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SYSTEMATIC REVIEW

Patients' experiences of cancer immunotherapy with immune checkpoint inhibitors: A systematic review and thematic synthesis

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Abstract

Aim: To obtain a deeper understanding of peoples' experiences of cancer treatments with immune checkpoint inhibitors (ICIs).

Background: ICIs are transforming survival outcomes for many with certain advanced cancers. Given the possibility of unique immune-related adverse events (irAEs), understanding treatment experiences is crucial to identify support needs and provide safe and effective person-centred care.

Design: A systematic review of qualitative research and thematic synthesis. To report this review, the Preferred Reporting Items for Systematic Analysis and Meta Analysis (PRISMA) checklist and Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidance have been used.

Data Sources: MEDLINE, EMBASE, PsycINFO, CINAHL and Web of Science databases were searched in January 2022 for eligible studies published in English from database inception.

Review Methods: Two reviewers independently screened records, identified papers for inclusion and appraised methodological quality using the Critical Appraisal Skills Programme checklist. Themes were developed using thematic synthesis.

Results: Eighteen papers were included and three analytical themes developed: immune checkpoint inhibitor treatment decision-making; the experience and impact of immune checkpoint inhibitor treatments; and appraising and responding to irAEs.

Conclusion: The synthesis renders visible individuals' unmet information, psychological and practical support needs. It identifies shortcomings in immune checkpoint inhibitor treatment decision-making processes and highlights the need for healthcare professionals to recognise and sensitively handle individuals' treatment expectations. Individuals' understandings of and responses to irAEs are also illustrated, and attention drawn to patients' concerns about healthcare professionals' checkpoint inhibitor and irAEs knowledge.

Implications for Patient Care: To sensitively manage treatment expectations and uncertainties, and optimise health outcomes, there are distinct points in treatment trajectories where care and support might require adapting and enhancing.

Impact: This review addresses people's experiences of immune checkpoint inhibitor treatments. The core findings reveal unmet information, psychological and practical support needs. Insights derived from this review will enhance individuals' experiences and outcomes and healthcare professionals' practice.

Patient or Public Contribution: No patient or public involvement.

KEYWORDS
cancer, immune checkpoint inhibitors, patient experience, qualitative research, systematic review

1 | INTRODUCTION

As early detection, diagnostics and cancer treatments advance while populations age and grow, more people will live with cancer and, in many cases, the impact of its treatment (Siegel et al., 2022). The treatment landscape for people affected by cancer has evolved substantially. One area is rapid progress in immunotherapy (Zhang & Chen, 2018), which is transforming treatment experiences and survival outcomes for people with some advanced solid and haematological cancers.

Immune checkpoint inhibitors (ICIs) are one of the most successful developments in immunotherapy (Bagchi et al., 2021). Results from numerous international clinical trials indicate ICIs are transforming survival outcomes and quality of life for a subset of people affected by various cancers where historically treatment options have been limited (see, e.g. Harrington et al., 2017; Larkin et al., 2019; Mok et al., 2019; Petrella et al., 2017). When evaluated against traditional anti-cancer treatments such as chemotherapy, consistent improvements in progression-free and overall survival have been reported, in people previously treated, and those new to any treatment (see, e.g. Antonia et al., 2018; Ascierto et al., 2019).

ICI treatment regimens are intensive and may last for up to 2 years. However, unique immune-related adverse events (irAEs), some of which can be life-threatening, are possible (Wang et al., 2018). Ramos-Casals et al. (2020) reported that of the 13,000 irAEs reported across 18 countries more than two thirds were related to ICIs. IrAEs vary according to ICI, cancer type and treatment duration. They include autoimmune and inflammatory related endocrine, musculoskeletal, joint, skin, breathing and bowel problems which can persist months to years post ICI treatment completion (Asher et al., 2019). IrAEs can be unpredictable, severe, challenging to manage and negatively affect people's quality of life (Schadendorf et al., 2017). While uncommon, they have also been reported as a cause of death (Wang et al., 2018). Early recognition of irAEs and rapid access to toxicity management are imperative.

With earlier access to some ICI's as standard care in certain cancers, more people will receive these treatments. Yet outside controlled trial settings there may be differences in how people experience and incorporate ICI treatments into their everyday lives. To enhance individuals' treatment experiences, health outcomes and quality of life and ensure timely, safe and effective person-centred care, support and education, it is imperative that across care settings, healthcare professionals understand how people experience ICI treatments.

Robust qualitative research can offer rich, nuanced insights into people's experiences. An abundance of research focuses on people's experiences of traditional anti-cancer treatments. However, the exploration of people's experiences with cancer immunotherapies generally, and ICI treatments specifically, would seem to be limited. Preliminary searches identified no systematic

What does this paper contribute to the wider global community?

- With earlier access to some immune checkpoint inhibitors (ICIs) as standard care in certain cancers, more people affected by cancer will receive these treatments which are associated with immune-related adverse events (irAEs) that can be unpredictable, severe and challenging to manage.
- As these treatments may be delivered over prolonged time periods it is imperative that healthcare staff working beyond specialist oncology settings are aware of and better understand individuals' checkpoint inhibitor treatment experiences particularly as some may present to acute medical or emergency departments rather than specialist oncology services when experiencing symptoms which could be irAEs.
- This systematic review and thematic synthesis offers rich, nuanced insights into individuals' experiences of cancer treatments with ICIs and draws attention to the urgent need to invest in accessible immunotherapy education for healthcare staff employed in generalist care settings.

reviews focusing on peoples' experiences of ICI treatments. Thus, this paper seeks to address and bridge this knowledge gap by examining what is currently known through a systematic review and thematic synthesis in order to enhance healthcare professionals' knowledge for practice.

2 | THE REVIEW

2.1 | Aim

This review aimed to obtain a deeper understanding of peoples' experiences of cancer treatments with ICIs through a systematic review and thematic synthesis of qualitative research exploring these treatments from the perspective of those receiving them.

2.2 | Methodology

Qualitative systematic review methodology was selected to explore the published literature on people's experiences with ICIs. Systematic reviews aim to synthesise available evidence on a topic by searching and selecting the literature in a systematic, explicit and reproducible way, while providing a critical assessment of included studies (Centre for Reviews and Dissemination, 2009; Munn et al.,2018). As this review aimed to explore cancer treatment experiences, a qualitative systematic review with thematic synthesis is a good fit. This is because collating and synthesising qualitative studies can help gain detailed, nuanced understandings of people's unique perspective of cancer treatment with ICIs. Highlighting potential similarities and differences in peoples' experiences can enhance understandings of cancer care provision, with consideration for different healthcare settings.

2.3 | Design

The study design was informed by standard systematic review methods (Centre for Reviews and Dissemination, 2009) with consideration for searching, selecting and synthesising qualitative primary research (Thomas et al., 2017). A systematic review protocol was published on PROSPERO prior to commencing the review (CRD42021261634). Reporting of this review was guided by the updated Preferred Reporting Items for Systematic Analysis and Meta Analysis (PRISMA) (Page et al., 2021) and Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (Tong et al., 2012) guidance (Please refer to online Data S1).

2.4 | Search method

The Population, Intervention, Comparison, Outcome, Study (PICOS) framework influenced the research question development, eligibility criteria and search strategy. This framework was deemed appropriate for this review as it has been found to balance sensitivity and specificity of searches when identifying qualitative literature (Methley et al., 2014).

The search strategy was developed and tested in collaboration with an expert information specialist. Following preliminary searches, relevant publications were checked for potential keywords that could be used for the search strategy. MeSH and textword terms for cancer, immunotherapy and ICIs were used alongside qualitative research filters. The search strategy was tailored for each database. Boolean operators (OR and AND) were used to enhance sensitivity and refine the searches.

