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Cancer Services During the COVID-19 Pandemic: Systematic Review of Patient's and Caregiver's Experiences

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Purpose: Cancer patients have faced intersecting crises during the COVID-19 pandemic. This review aimed to examine patients' and caregivers' experiences of accessing cancer services during the pandemic and its perceived impact on their psychological wellbeing.

Patients and Methods: A protocol-led (CRD42020214906) systematic review was conducted by searching six databases including EMBASE, MEDLINE and CINAHL for articles published in English-language between 1/2020 and 12/2020. Data were extracted using a pilot-tested, structured data extraction form. Thematic synthesis of data was undertaken and reported as per the PRISMA guideline.

Results: A total of 1110 articles were screened, of which 19 studies met the inclusion criteria. Studies originated from 10 different countries including the US, UK, India and China. Extracted data were categorised into seven themes. Postponement and delays in cancer screening and treatment, drug shortages and inadequate nursing care were commonly experienced by patients. Hospital closures, resource constraints, national lockdowns and patient reluctance to use health services due to infection worries contributed to the delay. Financial and social distress, isolation, and spiritual distress were also commonly reported. Caregivers in addition felt anxious about infecting cancer patients with COVID-19.

Conclusion: Patients and caregivers experienced delays in cancer screening, treatment and care during the COVID-19 pandemic and negatively affected their psychological wellbeing. Their views and preferences should be accounted to minimise the impact of the current and any future pandemics and ensure resilient cancer services.

Protocol Registration: Published protocol registered with Centre for Review and Dissemination CRD42020214906 (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=214906).

Keywords: cancer care, cancer screening, COVID-19, coronavirus, patients, caregivers

Introduction

Coronavirus disease 2019 (COVID-19), caused by the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2),¹ has challenged the resilience of healthcare systems and economies globally. The pandemic has placed an immense strain on cancer services, resulting in disruptions largely due to measures necessary to minimise patient exposure to the virus coupled with strains on health services resources. Such disruptions for cancer patients can accentuate the poor prognosis compared to non-cancer patients.² Notably, the overall case fatality rate due to COVID-19 for cancer patients during initial phase of the pandemic was reported to be 23.4% (95% CI= 9.7%

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to 40.5%) compared to 5.9% (95% CI= 1.9% to 11.7%) for non-cancer patients.³ Data estimates suggest that a reduction of up to 85% in US-based cancer screening services at the height of the first wave (March–July 2020).⁴ In England, urgent referrals for suspected cancer were down 16% (348,000 referrals) compared with data in the previous year.⁵ Given that early diagnosis and timely access to appropriate treatment modality are critical factors for positive patient outcomes,^{2,6–8} The number of avoidable cancer-related deaths is therefore predicted to substantially increase.⁶ These service interruptions are also likely to impact negatively those receiving or awaiting palliative care.

The pandemic and the consequent disruption in health services have led many to suggest that cancer has become the “forgotten C”.^{9,10} Whilst current research places appropriate emphasis on the relationship between COVID-19 and treatment adjustments and survival outcomes,^{3,6–8,11,12} it is important to consider patient and caregiver views and experiences. These could inform the further development of resilient cancer services for the current and future pandemics. This systematic review aimed to examine patients’ and caregivers’ experiences of accessing cancer services during the COVID-19 pandemic and the perceived impact on psychological wellbeing.

Methods

The systematic review was conducted and reported in accordance with the recommendation of Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines,¹³ based on a published protocol (CRD42020214906). Reporting was done as per PRISMA checklist [13] (electronic [Supplementary Material 2](#)).

Literature Search

CINAHL, EMBASE, MEDLINE, Google Scholar, Wellcome Open Research and Authorea (for unpublished studies and ongoing peer reviews) databases were searched systematically using medical subject headings (MeSH) and free-text keywords including “cancer”, ‘oncology, and “Coronavirus”, ‘COVID-19’ and related terms (electronic [Supplementary Material 1](#)) from January 2020 till December 2020. Boolean operators were used to refine the search.

Inclusion and Exclusion Criteria

Studies published in English on the views, experiences and perceived impact of COVID-19 on cancer screening and care from the perspectives of patients/public and/or their

caregivers (both formal and informal) were included. The search was not restricted to any cancer types (including palliative care), settings or participant demography.

