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Patient and Family Caregiver Perspectives on Therapy De-Escalation in Cancer: A Scoping Review

Rachel Hamilton[1,2] | Elham Hashemi[2] | Annothayan Uthayakumar[1] | Megan Liang[2] | Samantha Mayo[1,3] | Kellee Parker[4,5] | Lindsay Jibb[1,2]

[1]Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, Canada | [2]Research Institute, The Hospital for Sick Children, Toronto, Canada | [3]Department of Supportive Care, Princess Margaret Cancer Centre, Toronto, Canada | [4]Division of Pediatric Hematology and Oncology, University of Utah, Salt Lake City, Utah, USA | [5]Primary Children's Hospital, Salt Lake City, Utah, USA

Correspondence: Rachel Hamilton (Rachel.hamilton@sickkids.ca)

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ABSTRACT

Background: Cancer therapy de-escalation aims to reduce treatment intensity, minimizing the burden of short- and long-term toxicities on patients and family caregivers while maintaining current survival rates. While this approach holds potential benefits, it comes at a risk of worse patient health outcomes or treatment failure. An understanding of patient and family caregiver perspectives regarding cancer therapy de-escalation is required to design successful patient-and-caregiver-informed clinical trials, and optimally provide related patient-centered care.

Aim: To identify and synthesize the literature about patient and family caregiver perspectives of cancer therapy de-escalation to guide clinical care, research, decision-support resources, and education.

Methods: Following the Joanna Briggs Institute methodology, a systematic literature search was conducted in MEDLINE, EMBASE, PsycINFO, and CINAHL. We included quantitative, qualitative, and mixed-methods studies involving patients of all ages and cancer diagnoses and their family caregivers that focused on perceptions of cancer therapy de-escalation. Extracted data were organized according to the Framework for De-implementation in Cancer Care Delivery. Study quality was appraised.

Results: Twenty studies were included. De-escalation perspectives varied between patients and family caregivers, with factors including clinician trust and desire to improve quality of life noted as influential in de-escalation decisions. The decision-making process could be better supported through the provision of timely patient and family caregiver information and clinician communication training.

Conclusion: Cancer therapy de-escalation decisions are complex and multifactorial. Future research exploring which factors influence patient and family decision-making may offer insight into the design of optimal informational and supportive interventions.

1 | Background

Cancer treatment advancements typically focus on adding more drugs, treatment modalities, or adjuvant therapy [1]. Updates to treatment protocols are supported by evidence from clinical trials demonstrating improvements in patient outcomes [2]. Intensive, innovative treatment regimens and improved concurrent supportive care has resulted in impressive changes in survival rates for certain diagnoses, with 5-year survival rates for some cancers reaching > 90% [1]. However, cancer treatment often comes with

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short-term toxicities, chronic, sometimes life-limiting, long-term effects, and extensive burden on patients and families [2, 3]. These aspects negatively impact patient, survivor, and family quality of life, and burden health systems [3].

Cancer therapy de-escalation aims to reduce the intensity, cumulative dose, or duration of treatment [3] to minimize toxicities while maintaining cure rates—a priority for patients across ages and cancer types [4–6]. Successful de-escalation clinical trials have been conducted in adult and pediatric settings, showing therapy effectiveness [7] and in some cases, are subsequently used as standard therapy [8]. Despite the potential positive impacts of therapy de-escalation, the dose reduction of anti-cancer agents in unsuccessful de-escalation trials [9] have resulted in worse outcomes for patients, such as disease undertreatment leading to treatment failure, relapse or death [2]. This uncertainty complicates decision-making for patients and their family caregivers to decide whether to receive de-escalated anti-cancer treatment or to enroll in clinical trials investigating the non-inferiority of de-escalated therapy [10].

Given increasing interest in integrating de-escalated treatment protocols in cancer care to minimize treatment toxicities, it is crucial to understand the patient and family caregiver appetite to participate in de-escalated therapy [11]. The values and understanding of those choosing to take part, or not, in opportunities to de-escalate therapy greatly impacts their final decision, and these characteristics differ across age groups and decision-maker types [10]. Despite potential reduction in treatment toxicities, the potential survival risks related to de-escalation impact the willingness to adopt de-escalation in pediatric and adult contexts [2, 3, 10, 12]. Little is known about the trade-offs patient and family caregivers would accept in de-escalated cancer therapy and the factors impacting these decisions. It is crucial to understand the factors influencing patient and family caregiver decision-making regarding therapy de-escalation, as the opinions of these stakeholders ultimately underpin the direction of clinical care advancements and the success of clinical trials. Therefore, we aimed to identify and synthesize the literature describing patient and family caregiver perspectives of cancer therapy de-escalation to guide related clinical care, research, decision-support resources and education.

2 | Methods

This scoping review followed the Joanna Briggs Institute methodology and is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping reviews (PRISMA-ScR) checklist (Appendix I) [13, 14]. The objectives, inclusion criteria and methods were defined in advance, and documented in a publicly available protocol [15].

2.1 | Search Strategy

Our search strategy (Appendix II) was developed by one author (RH), refined collaboratively with three librarians and an oncologist (KP), and peer-reviewed by a librarian using the Peer Review Electronic Search Strategies (PRESS) checklist [16]. We searched MEDLINE, EMBASE, PsycINFO, and CINAHL from inception to November 23, 2024. Reference lists of included studies were subsequently searched and potentially relevant articles known to the authors were also considered.

2.2 | Study Screening and Selection

2.2.1 | Eligibility Criteria

2.2.1.1 | Participants. We included studies involving patients of any age, diagnosed with any cancer, or their family caregivers, who we defined as any person providing care to a person with cancer [17] who is not a clinician. This included parents, spouses or partners, other family members, or friends. We excluded studies focused on clinicians. Studies that included both patients and/or family caregivers and clinicians were considered for inclusion, so long as the data were discernible by group.