On January 28, 2022 one reviewer (JC) systematically searched five electronic databases, MEDLINE, EMBASE, and PsycINFO via Ovid; CINAHL via EBSCO; and Web of Science for records published in English language from inception until January 2022. To check for new research publications, an updated search was conducted on September 22, 2023. The search strategy is presented in online Data S3.

Reference lists of included papers were checked and Google Scholar was used to perform forward citation tracking. Grey literature was searched for relevant publications by exploring cancer-related organisational websites, university deposits and Ethos.

2.5 | Inclusion criteria

Qualitative and mixed methods studies where qualitative data were reported separately and could be clearly extracted were eligible for inclusion when they reported adults' experiences of being treated with ICIs for cancer and were published in the English language. No date limits were set. Detailed inclusion and exclusion criteria are set out in Table 1.

2.6 | Search outcomes

All search results were stored in Endnote™. Following deduplication results were imported into Rayyan™ for title and abstract screening by two reviewers (JC DR) independently. Full text of all potentially relevant abstracts were retrieved and independently assessed for inclusion by JC and DR using a bespoke screening sheet (Online Data S4) previously piloted on two full text papers. Two disagreements during second level screening were resolved by a third reviewer (TW), with the result that one paper was subsequently included.

2.7 | Quality appraisal

Study quality was assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (Critical Appraisal Skills Programme, 2019). Two reviewers (JC, DR)

TABLE 1 Review inclusion and exclusion criteria.

Review question: What do we know about how patients experience cancer immunotherapy treatment with immune checkpoint inhibitors?		
	Include	**Exclude**
Population	People affected by cancer over the age of 18 (with/without partners/carers); Any cancer type; Any stage	Children and young people under the age of 18 affected by cancer; People with conditions other than cancer; Healthcare professionals; Partners/carers only
Intervention	Immune checkpoint inhibitors (ipilimumab, tremelimumab, nivolumab, pembrolizumab, cemiplimab, atezolizumab, durvalumab or avelumab); Single agent or in combination; First or multiple line treatment	Immunotherapy drug not specified; Other cancer treatments without immune checkpoint inhibitors
Outcome	People's experiences with immune checkpoint inhibitors	Studies not reporting people's experiences with immune checkpoint inhibitors; Studies in which immune checkpoint inhibitor treatment experiences cannot be separated from other treatments
Study type	Qualitative; Mixed methods in which qualitative findings can be separated from quantitative	Quantitative; Mixed methods in which qualitative findings cannot be separated from quantitative
Language of publications	English	Not in English

independently appraised included full-text papers. During the appraisal process, each criterion was considered met if reviewers responded 'Yes'. If reviewers' responded 'Can't tell', or 'No', a mark was deducted from the overall quality score and detailed comments were provided. When disagreement occurred, a third reviewer (TW) interceded.

2.8 | Data extraction

Relevant study characteristics were extracted into a piloted data extraction form. Data extraction was performed by one reviewer (JC or DR) and checked for accuracy by a second reviewer (TW).

2.9 | Synthesis

Thematic synthesis was used (Thomas et al., 2017; Thomas & Harden, 2008) to collate findings from included studies. Thematic synthesis is a three stage process: text coding, developing descriptive themes and creating analytical themes. Based on the RETREAT criteria (Booth et al., 2018), thematic synthesis was deemed a good fit for this review as it enabled the rigorous and flexible combination of individuals' experiences.

All full-text reports were imported to NVivo™. Two reviewers (JC, DR) independently coded the findings sections of two data rich qualitative studies with good CASP results line by line. The inductively created codes were discussed by the two reviewers and a preliminary code book developed. One reviewer (JC) coded remaining studies based on the code book. New codes were added if data were identified that did not align with existing codes. On completion of coding, the two reviewers discussed potential themes. Finally, a third reviewer (TW) checked coding and themes for accuracy.

2.10 | Ethics

As this review was based on previously published research, ethical approval was not required. This systematic review was conducted following the principles of research integrity with honesty, rigour and transparency, as presented above in the research methods, and protocol registration on PROSPERO. All processes were conducted in double to minimise bias, including a thorough examination of the quality of included studies which encompassed an investigation of ethics and conflict of interest.

3 | RESULTS

The database searches conducted in January 2022 yielded 1318 records. Following deduplication ($n=296$), 1022 records were title and abstract screened and 988 excluded. No additional records were identified via grey literature searching. Originally, 23 papers were full-text screened and 15 publications were included. For the screening details see Figure 1.

The search update, conducted in September 2023, yielded 347 records. Four new papers were identified and three were included.

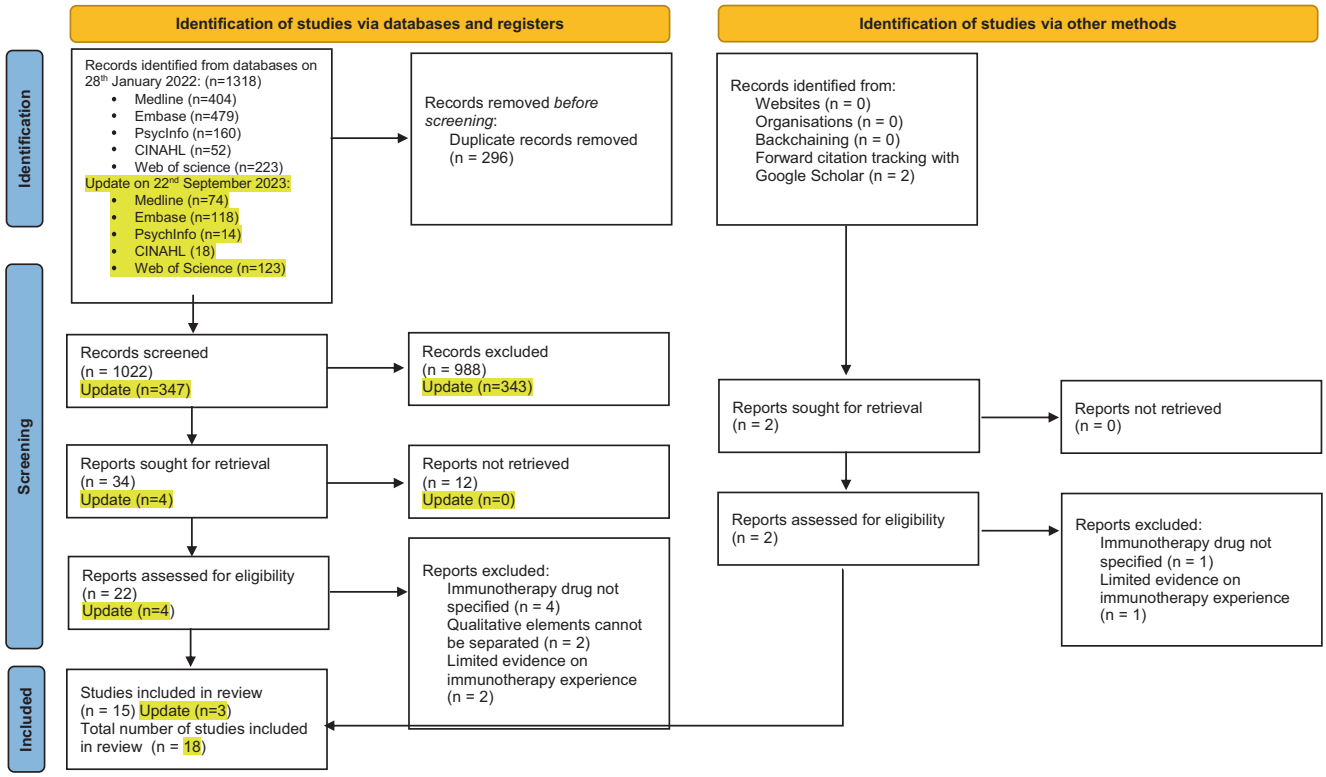

FIGURE 1 PRISMA flow diagram.