Screening and Selection

Initial screening of titles was conducted independently by two investigators (SD and VP), with any disagreements resolved through discussion and consultation with a third investigator where needed. Title screening was followed by abstract and full-text screening with reference to the inclusion and exclusion criteria.

Data Extraction and Analysis

Data were extracted by one author (SD) and confirmed by another author (VP) using a pilot tested, structured data collection form. A thematic synthesis was adopted to analyse the extracted data, which were reported into themes and subthemes.¹⁴

Quality Assessment

A Critical Appraisal Skills Programme (CASP) tool was used to assess the quality of qualitative studies¹⁵ and the “NIH Quality of Observational, Cohort and Cross-Sectional Studies Assessment Tool” for survey studies.¹⁶ Quality assessment was undertaken by SD and VP.

Results

Characteristics and Quality of Included Studies

The initial search yielded 1110 results, with 19^{17–35} included in data extraction and synthesis ([Figure 1](#)). Studies reported experiences from participants in 10 countries, largely Italy (n=4) the US (n=3), India (n=3), the UK and the Netherlands (n=2 each). The majority of studies employed a cross-sectional survey methodology (n=14) and five were qualitative ([Tables 1 and 2](#)). Results of quality assessment are presented in electronic [Supplementary Material 3 and 4](#).

Results of Thematic Synthesis

Seven key themes of synthesised data and several sub-themes were identified, relating to experiences of accessing cancer screening and diagnosis; experiences of accessing cancer treatment and care services; communication in relation to cancer care; perceived risks of infection; anxiety and fear; adverse impact on personal life, family and finances; resilience and coping mechanisms and caregivers’ specific concerns ([Table 3](#)).

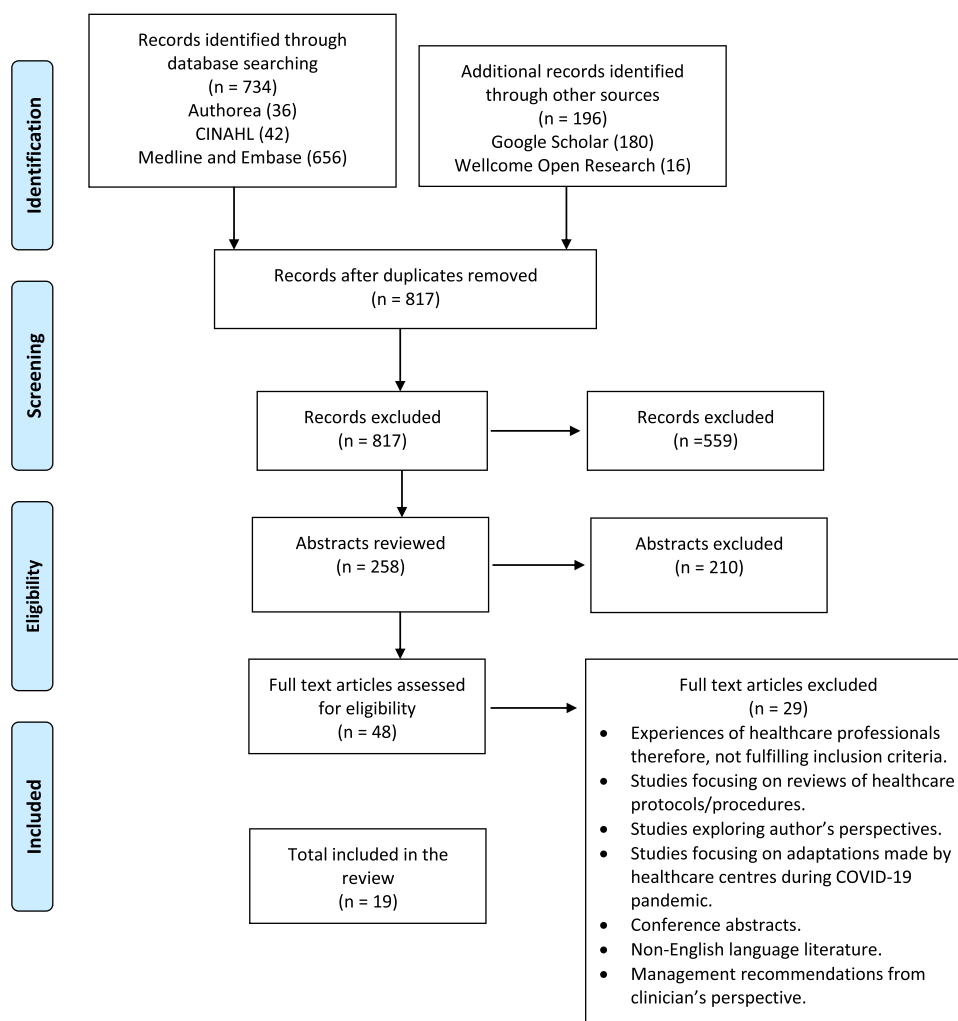


Figure 1 PRISMA diagram.

