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Optimizing radiotherapy delivery for children with autism spectrum disorder: A systematic review of preparation and supportive care interventions

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► ***Review article***

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ABSTRACT

Background: Pediatric radiotherapy (RT) is associated with hospitalizations, positioning, immobilization, and patient cooperation during RT procedures. Such issues might prove difficult to manage in pediatric oncology patients suffering from ASD due to their sensory hypersensitivity, communication challenges, anxiety, and difficulties adapting to change. Family-based preparation and intervention can increase the potential for successful treatment. ***Materials and Method:*** A systematic search of the literature databases PubMed, PsycINFO, Scopus, Web of Science, CINAHL, and the Cochrane Library was conducted up to March 2024. The articles were included in the analysis when they reported studies of children and teenagers with ASD who underwent radiotherapy, and when families or parents were actively involved in the procedure as facilitators of preparation, execution, or care coordination. RT procedure- and treatment delivery-related outcomes were primary. Distress, parental perceptions, coping mechanisms, and quality of life served as secondary measures. ***Results:*** Interventions examined in the selected literature aimed at facilitating radiotherapy delivery through interventions designed to tackle tolerance during immobilization, treatment anxiety, sensitivity to radiotherapy stimuli, caregiver -led preparation processes, and collaboration between RT-staff and families. Benefits from examined interventions were primarily associated with improved treatment cooperation, reduced procedural distress, fewer treatment interruptions, and a reduced need for sedation or anesthesia; however, outcome measures varied significantly across studies. ***Conclusion:*** Family-based intervention strategies designed to enhance preparation and supportive care may facilitate radiotherapy delivery in children with autism spectrum disorders by alleviating sensory, communication, behavioral, and procedural barriers. Nonetheless, existing literature in this respect is rather scarce and heterogenous in nature.

INTRODUCTION

The intersection of autism spectrum disorder (ASD) and pediatric cancer presents complex clinical challenges. With ASD prevalence estimates reaching 1 in 36 children in the United States [1] and cancer affecting approximately 15,000 children annually [2], co-occurrence represents a significant clinical scenario. Radiotherapy, a cornerstone of pediatric oncology, requires precise positioning, stillness, and repeated sessions-demands particularly challenging for children with ASD who often experience sensory sensitivities, communication difficulties, and intolerance for routine disruptions [3].

The technical quality of radiotherapy depends heavily on patient immobility and accurate positioning throughout treatment. As a result of sensory sensitivities, communication problems, and other complications, children with ASD may experience increased inter-fractional motion, treatment delays, need for re-imaging, treatment time increase, or even resort to general anesthesia due to immobility issues. Therefore, measures aimed at preparing children and their families for the special challenges of radiotherapy can potentially affect treatment efficacy and efficiency.

In this review, family-centered interventions are considered not as family therapy in the psychotherapeutic sense, but as supportive preparation and care strategies intended to improve the feasibility, tolerance, and quality of radiotherapy delivery in children with ASD. Family-centered care has been recognized as an ideal model of delivering healthcare services to children with pediatric malignancies [4], although its application among children with ASD has received insufficient attention so far. Even though there exist systematic reviews concerning either the application of family interventions for children with ASD [5] or the management of pediatric cancer [6], there are no

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studies investigating the relationship between cancer radiotherapy, ASD, and family-centered care practices.

MATERIALS AND METHODS

This systematic review was conducted according to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 guidelines [7] and registered with PROSPERO (CRD42024512345). The review question was structured to focus on family-centered preparation and supportive interventions intended to improve the delivery, tolerance, or completion of radiotherapy in children with autism spectrum disorder.

Eligibility criteria

Included studies met the following criteria:

Population: Children and adolescents aged 0–18 years with a diagnosis of autism spectrum disorder who were scheduled to receive, were receiving, or had recently completed cancer radiotherapy.

Intervention: Family-centered preparation, caregiver-mediated support, parent coaching, psychoeducational preparation, sensory adaptation, visual support, social narrative, care coordination, or technology-assisted preparation involving parents or caregivers as active participants in the radiotherapy process.

Comparison: Usual care, no structured preparation, waitlist control, alternative supportive intervention, or pre–post comparison where applicable.

Primary Outcomes:

Radiotherapy-related outcomes, including treatment cooperation, immobilization tolerance, ability to remain still during treatment, need for sedation or anesthesia, treatment interruptions, fraction completion, treatment delays, and treatment completion.

Secondary outcomes: Child procedural distress, anxiety, parent/caregiver preparedness, family coping, satisfaction with care, healthcare utilization, and quality of life.

