LEGGE, H., TOOHEY, K., KAVANAGH, P.S. and PATERSON, C. 2023. The unmet supportive care needs of people affected by cancer during the COVID-19 pandemic: an integrative review. *Journal of cancer survivorship* [online], 17(4), pages 1036-1056. Available from: https://doi.org/10.1007/s11764-022-01275-z

The unmet supportive care needs of people affected by cancer during the COVID-19 pandemic: an integrative review.

LEGGE, H., TOOHEY, K., KAVANAGH, P.S. and PATERSON, C.

2023

Journal of Cancer Survivorship (2023) 17:1036–1056
https://doi.org/10.1007/s11764-022-01275-z

REVIEW

The unmet supportive care needs of people affected by cancer during the COVID-19 pandemic: an integrative review

H. Legge[1,2] · K. Toohey[1,2] · P. S. Kavanagh[1,2,3] · C. Paterson[1,2,4,5]

Received: 20 June 2022 / Accepted: 7 October 2022 / Published online: 29 October 2022

Abstract

Purpose To critically synthesise evidence regarding the supportive care needs of those living with cancer during the COVID-19 pandemic.

Methods An integrative systematic review followed a pre-registered protocol, reported according to the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) Guidelines. We searched three databases (CINAHL, MEDLINE, and APA PsycINFO) using keywords and included all qualitative, quantitative, and mixed methods studies irrespective of research design published between December 2019 and February 2022. All articles were double screened according to a pre-determined eligibility criterion with reference lists of the final included studies checked for further studies. The review process was managed using Covidence systematic review software. Data from the studies were extracted, methodological quality appraisal conducted, and a narrative synthesis conducted.

Results Eighteen publications were included. The findings identified that individuals affected by cancer reported a range of physical, psychological, social, and health system unmet needs during the global pandemic. Unique to the pandemic itself, there was fear of the unknown of the longer-term impact that the pandemic would have on treatment outcomes, cancer care follow-up, and clinical service delays.

Conclusion Many individuals living with cancer experienced unmet needs and distress throughout the different waves of the COVID-19 pandemic, irrespective of cancer type, stage, and demographic factors.

Implications for Cancer Survivors We recommend clinicians use these findings to identify the individual person-centred needs to optimise recovery as we transition to the post-pandemic cancer care.

Keywords Supportive care · Cancer · Unmet needs · COVID-19 · Integrative review · Evidence synthesis

Introduction

Globally, cancer is a significant cause of mortality. In 2020, cancer caused ten million deaths, equating to nearly 1 in 6 people [1]. Many individuals affected by cancer require timely supportive care and rehabilitation in routine clinical service delivery [1]. In March 2020, the World Health Organization (WHO) declared COVID-19 as a global pandemic [2]. This pandemic has consumed peoples' existing way of life in every aspect, from lockdowns, mandated mask wearing, to transitioning new models of cancer care delivery [3], and adhering to ever changing social distancing requirements [4]. Cancer services had to manage burgeoning clinical service demand due to COVID-19 and adapt to adhere to constant changes in legislation, restrictions, and transition cancer service models of care to models of telehealth [5].

✉ C. Paterson
catherine.paterson@canberra.edu.au

[1] Faculty of Health, University of Canberra, Bruce, ACT, Australia

[2] Prehabilitation, Activity, Cancer, Exercise and Survivorship (PACES) Research Group, University of Canberra, Bruce, ACT 2601, Australia

[3] Justice and Society, University of South Australia, Adelaide, SA, Australia

[4] Robert Gordon University, Aberdeen, Scotland, UK

[5] Canberra Health Services, SYNERGY Nursing & Midwifery Research Centre | ACT Health Directorate, Level 3, Building 6, Canberra Hospital | GPO Box 825, Canberra, ACT 2601, Australia

Supportive care is defined as a person-centred holistic approach to the provision of cancer services for those living with or affected by cancer [3, 6]. This holistic lens to care encompasses the informational, social, psychological, spiritual, and physical needs during diagnosis, treatment, or follow-up phases, including issues of health promotion and prevention, survivorship, palliation, and bereavement [7]. An existing suite of systematic reviews have already identified the unmet supportive care needs in a variety of cancer groups [7–12] prior to the COVID-19 pandemic underscoring a range of unmet supportive care needs for people affected by cancer. Noteworthy, one recent systematic review [12] excluded patients reporting unmet supportive care needs during the COVID-19 pandemic because this was beyond the scope of their review. Therefore, evidence is yet to be pooled and critically synthesised to enable health care professionals and researchers to comprehensively understand the impacts of COVID-19 on supportive care experiences among people affected by cancer [3]. Gaining new insights about the supportive care needs experienced during the COVID-19 pandemic will not only inform transitions of care moving into the endemic but may highlight helpful knowledge insights which could be applied to learnings in the preparation for future pandemics within cancer health care systems and care needs.

An interruption or change to the accessibility of cancer screening, diagnostic, and treatment services has a significantly negative impact on the outcomes of cancer treatment for patients [13]. It has been suggested that addressing supportive care needs is the foundation of a successful intervention because of its positive influence on quality of life and psychosocial outcomes [6, 7, 10]. Therefore, the purpose of this systematic review was to critically synthesise evidence related to supportive care needs of those affected by cancer during the COVID-19 pandemic and address the research question: "What are the unmet supportive care needs among people diagnosed with cancer during the COVID-19 pandemic?".

Methods

This integrative systematic review [14] is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRIMSA) guidelines [15]. We pre-registered the integrative review protocol on the National Institute for Health Research PROSPERO – International Prospective Register of systematic reviews with the review available from: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=313525.

Pre-selection eligibility criteria

Types of studies

All qualitative, quantitative, and mixed methods studies irrespective of research design which identified supportive care needs among people affected by cancer during the COVID-19 pandemic. The WHO declared the first case of the Novel Coronavirus on the 31st December 2019 [16] and later declared COVID-19 as pandemic on the 11th March 2020 [2]. Therefore, the database search was limited to December 2019 to February 2022 to capture all studies related to the research question. All commentaries, editorials, and studies where supportive care needs were not reported and published in non-English language were excluded.

Types of participants

All participants affected by cancer irrespective of age, gender, cancer type, stage, or treatment and their family members and caregivers were included.

Types of outcome measures

The primary outcome of this review was related to unmet supportive care needs (e.g. the Supportive Care Needs Survey [17]) and qualitative experiences, informed by the definition of supportive care [7] explicitly reported in relation to the COVID-19 pandemic (see Table 1).

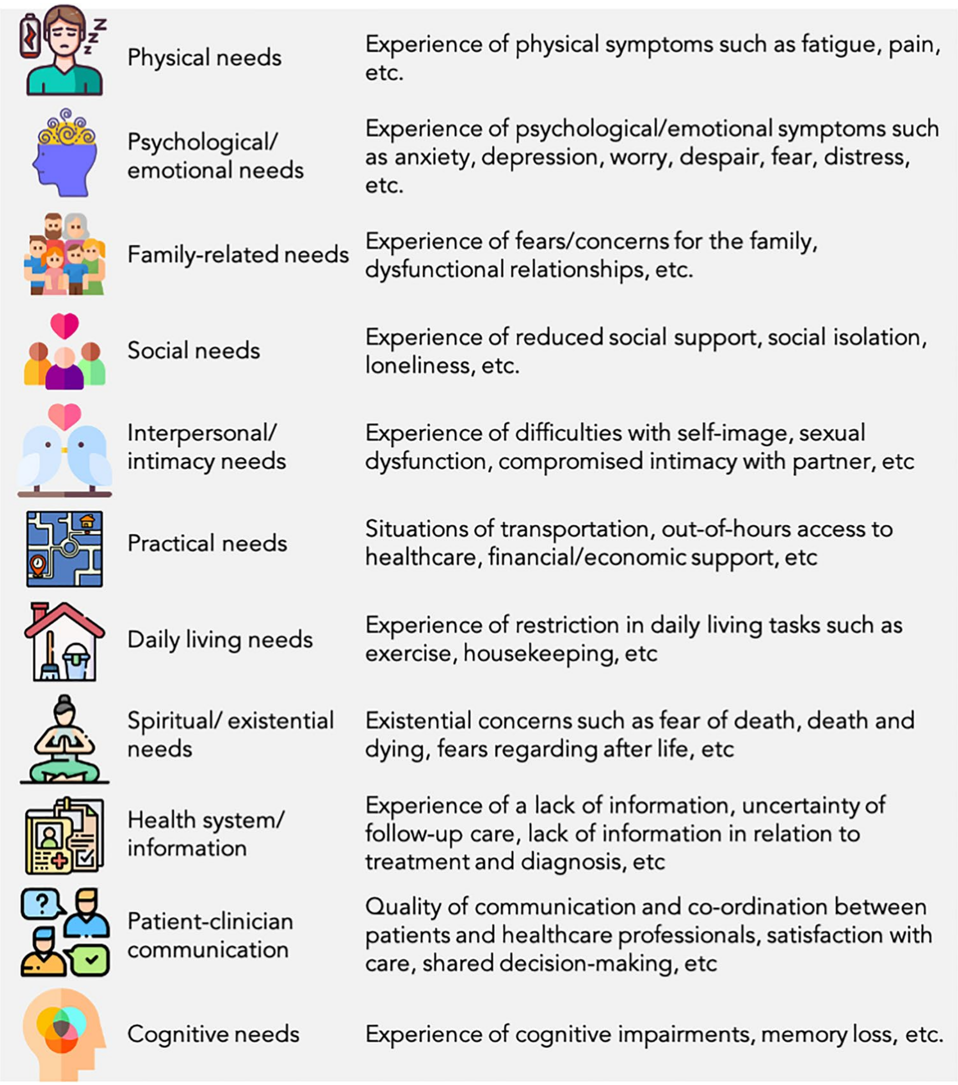
Literature search

We searched MEDLINE, CINAHL, and PsychINFO using a wide range of keywords and free text items to increase the sensitivity and inclusiveness (see Supplementary Table 1). The electronic searches began on 24th February 2022 and concluded on 25th February 2022. All records were managed using the software package Endnote X20 and uploaded to Covidence systematic review software with duplicate records were removed and pre-selection eligibility criterion applied to all records.

Study selection

Two authors (HL, CP) independently reviewed the publications (titles and abstracts) applying the eligibility criteria. One author (HL) retrieved all full-text articles that met inclusion criteria and all authors independently screening the full-text articles with disagreements resolved through consensus discussion.

Table 1 Classification of supportive care needs



Physical needs	Experience of physical symptoms such as fatigue, pain, etc.
Psychological/ emotional needs	Experience of psychological/emotional symptoms such as anxiety, depression, worry, despair, fear, distress, etc.
Family-related needs	Experience of fears/concerns for the family, dysfunctional relationships, etc.
Social needs	Experience of reduced social support, social isolation, loneliness, etc.
Interpersonal/ intimacy needs	Experience of difficulties with self-image, sexual dysfunction, compromised intimacy with partner, etc
Practical needs	Situations of transportation, out-of-hours access to healthcare, financial/economic support, etc
Daily living needs	Experience of restriction in daily living tasks such as exercise, housekeeping, etc
Spiritual/ existential needs	Existential concerns such as fear of death, death and dying, fears regarding after life, etc
Health system/ information	Experience of a lack of information, uncertainty of follow-up care, lack of information in relation to treatment and diagnosis, etc
Patient-clinician communication	Quality of communication and co-ordination between patients and healthcare professionals, satisfaction with care, shared decision-making, etc
Cognitive needs	Experience of cognitive impairments, memory loss, etc.

Data extraction and management

Data extraction was performed on the retained full-text studies meeting the inclusion criteria. The data were extracted by one reviewer (HL) and independently quality checked by a second reviewer (CP and PK). The data extraction tables were developed and tested on a small sample of studies and then further refined through discussion among the reviewers. The first table of data extraction included information on the purpose, setting, country, sample size, participant characteristics, sampling used, response rate, attrition, design, time points, and data collection tools. The second data extraction table related to the supportive care needs outcome data according to the classification of supportive care needs.

Quality appraisal

The quality appraisal of all included studies was conducted by utilising the Mixed Methods Appraisal Tool (MMAT) [18]. The MMAT enabled quality appraisal of qualitative research, randomised controlled trials, quantitative descriptive studies, and mixed methods studies. There are seven questions for each category of study design, ranked as “Yes” (green), “Unclear” (yellow), or “No” (red). The quality appraisal enabled the research team to identify limitations and potential bias within each of the individual studies. No study was excluded based upon individual methodological quality appraisal scores to enable an understanding of the current state of the evidence base.

Data synthesis

This review completed tabulation of primary research studies and use of narrative synthesis to generate findings. The data synthesis process followed the integrated review methodology proposed by Whittemore and Knafl [14]. Data synthesis involved data reduction (subgroup classification by study design and 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).

Results

Of the 122 publications retrieved from the search, we removed 19 duplicates (see Fig. 1). In total, 33 papers were reviewed in full-text and 18 papers included. There were a range of study designs underscoring that this is a developing evidence base; studies included five qualitative, 12 quantitative, and one mixed methods study. Across the included studies, there was a range of methodological quality (see Table 2), with the methodological quality overall considered good across the included studies. Studies were conducted in a range of countries, including USA ($n=7$), Germany ($n=1$), UK ($n=3$), Ireland ($n=1$), Italy ($n=1$), Canada ($n=1$), Iran ($n=1$), Brazil ($n=1$), Turkey ($n=1$), and Australia ($n=1$). Sample size varied from 16 to 1529 participants, with a total sample size of 3924 represented in the systematic review. Cancer type varied throughout the studies (neurological: $n=2$; haematological: $n=3$; head and neck cancers: $n=4$; breast cancer: $n=2$; varied cancer types: $n=4$; and unreported cancer types: $n=3$). Population across the studies varied from children and families ($n=3$), adults ($n=8$), older adults ($n=5$), and unreported ($n=2$) (see Table 3).