Notes: Adapted from Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6:7 e1000097. doi:10.1371/journal.pmed1000097.¹³

Experiences of Accessing Cancer Screening and Diagnostic Services

Disruption to cancer screening and diagnosis was a commonly reported theme. A cross-sectional survey assessing the experiences of sarcoma patients at two of the largest specialist sarcoma centres in Europe reported that one-third experienced postponement of appointments or scans by at least three months.³⁵ Patients also reported cancellations of routine follow-up clinic appointments in studies conducted in the UK and US.^{31,34} In a further two studies, patients expressed anxiety and fear due to postponement of cancer-related laboratory tests and diagnostic imaging.^{24,31} This overwhelming sense of anxiety amongst patients was further demonstrated in one study, with patients describing the pandemic as overshadowing the

needs of families and severely affecting the quality and scope of cancer services.²⁹ Some patients described their experiences of COVID-19 prevention taking precedence over cancer treatment and care.²⁹

Experiences of Accessing Cancer Treatment and Care Services

Participants in most studies reported treatment delays,^{17,18,20,22,24-31} for a number of varied reasons including hospital cancellations, city lockdowns and COVID-19 testing requirements. Deferral of planned radiotherapy and very long appointment waiting were amongst the issues cited by a number of participants in a study conducted in India.³⁰ Participants in a US study reported that radiation, infusion therapies and

Table 1 Characteristics of Qualitative Studies and Key Results

Study ID & (Country)	Study Aim(s)	Study Setting	Study Design & Methodology	Participant Numbers & Selection	Key Findings
Dhavale 2020 (India) ²²	To describe the challenges faced by patients and caregivers during the lockdown due to the COVID-19 pandemic.	Palliative care centre.	A qualitative study using an exploratory approach to review case notes followed by framework analysis.	Out of 30 patients, 9 families that had received care services during the lockdown period were invited to participate.	A range of challenges were faced by patients including: physical distress due to lack of availability of medicines and nursing care; emotional distress due to the interruption of cancer treatment; financial and social distress about loss of incomes, isolation; and spiritual distress due to the uncertainty of rites as well as fulfilment of last wishes. Three key themes were identified: swinging on the path of fear to adaptation, left-alone at emotional distances and care system confusion, and decreased quality of care.
Mirlashari 2020 (Iran) ²⁹	To investigate the perspectives of children with cancer and their family in the era of the COVID-19 pandemic.	Paediatric hospital.	Semi-structured, telephone interviews followed by thematic analysis.	21 participants: five children, thirteen mothers, a father and three paediatric oncology nurses were selected using the purposive sampling technique.	The children expressed their concerns about being exposed to an unknown and enormous threat. They pointed out other significant concerns, such as changes in the treatment process, the lack of effective treatment, and how the disease has become so widespread.
Hyland 2020 (United States) ²⁸	To characterise the behavioural and psychosocial responses of people with advanced lung cancer to the COVID-19 pandemic.	Cancer centre.	Baseline questionnaire and semi-structured interview were conducted and repeated after one month.	15 patients.	Several themes emerged from the data: cancer as the primary health threat, changes in oncology practice and access to cancer care, awareness of mortality and perceptions of risk, behavioural and psychosocial responses to COVID-19, sense of loss/mourning and positive reinterpretation/greater appreciation of life. All participants reported changing their behaviour in response to COVID-19.

(Continued)

Table 1 (Continued).