2.2.1.2 | Concept. For a treatment to be considered de-escalation, two conditions were required: (a) treatment involved a planned reduction from conventional dose, inclusive of decrease in: dose-density, intensity or total dose, the number of treatment cycles, treatment duration; or deletion of: segments of standard treatment, compounds or modalities of treatment; and (b) evidence of non-inferior survival outcomes was expected or estimated [3]. We included studies of de-escalation of chemotherapy, endocrine therapy, immuno therapy, or radiation therapy. Although efforts to de-escalate oncologic surgeries exist [18], surgical studies were excluded, as the degree of de-escalation in the surgical context can vary depending on individual surgeon and institutional approaches and expertise, which may uniquely influence patient and family caregiver experiences. Studies exploring active surveillance until diagnostic evaluations indicated a patient's condition had worsened and treatment was required were included as this approach may result in a de-escalated series of treatment [19]. We excluded studies focused on de-escalation in non-curative care circumstances, including studies of dose modifications or therapy omissions due to toxicities, poor quality of life, advanced age, frailty or patient preference. We defined perspectives as points of view, perceptions, priorities, opinions or preferences shared by patients and/or family caregivers about cancer therapy de-escalation [20, 21].

2.2.1.3 | Context. We included studies from any geographical location and published in any language focused on de-escalation perspectives before, during or after treatment, and studies of hypothetical de-escalation decision-making exercises.

2.2.1.4 | Types of Sources. We included primary quantitative, qualitative, and mixed-methods studies. Editorials, guidelines, abstracts, commentaries, and gray literature such as guidelines and websites were excluded [22].

2.2.1.5 | Screening Process. Following the search, all identified citations were uploaded into Covidence, and duplicates were removed. A pilot test of 200 citations to confirmed appropriateness of the study selection process [23]. Titles and abstracts, and then full texts were screened by two independent reviewers (RH, ML, AT). Any screening disagreements were resolved through discussion with an additional reviewer. Any non-English language articles were translated using online translation resources and checked for accuracy by a colleague fluent in the language.

2.3 | Data Extraction

We developed an electronic table to extract data on study, participant characteristics and elements included in Norton's Framework for De-Implementation in Cancer Care Delivery (Table 1) [42]. This framework offers an approach to understanding the de-implementation of unnecessary cancer management practices, including therapy de-escalation. On the continuum of factors influencing the de-implementation of cancer care, the model suggests identifying *(1) factors* impacting the patient and family caregiver perspectives, and corresponding *(2) strategies* to support the decision-making process. Therefore, this review will focus on factors that influence perspectives of de-escalation, and strategies that influence de-escalation, in efforts to explore how patient and family caregiver perspectives of cancer therapy de-escalation impact de-implementation.

A descriptive-analytic method [43] was used to extract standardized information from included sources according to the two chosen elements (*factors* and *strategies*) of the Framework for De-Implementation in Cancer Care Delivery [42]. The data extraction tool was piloted by two authors (RH and LJ) and revised during data extraction. Three articles were extracted in duplicate independently by RH and LJ, who met to compare extractions. This meeting demonstrated necessary data was captured by both authors [23] with good consistency. Data from the remaining articles were extracted by a single reviewer (RH) and double checked for accuracy (AT).

2.4 | Data Analysis and Presentation

A narrative synthesis was conducted to describe study characteristics and provide a general account of the literature. Data from study results were synthesized using a descriptive directed content analysis [44]. Pre-determined codes based upon the Framework for De-Implementation in Cancer Care Delivery [42] elements described were used to classify relevant text corresponding to patient, clinician, setting, and societal de-escalation perspectives and decision-support strategies [42, 44, 45]. Once data were categorized per the framework, they were organized into subcategories further detailing factors influencing de-escalation decisions [44].

2.5 | Methodological Quality Appraisal

We conducted a critical appraisal to present evidence on the validity and relevance of included studies [14, 45] and to inform recommendations for future research based on identified gaps in literature quality [46]. One author (RH) scored studies using the valid and reliable Mixed Methods Appraisal Tool (MMAT) [47], designed to concomitantly appraise qualitative, quantitative and mixed-methods studies. An overall quality score was calculated based on the number of MMAT methodological quality criteria met [47].

3 | Results

Our search identified 16,912 articles. Two articles were identified through other sources. After the removal of duplicates, 10,799 titles and abstracts were screened. The full-texts of 130 articles were reviewed and 110 excluded, leaving 20 papers reporting on 19 unique studies included for data extraction and analysis [10, 12, 24–41]. Our screening process is shown in Figure 1 [48].

Article characteristics are depicted in Table 1. Articles were published in six countries, mainly the United States (45%). Articles were published between 1997 and 2023, with most (95%) published in the last decade. Ten were quantitative (50%), six qualitative (30%), and four mixed-methods (20%) papers with sample sizes ranging from 16 to 1450 participants. Most articles focused on adult-onset cancers (80%), with four (20%) concentrated on childhood cancers. Most articles did not include family caregiver perspectives (75%). Studies reported on six different types of cancer: breast (50%), pediatric acute lymphoblastic leukemia (ALL) (15%), oropharyngeal squamous cell carcinoma (OSCC) (10%), prostate (10%), pediatric medulloblastoma (5%), and chronic myeloid leukemia (CML) (5%). De-escalation strategies involved reducing therapy dose (55%) or omitting a modality (45%). Patient and family caregiver perspectives were related to de-escalation in the context of radiation therapy (45%), chemotherapy (30%), tyrosine kinase inhibitors (5%), endocrine therapy (5%), adjuvant chemotherapy (5%) and combination chemoradiation (10%). Most commonly, sources reported perspectives of a participant reflecting on a real experience of de-escalation decision-making (80%), as opposed to a hypothetical context (10%) or both (10%).

