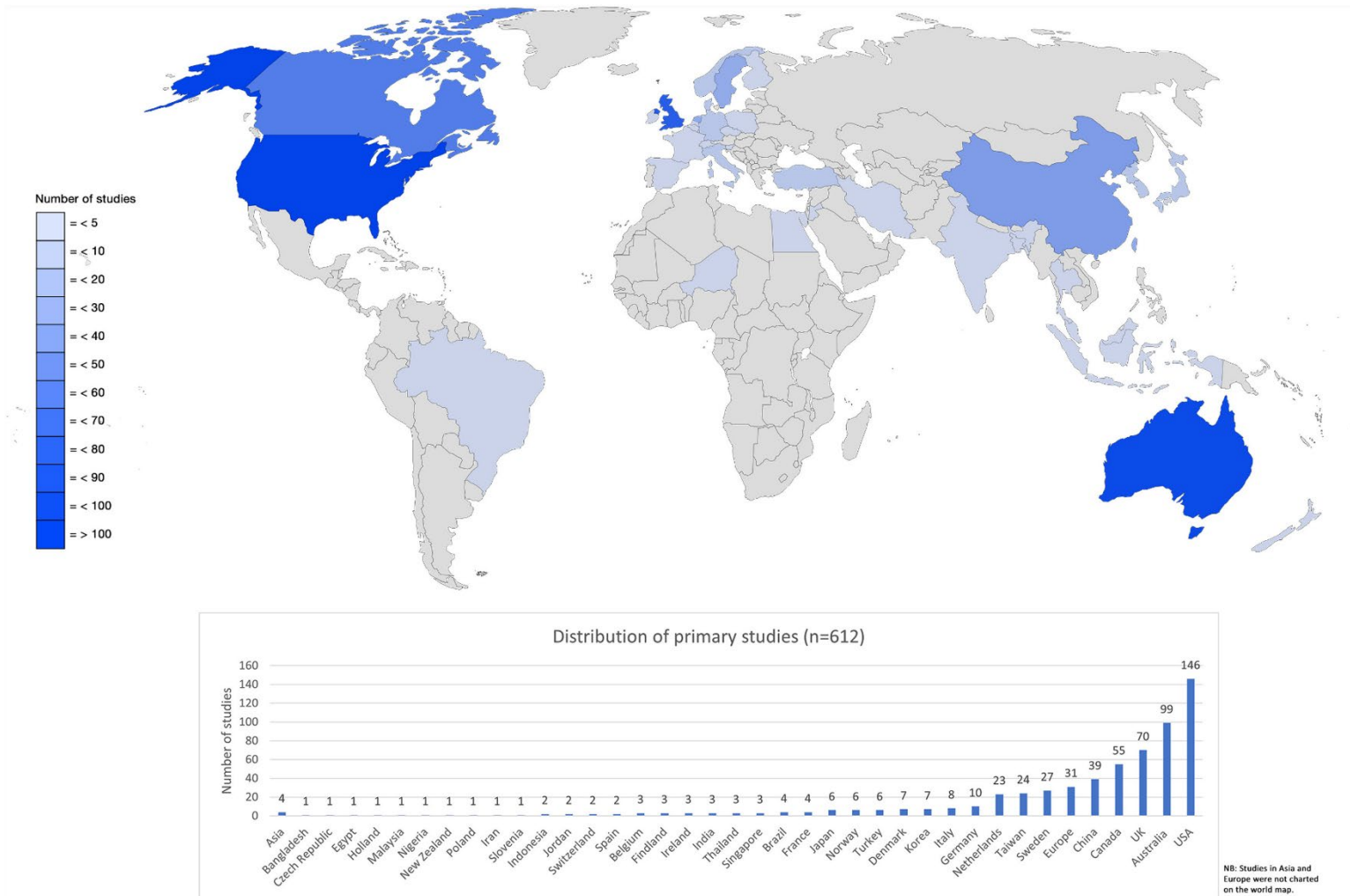


Figure 2. Distribution of the country of origin across the primary studies.

Table 1. Quality Appraisal Results

Reviews	Item number of check list									
	1	2	3	4	5	6	7	8	9	10
Alananzeh et al. 2016	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Beesley et al. 2016	Y	Y	Y	Y	U	Y	U	Y	Y	Y
Bibby et al. 2017	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Butow et al. 2012	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Doyle et al. 2022	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Fu et al. 2020	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Galan et al. 2016	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Ge et al. 2020	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hyun et al. 2016	Y	Y	Y	Y	Y	Y	Y	Y	N	N
King et al. 2015	U	Y	N	Y	Y	Y	Y	Y	Y	Y
Kotronoulas et al. 2017	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Lisy et al. 2018	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Lisy et al. 2019	Y	Y	Y	N	Y	U	Y	Y	Y	Y
Maguire et al. 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Maguire et al. 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Maqbool et al. 2017	Y	Y	Y	Y	N	Y	U	Y	Y	N
McIntosh et al. 2019	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Mirosevic et al. 2019	Y	Y	Y	Y	N	U	U	Y	Y	N
Moghaddam et al. 2016	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
Moore et al. 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Moore et al. 2014	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Nicklin et al. 2019	Y	Y	Y	Y	Y	U	Y	Y	Y	Y

O'Dea et al. 2021	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Paterson et al. 2015	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Paterson et al. 2018	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Paterson et al. 2020	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Paterson et al. 2021	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Puts et al. 2012	Y	Y	Y	Y	Y	U	U	Y	U	Y
Wang et al. 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wu et al. 2019	Y	Y	Y	Y	Y	U	Y	Y	Y	Y

Item number check list key*: 1. Is the review question clearly and explicitly stated, 2. Were the inclusion criteria appropriate for the review question, 3. Was the search strategy appropriate, 4. Were the sources and resources used to search for studies adequate, 5. Were the criteria for appraising studies appropriate, 6. Was critical appraisal conducted by two or more reviewers independently, 7. Were the methods used to combine studies appropriate, 8. Was the likelihood of publication bias assessed, 9. Were recommendations for policy and/or practice supported by the reported data, 10. Were the specific directives for new research appropriate.

*Three levels of assessment quality scores

Met (Y)
Not Met (N)
Unclear (U)

Table 2. Overview of the included systematic reviews

Author and Year Country	Objective of the included review	Type of review	Participant	Number of databases sourced and searched	Publications date range of the studies included in the review	Number of studies	Primary studies quality ratings
Alanzeh et al. 2016 Country: Australia	To identify the unmet supportive care needs of Arab people affected by cancer.	Integrative Review.	n=1186.	Databases: n=8 Search engines: n=1 Webpages: n=2.	1993 to 2003.	Number of studies: n=6 Type of included studies: Qualitative: n=2 Quantitative: n=4 (Cross-sectional x 2 / Descriptive survey x 2).	Instrument: Assessment criteria outlined by Kmet et al. Quality ratings: Cohen's Kappas were calculated for each study. The overall mean quality score was 16.5/20 (SD=1.83), indicating that, overall, the studies were of a sound standard. Only one study scored 1 SD below the mean, suggesting a less rigorous methodology was utilized.
Beesley et al. 2018 Country: Australia	To determine the prevalence of met and unmet needs, and the risk factors for unmet needs among people affected by gynaecological cancer.	Systematic literature review.	n=not reported.	n=6.	Not reported.	Number of studies: n=37 Type of included articles: Quantitative (cross-sectional): n=24 Qualitative: n=12 Reviews: n=1.	Instruments: Not reported. Quality ratings: Quantitative: Good (n=8), Fair (n=7), Poor (n=9). Qualitative: Poor (n=12)
Bibby et al. 2017 Country: Australia	To assess what is currently known about unmet needs and care experiences of adolescents and young adults (AYA's) with cancer.	Systematic review.	n=1088.	n=4.	Not reported.	Number of studies: n=39 studies (reported in 45 articles) Type of included articles: Quantitative: n=12 Qualitative: n=23 Mixed methods: n=4.	Instruments: Quality criteria were specifically developed with reference to the Cochrane Handbook for Systematic Reviews of Interventions, the Critical Appraisal Skills Programme (and other guidelines and checklists). Quality ratings: Average across all studies was in the adequate range (mean=10.6; SD=1.8). Quantitative: 10.3 (SD=2.3). Qualitative: 9.8 (SD=2.4). Mixed methods: 9.4 (SD=3.4).
Butow et al. 2012 Country: Australia	To describe what is known about levels of morbidity and the experiences and needs of people with cancer, and their informal caregivers, living in rural areas.	Systematic review.	n=19,310.	n=3.	1993 to 2010.	Number of studies: n=37 Type of included articles: Quantitative: n=25 Qualitative: n=12.	Instruments: Adapted checklists for quantitative and qualitative studies. Quality ratings: Studies achieving less than 40% = poor quality, 40% - 70% = good quality, Higher than 70% = very good quality. Quantitative: Kappa score K=0.857 (excellent). Poor: n=0, Good: n=9, Very good: n=15. Qualitative: Kappa score K=0.617 (good), Poor: n=1, Good: n=6, Very good: n=5.
Doyle et al. 2022 Country: Australia	To identify the supportive care needs of men affected by testicular cancer.	Systematic review	n=not reported	n=3	2010 to 2021	Number of studies: n=36 Type of included articles: Quantitative: n=30 Qualitative: n=5 Mixed methods: n=1	Instruments: Mixed Methods Assessment Tool (MMAT). Quality ratings: No studies were removed because of their appraisal score, but lower quality study findings should be interpreted with greater caution and in consideration of their limitations.
Fu et al. 2020 Country: Australia	To evaluate the supportive care and unmet supportive care needs and associated factors in patients with melanoma.	Mixed methods systematic review.	n=1820.	n=3.	2012 to 2019.	Number of studies: n=14 Type of included articles: Quantitative: n=10	Instruments: Mixed Methods Assessment Tool (MMAT). Quality ratings: All three qualitative studies met 100% of the critical appraisal criteria. The only mixed methods study met most critical appraisal criteria and only 2/10 quantitative studies met all

						<i>Qualitative:</i> n=3 <i>Mixed Methods:</i> n=1.	criteria. The main weakness across these studies was the risk of response bias as only one study achieved over 80% response rate.
Galan et al. 2016 Country: Spain	To report on the needs of adolescent and young adult cancer survivors after their treatment.	Systematic review	n=2821.	n=11.	2006 to 2014.	Number of studies: n=14 Type of included articles: <i>Quantitative:</i> n=8 <i>Qualitative:</i> n=6.	Instruments: A Checklist for Qualitative and Quantitative studies developed for a study by Hoekstra, Heins and Korevaar (2014) Quality ratings: The quality score ranged between 61 and 92 on a scale from 0 to 100. The average was 75.
Ge et al. 2020 Country: China	To explore male partners' caring experience and supportive care needs when caring for women with gynaecological cancer.	Qualitative literature review.	n=1301.	n=9.	1995 to 2019.	Number of studies: n=8 Type of included articles: <i>Qualitative:</i> n=8.	Instruments: Critical Appraisal Skills Programme (CASP) qualitative appraisal instrument. Quality ratings: Most of the studies rated well against the CASP, and total scores ranged from 15–22 with a mean score of 19.
Hyun et al. 2016 Country: Canada	To conduct a systematic review of the published English language literature, examining (i) the unmet information needs and (ii) the unmet psychosocial support needs of adult thyroid cancer survivors.	Systematic review.	n=6215.	n=7.	2010 to 2016.	Number of studies: n=7 Type of included articles: <i>Quantitative:</i> n=7	Instruments: Cochrane Risk of Bias tool or the Center for Evidence-Based Management Critical Appraisal of a Survey tool (depending on the study type). Quality ratings: The level of agreement between reviewers was estimated using a kappa statistic. At electronic citation review stage kappa statistic of 0.515 (CI 0.346-0.684). Full-text review stage kappa statistic was 0.516 (CI 0.230-0.803).
King et al. 2015 Country: UK	This article describes a qualitative systematic review and synthesis examining men's experience of a need for supportive care.	Systematic review and qualitative synthesis.	n=1003.	n=7.	2004 to 2013.	Number of studies: n=20 Type of included articles: <i>Qualitative:</i> n=20 (two were longitudinal surveys that included qualitative data).	Instruments: Critical Appraisal Skills Programme (CASP) quality appraisal tool. Quality ratings: The papers were generally of good quality and none were excluded due to poor quality overall. Negative scoring on reflexivity and ethical considerations were not sufficient to warrant rejection of individual papers. If the papers had scored poorly on the other criteria, the reviewers would then have conducted a sensitivity analysis.
Kotronoulas et al. 2017 Country: UK	To systematically assess the relevant literature and synthesise evidence in relation to the supportive care needs of people living with and beyond cancer of the colon and/or rectum.	Systematic review.	n=10,057.	n=5.	Pre 2000 to 2016.	Number of studies: n=54 Type of included articles: <i>Quantitative:</i> n=32 <i>Qualitative:</i> n=18 <i>Mixed methods:</i> n=4.	Instruments: QualSyst evaluation tool. Quality ratings: SQS ranging from 44% to 95%, with a median SQS of 80%. Over half studies (29; 54%) had SQS ≥80%. <i>Quantitative:</i> median SQS = 82%; range = 44% - 95%; 21/36 studies with SQS ≥80%. <i>Qualitative:</i> median SQS = 75%; range = 60% - 90%; 9/22 studies with SQS ≥80%.
Lisy et al. 2018 Country: Australia	To explore the cancer care experiences and unmet needs of people who identify as a sexual or gender minority.	Systematic review and meta-synthesis.	n=385.	n=2.	2004 to 2018.	Number of studies: n=13 studies (reported in 15 articles). Type of included articles: Not reported.	Instruments: Critical Appraisal Skills Programme Qualitative Research Checklist. Quality ratings: Overall studies were deemed to be of moderate to high quality, with studies meeting from 5 to 9 of 9 quality criteria. Based on methodological assessment, reviewers agreed that, across the studies, results could be considered valid in their credibility, transferability, and dependability.
Lisy et al. 2019 Country: Australia	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.	Systematic review.	n=6366.	n=2.	2007 to 2018.	Number of studies: n=17 Type of included articles: <i>Cross-sectional:</i> n=15 <i>Longitudinal:</i> n=2	Instruments: Centre for Evidence-Based Management Critical Appraisal Checklist for Cross-Sectional Study. Quality ratings: Studies that met 6 or more out of 11 quality criteria were included in the review (all studies were deemed to be appropriately conducted and of sufficient quality).

Maguire et al. (2013) Country: UK	To determine to supportive care needs of people affected by lung cancer.	Integrative review.	n=4645.	n=5.	2001 to 2012.	Number of studies: n=53 studies (reported in 59 articles). Type of included articles: <i>Quantitative:</i> n=25 <i>Qualitative:</i> n=34	Instruments: Quality Assessment Tool (Hawker et al. 2002) Quality ratings: All studies were reported as acceptable methodological quality scores. Mean quality score for quantitative studies 28.3 (SD, 4.1.61, range 17-37). Mean quality score of qualitative studies 29 (SD2.61, range 25-36).
Maguire et al. 2015 Country: UK	To understand the supportive care needs of women living with and beyond cervical cancer	Systematic review	n=1414.	n=7.	1993 to 2012.	Number of studies: n=12 studies (reported in 14 articles). Type of included articles: <i>Quantitative:</i> n=7 <i>Qualitative:</i> n=4 <i>Mixed Methods:</i> n=1.	Instruments: standardised QualSyst evaluation tool Quality ratings: Studies were retained in this review if they were awarded a summary score of ≥55%. This score has been suggested as a relatively liberal threshold, indicating acceptable study quality. Study scores ranged from 0.56 – 0.90.
Maqbool et al. 2017 Country: Canada	To summarise the supportive care needs of people affected by brain metastases and caregivers.	Systematic review.	n=219.	n=4.	2006 to 2013.	Number of studies: n=7 Type of included articles: <i>Observational:</i> n=6 <i>Intervention:</i> n=1	Instruments: Evaluation criteria were focussed on sample representativeness, sample size, degree of missing data, accounting for non-respondents and instrument validity. Quality ratings: All 7 included studies were found to involve high risk of bias, substantially being affected by sample representativeness, sample size and accounting for non-respondents in particular. The majority of studies also involved a high risk of bias in terms of degree of missing data (5/7=71%) and instrument validity (4/7=57%).
McIntosh et al. 2019 Country: Australia	To identify the specific unmet supportive care needs of men on active surveillance (AS).	Systematic review	n=1782.	n=4.	2003 to 2018.	Number of studies: n=8 Type of included studies: <i>Qualitative:</i> n=5 <i>Cross-sectional:</i> n=3	Instruments: JBI checklists for prevalence and qualitative studies. Quality ratings: Not reported.
Mirosevic et al. 2019. Country: Slovenia	To explore the prevalence and most frequently found unmet needs and to identify factors associated with higher levels of total unmet needs and with each domain separately.	Systematic review.	n=10,479.	n=5.	2007 to 2017.	Number of studies: n=26 Type of included articles: <i>Prospective longitudinal:</i> n=4 <i>Cross-sectional:</i> n=22	Instruments: An adapted 12-item pre-defined criteria for systematic review. Quality ratings: Most (20/26) of the studies were considered to be high quality, six to be moderate and none to be poor quality. General limitations were the absence of clinical information, low response rate and lack of information on finding factors associated with unmet needs.
Moghaddam et al. 2016 Country: UK	Identify areas for developing and targeting supportive interventions that best meet the changing needs of this population of patients (people living with advanced cancer).	Systematic review	n=3613.	n=4.	1987 to 2014.	Number of studies: n=23 Type of included articles: <i>Quantitative:</i> n=19 <i>Qualitative:</i> n=4	Instruments: Mixed Methods Appraisal Tool (MMAT) Quality ratings: Most (68%) were of a high standard (all criteria met). Low response rate (<60%) and questionable sample representativeness were recurrent methodological limitation of quantitative studies. One qualitative study did not report consideration of how findings might have been shaped by the researchers positioning or the context in which data was collected.
Moore et al. 2013 Country: Australia	To collate current literature detailing the supportive and palliative care needs of patients with Primary Malignant Glioma (PMG) and their carers, and to subject it to a novel approach of formal evaluation.	Systematic review	n=520.	n=4.	2000 to 2010.	Number of studies: n=21 Type of included articles: <i>Qualitative:</i> n=21	Instruments: Those selected for full text review (n=100) were screened according to The Critical Appraisal Skills Program (CASP). Those then included in final analysis (n=21) were reviewed against HEP to categorise studies according to their strength of evidence. Quality ratings: 2/21 studies met the criteria for highest level of evidence (generalisable studies). 8/21 studies met level II (conceptual studies) and 11/21 studies met level III (descriptive studies).

Moore et al. 2014 Country: Australia	To systematically review the literature describing quality of life (QoL) outcomes and support needs in patients with oral cancer along the cancer trajectory.	Systematic review.	n=6482.	n=6.	Not reported.	Number of studies: n=31 Type of included articles: All quantitative methodologies. <i>Cross-sectional:</i> n=21 <i>Longitudinal or prospective:</i> n=7 <i>Case-control:</i> n=2 <i>Retrospective chart review:</i> n=1	Instruments: The Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies. Quality ratings: The use of cross-sectional design by several of the studies contributed to a high number of 'weak' appraisals. Studies that used longitudinal or prospective methods were generally awarded a stronger EPHPP rating. <i>Weak:</i> 18/31, <i>Moderate:</i> 8/31, <i>Strong:</i> 5/31
Nicklin et al. 2019 Country: UK	To systematically review and narratively synthesis evidence on issues that AYA childhood brain tumour survivors and their caregivers face and their supportive care needs.	Systematic review	n=9943.	n=6.	1992 to 2017	Number of studies: n=49 studies (reported in 56 articles). Type of included articles: <i>Quantitative:</i> n=37 <i>Qualitative:</i> n=5 <i>Mixed Methods:</i> n=7	Instruments: Mixed Methods Appraisal Tool (MMAT) Quality ratings: Scores ranged from 25% to 100%. No studies were removed because of their appraisal score, but lower quality study findings should be interpreted with greater caution and in consideration of their limitations.
O'Dea et al. 2021 Country Australia	To identify the unmet needs of people affected by kidney cancer.	Systematic review	4464	n=3.	2010 to 2020	Number of studies: n=15 studies (reported in 18 articles). Type of included articles: <i>Quantitative:</i> n=15 <i>Qualitative:</i> n=1 <i>Mixed Methods:</i> n=2	Instruments: Mixed Methods Appraisal Tool (MMAT) Quality ratings: No studies were removed because of their appraisal score, but lower quality study findings should be interpreted with greater caution and in consideration of their limitations.
Paterson et al. 2015 Country: UK	To synthesise current available evidence with regard to the unmet supportive care needs of men living with and beyond prostate cancer.	Systematic review.	n=2914.	n=6.	1997 to 2014.	Number of studies: n=17 Type of included articles: <i>Cross-sectional:</i> n=8 <i>Qualitative:</i> n=9	Instruments: 2 x quality appraisal tools (one for quantitative and one for qualitative) Quality ratings: Overall, the methodological quality varied from 53.3% to 90.0%, with a median score of 70% (IQR 17.5%). <i>Qualitative:</i> A median score of 70%, (IQR 18.35%, range 53.3%-83.3%). <i>Quantitative:</i> A median score of 75% (IQR 22.5%, range 65.0%-90.0%).
Paterson et al. 2018 Country: UK	To determine the different domains of unmet supportive care needs for patients affected by Muscle Invasive Bladder Cancer (MIBC).	Systematic review.	n=260.	n=7.	1989 to 2016.	Number of studies: n=7 studies (reported in 8 articles). Type of included articles: <i>Cross-sectional:</i> n=6 <i>Feasibility RCT:</i> n=1	Instruments: 2 x quality appraisal tools used previously in a variety of cancer systematic reviews. Quality ratings: Overall the methodological quality varied from 50% to 80% with a median score of 58.5% (IQR 16.5% range 51.8%-68.3%).
Paterson et al. 2020 Country: Australia	To understand the unmet supportive care needs of men affected by penile cancer and their partners.	Systematic review.	n=469.	n=7.	1994 to 2018.	Number of studies: n=17 studies (reported in 18 articles). Type of included articles: <i>Qualitative:</i> n=7 <i>Survey:</i> n=10	Instruments: 2 x quality appraisal tools (one for qualitative one for quantitative). The tools were developed as part of a Health Technology Assessment Integrative Review Quality ratings: There are a number of shortcomings across the studies which included small sample sizes, lack of transparency in qualitative methodology and limited reporting of the clinical and demographic characteristics across study participants.
Paterson et al. 2021	To understand the supportive care needs of	Systematic review.	n=3394.	n=6.	1997 to 2018.	Number of studies: n=27	Instruments: two quality appraisal tools (one quantitative and one qualitative), which have been used in a similar systematic review

