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The journey of patients in cancer clinical trials: A qualitative meta-synthesis on experiences and perspectives

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ABSTRACT

Objective: To synthesize findings from qualitative studies focusing on adult cancer patients and their experiences and perspectives on clinical trials.
Methods: A meta-synthesis was conducted on the literature retrieved from Scopus, Embase, PubMed, and PsycInfo databases. Patient quotes from papers were coded line-by-line using Nvivo software, and themes were created.
Results: 45 papers were included. Three large themes were identified based on the timeline of trials: (1) "pre-trial participation" includes sub-themes regarding informational needs, experience with the decision, and representations. (2) "Ongoing trial" includes subthemes covering supportive care, practical and psycho-physical burdens, identity and comparison with others, and the importance of maintaining hope. (3) "Post-trial," with subthemes covering comprehension of results and attitudes towards data sharing, perception of being left unattended, and hindsight and regretful thoughts.
Conclusion: This work emphasizes the importance of contextualizing patient experiences and holistically viewing trials. Additionally, this review stresses that patient narratives in the post-trial period are underrepresented in the literature.
Practice implications: Further research should prioritize the post-trial stage to enhance patients' psychological well-being and address concerns such as regret to reduce trial dropout rates. Emphasizing patient connections, providing clear trial-related information, and offering remote participation options, particularly for rural patients, are crucial steps in improving patient experience and trial adherence.

1. Introduction

Cancer clinical trials represent the source of discoveries and treatments in oncology. Depending on the trial phase, it may aim to test the safety of a new drug and its efficacy or effectiveness compared to the standard treatment [1]. Conducting these experimental studies relies on patients' willingness to participate in them. Therefore, understanding patients' experiences regarding clinical trials is of utmost importance.

The complexity of the experience of patients undergoing or considering such studies mirrors the uncertainty surrounding clinical trials. Whether patients are adequately informed about trials is an ongoing debate, which leads to ethical considerations of informed consent [2]. Patients vary in their understanding and awareness of what a clinical trial entails [3], and their motivation to decline or accept participation thus differs as well. Some patients display optimism in the face of experimental treatments and expect personal therapeutic benefits [4,5]. In others, clinical trials elicit the fear of the unknown [6] and of being seen as just an experimental subject [7]. The latter is a perception of being treated as a *guinea pig* [8,9]. Such a wide range of perspectives and challenges of patients requires careful and in-depth consideration of their experiences.

The matter is further complicated for historically marginalized groups, particularly racial and ethnic minorities, who are significantly underrepresented in cancer clinical trials [10]. Studies show underrepresentation among Black patients [11,12] and Hispanic patients [13]. Additionally, individuals with immigrant backgrounds and limited language proficiency face further barriers, including language exclusion [14]. Socioeconomic factors, such as lower income and insurance limitations, also present significant challenges to participation, despite efforts to mitigate costs [15]. Considering both attitudinal and systemic

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barriers to trial participation is crucial, as these groups have been historically underrepresented in research, which not only limits the generalizability of findings but also marginalizes and excludes a valuable part of society.

To capture the complexity of patients' multifaceted experiences in trials, thematic synthesis has been previously applied to synthesize insights from qualitative studies focused on cancer patients and clinical trials. Namely, to our knowledge, three studies have utilized this methodology [16–18]. All of these works have explored patients' decision-making processes contemplating trial participation. This focus is of great importance; however, it does not capture other aspects of participation in a trial, such as general beliefs and attitudes towards trials (regardless of being offered to partake in one or not), challenges of patients enrolled in an ongoing trial, and retrospective thoughts of those who have completed one.

In this study, we aim to explore the perspectives of adult cancer patients and their experiences with clinical trials. We focus on overall narratives around clinical trials without limiting to a single patient experience (e.g., patients who are enrolled, those who were approached for participation), the period of the trial (e.g., initial phase, ongoing or finished), or specific topic related to participation (e.g., the decision about participation, the role of family, relationship with the doctor).

2. Methods

Qualitative research approaches are frequently used to gain deep insight into participants' perspectives and have shown to be particularly appropriate for studies focusing on oncological patients [19]. Qualitative methodology has been applied to explore patients' psychological wellbeing, coping mechanisms, and intervention preferences [20,21]. Among many other topics, the perspectives and experiences of patients regarding clinical trials have been widely explored with in-depth interviews [22,23] and focus groups [24,25].

However, observations from single qualitative studies may stand in isolation and do not define overarching themes of perspectives and experiences of patients in trials. Therefore, a thematic synthesis is applied to develop themes based on multiple qualitative studies [26]. The key points from different works are identified and 'translated' to one another. The translation process entails identifying concepts from one study in another study, even if the concept has been described in other words. This process develops a comprehensive conceptual framework that goes beyond the contents of original works [26].

2.1. Selection criteria

Qualitative studies exploring the experiences and perspectives of adult cancer patients about clinical trials were included in this review. These studies focused on patients with direct experience with clinical trials (considering participating, currently enrolled in a trial, or with past experience) or patients who shared their general perspectives about the trials (e.g., imagining being approached for a hypothetical trial).

Studies that used only quantitative methodology, non-primary research articles (literature reviews, commentaries), conference abstracts, studies that were not conducted with adult cancer patients, and non-English articles were excluded.

Studies that used qualitative methodology but did not provide quotes from patients (raw data) in the published papers were not included. The deliberate utilization of first-order data enhances the interpretative process, enabling a more profound exploration of the subtleties, emotions, and complexities inherent in patients' narratives. This decision also reduces the risk of interpretative bias, ensuring that the synthesized findings are directly anchored in the participants' own voices rather than interpretations by other researchers or authors. Aligning with methodological rigor, this emphasis on first-order data adheres to the fundamental principle of maintaining fidelity to participants' voices, thereby contributing to the robustness of our qualitative analysis.

Finally, given that our interest was the perspective of patients, studies that included both patient and caregiver quotes and did not identify the source for each quote (i.e., whether it came from the patient or the caregiver) were excluded as well.

2.2. Data sources and searches

We searched databases Scopus, Embase, PubMed, and PsycInfo with the pre-selected keywords. We did not limit the dates of published papers. The initial search was conducted on September 1, 2022, and was updated on October 1, 2023, to capture any newly published relevant articles. The search string used for each database can be found in Appendix A.

Guided by the inclusion and exclusion criteria, we screened the retrieved abstracts. As a final step, we examined full papers to make a final selection of relevant studies. For detailed information, view the online generated [27] PRISMA chart (Fig. 1).

2.3. Quality assessment of included studies

We opted for the Critical Appraisal Skills Program [28], a widely utilized tool in qualitative research assessment designed to encompass all fundamental principles and assumptions inherent to qualitative research methodologies [29]. CASP is endorsed by the Cochrane Collaboration [30] and has been widely used in the medical field. Following the approach adopted by Lachal et al. [31], in Table 1, we present the number of papers matching each CASP criterion, categorizing them as not met, partially, and totally met.

We deliberately chose not to exclude studies based on quality criteria in our meta-synthesis. This decision is rooted in the recognition that the principal purpose of quality assessment in a meta-synthesis is not to facilitate the selection of the most rigorous articles. Instead, our focus is on offering the reader a comprehensive overview of the included studies.