3.1 | General Perceptions of De-Escalation

3.1.1 | Willingness to De-Escalate

The general acceptance and willingness to take part in a de-escalation clinical trial varied across four cross-sectional survey studies. Across three breast cancer studies and one CML study reporting on questionnaire-measured willingness, 14%–79.8% of participants would be interested in participating in a de-escalation trial [28, 30, 36, 39]. In one study, de-escalation was described as desirable and valuable by 73% of participants with OSCC [37]. In contrast, 30%–43% of participants were unwilling to participate in a de-escalation trial, with examples in both pediatric and adult oncology studies [30, 39].

3.1.2 | Survival Rates

When considering de-escalation trial participation, 55% of participants considered survival rate as a key decision-making

TABLE 1 | Study characteristics.

Article	Study design	Pop.	Caregiver	Sample size & sex	Cancer type	Treatment & de-escalation type	De-escalation type	Type of decision	MMAT rating
Amols et al., 1997 ([24]) (United States)	Quantitative	Adults	No	NR	Not reported	Radiation	Dose reduction	Hypothetical	N/A
Andrews et al., 2022 ([25]) (United States)	Qualitative	Adults	No	23 (23 F)	Breast cancer	Chemotherapy	Dose reduction	Reflection on experience	*****
Rocque et al., 2021 ([26]) (United States)	Mixed-methods	Adults	No	115 (115 F) (24 qual, 91 quant)	Breast cancer	Chemotherapy	Dose reduction	Reflection on experience	****
Bromley et al., 2019 ([27]) (Australia)	Quantitative	Adults	No	94 (94 F)	Breast cancer	Chemoradiation	Omission	Hypothetical	*****
Brotherston et al., 2013 ([28]) (Canada)	Mixed-methods	Adults	No	51 (45 M, 6 F)	Oropharyngeal squamous cell carcinoma	Chemotherapy	Omission	Hypothetical + reflection on experience	*****
Chen et al., 2023 ([29]) (China)	Quantitative	Adults	No	1450 (795 M, 655 F)	Chronic myeloid leukemia	Tyrosine kinase inhibitor	Dose reduction	Reflection on experience	****
Gauna et al., 2022 ([30]) (France)	Qualitative	Adults	No	22 (22 F)	Breast cancer	Radiation	Dose reduction	Reflection on experience	****
Henrich et al., 2014 ([31]) (Canada)	Qualitative	Pediatrics	Yes	32 (16 caregivers + 16 HCP)	Medulloblastoma	Radiation	Dose reduction	Reflection on experience	*****
Ingersgaard et al., 2017 ([32]) (Denmark)	Qualitative	Pediatrics	Yes	16 (5 M patients + 11 caregivers (3 M, 8 F)	Acute lymphoblastic leukemia	Chemotherapy	Dose reduction	Reflection on experience	*****
Killelea et al., 2019 ([33]) (United States)	Quantitative	Adults	No	63 (63 F)	Breast cancer	Radiation	Omission	Reflection on experience	*****
O'Callaghan et al., 2014 ([34]) (Australia)	Qualitative	Adults	Yes	35 (21 M patients + 14 caregivers (1 M, 13 F)	Prostate cancer	Radiation	Omission	Reflection on experience	*****
Parker et al., 2020 ([12]) (United States)	Qualitative	Pediatrics	Yes	20 caregivers (3 M, 17 F)	Acute lymphoblastic leukemia	Chemotherapy	Dose reduction	Reflection on experience	*****
Savard et al., 2021 ([35]) (Canada)	Quantitative	Adults	No	102 (NR)	Breast cancer	Endocrine therapy	Omission	Reflection on experience	*****
Shaverdian et al., 2019 ([36]) (United States)	Quantitative	Adults	No	24 (21 M, 3 F)	Oropharyngeal squamous cell carcinoma	Chemoradiation	Dose reduction	Reflection on experience	*****

(Continues)

TABLE 1 | (Continued)

Article	Study design	Pop.	Caregiver	Sample size & sex	Cancer type	Treatment & de-escalation type	De-escalation type	Type of decision	MMAT rating
Shumway et al., 2018 ([37]) (United States)	Quantitative	Adults	No	1239 (999 F patients + 240 HCP)	Breast cancer	Radiation	Omission	Hypothetical + reflection on experience	*****
Sigurdson et al., 2022 ([38]) (Canada)	Quantitative	Adults	No	58 (58M)	Prostate cancer	Radiation	Dose reduction	Reflection on experience	****
Stafford et al., 2023 ([39]) (Australia)	Mixed-methods	Adults	No	400 (400 F)	Breast cancer	Radiation	Omission	Reflection on experience	*****
Tulstrup et al., 2019 ([10]) (Denmark)	Quantitative	Pediatrics	Yes	NR	Acute lymphoblastic leukemia	Chemotherapy	Dose reduction	Reflection on experience	*****
Waks et al., 2022 ([40]) (United States)	Quantitative	Adults	No	98 (91 M, 7 F)	Breast cancer	Adjuvant chemotherapy	Omission	Reflection on experience	*****
Wang et al., 2021 ([41]) (United States)	Mixed-methods	Adults	No	275 (275 F) (263 quant, 12 qual)	Breast cancer	Radiation	Omission		

factor and were reluctant to consider a trial where survival rates were even minimally threatened [37]. One study showed 35% of participants were unwilling to de-escalate if there was any difference in predicted survival rate, and another 34% were only willing to de-escalate if difference in survival was less than 5% [37]. One third of breast cancer patients reported a lack of proven efficacy data made them feel reluctant to accept de-escalated treatment, and projected survival rates below the 90th percentile were unsatisfactory [40]. For parental family caregivers, the chance of their child's survival was the most important factor impacting their likelihood of de-escalation trial enrollment [34].