Country: Australia	men and women affected by chemotherapy-induced alopecia (CIA).					Type of included studies: <i>Quantitative:</i> n=17 <i>Qualitative:</i> n=10	Quality ratings: Both quantitative (17 items) and qualitative (15 items) were scored using low risk, unclear risk and high-risk classifications of bias.
Puts et al. 2012 Country: Canada	To identify the unmet care needs of older persons diagnosed with cancer who are undergoing active treatment.	Systematic review.	n=7771.	n=5.	January 1996 to 06 December 2010.	Number of studies: n=30 Type of included articles: <i>Cross-sectional:</i> n=16 <i>Prospective:</i> n=7 <i>Quasi-experimental:</i> n=1 <i>Clinical database:</i> n=1 <i>Mixed Methods:</i> n=2 <i>Qualitative:</i> n=3	Instruments: Reporting of Observational Studies in Epidemiology, the Meta-analysis of Observational Studies in Epidemiology, and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. Qualitative studies used Quality Framework of the National Centre for Social Research. Quality ratings: All studies had a clearly formulated problem statement. Most used clear inclusion and exclusion criteria. Seven did not report the response rate and the majority didn't report reasons for nonparticipation. Most studies did not describe how much data were missing or how the missing data were handled. Few studies clearly described the limitations. Overall, the quality of qualitative studies was good.
Wang et al. 2018 Country: Hong Kong	To identify the unmet care needs and their associated variables in patients with advanced cancer and informal caregivers.	Systematic Review.	n=9152.	n=10.	1988 to 2016.	Number of studies: n=50 (advancer cancer patients n=33; Informal caregivers n=12; both n=5). Type of included articles: <i>Quantitative:</i> n=43 (42 surveys, 1 post intervention study) <i>Qualitative:</i> n=7	Instruments: Mixed Methods Appraisal Tool (MMAT) Quality ratings: Included studies were generally robust, with 17 and 18 studies satisfying all four criteria (34%) and three of the four criteria (36%) respectively. <i>Quantitative:</i> prominent weakness were poor sampling strategy and low response rate. <i>Qualitative:</i> three studies failed to interpret how findings related to study context, and two studies provided no explanation on how research process was influenced by the researchers.
Wu et al. 2019 Country: Australia	To identify the unmet supportive care needs of immigrant and native Chinese cancer patients and caregivers.	Systematic Review.	n=9815.	n=8.	1999 to 2019.	Number of studies: n=45 studies (reported in 47 articles). Type of included articles: <i>Cohort:</i> n=7 <i>Cross-sectional:</i> n=29 <i>Qualitative:</i> n=10 <i>Mixed Methods:</i> n=1	Instruments: Newcastle-Ottawa Scale for non-randomised studies (cohort studies). Appraisal Tool for Cross-Sectional Studies. Critical Appraisal Skills Program Qualitative Research Checklist for qualitative studies. Mixed Methods Appraisal Tool for mixed methods studies. Quality ratings: <i>Cohort:</i> 6/7 recruited from single centre. Samples may not have been representative. 5/7 confirmed diagnosis through medical notes, 2/7 did not provide this information. <i>Cross-Sectional:</i> 20/29 studies did not provide information on non-responders. 19/29 used convenience sampling (or did not provide details). 21/29 recruited from single centre only. <i>Qualitative:</i> Lack of detail regarding process of participant selection / recruitment. <i>Mixed Methods:</i> Risk of bias was limited. Low response rate and limited consideration of how findings relate to researchers' influence and integration of qual and quant data.

Table 3. Frequency of unmet needs by domain

Review	Physical Needs	Psychological/Emotional Needs	Cognitive Needs	Patient-Clinician Communications Needs	Health System /Information Needs	Spiritual Needs	Daily Living Needs	Interpersonal/Intimacy Needs	Practical Needs	Family Related Needs	Social Needs	Number of domains explored within each study
Alananzeh et al., 2016	✓	✓	-	✓	✓	-	-	✓	-	✓	-	6
Beesley et al., 2018	✓	✓	-	-	✓	-	-	✓	-	✓	-	5
Bibby et al., 2017	-	✓	-	✓	✓	-	-	-	✓	-	✓	5
Buttow et al., 2012	-	✓	-	-	✓	-	✓	✓	✓	✓	-	6
Doyle et al., 2022	✓	✓	✓	✓	✓	-	-	✓	✓	✓	✓	9
Fu et al., 2020	✓	✓	-	-	✓	✓	-	✓	-	-	✓	6
Galan et al., 2016	✓	✓	-	-	✓	-	-	-	✓	✓	✓	6
Ge et al., 2020	✓	✓	-	-	✓	✓	-	✓	✓	✓	✓	8
Hyun et al., 2016	-	✓	-	-	✓	-	-	-	-	-	-	2
King et al., 2015	✓	✓	-	-	✓	-	-	-	-	-	-	3
Kotronoulas et al., 2017	✓	✓	-	-	✓	-	-	✓	✓	✓	✓	7
Lisy et al., 2018	-	✓	-	-	✓	-	-	✓	-	✓	✓	5
Lisy et al., 2019	✓	✓	-	-	✓	-	-	-	-	✓	✓	5
Maguire et al., 2013	✓	✓	✓	✓	✓	✓	-	-	✓	-	✓	8
Maguire et al., 2015	✓	✓	-	✓	✓	-	✓	✓	✓	✓	✓	9
Maqbool et al., 2017	✓	✓	-	-	✓	-	-	✓	-	-	-	4
McIntosh et al., 2019	-	✓	-	-	✓	-	-	-	-	-	✓	3
Mirosevic et al., 2019	-	✓	-	-	✓	-	✓	✓	-	-	-	4
Moghaddam et al., 2016	-	✓	-	-	✓	-	✓	-	-	-	-	3
Moore et al., 2013	-	✓	-	-	✓	✓	-	-	-	-	✓	4
Moore et al., 2014	✓	✓	-	-	-	-	-	✓	✓	-	-	4
Nicklin et al., 2019	-	✓	✓	-	✓	-	-	✓	✓	✓	✓	7
O’Dea et al. 2021	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
Paterson et al., 2015	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	10
Paterson et al., 2018	✓	✓	-	-	✓	-	-	✓	✓	✓	✓	7
Paterson et al., 2020	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
Paterson et al., 2021	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
Puts et al., 2012	-	✓	-	-	✓	-	✓	✓	-	-	-	4
Wang et al., 2018	✓	✓	-	-	✓	✓	✓	✓	-	✓	✓	8
Wu et al., 2019	-	✓	-	-	✓	-	-	✓	✓	✓	✓	6
Total Number of domains across reviews	19 (60%)	30 (100%)	6 (14%)	9 (25%)	29 (96%)	9 (28%)	10 (32%)	21 (64%)	22 (50%)	18 (57%)	20 (64%)	

Supplementary Table 1. PRISMA checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both	Title page
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Abstract
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	1, 2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	2
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	2
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary Table 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Figure 1
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5,6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5,6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5, table 2
Section/topic	#	Checklist item	Reported on page #

Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	6
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	5,6
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Figure 1, page 6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1, page 4
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Table 3
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Table 4
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	6-12
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Table 3
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	12-14
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	13
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	14
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	None

Supplementary Table 2: Search strategy

Database: Cumulative Index to Nursing and Allied Health Literature (CINAHL)			
Date of Search: 05 May 2021			
Symbols:			
MH = Main Heading			
+ = Explodes the heading			
" " = finds a phrase			
Asterisk (*) = truncates stem of a word			
Search #	Concept/Explanation	Search Terms/Strategy	# of Results
#1	Cancer – Keywords	"cancer" OR "neoplasm*" OR "carcinoma*"	650, 001
#2	Cancer – CINAHL Subject Headings	(MH "Neoplasms+")	574, 076
#3		#1 OR #2	718, 767
#4	Unmet Needs - Keywords	"unmet needs" OR "supportive care needs"	3, 791
#5	Unmet Needs – CINAHL Subject Headings	(MH "Health Services Needs and Demand+")	12, 249
#6	Unmet Needs – CINAHL Subject Headings	(MH "Needs Assessment")	6, 590
#7		#4 OR #5 OR #6	21, 182
#8	Review – Keywords	"systematic review" OR "meta-analysis" OR "meta-synthesis" OR "meta-aggregation" OR "literature review" OR "rapid review" OR "scoping review"	206, 655
#9		#3 AND #7 AND #8	168
#10	Limitier: English Language		162

Database: MEDLINE			
Date of Search: 05 May 2021			
Symbols:			
MH = Main Heading			
+ = Explodes the heading			
" " = finds a phrase			
Asterisk (*) = truncates stem of a word			
Search #	Concept/Explanation	Search Terms/Strategy	# of Results
#1	Cancer – Keywords	"cancer" OR "neoplasm*" OR "carcinoma*"	3, 816, 395
#2	Cancer – MeSH	(MH "Neoplasms+")	3, 420, 508
#3		#1 OR #2	4, 310, 008
#4	Unmet Needs - Keywords	"unmet needs" OR "supportive care needs"	7, 178
#5	Unmet Needs – MeSH	(MH "Health Services Needs and Demand+")	26, 261
#6	Unmet Needs – MeSH	(MH "Needs Assessment")	9, 289
#7		#4 OR #5 OR #6	40, 662
#8	Review – Keywords	"systematic review" OR "meta-analysis" OR "meta-synthesis" OR "meta-aggregation" OR "literature review" OR "rapid review" OR "scoping review"	381, 689
#9		#3 AND #7 AND #8	229
#10	Limitier: English Language		224

Database: PsychINFO			
Date of Search: 05 May 2021			
Symbols:			
MH = Main Heading			
+ = Explodes the heading			
" " = finds a phrase			
Asterisk (*) = truncates stem of a word			
Search #	Concept/Explanation	Search Terms/Strategy	# of Results
#1	Cancer – Keywords	"cancer" OR "neoplasm*" OR "carcinoma*"	91, 441
#2	Unmet Needs - Keywords	"unmet needs" OR "supportive care needs"	2, 821
#3	Unmet Needs – Heading	(MH "Needs Assessment")	3, 400
#4		#2 OR #3	6, 005
#5	Review – Keywords	"systematic review" OR "meta-analysis" OR "meta-synthesis" OR "meta-aggregation" OR "literature review" OR "rapid review" OR "scoping review"	101, 463
#6		#1 AND #4 AND #5	65
#7	Limiters: English Language		63

Supplementary Table 3: Table of included review characteristics

Author and Year Country	Objective of the included review	Type of review	Participant details	Setting and context	Number of databases sourced and searched	Data range of the searches	Publications date range of the studies included in the review	Number of studies	Instrument used to appraise primary studies and quality ratings
<p>Citation: Alanzeh et al. 2016</p> <p>Country: Australia</p>	To identify the unmet supportive care needs of Arab people affected by cancer (patients and caregivers), and the impact of these needs on quality of life and psychosocial well-being.	Integrative Review.	<p>Sample size: Arab sample sizes n=20 to n=91.</p> <p><i>Quantitative:</i> n=968 Arabic: 429/968 (44%).</p> <p><i>Qualitative:</i> n=218 Arabic: 86/218 (39%).</p> <p><i>Total:</i> n=1186 across studies. Arabic: n=515/1186 (43%).</p> <p>Age: Not reported.</p> <p>Gender: Not reported across all studies.</p> <p>Cancer Type: Not reported.</p> <p>Treatment: Not reported.</p> <p>Stage: Not reported.</p>	<p>Cultural factors: Review was focussed on Arab populations (born in Arab countries or self-identified as having Arabic heritage).</p> <p><i>Study locations:</i> Australian studies (n=3) included Arab, Greek, and Chinese migrants.</p> <p>Jordan studies (n=2) involved Arab caregivers.</p> <p>USA studies (n=1) were American Egyptian cancer patients.</p> <p>Healthcare settings: Not reported.</p>	<p>Number: <i>Databases:</i> n=8 <i>Search engines:</i> n=1 <i>Webpages:</i> n=2</p> <p>Searched: <i>Databases:</i> Medline, PubMed, PsycINFO, Informit (RMIT), Web of science, ProQuest Central, Taylor and Francis Online, Arabic Collections online.</p> <p><i>Search Engines:</i> Google Scholar.</p> <p><i>Webpages:</i> Western Sydney University Islamic Studies, University of Pennsylvania Arabic Language and Culture).</p>	No date limit placed on publications. Search conducted July 2015.	1993 to 2003.	<p>Number of studies: n=6</p> <p>Type of included studies: <i>Qualitative:</i> n=2</p> <p><i>Quantitative:</i> n=4 (Cross-sectional x 2 / Descriptive survey x 2).</p>	<p>Assessment criteria outlined by Kmet et al.</p> <p>Quality ratings: Cohen's Kappas were calculated for each study. The overall mean quality score was 16.5/20 (SD=1.83), indicating that, overall, the studies were of a sound standard. Only one study scored 1 SD below the mean, suggesting a less rigorous methodology was utilized.</p>
<p>Citation: Beesley et al. 2018</p> <p>Country: Australia</p>	To determine the prevalence of met and unmet needs, and the risk factors for unmet needs among people affected by gynaecological cancer.	Systematic literature review.	<p>Sample size: Not reported.</p> <p>Age: Not reported.</p> <p>Gender: Female.</p> <p>Cancer type: Mix of gynaecological cancer types (with ovarian cancer being</p>	<p>Cultural factors: Participant factors not reported.</p> <p><i>Study locations:</i> Australia (n=10) USA (n=7) Canada (n=5) Netherlands (n=3) Turkey (n=2) Thailand (n=2)</p>	<p>Number: n=6</p> <p>Searched: PubMed, CINAHL, PsycINFO, EMBASE, Cochrane and Australian National Library (TROVE) for theses.</p>	Post 2005 to November 2016.	Not reported.	<p>Number of studies: n=37</p> <p>Type of included articles: <i>Quantitative (cross-sectional):</i> n=24</p> <p><i>Qualitative:</i> n=12</p> <p><i>Reviews:</i> n=1</p>	<p>Instruments: Not reported.</p> <p>Quality ratings: <i>Quantitative:</i> Good (n=8) Fair (n=7) Poor (n=9)</p> <p><i>Qualitative:</i> Poor (n=12)</p>

			<p>the most commonly studied individual cancer).</p> <p>Treatment: Not reported.</p> <p>Stage: Mix of phases across the cancer care continuum</p>	<p>UK (n=1) Denmark (n=1) Sweden (n=3) NZ (n=1) Japan (n=1) Spain (n=1)</p> <p>Healthcare setting: Not reported.</p>					
<p>Citation: Bibby et al. 2017</p> <p>Country: Australia</p>	<p>To assess what is currently known about unmet needs and care experiences of adolescents and young adults (AYA's) with cancer, identify gaps in the research literature, and highlight potential areas for improvement in future research.</p>	<p>Systematic review.</p>	<p>Sample size: <i>Quantitative:</i> median n=52 (16-1088). <i>Qualitative:</i> median n=15 (4-40). <i>Mixed methods:</i> median n=26 (10-523). <i>Total:</i> median n=23 (4-1088) across studies.</p> <p>Age: <i>Ranged:</i> 15 years to 30 years (numbers not reported).</p> <p>Gender: Both male and female represented (numbers not reported).</p> <p>Cancer type: Mixed cancer diagnoses.</p> <p>Treatment: Varied treatment modalities.</p> <p>Stage: Varied stages and time points. Review looked specifically at the period between symptom onset and 2 years post treatment.</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> UK (n=15) USA and Canada (n=15) Other (n=16)</p> <p>Healthcare setting: Majority of recruitment was via adult hospitals.</p>	<p>Number: n=4</p> <p>Searched: MEDLINE, PsycINFO, CINAHL, EMBASE.</p>	<p>01 January 1990 to July 2015.</p>	<p>Not reported.</p>	<p>Number of studies: n=39 studies (reported in 45 articles)</p> <p>Type of included articles: <i>Quantitative:</i> n=12 <i>Qualitative:</i> n=23 <i>Mixed methods:</i> n=4</p>	<p>Instruments: Quality criteria were specifically developed with reference to the Cochrane Handbook for Systematic Reviews of Interventions, the Critical Appraisal Skills Programme (and other guidelines and checklists)</p> <p>Quality ratings: Average across all studies was in the adequate range (mean=10.6; SD=1.8). <i>Quantitative:</i> 10.3 (SD=2.3). <i>Qualitative:</i> 9.8 (SD=2.4). <i>Mixed methods:</i> 9.4 (SD=3.4).</p>
<p>Citation: Butow et al. 2012</p> <p>Country:</p>	<p>To describe what is known about levels of morbidity and the</p>	<p>Systematic review.</p>	<p>Sample size: <i>Quantitative:</i> n=18834 <i>Qualitative:</i> n=476</p>	<p>Cultural factors: Regional or rural area(s) of Australia or as a rural area for</p>	<p>Number: n=3</p> <p>Searched:</p>	<p>RURAL: database inception until 2006</p>	<p>1993 to 2010.</p>	<p>Number of studies: n=37</p>	<p>Instruments: Adapted checklists for quantitative and qualitative studies.</p> <p>Quality ratings:</p>

Australia	experiences and needs of people with cancer, and their informal caregivers, living in rural areas.		<p>Total: n=19,310 across studies.</p> <p>Age: Not reported (adult cancer patients and family/friends involved in care).</p> <p>Gender: Both males and females (numbers not specified).</p> <p>Cancer type: Many cancer types represented across studies. However, most studies focussed on breast cancer.</p> <p>Treatment: Not reported.</p> <p>Stage: Not reported. However, study inclusion criteria open to current patients, survivors, or palliative patients.</p>	<p>other countries of the developed world.</p> <p>Study locations: Australia (n=15) USA, Canada, Norway, and UK (n=22 total)</p> <p>Healthcare setting: Rural and urban locations.</p>	RURAL (Rural and Remote Health Database), PsycINFO, MEDLINE.	PsycINFO and MEDLINE: database inception to March 2011.		<p>Type of included articles: <i>Quantitative:</i> n=25 <i>Qualitative:</i> n=12</p>	<p>Studies achieving less than 40% = poor quality 40% - 70% = good quality Higher than 70% = very good quality.</p> <p><i>Quantitative:</i> Kappa score K=0.857 (excellent)</p> <p><i>Poor:</i> n=0 <i>Good:</i> n=9 <i>Very good:</i> n= 15</p> <p><i>Qualitative:</i> Kappa score K=0.617 (good)</p> <p><i>Poor:</i> n=1 <i>Good:</i> n=6 <i>Very good:</i> n=5</p>
Doyle et al. 2022	To explore the needs of men affected by testicular cancer.	Systematic review	<p>Sample size:</p> <p>Age: 25.1 to 44.4 years</p> <p>Gender: Males</p> <p>Cancer type: Testicular</p> <p>Treatment: Mixed</p> <p>Stage: Majority localised disease</p>	<p>Cultural factors: Not reported.</p> <p>Study locations: UK (5), USA (5), Canada (4), Germany (4), Norway (4), Australia (3), Denmark (2), Italy (2), the Netherlands (2), Turkey (2), Greece (1), Lebanon (1), Serbia (1), and Sweden (1).</p> <p>Healthcare setting: Not reported.</p>	<p>Number: n=3</p> <p>Searched: CINAHL, Medline, PsycINFO.</p>	From November 2021	2021- 2010	<p>Number of studies: n=36</p> <p>Type of included articles: <i>Qualitative</i> n=5 <i>Quantitative</i> n=30 <i>Mixed methods</i> n=1</p>	<p>Instruments: Mixed Methods Assessment Tool (MMAT)</p> <p>Quality ratings: Mixed ratings in quality scores. Most of the studies were cross-sectional in design and therefore provide little information about how supportive care needs change over time. The studies had small sample sizes and used convenience sampling approaches.</p>
Citation: Fu et al. 2020	In patients with melanoma, this mixed-	Mixed methods systematic review.	<p>Sample size: <i>Quantitative:</i> n=1710 <i>Qualitative:</i> n=46</p>	<p>Cultural factors: Not reported.</p> <p>Study locations:</p>	<p>Number: n=3</p> <p>Searched:</p>	From January 2000 to November	2012 to 2019.	<p>Number of studies: n=14</p>	<p>Instruments: Mixed Methods Assessment Tool (MMAT)</p>

<p>Country: Australia</p>	<p>methods systematic review aims to evaluate the supportive care and unmet supportive care needs and associated factors.</p>		<p><i>Mixed Methods:</i> n=64 <i>Total:</i> n=1820 across studies.</p> <p>Age: <i>Mean range:</i> 50 years to 65 years.</p> <p>Gender: <i>Male:</i> n=1077 (59%) <i>Female:</i> n=708 (39%)</p> <p>Cancer type: Melanoma</p> <p>Treatment: Of those reported there were varied treatment modalities.</p> <p>Stage: Of those reported there were varied stages and time points.</p>	<p>Australia (n=4) Canada (n=1) Italy (n=2) UK (n=4) USA (n=3)</p> <p>Healthcare setting: Not reported.</p>	<p>CINAHL, Medline, PsycINFO.</p>	<p>2018 (updated in November 2019).</p>		<p>Type of included articles: <i>Quantitative:</i> n=10 <i>Qualitative:</i> n=3 <i>Mixed Methods:</i> n=1</p>	<p>Quality ratings: All three qualitative studies met 100% of the critical appraisal criteria. The only mixed methods study met most critical appraisal criteria and only 2/10 quantitative studies met all criteria. The main weakness across these studies was the risk of response bias as only one study achieved over 80% response rate.</p>
<p>Citation: Galan et al. 2016</p> <p>Country: Spain</p>	<p>To report on the needs of adolescent and young adult cancer survivors after their treatment.</p>	<p>Systematic review</p>	<p>Sample size: n=20 to n=1088.</p> <p><i>Qualitative:</i> n=351. <i>Quantitative:</i> n=2470. <i>Total:</i> n=2821 across studies.</p> <p>Age: Adolescents and young adults (14-39 years). <i>Mean range:</i> 16.2 years to 34 years.</p> <p>Gender: For the most part participants were women (ranging from 53% to 75% of samples).</p> <p>Cancer type: Mixed cancer diagnoses.</p> <p>Treatment: Cancer survivors. Previous treatments received were not reported.</p>	<p>Cultural factors: Not reported</p> <p><i>Study locations:</i> USA (n=6) Canada (n=4) Switzerland (n=1) Netherlands (n=1) Sweden (n=1) Australia (n=1)</p> <p>Healthcare setting: Not reported.</p>	<p>Number: n=11</p> <p>Searched: ERIC, MEDLINE, EMBASE, PILOTS (Published International Literature on Traumatic Stress), ProQuest, PsycARTICLES, PsycBOOKS, psycCRITIQUES, PsycINFO, Social Services Abstracts, Sociological Abstracts.</p>	<p>From the database inception to May 2016.</p>	<p>2006 to 2014</p>	<p>Number of studies: n=14</p> <p>Type of included articles: <i>Quantitative:</i> n=8 <i>Qualitative:</i> n=6</p>	<p>Instruments: A Checklist for Qualitative and Quantitative studies developed for a study by Hoekstra, Heins and Korevaar (2014)</p> <p>Quality ratings: The quality score ranged between 61 and 92 on a scale from 0 to 100. The average was 75.</p>