Experiences of unmet supportive care needs

There were a range of unmet supportive care needs related to physical, psychological/emotional, cognitive, patient-clinician communication, health system/information, spiritual,

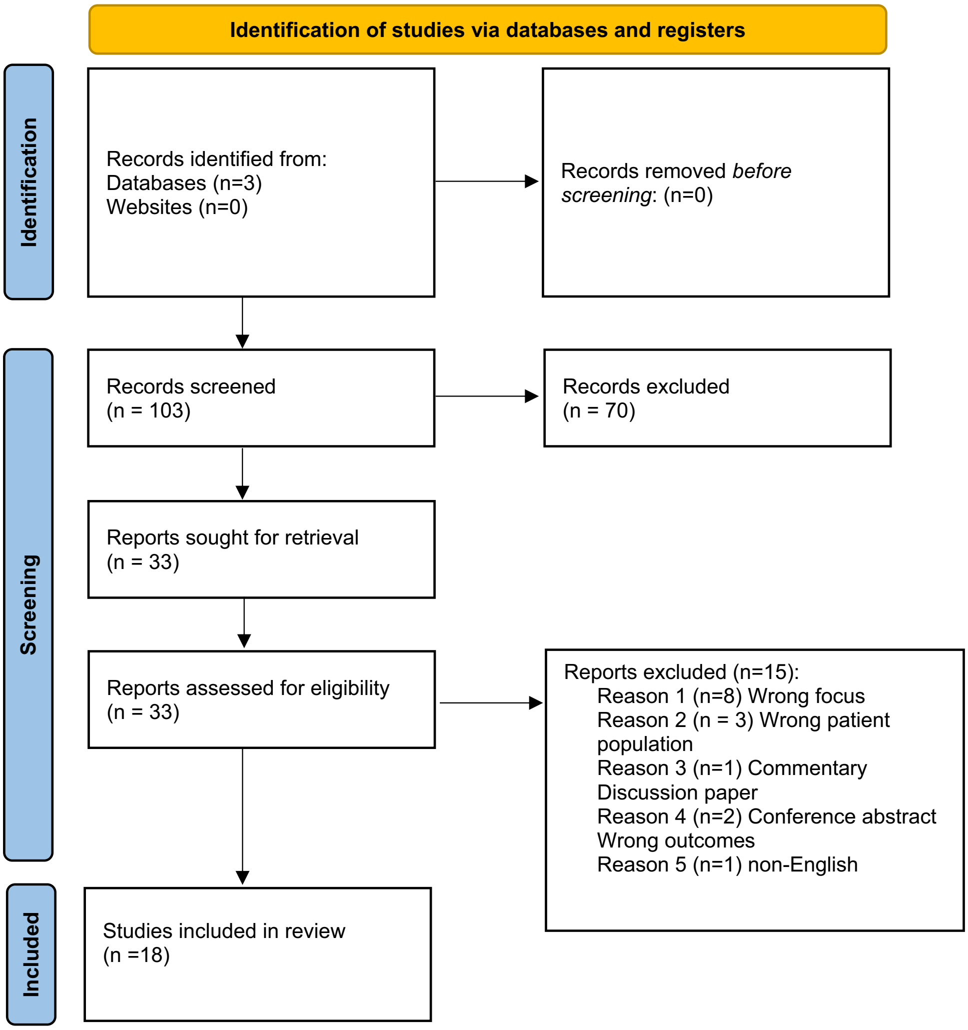
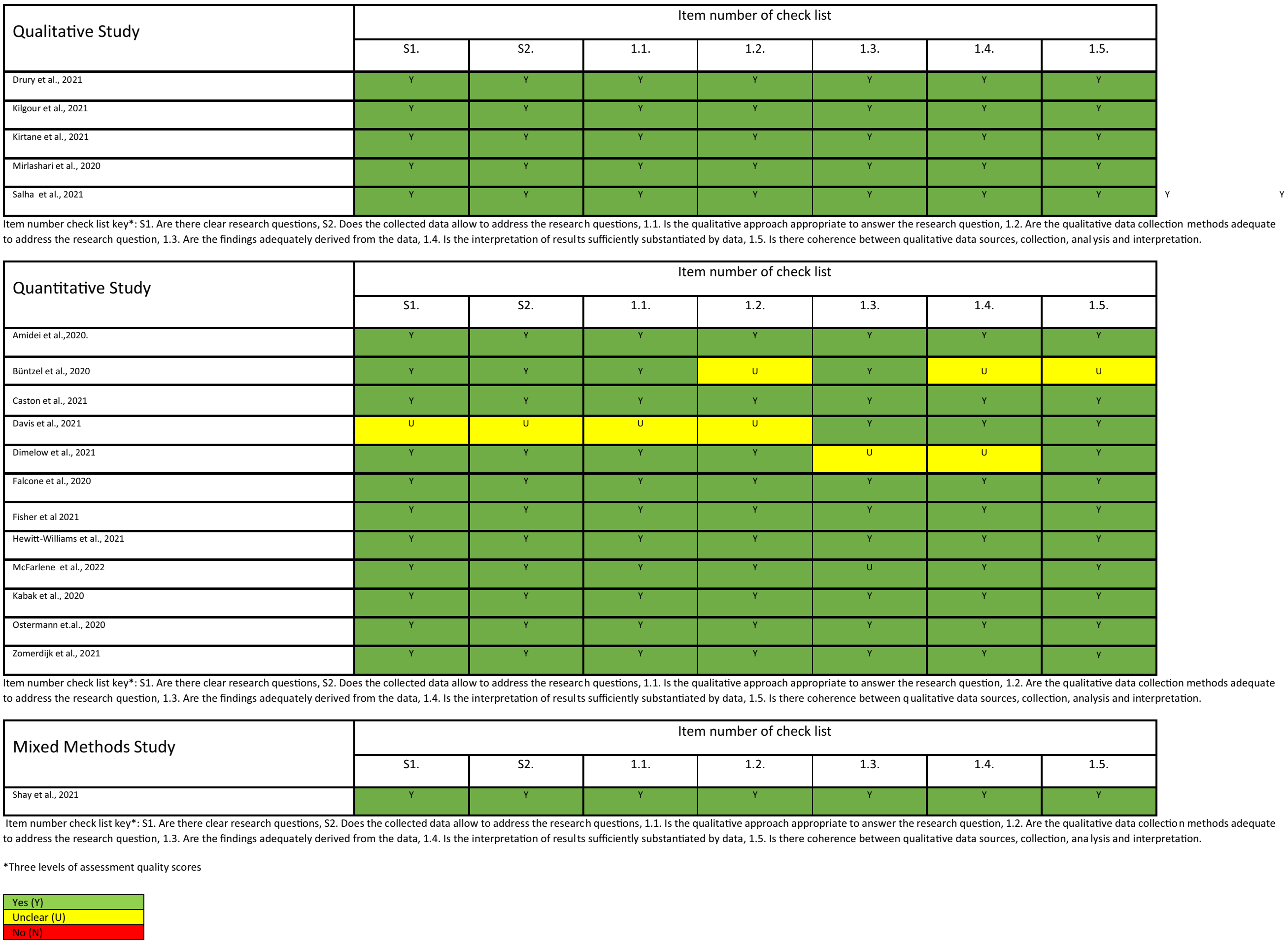


Fig. 1 PRSIMA diagram. From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. https://doi.org/10.1136/bmj.n71

Table 2 Quality assessment of included studies



Qualitative Study	Item number of check list								
	S1.	S2.	1.1.	1.2.	1.3.	1.4.	1.5.		
Drury et al., 2021	Y	Y	Y	Y	Y	Y	Y		
Kilgour et al., 2021	Y	Y	Y	Y	Y	Y	Y		
Kirtane et al., 2021	Y	Y	Y	Y	Y	Y	Y		
Mirlashari et al., 2020	Y	Y	Y	Y	Y	Y	Y		
Salha et al., 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y

Item number check list key*: S1. Are there clear research questions, S2. Does the collected data allow to address the research questions, 1.1. Is the qualitative approach appropriate to answer the research question, 1.2. Are the qualitative data collection methods adequate to address the research question, 1.3. Are the findings adequately derived from the data, 1.4. Is the interpretation of results sufficiently substantiated by data, 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation.

Quantitative Study	Item number of check list						
	S1.	S2.	1.1.	1.2.	1.3.	1.4.	1.5.
Amidei et al.,2020.	Y	Y	Y	Y	Y	Y	Y
Büntzel et al., 2020	Y	Y	Y	U	Y	U	U
Caston et al., 2021	Y	Y	Y	Y	Y	Y	Y
Davis et al., 2021	U	U	U	U	Y	Y	Y
Dimelow et al., 2021	Y	Y	Y	Y	U	U	Y
Falcone et al., 2020	Y	Y	Y	Y	Y	Y	Y
Fisher et al 2021	Y	Y	Y	Y	Y	Y	Y
Hewitt-Williams et al., 2021	Y	Y	Y	Y	Y	Y	Y
McFarlene et al., 2022	Y	Y	Y	Y	U	Y	Y
Kabak et al., 2020	Y	Y	Y	Y	Y	Y	Y
Ostermann et.al., 2020	Y	Y	Y	Y	Y	Y	Y
Zomerdijk et al., 2021	Y	Y	Y	Y	Y	Y	y

Item number check list key*: S1. Are there clear research questions, S2. Does the collected data allow to address the research questions, 1.1. Is the qualitative approach appropriate to answer the research question, 1.2. Are the qualitative data collection methods adequate to address the research question, 1.3. Are the findings adequately derived from the data, 1.4. Is the interpretation of results sufficiently substantiated by data, 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation.

Mixed Methods Study	Item number of check list						
	S1.	S2.	1.1.	1.2.	1.3.	1.4.	1.5.
Shay et al., 2021	Y	Y	Y	Y	Y	Y	Y

Item number check list key*: S1. Are there clear research questions, S2. Does the collected data allow to address the research questions, 1.1. Is the qualitative approach appropriate to answer the research question, 1.2. Are the qualitative data collection methods adequate to address the research question, 1.3. Are the findings adequately derived from the data, 1.4. Is the interpretation of results sufficiently substantiated by data, 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation.

*Three levels of assessment quality scores

🟩 Yes (Y)
🟨 Unclear (U)
🟥 No (N)

daily living, interpersonal/intimacy, practical, family, and social needs (see Tables 4 and 5 for an overview). Detailed information in relation to the unmet supportive care needs of the included studies is in Supplementary Tables 2 and 3.

Physical needs

The physical needs were commonly reported across the included studies as a well-being concern. Physical needs were well described in the palliative care cancer participants [19]. Common needs reported included fatigue, weakness, and mobility issues affecting physical functioning and activities of daily living because of restrictions during the COVID-19 pandemic [19–23]. People affected by cancer were socially isolated due to the implications of the COVID-19 pandemic. Many experienced exacerbations of additional onset of pain [19, 21, 24] because of a reduction to mobility which made accessing an already restricted health care service significantly more difficult. Furthermore, the negative effect of gastro-intestinal symptomatology of nausea, vomiting, poor appetite, a dry mouth, or constipation were also expressed [19] compounding the nutritional deficits experienced by those affected by cancer as a daily unmet need during the pandemic [21]. Lastly, participants noted that the COVID-19 pandemic negatively affected their physical well-being through disturbances to sleep, eating, and exercise [22].

Psychological needs

Many of the participants irrespective of age, cancer type, or treatment regimen expressed unmet needs related to psychological or emotional domains of well-being [19–21, 24–28]. The fear of contracting COVID-19 in people affected by cancer was further compounded due to their own recognition that they were at an increased risk of infection which led to anxiety and distress.

> It contributes to a little bit of anxiety because, you hear over and over and over, people that are in a higher risk category. And, you know, by you being diagnosed

Table 3 Overview of included studies

Author and year Country	Aim	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Amidei et al., 2020 Country: USA	To identify the impact of the coronavirus pandemic on brain tumour charities and not-for-profit organisations that support the brain tumour community	Different International Brain Tumour Organisations from around the world	$N=77$	Brain tumour organisations	Convenience	59%	NA	Categorical and qualitative survey	1	Questionnaires: An anonymous online 37 – question survey. Ran from May 6th 2020 to June 1st 2020 Responses were grouped into three categories, (1) Organisational characteristics (2) The impact of COVID-19 on services provided by brain tumour patient organisations (3) The impact of COVID-19 on financial and human resources for brain tumour patient organisations. Descriptive statistics were used to analyse categorical questions. Content thematic analysis was used to extract themes from the qualitative data obtained from the open-ended questions. Text responses were reviewed by 3 reviewers to assure themes were accurately captured
Büntzel et al., 2020 Country: Germany	To learn more about experiences of German patients affected by cancer during the pandemic	Germany Oncology Services System Südharz Hospital, Franziskus Hospital, University Hospital	$N=433$	The median age of our participants was between 50 and 60 years The cancer types most often reported were head and neck cancer ($n=92$) and breast cancer ($n=69$) 138 patients were still under treatment and 227 were survivors. Another 15 patients were in palliative situation. 53 have not reported their actual tumour status	Convenience	Not reported	NA	Categorical and qualitative survey	1	Questionnaires: 4 Anonymous Online Surveys were distributed to the Oncology Services across several German Hospitals to patients, physicians, other caregivers and psycho-oncologists and spiritual care givers. Between 16/04/2020 and 15/05/2020. Responses were split into Focus Groups based on the population Metric Data were only assessed concerning Federal State (physician, medical staff, patients, and psychologists), cancer entity (patients), and whether physicians, staff, psychologists were (1) mainly involved in care of in and or out-patients and (2) in contact with patients suffering from COVID-19 Scale questions were used to assess the impact and consequences of the German Measures of COVID-19 management for patients Simple or multiple-choice questions were used to determine the influence of COVID-19 on the treating physician's life Allegory of a thermometer was used for one question to capture the current emotional stress of the treating medical staff Free Answers: Psychologists/spiritual care givers had the possibility to add free answers for selected items

Table 3 (continued)

Author and year Country	Aim	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Caston et al., 2021 Country: USA	Evaluate the association between fear of COVID-19, mental health outcomes, and delays in care delivery for underserved patients with cancer during the pandemic	Nationwide Online survey distributed by Patient Advocate Foundation	$N=1529$	Breast, Gastro-intestinal, Genitourinary, Gynaecological, Haematology, Other Over 50% of population was aged between 56 and 75 Co-morbidities were self-reported 0- cancer only 1–2- + co-morbidity 3 + co-morbidity	Convenience	$N=1199$ 78%	1st survey: 1199 eligible responses 2nd survey: 448 (29%)	Observational longitudinal study	2 (1) 20th May–11th July 2020 (2) 2nd–23rd December	Surveys: were distributed via email to those who received PAF services from July 2019 to 2020; individuals received three reminder emails. Surveys contained questions that focused on individual experiences with COVID-19 and the psychological, emotional, physical, and material effects from the pandemic COVID-19 diagnosis was self-reported for either themselves, a household member, or both in either the first or second survey COVID-19 Specific Characteristics: perceived risk of COVID-19 was determined using the weekly average of COVID-19 cases per 100,000 for each respondent's county the week prior to survey submission Fear of COVID-19 Scale (FCV-19S): validated using the Hospital Anxiety and Depression Scale and the Perceived Vulnerability to Disease Scale Psychological Distress (outcome): determined using a four-item questionnaire by Holingue and colleagues assessing psychological symptoms for the past 7 days Delayed Care (outcome): question specific to whether care had been delayed or interrupted due to the COVID-19 pandemic. Answers were categorised into (1) patient election, (2) hospital or provider election, (3) income loss, (4) insurance loss, or (5) difficulty accessing medications or other medical care. Delayed care was dichotomised as any versus none for modelling
Davis et al., 2021 Country: USA	To explore oncology out-patients implementation of a standardised telephone outreach service during COVID-19	Comprehensive Cancer Care Centre (RHLCCC) of North-western Medicine	$N=63$	Over 50% of participants were aged 60–80 Cancer type unreported	Convenience	Not clearly reported	NA	Service evaluation	1	Patients with qualifying ICD-10 codes listed in their problem list or visit diagnosis were sent PROMs 72 h prior to an appointment in the cancer centre. Patients then completed the PROMs via personal computer, tablet, or smart phone. The assessment included depression, anxiety, fatigue, pain interference, and physical function, along with checklists of practical and psychosocial care needs. Patients receive the questionnaire no more frequently than once a month and can opt out