3.1.3 | Modality

Certain modalities of cancer therapy were perceived as more favourable for de-escalation, with up to 80% of participants preferring to reduce chemotherapy over radiation due to chemotherapy-associated illness, death, and disruption to daily life [35, 37]. For some who did opt to de-escalate therapy, there was a strong sense of gratitude for being able to avoid invasive treatment [26]. Participants in one study were more comfortable choosing de-escalation when a drug was substituted by a targeted, less toxic agent, reflecting the idea de-escalation is more palatable when an alternative therapy is offered [25].

3.2 | Factors Influencing Perspectives of De-Escalation

3.2.1 | Patient Factors

Patient attributes were noted as influencing willingness to consider de-escalated therapy [42].

3.2.1.1 | Age. Five studies reported patient age as influencing de-escalation decision-making [24, 27, 28, 31, 39]. In two studies, older patients were more likely to choose de-escalated therapy [27, 28] as these patients favored more convenient and shorter treatment schedules [27]. Older patients considered their stamina, anticipated lifespan, quality of life, and time with family as deciding factors related to de-escalation [24]. Further, those patients who had received the maximum treatment available reported being less inclined to pursue aggressive therapy had they been older when diagnosed [24]. Conversely, for those patients who had de-escalated treatment, most reported they would be more likely to pursue aggressive therapy if they had been younger at diagnosis [24]. Within a pediatric context, adolescents, compared to younger children, were more likely to be enrolled in a de-escalation trial [10] with treatments offering less side effects and injections being more desirable [33].

3.2.1.2 | Disease Characteristics. Six breast cancer specific articles described characteristics of the disease as influencing de-escalation decision-making [26, 28, 32, 38–40]. Patients who perceived themselves to be at higher risk [40], or had prior history of cancer [38], nonmetastatic disease [39], or more aggressive tumors [32] were less likely to select de-

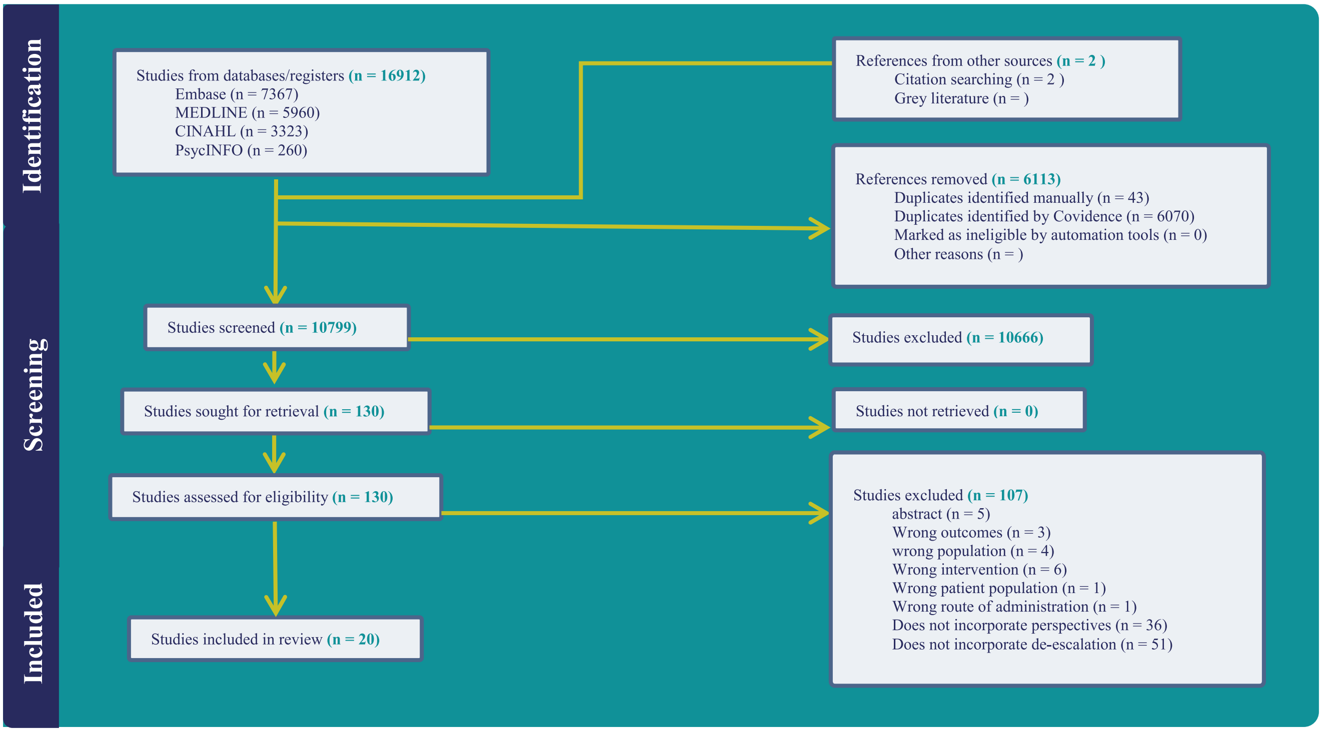

FIGURE 1 | Prisma diagram.

escalated therapy. Breast cancer patients with lower tumor grades were more likely to de-escalate therapy [28], as they perceived more treatment to be required only for those in poorer prognosis diseases [26].

3.2.1.3 | Acceptance of Uncertainty. Five sources describing four studies identified risk of decisional regret as a factor decreasing their likelihood to engage in cancer therapy de-escalation [12, 33, 34, 39, 40]. Two sources reported 23%–79% of adult patients feared regretting their decision, with those with this concern tending to decline de-escalated therapy [39, 40]. Three articles identified decisional regret as a major factor influencing parental decisions about de-escalation for their child with cancer, with perceptions their decision could result in inferior child health or survival being a major deterrent [12, 33, 34]. In contrast, no patients with OSCC who chose de-escalated therapy regretted their decision, with all reporting satisfaction with treatment [29]. In a separate study, most patients who opted to de-escalate adjuvant chemotherapy reported feeling positive or neutral about their decision [25].