			<p>Stage: Cancer survivors. Stage of disease when diagnosed was not reported.</p>						
<p>Citation: Ge et al. 2020</p> <p>Country: China</p>	<p>To explore male partners' caring experience and supportive care needs when caring for women with gynaecological cancer.</p>	<p>Qualitative literature review.</p>	<p>Sample size: <i>Total: n=1301 (male partners, patients, and other family caregivers)</i></p> <p><i>Male partners only: n=103.</i></p> <p>Age: Not reported.</p> <p>Gender: Male (however studies including non-spousal caregivers such as children, siblings or parents were also included – their genders were not reported.)</p> <p>Cancer type: Gynaecological cancers (mixed types).</p> <p>Treatment: Not reported</p> <p>Stage: Not reported.</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> USA (n=2) Sweden (n=1) Australia (n=1) Korea (n=1) UK (n=1) Turkey (n=1) Norway (n=1)</p> <p>Healthcare setting: Not reported.</p>	<p>Number: n=9</p> <p>Searched: PubMed, Medline, Embase, Springer and Wiley online library, China National Knowledge Infrastructure (CNKI), WanFang, WeiPu, China Biology Medicine disc (CBM).</p>	<p>From the date of inception to 01 January 2020.</p>	<p>1995 to 2019</p>	<p>Number of studies: n=8</p> <p>Type of included articles: <i>Qualitative: n=8</i></p>	<p>Instruments: Critical Appraisal Skills Programme (CASP) qualitative appraisal instrument</p> <p>Quality ratings: Most of the studies rated well against the CASP, and total scores ranged from 15–22 with a mean score of 19.</p>
<p>Citation: Hyun et al. 2016</p> <p>Country: Canada</p>	<p>To conduct a systematic review of the published English language literature, examining (i) the unmet information needs and (ii) the unmet psychosocial support needs of adult thyroid cancer survivors.</p>	<p>Systematic review.</p>	<p>Sample size: n=57 to n=2398</p> <p><i>Total: n=6215 across studies.</i></p> <p>Age: Not reported</p> <p>Gender: Majority of participants were female.</p> <p>Cancer type: Thyroid cancer</p> <p>Treatment: Therapeutic radioactive iodine use (including remnant ablation or</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> Not reported.</p> <p>Healthcare setting: Data collected via internet or paper-based questionnaires, in-person or telephone interviews.</p>	<p>Number: n=7</p> <p>Searched: MEDLINE, MEDLINE In-Process and Other Non-Indexed Citations, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, EMBASE, PsycINFO, CINAHL.</p>	<p>From database inception to December 2014 and September 2015.</p>	<p>2010 to 2016</p>	<p>Number of studies: n=7</p> <p>Type of included articles: <i>Quantitative: n=7</i></p>	<p>Instruments: Cochrane Risk of Bias tool or the Center for Evidence-Based Management Critical Appraisal of a Survey tool (depending on the study type).</p> <p>Quality ratings: The level of agreement between reviewers was estimated using a kappa statistic. At electronic citation review stage kappa statistic of 0.515 (CI 0.346-0.684). Full-text review stage kappa statistic was 0.516 (CI 0.230-0.803).</p>

			<p>adjuvant radioactive iodine) was variable across studies.</p> <p>Stage: Of those reported there were various stages and time points (low risk disease was most prevalent across 3 studies. The majority of patients were beyond the first year of treatment).</p>						
<p>Citation: King et al. 2015</p> <p>Country: UK</p>	<p>This article describes a qualitative systematic review and synthesis examining men's experience of a need for supportive care.</p>	<p>Systematic review and qualitative synthesis.</p>	<p>Sample size: n=8 to n=401</p> <p><i>Total across studies:</i> n=1003.</p> <p>Age: <i>Range:</i> 37 years to 88 years.</p> <p>Gender: Not reported.</p> <p>Cancer type: Prostate cancer</p> <p>Treatment: Of those reported, there were varied treatment modalities.</p> <p>Stage: Varied stages and time points.</p>	<p>Cultural factors: Of those reported (across the studies) participant ethnicities included African-Caribbean, African American, Asian, White, Latino, and other.</p> <p><i>Study locations:</i> Europe, USA, Canada, Australia and the UK (numbers of each not reported).</p> <p>Healthcare setting: Not reported.</p>	<p>Number: n=7</p> <p>Searched: MEDLINE, MEDLINE in process, EMBASE, PsycINFO, CINAHL, British Nursing Index, IBSS and Sociological Abstracts.</p>	<p>From inception to July 2013.</p>	<p>2004 to 2013.</p>	<p>Number of studies: n=20</p> <p>Type of included articles: <i>Qualitative:</i> n=20 (two were longitudinal surveys that included qualitative data).</p>	<p>Instruments: Critical Appraisal Skills Programme (CASP) quality appraisal tool</p> <p>Quality ratings: The papers were generally of good quality and none were excluded due to poor quality overall. Negative scoring on reflexivity and ethical considerations were not sufficient to warrant rejection of individual papers. If the papers had scored poorly on the other criteria, the reviewers would then have conducted a sensitivity analysis</p>
<p>Citation: Kotronoulas et al. 2017</p> <p>Country: UK</p>	<p>To systematically assess the relevant literature and synthesise evidence in relation to the supportive care needs of people living with and beyond cancer of the colon and/or rectum.</p>	<p>Systematic review.</p>	<p>Sample size: n=5 to n=3011 (median 50). <i>Total:</i> 10,057.</p> <p><i>Quantitative:</i> median n=113</p> <p><i>Qualitative:</i> median n=23</p> <p><i>Mixed methods:</i> median n=21</p> <p>Age: <i>Mean range:</i> 51.9 to 72 years (31 studies including samples with mean age ≥60yrs).</p> <p>Gender: <i>Men:</i> 64.5%</p>	<p>Cultural factors: Not reported</p> <p><i>Study locations:</i> European (n=28) North American (n= 11) Oceania (n=11) Asia (n=4)</p> <p>Healthcare setting: Single-centred: (n=27; 50%) Multi-centred: n=17; 32%)</p>	<p>Number: n=5</p> <p>Searched: MEDLINE, PubMed, CINAHL, PsycINFO, EMBASE.</p>	<p>Not reported.</p> <p><i>search occurred:</i> 20 March 2013 – 30 April 2013 (updated 25 October 2016).</p>	<p>Pre 2000 to 2016.</p>	<p>Number of studies: n=54</p> <p>Type of included articles: <i>Quantitative:</i> n=32 <i>Qualitative:</i> n=18 <i>Mixed methods:</i> n=4</p>	<p>Instruments: QualSyst evaluation tool</p> <p>Quality ratings: SQS ranging from 44% to 95%, with a median SQS of 80%. Over half studies (29; 54%) had SQS ≥80%.</p> <p><i>Quantitative:</i> median SQS = 82%; range = 44% - 95%; 21/36 studies with SQS ≥80%.</p> <p><i>Qualitative:</i> median SQS = 75%; range = 60% - 90%; 9/22 studies with SQS ≥80%.</p>

			<p>Cancer type: Colon and/or rectum.</p> <p>Treatment: Varied treatment modalities. (30% had a stoma)</p> <p>Stage: Varied stages and time points.</p>	<p>Community: (n=5)</p> <p>Population based: (n=5)</p>					
<p>Citation: Lisy et al. 2018</p> <p>Country: Australia</p>	To explore the cancer care experiences and unmet needs of people who identify as a sexual or gender minority.	Systematic review and meta-synthesis.	<p>Sample size: <i>Breast:</i> n=179 <i>Prostate:</i> n=165 <i>Any:</i> n=41</p> <p><i>Total:</i> n=385 across studies.</p> <p>Age: <i>Mean range:</i> 43.9 years to 73 years.</p> <p>Gender: Both male and female represented.</p> <p>Cancer type: Breast cancer (n=7 papers) Prostate cancer (n=6 papers) Any cancer type (n=2)</p> <p>Treatment: Not reported.</p> <p>Stage: Not reported.</p>	<p>Cultural factors: Not reported</p> <p><i>Study locations:</i> USA (n=7) Australia (n=3) Canada (n=2) UK (n=1)</p> <p>Healthcare setting: Not reported.</p>	<p>Number: n=2</p> <p>Searched: PubMed, PsycINFO (and google scholar).</p>	Pre 2002 to 22 March 2017.	2004 to 2018 (10/15 studies published from 2012 onwards).	<p>Number of studies: n=13 studies (reported in 15 articles).</p> <p>Type of included articles: Not reported.</p>	<p>Instruments: Critical Appraisal Skills Programme Qualitative Research Checklist.</p> <p>Quality ratings: Overall studies were deemed to be of moderate to high quality, with studies meeting from 5 to 9 of 9 quality criteria. Based on methodological assessment, reviewers agreed that, across the studies, results could be considered valid in their credibility, transferability, and dependability.</p>
<p>Citation: Lisy et al. 2019</p> <p>Country: Australia</p>	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.	Systematic review.	<p>Sample size: n=22 to n=1323</p> <p><i>Total:</i> n=6366 across studies.</p> <p>Age: <i>Range:</i> 18years to 89 years.</p> <p>Gender: Not reported (did involve male and female related cancers).</p> <p>Cancer type: Mixed cancer diagnoses.</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> Australia (n=17)</p> <p>Healthcare setting: Not reported.</p>	<p>Number: n=2</p> <p>Searched: PubMed, PsycINFO (and google scholar – sorted by relevance and the first 100 results screened).</p>	Not reported	2007 to 2018	<p>Number of studies: n=17</p> <p>Type of included articles: <i>Cross-sectional:</i> n=15 <i>Longitudinal:</i> n=2</p>	<p>Instruments: Centre for Evidence-Based Management Critical Appraisal Checklist for Cross-Sectional Study.</p> <p>Quality ratings: Studies that met 6 or more out of 11 quality criteria were included in the review (all studies were deemed to be appropriately conducted and of sufficient quality).</p>

			<p>Treatment: Not reported.</p> <p>Stage: Not reported. Involved cancer survivors (those who completed treatment with curative intent).</p>						
<p>Citation: Maguire et al. (2013)</p> <p>Country: UK</p>	To determine to supportive care needs of people affected by lung cancer.	Integrative review.	<p>Sample size: n=4645 across studies.</p> <p>Age: <i>Mean range:</i> 60.6 years to 69.0 years.</p> <p>Gender: Approximately equal representation of men and women.</p> <p>Cancer Type: Lung cancer.</p> <p>Treatment: Varied treatment modalities.</p> <p>Stage: Varied stages and time points.</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i></p> <p>Healthcare settings: Not reported.</p>	<p>Number: n=5</p> <p>Searched: Medline, CINAHL, EMBASE, PsycINFO, BNI.</p>	January 2000 to September 2012.	2001 to 2012.	<p>Number of studies: n=53 studies (reported in 59 articles).</p> <p>Type of included articles: <i>Quantitative:</i> n=25 <i>Qualitative:</i> n=34</p>	<p>Instruments: Quality Assessment Tool (Hawker et al. 2002)</p> <p>Quality ratings: All studies were reported as acceptable methodological quality scores.</p> <p>Mean quality score for quantitative studies 28.3 (SD, 4.1.61, range 17-37).</p> <p>Mean quality score of qualitative studies 29 (SD2.61, range 25-36).</p>
<p>Citation: Maguire et al. 2015</p> <p>Country: UK</p>	To systematically review current available evidence SCNs of women living with and beyond cervical cancer	Systematic review	<p>Sample size: n=10 to n=968 <i>Total:</i> n=1414 across studies.</p> <p>Age: 50.7 years (<i>mean range:</i> 33 years to 55 years).</p> <p>Gender: Women.</p> <p>Cancer type: Cervical</p> <p>Treatment: surgery, on its own or with RT, chemo, brachytherapy, or a combination.</p> <p>Stage: Majority stage II (no metastatic disease).</p>	<p>Cultural factors: Participants included mainly White Caucasian, but also Asian, African, and Latin American women, thus contributing to the diversity of cancer needs and experiences.</p> <p><i>Study locations:</i> USA, Canada, UK Indonesia, South Korea, Nigeria, Thailand.</p> <p>Healthcare setting: Not reported.</p>	<p>Number: n=7</p> <p>Searched: DARE, Cochrane, MEDLINE, CINAHL, BNI, PsycINFO, EMBASE.</p>	Not reported. <i>Search:</i> 20 March 2013 to 30 April 2013.	1993 to 2012.	<p>Number of studies: n=12 studies (reported in 14 articles).</p> <p>Type of included articles: <i>Quantitative:</i> n=7 <i>Qualitative:</i> n=4 <i>Mixed Methods:</i> n=1</p>	<p>Instruments: standardised QualSyst evaluation tool</p> <p>Quality ratings: Studies were retained in this review if they were awarded a summary score of $\geq 55\%$. This score has been suggested as a relatively liberal threshold, indicating acceptable study quality.</p> <p>Study scores ranged from 0.56 – 0.90.</p>

			Diagnosed <1-6 years prior to study.						
<p>Citation: Maqbool et al. 2017</p> <p>Country: Canada</p>	<p>To summarise (a) the information needs of Brain Metastases (BM) patients and caregivers (CGs), (b) their supportive care needs, and (c) studies evaluating existing programs and resources addressing one or more informational needs.</p>	<p>Systematic review.</p>	<p>Sample size: n=9 to n=46</p> <p><i>Patients:</i> n=108</p> <p><i>Caregivers:</i> n=65</p> <p><i>HCPs:</i> n=46</p> <p><i>Total:</i> n=219 across studies.</p> <p>Age: <i>Patients:</i> Median ranged from 50-64 years.</p> <p><i>Caregivers:</i> Median ranged from 42-55 years.</p> <p>Gender: <i>Patients:</i> Male (n=40) Female (n=43)</p> <p><i>Caregivers:</i> Male (n=8) Female (n=33)</p> <p><i>HCPs:</i> Male (n=19) Female (n=26)</p> <p>Cancer type: Brain metastases (of those that reported a primary cancer site 4/7=57.1% of the study population was primarily primary lung cancer based).</p> <p>Treatment: Of those mentioned treatments included whole brain RT or palliative RT.</p> <p>Stage: Metastatic disease but not specific stages reported.</p>	<p>Cultural factors: 6/7 studies conducted in Canada.</p> <p><i>Study locations:</i> Canada (n=6) UK (n=1)</p> <p>Healthcare setting: Of those 6/7 studies conducted in Canada, they were carried out across three institutions.</p>	<p>Number: n=4</p> <p>Searched: MEDLINE, Embase, CINAHL, PsycINFO.</p>	<p>From 2000 to April 2015.</p>	<p>2006 to 2013.</p>	<p>Number of studies: n=7</p> <p>Type of included articles: <i>Observational:</i> n=6</p> <p><i>Intervention:</i> n=1</p>	<p>Instruments: Evaluation criteria were focussed on sample representativeness, sample size, degree of missing data, accounting for non-respondents and instrument validity.</p> <p>Quality ratings: All 7 included studies were found to involve high risk of bias, substantially being affected by sample representativeness, sample size and accounting for non-respondents in particular. The majority of studies also involved a high risk of bias in terms of degree of missing data (5/7=71%) and instrument validity (4/7=57%).</p>

<p>Citation: McIntosh et al. 2019</p> <p>Country: Australia</p>	<p>To identify the specific unmet supportive care needs of men on active surveillance (AS).</p>	<p>Systematic review</p>	<p>Sample size: <i>Cross-sectional:</i> n= 3 to n=431 (M=169, SD= 229.6).</p> <p><i>Qualitative:</i> n=4 to n=37 (M=20.8, SD= 11.2).</p> <p><i>Total:</i> n=1782</p> <p>AS: n=596/1782 (33%) across studies.</p> <p>Age: <i>Mean range:</i> 64 years to 86 years.</p> <p>Gender: Male</p> <p>Cancer Type: Prostate Cancer.</p> <p>Treatment: AS.</p> <p>Stage: Not reported.</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> USA (n=3) Canada (n=2) UK (n=1) Sweden (n=1) Australia (n=1)</p> <p>Healthcare settings: Not reported.</p>	<p>Number: n=4</p> <p>Searched: PubMed, Embase, PsycINFO, CINAHL.</p>	<p>From database inception to July 2018.</p>	<p>2003 to 2018.</p>	<p>Number of studies: n=8</p> <p>Type of included studies: <i>Qualitative:</i> n=5</p> <p><i>Cross-sectional:</i> n=3</p>	<p>Instruments: JBI checklists for prevalence and qualitative studies.</p> <p>Quality ratings: Not reported.</p>
<p>Citation: Mirosevic et al. 2019.</p> <p>Country: Slovenia</p>	<p>To explore the prevalence and most frequently found unmet needs and to identify factors associated with higher levels of total unmet needs and with each domain separately.</p>	<p>Systematic review.</p>	<p>Sample size: n=63 to n=1668</p> <p><i>Prospective longitudinal:</i> n=2617</p> <p><i>Cross-sectional:</i> n=7862</p> <p><i>Total:</i> 10,479 across studies.</p> <p>Age: Not reported (adults ≥18 years old).</p> <p>Gender: Both male and female survivors represented in the review.</p> <p>Cancer type: Various cancer types included across studies.</p> <p>Treatment: Not currently undergoing treatment. Review focussed on cancer survivors.</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> Australia (n=9) UK (n=4) USA (n=3) China (n=3) Singapore (n=2) Canada (n=1) Ireland (n=1) Netherlands (n=1) Iran (n=1) South Korea (n=1)</p> <p>Healthcare setting: Not reported.</p>	<p>Number: N=5</p> <p>Searched: MEDLINE, PsycINFO, Web of Science, TRIP, CINAHL.</p>	<p>From 1994 to March 2018.</p>	<p>2007 to 2017.</p>	<p>Number of studies: n=26</p> <p>Type of included articles: <i>Prospective longitudinal:</i> n=4</p> <p><i>Cross-sectional:</i> n=22</p>	<p>Instruments: An adapted 12-item pre-defined criteria for systematic review.</p> <p>Quality ratings: Most (20/26) of the studies were considered to be high quality, six to be moderate and none to be poor quality. General limitations were the absence of clinical information, low response rate and lack of information on finding factors associated with unmet needs.</p>

			<p>Stage: For those reported, stage was varied (many of the included studies were missing this information). Various time points post-treatment completion.</p>						
<p>Citation: Moghaddam et al. 2016</p> <p>Country: UK</p>	Identify areas for developing and targeting supportive interventions that best meet the changing needs of this population of patients (people living with advanced cancer).	Systematic review	<p>Sample size: n=11 to n=629</p> <p><i>Total:</i> n=3613 across studies.</p> <p>Age: <i>Mean range:</i> 57 years to 75 years.</p> <p>Gender: Both male and female participants represented across the studies.</p> <p>Cancer type: Most studies included a mix of cancer types (some specifically looked at breast, prostate, lung, or ovarian cancers).</p> <p>Treatment: Not reported.</p> <p>Stage: Advanced disease (III-IV, recurrent, metastatic, palliative).</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> UK (n=5) USA (n=5) Australia (n=4) Canada (n=3) Netherlands (n=2) Hong Kong (n=1) Japan (n=1) Italy (n=1) Denmark (n=1)</p> <p>Healthcare setting: Not reported.</p>	<p>Number: n=4</p> <p>Searched: CINAHL, Medline, EMBASE, PsycINFO.</p>	Not reported.	1987 to 2014.	<p>Number of studies: n=23</p> <p>Type of included articles: <i>Quantitative:</i> n=19 <i>Qualitative:</i> n=4</p>	<p>Instruments: Mixed Methods Appraisal Tool (MMAT)</p> <p>Quality ratings: Most (68%) were of a high standard (all criteria met). Low response rate (<60%) and questionable sample representativeness were recurrent methodological limitation of quantitative studies. One qualitative study did not report consideration of how findings might have been shaped by the researchers positioning or the context in which data was collected.</p>
<p>Citation: Moore et al. 2013</p> <p>Country: Australia</p>	To collate current literature detailing the supportive and palliative care needs of patients with Primary Malignant Glioma (PMG) and their carers, and to subject it to a novel approach of formal evaluation.	Systematic review	<p>Sample size: <i>Patients:</i> n=3 to n=28 <i>Total:</i> n=219</p> <p><i>Caregivers:</i> n=4 to n=43 <i>Total:</i> n=301</p> <p><i>Total (pts and CGs):</i> n=520 across studies.</p> <p>Age: Not reported.</p> <p>Gender: Both males and females represented in patients and caregivers (higher proportion of female caregivers).</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> Sweden (n=8) USA (n=7) Australia (n=3) UK (n=2) Japan (n=1)</p> <p>Healthcare setting: A range of settings including medical, specialist and referral centres, tertiary hospitals (oncology and neuro-oncology)</p>	<p>Number: n=4</p> <p>Searched: MEDLINE, CINAHL, EMBASE, PsycINFO.</p>	From January 2000 to December 2010 (search conducted January 2011).	2000 to 2010.	<p>Number of studies: n=21</p> <p>Type of included articles: <i>Qualitative:</i> n=21</p>	<p>Instruments: Those selected for full text review (n=100) were screened according to The Critical Appraisal Skills Program (CASP). Those then included in final analysis (n=21) were reviewed against HEP to categorise studies according to their strength of evidence.</p> <p>Quality ratings: 2/21 studies met the criteria for highest level of evidence (generalisable studies). 8/21 studies met level II (conceptual studies) and 11/21 studies met level III (descriptive studies).</p>