Table 3 (continued)

Author and year Country	Aim	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Dimelow et al., 2021 Country: UK	To explore perceptions of fear of cancer and fear of COVID-19 and to report patient preference for follow-up consultation in HNC survivors	Online survey	$N = 103$	Previously treated head and neck cancer patients were eligible 64 males, 39 females Largest number of participants were over 75 (36/103)	Convenience	56%	NA	Categorical and qualitative survey	1	Clinical information retrieved from the hospital patient record system was anonymised and categorised as age (< 55, 55–64, 65–74,75 or over), gender (male, female), clinical stage (early T1N0/T2N0, or late), site (oral, oropharyngeal, laryngeal, other), osteoradionecrosis (Y/N), surgery (Y/N), free flap (non, soft, composite), radiotherapy (Y/N), chemotherapy (Y/N), and time since primary diagnosis (< 12 months, 12–23, 24–59, 60 months, or more) A postal survey was undertaken in the 2 weeks post-consultation, including fear of recurrence
Drury et al., 2021 Country: Ireland	Explored experiences of cancer care in Ireland during the COVID-19 pandemic	Ireland during the COVID-19 pandemic	$N = 16$	Melanoma, breast, prostate, lung, colon cancers	Convenience sampling via social media	100%	Not reported	Longitudinal descriptive qualitative study	3 in total This paper refers to 1	Interviews: Interviews were guided by a semi-structured interview schedule exploring participants' perceptions of changes in the continuity of care, perceived risks/benefits of new methods of care delivery, information needs, and worries about cancer relating to COVID-19. Both surveys provided a 5-point Likert Scale response: 1.The national comprehensive Cancer Network Distress Thermometer (NCCN-DT): is a validated self-reported screening tool to measure psychosocial distress in cancer settings 2.The two item Connor-Davidson Resilience Scale (CD-RISC2): evaluates participants resilience via two items; (1) able to adapt to change and (2) tend to bounce back after illness or hardship All interviews were conducted by a single researcher. Interviews were conducted by telephone ($n = 15$) and Microsoft teams ($n = 1$) and were recorded and transcribed verbatim to assist with analysis. Field notes were recorded immediately after each interview to support analysis and research reflexivity After T1 interviews, all participants received a copy of their interview transcript and were provided with an opportunity to amend or clarify their responses prior to data analysis. To enhance the depth of analysis and validation of the study findings, participants will receive a summary of the thematic analysis of interviews conducted at the previous timepoint

Table 3 (continued)

Author and year Country	Aim	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Falcone et al., 2020 Country: Italy	To explore the outbreak's impact on their emotional well-being and quality of life	Endocrine Cancer Centre, Rome Italy	$N=137$	Males = 30 Females = 40 Mean age = 57 Papillary thyroid cancer = 40 Follicular thyroid cancer = 5 Poorly differentiated thyroid cancer = 5 Medullary thyroid cancer = 15 Anaplastic thyroid cancer = 1 Adrenal cancer = 3 NSCLC = 1	Convenience	Survey 1 $n=70$ (51%) Survey 2 $N=61$ (44.5%)	NA	Categorical and qualitative survey	1	COVID-19 Patient Impact Survey- 21 item questionnaire designed ad hoc by their team to explore and measure the emotional/overall impact of the rapidly escalating COVID-19 pandemic in Italy a.Included a 6 item Core Component designed to explore and quantify the outbreaks emotional impact on the cancer patients b.Mandatory responses c.Produced a COVID-19 Concern Score (0–12) Validated Italian Translation of the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire. Consisted of 30 items representing global health/ quality of life, five function subscales (physical, emotional, role, cognitive and social) Scored in accordance with EORTC QLQ-C30 scoring manual
Fisher et al. 2021 Country: USA	Examined pandemic on psychosocial functioning of adolescent and emerging adult survivors and their parents	Neuro-oncology survivor clinic	$N=122$	55 participating families 44 survivors 48 parents The sample of survivors was 55% male, 84.2% White, and on average 19.62 years old at the time of participation Parents were mostly mothers ($n=43$, 89.6%) and 45.8% had at least a bachelor's degree)	Convenience	55/122 45.1%	NA	Categorical and qualitative survey	1	1.Survivors completed the Environmental Influences on Child Health Outcomes COVID-19 child self-reported form which assessed pandemic impacts on their psychosocial functioning. Included their ability to received health care services and their social connectedness relative to before the pandemic. 20 item questionnaire measured how satisfied survivors were with their life before and during the pandemic and well as the perceive impact of COVID-19 on survivors 2.Parents completed the COVID-19 Exposure and Family Impact Survey which measured disruptions in families lives due to the COVID-19 pandemic via 25 yes/no questions. The questionnaire also assessed the impact of COVID-19 on family functioning, the caregiver's ability to parent and the parents' mental health, using a 4-point Likert scale Parents completed a demographic form, and the survivor's tumour and treatment characteristics were abstracted from chart review to generate their Neurological Predictive Scale (NPS) score

Table 3 (continued)

Author and year Country	Aim	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Hulbert-Williams et al., 2021 Country: UK	To investigate the impact on unmet needs and psychosocial well-being via measuring participants unmet supportive care needs, psychological distress, and quality of life	UK-based Maggie's Cancer Centres	$N=144$ $N=41$ (2019) $N=103$ (2020)	77% were female Included people with cancer and their support networks were recruited. The most prevalent diagnosis was breast cancer 41 were recruited pre-pandemic and 103 participants were recruited during the COVID-19 pandemic	Convenience	Unreported due to the nature of advertisement via social media	NA	Prospectively planned, cross-sectional study	2 1 pre-pandemic June/July 2019 2 during pandemic June/July 2020	Questionnaire hosted by JISC Online Surveys. Participants were recruited by an on-site researcher and via social media advertisements Patient unmet needs were assess using the short form of the Supportive Care Needs Survey, a 34-item Support Network unmet needs were assessed using the closely related Supportive Care Needs Survey, a 44-item measure of four domains of unmet needs Depression, Anxiety and Stress were assessed in both groups using the 21 item DASS Patients QOL was assessed using the Functional Assessment of Cancer Therapy- General: a 33-item assessment oh physical, social/ family, emotional, and functional cancer-related well-being over the previous 7-day period QOL in support network participants: Caregivers Oncology QOL questionnaire; 29 item measure indicates ten dimensions of QOL including psychological well-being; burden; relationship with health care; administration and finance; coping; physical well-being; self-esteem; leisure time; social support; and private life
Kilgour et al., 2021 Country: Canada	To understand the needs and experiences of older adult cancer survivors across COVID-19	Cancer Centre of South-eastern Ontario	$N=24$	Ages ranged from 63 to 83 years old with slightly more participants who identified as female ($n=14$) and male ($n=10$) All participants had been discharged from cancer care within the last 12 months and had been diagnosed with Breast($n=12$) or colorectal cancer ($n=12$)	Convenience	Survey 1 $n=24$. Survey 2 $n=18$ and Survey 3 $n=18$ 75% response rate	6	Longitudinal descriptive qualitative study	3 (1) July/August 2020, (2) January/February 2021, and (3) March 2021	Conducted individual, semi-structured qualitative interviews. Authors completed telephone interviews with participants at three time points during the pandemic. Interviews lasted approximately 45 min, were audio recorded and transcribed verbatim by a professional transcription agency During the third interview, an infographic of the preliminary study findings created with the assistance of plain language editors. The infographic was used to discuss the interpretation of results from the first two data collection time points and elicit further perspectives Interview questions touched on a range of topics, including cancer-related concerns, coping, health challenges, and changes to health care appointment delivery. In this article, they focus on the cancer and health service delivery-related data and findings

Table 3 (continued)

Author and year Country	Aim	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Kirtane et al., 2021 Country: USA	To characterise the lived experiences of LA-HNC patients and their health care providers during the COVID-19 pandemic	NCI-designated comprehensive cancer centre during the COVID-19 pandemic	$N=33$ 20 = patients and 13 = HNC providers	Average age was 60.6 years old Cancer diagnosis: Oropharynx = 14 Nasopharynx = 3 Oral cavity = 1 Supraglottic Larynx = 1 Ethmoid sinus tumour = 1	Convenience	Not reported	NA	Categorical and qualitative Survey	1	After providing verbal informed consent, patients participated in individual interviews via telephone or zoom that were audio recorded and averaged 75 min in length. Patients also self-reported their demographic and clinical characteristics via an online survey using REDCap. And clinical data were confirmed via electronic medical record review Semi-structured interviews were informed by an interpretive approach, aiming to understand patient and provider experiences, perspectives, and meaning-making processes. Guides included questions and exploratory probes about treatment experiences during the COVID-19 pandemic, which is the focus of tis paper Patient interviews were conducted by trained study coordinators who were unknown to participants. Coordinator training was led by a qualitative specialist and included conducting a pilot interview with one patient each
McFarlane et al., 2022 Country: UK	To describe the care of hospitalised cancer patients dying with COVID-19	Tertiary referral cancer centre	N = 34	Aged between 64 and 76 $N=16$ males and $n=18$ females Breast = 7 GI = 5 Gynaecological = 4 Head and neck = 4 Lymphoma = 1 Melanoma = 2 Other haematological = 5 Renal = 1 Thoracic = 6 Urology = 1 Other = 2	Convenience	Wave 1 (25th March 2020–1st May 2020) $n=19$ and Wave 2 (5th December 2020–1st March 2021) $n=15$	29 non-ventilated COVID-19 PR positive patients died during the defined period. 5 patients with strong suspicion for COVID-19 also died	Retrospective study using thematic analysis	2	Data was extracted from medication charts and electronic patient records by clinicians using a standardised proforma. Including patient demographics and risk factors for COVID-19 infection such as age and gender Data was also collected to describe the main domains of palliative and end of life care service provision: Identification of individual patient needs-described using the validated integrated palliative outcome scale (IPOS)-17 IPOS items scored 0–4 with higher scores representing increased severity of symptoms/concerns Management of pain and other symptoms: prescriptions for medicators across the four main end of life symptom domains of pain, anxiety, nausea, and respiratory secretions Communicator and decision-making: Documentation of advance care planning discussions, including evidence of anticipatory care planning such as treatment escalation plans and DNACPR orders were described Responsiveness of the palliative care team: referrals and reason for palliative care referral, number of times the patients was reviewed by the palliative care team, time from onset of COVID-19 symptoms to initial palliative care review and time from first palliative care review to death were described

Table 3 (continued)

Author and year Country	Aim	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Mirlashari et al., 2020 Country: Iran	To investigate the perspectives of children with cancer and their families in this era of the COVID-19 pandemic	Paediatric Hospital in Tehran, Iran	$N = 21$	4 female children 13 mothers,1 father and 3 paediatric oncology nurses ALL = 13 AML = 1 Ewing's Sarcoma = 1 Lymphoma = 1	Purposive sampling	100%	NA	Categorical and qualitative survey using thematic analysis	1	Telephone interviews were conducted on participants. The sampling continued until sufficient knowledge about the research questions was obtained. Data collection stopped when data saturation was reached The participants were selected based on the researcher's previous knowledge of families with children living with cancer. The objectives of the study were explained to each participant, and they were well informed that interview would be recorded. If they agreed, the meetings were then scheduled. Interviews were semi-structured, using interview guidance
Ostermann et al., 2020 Country: USA	To explore risk stratification in haematology/oncology patients during the COVID-19 pandemic	University of North Carolina health care system	$N = 286$ were called	Not reported	Convenience	245 = 86% successful reached via phone	NA	Cross-sectional	1	Risk Stratification: Patients were risk stratified using a general medical health composite score (HCS) and a cancer-specific risk (CSR) stratification based on disease and treatment characteristics. The correlation between HCS and CSR was measured using Spearman's correlation. It includes in-patient admissions and ER visits in the past year, active medications, unique providers seen in the past year, high-impact chronic conditions, uncontrolled chronic diseases, in-patient psychiatry admission in the past 5 years, age, insurance, and primary care provider status. Each component is weighted to provide a total score of 0–100, with patients categorised as low (0–8), moderate (9–20), or high risk (21–100) Outreach: A multi-disciplinary team developed a focused needs assessment script with recommended interventions for patients categorised as high-risk by either method. The number of patient needs identified and referrals for services made in the first month of outreach are reported. The template outlined interventions for identified needs, including referral to social work, palliative care, and the patient and family resource centre, which includes staff and volunteers to provide emotional support and direct patients to additional resources. It concluded with a summary of active issues, interventions made, and time frame for follow-up

Table 3 (continued)

Author and year Country	Aim	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Salha et al., 2021 Country: Brazil	Understand individual demands and experiences during the COVID-19 pandemic Guiding question: who are you in the COVID-19 pandemic?	Caregivers who are registered users of a centralised state drug supple service in Goiania, Goias, brazil	$N=42$	Female = 23 Male = 19 Majority aged 31–60	Convenience	Not reported	NA	Qualitative phenomenological study	1	The data collection instrument was created by the researchers in the form of a questionnaire and included a sociodemographic assessment with eight questions on the familial relationship with the user of the oncological drug, age, gender, education, religion, marital status, number of people living in the home, and family income, in addition to five semi-structured questions that addressed self-care (the practice of physical activity, type of activity, frequency of exercise, and place where exercise is practised), concerns (financial and emotional), perceptions (physical and emotional health), and attitudes (compliance with health rules and what care practices they perform) of informal caregivers in the face of the COVID-19 pandemic
Shay et al., 2021 Country: USA	Explored adolescent and young adult cancer survivor experiences during COVID-19	University of Texas health science centre	$N=39$ AYA's completed the survey and 24 AYAs also participated in the focus groups	Young adult cancer patients, survivors, and caregivers. All AYA were aged 18–39 with a history of a cancer diagnosis regardless of time from diagnosis or treatment status	Convenience	39 surveys 24 focus group	N/A	Categorical and qualitative survey with content analysis	2	Semi-structured focus group guide. The guide was used to assess the impact of COVID-19 in the early stages of the pandemic, how AYA's responded, issues related to cancer care and access and barriers and coping strategies and resources during the ongoing pandemic Descriptive statistics: were used to summarise sample characteristics and proportions impacted by specific factors related to COVID-19 Thematic analysis: to examine focus group data. Themes and categories are obtained from the data on the context of the pre-determined questions

Table 3 (continued)