Nine articles reporting on eight studies highlighted fear of cancer recurrence as major barrier to de-escalation [12, 26–29, 31, 36, 39, 40]. Up to 85% of adult patients reported fear of recurrence was a driving reason for refusing treatment de-escalation [28, 36, 39, 40]. Among parents, up to 89% attributed fear of recurrence as the primary reason for refusing therapy de-escalation for their child [12]. The partners of prostate cancer patients also reported worrying about threat of disease progression when choosing active surveillance as opposed to treatment [31].

Following treatment selection, one quarter of women with favourable-prognosis breast cancer reported worries about their cancer returning in the last month, with no significant differences between those who had de-escalated therapy and those who had not [28]. In another breast cancer study, women who had de-escalated therapy had significantly lower rates of fear of cancer recurrence due to the belief they were at low risk for recurrence, and had access to reassuring imaging and monitoring [26]. Fear of cancer recurrence after de-escalated treatment was not as expected for most OSCC patients in one study, with 42% reporting it to be greater than expected, and 25% reporting it to be less than expected [29].

3.2.2 | Clinician Factors

Clinician-associated factors impacted willingness to participate in cancer therapy de-escalation [42].

3.2.2.1 | Trust. Eleven articles reporting on 10 unique studies commented on the magnitude trust in their clinicians had on patient and family caregivers' decisions, citing medical expertise as rationale for accepting clinician recommendations [12, 24–26, 31, 33–35, 37, 39, 40]. Adult patients who would consider de-escalation if their clinician recommended it included 37.5% ($n = 51$) to 72% ($n = 29$) early-stage breast cancer patients, 92% ($n = 12$) of breast cancer patients aged ≥ 70 years, and 47% ($n = 51$) of OSCC patients [24, 26, 37, 40]. Some participants were willing to take their clinician's recommendation unconditionally, due to their reliance on medical knowledge and qualifications [34, 35, 40].

3.2.2.2 | Clinicians' Risk Preferences. Clinicians were also perceived as varying in their personal risk-taking preferences, with some being less averse to de-escalation than others [41], which influenced patient de-escalation decisions. A clinicians' explanation to patients and family caregivers could act as a source of bias, swaying patients' views of de-escalation [35]. One study reported patients who had physicians who embraced de-escalation were two times as likely to de-escalate cancer therapy, although not statistically significant [28].

3.2.3 | Setting Factors

A patient's social setting impacted their perceptions related to de-escalation [42].

3.2.3.1 | Clinical Trials. De-escalation in the setting of a clinical trial was seen both positively and negatively [12, 30, 33, 39, 40]. Three articles reporting on two unique studies noted a general disinterest in trial participation [30, 39, 40]. Between 14% and 35% of participants expressed trial participation disinterest, with rationale including reluctance to be part of an experiment, misconceptions about trials, the time required to participate, and mistrust of research, specifically within the African American community [30, 40]. In contrast, participants in three articles referenced the importance of trials and associated altruism as a facilitator to participate in de-escalation studies [12, 33, 40]. Two such articles focused on parents' decision-making about their child's trial participation, and even parents who did not consent, acknowledged the importance of trials in improving outcomes for children with cancer [12, 33].

3.2.3.2 | Family Life. The family social setting was highlighted in eight articles reporting on seven unique studies as impactful in de-escalation decision-making [24, 27, 28, 31, 36, 37, 39, 40], with 10%–74% of participants considering the ability to care for their family as a factor in treatment decision-making [28, 37]. One study reported unmarried women with breast cancer were less likely to de-escalate than their married counterparts [39], while unmarried patients with CML were more likely to choose de-escalation [36], demonstrating varying effects of marital status on willingness to de-escalate. Three studies reported younger patients and their spouses preferred aggressive treatment due to expected longevity, especially when couples had children [31, 39, 40]. In one article, patients who opted to de-escalate therapy noted they would have made the opposite decision had they had young children [24, 40].

3.2.3.3 | Family Caregiver Involvement. Five studies mentioned family caregivers as being key participants in decision-making [10, 12, 31, 33, 34]. Parents of younger children with cancer reported making the de-escalation decision for their child alone, alongside their partner, and/or with their physician [12, 33]. Parents of adolescent patients encouraged collaborative decision-making with their child, but were willing to overrule the adolescent if they felt it necessary [10, 33]. Parents in two studies wished to make their decision according to their child's best interest, but often stated they preferred standard or intensified therapy to attain a perceived best chance of relapse-free survival [10, 33]. Worry of future immense guilt if their child did not survive greatly influenced parents' decision to de-escalate [12, 34]. Partner caregivers were not often part of de-escalation decisions, but reported supporting the patient's choice and helping manage the condition regardless [31].

3.2.4 | Societal Factors

Societal factors including cultural norms affected decisions to participate in de-escalation practices [42].

3.2.4.1 | Affinity for Aggressive Treatment. Three articles describing two unique studies identified a general preference for aggressive therapy as an argument against de-escalation [34, 39, 40], with up to 40% of participants favoring the notion of 'aggressive' treatment [40]. Most parents of children with medulloblastoma preferred aggressive treatment regardless of the impact on their child's quality of life, noting child survival as their priority [34].

3.2.4.2 | Affinity for Maximizing Quality of Life. Five articles reporting on six unique studies cited avoiding toxicities as the most compelling reason to choose de-escalated therapy [12, 33, 35, 36, 39, 40], with nine studies mentioning lessened side effects as an advantage to de-escalation [12, 25, 27, 31, 33, 35, 36, 39, 40]. Toxicities motivating the choice to de-escalate ranged from hair loss to death [40] to scars identifying one as a cancer patient [35].