Finally, 18 papers were included (a list of excluded papers can be found in online Data S5).

3.1 | Characteristics

Papers were published between 2017 and 2023. The majority of studies were conducted in Australia ($n=5$). Other countries were Canada ($n=2$), USA ($n=2$), China ($n=3$), Germany ($n=1$), Netherlands ($n=1$) and the UK ($n=1$). Three studies were conducted across multiple countries. Study methodologies were qualitative ($n=12$) and mixed methods ($n=6$), with data mainly collected via individual, semi-structured interviews. Additional data collection methods used in three studies included observations as part of an ethnographic study and focus groups. Sample size ranged from 12 to 59. Characteristics of included studies are summarised in Table 2.

Most focused on people with melanoma ($n=7$). Other diagnoses included metastatic Merkel cell carcinoma ($n=2$), lung cancer ($n=4$) and mixed cancer types ($n=5$). In most included studies, participants received ICIs as a single agent ($n=8$). In three studies, participants received ICIs as a single agent or combined with other treatments. Five studies did not disclose if participants received other treatments simultaneously. Five studies focused on a specific ICI, such as avelumab ($n=2$), pembrolizumab ($n=2$), and ipilimumab ($n=1$). Others included a mix of participants receiving different drugs ($n=13$). Participants in two studies had ICIs as a first line anti-cancer treatment, and in two as second- and third-line treatment. In seven studies, participants included those who received ICIs as first, second, or third line, or had previously received a different type of immunotherapy to the treatment line under investigation. In four studies it was unclear if participants had previously received other anti-cancer treatments.

3.2 | Quality of included studies

Included studies were of varying quality. None met all 10 CASP criteria, as all studies insufficiently explored the interviewer-interviewee relationship. Detailed quality appraisal results for each study are presented in Table 3.

3.3 | Thematic synthesis results

Three themes representing the range of experiences captured in the findings reported in the included studies were identified: Immune checkpoint inhibitor treatment decision-making; the experience and impact of ICIs; and appraising and responding to irAEs. Study contributions to each theme are presented in Table 4.

3.3.1 | Immune checkpoint inhibitor treatment decision-making

Most individuals reported that the first time they had heard about ICIs was via their oncologists in the context of treatment

TABLE 2 Summary of included studies (in alphabetical order).

Authors, date type of study	Participants geographical location	Cancer diagnosis	Immunotherapy type	Qualitative data collection methods analytic approach
Ala-Leppilampi et al., 2020 *Type of study* Qualitative	*Number of participants* *n* = 37 *Geographical location* Canada	*Cancer diagnosis* Endocrine (*n* = 2), gastrointestinal (*n* = 3), genitourinary (*n* = 3), gynaecology (*n* = 4), head and neck (*n* = 2), lung (*n* = 1), melanoma (*n* = 18), sarcoma (*n* = 4) *Stage* Advanced, incurable cancer	*Immunotherapy type* PD-1/PD-L1 inhibitor (*n* = 34), CTLA-4 inhibitor (Ipilimumab) (*n* = 16), CD40 stimulator (*n* = 1), GITR stimulator (*n* = 1), ICOS stimulator (*n* = 1), OX40 stimulator (*n* = 1)	*Qualitative data collection methods* Three in-person focus groups (*n* = 6, 6, and 2); Individual in-depth semi-structured interviews by phone or in-person as per participant preference (*n* = 23) *Analytic approach* Inductive interpretive description
Bharmal et al., 2018 *Type of study* Convergent mixed methods study nested within a clinical trial	*Number of participants* Baseline interview (*n* = 19); Week 13 interview (*n* = 14); Week 25 interview (*n* = 12) *Geographical location* Only available for baseline: USA (*n* = 17), Germany (*n* = 2)	*Cancer diagnosis* Merkel cell carcinoma *Stage* Metastatic	*Immunotherapy type* Avelumab	*Qualitative data collection methods* Individual semi-structured telephone interview *Analytic approach* Thematic analysis
Cappelli et al., 2020 *Type of study* Qualitative	*Number of participants* *n* = 14 *Geographical location* USA	*Cancer diagnosis* Melanoma (*n* = 7), endometrial (*n* = 1), Hodgkin lymphoma (*n* = 1), mycosis fungoides (*n* = 1), duodenal (*n* = 1), non-small cell lung (*n* = 1), neuroendocrine carcinoma (*n* = 1), oesophageal (*n* = 1) *Stage* Not mentioned	*Immunotherapy type* ICIs: targeting CTLA-4; PD-1; and/or PD-L1	*Qualitative data collection methods* Individual semi-structured in-person interviews and telephone interviews with two participants *Analytic approach* Inductive thematic analysis
Cheung et al., 2019 *Type of study* Qualitative	*Number of participants* *n* = 29 out of which *n* = 18 had ICIs *Geographical location* Canada	*Cancer diagnosis* Advanced melanoma *Stage* Stage III (*n* = 4), and IV (*n* = 18), no evidence of disease (*n* = 4), remission (*n* = 3)	*Immunotherapy type* CTLA-4 inhibitors (ipilimumab*n* = 14); PD-1 inhibitors (*n* = 4) (pembrolizumab *n* = 3; unspecified *n* = 1)	*Qualitative data collection methods* Individual in-person semi-structured interviews and telephone interviews with four participants *Analytic approach* Grounded theory
Hou et al., 2023 *Type of study* Qualitative	*Number of participants* N = 29 *Geographical location* China	*Cancer diagnosis* Lung cancer *Stage* Stage IV	*Immunotherapy type* Pembrolizumab (*n* = 1); Camrelizumab (*n* = 1); Atezolizumab (*n* = 3); Durvalizumab (*n* = 1); Tislelizumab (*n* = 4); Sintilimab (*n* = 7)	*Qualitative data collection methods* Face to face individual interview *Analytic approach* Inductive thematic analysis

TABLE 2 (Continued)

Authors, date type of study	Participants geographical location	Cancer diagnosis	Immunotherapy type	Qualitative data collection methods analytic approach
Ihrig et al., 2020 *Type of study* Mixed methods	*Number of participants* *n* = 12 *Geographical location* Germany	*Cancer diagnosis* Melanoma (*n* = 3); non-small cell lung cancer (*n* = 2); urogenital cancer (*n* = 2); head and neck cancer (*n* = 3); colon cancer (*n* = 1); germ cell tumour (*n* = 1) *Stage* Metastatic	*Immunotherapy type* Nivolumab (*n* = 8); Pembrolizumab (*n* = 4)	*Qualitative data collection methods* Individual semi-structured interview *Analytic approach* Content analysis
Jamieson et al., 2020 *Type of study* Mixed methods	*Number of participants* *n* = 13 *Geographical location* UK	*Cancer diagnosis* Lung (*n* = 11); bladder (*n* = 1); squamous cell cancer of skin (*n* = 1) *Stage* Not mentioned	*Immunotherapy type* Pembrolizumab (*n* = 10); atezolizumab (*n* = 3)	*Qualitative data collection methods* Individual semi-structured in-person interviews or telephone interviews based on patient preference *Analytic approach* Thematic analysis and descriptive content analysis
Lai-Kwon et al., 2021 *Type of study* Qualitative	*Number of participants* *n* = 20 *Geographical location* Australia	*Cancer diagnosis* Non-small cell lung cancer *Stage* Metastatic	*Immunotherapy type* Pembrolizumab; Atezolizumab; Nivolumab	*Qualitative data collection methods* Individual semi-structured in-person interviews *Analytic approach* Thematic Analysis
Lambert et al., 2020 *Type of study* Qualitative study nested in a phase 2 clinical trial	*Number of participants* Baseline interview: *n* = 29 At least one follow-up (*n* = 19): -Week 13 interview: *n* = 18 -Week 25 interview: *n* = 12 *Geographical location* Baseline interview (*n* = 29): Australia (*n* = 1), France (*n* = 7), Germany (*n* = 6), Italy (*n* = 6), USA (*n* = 9) At least one follow-up (*n* = 19): Australia (*n* = 1), France (*n* = 4), Germany (*n* = 3), Italy (*n* = 5), USA (*n* = 6)	*Cancer diagnosis* Merkel cell carcinoma *Stage* Metastatic	*Immunotherapy type* Avelumab	*Qualitative data collection methods* Individual semi-structured telephone interview *Analytic approach* Thematic analysis
Levy et al., 2019 *Type of study* Qualitative study embedded in a feasibility study	*Number of participants* *n* = 26 *Geographical location* Australia	*Cancer diagnosis* Melanoma *Stage* Advanced, metastatic	*Immunotherapy type* Pembrolizumab	*Qualitative data collection methods* Individual semi-structured in-person interviews (*n* = 24) or telephone interviews (*n* = 2) *Analytic approach* Interpretative phenomenological analysis (IPA)