2.4. Synthesis of findings

Thematic synthesis was applied to work with the findings of primary studies [26]. The included articles were first entered into Nvivo software. We considered quotations of cancer patients from each selected article as the data. The quotations were mostly found in the papers' Results and/or Discussion sections. Followingly, the quotations of each article were coded line-by-line, and created codes were recorded in Nvivo software. For each study, the concepts found in the quotations were added to existing codes, or new codes were made when necessary. Preliminary codes were discussed among all authors.

Following the guidelines for conducting thematic synthesis [26], we developed descriptive and analytical themes based on the created codes. The results of each primary study were extended and integrated into a larger picture. By following this procedure, we generated themes across studies that go beyond the findings of primary studies. To ensure that all concepts were included in our final themes, one author (MC) reread each primary article.

3. Results

3.1. Literature search and study descriptions

The search yielded 1369 articles. Of these, 1324 were excluded, view the PRISMA chart (Fig. 1). We included 45 studies involving more than 1294 participants. The studies were conducted across 14 countries. Data were collected using interviews (37 studies), focus groups (6 studies), or both (2). The included studies and their characteristics are reported in Table 2.

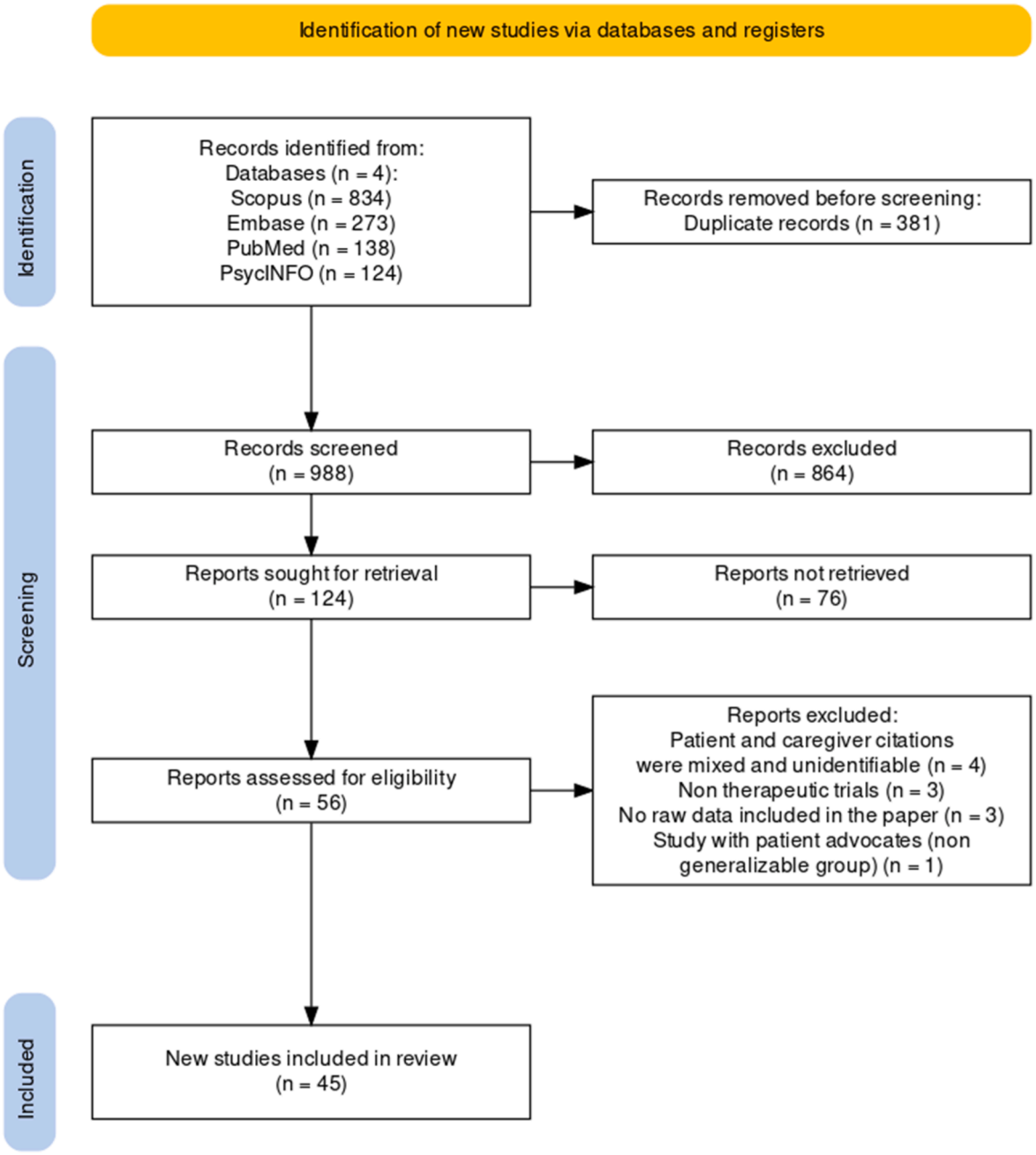

Fig. 1. A PRISMA Chart of the retrieved literature.

3.2. Synthesis

We identified three major themes based on the time they portrayed. These themes extend beyond the perspectives of patients who have directly experienced that particular period. Instead, they encompass the processes discussed by patients, irrespective of their clinical experience, across three distinct time points within clinical trials.

"Pre-trial participation" includes narratives shared by patients contemplating participation as an option or expressing general thoughts about being enrolled in trials. This theme contains subthemes of: "information needs," "experience with the decision," and "representations."

"Ongoing trial" captures narratives that concern the points relevant to the period of being part of the trial. This theme includes subthemes of: "supportive care," "practical and psycho-physical burdens," "identity and comparison with others," and "the importance of maintaining hope."

"Post-trial" portrays narratives about the end of the trial period (due to the study's end or the patient's withdrawal). The third theme includes subthemes of: "comprehension of results and attitudes towards data sharing, " "left unattended and without a safety net," and "hindsight and regretful thoughts."

Fig. 2 provides the main points related to each subtheme, and accompanying patient example quotes from primary studies.

3.3. Pre-trial participation – theme I

In this theme, we describe patient narratives regarding the pre-trial participation period. In the sections of subthemes, we synthesize widely addressed points in the literature.

Table 1
Evaluation of papers based on CASP.

Criteria	Totally met*	Partially met*	Not met*
1. Was there a clear statement of the aims of the research?	42	3	0
2. Is a qualitative methodology appropriate?	43	2	0
3. Was the research design appropriate to address the aims of the research?	39	6	0
4. Was the recruitment strategy appropriate to the aims of the research?	35	7	3
5. Was the data collected in a way that addressed the research issue?	41	4	0
6. Has the relationship between researcher and participants been adequately considered?	28	10	7
7. Have ethical issues been taken into consideration?	44	1	0
8. Was the data analysis sufficiently rigorous?	27	16	2
9. Is there a clear statement of findings?	37	6	2
10. How valuable is the research?	36	9	0

* Number of studies. Moreover, the latest edition of CASP, which we employed, evaluates each criterion using three options: "Yes," "Can't tell," and "No." Correspondingly, these labels in the table signify "Yes" as "Totally met, " "Can't tell" as "Partially met," and "No" as "Not met."