Author and year Country	Aim	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Yildiz et al., 2020 Country: Turkey	To assess supportive care needs, compliance with home exercise program, quality of life level, and anxiety level during the COVID-19	Hacettepe University Turkey	$N = 108$	62% were male, average age was 50 MM = 36 Lymphoma = 36 Leukaemia = 26 MDS = 3	Convenience	101 93%	NA	Categorical and qualitative survey	1	Supportive Care Needs: were assessed via the Supportive Care Needs Survey-Short form; inquiries about 4 different aspects of supportive care needs including health care and information, daily life, sexuality, and psychological needs Compliance with exercise program: interviewed over the phone regarding their compliance with exercise program. Assigned to the patients post performance measures and prescribed based on the ACSM cancer guidelines. Weekly compliance was recorded Quality of Life: The European Cancer Research and Treatment Organisation QOL Questionnaire- Cancer30: including 30 items which are scored between 1 and 4. Consisting of three sub-headings; general health, functionality, and symptoms Anxiety level: The state-trait anxiety inventory was used to determine anxiety level of the participants
Zomerdijk et al., 2021 Country: Australia	Identify the psychological impacts of the COVID-19 pandemic on haematology patients	Community groups (Leukaemia Foundation), professional member societies and working groups (Victorian COVID-19 and Cancer Network) and Clinical Trial Groups (Australian Leukaemia and Lymphoma Group)	$N = 394$	Age not reported Gender not reported Leukaemia = 107 Lymphoma = 136 Myeloma = 73 Other haematological cancers = 78	Convenience	Not reported	NA	Qualitative online cross-sectional survey	1	Demographics: collected on individuals information including age, gender, postcode, marital status, education level, employment status and number of dependents living in the home during COVID-19. Medical characteristics: regarding primary diagnoses, treatment, and disease state. Cancer care experience: 4 questions designed by the research team to better understand the care experiences of respondents during the pandemic. Financial concerns: two items were designed to explore respondents' financial well-being during the pandemic. Perceived risk and impact of COVID-19 on cancer management: 5 questions were designed to investigate respondents concerns about the impact of COVID-19 on their own health and their perceived risk of contracting COVID-19 Psychological distress: measured using the Kessler 10—item assessment Unmet supportive care needs: captured using the Subdomains Health Systema and Information needs (11 items) and Patient Care and Support needs (5 items) of the short form Supportive Care needs Survey Fear of Cancer recurrence: 9 item Severity Subscale of the Fear of Cancer Recurrence Inventory

Table 4 Overview of supportive care needs explored in quantitative studies

Author and year	Physical needs	Psychological/emotional needs	Cognitive needs	Patient-clinician communication needs	Health system/ information needs	Spiritual needs	Daily living needs	Interpersonal/ intimacy needs	Practical needs	Family-related needs	Social needs	Number of domains explored in each study
Amidei et al., 2020	✓	✓	-	✓	✓	✓	✓	-	✓	✓	✓	9
Büntzel et al., 2020	✓	✓	-	-	✓	-	-	-	✓	-	✓	5
Caston et al., 2021	-	✓	-	-	-	-	-	-	✓	-	✓	3
Davis et al., 2021	✓	✓	-	-	-	-	✓	-	-	-	-	3
Dimelow et al., 2021	-	✓	-	-	-	-	-	-	-	-	-	1
Falcone et al., 2020	-	✓	-	-	-	-	-	-	✓	-	✓	3
Fisher et al., 2021	✓	✓	-	-	-	-	-	-	✓	✓	✓	5
Hulburt-Williams et al., 2021	-	✓	-	✓	✓	-	-	✓	-	✓	✓	6
McFarlene et al., 2022	✓	✓	-	-	✓	✓	-	-	✓	✓	-	6
Shay et al., 2021	✓	✓	-	✓	✓	-	✓	-	✓	-	✓	7
Kabak. et al., 2020	✓	✓	-	-	-	-	-	-	✓	-	-	3
Ostermann et. al., 2020	✓	✓	-	✓	✓	-	-	-	✓	-	-	5
Zomerdijk et al., 2021	-	✓	-	-	✓	-	-	-	✓	✓	-	4

Table 5 Overview of supportive care needs explored in qualitative studies

Categories	Themes within a category	Findings	Synthesised findings
Anxiety and distress	About catching COVID-19	F12	Anxiety and distress regarding catching COVID-19 due to recognising this population are at an increased infection risk due to cancer diagnosis
	About the unknown of COVID-19	F16	
	About attending the hospital	F2 F4	
Infection control	At an increased risk of COVID-19	F1	How such feelings of anxiety led to individuals isolating themselves from their support systems to protect themselves and their family or being isolated by regulations imposed by governments causing disruptions to attendance to hospital appointments
	Complying with the health orders	F24	
	Developing strategies to mitigate 'corona phobia'	F17	
Social isolation	When attending appointments	F2, F4, F10, F14	
	To avoid catching COVID-19	F13, F26	The overall effect this had on their psychosocial well-being
	Lack of peer and social support	F7, F32	
Access to health care	Telehealth and decreased person-centred care	F6, F9	Patient-clinician communication and health system information disruptions due to transition to telehealth
	Restricted opportunities to engage with health care professionals and decreased quality of care	F5, F29, F11, F15, F27	
	Confusion around health orders	F20, F29	
Sacrifices	Sacrificing self-care due to work and financial demands	F22, F23	Daily living needs and practical needs related to work and financial demands
	Family needs sacrificed because of emphasis into COVID-19 Prevention	F19	
Positives	Increased Family time and a new perspective on life	F8	New perspectives on life due to increase time with loved ones, applying previous learned coping strategies
	Resilience from previous cancer diagnosis	F31	
	Coping strategies from previous cancer diagnosis	F30	
	Positive infection control measures in hospital	F3	

> with cancer, you're definitely put to the top of that list [29] page 4.

Children and their families also expressed fear of the unknown in relation to COVID-19. Many participants described that they had come to terms with living with cancer, but were afraid, experienced anxiety and a sense of a lack of control due to the ongoing pandemic as illustrated by this quote:

> corona is strange and unknown to me [30] page 3.

Many participants commented they were always wearing a mask and went to extreme levels in cleaning and sanitising; and for some individuals even showering after leaving and returning to their house [29]. People affected by cancer acknowledged that COVID-19 was frightening for everyone, not just for those affected by cancer [29]. Noteworthy, some individuals reported that an additional diagnosis of cancer during the pandemic further compounded a sense of an additional "phobia" [30]. Many participants expressed to only feeling safe and secure when at home [30] but when they left the house this caused significant heightened levels of anxiety. People living with cancer voiced [23] issues due to the public perception that they were not visibly ill, and therefore lacked insight into the additional infection control measures needed to protect people with cancer, including those who had immunocompromised status. Strategies driven by fear of contracting COVID-19 [31, 32] included taking extra precautionary measures to avoid people, places, hospitals, and for some even family members all of which had an emotional impact. Participants also expressed fear that staff in their local hospitals would not be wearing adequate personal protective equipment (PPE) to keep them safe and protected from the virus while receiving care and treatment [25]. There was also fear of the unknown of the long-term impact that the pandemic would have on treatment outcomes, care follow-up, clinical service delays, and the overall impact that this would have on them in the future [23, 24, 26]. However, in contrast, some participants [24, 33] had significantly higher levels of fear of cancer reoccurrence compared to the fear of COVID-19. Other psychological disturbances reported included how the pandemic negatively affected their sleep [22, 23], which compounded a lack of energy and tiredness [24] with temper outbursts [22]. There was also a positive association between fear of COVID-19 and increased symptoms of psychological distress and unmet psychological needs [32, 34].

Patient-clinician communication needs

Across the included studies, many expressed concerns with the transition to virtual appointments with their health care team, noting that the previous model of in-person appointments provided reassurance and feelings of comfort [35]. In contrast, telehealth appointments meant it was easier to just agree with their clinician and many patients forget to ask important questions that they wanted to ask:

> I think because on the phone it's very easy to just go, oh yeah everything, grand, and then the phone call is over in literally a minute or two and then you are like, oh I forgot to ask them that [31] page 8.

Many individuals affected by cancer during the COVID-19 pandemic expressed that the quality-of-care carried out over telehealth was suboptimal compared to in-person consultations. In contrast, only one participant positively noted that telehealth saved a lot of travel time in their day [35]. The transition to telehealth similarly restricted opportunities to engage with health care professionals, with some participants noting a change to empathy, and an attitude to blame COVID-19 for everything that goes wrong [31], while others displayed compounding uncertainty around the next steps in their treatment plans due to lack of interaction with their multidisciplinary care team [23]. Patients reported struggling with opting for support from health care professionals in what might be viewed as them being bothersome, but all they needed and wanted was just their normal follow-up for cancer care [35]. Lastly, some participants reported being most concerned with the reduction in hospital care and access to their care team because of the consequences of reduced face-to-face hospital appointments resulting from COVID-19 infection control policies [27].

Health system and information needs

Many participants represented in the included studies reported additional anxiety and fear during the COVID-19 pandemic when required to attend hospital. Some highlighted concerns regarding the infection control measures and how they varied between patients and staff:

> None of the patients were wearing masks and you know there was a lady in the bed, you know in the next bed to me who had a cough you know, not COVID but just, you know, things like that [31] page 7.
>
> While others expressed:
>
> I felt safe enough, they [hospital staff] were all wearing their masks and their gloves, and I found the whole place spotless as well. [31] page 7.

Some participants commented on the lack of available personal protective equipment (PPE) available to hospitals during different stages of the pandemic. Some participants noted that at the beginning of the pandemic accessing masks, gloves, and disinfectants came at high cost to them [30]. Participants often presented common concerns regarding interruptions to the quality and accessibility of care, flow and re-direction of service, and disturbances to the participation in clinical trials [19, 20, 25, 28]. Furthermore, scheduling issues, treatment delays, and miscommunication with health care teams were particularly concerning among the young adolescent cancer survivors [23]. Lastly, participants demonstrated confusion regarding government regulations and testing requirements when attending hospitals and noted that these did not align in every situation. Additionally, participants reported distress that the public were not respecting recommendations in the community to keep others safe given they were living with cancer [30].

Spiritual needs

The spiritual needs of people with cancer were rarely discussed throughout the included studies. These findings represent a potential lack of holistic assessment given the restrictions enforced for funerals, restricted visitors during in-patient, and out-patient hospital visits for people with cancer; however, some participants indicated feelings of peace over distress when describing end of life experiences in relation to COVID-19 in palliative patients [19]. People affected by brain cancer [25] expressed concerns with "end of life" care.

Daily living and practical needs

People affected by head and neck cancers noted periods of social isolation, which were exacerbated at holiday times, when they could not have family or friends over to visit due to the increasing infection risk. Many individuals did not have a support system available to them, resulting in poor diets and reduced oral intake [29]. Findings from several studies observed that participants commented on problems with accessibility of food delivery services and food during shortages causing similar nutritional deficits [21]. Patients sacrificed their self-care due to work demands [36]. Few participated in exercise or health self-management behaviours. Practically, participants expressed varying issues with transport [20, 25], resulting in deficits in the accessibility of care [20, 32] or medications [21], and causing an overall disruption to their daily lives [22]. Many experienced financial toxicities due to reduced household income. Many participants expressed concerns about reduced household income from not being able to attend work [36] due to enforced lockdowns. Others alluded to issues with medical insurance or reimbursement [25, 26], loss of employment, financial difficulties, reduction to working hours, or being forced to take sick or take annual leave [23, 28]. Many participants reported distressed about not being able to engage in usual activities of living with a loss of work as an additional practical concern for them [24, 26]. Financial concerns were a significant predictor of psychological distress [34] with a positive association between loss of income and unmet needs.

Interpersonal/intimacy needs

Only one study explored interpersonal/intimacy-related needs. Women with breast cancer were the only sample group that reported needs in relation to intimate relationships during the COVID-19 pandemic, noting statistically significant reductions in changes to sexual feelings, sexual relationships, and a lack of information regarding intimate relationships from their health care team during the pandemic [27].

Family-related needs

Children and family represented a small portion of the participants included in this review. Survivors of childhood brain cancer and their caregivers [22] noted that the closure of schools and day-care facilities plus the family's inability to care was disruptive to the family dynamic [25]. A positive association was reported between unmet needs and reduced support within the family to mobilise their own support [27]. Participants expressed feelings of isolation because they were not allowed to attend or support the patient during treatment or be present during discussions with the medical team due to COVID-19 restrictions [19, 23, 27]. The lack of family support during consultations leads to a significant change in opportunities that contributed to decisional regret in cancer treatment and care decision-making [27]. People affected by cancer also shared worries in relation to job security and the disruption that this causes to daily functioning and broader family-related needs [22, 23].

Social needs

Socially, participants of the included studies collectively presented a common theme due to recurrent restrictions and lockdowns leading to feelings of isolation. Across the included studies, many sub-themes of isolation were expressed by participants. One participant noted that not allowing anyone into their home held a substantial impact on their family life as their usual support systems were not readily available to them. Illustrated by the following quote:

> So you're very much on your own all of the time, you suffer in silence because you know it will end [31] page 7.

Feelings of social isolation extend further beyond support within their home, to simple daily living needs [29] or support when attending hospitals for cancer treatment. People diagnosed with cancer needed to have their family or support network at their side as an important psychosocial aspect of care; however, during the pandemic, this was not allowed. Participants demonstrated they felt mostly isolated by visitor restrictions in hospitals during their treatment journey [25]. Additionally, people affected by cancer were forced to attend review appointments alone:

> Let's say you're having a PET scan done to see if your if your cancer is gone and you don't have anybody there to celebrate with when you get a good report and you don't have anybody to cry with when you get a bad report. I just I can't imagine doing that all myself. [29] page 5.

Whereas others described having support during these appointments as peace of mind in knowing someone else can confirm what you have been told:

> It's so good to have that extra pair of ears to, you know, come home and discuss it with your partner or spouse and say this is what I heard, and they'll say, 'no, no, no, that's not what . . . she said at all [35] page 4.

When people affected by cancer attended appointments alone, they were distressed and conveyed that they needed to have a support person:

> I'd nobody with me, so nobody heard [the diagnosis], you know my husband wasn't there, so I phoned him when I was outside and I was bawling on the phone, sure he thought I was going to die [31] page 8.

Participants with endocrine-based cancers reported isolation negatively affected their quality of life [26] and others shared feelings of loneliness due to lack of social interaction during treatment [31]. Patients alluded to a positive association between feelings of restriction due to the isolation and psychological distress which significantly impacted their mental well-being [20, 23, 32]. Some expressed that they felt less connected with family and friends due to restrictions and the stay-at-home orders imposed on all during the pandemic [22]. However, some individuals reported positive feelings toward the pandemic, with participants noting they had increased family time and a new perspective on life [31], positively commenting on the infection control measures in hospital making them feel safe. Some participants [23] reported that they felt a sense of resilience because of the pandemic and they could apply the coping strategies which they developed when they were diagnosed with cancer. Females with breast cancer positively commented on the additional support when coping with house based caring pressures due to the lockdowns and regulations [27].