(Continues)

TABLE 2 (Continued)

Authors, date type of study	Participants geographical location	Cancer diagnosis	Immunotherapy type	Qualitative data collection methods analytic approach
Livingstone et al., 2021 *Type of study* Qualitative	*Number of participants* *n* = 36 -Patients (*n* = 24), -Partners (*n* = 12) *Geographical location* Australia	*Cancer diagnosis* Melanoma *Stage* Resected Stage III	*Immunotherapy type* Nivolumab or Pembrolizumab (*n* = 22/24), Refused ICIs (*n* = 2/24)	*Qualitative data collection methods* Three focus groups (*n* = 3, 4 and 7 patients); Individual semi-structured telephone interviews (*n* = 10 patients, *n* = 12 partners) *Analytic approach* Framework analysis
Milne et al., 2020 *Type of study* Qualitative	*Number of participants* *n* = 32 -Patients (*n* = 23), -Carers (*n* = 9) *Geographical location* Australia	*Cancer diagnosis* Melanoma *Stage* Stage IV	*Immunotherapy type* Ipilimumab; Nivolumab; pembrolizumab	*Qualitative data collection methods* Individual semi-structured telephone interviews *Analytic approach* Interpretive description
Park et al., 2020 *Type of study* Qualitative (Ethnographic)	*Number of participants* *n* = 24 *Geographical location* UK (*n* = 8), USA (*n* = 8), Denmark (*n* = 8)	*Cancer diagnosis* Non-small cell lung cancer *Stage* Stage IV	*Immunotherapy type* Pembrolizumab (*n* = 15); Nivolumab (*n* = 7); Atezolizumab (*n* = 2); Durvalumab (*n* = 1)	*Qualitative data collection methods* Multiple written exercises, observation, semi-structured interviews *Analytic approach* Multiple analytic methods derived from grounded theory, interpretative phenomenological analysis
Shuk et al., 2017 *Type of study* Mixed methods	*Number of participants* *n* = 41 *Geographical location* USA	*Cancer diagnosis* Melanoma, advanced *Stage* Locally advanced, unresectable (*n* = 1), Ballentyne I (*n* = 2), IIIC (*n* = 7), IV (*n* = 31)	*Immunotherapy type* Ipilimumab	*Qualitative data collection methods* Individual semi-structured face to face or telephone interviews as per patient preference *Analytic approach* Thematic analysis
Wong et al., 2019 *Type of study* Qualitative	*Number of participants* *n* = 23 *Geographical location* Australia	*Cancer diagnosis* Melanoma *Stage* Stage IV	*Immunotherapy type* Pembrolizumab	*Qualitative data collection methods* Individual semi-structured interviews *Analytic approach* Thematic analysis

TABLE 2 (Continued)

Authors, date type of study	Participants geographical location	Cancer diagnosis	Immunotherapy type	Qualitative data collection methods analytic approach
Xie et al., 2022 *Type of study* Mixed methods	*Number of participants* *n* = 21 *Geographical location* China	*Cancer diagnosis* Mouth and nasopharynx (*n* = 6), Gynaecological (*n* = 5), Breast (*n* = 2), Melanoma (*n* = 1), Lung (*n* = 4), Stomach (*n* = 2), Colorectal (*n* = 1) *Stage* Advanced with metastases (*n* = 6); No metastases (*n* = 15)	*Immunotherapy type* PD-1 (*n* = 19); PD-L1 (*n* = 2)	*Qualitative data collection methods* Individual semi-structured in-person interviews *Analytic approach* Colaizzi's method of analysis for phenomenological studies
Zhang et al., 2023 *Type of study* Sequential mixed methods	*Number of participants* *n* = 59 *Geographical location* China	*Cancer diagnosis* Lung *Stage* Stage III (*n* = 16) Stage IV (*n* = 43)	*Immunotherapy type* Pembrolizumab (*n* = 34) Nivolumab (*n* = 24) Camrelizumab (*n* = 1)	*Qualitative data collection methods* Individual semi-structured in-person interviews *Analytic approach* Summative content analysis
Zwanenburg et al., 2022 *Type of study* Qualitative	*Number of participants* *n* = 17 of which 13 had ICIs *Geographical location* Netherlands	*Cancer diagnosis* Melanoma (*n* = 8); Lung (*n* = 9) *Stage* Advanced	*Immunotherapy type** Ipilimumab (*n* = 1); Ipilimumab & Nivolumab (*n* = 1); Nivolumab (*n* = 4) Pembrolizumab (*n* = 6) *Data from one participant is missing	*Qualitative data collection methods* Individual, semi-structured in-person interviews *Analytic approach* Inductive thematic analysis

Abbreviations: CD40, cluster of differentiation 40 (protein); CTLA-4, cytotoxic T-lymphocyte-associated protein 4; GITR, glucocorticoid-induced tumour necrosis factor receptor; ICI, immune checkpoint inhibitor; ICOS, inducible T-cell CO stimulator; M, mean; PD-1, programmed cell death-1; PD-L1, programmed cell death ligand 1; TT, targeted therapy.

TABLE 3 Quality appraisal.

Title	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	SUM
Ala-Leppilampi et al. (2020)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9
Bharmal et al. (2018)	Y	Y	Y	Y	CT	N	Y	N	CT	CT	5
Cappelli et al. (2020)	Y	Y	CT	Y	CT	N	Y	CT	Y	Y	6
Cheung et al. (2019)	Y	Y	Y	Y	Y	N	CT	N	CT	Y	6
Hou et al. (2023)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9
Ihrig et al. (2020)	Y	Y	CT	CT	CT	N	Y	CT	N	CT	3
Jamieson et al. (2020)	Y	Y	Y	Y	Y	N	Y	CT	Y	Y	8
Lai-Kwon et al. (2021)	Y	Y	CT	Y	Y	N	Y	CT	CT	CT	5
Lambert et al. (2020)	Y	Y	Y	Y	Y	N	Y	N	N	N	6
Levy et al. (2019)	Y	Y	CT	CT	Y	N	Y	CT	CT	CT	4
Livingstone et al. (2021)	Y	Y	CT	Y	Y	N	Y	Y	Y	Y	8
Milne et al. (2020)	Y	Y	Y	Y	CT	N	Y	CT	Y	Y	7
Park et al. (2020)	Y	Y	Y	CT	CT	N	Y	CT	Y	CT	5
Shuk et al. (2017)	Y	Y	Y	CT	CT	N	Y	CT	CT	Y	5
Wong et al. (2019)	Y	Y	Y	Y	Y	N	Y	CT	Y	Y	8
Xie et al. (2022)	Y	Y	CT	Y	CT	N	Y	CT	CT	CT	4
Zhang et al. (2023)	Y	Y	Y	Y	Y	CT	Y	N	Y	Y	8
Zwanberg et al. (2022)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9