Return to a normal life was noted as a positive consequence of de-escalation in three studies [26, 36, 39, 40]. De-escalation was viewed as a means to support life normalcy through less frequent hospital visits and the ability to maintain social relationships [35]. A quick return to regular activities was a top reason to select de-escalated treatment [29]. Treatment duration and recovery time were also valued in the context de-escalation [27, 37, 39, 40] and, in one study, all participants cited less time committed to treatment as justification for de-escalation [37].

A perceived reduced financial burden was a facilitator for choosing de-escalated therapy, with 47.5%–64.7% of patients reporting financial concerns influenced their decision [36, 40]. De-escalating therapy was considered to mean fewer payments for care, less time off work, and fewer travel and out-of-pocket costs [40]. However, separate studies showed, despite reported cancer-related financial worries, < 1% of older women with breast cancer reported cost motivated their de-escalation decision [28] and only 4% of OSCC patients considered their career as a significant deciding factor [37].

3.3 | Strategies to Support De-Escalation Decision-Making

3.3.1 | Patient-Focused Strategies

3.3.1.1 | Meeting Informational Needs. Seven sources reporting on six unique studies noted communication with patients about de-escalation should clearly explain the anticipated immediate and long-term benefits and risks of each treatment option, and the rationale for offering this type of treatment, to support informed choices [12, 24, 25, 28, 35, 38, 39]. Patients and family caregivers report receiving de-escalation education from sources including physicians, other clinicians, other patients, tumor boards, family members, clinical trial materials, and the internet [12, 24, 31, 35, 37]. One study described the information provided to prostate cancer patients and their partner caregivers as confusing, particularly when coming from multiple sources [31]. Patients and family caregivers recommended acknowledgment of the psychological discomfort caused by de-escalation decisions, and discussion of clinical trial intracacies [25, 28, 33].

3.3.1.2 | Coping Strategies. Four studies described coping behaviors and strategies to manage the uncertainty associated with de-escalation to improve feelings of safety [26, 31, 35, 40]. Both women with breast cancer, and men with prostate cancer and their partners supported themselves with positive self-talk, distraction, trust in their clinician, living as normally as possible, leading a healthy lifestyle, and humor [26, 31].

3.3.2 | Clinician-Focused Strategies

3.3.2.1 | Providing Tailored Patient Education. Ten studies highlighted the importance of the information given by their physician [10, 12, 24, 25, 28, 31, 33, 35, 38–40]. One source identified physicians as the preferred source of education, followed by other clinicians [35]. Patients and family caregivers valued when clinicians dedicated sufficient time to de-escalation conversations, had clear communication style, and were reputable [12, 31, 35]. Parents suggested physicians clearly explain what would happen if their child relapsed during or after the trial and regularly communicate trial updates [12]. Parents also highlighted the need for conversations about de-escalation to be tailored to the audience, where families with young children preferred discussions where the child was not present, and families with adolescents wished the adolescent to be present and included in decision-making [10, 12].

3.3.3 | Setting-Focused Strategies

Parents requested resources like study handouts in laymen terms, videos or informational websites about de-escalation to be offered [12]. Parents wished to have contact with other parents to provide support, and suggested use of written or video testimonials to connect [12]. Regular monitoring for disease status was helpful in mitigating uncertainty about the effectiveness of de-escalated therapy and alleviating fear of recurrence [26, 40].

3.3.4 | Society-Focused Strategies

Current societal norms were a challenge to the acceptance and implementation of de-escalated therapy, with a general belief more aggressive treatment for cancer is superior [12, 40]. One participant suggested providing more information to the general population about de-escalation to promote trust and mitigate suspicion of the concept [40].

3.4 | Quality Appraisal

Fifteen studies (75%) met all five MMAT criteria, four studies (20%) met 4/5 criteria, and one study (5%) did not meet triage criteria (Table 2). Eight of 10 quantitative studies met all criteria, with one at risk for nonresponse bias, and one not meeting triage criteria. Five of six qualitative studies met all criteria, with one article not adequately describing data collection methods. Two of four mixed-methods studies met all criteria, with one not addressing converging and diverging features of the qualitative and quantitative data, and one identifying risk for nonresponse bias.

4 | Discussion

Patients and family caregivers have complex perspectives of cancer therapy de-escalation, and must consider many elements when making a decision about prospective participation in treatment de-escalation. In this review, we describe patient and family caregivers' de-escalation perspectives according to patient, clinician, setting and societal factors and strategies following Norton's (2019) Framework for the De-Implementation of Cancer Care Delivery (Table 3). The identified literature reported a variety of factors considered in de-escalation decision-making, including expected survival rate, treatment modality, and meeting patient and family informational needs. Factors related to acceptance of uncertainty, such as decisional regret and fear of recurrence were highlighted as influential in de-escalation decision-making. Clinician recommendations were highly impactful to patients and family caregivers due to their reliance on expert opinion. Although de-escalation is valued as means to improve the toxicities, burden, and quality of life of cancer patients and survivors, and contribute to science, the choice to participate in de-escalation, is multifactorial and complicated. The patient- and family-support strategies identified can provide clarity and guidance to aid the decision-making process.

Half the sources included in this review focused on breast cancer [49] and most (65%) samples were primarily (at least 88%) made up of one sex. This tempers our findings with important sex and gender considerations. For instance, research indicates, due to biological, social, and political reasons, younger men may be more risk-seeking than their female counterparts [50]. The adolescent patients in Ingersgaard et al. (2018) were all males, which may have contributed to the overwhelming favourability of de-escalated therapy in this study. Among articles reporting interest in de-escalation, women with breast cancer had lower levels of acceptance than patients with other diagnoses [28, 30, 36, 39]. Traditionally gendered family roles, and responsibilities have been shown to impact cancer experience [51], but it is not yet known their impact on de-escalation decision-making. Research is required to understand more fully sex and gender differences in perspectives on de-escalation, and how these differences may require tailored supports in practice.