3.3.1. *Information needs*

The lack of knowledge about trials was evident not only with patients who had been asked about hypothetical clinical trials [32], but also with those who had experience with trials and still lacked basic knowledge of what they entail [33]. Patients often did not understand what randomization entailed and, in some cases, were concerned about whether there was a placebo group and, if so, not to end up in it [3,34–36]. Multiple studies from the USA stressed that minority populations such as African-American and Hispanic cancer patients lack trial awareness even more [24,33,37]. Authors attribute this to cultural and language barriers, among others. Furthermore, systemic racism and historical abuses, such as the Henrietta Lacks' case, cited by patients themselves [24,38], and other forms of medical exploitation may contribute to a reluctance to engage with medical research and be a significant barrier to accessing knowledge about cancer clinical trials.

The difficulty absorbing and taking in all the points outlined by physicians, nurses, and informed consent was challenging for patients [37,39,40], especially when these points were worded in a heavily medical, technical language [33,41]. As a result, they preferred that their caregivers speak with the physicians on their behalf [39]. The complexity and length of informed consent made them question whether these steps were taken for patients or for liability reasons and to protect the physicians [40]. Overall, patients have expressed the desire for detailed yet accessible information.

Patient narratives offered possible solutions to these information needs, such as tailored information sheets and brochures [32,42]; reading the informed consent together with the physician [39]: online sources [3,32]; pictorial and video aids[25]. Overall, the literature describes patients expressed needs for additional assistance and support, as well as their preference for the type of support.

3.3.2. *Experience with the decision*

When reporting the decision-making process regarding enrolling in the study or not, many patients evaluate risks and benefits [32,34,43]. Among the reasons that foster participation were hope for the personal therapeutic benefit [25,43,44], the wish to help other patients [40,45,46], and the will to contribute to the advancements in medicine [37,39,47,48]. Some were inclined to participate to avoid future regret for not exhausting all the available options [39,49]. Others expressed that they had nothing to lose, so they might as well try [47]. When discussing enrollment, different factors played a facilitating role in decision-making.

Besides the facilitators, risk factors and barriers were considered as well. The main reason holding patients back from participation was the concern about the side effects [25,43], however they were more open to accept toxicity if they expected therapeutic benefits from the trial [50]. Especially off-putting was the possible death included among the risks of the trial in the consent form. The fear of dying from the experimental drug has been alarming for those who did not perceive themselves as being in the end-of-life phase [51]. Traditional treatments were described as having a more precise plan, already approved and tested, and therefore safer. Safety was a particular concern for African Americans, who referenced historical mistreatment of Black people in medical research, such as Tuskegee Syphilis Study [38,52], which fueled their concerns about the safety of the trial.

Time constraints have been another significant worry. On top of the emotional challenge of having cancer, the need for a quick decision about the experimental study may be too much of an emotional burden [43]. Patients shared that initially, emotions take over the decision-making process [37]. Only later, with some time, did awareness about the trials increase [35]. One patient even reported, "You don't know what it is you've accepted" [53]. Overall, patients are usually constrained in time and confronted with information overload.

Lastly, patients discussed their agency over the decision and the role of the doctor and the family. Some wanted doctors to take this responsibility and were surprised they were even asked their opinion regarding the possible treatments [53]. Sometimes, patients felt they had no choice [39,41,54]. For others, being asked was essential for perceiving the agency over their decision to participate [41,51,55] and it was essential to be able to make a final call [55,56]. The perception of freedom of choice was also associated with being reminded that saying "no" to the trial was also an option [55]. At times, declining the invitation increased the sense of control [46]. Family and their perceptions about the trials, whether they were discouraging due to safety concerns [43,57] or encouraging participation [44,57,58], were influential in patients' narratives.

3.3.3. *Representations*

Patient narratives included representations concerning the doctor, the trial, and oneself.

Patients reported that they initially made an explicit decision to trust their doctor [45,59]. Once trust was established, patients reported that if something were to go wrong, the doctor would naturally take responsibility and take the patient off the trial [3]. This expectation was associated with the belief that a doctor always has a patient's best interest at heart and would never offer anything that could harm them and put them at risk [44,53].

Even though the representations of doctors were mostly positive, some patients shared their doubts, too. This was the case for those who perceived the doctor's care to lack a personal approach [24]. Some expressed their understanding about the lack of time of the medical professionals but still could not help the perception of being treated like a number [22,41]. Specifically, patients of African American descent have reported distrust towards the healthcare system referencing examples where black patients have been mistreated, such as Tuskegee experiment and Henrietta lack's case [38].

Patients' trust or distrust in physicians often transferred onto the representation of the trial they suggested. Many saw clinical trials as a source of new hope [44,46] and improvements in medicine [43], and in some cases, more effective than the standard treatments [9]. At the same time, the experimental nature of trials evoked fear in many, as "experiment" was associated with "risk." Consequently, many believed that trials were only for those with no other options left – a last resort for untreatable [32,35,36,43]. The distrust towards experiments was also expressed by emphasizing that despite the amount of money spent on cancer research, they still do not perceive significant developments [60].

Finally, how patients perceived themselves was closely related to how they perceived the trial. For the skeptics, being part of one made

Table 2
Primary research papers.