Note: CASP questions:Q1. Was there a clear statement of the aims of the research?
Q2. Is a qualitative methodology appropriate?
Q3. Was the research design appropriate to address the aims of the research?
Q4. Was the recruitment strategy appropriate to the aims of the research?
Q5. Was the data collected in a way that addressed the research issue?
Q6. Has the relationship between researcher and participants been adequately considered?
Q7. Have ethical issues been taken into consideration?
Q8. Was the data analysis sufficiently rigorous?
Q9. Is there a clear statement of findings?
Q10. How valuable is the research?
Abbreviations: CT, can't tell; N, no; Q, question; Y, yes.

decision-making. In rapidly progressing, advanced disease and when alternative anti-cancer treatment options had either been unsuccessful or ruled out, ICIs were presented as management options or even recommendations (Hou et al., 2023; Ihrig et al., 2020; Jamieson et al., 2020; Livingstone et al., 2021; Park et al., 2020; Shuk et al., 2017; Wong et al., 2019).

> One of the professors said it's [Keytruda] a no brainer. (Wong et al., 2019, p. e1194)

Faced with the enduring existential threat of advanced cancer and fearful of dying (Lambert et al., 2020; Livingstone et al., 2021), the possibility of treatment with novel ICIs which might prolong life engendered hope and optimism for the future (Ala-Leppilampi et al., 2020; Cappelli et al., 2020; Hou et al., 2023; Ihrig et al., 2020; Jamieson et al., 2020; Lai-Kwon et al., 2021; Lambert et al., 2020; Levy et al., 2019; Livingstone et al., 2021; Milne et al., 2020; Park et al., 2020; Shuk et al., 2017; Wong et al., 2019; Xie et al., 2022).

> This is wonderful. If this were 10 years ago, I think I would have a death sentence, and this gives me an opportunity, you know, wonderful, wonderful thing to let me live, potentially live, and actually become free from this, this horrible thing. (Shuk et al., 2017, p. 2162)

Individuals also hoped that access to ICI treatment would allow them to re-engage in everyday activities and regain a sense of normalcy in their lives (Ihrig et al., 2020; Milne et al., 2020; Park et al., 2020). While individuals hoped they would not experience irAEs, many were prepared to take a risk rather than miss out on the chance of improving their life expectancy (Livingstone et al., 2021; Wong et al., 2019).

> There's 20% that will get some side effects like diarrhoea, a rash. Then there's another very small per cent who get a really bad reaction. I said I think I'll

TABLE 4 Study contributions to each theme and subtheme.

	ICI treatment decision-making			The experience and impact of ICI treatments					Appraising and responding to irAEs		
Studies	ICI treatment option	Hope and optimism	Information provision & preferences	Treatment experiences	Psychological impact	Physical impact	Social impact	Employment and financial impact	Knowledge and understanding	Symptom attribution	Responding to symptoms
Ala-Leppilampi et al. (2020)		x		x	x	x	x	x		x	x
Bharmal et al. (2018)				x		x					
Cappelli et al. (2020)		x	x		x	x	x	x	x	x	x
Cheung et al. (2019)				x		x	x				
Hou et al. (2023)	x	x	x	x	x	x		x	x	x	
Ihrig et al. (2020)	x	x	x	x	x	x			x	x	
Jamieson et al. (2020)	x	x	x	x	x	x	x		x	x	x
Lai-Kwon et al., (2021)		x	x		x	x	x	x			x
Lambert et al. (2020)		x	x	x	x	x			x		
Levy et al. (2019)		x	x	x	x	x			x	x	x
Livingstone et al. (2021)	x	x	x		x	x					x
Milne et al. (2020)		x			x	x	x	x		x	
Park et al. (2020)	x	x	x	x	x	x	x	x	x		x
Shuk et al. (2017)	x	x	x	x	x	x			x		
Wong et al. (2019)	x	x	x	x		x			x	x	x
Xie et al. (2022)		x	x	x	x	x	x	x	x		x
Zhang et al. (2023)						x	x				
Zwanenburg et al. (2022)					x		x	x		x	x

> go for it (commence immunotherapy). (Livingstone et al., 2021, p. 645)

Some individuals wanted the option of either sharing or making ICI treatment decisions (Ihrig et al., 2020). Others however felt insufficiently knowledgeable and trusted their oncologists to make the right treatment choice for them (Ihrig et al., 2020; Levy et al., 2019; Park et al., 2020). Several studies suggested that individuals felt sufficient immunotherapy or irAE information was provided (Ihrig et al., 2020; Jamieson et al., 2020; Lambert et al., 2020; Livingstone et al., 2021; Park et al., 2020; Shuk et al., 2017; Wong et al., 2019; Xie et al., 2022). Too much information was considered daunting and often resulted in individuals missing vital information or becoming anxious about the extent of potential irAEs (Cappelli et al., 2020; Wong et al., 2019). A few individuals explicitly mentioned not wanting any detailed treatment information about toxicities or efficacy (Hou et al., 2023; Wong et al., 2019; Xie et al., 2022).

Individuals recalled that ICI mechanisms were sometimes explained (Ihrig et al., 2020; Jamieson et al., 2020) and side effects, risks and benefits detailed. Frequently this information was supplemented with print materials (Jamieson et al., 2020; Livingstone et al., 2021; Shuk et al., 2017).

> They explained the idea of the treatment is that cancer cells use immune, part of the immune system to hide themselves from, sorry, they use certain enzymes, whatever, to hide themselves from the immune system and that this treatment helps the cancer, the immune cells find those cancerous cells. (Jamieson et al., 2020, supplementary information p. 3)

> The Dr (medical oncologist) came in, and he asked if everything (about immunotherapy) had been explained to us and were we aware of all the side effects, we ran through it all again … they gave us some paperwork to read as well. (Livingstone et al., 2021, p. 642)

However, accounts of insufficient and vague information were evident, particularly regarding prognosis or potential irAEs (Cappelli et al., 2020; Lai-Kwon et al., 2021; Levy et al., 2019; Park et al., 2020; Wong et al., 2019; Xie et al., 2022).

> You get so many handouts and literature on immunotherapy […] but they didn't have anything about [arthritis]. (Cappelli et al., 2020, p. 8)

Furthermore, some individuals articulated a preference for individualised information, tailored to their condition and needs (Lai-Kwon et al., 2021; Wong et al., 2019) and framed in accessible, rather than technical language (Wong et al., 2019).

> They told me this and that and I said well really there's no good explaining it to me cos I don't understand all that lingo. I said because the simple fact is if I ask them they're going to tell me big layman words which I'm not going to understand…so I mean I walk out there none the wiser. (Wong et al., 2019, p. e1194)

To bridge perceived knowledge gaps, some individuals sought further information about ICIs and irAEs from the internet, friends, family and peer support groups (Hou et al., 2023; Jamieson et al., 2020; Livingstone et al., 2021; Park et al., 2020; Xie et al., 2022). Some individuals; however, found peer support groups were often inadequate (Park et al., 2020).

3.3.2 | The experience and impact of ICI treatments

Several studies reported individuals' experiences of ICI treatment delivery and the impact of treatment on their lives (Bharmal et al., 2018; Cheung et al., 2019; Hou et al., 2023; Ihrig et al., 2020; Lambert et al., 2020; Shuk et al., 2017; Xie et al., 2022). Some individuals described how these treatments could be integrated into their everyday routine, not least because treatment administration was usually relatively quick.