Discussion

This systematic review sets out to understand the supportive care needs of people affected by cancer during the COVID-19 pandemic. The COVID-19 pandemic has had a significant negative impact on humanity, but more ominously for those living with or affected by cancer. Due to their immunocompromised state, they are required to be hypervigilant toward social endeavours and increased infection control measures when accessing health care facilities whether in- or out-patient. This review critically examined evidence published between December 2019 and February 2022 to identify the experiences of supportive care needs among those living with cancer. It was evident that people living with cancer reported physical, psychological/emotional, cognitive, patient-clinician communication, health system/information, spiritual, daily living, interpersonal/intimacy, practical, family, and social needs specific to the impact of COVID-19. It was evident that patients reported reduced assess and availability for symptom management support during the pandemic, further compounded by the rapid implementation of telehealth services in cancer. These findings have important implications because many individuals experienced poor symptom management because of reduced access to health care services (particularly with problems with pain, nutrition, fatigue, and psychological well-being).

Service reconfiguration, accompanied by social distancing, lockdowns, and curfews, was evident to have a negative impact on people affected by cancer. While it was a necessity that patients needed to be managed, for the most part, without visits to hospitals to minimise infection risk, this was identified as a health care system concern. A significant global push and rapid adoption to transition to cancer care to telehealth services remains [3] but for many participants represented in this review they expressed that they had concerns with this model of care. Patients valued the face-to-face in-person consultations with their care team and found that often the telehealth model lacked empathy and compassion at times, with missed opportunities to ask questions and gain the information that they needed. While momentum continues for the sustained use of cancer telehealth services post-pandemic [37], researchers and health care professionals cannot disregard the important concerns expressed by patients during COVID-19. Further research is needed to identify appropriate risk stratified telehealth models of cancer care [3], to ensure that the challenges of connectivity, communication, and access for remote areas, including safeguarding the elderly and vulnerable patients, are fully addressed.

Limitations

This systematic review has many strengths including the clear and specific methodology which followed a registered priori protocol. In addition, to the independent reviewer's contributions throughout the entirety of the systematic review process, the study provided insights across heterogenous study populations in terms experiences of unmet supportive care needs experienced during COVID-19. There are several limitations worthy of comment. This integrative review only included peer-reviewed studies published in the English language and as such it may have limited our understanding of the wider global impact of the COVID-19 pandemic on those living with cancer with cultural differences. The studies included for review were also conducted in mostly developed and western nations potentially biasing the management and impact the COVID-19 pandemic had on its participants. Despite these limitations, the review team followed a transparent prior review methodology to improve the rigour and validity of the findings.

Conclusion and implications for cancer survivors

The global negative consequences of the COVID-19 pandemic on experiences of supportive care for people living with cancer are evident. This review has identified important areas of unmet supportive care needs, which require careful consideration in the future development of cancer care services. The results of this review may also be applied to and used to inform the management of any future pandemics within cancer supportive care. Although the current emphasis is on managing COVID-19, the focus soon must centre on the recovery plan and restoration of the balance of cancer care in the era of COVID-19 and beyond.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s11764-022-01275-z.

Funding Open Access funding enabled and organized by CAUL and its Member Institutions This systematic review was funded by the University of Canberra PACES Research Scholarship.

Declarations

Conflict of interest The authors declare no competing interests.

References

1. World Health Organisation. Cancer WHO. 2022. Available from: https://www.who.int/news-room/fact-sheets/detail/cancer. Accessed June 2022.
2. World Health Organisation. WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020 WHO: WHO; 2020. Available from: https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020. Accessed June 2022.
3. Paterson C, Bacon R, Dwyer R, Morrison KS, Toohey K, O'Dea A, et al. The role of telehealth during the COVID-19 pandemic across the interdisciplinary cancer team: implications for practice. Seminars in Oncology Nursing. 2020;36(6):151090.
4. Paterson C, Gobel B, Gosselin T, Haylock PJ, Papadopoulou C, Slusser K, et al. Oncology nursing during a pandemic: critical reflections in the context of COVID-19. Semin Oncol Nurs. 2020;36(3):151028.
5. Sutherland K, Chessman J, Zhao J, Sara G, Shetty A, Smith S, et al. Impact of COVID-19 on healthcare activity in NSW, Australia. Public Health Research Practice. 2020;30(4):3042030.
6. O'Dea A, Gedye C, Jago B, Paterson C. Identifying the unmet supportive care needs of people affected by kidney cancer: a systematic review. J Cancer Surviv. 2021. https://doi.org/10.1007/s11764-021-01113-8.
7. Paterson C, Robertson A, Smith A, Nabi G. Identifying the unmet supportive care needs of men living with and beyond prostate cancer: a systematic review. Eur J Oncol Nurs. 2015;19(4):405–18.
8. Paterson C, Primeau C, Bowkerm M, Jensen B, MacLennan S, Yuan C, et al. What are the unmet supportive care needs of men and their partner/caregivers living with and beyond penile cancer? 2018;48:101805. https://doi.org/10.1016/j.ejon.2020.101805.
9. Paterson C, Jensen B, Jensen J, Nabi G. Unmet informational and supportive care needs of patients with muscle invasive bladder cancer: a systematic review of the evidence. Eur J Oncol Nurs. 2018;35:92–101.
10. Paterson C, Kozlovskaia M, Turner M, Strickland K, Roberts C, Ogilvie R, et al. Identifying the supportive care needs of men and women affected by chemotherapy-induced alopecia? A systematic review. J Cancer Surviv. 2021;15(1):14–28.
11. Doyle R, Craft P, Turner M, Paterson C. Identifying the unmet supportive care needs of individuals affected by testicular cancer: a systematic review. J Cancer Survivorship. 2022. https://doi.org/10.1007/s11764-022-01219-7
12. Hart NH, Crawford-Williams F, Crichton M, Yee J, Smith TJ, Koczwara B, Fitch MI, Crawford GB, Mukhopadhyay S, Mahony J, Cheah C, Townsend J, Cook O, Agar MR, Chan RJ. Unmet supportive care needs of people with advanced cancer and their caregivers: a systematic scoping review. Crit Rev Oncol Hematol. 2022;176:103728. https://doi.org/10.1016/j.critrevonc.2022.103728.
13. Hanna TP, King WD, Thibodeau S, Jalink M, Paulin GA, Harvey-Jones E, et al. Mortality due to cancer treatment delay: systematic review and meta-analysis. bmj. 2020;4;371:m4087. https://doi.org/10.1136/bmj.m4087.
14. Whittemore R, Knafl K. The integrative review: updated methodology. J Adv Nurs. 2005;52(5):546–53.
15. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. Int J Surg. 2021;88:105906.
16. World Health Organisation. COVID-19 China WHO. WHO 2019. Available from: https://www.who.int/emergencies/disease-outbreak-news/item/2020-DON229. Accessed June 2022
17. Boyes A, Girgis A, Lecathelinais C. Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). J Eval Clin Pract. 2009;15(4):602–6.
18. Hong QN, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, et al. The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. Educ Inf. 2018;34(4):285–91.
19. McFarlane P, Halley A, Kano Y, Wade N, Wilson S, Droney J. End-of-life experiences for cancer patients dying in hospital with COVID-19. J Patient Experience. 2022;9:23743735221074172.
20. Büntzel J, Micke O, Klein M, Büntzel J, Walter S, Keinki C, et al. Take care or "German Angst"? Lessons from cancer care during COVID-19 pandemic in spring 2020. J Cancer Res Clin Oncol. 2021;147(7):2093–105.
21. Davis K, Wilbur K, Metzger S, Garcia SF, Cahue S, Webster K, et al. Symptom and needs assessment screening in oncology patients: alternate outreach methods during COVID-19. Philadelphia, Pennsylvania: Taylor & Francis Ltd; 2021. Report No.: 0734–7332.
22. Fisher AP, Patronick J, Gerhardt CA, Radonovich K, Salloum R, Wade SL. Impact of COVID-19 on adolescent and emerging adult brain tumor survivors and their parents. Pediatr Blood Cancer. 2021;68(9):e29116.
23. Shay LA, Allicock M, Li A. "Every day is just kind of weighing my options." Perspectives of young adult cancer survivors dealing with the uncertainty of the COVID-19 global pandemic. J Cancer Survivorship : Res Pract. 2021.
24. Yildiz Kabak V, Atasavun Uysal S, Duger T. Screening supportive care needs, compliance with exercise program, quality of life, and anxiety level during the COVID-19 pandemic in individuals treated with hematopoietic stem cell transplantation. Support Care Cancer : Off J Multinatl Assoc Support Care Cancer. 2021;29(7):4065–73.
25. Amidei C, Arzbaecher J, Maher ME, Mungoshi C, Cashman R, Farrimond S, et al. The brain tumor not-for-profit and charity experience of COVID-19: reacting and adjusting to an unprecedented global pandemic in the 21st century. Neuro-oncol Adv. 2020;3(1):vdaa166.
26. Falcone R, Grani G, Ramundo V, Melcarne R, Giacomelli L, Filetti S, et al. Cancer care during COVID-19 era: the quality of life of patients with thyroid malignancies. Front Oncol. 2020;10:1128.
27. Hulbert-Williams NJ, Leslie M, Hulbert-Williams L, Smith E, Howells L, Pinato DJ. Evaluating the impact of COVID-19 on supportive care needs, psychological distress and quality of life in UK cancer survivors and their support network. Eur J Cancer Care. 2021;30(5):e13442.
28. Osterman CK, Triglianos T, Winzelberg GS, Nichols AD, Rodriguez-O'Donnell J, Bigelow SM, et al. Risk stratification and outreach to hematology/oncology patients during the COVID-19

pandemic. Support Care Cancer : Off J Multinatl Assoc Support Care Cancer. 2021;29(3):1161–4.

29. Kirtane K, Geiss C, Arredondo B, Hoogland AI, Chung CH, Muzaffar J, et al. “I have cancer during COVID; that’s a special category”: a qualitative study of head and neck cancer patient and provider experiences during the COVID-19 pandemic. Support Care Cancer : Off J Multinatl Assoc Support Care Cancer. 2022.
30. Mirlashari J, Ebrahimpour F, Salisu WJ. War on two fronts: experience of children with cancer and their family during COVID-19 pandemic in Iran. J Pediatr Nurs. 2021;57:25–31.
31. Drury A, Eicher M, Dowling M. Experiences of cancer care during COVID-19: phase 1 results of a longitudinal qualitative study. Int J Nurs Stud Adv. 2021;3:100030.
32. Caston NE, Lawhon VM, Smith KL, Gallagher K, Angove R, Anderson E, et al. Examining the association among fear of COVID-19, psychological distress, and delays in cancer care. Cancer Med. 2021;10(24):8854–65.
33. Dimelow J, Lowe D, Rogers SN. Balancing patients’ fears of recurrence and fears of COVID-19 when considering their preference for review consultations. European archives of oto-rhino-laryngology : official journal of the European Federation of Oto-Rhino-Laryngological Societies (EUFOS) : affiliated with the German Society for Oto-Rhino-Laryngology - Head and Neck Surgery. 2021;278(11):4441–8.
34. Zomerdijk N, Jongenelis M, Short CE, Smith A, Turner J, Huntley K. Prevalence and correlates of psychological distress, unmet supportive care needs, and fear of cancer recurrence among haematological cancer patients during the COVID-19 pandemic. Support Care Cancer : Off J Multinatl Assoc Support Care Cancer. 2021;29(12):7755–64.
35. Kilgour HM, Galica J, Oliffe JL, Haase KR. The needs of older adult cancer survivors during COVID-19: implications for oncology nursing. Semin Oncol Nurs. 2021;37(6):151229.
36. Salha LA, Silva JCS, Martins CA, Araújo CSdC, da Silva EAS, Alves AG, et al. Caregivers of individuals with cancer in the COVID-19 pandemic: a phenomenological study. Int J Environ Res Public Health. 2021;19(1).
37. Burbury K, Wong ZW, Yip D, Thomas H, Brooks P, Gilham L, et al. Telehealth in cancer care: during and beyond the COVID-19 pandemic. Intern Med J. 2021;51(1):125–33.

Supplementary Table 1. Electronic database searched and search terms used.

Database: Medline on EBSCOhost platform			
Date of search: 24/02/22			
Symbols used in this document:			
“ ” - finds a phrase			
Search #	**Concept/Explanation**	**Search Terms/Strategy**	**# of Results**
#1	Unmet Supportive Care	“unmet supportive care needs” OR “unmet needs” OR “care needs” OR “patient needs” OR “needs assessment” OR “family needs” OR “caregiver needs” OR “supportive care needs” OR “person centred needs” OR “holistic needs”	8,794
#2	Cancer	OR neoplasms	513,303
#3	Cancer AND Unmet Supportive Care Needs	#3 and #4	242
#4	COVID-19	OR coronavirus OR sars-cov-2 OR cov-19 OR 2019-ncov	227,165
#5	Unmet supportive care AND Cancer AND Covid-19	#1 AND #2 AND #4	84
Limiters	Date	December 2019- February 2022	

Database: CINAHL Plus with Full text on EBSCOhost platform			
Date of search: 24/02/22			
Symbols used in this document:			
“ ” - finds a phrase			
Search #	**Concept/Explanation**	**Search Terms/Strategy**	**# of Results**
#1	Unmet Supportive Care	“unmet supportive care needs” OR “unmet needs” OR “care needs” OR “patient needs” OR “needs assessment” OR “family needs” OR “caregiver needs” OR “supportive care needs” OR “person centred needs” OR “holistic needs”	7,245
#2	Cancer	OR neoplasms	116,111
#3	Cancer AND Unmet Supportive Care Needs	#3 and #4	834
#4	COVID-19	OR coronavirus OR sars-cov-2 OR cov-19 OR 2019-ncov	89,003

#5	Unmet supportive care AND Cancer AND Covid-19	#1 AND #2 AND #4	30
Limiters	Date	December 2019- February 2022	

<table>
<tr><td colspan="4">Database: APA PSYC Info on EBSCOhost platform</td></tr>
<tr><td colspan="4">Date of search: 24/02/22</td></tr>
<tr><td colspan="4">Symbols used in this document:</td></tr>
<tr><td colspan="4">“   ” - finds a phrase</td></tr>
<tr><td>Search #</td><td>Concept/Explanation</td><td>Search Terms/Strategy</td><td># of Results</td></tr>
<tr><td>#1</td><td>Unmet Supportive Care</td><td>“unmet supportive care needs” OR “unmet needs” OR “care needs” OR “patient needs” OR “needs assessment” OR “family needs” OR “caregiver needs” OR “supportive care needs” OR “person centred needs” OR “holistic needs”</td><td>1,926</td></tr>
<tr><td>#2</td><td>Cancer</td><td>OR neoplasms</td><td>9,238</td></tr>
<tr><td>#3</td><td>Cancer AND Unmet Supportive Care Needs</td><td>#3 and #4</td><td>228</td></tr>
<tr><td>#4</td><td>COVID-19</td><td>OR coronavirus OR sars-cov-2 OR cov-19 OR 2019-ncov</td><td>14,342</td></tr>
<tr><td>#5</td><td>Unmet supportive care AND Cancer AND Covid-19</td><td>#1 AND #2 AND #4</td><td>7</td></tr>
<tr><td>Limiters</td><td>Date</td><td>December 2019- February 2022</td><td></td></tr>
</table>