			<p>Cancer type: Primary Malignant Glioma</p> <p>Treatment: Not reported.</p> <p>Stage: Varied stages (I-IV as well as bereaved family members).</p>	departments), and outpatient services (brain tumour clinics and support services).					
<p>Citation: Moore et al. 2014</p> <p>Country: Australia</p>	To systematically review the literature describing quality of life (QoL) outcomes and support needs in patients with oral cancer along the cancer trajectory.	Systematic review.	<p>Sample size: <i>Cross-Sectional:</i> n=5469 <i>Prospective:</i> n=335 <i>Longitudinal:</i> n=290 <i>Case-Control:</i> n=110 <i>Retrospective:</i> n=278 <i>Total:</i> n=6482 across studies.</p> <p>Age: Not reported.</p> <p>Gender: Not reported.</p> <p>Cancer type: Oral cancers (head and neck included If they reported on those with oral cancers).</p> <p>Treatment: Not reported</p> <p>Stage: Varied stages and time points.</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> Not reported.</p> <p>Healthcare setting: Not reported.</p>	<p>Number: n=6</p> <p>Searched: Cochrane, Embase, PubMed, CINAHL, Scopus, PsycINFO.</p>	Not reported	Not reported	<p>Number of studies: n=31</p> <p>Type of included articles: All quantitative methodologies.</p> <p><i>Cross-sectional:</i> n=21</p> <p><i>Longitudinal or prospective:</i> n=7</p> <p><i>Case-control:</i> n=2</p> <p><i>Retrospective chart review:</i> n=1</p>	<p>Instruments: The Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies.</p> <p>Quality ratings: The use of cross-sectional design by several of the studies contributed to a high number of 'weak' appraisals. Studies that used longitudinal or prospective methods were generally awarded a stronger EPHPP rating.</p> <p><i>Weak:</i> 18/31 <i>Moderate:</i> 8/31 <i>Strong:</i> 5/31</p>
<p>Citation: Nicklin et al. 2019</p> <p>Country: UK</p>	To systematically review and narratively synthesis evidence on issues that AYA childhood brain tumour survivors and	Systematic review	<p>Sample size: n=7 to n=1334</p> <p><i>Total:</i> n=9943 across studies (of those 37% n=3692/9943 were brain tumour survivors within required 14 years to 39 years age range).</p> <p>Age:</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> USA (n=32) Canada (n=4) Finland (n=3) Germany (n=3) UK (n=2) Italy (n=2)</p>	<p>Number: n=6</p> <p>Searched: Medline, Embase, PsycINFO, PubMed, CINAHL, Cochrane Library (grey literature also searched through Web of Science and NHS Evidence).</p>	Searched until September 2017 (no restriction on publication date).	1992 to 2017 (Over half the studies were published after 2013 = 57%).	<p>Number of studies: n=49 studies (reported in 56 articles).</p> <p>Type of included articles: <i>Quantitative:</i> n=37 (76%)</p>	<p>Instruments: Mixed Methods Appraisal Tool (MMAT)</p> <p>Quality ratings: Scores ranged from 25% to100%. No studies were removed because of their appraisal score, but lower quality study findings should be interpreted with greater caution</p>

	their caregivers face and their supportive care needs.		<p><i>Mean range:</i> 15.7 years to 29 years.</p> <p>Gender: Not reported.</p> <p>Cancer type: Brain tumours (most studies were mixed brain tumour samples).</p> <p>Treatment: Not reported.</p> <p>Stage: Study focussed on survivors, stage at diagnosis was not reported.</p>	<p>France (n=2) Sweden (n=2) Taiwan (n=2) Holland (n=1) Slovenia (n=1) Norway (n=1) Netherlands (n=1)</p> <p>Healthcare setting: Not reported.</p>				<p><i>Qualitative:</i> n=5 (10%)</p> <p><i>Mixed Methods:</i> n=7 (14%)</p>	and in consideration of their limitations.
<p>Citation: Paterson et al. 2015</p> <p>Country: UK</p>	To synthesise current available evidence with regard to the unmet supportive care needs of men living with and beyond prostate cancer.	Systematic review.	<p>Sample size: n=7 to n=1001.</p> <p><i>Total:</i> 2914 across studies.</p> <p>Age: <i>Range:</i> 22 years to 86yrs (including carer-based studies).</p> <p>Gender: Male (and in some instances their carers).</p> <p>Cancer type: Prostate cancer.</p> <p>Treatment: Mixed treatment types.</p> <p>Stage: Varied stages and time points.</p>	<p>Cultural factors: For the most part the study samples were biased in favour of married, white Caucasian individuals with good educational attainment.</p> <p><i>Study locations:</i> Canada (n=4) UK (n=6) USA (n=4) Australia (n=1) Sweden (n=1) Various European countries (n=1)</p> <p>Healthcare setting: 10/17 studies were multicentred 6/17 were conducted at one clinical site.</p>	<p>Number: n=6</p> <p>Searched: DARE, Cochrane, MEDLINE, BNI, PsycINFO, EMBASE.</p>	1990 – October 2014.	1997 to 2014.	<p>Number of studies: n=17</p> <p>Type of included articles: <i>Cross-sectional:</i> n=8 <i>Qualitative:</i> n=9</p>	<p>Instruments: 2 x quality appraisal tools (one for quantitative and one for qualitative)</p> <p>Quality ratings: Overall, the methodological quality varied from 53.3% to 90.0%, with a median score of 70% (IQR 17.5%).</p> <p><i>Qualitative:</i> A median score of 70%, (IQR 18.35%, range 53.3%-83.3%)</p> <p><i>Quantitative:</i> A median score of 75% (IQR 22.5%, range 65.0%-90.0%).</p>
<p>Citation: Paterson et al. 2018</p> <p>Country: UK</p>	To determine the different domains of unmet supportive care needs for	Systematic review.	<p>Sample size: n=20 to n=30</p> <p><i>Total:</i> n=260 across studies.</p> <p>Age:</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> Canada (n=2) USA (n=2)</p>	<p>Number: n=7</p> <p>Searched: DARE, Cochrane, MEDLINE, BNI, PsycINFO, EMBASE, CINAHL.</p>	Earliest date available to January 2017.	1989 to 2016	<p>Number of studies: n=7 studies (reported in 8 articles).</p>	<p>Instruments: 2 x quality appraisal tools used previously in a variety of cancer systematic reviews.</p> <p>Quality ratings:</p>

	patients affected by Muscle Invasive Bladder Cancer (MIBC).		Not reported. Gender: Not reported. Cancer type: Bladder cancer. Treatment: Range of treatment types. Stage: Varied stages and time points.	Sweden (n=2) Egypt (n=1) Italy (n=1) Healthcare setting: Not reported.				Type of included articles: <i>Cross-sectional:</i> n=6 <i>Feasibility RCT:</i> n=1	Overall the methodological quality varied from 50% to 80% with a median score of 58.5% (IQR 16.5% range 51.8%-68.3%).
Citation: Paterson et al. 2020 Country: Australia	To systematically evaluate the evidence regarding the unmet supportive care needs of men affected by penile cancer and their partners to create a holistic model of care and inform clinical practice guidelines.	Systematic review.	Sample size: n=40 to n=90 <i>Quantitative:</i> n=312 <i>Qualitative:</i> n=157 <i>Total:</i> n=469 across studies. Age: Most participants were >50yrs. Gender: Male (and their partners). Cancer type: Penile cancer Treatment: Heterogenous therapies, from minimally invasive therapy to total penectomy. Stage: Various stages and time points.	Cultural factors: Not reported. <i>Study locations:</i> Brazil (n=1) India (n=1) UK (n=2) Germany (n=1) France (n=1) France/Spain (n=1) Italy (n=1) USA (n=1) Denmark (n=2) Norway (n=1) Sweden (n=3) Poland (n=1) China (n=1) Healthcare setting: Hospitals, tertiary cancer centres, GP, sexologists, and multidisciplinary healthcare teams.	Number: n=7 Searched: CINAHL, MEDLINE, PsycINFO, EMBASE, Cochrane (CCTR and CDSR), clinicaltrial.gov.	From 1990 to April 2020.	1994 to 2018	Number of studies: n=17 studies (reported in 18 articles). Type of included articles: <i>Qualitative:</i> n=7 <i>Survey:</i> n=10	Instruments: 2 x quality appraisal tools (one for qualitative one for quantitative). The tools were developed as part of a Health Technology Assessment Integrative Review Quality ratings: There are a number of shortcomings across the studies which included small sample sizes, lack of transparency in qualitative methodology and limited reporting of the clinical and demographic characteristics across study participants.
Citation: Paterson et al. 2021 Country: Australia	To systematically evaluate evidence regarding the unmet supportive care needs of	Systematic review.	Sample size: n=5 to n=36 <i>Total:</i> n=3394 across studies. Age: <i>Mean range (patients):</i> 45.5 years to 59 years.	Cultural factors: Not reported. <i>Study locations:</i> Netherlands (n=2) Sweden (n=1) Turkey (n=3)	Number: n=6 Searched: CINAHL, MEDLINE, PsycINFO, Scopus, Cochrane Library (CCRT and CDSR) controlled trial databases, clinicaltrials.gov.	January 1990 to June 2019.	1997 to 2018.	Number of studies: n=27 Type of included studies: <i>Quantitative:</i> n=17	Instruments: two quality appraisal tools (one quantitative and one qualitative), which have been used in a similar systematic review Quality ratings:

	men and women affected by chemotherapy-induced alopecia (CIA) to inform clinical practice guidelines.		<p>Gender: The majority of the studies included women, with only 5 studies recruiting men affected by CIA.</p> <p>Cancer Type: Large breast cancer representation across studies. Others included mixed diagnoses.</p> <p>Treatment: Chemotherapy related.</p> <p>Stage: Varied stages and time points.</p>	<p>Malaysia (n=1) Korea (n=2) UK (n=3) USA (n=3) Germany (n=2) France (n=2) Brazil (n=2) Ireland (n=1) India (n=1) Australia (n=2) Belgium (n=1) Denmark (n=1)</p> <p>Healthcare settings: Not reported.</p>				Qualitative: n=10	Both quantitative (17 items) and qualitative (15 items) were scored using low risk, unclear risk and high-risk classifications of bias.
<p>Citation: O’Dea et al. 2021</p> <p>Country: Australia</p>	To identify the unmet supportive care needs of people affected by kidney cancer.	Systematic review	<p>Sample size: n=28 to n-1990, Total: n=4464</p> <p>Age: <i>Mean range (patients):</i> 56 years to 74 years.</p> <p>Gender: Mixed</p> <p>Cancer Type: Kidney cancer</p> <p>Treatment: Mixed</p> <p>Stage: Varied stages and time points.</p>	<p>Cultural factors: Not reported.</p> <p>Study Locations: USA (n=8) Canada (n=3) Germany (n=2) Australia (n=1) Korea (n=1) Norway (n=1) Denmark (n=1) Italy (n=1)</p> <p>Healthcare settings: Not reported.</p>	<p>Number: N=3</p> <p>Searched: CINAHL, MEDLINE, PsycINFO</p>	November 2010 to 2020	2010 to 2020	<p>Number of studies: n=18</p> <p>Type of included studies: mixed studies n=2 quantitative studies n=15 qualitative study n=1</p>	<p>Instruments: Mixed Methods Appraisal Tool (MMAT)</p> <p>Quality ratings: No studies were removed because of their appraisal score, but lower quality study findings should be interpreted with greater caution and in consideration of their limitations.</p>
<p>Citation: Puts et al. 2012</p> <p>Country: Canada</p>	To systematically review evidence with regard to answering the following questions: (1) What are the unmet care needs of older persons diagnosed with cancer who are	Systematic review.	<p>Sample size: n=19 to n=988</p> <p><i>Total:</i> n=7771 across studies.</p> <p>Age: <i>Range:</i> 20 years to 99 years.</p> <p>Gender: Both males and females represented (both separately and together, across the studies).</p> <p>Cancer type:</p>	<p>Cultural factors: Not reported.</p> <p><i>Study locations:</i> Australia (n=9) USA (n=5) Taiwan (n=4) UK (n=3) Canada (n=3) Netherlands (n=2) Sweden (n=1) Germany (n=1) Finland (n=1)</p>	<p>Number: n=5</p> <p>Searched: MEDLINE, Cochrane Library, EMBASE, CINAHL, PsycINFO.</p>	Not reported.	January 1996 to 06 December 2010.	<p>Number of studies: n=30</p> <p>Type of included articles: <i>Cross-sectional:</i> n=16 <i>Prospective:</i> n=7 <i>Quasi-experimental:</i> n=1</p>	<p>Instruments: Reporting of Observational Studies in Epidemiology, the Meta-analysis of Observational Studies in Epidemiology, and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. Qualitative studies used Quality Framework of the National Centre for Social Research.</p> <p>Quality ratings:</p>

	undergoing active treatment? (2) What are the predictors of unmet needs of older persons while undergoing active cancer treatment?		Mixed cancer diagnoses. Treatment: Range of treatment types across studies. Stage: Majority were diagnosed within the last 12 months and those not receiving active treatment (i.e., hospice and palliative care) were excluded.	Singapore (n=1) Healthcare setting: Those listed include a range of settings (registries, community / outpatient, cancer centres, wards)				<i>Clinical database:</i> n=1 <i>Mixed Methods:</i> n=2 <i>Qualitative:</i> n=3	All studies had a clearly formulated problem statement. Most used clear inclusion and exclusion criteria. Seven did not report the response rate and the majority didn't report reasons for nonparticipation. Most studies did not describe how much data were missing or how the missing data were handled. Few studies clearly described the limitations. Overall, the quality of qualitative studies was good.
Citation: Wang et al. 2018 Country: Hong Kong	To identify the unmet care needs and their associated variables in patients with advanced cancer and informal caregivers, alongside summarising the tools used for needs assessment.	Systematic Review.	Sample size: <i>Cancer Patients:</i> n=5772 <i>Caregivers:</i> n=3377 <i>Clinical Staff:</i> n=3 <i>Total:</i> n=9152 across studies. Age: <i>Patients:</i> Range 18 years to 96 years. <i>Caregivers:</i> Range 23 years to 85 years. Gender: PATIENTS <i>Female:</i> n=2816 <i>Male:</i> n=2182 CAREGIVERS <i>Female:</i> n=1967 <i>Male:</i> n=1165 Cancer type: Mixed cancer diagnoses. Treatment: Not reported. Stage: Advanced Cancer (studies defined this as cancer with metastasis or stage III/IV according to TNM staging system).	Cultural factors: Not reported. <i>Study locations:</i> USA (n=9) Mainland China (n=7) Australia (n=5) Netherlands (n=5) Canada (n=4) Japan (n=3) Taiwan (n=3) UK (n=2) Denmark (n=2) Hong Kong (n=2) Italy, France, South Korea, Spain, Indonesia, Czech Republic, India, and Bangladesh (n=1 each). Healthcare setting: <i>Outpatient:</i> n=16 <i>Inpatient departments:</i> n=11 <i>Home/home-based care units:</i> n=10	Number: n=10 Searched: PubMed, CINAHL, Embase, Cochrane Central Register of Controlled Trials (CEN-TRIAL), PsycINFO, Web of science, Wan Fang Data, China National Knowledge Infrastructure (CNKI), Chong-qing VIP (CQVIP), Chinese Biomedical Literature Database (CBM).	Inception of each database to December 2016.	1988 to 2016	Number of studies: n=50 (advancer cancer patients n=33; Informal caregivers n=12; both n=5). Type of included articles: <i>Quantitative:</i> n=43 (42 surveys, 1 post intervention study) <i>Qualitative:</i> n=7	Instruments: Mixed Methods Appraisal Tool (MMAT) Quality ratings: Included studies were generally robust, with 17 and 18 studies satisfying all four criteria (34%) and three of the four criteria (36%) respectively. <i>Quantitative:</i> prominent weakness were poor sampling strategy and low response rate. <i>Qualitative:</i> three studies failed to interpret how findings related to study context, and two studies provided no explanation on how research process was influenced by the researchers.

				Mixed settings n=7 Not reported: n=6					
Citation: Wu et al. 2019 Country: Australia	To identify the unmet supportive care needs of immigrant and native Chinese cancer patients and caregivers.	Systematic Review.	Sample size: PATIENTS <i>total:</i> n=8419 across studies. CAREGIVERS <i>Total:</i> n=1396 across studies. Age: Not reported. Gender: PATIENTS <i>Male:</i> n=3368 <i>Female:</i> n=4401 CAREGIVER <i>Male:</i> n=535 <i>Female:</i> n=861 Cancer type: Mixed cancer diagnoses. Treatment: Not reported. Stage: Not reported.	Cultural factors: Immigrant and native Chinese cancer patients and caregivers. Identified Mandarin or Cantonese as their main language spoken. <i>Study locations:</i> Mainland China (28.9%) Taiwan (28.9%) Hong Kong (15.6%) Healthcare setting: Not reported.	Number: n=8 Searched: Scopus, CINAHL, PsycINFO, MEDLINE, Embase, PubMed, Web of Science and ProQuest (ASSIA, Family Health, Health and Medical Collection, Health Management, Nursing and Allied Health, Psychology, Public Health Research Library, Health & Medicine, India Database: Health and Medicine).	Earliest date available to January 2018.	1999 to 2019	Number of studies: n=45 studies (reported in 47 articles). Type of included articles: <i>Cohort:</i> n=7 <i>Cross-sectional:</i> n=29 <i>Qualitative:</i> n=10 <i>Mixed Methods:</i> n=1	Instruments: Newcastle-Ottawa Scale for non-randomised studies (cohort studies). Appraisal Tool for Cross-Sectional Studies. Critical Appraisal Skills Program Qualitative Research Checklist for qualitative studies. Mixed Methods Appraisal Tool for mixed methods studies. Quality ratings: <i>Cohort:</i> 6/7 recruited from single centre. Samples may not have been representative. 5/7 confirmed diagnosis through medical notes, 2/7 did not provide this information. <i>Cross-Sectional:</i> 20/29 studies did not provide information on non-responders. 19/29 used convenience sampling (or did not provide details). 21/29 recruited from single centre only. <i>Qualitative:</i> Lack of detail regarding process of participant selection / recruitment. <i>Mixed Methods:</i> Risk of bias was limited. Low response rate and limited consideration of how findings relate to researchers' influence and integration of qual and quant data.

Key: AS = Active Surveillance; MIBC = Muscle Invasive Bladder Cancer; QoL = Quality of Life;

Supplementary Table 4: Unmet supportive care needs

Author and Year	Unmet supportive care needs	Method of synthesis in primary reviews	Comments or notes that that the reviewer authors may have
Alananzeh et al. 2016	<p>Patients Unmet Needs Health System/informational needs: Patients needed to know more about cancer, treatment effectiveness, symptoms and how to connect with other patients. Materials provided were in English and strong preferences were expressed for information in their home language. They also had difficulty navigating the health care system due to language barriers.</p> <p>Physical needs: Problems with constipation, vomiting, chest pain and heaviness, fatigue, lack of energy, muscular tightness, hair loss, weight loss, lack of appetite and changes in taste and smell.</p> <p>Family related needs: The need to obtain relief from dependency (unique to Egyptian cancer patients). They were bothered by their dependency on others, their perception of self as a burden and they were unsure how long the dependency would last.</p> <p>Patient-Clinician communication needs: Some patients felt they received less information, as the doctor didn't take time to overcome communication barriers. They had difficulty understanding English in consultations with doctors/nurses.</p> <p>Sexual well-being/intimacy needs: 26% (FACT-G) and 18% (SCNS) did not answer survey items relating to sexual relationships.</p> <p>Psychological: Only examined in 1 study. Unmet needs correlated negatively with QoL and positively with depression and anxiety within Arab migrant groups.</p> <p>Caregiver Unmet Needs Reported in 2 x papers. Caregivers experienced fatigue, sleep disturbance, anxiety and mood disturbance and financial constraints. They wanted to know about symptom management, how to provide good care (including how to help with patients emotional needs), how to encourage the patient to self-manage and they wanted to talk with others who have similar experience.</p> <p>Parent Caregiver Unmet Needs Highest ranked needs: related to their child's treatment and side effects, sincerity of treatment team in caring for the child and feeling they could ask questions. Lowest ranked needs: related to what information to give to other siblings and respond to sibling emotions.</p>	Not reported	<p>The review is limited due to design and methodological quality of the included studies. There have been no intervention studies designed to address unmet needs in Arabic cancer patients and family caregivers. While sexuality needs did not emerge as a core area it was significantly associated with reduced QoL and higher levels of anxiety and depression - may be seen as a taboo topic for some migrant populations resulting in underreporting.</p> <p><i>Recommendations for future research:</i> (1) Specific studies investigating the information needs of Arabic cancer patients and how unmet needs influence both psychical and psychological outcomes, so that relevant and effective interventions can be developed.</p>
Beesley et al. 2018	<p>Health system/informational needs: Information in general or specifically related to likelihood of a cure, coping with spread of disease and fear of recurrence, treatments, side effects, self-management, bowel changes, managing pain, fatigue, nausea, vomiting and daily activities, relaxation techniques and alternative therapies,</p>	Not reported.	<p>Authors did not mention which quality appraisal tool was used. Unsure if it was a standardised measure. Existing studies have methodological limitations. Most quantitative studies lacked measures of needs specific to gynaecological cancers. Overall burden of need for women</p>

	<p>nutritional information, and cancer risk to family members. Also ways to manage symptoms of lymphoedema, how to manage pain/discomfort in legs and groin.</p> <p>Psychological / emotional needs: Feelings of depression and sadness (and support for this), fear of cancer spreading, and concerns about the worries of those closest to them. Women described a need for distress screening and support. Psychological needs were present immediately after first line treatment and remained persistent two years later.</p> <p>Physical needs: Fatigue (lack of energy and tiredness) was consistently high prior to treatment and three months after. Pain in the legs and groin for those with lymphoedema (associated costs of lymphoedema), lack of appetite. Physical needs were also present immediately after first line treatment and persisted for the next two years.</p> <p>Sexual well-being/intimacy needs: Information and support for both women and caregivers regarding effect of treatment on fertility, preservation of fertility for younger women, when sexual intercourse becomes safe, managing vaginal changes, coping with premature menopause, pregnancy care recommendations, treatment focussed genetic testing.</p> <p>Caregivers Caregivers were included in (n=3) studies. Needs related to knowing that doctors had communicated to coordinate care, more accessible hospital parking and how to reduce stress in the survivor's life. In palliative cases, caregivers' unmet needs peaked 3-6 months before death. They needed help with reducing the patient's stress, disappointment with lack of recovery, fear of cancer spreading and making decisions in the context of uncertainty. Partners considered it desirable to be involved in sexual healthcare provision.</p> <p>Risk Factors More likely to report unmet needs: younger, advanced disease, recent treatment, not in remission, live with lymphedema or lower limb swelling, unable to work due to illness, have anxiety depression, insomnia or post-traumatic stress, poorer QoL / greater cancer symptoms, less social support, live in rural or remote locations and have lower income and minority status.</p>		<p>and their caregivers relate to comprehensive care and psychological concerns. While towards the end of life, needs relate to physical symptoms and depression.</p> <p><i>Recommendations for future research:</i> (1) Women with cervical or vulval cancer and gynaecological caregivers. (2) Well-designed quantitative studies by gynaecological subtype, including caregivers, to determine total burden of needs and how needs change over the continuum.</p>
Bibby et al. 2017	<p>Patient-clinician communication needs: Communication delivery – HCP qualities of listening skills, sensitivity, empathy, and trust regarded as key facilitators of information exchange. Being cared for by staff that were knowledgeable about AYA cancers/treatments (key pre-requisite for trust and confidence). HCPs understanding AYAs' psychosocial needs.</p> <p>Health system/Information needs: Higher unmet informational needs were associated with greater distress and lower satisfaction with care. AYA's wanted honest, timely and age-appropriate information on diagnosis, treatment, healthy lifestyle, and survivorship. Information specifically related to AYA topics (fertility preservation, appearance changes, education, finances).</p>	Not reported	<p>Only two studies used standardised assessment tools (no tool was used in multiple studies) Both of these tools were validated for use on adult populations. Guidelines for the care of AYAs with cancer need to ensure that fertility preservation is addressed in the post-treatment phase as well as at diagnosis and during treatment. Increased use of standardized age-appropriate measures would facilitate comparisons between studies, care settings, diagnoses, and treatment stages.</p> <p><i>Recommendations for future research:</i></p>