> The ipilimumab was an hour and a half infusion. This [pembrolizumab] is a half hour. So time-wise, it has been beautiful. (Cheung et al., 2019, p. 225).

Across the studies, ICI treatment experiences were compared with previous cancer treatments, notably chemotherapy, but also radiotherapy, and surgery (Ala-Leppilampi et al., 2020; Bharmal et al., 2018; Cheung et al., 2019; Hou et al., 2023; Ihrig et al., 2020; Jamieson et al., 2020; Levy et al., 2019; Park et al., 2020; Shuk et al., 2017; Xie et al., 2022). Chemotherapy and the associated impacts were frequently viewed negatively compared with ICIs (Bharmal et al., 2018; Hou et al., 2023; Ihrig et al., 2020; Jamieson et al., 2020).

> I'd rather die than go back to chemo. It's too painful. I didn't want to eat anything at that time, even the smell of food made me sick. In my feelings, these two (treatments) are quite different. (Hou et al., 2023, p. 497-498)

ICIs were generally perceived as less toxic than chemotherapy with some individuals reporting feeling well between treatments (Levy et al., 2019) and being able to resume activities relatively quickly following treatment (Bharmal et al., 2018; Cheung et al., 2019; Park et al., 2020; Shuk et al., 2017).

Invariably individuals were grateful and felt fortunate for the chance of treatment. However, as ICIs were often a final treatment option, this was frequently underpinned by the realisation that ICIs represented their last opportunity for improved survival (Ala-Leppilampi et al., 2020; Ihrig et al., 2020; Jamieson et al., 2020;

Lambert et al., 2020; Milne et al., 2020; Park et al., 2020; Shuk et al., 2017; Xie et al., 2022).

> If I'm not on the treatment, will I start deteriorating, because I do know this was, more or less, a last chance, basically, there wasn't much else they could do for me. So it's a kind of a double-edged sword that, to be on it and to be so well is fabulous, but the other side, you know, in the back of your head was a little, every now and then a little voice says, "Aha, but when it finishes…" (Jamieson et al., 2020, p. 9)

Psychological distress arising from layers of uncertainty about the future and life expectancy, treatment effectiveness and irAEs was prominent. Individuals articulated anxieties around ICIs effectiveness and duration of response (Hou et al., 2023; Jamieson et al., 2020; Levy et al., 2019; Livingstone et al., 2021; Milne et al., 2020; Park et al., 2020; Shuk et al., 2017; Xie et al., 2022).

> I really don't know what the future holds, or…how long the future's gonna be for me. And that's…the biggest anxiety…its uncertainty. It's uncertainty. You know, of whether it's, it's, it's gonna be effective or not, and if it is effective, how long, how long it will last. Will it, you know, could it be a complete remission? Will it—is it just slowing it down? I mean, it's the uncertainty of those, those issues. (Shuk et al., 2017, p. 2162-2163)

Many experienced anxiety immediately before routine interval surveillance imaging and while awaiting results (Hou et al., 2023; Jamieson et al., 2020; Lai-Kwon et al., 2021; Levy et al., 2019; Shuk et al., 2017; Zwanenburg et al., 2022). Others feared cancer recurrence either on treatment completion (Jamieson et al., 2020) or if irAEs meant ICIs were paused or discontinued (Cappelli et al., 2020; Lai-Kwon et al., 2021; Levy et al., 2019; Park et al., 2020; Xie et al., 2022):

> I was super scared of being off treatment. I was just really afraid of the melanoma coming back. (Cappelli et al., 2020, p. 6)

Furthermore, the array of potential irAEs' juxtaposed against unpredictability of their onset, duration, severity and impact on their health in the longer term meant some individuals often felt suspended in a permanent state of uncertainty (Ala-Leppilampi et al., 2020).

> What kind of SEs am I going to get down the road? Because all of this stuff is so new, so they don't really know right? What's going to happen to me in another 15 years from all these drugs? (Ala-Leppilampi et al., 2020, p. 5)

Across all included studies, individuals reported experiencing a range of ICI related physical problems. As Table 5 shows, fatigue and skin, gastrointestinal and musculoskeletal problems were prominent. Zhang et al. (2023) found that individuals experienced physical problems across treatment cycles, even when they had received three or less treatments.

Some individuals stated that irAEs experienced were not problematic and did not affect their lives. Others however described debilitating effects of irAEs which could be difficult to manage and impacted negatively on their everyday lives and life quality (Cappelli et al., 2020; Jamieson et al., 2020; Milne et al., 2020; Zhang et al., 2023).

> I could hardly walk. […] So, there came a point where I went out on disability, not because of the cancer itself, but because of the side effects from the cancer treatment. So, to say how [ICI-induced IA] affected my life, oh, my God! (Cappelli et al., 2020, p. 3)

> I had absolutely no appetite at all, I was very, very, very short of breath, I mean, I couldn't walk more than about six or eight feet, I was in a dreadful state…I actually virtually crashed in the Clinic. …it would have been cycle twenty, I think, somewhere around there, I went along, had cycle twenty as normal and after a few days I started getting a range of symptoms. (Jamieson et al., 2020, supplementary information p. 4)

Some individuals reported supportive family and friends who provided emotional and practical help (Ala-Leppilampi et al., 2020; Cappelli et al., 2020; Park et al., 2020; Xie et al., 2022).

> I've been lucky to have had very good support. My friends really rallied around. When I had to go to treatment they offered to take me…I have a lot of friends now that will call to find out how I am doing. I also have a supportive family that are there to help if I need it. (Ala-Leppilampi et al., 2020, p. 6)

Family members often motivated individuals to keep going, even when they felt limited by the impact of irAEs (Cappelli et al., 2020). However, irAEs could also have a negative impact on relationships (Ala-Leppilampi et al., 2020; Cheung et al., 2019; Milne et al., 2020; Park et al., 2020; Zwanenburg et al., 2022). This was two-pronged. On one hand, irAEs meant individuals felt unable to interact with others and participate in social events (Ala-Leppilampi et al., 2020; Milne et al., 2020). On the other, some individuals felt important people in their lives considered cancer to be a bigger problem than irAEs. This meant individuals often felt dismissed when they experienced debilitating side effects (Cappelli et al., 2020; Lai-Kwon et al., 2021).

> It's really easy for someone to understand that if you have cancer you may not be able to do certain things

TABLE 5 Study contributions to each identified physical irAE.

Studies	Physical problems experienced									
	Cardio-respiratory	Skin problems	Gastrointestinal	Musculoskeletal	Thyroid issues	Abnormal temperature	Fatigue	Nutrition & Metabolism	Pain	Sleep disturbance
Ala-Leppilampi et al. (2020)	x	x	x	x		x	x	x		
Bharmal et al. (2018)				x			x		x	
Cappelli et al. (2020)			x	x	x		x			
Cheung et al. (2019)		x	x		x		x			
Ihrig et al. (2020)		x								
Jamieson et al. (2020)	x	x	x				x			
Lai-Kwon et al. (2021)		x	x				x			
Lambert et al. (2020)	x	x		x			x	x	x	x
Levy et al. (2019)					x			x		
Livingstone et al. (2021)			x						x	
Milne et al. (2020)							x			
Park et al. (2020)		x								
Shuk et al. (2017)		x	x				x			
Wong et al. (2019)		x	x	x						
Xie et al. (2022)				x			x		x	
Zhang et al. (2023)	x	x	x	x		x	x	x	x	x

> or function in the same ways, but [arthritis] might not be as understood, and so I may have a colleague or two who doesn't quite understand why I'm not as physically agile. (Cappelli et al., 2020, p. 7)

Living with uncertainty and debilitating irAEs meant some individuals withdrew from their usual everyday activities and hobbies (Ala-Leppilampi et al., 2020; Cappelli et al., 2020; Lambert et al., 2020; Milne et al., 2020). Holidays and social trips were delayed or avoided as individuals believed participating in clinical trials and receiving treatment were more important (Lai-Kwon et al., 2021; Park et al., 2020). Reported consequences included relationship breakdown and renegotiation of family dynamics (Ala-Leppilampi et al., 2020; Park et al., 2020).