Primary Papers (ordered by year)	Country	Aims of the study	Number of patients	Cancer Type / Location	Instruments
(Cox, 1999)*	United Kingdom	To gain insight into the impact of trial participation from the participant's perspective.	N = 55	Gastrointestinal tract, Breast, Lung, Ovary	Interviews
(Cox, 2000)*	United Kingdom	To gain insight into the impact of trial participation from the participant's perspective.	N = 55	Gastrointestinal tract, Breast,Lung, Ovary	Interviews
(Cox, 2002)*	United Kingdom	Gain insight into the impact of trial participation from the participant's perspective.	N = 55	Gastrointestinal tract, Breast, Lung, Ovary	Interviews
(Madsen et al., 2007)	Denmark	To study patients' strategies in managing choices about trial participation and their decision-related experiences in a potentially life-threatening situation.	N = 29	Breast, Ovary	Interviews
(Quinn et al., 2007)	United States	To examine lung cancer patients' knowledge, attitudes, and behavior regarding clinical trials and to develop an effective intervention for increasing patient knowledge and awareness of clinical trials for lung cancer patients.	N = 43	Lung	Interviews
(Sulmasy et al., 2010)	United States	To explore research patients' justifications for their estimates of expected therapeutic benefit when enrolling in clinical trials	N = 45	Not Specified	Interviews
(R. F. Brown et al., 2011)	United States	To explore patients' trial information needs and views about the utility of the Question Prompt Lists (QPLs)	N = 20	Breast, Lung, Genitourinary	Focus groups
(Wootten et al., 2011)	Australia	To explore the impact of social and family support, the challenges and advantages of participating in a clinical trial, and the patient's experiences at the trial's conclusion.	N = 14	Prostate, Breast,Leukaemia	Focus groups and interviews
(Quinn et al., 2011)	United States	To explore the application of thetheory of planned behavior to patient's decisions about clinic trial participation.	N = 21	Lung	Interviews
(Sarradon-Eck et al., 2012)	France	To explore how participants understand the scientific results from clinical trials in view of their experience and illness in general and what modes of disclosure they preferred.	N = 29	Breast	Interviews
(Wells et al., 2012)	United States	To describe processes to develop a multi-media psycho-educational intervention to prepare patients for a discussion about cancer clinical trials(CTs).	N = 23	Breast, Melanoma, Multiple myeloma, Prostate, Ovary,Colon, Uterine, Hodgkin's disease	Interviews
(Quinn et al., 2012)	United States	To examine the role of fear in cancer patients' perceptions of participating in cancer clinical trials and what role clinicians play in addressing or perpetuating this.	N = 48	Lung, Breast, Hematological, Genitourinary, Head and neck	Interviews
(Nelson et al., 2013)	United Kingdom	To understand the experiences of people taking part in a clinical trial of a supportive care intervention and to explore the different experiences between taking a supportive care intervention by IV infusion or orally.	N = 42	Breast	Interviews
(Godskesen et al., 2013)	Sweden	To explore the difficult ethical problems related to patient information and motives for participation in such trials.	N = 14	Prostate, Melanoma, Lung, Pancreas	Interviews
(R. F. Brown et al., 2013)	United States	To: (1) explore trial refusal reasons in a sample of African American (AA) patients with cancer who declined trial participation and (2) gather patients' perceptions of the potential benefit of an array of decision support tools.	N = 22	Breast, Colon,Mouth / throat	Interviews
(Quinn et al., 2013)	United States	To develop a media product to prepare Hispanic cancer patients for clinical trial decision-making using audience segmentation within a social marketing approach.	N = 36	Pelvic / stomach, Breast, Prostate, Colorectal, Lymphatic, Pulmonary with metastasis to bone, Pancreas, Ovary, Multiple myeloma, Brain, Leukemia, Bones and stomach, Colon	Focus groups
(Thorne et al., 2013)	Canada	To explore conversations between patients and their clinicians around clinical trials.	N = 22	Breast, Prostate, Lung, Melanoma, Gynaecological, Gastrointestinal, Abdominal, Pancreatic, Hematologic	Interviews
(Ramers-Verhoeven et al., 2014)**	United States, United Kingdom, Germany, France, Italy, Japan.	To gain insight into cancer patients' attitudes to CTs based on their experience and discussion.	N = 48	Not specified	Interviews
(Keusch et al., 2014)**	United States	To examine patient-centered barriers, facilitators, and motivations regarding clinical research studies to develop a questionnaire targeted at the HSCT (hematopoietic stem cell transplantations) population.	N = 17	Haematological	Focus groups
(Mc Grath-Lone et al., 2015)	United Kingdom	To explore data from in-depth interviews with cancer patients and a large national survey to investigate variation in who is asked to participate in research and who takes part.	N = 25	Brain, Breast,Colorectal / Lower GI, Gynaecological, Haematological, Head and Neck, Lung, Prostate, Sarcoma, Skin, Upper GI	Interviews

(*continued on next page*)

Table 2 (*continued*)

Primary Papers (ordered by year)	Country	Aims of the study	Number of patients	Cancer Type / Location	Instruments
(Wenzel et al., 2015)	United states	To examine the processes and motivations of African-American cancer patients at the Johns Hopkins Sidney Kimmel Comprehensive Cancer Center (JH-SKCCC) for accepting or declining participation in cancer trials and to elucidate the outcomes of these decisions.	N = 32	Breast, Prostate, Colorectal, Lung	Focus groups
(Krieger et al., 2015)	United States	To examine patient comprehension of the randomization process and sources of ongoing uncertainty that may inhibit a patient's ability to provide informed consent to participate in RCTs.	N = 49	Breast, Multiple myeloma, Prostate, Colon, Lung	Interviews
(P. Brown et al., 2015)	Netherlands	To explore the experience of hoping in cancer clinical trials.	N = 13	Pancreas, Multiplemyeloma, Colon, Kidney	Interviews
(G. E. Lee et al., 2016)	Singapore	To examine the barriers and facilitators for participation in trials among multi-ethnic Asian women with breast cancer.	N = 16	Breast	Focus groups
(Geana et al., 2017)	United States	To explore inner-city and rural patients' awareness and perceptions of cancer clinical trials and their perceptions of patient-provider interactions related to discussing cancer clinical trials to improve accrual in cancer clinical trials.	N = 66	Not specified	Interviews
(Brédart et al., 2017)	France	To explore cancer patients' perceived tolerance of side effects in phase I drug trials.	N = 17	Choroid melanoma, Breast, Cervical, Endometrial, Ovary, Leiomyosarcoma, Nasopharyngeal	Interviews
(Garrett et al., 2017)	United States	To examine advanced cancer patients' understanding of clinical research in the treatment period before consent.	N = 78	Breast, Genitourinary, Gastrointestinal, Melanoma	Interviews
(Asiedu et al., 2018)	United States	With the applications of the concept of relational autonomy, to understandhow relational encounters with family members and care providers may shape decisions around ovarian cancer patients' clinical trial participation.	N = 33	Ovary	Interviews
(Palmer-Wackerly et al., 2018)	United States	To explore (1) how and why illness identity is framed across identity layers concerning one particular cancer treatment: participation in a cancer clinical trial (CT); and (2) how and why patients experience identity conflicts while making their treatment decisions.	N = 46	Breast, Multiple myeloma, Prostate	Interviews
(Broes et al., 2020)	Belgium	To explore the attitudes of patientstoward re-using clinical trial samples and data and determining how they would prefer to be involved in this process.	N = 16	Colorectal, Ovary, Gastric, Lung, Pancreas, Cholangiocarcinoma	Interviews
(Bellhouse et al., 2020)	United Kingdom	To explore patients' care needs and their perceptions of specialist palliative care.	N = 10	Colorectal, Parotid, Cervix, Colon, Breast, Metastatic Cancer of Unknown Primary (MCUP), Stomach, Rectum, Adenoid cystic carcinoma	Interviews
(Dance et al., 2021)	United States	To understand African Americans' lymphoma needs in clinical trial enrollment and outcomes.	N = 14	Lymphoma	Interviews
(Castillo et al., 2021)	Canada	To identify potential patient barriers and enablers to participating in an early phase chimeric antigen receptor T cell therapy trial.	N = 13	Haematological	Interviews
(Ulrich et al., 2021)	United States	To examine patient-participants' experiences during withdrawal from cancer clinical trials.	N = 20	Gastrointestinal, Genitourinary, Hematological or lymphatic malignant disorders, Lung, Breast, Gynecological	Interviews
(Sawyer et al., 2021)	United Kingdom	To explore patients' experiences of experimental cancer medicine clinical trials.	N = 34	Breast, Colorectal, Head and neck, Haematological, Lung, Leukaemia, Lymphoma, Penile, Renal	Focus groups and interviews
(Hernandez et al., 2021)	United States	To explore minority participation in cancer clinical trials in safety-net settings.	N = 25	Bone, Breast, Lung, Prostate, Nasopharyngeal carcinoma, Colon	Focus groups
(Gangeri et al., 2022)**	Italy	To explore (1) informed consent (IC) representations, level of understanding, needs, and factors that influence the willingness of cancer patients to participate in randomized controlled trials and (2) representations, experiences, and critical issues of physicians involved in the same process.	N = 20	Prostate adenocarcinoma, Breast, Pharynx, Ovary, Squamous cell carcinoma,Uterine leiomyosarcoma,Lung adenocarcinoma, Thymoma,Liposarcoma,Parotid gland,Sarcoma, BCC multiple,Liposarcoma,Myeloma	Interviews
(Sherratt et al., 2022)**	United Kingdom	To compare patient and practitioner views and experiences of PETReA before and during COVID−19.	N = 26	Haematological	Interviews
(Pye et al., 2023)	Australia	To explore experiences of rural cancer patients who were receiving treatments by remote video-assisted chemotherapy (RVAC) or participating in clinical trials remotely.	N = 7	Breast, Bladder, Colon, Renal cell carcinoma, Lymphoma	Interviews
(Flood et al., 2023)	United States, United Kingdom	To capture information on clinical trial endpoints that would be most important and	N = 32	Breast	Interviews