Study ID & (Country)	Study Aim(s)	Study Setting	Study Design & Methodology	Participant Numbers & Selection	Key Findings
AlWaheidi 2020 (Gaza) ¹⁸	To assess whether COVID-19 could lead to further inequity in cancer care and poorer outcomes for Palestinians with cancer.	Tertiary care setting.	Semi-structured qualitative interviews were conducted prior to the introduction of COVID-19. The women were then followed-up in order to examine the changes in health and experiences of care.	20 women with a breast cancer diagnosis between 2017 and 2018.	A number of women expressed concerns about catching COVID-19 in the hospital setting. New concerns emerged about the impact of COVID-19 on treatment.
Casanova 2020 (Italy) ¹⁹	To assess the perception of risks and level of stress concerning COVID-19 amongst young patients with cancer.	Paediatric oncology unit.	Semi-structured qualitative, online questionnaire.	75 patients: 25 were receiving treatment, 25 were in follow-up and had completed their treatment and 25 were healthy peers.	Whilst the majority of healthy peers did not expect to be affected by the virus, a large proportion of patients (more than those in follow-up), were worried and felt at risk of severe complications. Most responders in all three groups reported that they changed their daily habits.

surgical tumour removal were subject to severe disruption.³¹ The impact on cancer surgery was highlighted in a US study, where 10 of 38 participants experiencing delays for ovarian cancer surgery.²⁴ A study conducted at a tertiary-care referral hospital in Italy reported a median surgery waiting time of 53 days (IQR: 35–72 days) which was reported to be a marked increase on pre-pandemic waiting times.²⁶

A study based in India reported additional issues of access including the deferral of nutritionist input, lack of availability of psychological counselling and peer group support services.³⁰ There was a dearth of availability to online counselling services.

Emotional distress was common in patients who had experienced disruption.²⁸ The uncertainty surrounding medication availability and the lack of nursing care available for patients was an issue, particularly for those living alone.^{22,30} For example, patients with cervical and oral cancer struggled to source certain dressing materials and had utilise defective dressings.²² Family and friends were prohibited from accompanying patients to appointments and visiting inpatients, leading to distress for both. In a study conducted at a palliative care centre in the US, participants likened the experience to being “prisoners in a cage”.²¹

Communication in Relation to Cancer Care

Disruptions to regular communications between patients and health services were commonly reported, with many studies reporting the use of remote forms of communications including telecommunication and telephone.^{17,20,22,30,35} Patients identified positive aspects of telecommunication for example, the ease of accessing care from the privacy and comfort of one’s home and the ability to maintain physical distance.²² The majority of patients in one study hoped for continuation of online services post-pandemic.²⁵ In another study, almost two-thirds of patients felt that they were still able to contact the healthcare team and so expressed feelings of reassurance.³⁵ However, in one study conducted in India, patients reported difficulties in booking virtual appointments and unpredictable network issues.³⁰

Anxiety, Fear and Perceived Risk of Infection

Feelings of anxiety and fear surrounding the pandemic were common, with eighteen studies referencing changes in emotional and psychological functioning.^{17–30,32–35} Approximately 55% of the 204 participants in one study

Table 2 Characteristics of Quantitative Studies and Key Results

Study ID & (Country)	Study Aim(s)	Study Setting	Study Design and Methodology	Participant Numbers and Selection	Key Findings
AlShahrani 2020 (Saudi Arabia) ¹⁷	To assess the impact of the COVID-19 pandemic on children with in terms of the medical service provided, precautionary measures implemented by the hospital cancer unit to prevent the spread of infection, the acceptance of virtual platforms and the psychological and mental impact.	Tertiary institution within a hospital setting.	Cross-sectional observational study. Participating parents were asked to complete a booklet type survey questionnaire at the clinic visit or via a virtual platform.	204 cancer patients between 0–14 years of age diagnosed with or recently diagnosed with cancer.	63% of patients reported a delay in treatment received during the COVID-19 pandemic. Key reasons include hospital cancellations or procedure delays. A third of patients (30.8%) reported lack of cancer support and shortage of medications during the pandemic. Almost all were fearful of contracting the virus in healthcare settings and over 80% experienced an adverse impact on quality of life.
Swainston 2020 (United Kingdom) ³⁴	To explore the effect of disruption to scheduled oncology services and the UK government shielding letter on emotional and cognitive vulnerability amongst a group of women affected by primary breast cancer; examine the relationship between COVID-19 related emotional vulnerability (COVID-EMV) and general anxiety, depression and perceived cognitive function.	Breast cancer unit.	Cross-sectional study design. Participants were asked to complete a series of online questionnaires.	234 women with a diagnosis of primary breast cancer were recruited through voluntary sampling using advertisements placed on support platforms.	About a third (31.6%) had been impacted by disruption to their scheduled oncology services (for example, had appointments cancelled or delivered over the phone). Disruption to scheduled oncology services had a significant main effect on women's COVID-EMV; a measure of COVID-19 related emotional vulnerability, their general anxiety and depression. Women who experienced severe disruption showed greater levels of general emotional vulnerability and COVID-EMV.
Desideri 2020 (Italy) ²¹	To prospectively assess patient satisfaction using patient reported measures (PREMs) about doctor-patient interaction in a high-volume radiation therapy and oncology centre during the COVID-19 pandemic.	Radiation oncology unit.	A prospective monocentre study. Surveys consisting of two validated questionnaires (EORTC QLQ-C30 and FACIT-TS-G version 1) and 14 specific questions were administered to the recruited outpatients.	125 patients.	The average Global Health Status score (GHS) was 61.67. Emotional functioning, social and cognitive domains obtained scores of 75.48, 80.13 and 84.67, respectively. Majority of patients (89.6%) rated their treatment as good, very good or excellent. Despite stringent measures to contain the spread of COVID-19, there was a high level of cancer outpatient satisfaction.