	<p>Fertility: Females more likely to find fertility information lacking or confusing. AYAs wanted preservation options from time of diagnosis tailored to age, developmental stage and relationship status and to be accompanied by written/online materials. Fertility discussions were associated with distress and embarrassment. Emotions impacted on decision-making. Sperm banking facilities were seen as inadequate, difficult to access and insensitive. Wanted referrals to fertility specialists.</p> <p>Psychosocial/emotional needs: Need for assistance with managing difficult feelings – fear, residual trauma and worries about family, identity, guilt, and uncertainty. Support needs were mostly related to diagnosis, decision-making, fertility and transitioning off treatment. Opinions of seeking professional help varied. Some preferred to turn to family and friends for support. Access to psychological services was limited (especially in adult treatment facilities).</p> <p>Social needs: AYA's placed importance on peer support and meeting other young people with cancer. Peers were a source of emotional and informational support. Valued opportunity to mix with other young people on wards and in waiting rooms (major advantage of AYA specialist services). Also wanted guidance on how to maintain relationships with existing friends and how to communicate their experiences to healthy peers.</p> <p>Physical/daily living needs: Access to facilities for recreation/distraction, relaxation and studying. Privacy. AYA friendly schedule (sleep, wake times, visiting hours).</p>		<p>(1) Studies that assess care experiences and unmet needs closer to treatment (to limit recall and survival bias).</p> <p>(2) A priority for future research is utilizing AYA-specific, standardized survey tools to evaluate specialist AYA services and determine whether they make a difference to AYAs' care experiences.</p> <p>(3) Longitudinal studies to provide information on how patient needs and experiences change over time.</p> <p>(4) The impact of demographic factors such as socioeconomic status, residential location (urban vs rural) may have on care experiences or unmet needs.</p>
Butow et al. 2012	<p>Information needs: Those in rural areas had significant information needs, particularly if it involved travel for treatment – they wanted access to information before they travelled, someone to help decipher the information, access to information about supportive care services while away from home and sensitivity to personal needs in making arrangement for travel.</p> <p>Health system needs: Rural and urban communities responded differently to care, delays in presentation were more common in rural communities but most rural communities were happy to wait for their GP to act on their behalf and a quickly moving system seemed impersonal. Whereas urban counterparts were more insistent. Transition of care/shared care was especially important to rural patients and more received care from their family practitioner than urban counterparts. Follow-ups consisting of examination only (rather than invasive tests) was perceived to be inferior, particularly for rural patients who were required to travel. Patients found the most difficult thing to be waiting for results, answers, and information. Some of the benefits of staying local outweighed travelling – support of a close community but not having access to biomedical expertise was a disadvantage.</p> <p>Physical/daily living needs: Functioning and symptoms likely to be worse in rural samples. Lack of energy and tiredness</p> <p>Psychological/emotional needs: Rural patients reported significantly poorer mental health functioning, higher levels of anxiety and depression, greater distress, and more emotional problems than non-rural cancer survivors. Worries of those close to them, fear of cancer spread or returning and anxiety about having treatment.</p>	Not reported. (the review states that due to the very disparate nature of designs and measures used, meta-analysis was not possible).	<p>Settings and rurality were poorly defined across studies included in the review and they predominantly focussed on breast cancer, limiting generalisability of findings. Self-developed measurement tools were often used prior to psychometric testing and design was mainly cross-sectional, so long-term outcomes and causality could not be assessed. The review itself did not use intervention studies (only descriptive) and meta-analysis was not possible so comparisons between studies are conceptual rather than statistical.</p> <p><i>Recommendations for future practice:</i></p> <p>(1) Research into different cancer types addressing psychosocial morbidity.</p> <p>(2) Well-designed, prospective studies of people with heterogenous cancers with control groups, using standardised measures and reporting methods to confirm disparities and establish priorities.</p> <p>(3) Research is needed on differences in physical, psychological, and social outcomes between urban and rural control groups. General population control groups should be included.</p> <p>(4) People with cancers other than breast cancer is a priority, including men as well as women, as needs and</p>

	<p>Practical needs: Patients staying at home described a better sense of normality in their lives. Patients who travelled perceived themselves to have better social support benefitting from contact with those in similar situations in accommodation centres. Those who travelled who were also responsible for the care of another worried their absence would negatively affect that person. Treatment side effects in an unfamiliar environment were also seen as difficult by patients. Financial burden of travelling for treatment on top of maintaining a rural household. Difficulties organising and claiming financial assistance. Some patients felt that being away from all responsibilities gave them the opportunity to rest without feeling guilty. Some patients felt they had to disclose their diagnosis wider than they may have liked when required to travel for intervention.</p> <p>Interpersonal/intimacy needs: (Study on women with breast cancer) – other areas of needs significantly decreased between 1- and 3-months post-diagnosis however, sexuality needs increased over this timeframe.</p> <p>Family-related needs: Patients concerns centred on their family coping with their absence from family and business responsibilities and the strain put on family relationships Many reported that they felt they were a burden to their family and friends.</p> <p><u>Caregivers:</u> Had more needs than patients regarding side effects of treatments, the symptoms to expect as the disease progressed, help to communicate with the patient, for comfort and support from other family members, personal care, activity management, involvement with health care and interpersonal involvement. During palliative care there was emphasis on family needs for information, equipment and 24-hour care. Had higher travel anxiety than patients and reported disruption to family life of forced was difficult to manage.</p>		<p>challenges may be different to those of women in a rural setting.</p> <p>(5) Qualitative studies exploring, in depth, resilience factors which protect some rural families from distress.</p> <p>(6) Intervention research including methods of overcoming distance barriers (internet/telehealth deliveries).</p>
Doyle et al. 2022	<p>Psychological/emotional needs Individuals affected by testicular cancer commonly reported unmet psychological/emotional needs.</p> <p>Physical needs Across the studies, there were a range of physical needs which required self-management support from healthcare professionals. Commonly, testicular cancer survivors experienced fatigue, lack of energy, drowsiness, pain, hair loss, and sleep disturbances. Men grappled with chemotherapy-induced alopecia and reported needing help with hair loss but was not provided with any support or education on preventative strategies, such as scalp-cooling.</p> <p>Interpersonal/intimacy needs Individuals affected by testicular cancer reported needing help with their sex life because they were embarrassed to discuss this with healthcare professionals.</p> <p>Health system/information needs Men wanted improved communication in the healthcare system to address problems with co-ordination of their care.</p>	Narrative synthesis	<p>Future directions for research should focus on developing a core outcome set (COS) for testicular cancer survivorship research. This review has identified significant heterogeneity of study outcomes and in particular patient reported outcomes measures (PROMs). There was a total of 57 different PROMs used across the studies in this systematic review and a range of diverse methods used.</p>

	<p>Cognitive needs Men experiences impairment or cognitive decline over time post-treatment and into survivorship.</p> <p>Social needs Testicular cancer survivors needed help knowing how to deal with this impact on relationships and were found to have lower social functioning than healthy populations.</p> <p>Family-related needs Young men expressed needs in knowing how to support their partners or families, how to communicate with their young children, and concerns about being unable to have children due to fertility issues. It was common for men to experience issues within their existing relationships which caused emotional strain.</p> <p>Practical needs Practical unmet needs included a lack of assistance to access government benefits, guidance on life insurance, and accessible parking at the hospital.</p> <p>Patient-clinician communication needs Men expressed that they wanted to feel more supported in the self-management of their health in partnership with their healthcare team.</p> <p>Spiritual needs No concerns</p> <p>Practical needs No concerns</p>		
Fu et al. 2020	<p>Information needs: Present in 14/14 studies. Patient dissatisfaction in overall quality and quantity of information. Requests for education on diagnosis, treatment, effects, risks, and prevention of melanoma, more HCP and service involvement. Unmet needs in relation to the way the information is delivered. Needed more non-conflicting comprehensible information in written format and more education regarding treatment, diagnosis, prognosis, skin checks and sun protection to prevent recurrence. More frequent follow-up care between appointments (diagnostic scans, calls to treating teams) for reassurance.</p> <p>Prevalence: Overall median was 64% (range 9% – 92%). Newly diagnosed was 77% – 92%, compared with 9% – 64% for patients not newly diagnosed with melanoma.</p> <p>Correlates: Lack of higher education linked with greater information needs, as well as discomfort asking questions of their clinical team. Certain clinical procedures (SLNB or treatment in addition to WLE) were associated with unmet information needs. Distressed patients had higher unmet needs and those with higher emotional QoL had lower needs.</p> <p>Psychological needs: Reported in 13/14 studies. Needs in regard to emotional support for mental health and future concerns, which also considered personnel involved. Anxiety, fear of disease spreading, recurrence, uncertainty about the future</p>	The Segregated Approach (JBI Methods)	<p>Needs of patients with melanoma differ to other cancer types. Review may not capture the unmet needs associated with recent advances in treatment (e.g., immunotherapy), as very few studies explored this. There was clinical heterogeneity in assessment tools and a lack of data in some studies leading to uncertainty of population characteristics.</p> <p><i>Recommendations for future research:</i></p> <ol style="list-style-type: none"> (1) Should use strong study designs, melanoma specific validated outcome measures and complete reporting data in terms of disease stage. (2) Target the development and validation of extensive melanoma specific tool that considers recent developments in care (immunotherapy) and its associated care needs. (3) Systematic reviews would benefit from mixed-methods approach.

	<p>and worry for family and friends. Lack of emotional support worsened anxiety and helplessness. Frustration and anxiety regarding lack of preventative medicine to avoid recurrence which resulting in hypervigilance with skin checks. Altered body confidence related to post-surgical scarring and fear/anxiety related to sun exposure and unrealistic association with unavoidable sunburn. Needs are predicted to reduce as patient progressed through cancer journey.</p> <p><u>Prevalence:</u> Overall median was 76% (range 12%-93%).</p> <p><u>Correlates:</u> Being distressed, retired, less than 50yrs or between 60-69yrs, history of SLNB or receiving treatments in addition to WLE. Patients with higher social and emotional QoL had lower needs.</p> <p>Physical needs: Reported in 9/14 studies. Physical health concerns and associated interference with ADLs. Lymphedema, pain and to lesser extend fatigue were most commonly reported. Subsequent negative affect on mood, daily activities and QoL.</p> <p><u>Prevalence:</u> Overall median was 59% (range 52%-67%).</p> <p><u>Correlates:</u> Being distressed, unemployed, depressive symptoms and lower QoL.</p> <p>Social needs: Reported 5/14 studies. Unmet needs with regards to talking with others about their diagnosis, effects of diagnosis on relationships and others understanding the seriousness of melanoma.</p> <p><u>Prevalence:</u> Not reported.</p> <p><u>Correlates:</u> Lack of public awareness contributed to many unmet social needs (patients believed increased awareness could help to overcome the common misconception that melanoma isn't as serious as other cancer types and a way to ensure families, friends, workplaces, and HCPs respected the severity of their cancer-related concerns).</p> <p>Spiritual needs: Reported in 2/14 studies.</p> <p><u>Prevalence:</u> Not reported.</p> <p><u>Correlates:</u> Not reported.</p> <p>Sexual needs: Reported in 2/14 studies.</p> <p><u>Prevalence:</u> Not reported.</p> <p><u>Correlates:</u> Those who were distressed had higher odds of unmet psychological needs.</p> <p>Other needs: 1/14 studies reported unmet financial needs.</p> <p><u>Prevalence:</u> Not reported.</p> <p><u>Correlates:</u> Not reported.</p>		
Galan et al. 2016	<p>Health system/information needs: Unmet needs related to healthcare provision and hospital experience for those having treatment less than a year before. Inadequate cancer follow-up care. Men were more likely to report unmet information needs however, younger women in particular requested more fertility-related information. Older people wanted more age-appropriate information and having autonomy in healthcare and decision making. Generally young adult cancer survivors have information needs around physical appearance, fertility, and late effects.</p>	<p>Method not specifically reported.</p> <p>Classifications according to theme.</p>	<p>Inconsistency in the literature regarding how AYA age group is defined with different countries using different age ranges. Studies did not use validated measures to assess participants needs. At the time of this study there were no validated questionnaire's available to assess the needs of the AYA population.</p> <p><i>Recommendations for future research:</i></p>

	<p>Psychological / emotional needs: Survivorship and life direction were unmet needs for those having treatment more than 1 year before. Older people had greater concerns about getting another type of cancer and wanted access to psychological counselling.</p> <p>Physical needs: People having chemotherapy had greater unmet needs related to long-term side effects of treatment. Intensity of the treatment correlated with the number of late effects experienced. Older people were more likely to report unmet needs related to treatment and long-term side effects.</p> <p>Social needs: Younger people gave greater importance to support from family and friends. Young adult cancer survivors have needs related to social relationships and changing priorities. Lack of support, isolation from other cancer survivors, from peers without cancer and during treatment.</p> <p>Practical needs: Older people had unmet needs related to financial support for care. Younger people were more concerned with scheduling treatments to fit their lifestyle.</p> <p>Family related needs: Young adult cancer survivors were concerned with protecting parents.</p>		<p>(1) Units of analysis beyond the individual (analyse the relationship between family characteristics and patient outcomes).</p> <p>(2) Research on how and whether the needs of AYA survivors are met.</p> <p>(3) Which of the identified needs are not adequately addressed and why so specific support programmes can be developed.</p> <p>(4) Additional studies in other countries to identify specific needs that may be culturally tied.</p>
Ge et al. 2020	<p>Health system/information needs: Preferred disclosure of diagnosis from gynaecologist directly. Felt excluded if weren't informed immediately by wife. They needed sufficient and comprehensible information about cancer diagnosis, treatment, physical care, adverse effects, and management of symptoms. They were frustrated by insufficient information. They needed relevant counsel from healthcare providers to resume a normal sex life, but they rarely received information on how to cope with sexual complications.</p> <p>Psychological needs: Shock, uncertainty, and psychological crisis at time of diagnosis. Ovarian cancer was associated with greater shock due to asymptomatic, high mortality and advanced stages. Psychosocial needs did not diminish over time. Almost all experienced anxiety over the potential of cancer recurrence and metastasis, as well concerns about their ability to provide sufficient support for their effected spouse. Guilt, self-blame about whether their genital hygiene or former sexual habits contributed to disease. Need for psychological support to overcome fears of the impending death of their spouse.</p> <p>Physical/daily living needs: The man experienced role changes from husband and father to caregiver and income-generator – they grew used to it. Gained a new focus and caring for their sick wife was the most important thing. They made lifestyle changes and eliminated harmful habits.</p> <p>Social needs: Men would feel extremely lonely and isolated and had limited social and professional support. Caregiving impacted the men's social interaction. They arranged their activities based on the patient's preference (plans were postponed or cancelled). Some lost friendships as a result of the cancer. Informal support was appreciated but at times seen as an intrusion – patients' parents often involved</p>	Inductive thematic analysis.	<p>Small number of articles included in the review which may result in unveiled caregiving experiences and supportive care needs. Mixed carer groups included, and 3/8 studies involved both male caregivers and patients, which may limit the generalisability of the study.</p> <p><i>Recommendations for future research:</i></p> <p>(1) More qualitative research on male partners of women with gynaecologic cancer</p> <p>(2) Development of a specific supportive care needs measurement that can characterise the type and extent of needs of male partners of gynaecologic cancer patients.</p> <p>(3) Further research to identify and test interventions for male partners of gynaecologic cancer patients.</p>

	<p>themselves leaving less time alone with their spouse and disrupting the balance between the couple and the wider family. Male partners found comfort in sharing information and symptom coping strategies with peers whose wives suffered from the same disease.</p> <p>Spiritual needs: Male partners gained internal strength by being close to nature, seeking faith and praying.</p> <p>Interpersonal/intimacy needs: Men reported they couldn't be as intimate or talk openly with their spouse about the disease and its treatment. The disease disrupted the balance / obligations in the marriage. Sexual dysfunction was a long-term complication with cessation or decreased frequency of intercourse being the most prevalent concerns. Some men feared re-bleeding, and some feared cancer recurrence or transmission if they restarted their sexual activity. Difficulties were seldom discussed within the couple.</p> <p>Family related needs: For those with children, it was difficult to take care of their wife and offspring simultaneously. Men worried about deficient care for their children. Younger men with no children worried about having biological children. Couples developed a sense of inferiority when faced with infertility, which impacted their social interactions. Men also worried about whether their daughters would inherit their mothers cancer.</p> <p>Practical needs: Financial burden including outright medical expenses as well as reduced income.</p>		
Hyun et al. 2016	<p>Information needs: Unmet information needs on their disease and its treatment at the time of diagnosis. Little or no information received about thyroid cancer, thyroid function or the cause of their cancer. Unmet need related to family members risk of malignancy. Little to no information on aspects of treatment and a lack of communication by healthcare providers about the risks of surgery. Information on radiation safety was difficult to access and the risks of radioactive iodine treatment was not adequately explained by physicians. Unmet need related to information related to diagnostic tests or new treatments. Information on after-care was lacking including long-term effects of treatment and medication use and rehabilitation options. Low-risk survivors had unmet information needs relating to after-care specifically long-term side effects of treatments, how to check for signs that cancer has returned, physical fitness/exercise, nutrition/diet, and impact on fertility. Survivors recommended provision of more information about the disease and treatment options, as well as quicker access to test results.</p> <p>Psychosocial needs: Survivors indicated they did not receive information on patient support organisations, or support from a psychologist, counsellor, nurse or other support person at the time of diagnosis. There was little or no information provision for psychological assistance, additional help, expected impact of their diagnosis and treatment on their social life. There was a perceived lack of support from their physicians and their family members. They had unmet needs managing concerns of cancer recurrence, a second primary malignancy, financial support for medical care, how to discuss their cancer experience with family and friends and meeting other AYA</p>	Summarised descriptively.	<p>Levels of agreement between reviewers on inclusion of studies were limited. Some of the primary studies may have overlapped study populations if any of the respondents participated in more than one survey study. Specific personalised information and psychosocial support needs according to important variables such as clinico-histopathologic subgroup, life stage, or disease status in response to treatment were not identified.</p> <p><i>Recommendations for future research:</i> (1) Research is needed on how to optimise psychosocial support and related health outcomes in thyroid cancer survivors.</p>

	<p>survivors. Survivors recommended psychological support, introduction to patient support groups and/or individual peer support.</p> <p>Health system needs: Thyroid cancer survivors received little or no information about different care locations. Lack of information and support in communicating with medical teams and accessing their medical records. Survivors recommended access to a specialist or oncology nurse and easier access to cancer teams.</p> <p><u>Complementary and alternative medicine:</u> Thyroid cancer survivors indicated an unmet need on information about complementary and alternative treatments.</p>		
King et al. 2015	<p>Information needs: Men received information about prostate cancer and its treatment from a variety of sources (oncologists, urologists, nurses, GPs, cancer charities, the internet, friends, and family members). Peer networks were a source of major value. Two issues with information from health professionals (1) not enough information about treatment options, presuming the men understood more than they did and (2) timing of information delivery. Men needed information after diagnosis – PSA testing and what the changes meant and appropriateness of treatment/options. Timing was felt to be inappropriate (too little too late for side effects) and men felt unprepared for severity and duration of the side effects. Hard to absorb information directly upon diagnosis. Men experienced uncertainty due to lack of information linked to treatment options and outcomes (particularly on active surveillance or with advanced and recurrent disease)</p> <p>Health system needs: Men wanted assistance interpreting information and more contact time with a specialist cancer nurse particularly after diagnosis and after active treatment. Men were uncertain about the care pathway – they did not understand the link between their illness experience and the process of care such as when events were going to take place and who was responsible for particular aspects of care.</p> <p>Psychological/emotional needs: There was a long-term need for emotional and psychological support from diagnosis through to survivorship. Men felt there was a lack of understanding by health professionals about the emotional impact of prostate cancer particularly in the longer term. Distress and need for psychological support especially evident at diagnosis. Needed support for and information about treatment side effects (length and duration of incontinence and erectile dysfunction). Men wanted psychological support for both them and their partners and would have considered organised counselling if it was an option.</p> <p>Physical needs: Men failed to gain a good understanding of treatment and side effects, their severity and longevity.</p>	Thematic synthesis.	<p>Identified early information needs, later psychological needs, and ongoing support for psychosexual needs. Communication issues with the medical team were ameliorated if a specialist nurse was involved. The review excluded articles focussing on diagnosis and treatment decision making and the papers were predominantly from North America and therefore findings may not be universally applicable.</p> <p><i>Recommendations for future research:</i> (1) Experiences of men from minority ethnic groups, single men, and gay men.</p>
Kotronoulas et al. 2017	<p>Female gender, and younger age were the most consistent predictors of unaddressed concerns, greater need for support and greater need for shared decision making.</p> <p>Physical/cognitive needs: fatigue/lack of energy, abdominal pain, defecation problems, digestive dysfunction, and sleep loss. Pain, fatigue, and sleep loss were particularly troubling in post-op period.</p> <p><u>Correlates:</u> Recent treatment, rectal cancer diagnosis, presence of stoma, late-stage disease.</p>	Narrative synthesis.	<p>There were 136 unique supportive care needs identified based on moderate-to-good quality research. Half of these needs were related to information provision and patient-clinician communication. There were mixed patient samples in the majority of studies, and this prevented distinction in patients' needs based on tumour sub-type. However, the diversity in demographics and clinical characteristics enabled an exploration of the needs of this patient population as a whole.</p>

	<p>Psychosocial/emotional needs: Fear (of cancer return/spread), uncertainty about the future, shock, mental isolation, feelings of abandonment following treatment completion and dependence (burden) to others. <u>Correlates:</u> Presence of stoma. Negative perceptions about the illness and the effectiveness of treatment, uncertainty, symptom distress, cancer-related rumination, depression, and type D personality (“distressed personality”) were invariably linked to a greater need for support, help with physical symptoms, and provision of information.</p> <p>Family related needs: Support for the family (especially children) with their own worries/concerns, support of patient with his/her concerns about families future and informational needs of the family. <u>Correlates:</u> Not reported.</p> <p>Social needs: Accessing support groups was most prominent. Planning ahead and knowing proximity to bathrooms to prevent stoma related embarrassment. <u>Correlates:</u> Recent treatment, more bowel symptoms, shorter symptom duration.</p> <p>Interpersonal/intimacy needs: Help for adjusting to changes in sexuality, altered body image, sexual dysfunction. <u>Correlates:</u> Not reported.</p> <p>Practical/daily living needs: Help to adjust to restrictions imposed by treatments/side-effects. Transport and access issues, financial and work issues and making dietary changes. <u>Correlates:</u> Presence of uncontrolled pain.</p> <p>Information/education needs: Information about diet/nutrition, long-term self-management and controlling fatigue. Information around diagnosis, test results, treatment options, side effects and what to expect post treatment/discharge. <u>Correlates:</u> Overweight/obese status, poorer preoperative health status, rectal cancer diagnosis.</p> <p>Health system/patient-clinician communication needs: Quality and delivery of information, on-going patient contact with trusted health professional, qualities of a caring professional and better coordination of primary and secondary health services. Post-treatment follow-up by specialist nurse. <u>Correlates:</u> Overweight/obese status, poorer preoperative health status, rectal cancer diagnosis.</p>		<p><i>Recommendations for future research:</i></p> <ol style="list-style-type: none"> (1) Interventions for insomnia countermeasures (2) Needs of those with advanced / metastatic cancer of the colon/rectum. (3) Female patient groups and younger patient groups to understand the correlates for greater unmet need in this population (and the sharp rise in rates of cancer of colon/rectum among young adults). (4) Fluctuation of needs pre-to-post-operative and then post-treatment and survivorship period.
Lisy et al. 2018	<p>Health system/patient-clinician communication needs: Reported needs of ongoing supportive care, structured care plans, shared care between patient and HCP and patient centred care. Respect for individual patient preferences (i.e. declining breast reconstruction after mastectomy). Dissatisfaction with the information provided by HCPs. Expressed preference for LBG-friendly providers. HCP frequently perceived as reluctant to discuss LGB sexuality – ranged from ‘over sanitised’ discussions to refusal to discuss LGB sexual matters raised by the patient. HCPs lacked knowledge in impacts of cancer and treatments on LGB sex. Showing an interest and trying to seek resources to support the patient was appreciated.</p>	Thematic Analysis	<p>HCPs should be equipped with cultural competency training encompassing LGB sexuality, relationships and other LGB specific issues. Provision of clear antidiscrimination policies. Inclusion of LGB specific domains in PROs to enable care improvements.</p> <p><i>Recommendations for future research:</i></p> <ol style="list-style-type: none"> (1) Extend research to include transgender people, as this group experiences a range of unique issues.