TABLE 2 | MMAT.

Category of study designs	Methodoligical quality criteria	Article																			
		Amols et al., 1997[31]	**Andrews et al., 2022[32]**	**Bromley et al., 2019[34]**	**Brotherston et al., 2013[35]**	**Chen et al., 2023[36]**	**Gauna et al., 2022[38]**	**Henrich et al., 2014[39]**	**Ingersgaard et al., 2017[40]**	**Killelea et al., 2019[42]**	**O'Callaghan et al., 2014[41]**	**Parker et al., 2020[12]**	**Savard et al., 2021[43]**	**Rocque et al., 2021[33]**	**Shaverdian et al., 2019[37]**	**Shumway et al., 2018[44]**	**Sigurdson et al., 2022[45]**	**Stafford et al., 2023[46]**	**Tulstrup et al., 2019[10]**	**Waks et al., 2022[47]**	**Wang et al., 2021[48]**
Screening questions (for all types)	S1. Are there clear research questions?	C	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y
	S2. Do the collected data allow to address the research questions?	C	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions																				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?		Y		Y		Y	Y	Y		Y	Y		Y				Y			Y
	1.2. Are the qualitative data collection methods adequate to address the research question?		Y		Y		C	Y	Y		Y	Y		Y				Y			Y
	1.3. Are the findings adequately derived from the data?		Y		Y		Y	Y	Y		Y	Y		Y				Y			Y
	1.4. Is the interpretation of results sufficiently substantiated by data?		Y		Y		Y	Y	Y		Y	Y		Y				Y			Y
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?		Y		Y		Y	Y	Y		Y	Y		Y				Y			Y
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?																				
	2.2. Are the groups comparable at baseline?																				
	2.3. Are there complete outcome data?																				
	2.4. Are outcome assessors blinded to the intervention provided?																				
	2.5 Did the participants adhere to the assigned intervention?																				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?																			Y	
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?																			Y	
	3.3. Are there complete outcome data?																			Y	
	3.4. Are the confounders accounted for in the design and analysis?																			Y	
	3.5. During the study period, is the intervention adminstered (or exposure occured) as intended?																			Y	

(Continues)

In the context of cancer decision-making, patients may misjudge their treatment knowledge and understanding [52]. Furthermore, patients may overestimate the benefits or risks of de-escalated therapy despite education [28, 32]. With de-escalation being a complex and paradoxical concept, it is perhaps unsurprising patients and family caregivers report confusion [31]. This underscores the vulnerability of certain populations, such as those who are non-English speaking [28] or have lower educational attainment [12, 52], who are more likely to consent to de-escalation [12, 28]. Patients and their partners have reported satisfaction with information provided by physicians about de-escalation even when not comprehending the data [31], creating risk of choosing based only on clinician recommendations. A thorough assessment of understanding is therefore required to avoid decisions based on false assumptions [33]. The co-development of patient-centred educational [2] and decision-making support materials in multiple languages, with patients and family caregivers can help ensure the provision of appropriate information to support informed decisions.

Several articles revealed patients and family caregivers heavily rely on the medical expertise of their clinicians, with many following the recommendations of their healthcare team [12, 24–26, 31, 33–35, 37, 39, 40]. However, clinicians' biases and personality traits can influence how information is presented to the patients and family caregivers and distort the way information is interpreted [53, 54]. Risky Choice Framing, developed from Prospect theory [53, 55], proposes people will perceive the impact of losses to exceed those of equal gains, creating risk aversion even in the face of potential gains [53, 55]. To minimize the impact of inadvertent bias infiltrating patient and family caregiver decisions, effort should be made to ensure clinicians

Category of study designs	Methodoligical quality criteria	Article																			
		Amols et al., 1997[31]	Andrews et al., 2022[32]	Bromley et al., 2019[34]	Brotherston et al., 2013[35]	Chen et al., 2023[36]	Gauna et al., 2022[38]	Henrich et al., 2014[39]	Ingersgaard et al., 2017[40]	Killelea et al., 2019[42]	O'Callaghan et al., 2014[41]	Parker et al., 2020[12]	Rocque et al., 2021[33]	Savard et al., 2021[43]	Shaverdian et al., 2019[37]	Shumway et al., 2018[44]	Sigurdson et al., 2022[45]	Stafford et al., 2023[46]	Tulstrup et al., 2019[10]	Waks et al., 2022[47]	Wang et al., 2021[48]
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?			Y	Y	Y				Y			Y	Y	Y	Y	Y	Y	Y		Y
	4.2. Is the sample representative of the target population?			Y	Y	Y				Y			Y	Y	Y	Y	Y	Y	Y		Y
	4.3. Are the measurements appropriate?			Y	Y	Y				Y			Y	Y	Y	Y	Y	Y	Y		Y
	4.4. Is the risk of nonresponse bias low?			Y	Y	C				Y			C	Y	Y	Y	Y	Y	Y		Y
	4.5. Is the statistical analysis appropriate to answer the research question?			Y	Y	Y				Y			Y	Y	Y	Y	Y	Y	Y		Y
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				Y								Y					Y			Y
	5.2. Are the different components of the study effectively integrated to answer the research question?				Y								Y					Y			Y
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				Y								Y					Y			Y
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				Y								Y					C			Y
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				Y								Y					Y			Y

participate in reflexive practice about their beliefs and preferences [28, 35]. Specific training for clinicians, including risk and research agenda communication, is suggested to improve information delivery about de-escalation [24, 28, 33]. Decision-making tools, such as educational videos, information packages, or websites could lend to standardization of communication by alleviating biases.