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Table 2 (*continued*)

Primary Papers (ordered by year)	Country	Aims of the study	Number of patients	Cancer Type / Location	Instruments
		relevant for patients with advanced breast cancer, based on patient-reported outcomes.			
(Mokhnatkin et al., 2023)**	United States	To explore the aligned and misaligned perspectives around clinical trial enrollment among patient-caregiver dyads.	N = 32	Breast	Interviews
(Wegge-Larsen et al., 2023)	Denmark	To investigate participants motivation to continue their participation in the trial.	N = 21	Breast	Interviews
(Riggan et al., 2023)	United States	To explore the perceptions and experiences of black women on cancer research participation and their recommendations for the inclusion of black participants in clinical research.	N = 61	Breast, Ovary	Interviews
(Yang et al., 2023)	Singapore	To explore the perspectives of persons with advanced cancer in order to understand the motivations for participating in Phase 1 clinical trials, experiences while being on trial and views on palliative care provision.	N = 20	Lung, Colorectal, Hepatobiliar, Ovary, Skin	Interviews
(Delforge et al., 2023)	United States, France, Spain, Germany	To understand the long-term experience of patients receiving ide-cel chimeric antigen receptor T (CAR T) cell therapy for relapsed or refractory multiple myeloma in the pivotal phase 2 KarMMa trial.	N = 45	Multiple myeloma	Interviews

* The first three studies belong to the same large project; all three were included in this review, as each provides different patient quotes. These papers include the same 55 patients.

** These studies were not conducted with only adult cancer patients. However, our review considers only adult patient narratives. Therefore, the number of participants reported in the study refers to only adult patients (excluding other participants in primary studies, e.g., parents of children with cancer, caregivers).

them develop a self-representation as an experimental guinea pig [35] or a lab rat [3]. Some expressed that being offered to partake in an experiment meant they were in a terminal stage [39]. It is important to note that a patient's representation of themselves can be influenced by the type of cancer they have. For example, lung cancer is often associated with guilt and shame, as it is sometimes viewed as a self-inflicted disease [8]. This perception may impact a patient's willingness to participate in clinical trials, as the feeling of being less deserving of treatment or research attention can further discourage trial participation.

3.4. Ongoing trial – theme II

In this theme, we describe patient narratives regarding the ongoing trial period. In the sections of subthemes, we synthesize the points that were expressed about being in a trial.

3.4.1. Supportive care

Strong family support has been described as the key to coping with all the challenges of trials [58]. Family members may express care in various ways, from practical assistance, such as driving the patient to the facility [32], to spiritual support, such as praying for them [48]. In some cases, patients spoke about their experiences using the plural "we" and involving their caregivers in the narrative as if they also had first-hand experience [44,58]. Patients acknowledged that caregivers have to cope with the given circumstances [41] and the treatment-related disappointment, too [51]. Many reported they kept taking the drug and saw meaning in going on with the treatment as it meant they could stay with their families [39,48,58,59]. Overall, patients would describe themselves as fortunate and blessed for receiving support from their family and friends.

Most patients have reported feeling followed and monitored by medical professionals as well. One patient described the experience in a trial as "a first-class patient" regarding frequent monitoring and testing [51]. The perception of being followed deepened the trust and faith in doctors [3,39]. Perception of a personal approach [39], the use of reassuring language [24], and humor [45] were aspects deemed necessary by patients. Wording patient experiences in plural has also been important for them. As one patient said, hearing the doctor say "we" meant they were not alone but rather in a team with the doctor [8]. Due to COVID-19 restrictions, some patients described having less frequent contact with their medical team and consequently feeling less clear about their trial pathway; others reported maintaining a collaborative relationship with the trial team that has reassured them during those times [61]. Overall, patients spoke highly of their quality of care [22,48,62].

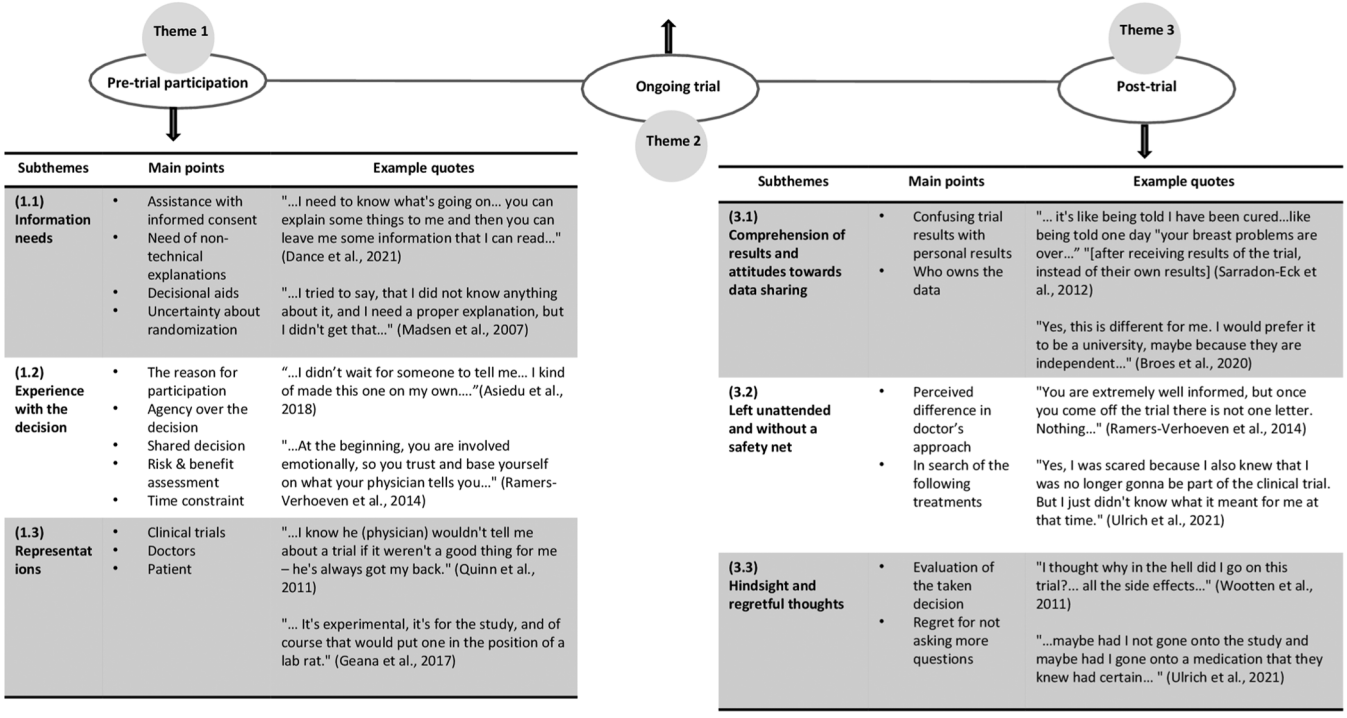
A specific type of medical care that patients addressed was palliative care. For some, it was associated with helplessness and the end of life [63,64]. Participation in the trial and accepting palliative care seemed contradictory, as the former indicated fighting, while the latter meant accepting the inevitable and "checking out." This initial resistance towards palliative care was often replaced with an understanding that palliative care can be received throughout the continuum from diagnosis to advanced stages of illness, alongside life prolonging and curative treatments including clinical trials. This knowledge resulted in greater acceptance once patients were exposed to it [51,63].