Supplementary Table 2 Qualitative Findings

Authors: Drury A et al., 2021					
Findings (themes in papers)	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
1. Being careful, keeping safe and feeling safe Recognised their increased risk of infection and endeavoured to minimise their risks of contracting COVID-19 through shielding and cocooning measures. Avoiding public places even for essential purposed such as shopping.	*I was very careful I mean I didn't go into a shop from March until ... probably October or November even (7)* *I was terrified. I was terrified. No other way of describing it, [laughing] our shopping would be delivered, and I hated shopping day because we had to clean every item down before it came in. (7)* *[...] they [children] wanted to go out and play with the kids out the back, as time went on it was hard to keep them in. We were trying our best to keep them away from other people. We were told you know that was important. But that was the biggest challenge as opposed to anything else. (7)* *There is a massive risk coming into our house every day but we're very lucky, we're clean, we have to extra sanitize and to do 3 h cleaning extra that I never did before. And sometimes you just, you have no choice. I can't bring anyone in, I have no one to help me, I have no support, my family don't live near me. And I can't risk a friend of mine coming in case she's been around someone. So, you're very much on your own all of the time, you suffer in silence because you know it will end. (7)*	**X**			**F1**
1. Being careful, keeping safe and feeling safe (II) Despite implementing shielding measures, for some participants, admission to hospital or attendance at hospital appointments was unavoidable. Several participants described anxiety and distress at the prospect of attending these appointments and being admitted to hospital.	*I probably was a bit more concerned when I was in hospital after the surgery as well, just you know, even within the ward. None of the patients were wearing masks and you know there was a lady in the bed, you know in the next bed to me who had a cough you know, not COVID but just, you know, things like that. I think you know, would make you a bit more on edge, which if it was another year you probably wouldn't think anything of it. But again, you know it's only smaller things like that. (7)*	**X**			**F2**

1. Being careful, keeping safe and feeling safe (III) Those who attended hospital appointments spoke positively of safety measures taken by hospitals to protect patients including pre-appointment COVID questionnaires, use of PPE and visibility for cleaning and disinfection in public areas.	*I felt safe enough, they [hospital staff] were all wearing their masks and their gloves, and I found the whole place spotless as well. I had no trouble that way, no worries at all [...] it's [COVID] had made people more hygienic you know what I mean, more cleaning I suppose compared to maybe when I thought about hospitals before they are more sterilized now. (7)* *If anything, I'd probably nearly feel more nervous of other patients, or you know, sometimes some people can be a bit more lax you know. I suppose with how they wear their masks. [...] I've seen the difference since I initially went to the hospital and went to the various clinics; just you know, it was unrecognizable. I suppose just the amount of people who were in the clinics, you know, at that stage compared to what they were later in the year. (7)* *I did feel very safe like, all the social distancing, the nurses would ring you like regarding COVID before you went in and like when you got there you were tested and brought in different doors. You felt very, very safe. So then it was just a matter of getting your chemo and getting home. (7)* *[...] you feel that you are prioritized more and it's a more organized system in place perhaps to get things moving through. (7)* *He was in hospital twice and each time was for about a week, it really took its toll mentally on him. Because again, the symptoms he had, he had to be isolated. And you know, simple things like being able to work the television, you know and he didn't have, you know just the company or the chitchat or whatever. (7)*	**X**			**F3**
2. Shrinking supports and feeling isolated (I) The experience of being alone for hospital visits at critical points in their diagnosis, treatment and follow-up care was described by several participants. While participants noted efficiencies in cancer services, several described the isolation, loneliness and distress of attending hospital appointments without their support networks.	*I'd nobody with me, so nobody heard [the diagnosis], you know my husband wasn't there so I phoned him when I was outside and I was bawling on the phone, sure he thought I was going to die [...] (8)* *Then with radiotherapy you'd have to, you'd arrive, you'd have to ring and wait outside and be called in have your temperate taken. Go back to the car and wait in the car until you were called to go into radiotherapy. And then you wouldn't meet anyone until you went in, you met your radiation therapist. They were cleaning down when you went in which was comforting, but I had to go on my own. Nobody could travel with me because we were in, it was in lockdown. And so, I found it lonely in the car on my own. I found my first session really,*	**X**			**F4**

	really stressful. I was crying coming home and I was never going back again. I found, I hated it, I hated every minute of my radiotherapy. (8)				
2. Shrinking supports and feeling isolated (II) However, many narratives highlighted how COVID-19 dominated the cancer care agenda during appointments and when seeking advice, restricting opportunities for engagement with healthcare professionals and the person-centredness of care. Some believed that healthcare professionals' preoccupation with COVID- 19 compromised empathy and care, acting as a barrier to care and support during treatment.	*[...] in the last year and a half when I was first diagnosed, I noticed the empathy has changed completely since COVID. There's a lack of empathy. There is very much a lack of communication from the hospital to the patients. And really without sounding very dramatic, there's a lack of care at the moment because they seem to presume that COVID only exists now, even in the hospitals its very much well COVID, well COVID, well COVID [...] it's like they don't want to communicate, they don't feel they need to now, because COVID has taken over from their care, so they can use any excuse they want to now and they can blame it on COVID. (8)* *Trying to ring and just get information about how he was, it was very difficult. And even there was one instance where he rang me, and he was sitting in a chair for hours because there were no beds [...] or he'd ring me because he was freezing cold in a place where he was, and I'd have to try and ring to see was there anyone that could give him a blanket. So there was those two bits, I suppose, out of the whole year, that you know it just, it was very frustrating. But again, you know, look it I understand, I know myself the way things work. (8)*	**X**			**F5**
2 Shrinking supports and feeling isolated (III) The transition to telephone consultations for some participants was an added barrier to support and limited person-centeredness in care interactions.	*I just feel at the moment that I'm not being listened to, you know, one of my phone consultations back during COVID lasted 2.5 min. (8)* *[...] I suppose it's nicer to sit there with the consultant because I suppose you have more of an opportunity to, to you know I suppose go into things with them you know if you need to. The face-to-face I suppose is a bit more personal always isn't it. So, you know I had missed that a little bit but look, I understand the way things are, and you know it's for our own safety, and they don't want to be bringing people in needlessly like, you know. (8)* *[...] it's not ideal I guess in a way you kind of need to be maybe a bit more prepared, I think because on the phone it's very easy to just go, oh yeah everything, grand, and then the phone call is over in literally a minute or two and then you are like, oh I forgot to ask them that, or I didn't bring that up or whatever. I think you know when you are face-to-face, it's more of a natural conversation, it's more, you know,*	**X**			**F6**

	you are more inclined to maybe talk about things maybe a little bit more. (8) *COVID hasn't reached my hospital yet, but yet any time I enter the hospital or speak to a nurse, they're very much like, they bring in the COVID line, which doesn't, it doesn't wash with me as a patient. They try to insult your intelligence by thinking that this will take back, you know, to times where you'd ring with a sore pain, or you'd ring with the side effects that they want you to ring with. But now, you don't get a call back for two days, even though COVID is not in their hospital. That's what I see a lot of. (8)* *I actually called them up [the cancer care team] for the first time in a long time about the vaccines because I was a bit concerned about any interaction between Tamoxifen and the vaccines, and you know, between that and the fake news that you hear like I just wanted more advice. And so, I left a voicemail, and within two days, she got back to me; we had a long conversation. So, no, I do feel, you know, I feel quite well supported by them. (8)*				
2 Shrinking supports and feeling isolated (IV) Several participants also acknowledged how the variety of peer support and cancer support services that would be available under normal circumstances were no longer accessible to them.	*[...] when it [radiotherapy] started, I found it very lonely because I was used to in chemo, my mother would come with me to all my chemo sessions. And there would be in [hospital] there's four patients sit around a table, and their family members can sit with them, we used to have a great laugh at chemo. [...] (8)* *[...] you actually don't get the chance to chat to anybody. That's the only, I suppose, negative side of COVID; you don't get anyone to talk to through the whole thing. (8)* *I suppose the one thing that I found difficult with it all, because of COVID, it was difficult to reach out for support from a mental health point of view, because normally you would have [cancer support centre]. And they shut down kind of petty much completely other than you know phone support. But they offer a whole range of other services, and I wasn't able to avail of any of those and they also have services for children and partners as well. None of that was available. (9)*	**X**			**F7**

	We did as much as we could ... I'd leave; you know, medicines, or whatever, at the door, and she would kind of, she would be up at night with him you know when he was sick. (9)				
3. Not missing out Many felt that COVID-19 had introduced a new-found perspective on life, whereby the appreciated the opportunity to foster closeness with their families.	*It's just being close to them, so the positive I can take is just, kind of, figuring out what's really important. And its family and just being able to kind of spend time with them while I can. It's been cruel. Just the distance and looking in the window when someone is so sick and not being able to, the helplessness not being able to do anything about it for fear. (9)* *I suppose everybody is in the same boat. I feel I'm not missing out as much. (9)* *[...] I've been saved because of COVID, from walking down the streets and having 20 million people looking at my baldy head and my no eyebrows; and ask me the question, and have to deal with the 'oh I'm so very sorry to hear that,' etc., etc., etc. Which I can imagine, at the start, when you're told you have cancer, every time that you have to tell someone else, it's like hearing the news all over again. So, I think in that sense, because of COVID, I was saved a lot of that. I was able to do a lot of it on my own terms. I was able to manage the flow of information. (9)* *Everybody keeps looking at me when, you know, when I was completely bald, and I was thinking, well I don't have to go anywhere so nobody else seen me [laugh]. (9)*	**X**			**F8**

Authors: Kilgour. H et al., 2021					
Findings (themes in papers)	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	

1. Concerns about virtual versus in person appointments	*"It's just reassuring to see them in person, to see their face, to watch their non-verbal. You know what I mean? It's just nicer." (3)* *"There [was] something wrong and she [oncologist] knew right away that there was a problem. But had that been a phone-call, I don't think she'd have ever diagnosed it." (3)* *"I've had three appointments in the pandemic, and I haven't spoken to my actual staff person yet." (3)* *"Well, all my appointments were across the phone. . . .I don't think they're as good as the in-person ones. I guess it saved us a lot of trips because . . . well, if I go to appointments, half a day is shot by the time we drive there and back, . . . but I would sooner have the in-person appointments when you're only having them every six months or so anyways." (3)*	**X**			**F9**
2. Barriers to Caregiver Attendance at Appointments	*"Well, the main difference, the main problem is the fact that she can't come in with me," explaining, "we do everything together." (3)* *"It's so good to have that extra pair of ears to, you know, come home and discuss it with your partner or spouse and say this is what I heard, and they'll say, 'no, no, no, that's not what . . . she said at all.' . . . So, I think it's really important that when people get back on track that they are allowed to take a person with them to appointments, because it's so, so beneficial." (4)* *"I'm finding that my memory is poorer, and I don't always think of things. So, with [partner's name] comments, they're very pertinent." (4)* *One participant described how they had initially attempted to record their appointments with their oncologist, however, noted this was challenging and that they "haven't been doing that lately." (4)* *"what I started to do was I made a list of questions myself. So, when I went in . . . I didn't forget any questions I would jot down the answers. So, when I couldn't take anybody that was fine." (4)*	**X**			**F10**
3. Impediments to Accessing Health Care Services	*"It's a little disappointing because the COVID-19 has really backed up any type of appointment you can get. And you know it's gone from a couple weeks to three or four months for things." (4)* *"Have been put on hold since the pandemic," (4)*	**X**			**F11**

	“They want you to do these follow-up check-ups, but you can’t get in [to see them].” (4) *“with the systems and the pressure on the system right now, I want to do everything I can to stay as healthy as I can. Mentally and physically.” (4)* *“The whole social structure is under pressure, so the less you have to rely on other people or other services the better off you’ll be, I think.” (4)* *“You don’t really want to be bothersome with what’s relatively minor compared to what they’re really dealing with.” (4)* *“I don’t think it had anything to do with the pan- demic. To me it’s irrelevant. You know? Just a fear that you have of the results—and no matter what’s going on in the world.” (4)* *“It’s lasting longer, and I always think if the cancer’s going to come back it’s probably not going to be the first six months, right? It’ll be you know, maybe a year, year into it you know, and so maybe as it gets longer—or if COVID goes longer I may have more concerns about cancer recurrence and the support. (4)* *If there is a complication or say the cancer resurfaces, will treatment and access to facilities be available? And we all know the pressure that’s being put on hospitals and ICUs and surgeries. And they mentioned cancer surgeries that are being put on the back burner or cancelled until further notice. So, if it comes up again, it might be a lot different than the first time.” (4)*				

Authors: Kirtane. K et al., 2021					
Findings (themes in papers)	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
1. Increased Psychological distress	*It contributes to a little bit of anxiety because, you hear over and over and over, people that are in a higher risk category. And, you know, by you being diagnosed with cancer, you’re definitely put to the top of that list. So, it’s very worrisome. ‘Are you going to get COVID while you’re getting treatment? ...What is that gonna do to your body? Are you even going to be able to deal with that? Are there medicines that are going to help you through that?’ Just a lot of questions in your mind. (4)*	**X**			**F12**