(Continued)

Table 2 (Continued).

Study ID & (Country)	Study Aim(s)	Study Setting	Study Design and Methodology	Participant Numbers and Selection	Key Findings
Güven et al, 2020 (Turkey) ²⁷	To assess the perspectives and fears of cancer patients about COVID-19.	Outpatient infusion chemotherapy unit.	Questionnaire consisting of 13 multiple-choice questions.	250 adult cancer patients. A response rate of 78% (195/250) was achieved.	Most patients saw treating oncologists at least once during the pandemic, mostly in hospital. Almost all patients had some degree of COVID-19 fear and more than 80% expected disruptions in cancer care.
Schellekens 2020 (Netherlands) ³³	To explore experiences with the COVID-19 pandemic in patients or family members who sought help at a mental healthcare institute for psycho-oncology.	Mental health institute specialising in psycho-oncology care.	12-item survey assessing the psychosocial burden of the COVID-19 pandemic followed by thematic analysis.	871 patients invited, 274 responded (233 patients and 41 family members). A response rate of 31.5% achieved.	The pandemic added uncertainty for many patients. 46% of patients feared not being able to say farewell to family and friends in case of dying from COVID-19. 36% of patients described feeling lonely which stimulated their worries regarding cancer. A large proportion of patients felt more at ease because of lockdown.
Greco 2020 (Italy) ²⁶	To investigate the health-related quality of life of uro-oncologic patients whose surgery was postponed without being rescheduled during the COVID-19 pandemic.	Tertiary-care referral hospital.	SF-36 online questionnaire measuring eight domains.	50 patients (70% response rate).	86% of patients reported an almost intact physical function but a significant emotional alteration characterised by a prevalence of anxiety and loss of energy.
Mitra 2020 (India) ³⁰	To study the challenges faced by cancer patients in India during the COVID-19 pandemic and assess the effectiveness of adopted interventions.	Hospital.	Cross-sectional study. Participants completed an online pre-structured questionnaire. Data analysed using descriptive statistics.	100 randomly selected cancer patients in different stages of treatment and follow-up. (36% response rate).	92% of patients reported an increase in anxiety levels. Reasons include: fear of COVID-19, fear of their inherent disease getting aggravated due to treatment delays, fear of death and fear of losing job and financial crisis for family members.
Younger 2020 (United Kingdom) ³⁵	To assess the impact of the COVID-19 pandemic on care experiences, worry and health-related quality of life (HRQoL) in patients with sarcomas.	Medical oncology and radiation oncology departments at two sarcoma centres.	Cross-sectional survey.	350 patients. Response rate of 44%.	Patients identified the following care modifications as a result of the pandemic: telemedicine (74%), postponement of appointments/scans (34%) and treatment (10%). Worry about COVID-19 infection was moderately high (5.8/10). Cancer-related worry, low resilient coping and uncertainty about treatment intent were associated with COVID-19 worry.

(Continued)

Table 2 (Continued).