	<p><u>Disclosure:</u> Felt uncomfortable disclosing sexual orientation and they had no appropriate opportunities to do so. Lack of disclosure linked to additional psychological burden and it was a source of regret. Fear of homophobia and discrimination and sense of safety in the environment led to non-disclosure. Some patients felt it should be HCPs responsibility to ask patients to self-identify. Others wanted privacy and considered their sexuality to be separate from their cancer care experience. Disclosure was seen as a risk.</p> <p><u>Homophobia:</u> Fear of homophobia and potential sub-standard care. Fear of poorer treatment or poorer quality of care. LGB patients conducted preparatory research “screening” HCPs and their attitudes regarding sexual orientation. Some directly described homophobic reactions and denial of standard care. Feeling apprehensive or heightened sense of alertness around providers.</p> <p><u>Heterocentric Care:</u> Assumed heterosexuality was widely reported – this assumption added to patients’ distress and feelings of being invisible. There was a “one-size-fits-all” approach that didn’t meet the needs of sexual minority patients. Felt they were left to self-educate with little or no guidance from HCPs.</p> <p><u>Partners:</u> Important for same-sex partners/spouses be treated equally to heterosexual partners/spouses if patient chose to include them in care. Inclusion in appointments, treating partners with respect and recognising partners as legitimate next of kin.</p> <p>Information needs: Support resources were seen as Heterocentric, irrelevant and inappropriate leaving LGB patients feeling isolated, dissatisfied, anxious and frustrated. Written support did not address LGB needs, cover LGB issues or include LGB relationships. Lack of targeted materials for LGB people with cancer. Expressed the needs for LGB specific information on sexuality and relationships, side-effects of treatment/different treatment options and the psychological impacts of treatment.</p> <p>Social needs: Lack of adequately resourced LGB-specific support groups. Lack of support groups for partners of LGB people with cancer. Uncomfortable disclosing sexuality in heterosexual groups. Unable to openly discuss relationships and sexuality. LGB cancer specific support groups were seen as safe spaces and provided emotional support. Desire to hear first-hand experiences from other LGB people with cancer to aid in decision making.</p>		<p>(2) Focussing on bisexual people as a distinct group with unique needs.</p> <p>(3) Establishing further domains of LGB cancer care experiences (rather than using generic PRO measures with sexual minority populations).</p>
Lisy et al. 2019	<p>Psychological/emotional needs: The top 4 unmet needs reported by cancer survivors were in the psychosocial domain. Needs included help with fear of recurrence and progression (14-42%), uncertainty about the future (26%) including not being able to set future goals or make long-term plans, help to reduce stress (34%). Worries of partners, family, and friends (12%-26%).</p> <p>Interpersonal/intimacy needs: Survivors had unmet needs for help with changes to sexual feelings and relationships (11%-29%).</p>	Narrative Synthesis (and vote counting)	<p>Existing quantitative measures may not comprehensively address the unmet needs of people after cancer treatment. For example, cognitive issues (unmet needs for help with memory and concentration), which are reported frequently in cancer survivors. Available data are limited by the measures used to assess unmet needs. Cancer types were not fully or equally represented, so results may be skewed in favour of unmet needs relating to specific cancer types.</p> <p><i>Recommendations for future research:</i></p>

	<p>Physical/daily living needs: Affordable car-parking when attending hospital appointments (12%-26%). Help with fatigue (10-27%) and limitations carrying out usual activities (13-27%).</p> <p>Patient-clinician communication needs: Knowing that healthcare professionals (HCPs) communicated to coordinate care (15%-31%).</p> <p>Information needs: Information about available support services (11%-33%). Access and information about complementary and alternative therapies (17%-31%).</p> <p>Social needs: Peer support (13%-26%)</p> <p><u>Correlates with unmet needs:</u> Correlations between unmet needs and psychosocial issues with anxiety, depression, low mental QoL and post-traumatic stress disorder were found. Younger people with lower physical and overall QoL, and those with more advanced disease correlated with greater unmet needs.</p>		<p>(1) Future studies to utilise more comprehensive measures and to specifically ask about unmet needs for problems commonly experienced after treatment (cognitive issues, fatigue, sleep).</p> <p>(2) Further research using sensitive measures to ascertain the unmet needs of discrete populations (such as Aboriginal and Torres Strait Islander people, other cultural groups and those who identify as sexually or gender diverse).</p>
Maguire et al. 2013	<p>Physical needs: Patients reported a loss of energy, breathlessness, pain, and sleeplessness which caused distress. At two-years following diagnosis lack of energy and tiredness were persistent.</p> <p>Daily living needs: Concerns with not being able to hold down employment and do household chores (50-60%) of participants or being able to do the things that they used to be able to do (45-65%). Among those newly diagnosed quitting smoking was a considerable loss of daily living and frustration. Those with higher levels of education were identified to have high daily living unmet needs.</p> <p>Psychological/emotional needs: Patients reported feeling anxious, worrying about being unable to control the side-effects of treatment, feeling sad, feelings of guilt, fear of the cancer spreading, and feeling like a burden were common. Patients also reported losing their identity and altered self-perception.</p> <p>Spiritual/Existential needs: Uncertainty about the future ranged from 13% to 70%. Some reported the importance of faith and trusting in God as a coping mechanism. At least half of patients in some studies reported to fear death and dying.</p> <p>Informational needs: One of the most consistent aspects of unmet informational needs were not being informed about things that they could do in their own self-management of their condition. Patients needed to be informed about timely access to information about test results and self-management of side-effects, and important aspects such as diet, exercise and breathing exercises. Patients noted that lung cancer was a life-limiting illness and therefore needed to be informed about timely access to palliative care services and end-of-life discussions.</p> <p>Patient-clinician communication needs: It was important to have a trusting clinician and who were available to talk about all aspects of their condition, treatment, and follow-up in comprehensible terms. Patients valued services such as rehabilitative-style follow-ups, support from peers and counselling.</p>	Narrative Synthesis	<p>The unmet needs in this review varied from general to those which were highly complex. Of note there were no unmet needs related to sexual well-being/intimacy.</p> <p><i>Recommendations for future research:</i></p> <p>(1) Understanding how unmet supportive care needs change over the illness trajectory and vary with clinical and demographic variables.</p>

	<p>Practical needs: Patients experienced stress due to prolonged diagnosis and delays due to wait-times with starting treatment. Other practical needs related to transportation to and from clinical appointments, out-of-hours accessibility to healthcare professionals, support for getting their affairs for making funeral arrangements or making a living will/advanced directive. Stigma was also an issue experienced due to the nature of the illness and issues in accessing financial support due to system process challenges.</p> <p>Social and family-related needs: Patients reported worries about the impact of this illness on their family members. Patients also reported issues with stigma because of their diagnosis which consequently reported in isolation and feelings of loneliness.</p> <p>Cognitive needs: Only one study reported cognitive needs of people living with lung cancer, related to issues of forgetfulness, poor cognition and/or confusion which affected their quality of life.</p>		
<p>Maguire et al. 2015</p>	<p>Physical needs: In at least two studies, dealing with pain, bleeding/spotting, urinary incontinence, poor sleep, and hair loss were described as being the most prevalent needs of women. Fatigue, bad dreams, bowel dysfunction, prolonged/irregular menstruation, and prolonged/excessive vaginal discharge post-sexual intercourse were frequently reported (single studies). Over 75% of Nigerian women receiving RT >1-year post-diagnosis described bad odour emerging from their body that could be attributed to concurrent gynaecologic symptoms.</p> <p>Psychological/emotional needs: Fears of cervical cancer recurrence were consistently reported (within study occurrence rates reaching 90%). Those with early-stage disease rated their post-surgery worries about cancer recurrence persistently high throughout a six-month and the two-year follow-up period, even after controlling for type of surgery (hysterectomy. trachelectomy). Additional needs/concerns reported included fear of potential metastasis, fear of early or painful death, feeling depressed, feeling tensed up and unable to relax, dealing with loss of self-confidence/self-esteem, worrying about emotional well-being, dealing with uncertainty, self-blame feeling old or 'empty', dealing with intrusive thoughts about the illness, feeling easily irritated, and feeling a need for help to come in terms with illness.</p> <p>Family-related needs: Reported in one study only. Worries about daughters developing cancer/inheriting the disease; worries about the family/emotional impact of cancer; concerns about own inability to care for children and fulfil family responsibilities; and concerns about their family living without a caregiver especially as a result of their premature death. Women felt the need to keep the diagnosis from the family to avoid burdening them.</p> <p>Social needs: Women experienced feelings of isolation, shame, or embarrassment, particularly with concerns of unpleasant body odour being noticed by others (compromised social desirability). Relationships with others seemed to be unaffected by time since treatment completion. Minority patient groups (Latino or African Americans) were particularly concerned about neighbours or friends' perceptions of them, whilst others worried about thoughts, judgments, or insensitivity of other people towards them.</p>	<p>Narrative synthesis.</p>	<p>Search was not exhaustive; it was limited to most common databases and peer-reviewed articles excluding grey literature. Language limiters to English may have missed information from developing countries (where cervical cancer is primarily diagnosed). Cervical cancer seems to heighten women's concerns about cancer recurrence, impact on the physical and psychosocial aspects of sexuality, and be accompanied by physical and psychological sequelae that collectively raise the requirement for more, tailored and sensitively provided information.</p> <p><i>Recommendations for future research:</i></p> <ol style="list-style-type: none"> (1) Rigorously designed, adequately powered and fairly representative quantitative studies, utilising validated patient-reported outcome measures, to fully describe the range of cervical cancer-related needs of women at different stages, with different backgrounds, exploring sociodemographic, clinical, and behavioural factors that may place women with cervical cancer at risk for greater unmet needs and compromised psychosocial adjustment. (2) Psychosocial researchers in developing countries are urged to contribute to the existing body of knowledge. (3) Intervention studies with robust research designs and protocols could also explore the feasibility and/or effectiveness of patient feedback through the routine use of patient-reported outcome measures. (4) Dyadic quantitative and qualitative studies and intervention programmes to enhance understanding of relationship dynamics and interrelated needs of partner and families.

	<p>Interpersonal/intimacy needs: Most common needs expressed included dealing with lack of sexual desire due to dyspareunia, bleeding, foul smelling discharge, bladder and/or bowel dysfunction, or loss of libido. Fear of infecting partner through sexual intercourse, fear about injuring/aggravating the affected area during sex, fear of resuming sexual activity due to negative thoughts and emotions about sexuality, and anxiety about sexual intercourse after treatment due to fear of cancer recurrence. Despite desire, they felt unable to engage in intercourse. Worried about not being able to enjoy sex. Some women with cultural pressures / expectations felt forced to fulfil the partner's sexual desires. Women expressed a need to have sexual counselling (10/61 = 16.4%). These issues resulted in tension, confrontations, compromised intimacy, and adversely affected relationships with their partner. Relationship concerns increased closer to completion of treatment. Fear of rejection or abandonment for another women. Women sought sexual satisfaction with partner regardless of whether this involved sexual intercourse. Concerns about appearance (hair loss, weight gain) self-image, attractiveness, desirability and/or femininity were expressed. Concerns of hysterectomy related stigma, as well as difficulty in dating (if single). Some fertility and/or ability to maintain pregnancy were expressed.</p> <p>Practical needs: General practical needs included long wait for appointments, financial constraints, concerns about being unable to continue working, fear of becoming redundant and being unable to provide for their family. Culturally, needs included women having to deal with language barriers, fear of being reported to immigration officials, or feeling ashamed in having to ask for financial assistance despite current financial difficulties.</p> <p>Daily living needs: Reported in 2 studies. Women seemed to strive to maintain an equilibrium between fear of becoming incapacitated or dependent on others, and an urge to act towards preventing recurrence and staying healthy overall.</p> <p>Spiritual/existential needs: Reported in 1 study only. Need included Fear of the unknown.</p> <p>Health system/information needs: Women perceived a lack of information from physicians especially about the short-or long-term effects of treatment. Would have valued information about the cause and potential for recurrence, available treatment options and medical tests and sexuality-related information. Information on prognosis was the greatest need for short-term survivors. Expressed a need for counselling, support groups, access to psychologist or social worker and the experiences of peers. Information needs for practical matters, financial, home or transportation assistance, ways to self-care, use of complimentary or alternative medicine and appropriate nutrition. Timing, quality, and environment of information delivery were important considerations.</p> <p>Patient-clinician communication needs: Lack of support, insufficient time with doctors, and dissatisfaction with the explanation of test results or the impact treatment may have on sexuality were reported. Women identified a lack of continuity in care as well lack of sensitivity during physical examinations. Presence of a health professional during treatment was suggested to improve satisfaction with</p>		<p>(5) Research spanning extended periods could effectively reveal variations in unmet need and time points where immediate and intensive clinician support is required.</p>
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	care. Women who completed treatment within the previous 12 months had greater concerns related to communication with the treatment team than those whose treatment was completed ≥ 12 months earlier.		
Maqbool et al. 2017	<p>Informational needs: Reported in 3/7 studies. Both patients and caregivers largely expressed a desire to have proactive, forthcoming, honest, and complete disclosure of information regarding their medical condition (n=2, 67 %). and decision making</p> <p>Patients: Wanted information on available treatment options (n = 2, 67 %), and information on available resources and accessing information (n=2, 67 %). Patients generally wanted information related to their present condition such as side effects and treatment risks (n=2, 67 %) and on managing their symptoms/side effects from treatment (n=2, 67%).</p> <p>Caregivers: Wanted information about the future (prognosis). They expressed the need for anticipatory guidance to help patients and caregivers prepare for progression of the disease.</p> <p>Supportive Care needs: A large proportion of patients and caregivers mutually identified pain and fear of physical suffering as two unmet patient needs requiring supportive care. Both required pre-arranged follow-up appointments and phone access to the healthcare team as part of their management and supportive care.</p> <p>Patients: Greatest patient indications of unmet needs for supportive care were housework, pain, fatigue, and activities of daily living.</p> <p>Caregivers: Perceived that the patients greatest unmet needs were sexual dysfunction, psychosocial issues (relationship problems, lack of emotional expression, denial) and financial concerns.</p> <p>HCPs: Found that the greatest need for patient support was identified as activities of daily living (i.e., bathing, dressing, and eating)</p>	Method not specifically reported. Summarised qualitatively without meta-analysis.	<p>Review did not use a standardised quality assessment tool – a novel risk of bias tool for cross-sectional studies was adapted and may have influenced reported findings or may explain heterogeneity in results.</p> <p>Limited published evidence, small sample sizes, and design limitations.</p> <p>There may be some discordance between perspectives of patients, caregivers and healthcare professionals regarding patient needs warranting supportive care.</p> <p>Dearth of information regarding social, emotional, and spiritual domains.</p> <p><i>Recommendations for future research:</i> (1) Information needs from within social, emotional, and spiritual domains (for both patients and caregivers).</p>
McIntosh et al. 2019	<p>Informational: Reported in 7/8 studies. Existing information on PCa, signs of progression, future treatment options and adjuvant treatments (diet/exercise) were not always provided/available. The information that was provided on PCa and AS was contradictory and confusing due to jargon used and men not always understanding their diagnosis. Unmet information needs were stressful and may lead to additional unmet emotional/psychological needs.</p> <p>Emotional/Psychological: Reported 3/8 studies. Lack of emotional support in addition to unmet informational needs lead to feelings of depression, irritability, anxiety, fear, worry, embarrassment, and stress. Men needed support to manage fears related to AS specifically. The need for separate support groups for men with AS was identified. Peer support and information on future treatment options was important to them.</p> <p>Social: Reported 1/8 studies. There was a need to socialise with other men on AS.</p> <p>Other: Reported 2/8 studies. Unmet needs in relation to self-management strategies such as tracking PSA results. There was also a desire to participate in exercise programs for men on AS.</p>	Thematic Synthesis	<p>Limited research exploring unmet needs of men on AS. Only a small number of studies included in the review. Not all studies were AS specific – 6/8 studies had mixed PCa participants. Cross-sectional studies did not explore unmet needs using supportive care needs framework or well-validated measures.</p> <p><i>Recommendations for future research:</i> (1) The application of the Social-Ecological Model (SEM) would be useful in identifying the factors contributing to the unmet needs in AS (this theoretical model has been used in cancer context previously).</p>
Mirosevic et al. 2019.	Psychological/emotional needs: Strongest evidence was found for anxiety and QoL. Worrying/symptoms of anxiety, lower physical and mental and global QoL had significant effects on domain score. Fear of cancer recurrence was recognised in	Not reported	Review used adapted criteria (checklist) for quality assessment. Most of the included studies were cross-sectional, which means there was little insight into how the

	<p>countries with well-developed health care and included survivors who more recently ended treatment.</p> <p>Physical/daily living needs: Strong evidence was found for factors relating to physical wellbeing (lack of energy, pain, comorbid disorder), type of treatment (hormonal, chemo, RT), and HNC recurrence. Survivors that reported higher levels of unmet needs had significantly worse QoL in areas of social avoidance, finance, and appearance. Haematological and HNCs were more likely to report feeling tired and also inability to carry out tasks they used to be able to do.</p> <p>Health system (patient care) needs: Those reporting more unmet needs were younger, more anxious, had lower QoL (mental and physical health QL included) and reported higher levels of fear of cancer recurrence (FCR). More unmet needs were found when survivors were not car users or did not have a medical card and had financial concerns that started after diagnosis.</p> <p>Information needs: Strong evidence was found for time since treatment/diagnosis and physical health. Those with more unmet needs were usually at the beginning of their post-treatment path and reported more comorbid disorders, lack of energy and HNC recurrence. Information needs was recognised in studies conducted in countries with less-developed health care.</p> <p>Interpersonal/intimacy (relationship and sexual) needs: Correlated with time since last treatment/diagnosis and QoL. Survivors for whom less time had passed since treatment/diagnosis and those with worse physical and mental QoL reported higher levels of unmet needs concerning relationships. Younger survivors reported having more unmet needs that concerned general and sexual relationship issues. Unmet needs related to sexuality was more common in men and those who were married.</p> <p><u>Overall Prevalence:</u> A high prevalence was mostly observed in breast cancer studies (49% to 62%) prevalence rates. Studies that included gynaecological cancer with a roughly similar time since treatment (3.7- and 4-years post-diagnosis) reported similar prevalence rates (52% to 56%) and so did the studies in younger patients (mean age less than 40yrs) with testicular cancer (63% to 66%).</p> <p><u>Correlates:</u> Younger patients, those with less than 5 years post-treatment/diagnosis, anxiety, reduced QoL, comorbidities and symptoms reported more unmet needs. Survivors of breast, gynaecological and testicular cancers with symptoms of depression demonstrated significantly higher levels of unmet needs.</p>	<p>(Categorisation for domains and pooled percentages for prevalence).</p>	<p>unmet needs changed over time. Several articles were lacking information either on prevalence, the factors associated with specific domains, or the stage of the cancer at diagnosis, thus making comparisons between studies limited. many of the reviewed studies recruited a homogenous sample (white, breast cancer and patients who are well) drawn from single centres, reducing the generalisability of the results.</p> <p><i>Recommendations for future research:</i> (1) Future studies on unmet needs should not only report the factors associated with a total higher level of unmet needs, but also how these factors are associated with each domain separately.</p>
<p>Moghaddam et al. 2016</p>	<p>Health system/information: Being informed about self-care and having a professional contact with whom to discuss concerns. <u>Prevalence:</u> 30% - 55%</p> <p>Psychological/emotional: Illness related fears and concerns about those close to them. Need help managing worries with fear and anxiety emerging as prominent emotional needs. <u>Prevalence:</u> 18% - 42%</p>	<p>Content analytic approach to narrative synthesis (with meta-analysis for studies that reported prevalence of unmet needs by domain).</p>	<p>Inconsistency in approaches to assessing unmet needs was a source of heterogeneity. SCNS was the most commonly used assessment but it was only used in 6/23 studies and they used different variants of the tool and classified needs in different ways, with different thresholds for classifying the need as unmet.</p>