	"COVID is stressful to everybody right now... I think that we're worried about lots of stuff and, you know, throw the cancer in on top of it, it's like a double whammy." (5) *"I'm more careful when I do go out. I wear a mask...I always consider myself clean, but I take it to another level; I come in and I take a shower for just going out to a grocery store. I don't know if it's a phobia...I guess that's the best way I can describe it." (5)* *"I think a lot of [patients] are just very anxious... because they're receiving chemotherapy and they're potentially immunocompromised." (5)*				
2. Exacerbated social isolation	*One of the less obvious symptoms would be social isolation...let's just say it's Thanksgiving time...they're not going to be able to eat typical foods with other people...so that adds a social component to this as well, unfortunately. (4)* *Because of COVID, I was by myself over there... if I would have had that support, I may have eaten better; for someone to be there to push me to drink a Boost or you're going to make [food] for me. Because I had to get up and make it myself, which was tiresome in and of itself. But, you know, I got to say a few times I said, 'Gee, I wish my mother would fix me breakfast' or something like that... and you'd sit there in bed and think, 'I got to get up and eat. I got to get up and eat.' But, you know, an hour later, you still find yourself sitting in bed and you still haven't eaten. (4)* *I would say the that the pandemic has had at least as much to do with its effect on my personal relationships as my cancer treatment has because I was told very early on to pretty much just sequester myself because of the radiation and chemotherapy treatment. Any exposure to COVID-19 would be extraordinarily difficult for me to survive... So, it's had an obviously large effect on all my relationships." (5)* *"I was scared my resistance [to COVID-19] was low, so I didn't go anywhere... I didn't even go to the grocery store because I was worried about getting sicker. So, for a couple of months, I don't want to say I didn't have a life, but I didn't do anything but what I had to around the house. That was it." (P5)* *"I also have another illness that I've had for 33 years, which is an immunity disease. My immune system is very low, so having cancer along with that, we've been isolating ourselves since March, my wife and I. And so we haven't seen anybody except a doctor, the grocery store, or gas station for 8 to 7 months now, I guess. It's been very, very confined. We do have social things on Zoom and other medias that we frequent. But of course, it's not the same as being with someone physically." (5)* *"This just leads to isolation, that's all. And again, if this is a different time frame with no COVID, it would be different...Number one, I didn't want anybody coming over. Number two, I can't eat, you know? They're like, 'Well, what do you like to eat? We'll make you food.' I said, 'You're great and I love*	**X**			**F13**

	you guys, but you're not understanding. I can't even swallow liquid right now. That's how bad the sores are.' So, I think they begin to understand that. So, it's just the isolation. And again, I think I'm an outlier because it is, I have cancer during COVID. So that's...kind of a special category. (5)				
3. Added stress in clinic for patients and providers	*I really don't like the fact that when I go to a hospital, even Moffitt, my wife can't come in now. You know, she was with me through the whole thing...She's my sounding board when I'm asking questions. So that made it harder." (5)* *"Some [patients] are angry because Moffitt won't let their loved one in... What they're thinking about is what's going on in their world right now and they want that person. It's important for that person to be there with them and they can't... Let's say you're having a PET scan done to see if your if your cancer is gone and you don't have anybody there to celebrate with when you get a good report and you don't have anybody to cry with when you get a bad report. I just I can't imagine doing that all myself." (5)* *"I think one of the hardest things is when we could not have visitors come to our outpatient appointments... That was tough on everybody. That was tough from a clinician standpoint, making sure that the patient thoroughly was educated and understood the information we were giving them. And I think it was very hard on the patients because they rely on that social support and their family to be there at their appointments." (5)* *Not having my husband at the appointments because he comes, well, he used to come to every appointment that I took at Moffitt. So, him not being there, especially on those days when I was kind of nervous. Just like, when I had to do my scans; my first scans three months ago. And then, just dealing with like, not so pleasant news, but you're by yourself. I think that's been the most challenging part. (5+6)* *It adds an extra layer onto what is already a stressful thing for the patient... A lot of them feel a little bit more alone, and just kind of enhances what they're feeling and their anxieties. And then, they're not able to focus on what we're telling them, some of the education and things like that... I found that I've had to repeat myself a little bit more on education things, or what types of things that we're wanting patients to do, just because they don't have that extra set of ears or that support system... You're having to give a lot more support to the patients, which you don't mind, but it just kind of drains you a little bit more than you're probably used to. So, you kind of take it home with you a little bit more. (6)*	**X**			**F14**

. 4. Delays in health care	*What has ended up happening is that a lot of patients have put a lot of their cancer care sort of on the back burner and have waited a long time to seek cancer care because they were just very afraid of COVID. That's something that we've seen a lot lately." (5)* *"When I first heard COVID on the increase, I missed y'all's doctor's appointment. I don't want to go nowhere. I didn't want to take the risk. And then, of course, I came over and saw you like a month later." (5)* *"Well, I'm due a colonoscopy this year and they said they weren't handing out any appointments until after COVID calmed down. So, I'm still waiting for that appointment." (5)* *I wanted to see if [the swelling] would go down on its own, because I do tend to get swollen glands when I'm fighting any kind of illness. So, it didn't go down and then that's when...COVID hit. And so, I talked to a couple of friends of mine that are doctors, actually, and they're like, 'You know, I wouldn't do any elective procedure right now,' because COVID was starting to get really bad. And they said, 'You don't want to go to hospital for anything elective.' So, I kind of waited a little bit, but then it never went down. (6)* *I really haven't been to my primary care. I did one... tele-video thing, but I haven't had my annual physical and I haven't been to my dentist in 2020. So, [COVID- 19] changed that. (6)*	**X**			**F15**

Authors: Mirlashari J et al., 2020

Findings (themes in papers)	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
1. Swinging on the path of fear to adaptation a. Exposed to an unknown and enormous threat	*"I have gotten used to cancer, I mean I know about it. However, corona is strange and unknown to me. So I am afraid of it more, and I am worried about getting the coronavirus."(3).* *"I am afraid of the corona. I am afraid of getting infected because everyone who gets it will die."(3).* *"The immune system of my child is weakened because of cancer. My child is at an increased risk of COVID-19."(3).* *"At the beginning of the outbreak, we had trouble getting masks, gloves, and disinfectants because of the shortages and high costs. Because of the cancer treatment, my child needs these." (3)*	**X**			**F16**

1. Swinging on the path of fear to adaptation a. Developing strategies to address corona phobia	*“I was constantly following the corona news to get more information.” (3)* *.“I was washing my hands constantly until my skin became dry. Whenever I touched anything, I washed my hands immediately because I was afraid of getting infected.” (3)* *“We were terrified and anxious, but when we all stayed at home, the chance of getting the infection was reduced, and our anxiety was minimized.” (3)* *“Even talking about corona is scary. I do not talk about it, and I do not listen to the news to make myself less worried.” (3)* *“We try to follow hygiene principles and teach our children how and when to use a mask or wash their hands.” (3)* *“In coordination with the doctor, we made the treatment program more compact and changed it to outpatient treatment.” (3)* *“It is stressful for me that children with cancer are at increased risk of Coronavirus infection. However, when praying to God, I feel calm.” (3)*				**F17**
2. Left alone at emotional distances	“It has been about two months since my father avoided close contact with me so that I do not get corona. We cannot communicate with our relatives. *Corona has created a gap between our loved ones and us and reduced affections.” (3)* *“My daughter is very dependent on her father. She misses him so much. Children are very bored here.” (3)* *“Fathers are not allowed to enter the ward, which makes children and their fathers upset.”(M5). (3)* *“Playroom is closed. Children are not allowed to go out, and they are not allowed to play with other children.”(M6). (3)* *“Children are not allowed to go to the Playroom. No one comes here to amuse them. Mothers and children are not allowed to go to other rooms or to talk in the corridors. The feeling of empathy and happiness of mothers and children is gone. I feel bored and lonely.”(C2). (3)* *“It is tough for us. Corona has driven us crazy. We have been hospitalized for twenty days. My daughter misses her father. She doesn't eat. We are imprisoned in this room like a cage. We do not even leave the room, unless*	**X**			**F18**

	when they want to inject the medicine in my daughter's spinal cord. No one is allowed to visit us."(M8). (3) *"Since nurses and doctors are using masks and shields, the children and their mothers are not able to identify them. Wearing mask along with social distancing in the unit has led to severe communication problems and intensifies the feeling of loneliness and emotional distancing among the children and their families."(M10). (3)* *"One of the favourite activities that brought me beautiful joy was attending school. When schools were closed, I lost my friends."(C4).(4)* *"We had a plan to travel, but it was cancelled because of the corona. My daughter was attending music classes, and she was in contact with her friends. However, because of corona and the quarantine, everything ceased, and she feels bored and lonely. I feel her anger." (F1) (4)* *"We had a lot of misfortune, the corona was added! Before corona, at least I used to take my son to the park once a month, but now I can no longer do that. Staying at home and being alone has made him more restless and troubled." (m7) (4)*				
3. Care system confusion and decreases quality of care a. Sacrificing children and family's needs due to concentration on COVID-19 prevention.	*"To be allowed to enter the ward, the mother and child must take a Corona test, which is expensive."(M5). (4)* *"We did not allow fathers to visit their children, who caused many objections, from families and the children themselves."(N1). (4)* *"Initially, I was not allowed to enter the ward. They said my daughter is old enough and does not need a companion. I spoke with the supervisor, and she said that if you had a corona test, you could enter the ward, and she informed the head nurse."(F1). (4)*	**X**			**F19**

	"As before, there was no disinfectant in all rooms and inside the ward. If necessary, we should have asked the nurses to deliver us some disinfectant."(M2). (4)				
3.Care system confusion and decreases of quality of care b. Confusion about issuing and implementing instructions	*"Some people do not respect public health instructions in the community or the hospital. Some people do not fully follow the principles of personal hygiene and health advice. Some doctors were using full personal protective equipment at the hospital, but some others only wore masks."(M1).(4)* *"Many people emphasized that mothers and children should be tested for corona before hospitalization, but these rules were only for us children. Nurses and doctors or other non-cancer patients were not required to observe these rules."(M2). (4)* *"Mothers and children were not allowed to enter the cancer ward with their shoes and were re- quired to use special slippers provided by the hospital. This is for our children's health, but why do they not observe this rule themselves and enter the wards with high heels? They are making it hard on us so that we do not carry corona to the ward. We do not even have the right to choose the right slippers for ourselves and our children, and we have to wear whatever they give us."(M2). (4)*	**X**			**F20**
3.Care system confusion and decreased quality of care c. Children and Family expectations from medical staff and health system in the context of the COVID-19 pandemic.	*"These disinfectants are vital during the COVID-19 pandemic. When the pandemic is over, they no longer have value for us. We need these sub- stances, and they should provide sufficient disinfectant for us. We are faced with different stresses. We do not want the medical staff to upset us and make the situation worse by creating such tensions."(M2).(4)* *"The Corona test is expensive, and we cannot afford it. The head nurse or head of the cancer department should consider this issue and negotiate with the hospital to make this test free."(F1). (4)* *"Nurses are more nervous than before and stay away from us. They do not spend enough time to answer our questions, and they just lead us to our rooms and tell us not to leave the room."(M2). (4)* *"Some children want to play with me or talk to me or even hug me, but I have to avoid them. Because I have less time, and I have to observe COVID-19 related protocols."(N1). (4)*	**X**			**F21**

Authors: Salha A L et al., 2021					
Findings (themes in papers)	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
1. Sacrificing Self-care due to work demands	*It's impossible to do any activity because you can't leave the house (C1) (4)* *I do not practice specific physical activities, only those related to housework and those related to remote work. (C17) (4)* *I work most of the time, I don't practice much activity because I take care of my father. (C35) (4)* *Not very active. Walking. Around the block. Almost every day (3 to 4 times a week). (C42) (4)*	**x**			**F22**
2. Worrying about the future: suffering and Unemployment	*My concern is about getting sick and not being able to take care of my father. (C4) (5)* *...how I can survive without income... (C13) (5)* *. . . staying healthy and taking care of emotional and financial health. (C17) (5)* *. . . with my mother's health! Fear of her contracting the virus because her immunity is low due to her treatment! (C33) (5)* *. . . always hoping to improve. Because we trust in God always to give us strength. (C5) (5)* *. . . get worse. We get worse every day in this life. (C12) (5)* *I hope to improve with the end of my son's chemotherapy. (C26) (5)* *Look, I have faith in God that my health will improve in Jesus' name. (C28) (5)* *. . . and the emotional one too, with faith in God, that they will soon find the vaccine for this virus. (C30) (5)*	**X**			**F23**
3. Complying with Public Health Rules as Closely as Possible	*I need to come and go all the time, but I take care of myself. (C19) (5)* *In part, we are very careful to use a mask, hand sanitizer, hygiene, but I go to hospitals a lot. (C26) (5)*	**X**			**F24**

	I started following all the protocols, but I had to keep going to work, even knowing that the number of infected and dead in my own service was getting closer to me. (C31) (5) *I'm avoiding crowding, but social isolation is a little difficult to meet due to my service. (C33) (5)*				
4. Positive actions and reclaiming feelings in the post-pandemic world	*Give a hug to my children who live far away from me, I miss them a lot. (C1) (5)* *Carefully go back, due to low immunity, to having contact with my family. (C2) (5)* *Embrace the people I love! Including my mother who, due to the disease, we are taking great care to avoid, I will hug her a lot. (C33) (5)* *Thank God for having passed this challenge. (C40) (5)* *Thank God for taking care of me and my family, for not having COVID, thank God. (C41) (5)*	**X**			**F25**

Authors: Shay. L Aubree et al., 2021					
Findings (themes in papers)	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
1. AYA behavioural responses to the pandemic a. Social Distancing b. Impact of social distancing on AYA's	*"not when it became mandated but like when it became recommended by health officials" (4)* *"I try to go to the grocery store for [my parents] be- cause they're older, and I feel like I'm in better health than they are." (4)* *"very serious about staying far away from people who aren't wearing face masks." (4)* *"I'm definitely seen as the bad guy in my family, because I don't agree to birthday parties, I won't agree to taking my mask off, I won't go into people's houses, I won't let my child go into people's houses, I won't let people visit." (4)* *"I'm still in treatment. I still have cancer. Like, they just wouldn't get it. And so, I had to cut some of those friends off, which was unfortunate." (4)* *"I had a really good friend that got married in May, and so I kind of had this internal conflict back and forth of, the wedding still happened, and I wanted to go, and so it was just...there's been a lot of situations and social situations like that that I feel like I've been having a lot of internal battle with what is the right thing to do." (4)* *"So yeah, there has been job changes. And not only, like, my role changing, but hours lost, financial status, conversations just get weird." (4)* *"I was really glad when the order came down that all these places you have to wear a mask every time you go in there. Because I just felt a sense of kind of like peace, that even though there are people who fight that, that it's a we're all in it together type of thing." (4)* *"So the cool thing, and I can't believe I'm actually saying it's a cool thing, about COVID is that Stupid Cancer had their CancerCon virtually this year. And it's something I probably would not have gone to in person, but I went to the digital CancerCon, and that's how I met [name redacted] And now I'm in an Instagram group chat with like a dozen other adolescent and young adult cancer survivors. I have my tribe. This is not something I had before this. You know, I'm almost four years out. Had not met a group of people, despite trying*	**X**			**F26**

	different things. This, it just wouldn't have happened without COVID and without having done the virtual confer ence." (4)				
2. The added burden due to cancer a. Difficulties and delays in medical care	*"I don't care where on the totem pole you think I am, but I think I'm important enough to get that treatment." (5)* *"nothing's changed" (5)* *"I think I'm at the point where I go in every other year and don't have to go in until next-next year." (5)* *"I really wanted to get the scans done. So, it was a little hard to have it delayed, but it's just something I have to deal with." (5)* *But it's not as easy as it was prior to COVID, right? Where you could call and say, "I need my MRI." "Okay, what date are you available?" They're asking me. Now I'm asking them, "What do you have avail- able?" And let me throw my*	**X**			**F27**