3.4.2. Practical and psycho-physical burdens

Patients often described practical burdens such as reaching the hospital [55] and waiting for the treatment to be administered [54]. It was important for them whether they would have to stay at the hospital overnight or if they could go home [33]. Additionally, patients described a financial burden related to being part of a trial [32,41]. The costs varied, starting as simple as car parking at the hospital and expanding to the accommodation costs that had to be anticipated for the patient and accompanying caregiver [32]. Overall, patients reported a significant organizational effort that they and their caregivers were putting in. In this regard, patients who partook in "teletrials" described them as highly favorable, emphasizing the importance of continuity of care, maintenance of support networks, and reductions in both physical and emotional travel burdens and associated costs, especially for patients residing in rural areas [65].

Apart from the practical issues, side effects have been one of the core topics among patient narratives, and their impact was expanded on a psychological dimension. Patients discussed the intensity and controllability of side effects [59,66]. According to them, harsh side effects interfered with daily activities, which frustrated and angered them, given that they could no longer engage in the work, activities, or social settings they previously enjoyed [22]. Side effects elicited other more practical fears, such as nausea while on public transport. Patients could

Subthemes	Main points	Example quotes
(2.1) Supportive care	• Social/family support • Feeling of being followed • Palliative care	"I have a great faith in the physicians in the hospital department because they are following me very carefully and I trust them." (Gangeri et al., 2022) "...And you need a strong family. That's the whole key to all of this stuff." (Palmer-Wackerly et al., 2018)
(2.2) Practical and psycho-physical burdens	• Financial and transportation concerns • Practical and social implication of side effects	"...We can't plan anything. I just feel as though I'm not in control of my life at all. All I see is hospitals, white coats and nurses." (Cox, 2000) "" Tiredness. Fatigue. Nausea. And, um, you do something and you just can't go. Or you do it and that's your day ended..." (Nelson et al., 2013)
(2.3) Identity and comparison with others	• Sick person • Warrior for a larger cause / Fighter in a personal battle • Curiosity about other patients in trials	"I am not the kind of person who cries over myself... it is both instinctive and intentional." (Brédart et al., 2017) "I would like to know what has happened to other guys in the same situation. ... how am I fitting in with the rest of the group?" (R. F. Brown et al., 2011)
(2.4) Importance of maintaining hope	• Benefits on recovery • Waiting for the development of new drugs	"...You have to have a positive attitude. If you sit around and worry about it all day, its going to drag you down." (Sulmasy et al., 2010) "...You hope that a cure will be found, or that you are the one who can be operated upon. That is a hope I do have." (P. Brown et al., 2015)



Subthemes	Main points	Example quotes
(1.1) Information needs	• Assistance with informed consent • Need of non-technical explanations • Decisional aids • Uncertainty about randomization	"...I need to know what's going on... you can explain some things to me and then you can leave me some information that I can read..." (Dance et al., 2021) "...I tried to say, that I did not know anything about it, and I need a proper explanation, but I didn't get that..." (Madsen et al., 2007)
(1.2) Experience with the decision	• The reason for participation • Agency over the decision • Shared decision • Risk & benefit assessment • Time constraint	"...I didn't wait for someone to tell me... I kind of made this one on my own...."(Asiedu et al., 2018) "...At the beginning, you are involved emotionally, so you trust and base yourself on what your physician tells you..." (Ramers-Verhoeven et al., 2014)
(1.3) Representations	• Clinical trials • Doctors • Patient	"...I know he (physician) wouldn't tell me about a trial if it weren't a good thing for me – he's always got my back." (Quinn et al., 2011) "... It's experimental, it's for the study, and of course that would put one in the position of a lab rat." (Geana et al., 2017)

Subthemes	Main points	Example quotes
(3.1) Comprehension of results and attitudes towards data sharing	• Confusing trial results with personal results • Who owns the data	"... it's like being told I have been cured...like being told one day "your breast problems are over..." "[after receiving results of the trial, instead of their own results] (Sarradon-Eck et al., 2012) "Yes, this is different for me. I would prefer it to be a university, maybe because they are independent..." (Broes et al., 2020)
(3.2) Left unattended and without a safety net	• Perceived difference in doctor's approach • In search of the following treatments	"You are extremely well informed, but once you come off the trial there is not one letter. Nothing..." (Ramers-Verhoeven et al., 2014) "Yes, I was scared because I also knew that I was no longer gonna be part of the clinical trial. But I just didn't know what it meant for me at that time." (Ulrich et al., 2021)
(3.3) Hindsight and regretful thoughts	• Evaluation of the taken decision • Regret for not asking more questions	"I thought why in the hell did I go on this trial?... all the side effects..." (Wootten et al., 2011) "...maybe had I not gone onto the study and maybe had I gone onto a medication that they knew had certain... " (Ulrich et al., 2021)

Fig. 2. Major themes and subthemes.

not make plans with their loved ones due to the fear their health might worsen [59]. Some side effects, such as gradual weight loss, were perceived by patients as an indication of an approaching end, which had a significant toll on their psychological state [51].

Some patients hesitated to disclose side effects to their doctor as they feared that this would lead to the doctor's decision to take them off the trial and, as a result, they would be left without treatment [41]. In line with this, patients stressed the importance of being informed beforehand about what would happen if they disclosed the side effects.

3.4.3. Identity and comparison with others

Patients differed in the way they spoke of themselves. Some perceived themselves as sick and weak, dependent on others, and without perspective [59]. Some patients found it challenging to recognize themselves as if the person before the illness and the treatment were someone else.

Others described cancer as an enemy and themselves as fighters [48]. Direct quotes representing the emotional charge of these patients include: "I'm fighting tooth and nail" [32], "I have always been a fighter" [59], and "I need to survive" [58]. Numerous individuals expressed the notion that clinical trials represent progressive studies in the fight against cancer [3], thus, participation in them serves the common good [37]. Considering this perspective, some patients saw their participation as a contribution to medicine, an honorable act that would benefit many [39,47,49].

Self-comparison with others was expressed in the patient quotes as well. In some cases, being in a trial was considered as being given a higher priority than other patients who were not part of a trial, leading patients to experience guilt [44]. When it came to self-comparison with other patients who are also in trials, patients focused on the experiences of side effects. The perception of how others dealt with side effects was informative for patients to understand their own experience. In some cases, participants felt their condition was relatively good compared to other patients who were more affected by side effects[59].

Even though many expressed their curiosity about the experiences of other patients in trials [47,49,67], some patient quotes portrayed hesitance to receive information about how others react to trials [68]. This resistance acted as a coping strategy and was associated with an attempt

to prevent oneself from being discouraged and losing hope.

3.4.4. Importance of maintaining hope

Patients have emphasized that once in the trial, one has to look forward and be positive [44]. According to them, staying optimistic contributes to recovery, embodying the fighting spirit [48].