Study ID & (Country)	Study Aim(s)	Study Setting	Study Design and Methodology	Participant Numbers and Selection	Key Findings
Ghosh 2020 (India) ²⁵	To analyse patients' willingness to continue chemotherapy during the pandemic and identify factors influencing decisions.	Hospital medical oncology department.	A prospective observational study. Questionnaire-based survey given to eligible patients.	302 patients, >18 years, undergoing systemic therapy for solid malignancies and who visited the centre during lockdown (1 st -10 th April 2020).	203 patients wanted to continue chemotherapy, 40 wanted to defer and 56 wanted the physician to decide. The worry about catching COVID-19 was high in those with controlled disease.
Qian 2020 (China) ³²	To explore the intensity of physical and mental distress among cancer patients during the epidemic.	Hospital radiation oncology department.	53 question survey assessing patient's perception of the impact of COVID-19 using the Edmonton Symptom Assessment Scale (ESAS) and the Hospital Anxiety and Depression Scale (HADS).	129 confirmed cancer patients. Response rate of 64.5%.	All symptoms assessment scores on ESAS were mild except financial distress. The majority of patients expressed fear of becoming infected themselves (85%) or their family member (91%). 127 participants reported that their life was affected by COVID-19 and 91 reported they needed mental health support.
Frey 2020 (United States) ²⁴	To evaluate the experience of women with Ovarian cancer during the Coronavirus disease 2019 pandemic.	Oncology department.	Online survey focussing on treatment interruptions and quality of life.	603 women with current or previous diagnosis of cancer. 92% response rate.	175 participants experienced a delay in some component of their cancer care. 133 participants had a delayed physician appointment. 285 participants reported borderline anxiety and 147 reported borderline depression.
Papautsky 2020 (United States) ³¹	To assess healthcare needs of breast cancer patients requiring access to crucial services during the COVID-19 pandemic.	Oncology department.	50-item survey.	609 adult breast cancer survivors. Snowball sampling technique used to recruit participants.	44% of participants reported cancer treatment delays. 30% of respondents reported delays in hospital or clinic-based cancer therapies.
De Joode 2020 (Netherlands) ²⁰	To assess the impact of the COVID-19 pandemic on patients with cancer and the consequences for their treatment.	Hospital.	Online survey consisting of 20 questions on four topics: patients' characteristics, contact with the hospital, consequences of the COVID-19 pandemic and concerns about COVID-19.	5302 patients with cancer.	30% of patients reported consequences for their oncological treatment or follow-up. In most cases, this resulted in conversion from hospital visits to consultation by video or phone. Chemotherapy (30%) and immunotherapy (32%) were most frequently adjusted.

(Continued)

Table 2 (Continued).

Study ID & (Country)	Study Aim(s)	Study Setting	Study Design and Methodology	Participant Numbers and Selection	Key Findings
Falcone 2020 (Italy) ²³	To explore the impact of the COVID-19 pandemic on emotional well-being and quality of life of cancer patients.	Thyroid cancer centre.	Two online questionnaires: a 21-item questionnaire and EORTC QLQ-C30 questionnaire.	137 patients. Response rates were 51% and 44.5% for each questionnaire respectively.	The median COVID-19 concern score was 8/12. Most responders reported being satisfied with the support they had received from health-care professionals since the start of the pandemic.

conducted in a tertiary-institution felt that it was not safe to visit the hospital.¹⁷ Notably, cancer patients expressed fear about the consequences and complications arising from them contracting COVID-19.¹⁷ There were emotional reactions to the prospect of not being able to say a final farewell to family and friends.³³ References were also made to fears surrounding family members contracting the virus and patients expressed worries and concerns about treatment delays due to the postponement of elective procedures.³² More than half of the participants in a US study reported new-onset of anxiety or depression.²⁴ Nearly a quarter (23% of the 204) participants in one study were in receipt of the government “shielding” advice.³⁴

Studies conducted in Saudi Arabia and Iran examined anxiety responses amongst children and their caregivers.^{17,29} Parents reported fears surrounding COVID-19 mortality rates and expressed concerns about the high transmissibility and limited knowledge surrounding the virus.²⁹ In one of these studies, over two-thirds of parents reported the onset of new behavioural issues amongst their children since the pandemic.¹⁷ Parents were worried about the negative effects of the pandemic on children’s mental and physical health, both now and in the long-term.