Although de-escalation of cancer therapy is a unique decision, it offers similarities to the decisions made by older adults considering to accept or decline cancer treatment [56]. A variety of treatments or adaptations of treatments are offered [57] which may include dose reductions or modality omission to enhance tolerability, and quality of life, particularly when older age and comorbidities may impact life expectancy [56]. A systematic review [56] reporting on factors impacting older adults' decisions about cancer therapy, too, identified survival rate, trust in clinician recommendations, and considerations about toxicities to be influential in decision-making. It was noted older adults were less likely to select treatments that prolonged life at the cost of quality of life [58] and reported side effects, and uncertainties were not as impactful in their decisions when compared to their younger counterparts [56]. The similarities and differences in preferences between groups within cancer care emphasizes the importance of assessing patient and family caregiver needs. Supportive clinical decision-aids represent a potentially useful modality to support de-escalation decisions [58].

The roadmap designed by Piccart et al. (2020) may provide a way forward in the field of de-escalation. This model addresses methodological weaknesses in de-escalation trials to facilitate successful research and subsequent treatment protocols [2]. One recommendation is to engage patients and family caregivers early in clinical trial planning and include their perspectives about the decision-making process to co-design feasible trials [2, 37, 40]. Consistent with our results, an emphasis on physician-patient-caregiver communication and related training for physicians is recommended to provide comprehensive de-escalation information [2]. The design of decision resources is proposed to better explain trials to patients and family caregivers [2]. Despite this roadmap, little research about patient and family caregiver perspectives in de-escalation exists or is included in ongoing de-escalation trials, underscoring the urgent need for efforts in these areas [2]. This scoping review synthesizes what is known about patient and family caregiver perspectives of cancer therapy de-escalation in efforts to inform future trials and care and support the informational needs required for decision-making.

4.1 | Clinical and Research Implications

This scoping review identifies factors influencing decisions regarding cancer therapy de-escalation, and emphasizes

TABLE 3 | Study reference to factors and strategies to de-escalation.

Factor	Subfactor	Number of studies	Studies
Patient factors influencing perspectives of de-escalation	Age	5	[24, 27, 28, 31, 39]
	Diagnosis	6	[26, 28, 32, 38–40]
	Acceptance of uncertainty	11	[12, 26–29, 31, 33, 34, 36, 39, 40]
Clinician factors influencing perspectives of de-escalation	Trust	11	[12, 24–26, 31, 33–35, 37, 39, 40]
	Clinicians' risk preferences	3	[28, 35, 41]
Setting factors influencing perspectives of de-escalation	Clinical trials and research	5	[12, 30, 33, 39, 40]
	Family life	8	[24, 27, 28, 31, 36, 37, 39, 40]
	Family caregiver involvement	5	[10, 12, 31, 33, 34]
Societal factors influencing perspectives of de-escalation	Affinity for aggressive treatment	3	[34, 39, 40]
	Impacts of treatment		[12, 25–28, 31, 33, 35–37, 39, 40]
Patient strategies for influencing de-escalation	Education	7	[12, 24, 25, 28, 35, 38, 39]
	Coping strategies	4	[26, 31, 35, 40]
Clinician strategies for influencing de-escalation	Education approach	11	[10, 12, 24, 25, 28, 31, 33, 35, 38–40]
Setting strategies for influencing de-escalation	Clinical trial resources	1	[12]
	Community building	1	[12]
	Monitoring	2	[26, 40]
Societal strategies for influencing de-escalation	Societal norms	2	[12, 40]

strategies required to support patients and family caregivers during decision-making processes. Understanding their perspectives provides opportunity to develop and provide future patient-and-family-caregiver informed resources to facilitate informed therapy de-escalation decisions. Our findings also emphasize the importance of promoting de-escalation communication skill development amongst clinicians to cultivate a collaborative patient-caregiver-clinician relationship, minimizing bias and fostering trust.

4.2 | Limitations

The term de-escalation is a novel concept, and not well-defined or associated with index terms within the literature. Thus, there is potential, despite our thorough search, relevant studies were missed. Additionally, this review covers the entire lifespan, and includes all cancer types. Although this allowed us to appraise the literature pertaining to a large and diverse group, patient and disease characteristics can influence perspectives about de-escalation and therefore conclusions may not apply to nuanced patient circumstances. Quality appraisal was done by one author, and could have been strengthened by completion in duplicate. Finally, using a deductive approach to organizing our data may have limited our capacity to highlight data that did not fit within the framework's bounds.

5 | Conclusion

A small, heterogenous collection of literature explores patient and family caregiver perspectives on cancer therapy de-escalation, but little is known about how factors influencing de-escalation decisions are prioritized or how they affect choices across cancer diagnoses, patient age, race/ethnicity, language, and treatment plans. Consideration to differences between hypothetical and actual de-escalation choices, and the perspectives of patients and family caregivers for whom de-escalation led to treatment failure are recommended in future research. Future patient and family caregiver preference studies, using well-designed discrete choice experiment methodologies, could lay the groundwork for developing decision aids, improving clinician-patient-caregiver communication, and supporting trial design [59]. The goals of medicine focus on achieving cure and relieving suffering [60], sharing aims with cancer therapy de-escalation. Understanding de-escalation decision-making and the required resources will be crucial for informed decision-making when balancing therapy effectiveness with risk in cancer care.

Author Contributions

Rachel Hamilton and Lindsay Jibb conceptualized and developed the research questions. Rachel Hamilton, Lindsay Jibb, and Elham Hashemi developed and wrote the project protocol. Search strategy was developed

and run my Rachel Hamilton. Screening was completed by Rachel Hamilton, Megan Liang, and Annothayan Uthayakumar. Data extraction was completed by Rachel Hamilton and Lindsay Jibb, and checked by Annothayan Uthayakumar. The first draft of the manuscript was written by Rachel Hamilton, and was revised by Lindsay Jibb, Samantha Mayo, and Kellee Parker.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The 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.