	whole schedule around just so I can make this appointment. Because I know if I don't go to this appointment this week, I have to wait six weeks from now." (5) *"It feels like a lot of the onus is on the patient. Instead of providing actual medical care, they're just kind of giving you whatever you think you have is kind of what it feels like." (6)* *I think that, at least what I've experienced at the hospitals, like, I know that they are stressed, and they are losing out on all this money. And so it seems kind of like they're scheduling things for people by de- fault. And when you even bring up, like, is it safe, like, I'm worried about it, they're...they admit that it's not really safe and that you should probably just reschedule. But they're scheduling everybody even though it's not safe necessarily. And so that's really not reassuring." (6)* *"felt like they [healthcare providers] weren't taking it [COVID-19] as seriously as they should" (6)* *"I've exhausted most of my baseline courses of treatment, so clinical trials are essential for me. And when you hear, like, oh, there's one where you are an ideal fit, you fit all of the inclusion criteria, there's no exclusion bumping you out, this looks like a perfect fit for you, but you can't do anything about it, because we're on hold and don't know when we're going to get off of hold. That's a little bit nerve-racking" (6)* *"My last scan showed that my cancer progressed, and we were hoping to move me onto a trial. And yeah, they're on pause right now. So right now, the next course of treatment would be one of the drugs on the trial and we're hoping that we can then make an appeal to my insurance company for a compassionate whatever that they would let me use the other drug that is showing promising results in the trial." (6)*				
2.The added burden due to cancer b. Mental health and Stressors	*"not doing what they're supposed to be doing" (6)* *"And it's just incredibly frustrating to feel like a lot of people aren't taking it seriously. But for anything to actually change, and for us to move forward, everybody has to take it seriously. We've all been in the cancer boat, we know what it takes to adapt. Why can't these other fools do that as well?" (6)* *"It's increased my anxiety quite a bit. It's made me really scared to go out in public... Because I don't look actively ill, so people don't think that I have any kind of issues with my health. So, I don't outwardly appear to have any kind of illness, which I think makes people think that I'm overreacting." (6)* *"I think people who haven't been through cancer or who haven't been compromised, I think they just have trouble having empathy for those of us*	**X**			**F28**

	who have experienced that. And so, they can't see the severity of the situation. I've definitely seen that in a lot of my friends and family." (6)				
2.The added burden due to cancer c. Compounding uncertainty	*"When I was in treatment, I knew I was going to have eight treatments. It was going to take six months. I knew I would be hopefully done at the end of that. But with this, they said two weeks, and here we are four months later. So, there is not really a solid end. And the feeling of not knowing when you're going to be able to...or if you're going to be able to return to anything that you used to do has been very unsettling and very hard." (7)* *"We don't know if there is other health issues that are going to come up, like if history [of cancer] is going to somehow make a COVID case worse or it would make me more susceptible." (7)* *"So every day is just kind of a, to me, it's kind of weighing my options. What's worse, getting a recurrence or getting COVID?" (7)*	**X**			**F29**
3. The unexpected advantages of a cancer history a. Coping strategies	*"I've been trying to talk to a lot of friends and stay in touch with people. Because I think for me one of the hardest parts is the isolation piece. And struggling with depression and wanting to isolate on my own, and then being forced to, is its own different thing. And it's really hard. And so, trying to fill my time, because I'm stuck at home all day, and just getting a schedule and trying to reach out to friends more often." (7)* *"I feel like I kind of reverted back to my old coping mechanisms for when I was immunocompromised, and I had to stay home. I literally still have all the old colouring books and everything that I used to have from then, and I was just doing them again because I didn't know what else to do. And I was like, well, it worked then, so it might work now." (7)*	**X**			**F30**
3.The unexpected advantages of a cancer history b. Resiliency	*"But for the first time I feel like other people who haven't had cancer realize what the fear of getting sick is. Because I was scared about getting sick before this happened, just, it wasn't of COVID, it was of relapse. Well, now people who don't have COVID are scared they're going to get COVID. And I feel like, for the first time, people are on my level." (8)* *"I feel like I have an advantage to some aspect on the mental game we're playing. Because I know what it's like. So I noticed, really when this all started, where people were like, 'Oh, my gosh, we need masks. Oh my gosh, all this.' Like, you guys are all freaking out. I've been doing this for four years. Like, I'm going to put a mask on and go to the store. Like, chill out. It's not the end of the world. So, I feel like people are starting to understand what it's like to not have a certain future. And everybody's response to that is, to some extent, funny to me, because you guys all gave me crap about it for the last four years. And now*	**X**			**F31**

	you're starting to be like, 'Oh, wow, this is legit. Like, it's scary.' And it's like, 'Yeah, it is.' Shocker." (8)				
4. AYA recommendations and resources	"I think for me, it's just a simple phone call [from loved ones], simple phone calls go through a long way with me" (8) "I don't know if it's necessarily just pandemic wise, but at least for me and others I've talked with, young adults really aren't told about other young adult people or groups or things to do outside of getting sick. Like, I didn't know anybody, and it was all on me to figure it out. But I walk in the hospital and there's flyers for all, like, breast cancer groups and, you know, older adult groups. And it seems like the young adult community is something that isn't talked about, isn't looked at." (8)	**X**			**F32**

Supplementary Table 3 Quantitative Findings

Author and Year	**Physical Needs**	**Psychological/Emotional Needs**	**Cognitive Needs**	**Patient-Clinician Communication Needs**	**Health System/Information Needs**	**Spiritual Needs**	**Daily Living Needs**	**Interpersonal/intimacy Needs**	**Practical Needs**	**Family Related Needs**	**Social Needs**
Amidei C et al.,2020. USA	6% of patients were asked to complete DNRs when at this time point in the patient's care they were "doing well".	92% reported generally greater anxiety. 69% feared being diagnosed with covid 27% reported increases or new emerges of mental health challenges 37% of patients had concerns that the hospital staff working where they were being treated didn't have sufficient PPE	**Not reported**	31% reported substantial interruption to contacting clinical teams regarding medical concerns	71% of individuals in their brain tumour constituencies feared contracting COVID-19 while attending doctor visits or being hospitalised. 69% of brain tumour patient organisations said that in the communities they serve, patients and caregivers were concerned about treatments being delayed, cancelled, modified, or substituted because of the pandemic. 24% were redirected to a different treatment centre. 35% Challenges in participating in clinical trials/ participation being delayed or cancelled	31% End of life issues- they did not report on the exact issues.	22% had problems with the supply of medicine/ shortages 34% reported food shortages 16% had difficulties with food delivery or click and collect services at their local supermarket	**Not reported**	37% reported interruptions to transportation due to COVID-19 12% had issues with medical insurance / reimbursement 25% experience loss of employment 37% had concerns about meeting financial commitments (i.e., mortgage repayments, loans, insurances)	49% reported an additional childcare pressure (i.e., home school)	71% reported an increased pressure of self-isolation (i.e., visitor restrictions)
Büntzel J et al., 2020 Germany	"During the lockdown 127/342 (37.1%) participating patients have already registered minor physical wellbeing."	42.9% (150/350) of patients felt strong or very strong mental stress with this actual pandemic situation 119 patients reported about beginning mental stress. 57% (69/121) Hospitalised patients reported additional mental stress because of visitor restrictions.	**Not reported**	**Not reported**	69.2% (247/357) of participants reported to be confused by the public discussion and information about COVID-19.	**Not reported**	**Not reported**	**Not Reported**	38.5% (132/342) expected difficulties to get their individual therapies itself. 52.5% (186/354) were afraid of prolonged breaks between therapies or waiting times for necessary treatments because of the COVID-19 pandemic.	**Not Reported**	67.3% (239/355) persons felt strongly or very strongly restricted by the official regulations. 73.1% (226/309) Out-patients/ cancer survivors reported distress because of isolation.
	Not reported	25% reported social distancing behaviours	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	47% reported delaying any type of care due to COVID-19	**Not reported**	25% reported

Caston N et al., 2021 USA		affected their mental health a lot. 39% reported as having more fear of COVID-19 Positive association between fear of COVID, symptoms of psychological distress and delay in receiving care.							(1% reported income loss 1% reported to insurance loss 27% Hospital or provider election 13% patient election 5% difficulty accessing medications or other medical care)		social distancing behaviours affected their mental health a lot.
Davis K et al., 2021 USA	1% of “My Chart” responses reported fatigue 3% of telephone responses reported fatigue 1% Of “My Chart” responses Reported pain interference with activities of daily living 4% Of telephone responses Reported pain interference with activities of daily living 6% of “My Chart” responses reported deficits to physical function. 9% telephone responses reported deficits to physical function	4% of “My Chart” responses reported anxiety 11% of telephone responses reported anxiety 5% of “My Chart” responses reported depression 6% of telephone responses reported depression 10% of “My Chart” responses reported practical or psychosocial needs 21% of telephone responses reported practical or psychosocial needs	**Not reported**	**Not reported**	**Not reported**	**Not reported**	5% of “My Chart” responses reported nutritional needs 10% of telephone responses reported nutritional needs**.**	**Not reported**	**Not reported**	**Not reported**	**Not reported**
Dimelow J et al., 2021 United Kingdom, UK	**Not reported**	“Fears of getting the COVID-19 virus were slightly lower than fears of cancer recurrence in that 34 had little or no fears of the virus compared to 21 of having recurrence. Similar numbers (7 virus, 9 recurrence) either had a lot of fears or were fearful all the time, with 4 patients having significant fears for both	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**

		and 12 patients with either or both.”									
Falcone R et al., 2020 Italy	**Not reported**	65.70% of all patients reported fear/anxiety related to the COVID-19 pandemic. Patients reported that the COVID-19 outbreak is having on their emotional state Little= 15.7%, some= 34.3%, quite a bit= 31.4% and very much 18.6%.	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	55.7% of all patients reported feeling less medically protected due to the COVID-19 outbreak 41.4% reported feeling that their disease will be affected by the COVID-19 outbreak	**Not reported**	Impact of the COVID-19 pandemic on quality of life, little= 14.3%, some= 34.3%, quite a bit= 38.6% and very much= 12.9%
Fisher P. A et al 2021 USA	Over half of parents indicated that the COVID-19 pandemic negatively affected their physical well-being in the following areas: **Sleep 53.4%, Eating 52.3%, Exercise 53.4%**	40.9% had difficulty sleeping when thinking about COVID-19 27.3% had temper outbursts thinking about COVID-19 22.7% were easily distressed when seeing something that reminds them of COVID-19 62.3% Parents also reported the pandemic negatively affected their mood 71.1% parents reported increased anxiety	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	Parents reported a mean of 7.52 disruptions to their lives.	89.6% reported the closure of schools/childcare centres due to the pandemic was disrupting 68.8% reported an inability to visit or care for a family member was disruptive	45.2% reported feeling less to much less socially connected 47.6% felt slightly less socially connected 93.8% reported the stay-at-home order due to the COVID-19 pandemic was disruptive
Hulbert-Williams J. Nicholas et al., 2021 United Kingdom	**Not reported**	More symptoms of anxiety, stress, depression, and poorer QOL following pandemic onset.	**Not reported**	High unmet needs in relation to care co-ordination and treatment decision making involvement, highlighting the broad reaching consequences stemming from the discouragement of active hospital attendance.	Four of the top 5 most increased patient needs related to hospital care and access, reflecting the consequences of reduced face to face hospital attendance in view of COVID-19 transmissions. care	**Not reported**	**Not reported**	Clinically significant changes to sexual feelings, sexual relationships, and information regarding sexual relationships.	**Not reported**	Positive association between unmet needs in patients whose support networks focus on family communication, practical caring tasks and accessing their own support.	The most significant domain of unmet needs relates to work and social settings.

										Reported additional support in coping with the demands of home- based caring pressures. Significant change to the opportunities to participate in decision making about the persons cancer treatment, communication with the family, and caring for the person with cancer.	
McFarlene. P et al., 2022 United Kingdom	30% of patients reported pain 47% of patients reported shortness of breath 75% of patients reported weakness of lack of energy 20% of patients reported nausea 12% of patients reported vomiting 37% of patients reported poor appetite 15% of patients reported constipation 10% of patients reported sore or dry mouth	50% of patients reported feeling anxious or worried 27% of patients reported feeling depressed	**Not reported**	**Not reported**	5% felt they had received as much information as they wanted to	37% of patients reported feeling at peace	**Not reported**	**Not reported**	27% had practical issues from their illness.	75% of patients reported their family and or friends felt anxious or worried 30% of patients reported feeling able to share feelings with family and friends	**Not reported**

	35% of patients reported feeling drowsy 65% of patients reported having poor mobility										
Shay. L Aubree et al., 2021 USA	39% reported being less physically active	90% reported anxiety due to worry about their health or their family's health 46% are worried about their job security 36% reported having less sleep 18% reported sleeping more	**Not reported**	36% reported scheduling delays in relation to treatment 28% reported delayed or reduced communication with my healthcare team	28% reported reduced access to treatment services	**Not reported**	7% reported trouble getting food and other personal necessities 15% reported trouble getting their medications	**Not reported**	36% reported decreased productivity at work 28% reported a reduction to job hours or wages 18% reported being temporarily laid off from work 8% reported being forced to use vacation of sick time 5% reported loss of employment	**Not reported**	64% reported feeling more isolated
Kabak. V. et al., 2020 Turkey	20.8% reported feeling unwell a lot of the time 24.5% reported pain	18.9% reported feeling down or depressed 19.8% reported lack of energy/ tiredness 20.8% reported feelings of sadness 26.4% reported anxiety 46.2% reported worry about the results of treatment are beyond their control 48.1% reported fear about the cancer spreading 51.9% reported uncertainty about the future	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	**Not reported**	36.8% reported not being able to do the things they used to do	**Not reported**	**Not reported**

Ostermann. C et. Al ., 2020 USA	15% reported uncontrolled symptoms	6% had a distress score of greater than or equal to 8/10	**Not reported**	13% reported medication issues (i.e., refills, questions, compliance, cost) 10% reported feeling uncertain about how to contact the care team 7% reported a question about the plan of care 7% reported being unaware of the next oncology appointment 3% had no future appointment scheduled or schedule is incorrect	13% reported an interest in advance directives or healthcare power of attorney	**Not reported**	**Not reported**	**Not reported**	17% reported financial difficulties	**Not reported**	**Not reported**
Zomerdijk. N et al., 2021 Australia	**Not reported**	Psychological distress and concern about impact of COVID-19 on cancer management were significant predictors of fear of cancer recurrence. (*B*-0.28 *p=0.001*) and *B* -0.25 *p=0.004*) Unmet supportive care needs was a significant predictor of psychological distress (*B-0.27 p=0.000)* Positive association between psychological distress and unmet needs. (B- 0.27 p=0.000)	**Not reported**	**Not reported**	Concern about impact of COVID-19 on cancer management was a significant predictor of psychological distress (B- 0.09 p=0.096)	**Not reported**	**Not reported**	**Not reported**	Financial concerns were a significant predictor of psychological distress *(B=0.20 p=0.000)* Lost income was a significant predictor of unmet supportive care needs (*B-0.13 p=0.009)*	Limited opportunity for family support was a significant predictor of psychological distress (*B- 0.08 p=0.077)*	**Not reported**