	<p>Physical/daily living: Loss of previous functional abilities, pain, and fatigue. <u>Prevalence:</u> 17% - 48% (physical) and 17% - 37% (functional).</p>		<p>Information seeking: there is an apparent necessity to individualise provision (there was no topic for which all respondents desired additional information).</p> <p><i>Recommendations for future research:</i> (1) Interventional studies demonstrating that assessed unmet needs can be addressed.</p>
<p>Moore et al. 2013</p>	<p>Information needs: Specific needs in relation to the type and delivery of information. Patient and carers identified specific information needs including postoperative information, disease/treatment information, side effects, effect of diagnosis on QoL, medication management, prognosis, proactive and understandable financial resources, information to support the effective navigation of the health system. Needs were specific and changing over time. Individualised information for each patient (i.e., specific prognosis) via different media and delivered in a timely-manner pre-empting crisis events.</p> <p><u>Patients:</u> Expressed satisfaction in information provided but few posed the crucial question about prognosis and were satisfied with simply knowing their diagnosis and treatment regime, and information about how to access support groups.</p> <p><u>Caregivers:</u> Were dissatisfied with the lack of consistent advice to support them in their role. Timely and individualised information supports the transition to caregiver role, brings awareness to support services, supports treatment decisions, enables advocacy for the patient and prepares them for financial implications due to loss of income.</p> <p>Opportunities for communication with health care professionals (HCPs) and assistance with treatment and care decisions, facilitated discussion around reduced life expectancy and independence and conversations about their illness. Opportunities to discuss their expectations of the patients' impending death, which was often perceived to be unspoken by HCPs. Separate patient and family consultation to discuss the dying process if required.</p> <p><u>Patient:</u> Timely communication to ensure PMG patients have the opportunity to express their desires and coordinate care plans early enough prior to cognitive and communication difficulties. Supportive communication between patients and HCPs during key points (diagnosis, discussion of prognosis, anticipation of scan results, point of recurrence and preparation of end-of-life discussion).</p> <p><u>Caregivers:</u> The opportunity for bereaved families to communicate after the patient has died.</p> <p>Health system needs: <u>Patient:</u> A dedicated case manager or primary nurse for each patient to assist with uncertainty, social isolation and facilitate discussion around end-of-life issues. Rehabilitation for PMG patients with specific interventions aimed at addressing financial and psychological distress. <u>Caregivers:</u> Current support is inadequate to meet carer needs for patients with PMG. Service provision responses to address these unmet needs of the patient and carer. Recommended to have a specialist nurse as a contact to assist carers in managing the multiple care needs such as medication management, combining caring and working, support groups, financial issues, and expectations after neurosurgery. HCPs to</p>	<p>Narrative Synthesis</p>	<p>There remains a lack of about the needs of patients and their caregivers during the end-of-life period. None of the included studies were conducted in a palliative setting. Bereavement needs of carers was inconclusive due to lack of available evidence. Only direct patient and carer reports were included confining the literature to qualitative data which resulted in less methodological heterogeneity than other narrative syntheses. Lack of generalisability as key stages of the care pathway were missed.</p> <p><i>Recommendations for future research:</i> (1) Rigorous prospective qualitative study including views of HCPs, to delineate an evidence-based model of supportive and palliative care. (2) A comprehensive needs-based model of care requires further investigation to ensure patients and families receive individualised, responsive, and relevant care.</p>

	<p>provide opportunistic carer education (particularly seizure medication). Neuropsychological assessment with a particular focus on managing difficult patient behaviours. Respite to reduce care burden with additional support such as seizure first aid.</p> <p>Psychological needs: Maintaining hope, methods of coping, the importance of relationships, information, supportive counselling, quality of survival, cognitive changes and associated sense of loss, emotional pain, dependency, and isolation, particularly for those struggling with cognitively impaired patients.</p> <p><u>Caregivers:</u> Without the presence of a key support, carers focused on practical tasks and activities to cope with grief and uncertainty. HCPs may decrease the strain on carers by providing information on formal and informal support systems, acknowledge the need to ask for assistance, symptom management and insight into neuro-cognitive and psychiatric changes.</p> <p>Social needs:</p> <p><u>Caregivers:</u> The rapidity of change forced the carer to renegotiate relationships and responsibilities while continuing to advocate for the patient.</p> <p>Spiritual/existential needs: Patients and families reported satisfaction with medical treatment but not with existential support which was often unaddressed or unacknowledged.</p> <p><u>Patients:</u> Were grateful for the opportunity to talk about death and felt the HCPs were afraid to broach the subject. The existential fears and 'death anxieties' were often hidden and not discussed. Obstacles that were seen to hamper staff responding to these needs were their lack of skill, time, and confidence.</p>		
Moore et al. 2014	<p>Physical needs: Issues related to oral health and rehabilitation, nutrition, dysphagia, difficulties in speech, or shoulder morbidity.</p> <p><u>Oral health related:</u> Primarily related to side-effects of RT and chemotherapy – pain, mucositis, xerostomia and eating difficulties. Concern or embarrassment with speech or eating. Issues with speech and oral pain at the end of treatment. Continued issues with chronic pain, xerostomia, taste, and speech 6 months post-treatment. Lack of teeth / dentures was related to worse QoL and weight loss.</p> <p>12 months post-treatment A lack of clinical or statistical improvement for the symptoms of xerostomia and taste dysfunction with chemoradiotherapy for advanced-stage disease (58%).</p> <p>1-2yrs post treatment Long term support with xerostomia, chewing, trismus and sticky saliva.</p> <p>1-5yrs post treatment A clinically significant deterioration in sticky saliva in patients who had received radiotherapy or as an adjunct to surgery.</p> <p>7-11yrs post treatment xerostomia.</p> <p><u>Dysphagia</u> Significant issues following RT. Most severe immediately following treatment with gradual improvement up to 12 months after treatment. Swallowing was among the most frequent concerns.</p> <p><u>Nutrition and Weight Loss:</u> 32% of patients were malnourished. A small number who received nutritional support from a dietician did not report malnutrition during treatment. Lower BMI was associated with depression and poor physical well-being at least 6 months post treatment (for advanced disease). PEG feeding associated with</p>	<p>Method not specifically reported.</p> <p>Support needs were interpreted by the author.</p>	<p>Several of the included studies had small sample sizes and a lack of statistical power limited the conclusions.</p> <p>The heterogeneity of outcome measures and study populations limited the comparability of findings.</p> <p>The findings include studies with heterogenous head and neck cancer samples, which assumes the broader population share the same support needs and QoL issues of those with oral cancers. Ambiguity exists in the literature relating to the definition of head and neck cancer and oral cancer, with the term 'head and neck cancer' often being used to refer to cancers of the oral cavity and oropharynx.</p> <p><i>Recommendations for future research:</i></p> <ol style="list-style-type: none"> (1) Sexuality and intimacy should be considered as an issue affecting QoL in future research in the light of the relationship of intimacy issues with depression, mood, and body image. (2) Future research is required to investigate the short- and long-term support needs of patients with oral cancer. (3) Exploration into ways the multidisciplinary team can better meet support needs in the local setting, especially related to oral health-related support needs.

	<p>limited chewing, swallowing, taste and worse overall QoL (8%). PEG interfered with family life, intimacy, social activities, and hobbies.</p> <p><u>Neck and shoulder morbidity:</u> was associated with depression and poorer physical and social functioning 1 year post treatment.</p> <p>Psychological/emotional needs: Wider social or emotional issues affecting QoL that had the potential to be improved with appropriate professional support.</p> <p><u>Depression, anxiety, and emotional distress:</u> 18% and 25% reported depression following treatment. Depression was associated with lower physical wellbeing, functional impairment, pain, disfigurement and worse QoL.</p> <p>18% had high levels of distress at diagnosis with 25% at follow-up (4.2 months post diagnosis). However, only 21% of patients were referred for psychological support. Worse QoL in patients who wanted psychological intervention but did not receive it.</p> <p><u>Appearance and body image:</u> Appearance and dissatisfaction with body image were more frequent in those with speech and eating concerns. This group reported greater interest in psychological support (34%) to address appearance related issues (than those without speech and eating concerns).</p> <p><u>Alcohol use:</u> Alcohol abuse 12months post treatment was associated with depressive symptoms. In a cross-sectional study 22% were classified as problem drinkers and reported worse QoL and more depressive symptoms.</p> <p>Practical needs:</p> <p><u>Financial support:</u> treatment resulted in reduced ability to work and significant decrease in household income. Poorer social and emotional functioning was associated with increased financial burden. For those unable to return to work or those who changed jobs, employment difficulties were associated with significantly worse QoL, relating to loss of appetite, social contacts, social eating, high anxiety, and oral dysfunction.</p> <p>Interpersonal/intimacy:</p> <p><u>Sexuality, intimacy, and relationships:</u> 1/3 of postal survey respondents reported substantial issues with sexuality and intimacy after cancer treatment. A further 1/3 refused to answer questions related to sexuality and intimacy. Patients over 65yrs had more problems with sexuality 5 years post treatment than younger patients. QoL was associated with high levels of marital satisfaction and stability.</p>		
Nicklin et al. 2019	<p>Health system/information needs: Current healthcare delivery did not meet their needs. Unsure how to discuss issues with physicians. Information they received was inadequate, as medical staff communicated solely with their parents. Need for comprehensive follow-up services.</p> <p><u>Caregivers:</u> Felt there was not enough support available for themselves or the survivor. The support declined as they moved further from treatment. Wanted parental support groups, survivorship education classes, parental health and self-care classes and practical support (financial assistance).</p> <p>Psychological/emotional needs: Most frequently reported were internalising problems and withdrawal. Worries about recurrence affecting survivors ability to plan for the future or feel engaged in life. A small number were diagnosed with psychotic</p>	Narrative Synthesis	<p>There were little data reported that specifically focused on the supportive care needs and/or unmet needs of AYA childhood brain tumour survivors. Equally none of the studies included in our review assessed the needs of the AYA survivor's caregiver.</p> <p>The quality of the evidence varied per study. The majority of the studies involve a cross-sectional design. This is problematic as adolescence is a period of rapid development and change. Views of mothers dominated the sample (little representation from fathers). Some survivors had been treated up to four decades ago and these results may not be related to current survivors.</p>

	<p>symptoms with medication having little effect. Although survivor mental health did not differ from the general population.</p> <p><u>Caregivers:</u> Parents were worried about survivors well-being, whether they would recover their existing social networks and about potential future issues such as ability to find a romantic partner or feared their forever dependent children may outlive them. Threat of relapse stopped parents planning future activities, whether their child would reach independence.</p> <p>Social needs: Reported in 34/56 articles. Experienced impaired social functioning (avoiding social situations), social isolation, difficulty re-integrating following treatment required isolation, physical issues like headaches, impaired fitness and cognitive function impacted their ability to participate in sports and hobbies. Valued social support groups and social activities with peers were valued more than information-based workshops and individual counselling.</p> <p><u>Caregivers:</u> Had difficulty maintaining their own social relationships as caring became their main priority.</p> <p>Spiritual needs: Experience poorer optimism, self-esteem, and vitality. However, they were not less resilient. Some saw themselves as “losers” for their deficits or felt others pitied them. Some survivors positively viewed their experience of surviving making them more mature and were trying to move beyond the illness.</p> <p>Physical/daily living needs: Reported in 6/56 articles. Experienced difficulty with reading, handling finances and managing medications. Rarely lived independently which led to frustration. More likely to face unemployment (rates from 8% to 70%) or challenges in keeping a job (due to fatigue, cognitive, social, and physical issues). Lower levels of vocational/career readiness. Higher likelihood of receiving disability benefits. They experience impaired general physical health – poor mobility, reduced bone density, hearing and/or vision issues, poor fitness, small stature, hair loss, weight issues and scars. Issues with appearance contributing to difficulty starting and maintaining peer relationships (worried they looked different). Endocrine deficiency and greater levels of fatigue.</p> <p>Interpersonal/intimacy needs: Survivors see themselves as less valuable partners. Likely to be sexually inactive (compared with other cancer groups) and less likely to have children compared to general population controls and other survivors. Were less concerned with fertility than other cancer types, as it was not a current issue but were anxious about facing it in the future. Desire to have children was significantly lower and fell pregnant less often than healthy peers.</p> <p><u>Caregivers:</u> For some their marriage suffered causing separation, strain from care duties and discrepancies regarding how best to care for their child. However, some became closer as a couple.</p> <p>Family related needs: Not reported</p> <p><u>Caregivers:</u> Increased responsibility assisting survivors in everyday tasks (cooking, finances, promoting hygiene) managing medications and education, arranging social contacts and support with hobbies. Some home-schooled so they could provide extra assistance/support. They had less time and energy to self-care or pursue their own</p>	<p><i>Recommendations for future research:</i></p> <ol style="list-style-type: none"> (1) Focus on collecting longitudinal data to examine if survivor and caregiver needs change as they progress into adulthood. (2) Additional studies in other countries to identify specific issues and needs that may be culturally tied or dependent upon differences in health and social care systems. (3) The extent to which unmet needs are related to tumour and treatment characteristics. (4) Studies are needed to describe the needs and unmet needs of both AYA childhood brain tumour survivors and their caregivers. (5) Descriptive studies to fully investigate survivor and caregiver expectations for supportive care and how these comply with current use of long-term follow-up care and supportive services. (6) The perspective of health professionals in regard to development and evaluation of effective interventions to support AYA survivors and their caregivers.
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	<p>careers. Parents worried about their relationship with the survivors siblings – anxious that they felt alone or got “the short end of the stick”.</p> <p>Cognitive needs: Reported in 28/56 articles. Seen as an invisible effect hence additional support may not be offered. Higher risk of cognitive issues than other cancer survivors – impaired memory affecting their ability to self-care, make friends and reach developmental and educational milestones. Attention deficits, lower IQ and mathematical skills, poor processing speeds, language and vocabulary issues, impaired motor skills and poor executive functioning (planning/organising, preservation, set sifting and flexibility). Survivors self-report less dysfunction compared to what their parents report and therefore may not pursue help or support. The education environment is not equipped to handle their needs. Require extra time for assessments, one-to-one support, extra encouragement. They want special considerations but also don’t want to be singled out among their peers.</p>		
<p>Paterson et al. 2015</p>	<p>Physical needs: Reported in 8/17 studies. Needs included urinary symptoms, hot flushes, enduring bowel symptoms, fatigue, weight gain and breast soreness. <u>Carers:</u> How to provide physical care to their husbands due to lack of information. <u>Healthcare professionals:</u> Perceptions of unmet needs of men affected by advanced prostate cancer include pain control and symptom management (due to limited time and resource in the clinical setting).</p> <p>Psychological/emotional needs: Reported in 9/17 studies. Anxiety (PSA results), fear (of the future and recurrence / spreading), anger, sadness, frustration, regrets (unresolved treatment regret more than 10yrs post diagnosis) and concerns about those close to them. Greater psychological need correlated with uncertainty of remission status, and lack of information about long term treatment effects. Men also experienced profound psychological/emotional need related to sexual function. <u>Healthcare professionals:</u> Limited time to discuss issues and provide the emotional support to help men cope with their fear of disease and progression.</p> <p>Family related needs: Reported in 7/17 studies. “loss of manhood” secondary to sexual dysfunction. <u>Carers:</u> Report inadequate emotional support to help adjust to the diagnosis. Lack of support from family/friends because of the patient’s reluctance for others to know about the diagnosis. Suppressing own emotions to protect husbands.</p> <p>Social needs: Reported in 2/17 studies. Urinary symptoms and fatigue impacted social / sport / daily activities. Sense of loneliness with no one to speak to about their illness.</p> <p>Interpersonal/intimacy needs: Reported in 11/17 studies. Sexual dysfunction affected relationships and was poorly explored in consultations. Older men were too embarrassed to admit they had a sexual need. Self-management needs for impotence and some men were reluctance to have sex in case semen contained cancer or it caused their PSA to rise. <u>Carers:</u> Partners needed support in how to discuss sexual changes with husband, who to contact for help and they were hindered by their reluctance / lack of confidence.</p>	<p>Narrative Synthesis</p>	<p>Wide heterogeneity across the studies. Lack of information on how needs change over time. All studies to date are cross-sectional and do not measure or control for comorbidities which may impact the level / type of unmet needs reported. Existing research relies on retrospective questionnaires and memory recall which may introduce bias and the real-life validity of the data presented is unknown. PRO’s should be used in routine clinical practice to enable effective communication, targeted interventions, symptom management, self-management and to facilitate discussion for those potentially embarrassing topics.</p> <p><i>Recommendations for future research:</i></p> <ol style="list-style-type: none"> (1) Development of evidence-based self-management guidelines. (2) Further exploration into spiritual, daily, social, and wider family needs.

	<p>Practical needs: Reported in 4/17 studies. How to get financial support and travel insurance, housekeeping, where to source continence resources, parking access, and the financial burden of living with a long-term disability (costs of treatments) and unemployment.</p> <p>Daily living needs: Reported in 5/17 studies. Related to treatment modality. Men on ADT, combination therapy or chemotherapy experienced greater need. Fatigue, hot flushes, sweating, weakness, and weight gain impacted daily activities.</p> <p>Spiritual needs: Reported in 4/17 studies. Fear of cancer spreading or returning. Men with advanced disease were worried about disease progression, prognosis, and end-of-life. Uncertainty about the future and possibility of death.</p> <p>Health system/information needs: Reported in 13/17 studies. Problems with provision of information, contradictory statements by staff, lack of information about test results, treatments and arrangement for treatments, continence management, the role of primary care, self-management, psychological care, support groups and complimentary medicine.</p> <p><u>Careers:</u> Written information on the condition. Information needs in relation to the care of the patient in all phases of the care pathway and how to deal with social and emotional implications of prostate cancer.</p> <p><u>Healthcare professionals:</u> Reported men had difficulty understanding and retaining information leaving them unprepared for negative effects of treatment. Men requested information about treatments, side effects and alternative therapies.</p> <p>Patient-clinician communication needs: Reported in 5/17 studies. Not enough time with the doctor in consultation and they focussed on physical aspects rather than psychological consequences of sexual dysfunction. Men needed more 'honest' information and self-management advice to cope with adverse effects. Lack of continuity in hospital follow-up appointments impacted rapport and men had difficulty disclosing problems with sexual dysfunction.</p>		
<p>Paterson et al. 2018</p>	<p>Physical needs: Reported in 7/8 studies. Included difficulties with urinary function, sexual function, and bowel problems. Patients found coping with stoma appliance frustrating and debilitating with a lack of information and education.</p> <p><u>Careers:</u> unknown supportive care need – patients depend on them for support and stoma plate attachment following surgery and into survivorship.</p> <p>Psychological/emotional needs: Reported in 7/8 studies. Patients experienced anxiety and depression before treatment and into survivorship. 33.3% patients reported feeling severely depressed but did not receive appropriate referral for care. Patients felt uncertainty about the future, fear of the cancer returning/spreading, frightened, sadness, guilt, distress, avoidance of future planning and concerns about those close to them.</p> <p>Family related needs: Reported in 5/8 studies. Patients worried about the burden of care and how it impacted loved ones.</p>	<p>Narrative synthesis.</p>	<p>Wide heterogeneity of studies included in the review and findings were constrained due to methodological limitations. The studies conducted to date have been cross-sectional. There is a strong need for consistent and clear communication and information between the healthcare provider and patient/caregiver. To overcome and address areas of unmet needs, literature supports the use of patient reported outcome measures (PROMs) in routine clinical practice.</p> <p><i>Recommendations for future research:</i></p> <p>(1) Exploration of how patients' needs change over the cancer care continuum and during times of disease recurrence and progression.</p> <p>(2) How potential complications based on a validated grading system, such as Clavien- Dindo classification, affect unmet supportive care needs.</p>

	<p>Carers: They felt unprepared with limited knowledge about the cancer and treatments and received limited guidance on how to support and care for the patients, which altered relationships.</p> <p>Social needs: Reported in 6/8 studies. Patients experienced a sense of loneliness, social isolation, and feelings of abandonment. Were unable to participate in usual social / sporting activities due to incontinence and associated unintentional stoma plate detachment. They had a constant fear of accidental leakage of their daily social activities.</p> <p>Interpersonal/intimacy needs: Reported in 8/8 studies. Sexual dysfunction affected emotional outcome. There was reduced sexual satisfaction due to loss of sensation and disintegration of marital relationships. Sexuality needs were poorly explored in consultations, if explored at all.</p> <p>Practical/daily living needs: Reported in 4/8 studies. Patients spoke about difficulties returning to work, inability to perform normal daily activities and the financial burden of long-term disability, unemployment, treatment, stoma supplies and insurance. Patients were also unaware of where to source stoma supplies.</p> <p>Health system/clinician-patient communication needs: Reported in 5/8 and 4/8 studies, respectively. Needs identified at diagnosis, post-treatment and into survivorship. There was lack of understanding about treatment options and consequence of treatments. Patients reported the focus of consultations was on physical aspects and cancer surveillance rather than psychological and sexual dysfunction. No opportunity to discuss changes in body function, sexuality/body image during consultations. There was a lack of training and support in continence and diversion appliance management.</p>		<p>(3) Greater attention should be focused on the side-effects that patients are embarrassed or reticent to discuss, perhaps due to the stigma associated with them.</p>
<p>Paterson et al. 2020</p>	<p>Interpersonal/intimacy: Reported in 16/17 studies. Participants (both single and married) shared anxieties and concerns about sexual performance. Married men expressed long-term concerns about satisfying their partner and single men avoided relationships out of fear of ridicule and rejection. Experienced sexual distress related to sexual interest, quality of erections, early ejaculation, dyspareunia. Men felt deprived of a sex life and sexual urges after total penectomy contributed to a disconnect between the sensory and physical self. Little or no support was provided in care delivery.</p> <p>Psychological/emotional: Reported in 14/17 studies. Men articulated concerns related to disclosure of diagnosis to family and friends due to feelings of embarrassment. Difficulties coping with fear of dying, lack of sexual pleasure, mutilation and altered perceptions of masculinity. Experienced panic attacks, social phobias, major depression related to complete sexual dysfunction, post-traumatic stress and subsequent alcohol abuse, and suicidality. Severe mood swings impacted relationships with partners. Expressed a need for psychosocial intervention but did not receive help or necessary referrals.</p> <p>Physical needs: Discomfort and difficulties urinating, problems with sleep, reduced physical strength, mobility limitations, genital pain, exhaustion, altered penile</p>	<p>Narrative synthesis.</p>	<p>Included studies did not necessarily have the primary objective of assessing unmet needs – may have introduced bias. There is a profound negative psychological impact and lack of support provided in care provision. Routine use of PRO Holistic Need Assessments are needed to trigger timely psychological referrals and follow up with psychologists trained in sex therapy in prehabilitation phase to help patients and partners discuss feelings around intimacy and sexual well-being.</p> <p><i>Recommendations for future research:</i></p> <ol style="list-style-type: none"> (1) Examine predictor variables such as education, socio-economic status, employment, and clinical variables across various coping strategies to help stratify those at risk of distress. (2) Further exploration of the needs and preferences for support from the partners' perspective. (3) Develop and evaluate pre-surgical interventions and patient counselling to foster realistic expectations for the couple about recovery and QoL