For some individuals returning to work was problematical (Lai-Kwon et al., 2021; Zwanenburg et al., 2022). Some felt the need to take leave during treatment was perceived to negatively impact on their work performance (Lai-Kwon et al., 2021).

> On my yearly reviews there's still comments about the amount of time I've had to have off-work, which they feel reflects on my work performance, which I'm sure it would. So that's also been very stressful. (Lai-Kwon et al., 2021, p. 395)

The unpredictability and impact of irAEs meant some individuals' employment was disrupted. Working hours had to be reduced and some were unable to sustain employment and were even required to retire early (Ala-Leppilampi et al., 2020; Cappelli et al., 2020; Lai-Kwon et al., 2021; Milne et al., 2020; Park et al., 2020). Inevitably individuals' finances were negatively affected, placing additional pressures on families and individuals' sense of self (Milne et al., 2020).

The financial burden of ICI treatment often caused distress (Milne et al., 2020). Some individuals had access to financial support (Cappelli et al., 2020). Others, particularly those residing in countries where ICI treatments were not supported financially, reported facing grave economic consequences of financing treatment (Hou et al., 2023; Lai-Kwon et al., 2021; Xie et al., 2022).

> I have received four courses of treatment, but my family can't bear the expenses any longer. I raised some money through Shuidichou App the year before last, but this drug is so expensive and can't get reimbursed (Xie et al., 2022, p. 7)

There was also the burden of frequent out-of-pocket treatment-related travel and accommodation expenses, particularly when specialist treatment centres were geographically distant (Hou et al., 2023; Milne et al., 2020). While some individuals reported foregoing holidays to finance their treatment related costs (Milne et al., 2020), the substantial cost for ongoing ICI treatments meant some even considered selling their homes (Xie et al., 2022).

3.3.3 | Appraising and responding to irAEs

Individuals' appraisal of and responses to actual and potential irAEs were multifaceted, bounded in irAE knowledge, understanding, interpretation of symptoms experienced and uncertainty (Cappelli et al., 2020; Jamieson et al., 2020; Park et al., 2020). Responses involved an array of strategies which, for several reasons, often appeared to be connected to an aversion to seek timely professional help.

Individuals had variable knowledge and understanding of ICIs and irAEs, and their optimal management (Cappelli et al., 2020; Hou et al., 2023; Ihrig et al., 2020; Jamieson et al., 2020; Lambert et al., 2020; Levy et al., 2019; Park et al., 2020; Shuk et al., 2017; Wong et al., 2019; Xie et al., 2022). Some could name their treatments (Jamieson et al., 2020) and recognised symptoms experienced as potential irAEs (Cappelli et al., 2020). However, despite recalling information that ICIs could have adverse effects, that could be serious, life-changing and even life threatening, individuals did not always connect symptoms experienced with ICI treatments (Cappelli et al., 2020; Jamieson et al., 2020; Park et al., 2020; Wong et al., 2019).

> After the 5th cycle. I started to get the diarrhoea and I never actually gave it a thought that it was anything to do with the treatment. (Jamieson et al., 2020, supplementary information, p. 4)

Symptoms appraised as mild were not always recognised as actual or potential irAEs (Hou et al., 2023; Jamieson et al., 2020; Milne et al., 2020). Individuals also attributed symptoms experienced to a range of perceived causes including cancer progression, late effects of previous cancer treatments, an indication that ICI treatment was working, existing comorbidities, other medications, lifestyles, family history and ageing (Ala-Leppilampi et al., 2020; Cappelli et al., 2020; Hou et al., 2023; Ihrig et al., 2020; Jamieson et al., 2020; Levy et al., 2019; Wong et al., 2019).

> I had forgotten about the side effects. It was after a year and a half. You think that you're safe. (Cappelli et al., 2020, p. 3).

> A little bit of joint pain… fatigue. But I also put it down to running a business, running a farm, having a family…and I'm getting a little bit older. (Levy et al., 2019, p. 1847)

Various irAE self-management strategies were reported including self-monitoring (Levy et al., 2019; Zwanenburg et al., 2022), adjusting diets, using skin creams and over the counter medications.

> I got some cream and I put it on to it…Just ordinary cream you know, that stops kind of an itchy rash. (Jamieson et al., 2020, supplementary information, p. 7)

Other strategies included focusing on self-care, reappraisal and adjustment of lifestyles, life goals and priorities and embracing a positive mental attitude (Ala-Leppilampi et al., 2020; Lai-Kwon et al., 2021; Zwanenburg et al., 2022).

Some individuals promptly reported symptoms via appropriate channels (Jamieson et al., 2020; Wong et al., 2019). Others, however, either ignored or concealed symptoms experienced (Cappelli et al., 2020; Jamieson et al., 2020). In part this was associated with treatment uncertainty. However, individuals also feared disclosure would mean their ICI treatment might be paused or curtailed and their cancer would return (Cappelli et al., 2020; Park et al., 2020).

> I was only a few months into [the immunotherapy], but the change [in the cancer] that they had seen was so drastic and so fast. And I stayed on the immunotherapy drug … and at that time, the cancer could have been gone, but I didn't even want to stop then …. I thought that if I told them that I was in pain, they would stop giving me the immunotherapy, and I wasn't going to have that. (Cappelli et al., 2020, p. 6)

Some individuals perceived that by speaking up they would be labelled as complaining and ungrateful for treatments which were potentially enhancing survival outcomes (Ala-Leppilampi et al., 2020; Cappelli et al., 2020; Jamieson et al., 2020). There was also an underlying perception that healthcare professionals were either too busy to deal with their problems (Jamieson et al., 2020) or uncertain about irAEs (Cappelli et al., 2020; Jamieson et al., 2020; Levy et al., 2019; Park et al., 2020; Wong et al., 2019; Xie et al., 2022), particularly given ICIs newness (Ala-Leppilampi et al., 2020; Cappelli et al., 2020; Park et al., 2020; Xie et al., 2022)

> It's so new that the nurses don't really know everything, and the doctors are very careful not to say too much. (Park et al., 2020, p. 370)

A few individuals felt all healthcare professionals had issues with identifying irAEs (Cappelli et al., 2020; Jamieson et al., 2020; Levy et al., 2019; Park et al., 2020). However, it was more often perceived that GPs and general hospital staff lacked the specialist knowledge and confidence to accurately identify and treat irAEs in a timely way (Jamieson et al., 2020; Wong et al., 2019). Individuals trusted and felt confident in their cancer treatment teams (Ala-Leppilampi et al., 2020; Jamieson et al., 2020; Levy et al., 2019; Livingstone et al., 2021; Wong et al., 2019) and many preferred to wait until their next scheduled oncology appointment (Jamieson et al., 2020; Wong et al., 2019).

> I was coughing a little bit, but I wasn't feeling that unwell, and I thought, you know what, I'll wait until I see the people that know what they're talking about rather than having to go through the A&E system again. ….I discovered that if you phone out-of-hours, you don't necessarily get to know, get to talk to someone that knows anything about what you're talking about (Jamieson et al., 2020, Data S3).

Ultimately, however, delayed irAE reporting led to a lack of timely care and early professional intervention. In some cases delay resulted in hospitalisation with serious and potentially life-threatening situations (Jamieson et al., 2020).