The effort to stay optimistic was also evident in patients whom the medical professionals explicitly told not to develop any expectations about the trial [69]. Even when acknowledging that the primary goal of a given trial is not therapeutic, patients still expressed their hope to be the lucky ones. Even if the drug they received did not work, patients hoped there would be another one. As one patient said, "You can hang on long enough, something might just come along" [9]. Finally, hope was sometimes associated with the beliefs of the patients and their religious faith [58]. Religious rituals, such as prayers, offered them practical execution of the acts of hope.

3.5. Post-trial – theme III

In this theme, we describe patient narratives after the trials are finished or after the withdrawal from a trial. In the sections of subthemes, we synthesize the points that were expressed about experiencing the post-trial period.

3.5.1. Comprehension of results and attitudes towards data sharing

Patients said that even if they passed away, they cared whether at least their family members would find out about the study results they had participated in [8]. The results were significant for patients as they indicated whether their participation made a difference and changed the lives of others for the better. In line with this desire, some patients found it unexpected when physicians did not communicate the study results [35]. Even if many patients expressed curiosity, some were indifferent to this topic [68]. These patients were interested in how the participation benefited them rather than its global impact. Interestingly, some patients were unaware of the distinction between study and individual results. This was evident when patients spoke about their relief and the perception of being cured once they were informed about the study results [68].

In one study [70], patients were asked about their preferences and attitudes toward sharing and re-using their data. Some patients were more open to this idea if the researchers would use the data for research purposes rather than pharmaceutical companies. They expressed more trust in researchers as they described them as "*independent*." Others did not differentiate between these groups as they perceived all parties as working for the same goal. Finally, some patients remained indifferent towards the data sharing and re-using altogether, reporting signing the informed consent without reading it carefully.

3.5.2. Left unattended and without a safety net

After the end of the trial or after withdrawal from one, patients spoke of their current prospects. In contrast to having regular checkups, medical visits, and tests, being finished with the study felt unsafe. Patients felt the urgency to plan the next step and find the proper treatment [22]. Otherwise, being done with the study felt like they were left without a safety net. This state evoked fear in patients and made them more vulnerable. One patient noted that after the end of their participation, they decided to keep taking the trial drug as they saw no other better options [54].

Apart from the treatment concerns, patients spoke about their feelings concerning their communication with the physician after the end of the trial. A change in the doctors' approach was noted from the side of the patients when comparing doctors' attitudes during and after their participation. One of the indicators of such change was how the trial results were communicated to them. Patients who received a phone call regarding the results found this unexpected as they preferred to be informed in person, even if it meant they would have to travel to the hospital [68]. These patients felt entitled to a more personal approach as they volunteered to participate, complied, and adhered to a demanding treatment. They thought discussing the results with them in person was the least the physicians could do. Others reported that they had not even received a phone call [51]. According to their perspective, this suggested that post-trial, the doctors exhibited a lack of concern for their well-being, as if it were no longer a priority. Overall, patients found it problematic that compared to the period in the trial, during which they were well-informed and followed, after the end of participation, they were not considered anymore [35].

3.5.3. Hindsight and regretful thoughts

Patients retrospectively assessed their decision about participating in the clinical trial. Some reported having counterfactual thoughts, considering what might have happened if they had chosen a traditional treatment instead of an experimental drug [22]. This way of thinking was associated with doubts and a lack of clarity about whether the decision was optimal for the patient. Others expressed apparent decision satisfaction or regret [37]. The regretful patients referred to the side effects they experienced due to participation and saw the trial as a "waste of time" [51]. Regret and disappointment were also related to the ineffectiveness of the drug and were shared not only among patients but also by their caregivers. Not withdrawing from a trial earlier was another regret some patients who did not find the drug beneficial for them had [59].

When discussing their disappointment and regret, in some cases, patients attributed the responsibility to doctors. According to some, facing reality would have been easier if the doctors had notbuilt up their expectations right from the beginning [41]. Some patients felt cheated by the doctors. As put by one patient recalling their experience, they felt as if older siblings were deceiving them for their amusement [40]. In retrospect, patients wished to have asked more questions to make more informed choices [37].

4. Discussion and conclusion

4.1. Discussion

Our results confirm some of the findings of other similar reviews. As in other reviews [16–18], patients' experience in deciding whether to participate or not, the variables that are considered in this decision, their information needs and their expectations for the trials were described. More specifically, in the first major theme, "pre-trial participation," we synthesize patient narratives about the lack of trial-related knowledge and difficulty understanding all the provided information, especially when it is only available in a medical language. Patients wish to deepen their understanding of the trials [71], but informed consent may present an informational overload and a source of emotional overwhelm [72]. In our findings, patients described being overwhelmed when facing a decision on whether to enroll or not. Finally, they differed from one another in how they perceived the intentions of doctors and doctor roles in general, the trials proposed by them, and their role as participants of such trials. These perceptions were heavily influenced by the historical mistreatment of specific groups, particularly African Americans, who expressed mistrust toward doctors and medical research. This mistrust was rooted in well-known cases such as the Tuskegee Study and Henrietta Lacks' case.

A more recent review [73] went beyond the decision-making period and studied participants' experiences in trials. The review discussed important aspects of participation, such as coping with the strain of being in a trial, the importance of hope, the effect of trials on patients' quality of life, and the decision to terminate participation. Given the extended amount of literature we considered, in the second major theme, "ongoing trial," our work expands on these issues by offering more detail and nuance for each and adding other points, such as differences in patients' identity and self-comparison with other patients in

the trial. While we did explore the comparison with others, the studies we reviewed mostly focused on patient perspectives about active arms. In future studies, it would be interesting to also consider and explore the perspectives of patients in standard treatment or control arms, as they sometimes feel excluded from receiving experimental treatments, which can lead to distress, especially when trials are stopped early without clear outcomes [74,75].

Finally, in the last theme, we take a step further than previous reviews by focusing on yet another stage—the post-trial life of patients. In this stage, some patients described feeling left unattended and abandoned by their medical team. This sentiment mirrors the coverage the post-trial stage receives in the literature. While many of our retrieved papers focus on pre-trial and ongoing trial perspectives, only nine out of 45 articles considered the post-trial period. The reason for this unequally distributed research interest is unclear. However, we may speculate that research on post-trial experiences may lack clinical implications at first glance (unlike research focusing on the pre-trial phase that may increase enrollment or ongoing phase that may enhance adherence).

When interpreting our results, it's important to acknowledge the limitations. Our study did not consider clinical trial or patient characteristics, nor differentiate between phases or types of patients. However, our broad focus allowed for a comprehensive description of the participation process. Additionally, our exclusive use of first-order data may have overlooked valuable insights from second-order data. We emphasize transparency in our scope and intentional focus on first-order data for its unique contributions.

4.2. Conclusion

The present meta-synthesis summarizes the main themes related to adult cancer patients' narratives concerning clinical trials. By analyzing patients' perspectives, three major themes corresponding to three time points were discussed: pre-trial, ongoing trial, and post-trial experiences. Each of them was then subdivided into more detailed subthemes representing the main topics patients spoke of regarding the specific time points of care. To our knowledge, this is the only comprehensive review synthesizing qualitative studies, providing a holistic understanding of the clinical trial journey across these three time points. By doing so, we go beyond discussing extracts of patient experiences and contextualize them, providing a more holistic picture of what trials entail. Additionally, we identify the gap in research and emphasize the importance of focusing on the experiences of patients in post-trial phase both in medical practice and academic research.