	<p>appearance and sensation, bleeding, penile swelling and itching, sexual dysfunction, lymphoedema concerns and post-surgical infections.</p> <p>Family related needs: Reported in 7/17 studies. Concerns regarding younger men and implications for having children, difficulties maintaining their role as husband, lover, and father. There was communication break down and marital crisis after treatment. Men viewed support from wives as an important factor coping with the impact of surgery.</p> <p>Health system/information needs: Reported in 7/17 studies. Men felt poorly informed in relation to the consequence of treatment on QoL and sexuality. There was a general lack of information along the cancer trajectory. A perceived lack of doctor's knowledge with some men misdiagnosed for many months. Care pathways were fragmented with little or no access to supportive care of rehabilitation. Would have benefited from psychology services within their healthcare system but were never offered. There is a need to raise the public profile of awareness of the early signs and symptoms – some men delayed seeking treatment due to lack of knowledge and feelings of embarrassment.</p> <p>Social Needs: Reported in 5/17 studies. Men experienced low confidence and struggled to interact in social circles. Altered body image prevented participation in social activities (avoided wearing shorts due to concern the public would see they have had a penectomy). Access to cubicles to urinate.</p> <p>Daily living needs: Reported in 3/17 studies. Restriction to daily activities due to urination challenges post-treatment. Public access to disabled toilets, inability to work and remain the 'breadwinner'.</p> <p>Patient-clinician information needs: Reported in 3/17 studies. Lack of self-management advice in relation to sexuality and new ways to urinate post treatment. Lack of person-centred care with lack of trust and compassion from their treating clinician. No access to specialist nurses at any stage of the cancer continuum.</p> <p>Spiritual needs: Reported in 3/17 studies. Diagnosis challenged men's manhood with multiple accounts of suicidal ideation. Experienced shock, disbelief, and fear. Several men expressed losing faith.</p> <p>Practical needs: Reported in 2/17 studies. Needs related to mobility and urination. Aids (funnels) and self-management (sitting to urinate in a cubicle) was important to reduce spraying and dribbling of urine down the leg.</p> <p>Cognitive needs: Was not reported in included studies.</p> <p>Partners: Reported in 2/17 studies. All partnered relationships were affected by sexual dissatisfaction. Partners reported risk of anxiety at the time of their partners diagnosis and 12 months later. Cancer affected the dyadic processes of communication and adjustment. Partners expressed a need to share their own perspectives and experiences related to penile cancer.</p>		<p>(4) Develop and evaluate pre-surgical interventions and patient counselling to foster realistic expectations for the couple about recovery and the impact on broader aspects of quality of life. Currently there is no penile cancer QoL</p> <p>(5) There is currently no penile cancer specific QoL instrument with demonstrated reliability and validity. Therefore, future research should focus on developing an instrument for research and clinical use in practice.</p>
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<p>Paterson et al. 2021</p>	<p>Physical needs: Reported in 19/27 studies. Hair loss resulted in decreased physical wellbeing and was most confronting (for men and women) when they experienced clumps of hair on their pillow or lost handfuls during washing. Scalp soreness/pain, skin irritation, dryness inside the nose, eye irritation and risk of debris entering due to lack of lashes. Pruritis with re-growth of lashes. Wearing a wig was a burden and trying multiple wigs on led to exhaustion.</p> <p>Psychological needs: Reported in 25/27 studies. Hair loss ranked second and third most distressing symptom in women and men, respectively. Younger men had as much difficulty adjusting to hair loss and other's reactions, as women did. Some women expressed it was more difficult than losing their breast. CIA was a psychological acknowledgement that they were unwell. CIA invoked shame, guilt, reduced self-esteem, uncertainty, stress, hopelessness, anxiety, depression, and loss of control. The difficulties continued even following hair re-growth. Scalp cooling improved QoL domain scores in some women.</p> <p><u>Children:</u> Expressed distress at observing side-effects and seeing their mothers lose their hair.</p> <p>Cognitive needs: Reported in 5/27 studies. Expressed needs around madarosis and hypervigilant hair care behaviours. Some found CIA beneficial as they perceived that the chemotherapy was working.</p> <p>Patient-clinician communication needs: Reported in 6/27 studies. Expressed a lack of preparedness and information about how to self-manage CIA. Wanted self-care strategies, such as information on scalp cooling and how it worked. Would have liked information to provide their hairdressers about hair care.</p> <p><u>Children:</u> Felt excluded from the consultations and wanted more information about cancer and therapy regimes.</p> <p>Health system needs: Reported in 9/27 studies. Wanted more information about how to self-manage hair loss, how and where to source correct fitting wigs and headwear. Wanted information available to help them to plan how to conceal hair loss before it happened. Expressed disappointment that scalp cooling was not offered and they felt unprepared to approach the difficult conversation regarding CIA with their children.</p> <p>Spiritual needs: Reported in 2/27 studies. Some conceptualised their baldness with illness and the hair re-growth representing hope and renewed life. Others used spirituality to cope with feelings of hopelessness.</p> <p>Daily living needs: Reported in 7/27 studies. CIA impacted daily activities (in the community and workplace), unable to go out in public. Almost all used camouflage strategies (wigs, scarves) but this came with an economic burden for purchasing and upkeep.</p> <p>Interpersonal/intimacy needs: Reported in 11/27 studies. Hair was part of identity and sexuality. A small number feared rejection from their partner. Women felt a lack of connection with their appearance and were worried it would alter their identity. They did not speak of hair loss below their eyes.</p>	<p>Narrative Synthesis.</p>	<p>Lack of research focussing on men affected by CIA in comparison with women. A challenge of the review was combining heterogenous methodologies with findings constrained due to methodological limitations. Articles included limit the understanding of potential global, cultural, and societal differences.</p> <p><i>Recommendations for future research:</i></p> <p>(1) A focus on the supportive care needs of men affected by CIA and explore potential differences in demographic and clinical factors.</p>
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	<p>Men expressed concerns that they looked less masculine and felt vulnerable. They commented of hair loss from other areas of their body linked to their masculinity with young men finding it difficult to start a new relationship.</p> <p>Practical needs: Reported in 10/27 studies. Related to the need to conceal their hair loss via wigs, scarves, and hats. Women used eyebrow pencils, eyeliners, and eye shadows to cover patchy hair loss, but they were dissatisfied with the result. Expressed importance in taking time to choose their wig.</p> <p>Family related needs: Reported in 12/27 studies. Worried about how CIA would affect loved ones. Expressed the need to wear the wig at home due to fear of that their children may be teased by friends. Relied on support from family but found support groups helpful to discuss feelings they felt unable to share at home.</p> <p><i>Partners:</i> Reported it was more difficult for them to cope with impact of cancer and treatments that for the women themselves</p> <p><i>Children:</i> Distressed seeing their mothers wearing a wig as it no longer looked like their mother.</p> <p>Social needs: Reported in 9/27 studies. Reduced social function was associated with CIA distress. Men and women voiced worries about being perceived as aggressive (being labelled a skin head). The social impact of CIA forced them to confront that they had cancer. Experienced decreased ability to communicate with others, stayed home to avoid sympathy from others. CIA prevented them from enjoying a social life.</p>		
<p>Paterson et al. 2021</p>	<p>Psychological/emotional needs Psychological or emotional needs were the most reported domain of need. The second most common emotional need included feelings of depression, sadness, dread, and post-traumatic stress symptoms.</p> <p>Physical needs Pain was the most identified distressing physical need followed by fatigue and sleep disturbances. These needs were identified across studies that included people with both localized and metastatic kidney cancer; however, it was unclear whether these physical consequences were attributed to the cancer, treatment, or some other cause, such as existing comorbidity. Additionally, distress related to the side effects of treatment and changes in their physical appearance was common in patients affected by metastatic kidney cancer.</p> <p>Social needs Three studies reported a decrease in social functioning.</p> <p>Interpersonal/intimacy needs The evidence identified unmet needs related to intimacy, relationships, and sex. A loss of intimacy and a feeling of estrangement from loved ones were also highlighted as problematic, which were not explored with them during clinical consultations.</p> <p>Patient-clinician communication needs</p>	<p>Narrative synthesis</p>	<p>Future research designs might adopt a qualitative methodology to provide “voice” to people affected by kidney cancer as an important consideration moving forward. Furthermore, most of the study designs were cross-sectional in nature and only provided a snapshot of the unmet supportive care needs experienced and provided little insight into how needs change over the cancer care continuum.</p>

	<p>Evidence identified a discrepancy between the needs and preferences of the actual communication and information provided to patients and their caregivers before and after surgery and what they wanted and needed from their clinical care teams.</p> <p>Family-related needs Worries about how the patient’s family would cope were considered by those living with kidney cancer and caused high distress.</p> <p>Health system/information needs Some people were not provided with the care coordination to understand their treatment options, and other people experienced a lack of signposting to community resources which caused distress for some participants.</p> <p>Spiritual needs Spirituality was identified as both an unmet need as well as a coping strategy.</p> <p>Daily living needs People affected by metastatic kidney cancer often found walking/climbing stairs and eat/ chewing/swallowing difficulties to cause high distress.</p> <p>Practical needs Practical problems that were identified as causing high distress included finances, transportation, and needing help coordinating care.</p> <p>Cognitive needs Only one publication discussed cognitive needs of people affected by kidney cancer.</p>		
<p>Puts et al. 2012</p>	<p>Needs were highest at diagnosis and the start of treatment and decreased over time. Across different time points, most needs related to the relationship with healthcare professionals followed by information and support networks. The needs varied for the different critical points, and by age group, gender, tumour type, health status, and socioeconomic status. Despite reporting a need, not all patients wanted help with that need from a healthcare professional.</p> <p>Health system /information needs: Longitudinal studies showed before treatment, 50%–90% of the sample had concerns about the information received about treatment, as well as about lifestyle and social functioning at diagnosis. But pre- and posttreatment, between 10% and 60% had not received that information, and post-treatment, between 20% and 60% wanted additional information about treatment, lifestyle, and social functioning. Information needs during and after completion of chemotherapy did not change. At 3 and 6 months after discharge, information support needs decreased or remained stable.</p> <p>Psychological / emotional needs: For those undergoing chemotherapy the most prevalent needs were concerns about disease spread and recovery; during</p>	<p>Not reported.</p>	<p>Some of the included studies used researcher designed measurement tools and reliability and validity was not always clear. Several used questionnaires that were not designed to measure supportive care (using depression and distress measures which may have influenced the high prevalence of psychological needs. Authors excluded studies if they did not explicitly state older adults were diagnosed and receiving active treatments, so data may have been missed. Some of the studies were quite old and therefore treatments may be outdated, which could impact the type and severity of need. Only one paper focussed on older adults alone, the rest were mixed populations.</p> <p><i>Recommendations for future research:</i></p> <p>(1) Measurement tools to measure needs as well as predictors should be carefully considered.</p> <p>(2) Further research to examine the influence of comorbid conditions in older adults diagnosed with cancer on the level of unmet needs.</p>

	<p>chemotherapy, it was concern about the side-effects of chemotherapy; and after completion, the most prevalent concern was about disease recurrence.</p> <p>At 1-month post-diagnosis the most reported unmet needs were concerns about the worries of those closest to you (40%) and fears about cancer spreading (35%). Head and neck patient sample showed that at diagnosis and at first follow-up visit, 18% and 25% were distressed with only 7% reporting persistent distress</p> <p>Physical / daily living needs: At 3-months post-diagnosis needs were higher in this domain for lack of energy and tiredness (31 %) and not sleeping well (26 %). 3-months post-discharge physical needs increased.</p> <p>Interpersonal / intimacy needs: In men with prostate cancer, it was shown that common needs were health related to sexual function, especially in younger men.</p>		<p>(3) Future studies should provide more information on the participants and nonparticipants, report response rates, reasons for refusal, and the type and amount of missing data, and how the missing data was dealt with in the statistical analysis.</p> <p>(4) More research focussing on the needs of older adults specifically, as well as the impact that comorbid conditions have on the level of unmet needs.</p>
Wang et al. 2018	<p>Health system/information needs: <u>Patients:</u> Most common need in quantitative studies included being informed about the benefits of treatment. Insufficient information from professional staff. Not being regarded as a person. <u>Caregivers:</u> Prevalence of illness and treatment information was 26%-100% and in care-related information it was 21%-100%. Information needs for disease, treatment, side effects, care services, symptom management, nutrition, medication, and nursing aids.</p> <p>Psychological needs: <u>Patients:</u> Most common need in quantitative studies was the need for emotional support. Feelings of sadness, anger, anxiety, frustration, and desperation. <u>Caregivers:</u> Prevalence of 17%-78.3%. Feelings of sadness and loneliness, sense of abandonment, fear and helplessness or insufficient listening and encouragement from other family members and professionals.</p> <p>Physical needs: <u>Patients:</u> Most common need in quantitative studies was fatigue. Pain, fatigue, or side effects of treatment, such as urinary incontinence and loss of sexual function. <u>Caregivers:</u> Prevalence of 42.8%. Managing concerns about the cancer coming back (78.3%).</p> <p>ADL needs: <u>Patients:</u> Most common need in quantitative studies was not being able to do the things they used to do. <u>Caregivers:</u> Practical assistance such as cleaning the house and walking the dog.</p> <p>Patient care and support needs: <u>Patients:</u> Two most common needs in quantitative studies were reassurance by medical staff that the way you feel is normal, doctor acknowledges and shows sensitivity to their feelings and emotional needs. <u>Caregivers:</u> Not reported.</p> <p>Sexual needs: <u>Patients:</u> Not described.</p>	Content analysis (to identify unmet needs). Descriptive analysis (to synthesise other outcomes).	<p>Heterogeneity of included studies, which were conducted within different cultural contexts, healthcare systems, and economic levels may impact level and type of unmet need. Different methods of needs classifications were used within the studies and approaches to defining unmet needs were inconsistent.</p> <p>Needs assessments used in several studies were inappropriate and may not be relatable to those with advanced cancer.</p> <p><i>Recommendations for future research:</i></p> <p>(1) More longitudinal studies with rigorous research designs adopted to explore unmet needs per patient variables unmet needs (gender, marital status, educational level, cancer site, and depression).</p> <p>(2) More studies to focus on caregiver variables (such as whether caregivers' health outcomes were associated with the unmet needs of patients).</p> <p>(3) Care needs comprehensively evaluated from all stakeholders (patients, caregivers and healthcare providers) to help develop evidence-based and tailored interventions.</p>

	<p><u>Caregivers:</u> Not reported.</p> <p>Social needs: <u>Patients:</u> Most common in quantitative studies included the need for family and friend support. Need more social security. <u>Caregivers:</u> Prevalence of 42.9%-71.4%. Lack of social life (71.4%). Feelings of isolation due to the lack of social activities.</p> <p>Communication needs: <u>Patients:</u> Not described. <u>Caregivers:</u> Not reported.</p> <p>Financial needs: <u>Patients:</u> Not described. <u>Caregivers:</u> Prevalence of 17%-67.3%. Finding out about financial support and government benefits for them and the person with cancer (60.9%).</p> <p>Spiritual needs: <u>Patients:</u> Most common need in quantitative studies included meaning of death. Feelings of fear, hopelessness, and uncertainty about the future. <u>Caregivers:</u> Prevalence of 3.8%-100%. Help to realise the persons wishes (100%).</p> <p>Autonomy needs: <u>Patients:</u> Doing less than before was the most prominent need in quantitative studies. Patients wanted to be proactive in problem solving but didn't know how to do it. <u>Caregivers:</u> Not reported.</p> <p>Nutritional needs: <u>Patients:</u> Not described. <u>Caregivers:</u> Not reported.</p> <p>Cancer care service needs (carers only): 21%-72.3% presented unmet needs in terms of quality of care and 14%-100% reported unmet needs in transitional care services.</p> <p>Variables: (only listed those consistently reported here) <u>Patients:</u> (1) Female patients indicated more physical and psychological unmet needs than those of male patients. (2) Those living alone experienced high psychological needs, and patients with high educational level presented considerable unmet needs in physical, ADL, information, community service, and sexuality domains. Moreover, financial needs were less reported in patients with high income. (3) Patients with symptom distress experienced more unmet needs in the psychological, physical, and ADL domains. (4) Poor ability in daily living indicated more unmet needs than those of independent patients, especially in terms of information, communication, psychological, and occupational needs.</p>		
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	<p>(4) Patients with anxiety experienced high levels of physical, psychological, healthcare, and information, as well as ADL unmet needs.</p> <p>(5) Patients with low QoL showed high unmet needs, especially in physical and psychological domains.</p> <p>(6) Patients reported more unmet needs when their caregivers were male, young people, or those who suffered from psychological distress.</p> <p><u>Caregivers:</u></p> <p>(1) Older caregivers showed less unmet needs in terms of financial, social, and care-related information.</p> <p>(2) Caregivers in different caregiving settings reported different levels of unmet needs (home > general hospital > hospice care unit).</p> <p>(3) Caregivers with many physical problems experienced many unmet needs.</p> <p>(4) Caregivers had higher levels of unmet needs when patients suffered from anxiety, depression, or low physical performance.</p>		
Wu et al. 2019	<p>Health system/information needs: 37% to 73% reported at least one unmet HSI need. Mean SCNS-SF34 scores ranged from 20.3 to 51.3/100 and mean CNQ-SF scores ranged from 40.4 to 67.9/100.</p> <p><u>Native Patients:</u> Desired one member of hospital staff to communicate all aspects of care and follow-up (37% to 72% of patients). Being informed about their test results as soon as feasible (47%– 86%). Information about recovery and self-management (19% – 84%).</p> <p><u>Immigrant patients:</u> Being adequately informed about the benefits and side effects of treatments (67%)</p> <p><u>Correlates:</u> Greater patient HSI needs and lower education, less time post-diagnosis and poorer outcomes.</p> <p>Caregivers: Information and healthcare needs were the highest scoring domain with SCNS-PC means of 40.7 to 48.0/100 and 31.9 to 49.1/100 respectively.</p> <p><u>Native Caregivers:</u> Accessing information about the patient's prognosis and likely outcome (65%– 84%). Accessing information on patients' likely physical needs (68% – 96%) and accessing information about treatment benefits and side effects to participate in decision-making (61%– 93%).</p> <p><u>Immigrant Caregivers:</u> Unmet needs relating to accurate and consistent information about cancer, as well as lack of disclosure of information by doctors to allow for future planning.</p> <p>Psychological needs:</p> <p><u>Native Patients:</u> Concerns that their results are beyond their control (12% – 73%).</p> <p><u>Immigrant Patients:</u> Support on how to cope with fear related to the illness (51%).</p> <p><u>Correlates:</u> Greater unmet needs being negatively associated with age, time post-diagnosis and overall quality of life.</p> <p><i>Caregivers:</i> SCNS-P&C mean scores ranged from 28.2 to 39.6/100.</p> <p>Physical and daily living needs:</p>	Narrative synthesis.	<p>Associations between domains of unmet need and patient-reported outcomes should be interpreted with caution due to inconsistent findings.</p> <p>Single centre recruitments may limit sample representativeness.</p> <p>Paucity of studies exploring unmet needs of immigrant caregivers.</p> <p>None of the individual studies directly compared native and immigrant groups.</p> <p>Search excluded those that did not speak Mandarin or Cantonese, which limits generalisability to Chinese communities speaking other dialects.</p> <p><i>Recommendations for future research:</i></p> <p>(1) Distinguish between individuals whose sexuality needs have actually been met versus those who are unwilling to disclose their unmet sexuality needs.</p> <p>(2) Consider including studies published in other languages.</p>

	<p>Native Patients: Not being able to do the things they used to do including physical and social activities (7% –44%).</p> <p>Immigrant Patients: experience difficulties fulfilling their responsibilities during treatment and recovery.</p> <p>Correlates: Associations were found between greater patient needs and patient physical function, physical distress, and total distress.</p> <p>Caregivers: Mean SCNS-P&C scores not reported.</p> <p>Patient care and support: reported in 4/22 studies. PCS mean scores from 14 studies using the SCNS-SF34 were 14.2 to 47.9/100.</p> <p>Native Patients: Hospital staff to attend promptly to their physical needs (21%– 79%).</p> <p>Immigrant Patients: lack of continuity and organized patient care.</p> <p>Correlates: Greater anxiety and poor physical function were associated with greater patient needs.</p> <p>Caregivers: Mean SCNS-P&C scores not reported.</p> <p>Sexual needs: 14/16 studies used the SCNS-SF34 and reported that sexual needs had the lowest mean scores ranging from 2.5 to 25.6/100.</p> <p>Native Patients: To be given information about sexual relationships (3% – 24%).</p> <p>Immigrant Patients: Not reported.</p> <p>Correlates: patients who were younger, more educated, more anxious, and distressed were more likely to have unmet sexual needs.</p> <p>Caregivers: Mean SCNS-P&C scores not reported.</p> <p>Social and interpersonal communication needs: prevalence was not reported.</p> <p>Native Patients: support from people close to them (one study 62%)</p> <p>Immigrant Patients: Need for social support</p> <p>Correlates: Greater anxiety was associated with greater patient communication needs.</p> <p>Caregivers: Overall SCNS-P&C means ranged from 26.90/100 to 31.82/100.</p> <p>Financial needs: Overall means were not reported.</p> <p>Native Patients: Monetary allowance for travel, treatment, and equipment expenses (25% -44%).</p> <p>Immigrant Patients: more information about available financial services.</p> <p>Correlates: Having health insurance and the type of health insurance impacted on financial needs.</p> <p>Caregivers: Overall SCNS-P&C means ranged from 32.35/100 to 37.25/100.</p> <p>For caregivers’ anxiety was associated with health services / information needs, psychological needs, patient care and support needs and social and interpersonal communication needs.</p>		
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