Adverse Impact on Personal Life, Family and Finances

Ten studies reported consequences of the pandemic on cancer patients’ personal lives, their families and the potential finances.^{17,19,22,24,28,29,32–35} Impact on social activities due to lockdowns was also described, with loneliness fuelling patients’ worries about their cancer.³³ Concerns surrounding loss of income and employment instability for cancer patients and family members were

reported.³⁵ Those receiving palliative care expressed frustration and fear at the possibility of not being able to fulfil their last wishes.²²

Caregiver Specific Concerns

Concerns raised by caregivers were reported in two studies.^{22,33} In one study, conducted in the Netherlands, more than half of the participants reported being worried about infecting cancer patients with COVID-19.³³ In another study, caregivers reported feelings of guilt due to their inability to ease their relatives’ suffering and, in some cases, were reluctant to provide appropriate care (eg, changing dressings) due to worries about transmitting COVID-19.²² Moreover, caregivers reported that once lockdown commenced, they experienced feelings of helplessness as social distancing impacted their ability to provide adequate care.²²

Employment uncertainty was often reported to divert caregivers’ focus from caring to attempting to address the financial strain, worsening feeling of guilt.²² There were also reports of the difficulties arising from a lack of clear information and guidance about COVID-19 and its potential impact on already vulnerable cancer patients.²²

Developing Resilience and Coping Mechanisms

Patient and/or carer strategies to developing resilience and coping mechanisms were described in five studies.^{19,28,29,33,35} For example, in one paediatric hospital-based study, patients reported that, together with their families, they altered their attitudes towards COVID-19 nervousness and fear to regain control of living with the virus.²⁹ In two further studies, patients emphasised their appreciation for everyday life and reported feeling content as a result of lockdown.^{28,33} They reported that the

Table 3 Emerging Themes and Subthemes from Thematic Synthesis

Themes	Subthemes
I. Experiences of accessing cancer screening and diagnosis.	<ul style="list-style-type: none"> • Oncology appointment cancellations. • Reductions in referrals. • Screening non-attendance. • Delays in diagnosis.
II. Experiences of accessing cancer treatment and care services.	<ul style="list-style-type: none"> • Postponement/delays to treatment schedules. • Medicine shortages. • Not allowing visitors in hospitals. • Changes to the prioritisation of care. • Cancellations of psychological counselling sessions. • Changes to nursing practices.
III. Communication in relation to cancer care.	<ul style="list-style-type: none"> • Views and experiences of remote consultations.
IV. Perceived risks of infection, anxiety and fear.	<ul style="list-style-type: none"> • Fear of self and family members contracting the virus. • Fear of incomplete cancer treatment. • Concerns about contracting COVID-19 and the associated consequences. • Depression and changes in cognitive and emotional functioning. • Government shielding letter.
V. Adverse impact on personal life, family and finances.	<ul style="list-style-type: none"> • Consequences of quarantine. • Feelings of loneliness and isolation. • Disruption to work-life. • Fulfilment of end of life wishes.
VI. Caregivers specific concerns.	<ul style="list-style-type: none"> • Stressful aspects of care giving during a pandemic. • Grieving the loss of a relative. • Caregivers own health concerns.
VII. Resilience and coping mechanisms	<ul style="list-style-type: none"> • Feelings of peace and belonging. • Greater appreciation of life. • Time to develop resilient coping mechanisms.

lockdown offered them the time to reflect positively and focus on the “silver lining”, creating a sense of peace which appeared to ease their worries.²⁸ Several patients who were house bound due to their cancer reported a sense of belonging with the rest of the community being in lockdown.³³

Discussion

Discussion of Key Findings and Implications

This is the first systematic review that has explored the impact of the pandemic on the experiences of cancer patients and their caregivers regarding the impact on aspects of cancer screening and care. The review has identified major recurring themes of barriers to accessing cancer screening and diagnosis; anxiety and fear; perceived risks of infection; adverse impact on personal life, family and finances; caregivers concerns and resilience; and coping mechanisms adopted by patients and carers.

The entire landscape of cancer management has changed as a result of the COVID-19 pandemic.³⁶ This is reinforced by findings of this review which also adds to the evidence based on the experiences of patients and carers. As a result of diagnostic and treatment delays, governments and health systems are expecting a surge in the number of avoidable, cancer-related deaths.² Participants in studies included in this review expressed concerns surrounding incomplete treatment, complications associated with contracting COVID-19 and changes to their psychological and emotional wellbeing. The suspension of cancer screening, cancellation of routine oncology appointments and postponement of treatment were linked to increased feelings of stress and anxiety; suggesting that there is a critical gap in disaster preparedness.³⁷ Consequently, vulnerable patients were at greater risk of poor cancer outcomes, with further implications for mental health, symptom control and quality of life. For patients actively seeking end of life treatment, it was evident that strict social distancing measures limited caregiver–patient interactions and many caregivers felt disheartened that they could not provide support during this crucial time.^{22,33} However, the evidence base relating to caregivers is limited, with only two studies reporting their perspectives. Further research in this key population is warranted.