4.3. Practice Implications

We argue that further research should increase the focus on the post-trial stage for two reasons: (1) By doing so, psycho-oncological research shifts the focus back on patients and primarily aims to enhance their psychological wellbeing, following the values of patient-centered care [76]; (2) For cases where the primary goal of the research is to assist medical professionals in promoting patient enrollment or their adherence to trials, focusing on some narratives expressed in the post-trial stage is still of great value. For instance, studying a complex emotion such as regret about participation can be informative in preventing future patients' regret [77]. Preventing regret, in turn, may decrease the trial dropout rate.

With this work, we once more emphasize the importance of patient connections and support. In line with the literature [78], we saw that patients often speak in the plural form (referring to their caregivers), indicating that their journey is a shared experience. Moreover, patients deeply value their relationships with doctors and wish to maintain closeness to their medical team at all stages of their journey. This may be essential for medical professionals to consider in their practice. Additionally, given that many patients found it challenging to understand the aims of the trials (in the pre-trial stage) and the results (in the post-trial stage), physicians may support them by communicating the trial-related information in a graspable fashion. As discussed in this synthesis, this could be achieved by tailored informational aids.

Aside from family members and the medical team, peer support can play a unique role. While caregivers may empathize and medical professionals provide reassurance through their competence and support, patients who share similar experiences can offer unparalleled support to one another. A good example of this is the value patients find in online support groups, where they can ask questions, offer advice, and share experiences with others in similar situations [79,80]. However, it is important to note that connecting patients participating in the same trials could introduce bias and influence their trial participation, so this must be approached with caution.

Finally, it is crucial to address patients' practical burdens when participating in trials, including financial concerns, transportation, and accommodation. Giving patients the flexibility to participate in the trials remotely is greatly valued, especially by those living in rural areas [65]. This practice is part of telehealth, and while not all aspects of clinical trial care can be delivered remotely, a hybrid approach may be greatly beneficial for patients [81].

CRediT authorship contribution statement

Davide Mazzoni: Writing – review & editing, Supervision, Methodology, Investigation, Formal analysis. **Chiara Marzorati:** Writing – review & editing, Methodology, Investigation, Formal analysis. **Mariam Chichua:** Writing – review & editing, Writing – original draft, Visualization, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Gabriella Pravettoni:** Writing – review & editing, Methodology, Investigation, Formal analysis.

Declaration of Competing Interest

The authors have declared that no competing interests exist.

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Appendix A

Search Strategy For Scientific Literature

Search Engine:	Search String:	Hits	Relevant[a]	Included[b]
Scopus	TITLE-ABS-KEY ("cancer patient*" OR "adult patient*") AND TITLE-ABS-KEY ("qualitative" OR "interview*" OR "open-ended" OR "focus group*") AND TITLE-ABS-KEY ("experience*" OR "attitude*" OR "perspective*" OR "representation*" OR "belief" OR "perception") AND TITLE-ABS-KEY ("clinical trial*" OR "experimental drug*" OR "new drug*" OR "experimental treatment*")	834	62	21

(*continued on next page*)

(*continued*)

Search Strategy For Scientific Literature				
Search Engine:	Search String:	**Hits**	**Relevant[a]**	**Included[b]**
Embase	('clinical trial':ab,ti OR 'clinical trials':ab,ti OR 'experimental drug':ab,ti OR 'experimental drugs':ab,ti OR 'new drug':ab,ti OR 'new drugs':ab,ti OR 'experimental treatment':ab,ti OR 'experimental treatments':ab,ti) AND ('adult patient':ab,ti OR 'cancer patient':ab,ti OR 'adult patients':ab,ti OR 'cancer patients':ab,ti) AND ('experience':ab,ti OR 'perspective':ab,ti OR 'attitude':ab,ti OR 'perception':ab,ti OR 'representation':ab,ti OR 'belief':ab,ti) AND ('qualitative':ab,ti OR 'interview':ab,ti OR 'interviews':ab,ti OR 'open-ended':ab,ti OR 'focus group':ab,ti OR 'focus groups':ab,ti) AND [01 −09 −1900]/sd NOT [01 −10 −2023]/sd	273	46	14
Pubmed	(("clinical trials"[Title/Abstract] OR "clinical trial"[Title/Abstract] OR "experimental drug"[Title/Abstract] OR "experimental drugs"[Title/Abstract] OR "new drug"[Title/Abstract] OR "new drugs"[Title/Abstract] OR "experimental treatment"[Title/Abstract] OR "experimental treatments"[Title/Abstract]) AND ("adult patient"[Title/Abstract] OR "adult patients"[Title/Abstract] OR "cancer patients"[Title/Abstract] OR "cancer patient"[Title/Abstract]) AND ("experience"[Title/Abstract] OR "perspective"[Title/Abstract] OR "attitude"[Title/Abstract] OR "perception"[Title/Abstract] OR "representation"[Title/Abstract] OR "belief"[Title/Abstract]) AND ("qualitative"[Title/Abstract] OR "interview"[Title/Abstract] OR "interviews"[Title/Abstract] OR "open-ended"[Title/Abstract] OR "focus group"[Title/Abstract])) AND (1000/1/1:2023/10/1 [pdat])	138	13	8
PsycINFO	((abstract: (qualitative)) OR (abstract: (interview)) OR (abstract: (open-ended)) OR (abstract: (focus group)) OR (abstract: (interviews)) OR (abstract: (focus groups)) OR (Title of Reviewed Item: (qualitative)) OR (Title of Reviewed Item: (interview)) OR (Title of Reviewed Item: (open-ended)) OR (Title of Reviewed Item: (focus group)) OR (Title of Reviewed Item: (interviews)) OR (Title of Reviewed Item: (focus groups))) AND ((abstract: (experience)) OR (abstract: (perspective)) OR (abstract: (attitude)) OR (abstract: (perception)) OR (abstract: (representation)) OR (abstract: (belief)) OR (Title of Reviewed Item: (experience)) OR (Title of Reviewed Item: (perspective)) OR (Title of Reviewed Item: (attitude)) OR (Title of Reviewed Item: (perception)) OR (Title of Reviewed Item: (representation)) OR (Title of Reviewed Item: (belief))) AND ((abstract: (adult patient)) OR (abstract: (adult patients)) OR (abstract: (cancer patient)) OR (abstract: (cancer patients)) OR (Title of Reviewed Item: (adult patient)) OR (Title of Reviewed Item: (adult patients)) OR (Title of Reviewed Item: (cancer patient)) OR (Title of Reviewed Item: (cancer patients))) AND ((abstract: (clinical trial)) OR (abstract: (clinical trials)) OR (abstract: (experimental drug)) OR (abstract: (experimental drugs)) OR (abstract: (new drug)) OR (abstract: (new drugs)) OR (abstract: (experimental treatment)) OR (abstract: (experimental treatments)) OR (Title of Reviewed Item: (clinical trial)) OR (Title of Reviewed Item: (clinical trials)) OR (Title of Reviewed Item: (experimental drug)) OR (Title of Reviewed Item: (new drug)) OR (Title of Reviewed Item: (new drugs)) OR (Title of Reviewed Item: (experimental treatment)) OR (Title of Reviewed Item: (experimental treatments)))	124	3	2
Subtotal		1369		
Duplicates		381		
Total		988	124	45

[a]Relevant: number of relevant articles based on title, abstract, and keywords
[b]Included: number of included articles based on full article

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