4 | DISCUSSION

This review reports synthesised findings from studies from across the globe involving people living with advanced cancers and treated with ICIs. To the best of our knowledge, this is the first qualitative systematic review and thematic synthesis of people's experiences of ICI treatments in the context of advanced cancer. The findings draw attention to apparent shortcomings in the ICI treatment decision-making process, the range of unmet needs and individuals' experience-based concerns about healthcare professionals' ICI and irAE knowledge and self-efficacy.

This review has revealed that when confronted with advanced cancer, and despite the possibility of a myriad of irAEs, the unanticipated prospect of treatment with unfamiliar, novel and promising ICIs was an alluring, motivating force that imbued individuals with hope for survival in terms of remission, extended life expectancy and even cure. This may not be surprising for the news of advanced cancer and the spectre of impending death disrupts and fractures individuals' lives, renders them emotionally and existentially vulnerable and engenders a profound sense of uncertainty regarding their future (Watts & Bower, 2019). In this difficult situation, ICIs symbolised hope. The apparent preparedness to prioritise a potentially longer life against risks of treatment related adverse events aligns with and reflects findings of previous studies investigating patients' treatment preferences and decisions in the wake of advanced cancer (see, e.g. Livingstone et al., 2020; Rodenbach et al., 2021; Younger et al., 2021). Nonetheless, treatment decision-making in advanced cancer is an inherently complex process which, at an emotionally charged time, can be difficult (Thorne et al., 2013). In the case of ICIs this difficulty is potentially magnified given the relative newness of treatments, the continuing inability to predict responses to treatments and irAEs and individuals' expectations.

Although evidence suggested that individuals mostly wished to participate, at some level, in ICI treatment decision-making, the extent to which they were afforded the opportunity to do so meaningfully, and at their preferred level, remains uncertain. A key finding was that information appeared to flow in one direction, namely from the oncologist to the individual and in terms of its nature and content, did not always meet individuals' needs. In addition, it appeared that options were presented as treatment or no treatment. Alternative management approaches, notably palliative or best supportive care, do not appear to have been explored, thus raising

questions as to the extent to which individuals' treatment decisions were adequately informed.

Of course, it is important to consider the potential for recall bias when generating data using retrospective interviews, rather than in real time, naturally occurring contexts using, for example ethnographic methods. Nonetheless given that recent studies have suggested that shared-decision making does not always occur in the context of advanced cancer (Brom et al., 2017; Wasp et al., 2022), variation in the amount and type of information people desire (Lehmann et al., 2020) and uncertainties surrounding the potential benefits of immunotherapies (Tarbi & Pirl, 2022), further work in this area is clearly needed. Building on Hyatt et al.'s (2021) findings, this work might usefully include exploring strategies to co-develop and enhance the content and format of culturally appropriate, reliable and accessible ICI treatment information, including decision support tools, and enhanced integration with specialist palliative care, not least to counter the possibility that the idea of forgoing treatment is equated to doing nothing and therefore no choice.

In terms of the experience and impact of ICI treatments, this review illustrates that while grateful for the opportunity for treatment, unremitting ambiguity regarding treatment efficacy and irAEs permeated individuals' experiences. This was underpinned by a sense of existential boundedness in terms of an uncertain future. In navigating ICI treatments, and the attendant regular surveillance, individuals' everyday lives were disrupted and fractured by the complex amalgamation and interaction of negative outcomes on psychological, physical, social and financial levels.

These findings reflect those of earlier studies where individuals living with advanced cancer have reported experiencing profound uncertainties (see, e.g. Lobb et al., 2015; Petrillo et al., 2021; Shilling et al., 2017). What is important about the findings reported here is that ICI treatments, their modes of delivery and approaches to the management of adverse effects are different to traditional anti-cancer treatments. Despite hopes and expectations for the future, ambiguity and disruption persist across lengthy treatment trajectories, generating new forms of everyday suffering hitherto seldomly documented in the literature. Crucially, this subset of patients is likely to expand as more people are diagnosed with and treated for cancer and novel ICIs become more accessible and part of the standard of care. By drawing healthcare professionals' attention to these important insights into individuals' ICI treatment experiences in the context of their everyday lives, innovative and sustainable models of care might be devised and evaluated. Furthermore, appropriate, theoretically informed, proactive supportive care interventions may be co-developed, tested and implemented at discrete points along the ICI treatment pathway.

This review offers a glimpse into the ways in which individuals appraised and responded to actual and potential irAEs experienced. It demonstrates that individuals did not always connect symptoms experienced with their ICI treatment. Furthermore, while specialist oncology staff were held in high regard, shortcomings in immunotherapy knowledge and understanding of generalist healthcare professionals in primary and secondary care were reported. This lends support to findings reported by Khalid et al. (2022) and is a cause for concern given the need for and importance of early detection and appropriate, timely, interventions for irAEs to optimise patients' treatment outcomes. This knowledge gap is an aspect identified for development, not least because as more people with cancer have access to ICIs, demand across primary and secondary care services will likely rise. Accordingly, investment in accessible immunotherapy education for generalist healthcare professionals is urgently needed.

4.1 | Strengths and limitations

The strength of this review is that established, rigorous systematic review processes were followed to identify and select relevant qualitative literature. Methods and thematic synthesis procedures were reported explicitly, providing an audit trail for dependability. To maximise study identification the search strategy was developed with the assistance of an expert information specialist. However, as qualitative research filters were used, relevant publications that did not mention these terms in titles or abstracts or were not indexed as qualitative research, might have been missed (Booth, 2016). Nevertheless, multiple electronic databases and grey literature were also searched along with backchaining and forward citation tracking, which maximised the chances of identifying relevant literature (Booth, 2016). However, as searches were limited to the English language, views of non-English speaking individuals might not be represented, limiting transferability of the findings of this qualitative synthesis.

The unit of analysis in qualitative systematic reviews is primary research, and not raw data. Accordingly, reviewers can only analyse verbatim quotes included and the authors' interpretations. Hence, reflexivity and a clear declaration of researcher and participant relationships are important. However, these aspects were not reported in any of the included studies, raising further questions about confirmability. Additionally, as several included studies were data thin, verbatim quotes to support authors' interpretations were few (Bharmal et al., 2018; Lai-Kwon et al., 2021; Lambert et al., 2020), potentially compromising the credibility of primary study findings. In some included studies, insufficient detail regarding methodological decision-making meant there was no clear audit trail (Cappelli et al., 2020; Cheung et al., 2019; Lambert et al., 2020). This raises questions regarding dependability and confirmability. Thus, findings of this systematic review should be interpreted with caution. However, consistency in patient experiences between studies and across international healthcare settings indicates a level of trustworthiness in the findings.

5 | CONCLUSION

This systematic review identified a small, yet rich body of qualitative evidence investigating individuals' experiences of cancer treatments

with ICIs. The review established that individuals' had unmet ICI treatment related information as well as unmet psychological and practical support needs. Shortcomings in ICI treatment decision-making processes were also revealed and the need for healthcare professionals to recognise and sensitively handle individuals' ICI treatment expectations was highlighted. Individuals' understandings of and responses to irAEs were also illustrated, and attention drawn to patients' concerns about healthcare professionals' knowledge of ICIs and irAEs. Thus, the review sheds new light on, and provides better understandings of the broader impacts of ICI treatments and their associated management from individuals' perspectives and in the context of their everyday lives.

6 | RELEVANCE TO CLINICAL PRACTICE

Given the rapidly evolving use of ICIs globally, outside of clinical trials, the findings are important. The findings are relevant to and should raise awareness and inform generalist and specialist healthcare professionals internationally. In terms of healthcare professionals' practice, better understanding of individuals' ICI treatment experiences should support and enable healthcare professionals to handle ICI treatment expectations and uncertainties, and optimise patients' experiences and health outcomes.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

Data supporting this study's findings are available in this article's supplementary material. Further data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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