Anxiety and fear, and perceived risk of infection when using cancer services were commonly reported. For example, a study conducted in Gaza reported that prior to COVID-19, only one toilet was available for public use in the oncology department and with cancer patients expressing their fears about the lack of social distancing and, close proximity.¹⁸ The World Health Organization (WHO) has also voiced concern about the lack of personal protective equipment (PPE) and drug deficit.³⁸ The

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repercussions of resource limitations on cancer treatment outcomes outlined above needs to be explored further.³⁹

Lessons learnt from this pandemic should become an integral part of the management of cancer patients, including those receiving palliative care, ensuring a continuum of cancer care. Future pandemic preparedness is necessary in order to minimise the disruption experienced by both cancer patients and their caregivers. Efforts should firstly be placed on restoring cancer services with the prioritisation of screening, early detection and diagnosis. As primary care is focal to diagnosis, it is vital that patients with symptoms are encouraged to present, feeling comfortable to seeking medical help and are then assessed in a timely manner.⁴⁰ Remote consulting comes with many communication challenges for example, “missed cues” which would may be more apparent in face-to-face consultations.

Introducing innovations such as triage tests for patients reporting a specific set of symptoms may help to address such challenges and ensure that prompt referrals are made.⁴⁰ The consequent delay of treatment due to COVID-related measures should be considered on an individual, case by case basis for each patient; ensuring that critical patients receive adequate therapy. Alongside this, the public health implications of potentially delaying treatment versus COVID-19 prevention should be assessed.

Internationally, the professional cancer societies, including The American Society of Clinical Oncology (ASCO), have produced guidance in relation to safe provision and continuity of cancer care during the pandemic.^{41,42} While this guidance advocates greater flexibility and alternative treatment options to suit patient circumstances, the impact on personal, psychological and financial wellbeing on patients need to be considered. Patient centred communications from health service providers to address patient fears of contracting the virus while on treatment and reluctance to use health services are essential.

Throughout the pandemic, it is necessary to evaluate detection rates, treatment uptake and outcomes so that valid pre-pandemic comparisons can be made. It is also imperative to consider healthcare professionals’ and wider stakeholders’ experiences of delivering cancer services. Roles of non-medical healthcare professionals including pharmacists can be diversified to support cancer services^{43–45} including their roles in administering COVID-19 vaccination.⁴⁶ Novel, faster and accurate methods of detection of symptomatic and asymptomatic

COVID-19 can minimise disruptions to the services in the future.^{46,47}

Strengths and Limitations

The review was conducted using a rigorous and systematic approach in line with best practice. There are, however, a number of limitations. The search period was limited to one year; given the very dynamic and ever changing nature of the pandemic and the associate literature, it is possible that new studies will rapidly emerge. In synthesising data from studies conducted in a number of countries, the differing healthcare structures and processes may impact the generalisability and transferability of the findings.

Conclusion

This systematic review suggests that globally cancer patients are experiencing postponement and delays in the cancer screening and treatment, drug shortages and inadequate nursing care were commonly experienced. These factors contributed to anxiety, loneliness and fear amongst patients and carers. Lockdowns, financial issues faced by patients and patient reluctance to use services contributed to the treatment delays and cancellations. Future service models should incorporate patient and caregiver views identified from this study. Improving infection control measures and vaccination rates can bring COVID-19 infection down to manageable levels and minimise cancer service disruptions.

Abbreviations

ASCO, The American Society of Clinical Oncology; CASP, Critical Appraisal Skills Programme; NIH, National Institute of Health; PPE, personal protective equipment; PRISMA, Preferred Reporting Items for Systematic Review and Meta-analysis.

Data Sharing Statement

The data underlying this article are available in the article and <https://www.dovepress.com/get-supplementary-file.php?f=318115.docx> Supplementary Materials submitted with the manuscript.

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Disclosure

The authors declare that they have no conflicts of interest in this work.

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