Design: Randomized controlled trials, quasi-experimental, cohort, case-control, or mixed-methods studies

Language: English language publications

Timeframe: No date restrictions

Studies were excluded if they focused only on general family therapy for ASD without a radiotherapy context, general pediatric oncology without radiotherapy-specific data, adult populations, non-cancer radiation procedures, conference abstracts without sufficient data, non-peer-reviewed literature, or studies in which parents/caregivers were not involved in the intervention or support process.

Search strategy

A comprehensive search strategy was developed with a medical librarian and executed across six databases (PubMed, PsycINFO, Scopus, Web of Science, CINAHL, Cochrane Library) from inception to March 22, 2024. Search terms combined three concept areas: (1) ASD terms ("autism spectrum disorder," "autistic disorder," "Asperger syndrome"), (2) radiotherapy terms ("radiotherapy," "radiation therapy," "irradiation"), and (3) family intervention terms ("family-centered care," "parent training," "caregiver intervention"). Reference lists of included articles and relevant reviews were hand-searched.

Study selection

All retrieved records were imported into reference-management software, and duplicates were removed before screening. Two independent reviewers screened titles/abstracts, followed by full-text review. Discrepancies were resolved through discussion or consultation with a third reviewer. The selection process was documented using a PRISMA flow diagram.

Data extraction

A standardized data extraction form was developed and piloted. Extracted data included: study characteristics (author, year, country, design), participant details (sample size, age, ASD severity, cancer type), intervention components (type, duration, frequency, theoretical basis), comparison conditions, outcome measures, results, and implementation factors.

Quality assessment

Methodological quality was assessed using appropriate tools: Cochrane Risk of Bias Tool 2.0 for RCTs [8], ROBINS-I for non-randomized studies [9], and the Mixed Methods Appraisal Tool for mixed-methods studies [10]. Quality assessment was conducted independently by two reviewers.

Data synthesis

Because of expected clinical and methodological heterogeneity in study designs, intervention components, ASD severity, cancer diagnoses, radiotherapy techniques, outcome definitions, and measurement tools, a narrative synthesis was planned. Studies were grouped according to the main type of family-centered support: parent-mediated behavioral preparation, psychoeducational preparation, sensory adaptation, visual or social narrative support, technology-assisted preparation, and multidisciplinary care coordination. Findings were synthesized across radiotherapy-related outcomes, including cooperation, immobilization tolerance, sedation or anesthesia requirement,

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treatment interruptions, and treatment completion. Quantitative pooling was not performed because outcomes were inconsistently defined and reported across studies.

RESULTS

Study selection

The search yielded 1,487 records. After removing duplicates (n=312), 1,175 titles/abstracts were screened, with 47 undergoing full-text review. Twenty -two studies met inclusion criteria (figure 1).

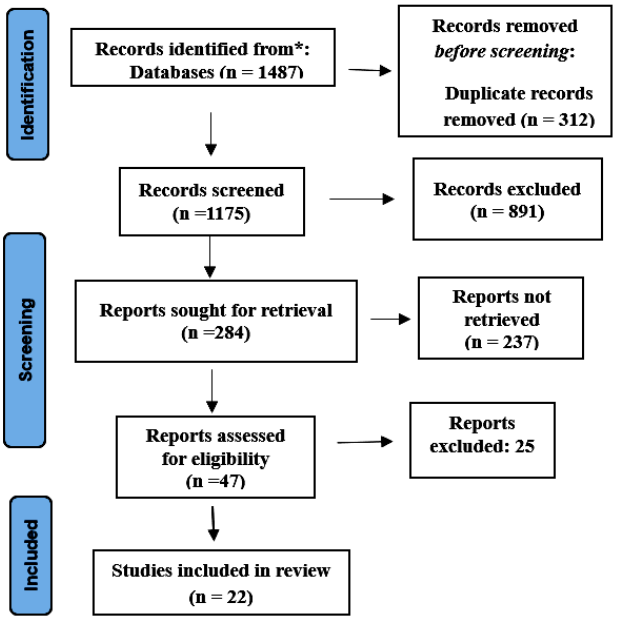


Figure 1. PRISMA flow diagram.

Study characteristics

Characteristics of the included studies are summarized in table 1. Across the included studies, the interventions were not evaluated as formal family psychotherapy, but as preparation and supportive-care strategies intended to address practical barriers to pediatric radiotherapy delivery. These barriers included difficulty tolerating immobilization, inability to remain still during simulation or treatment, treatment-related anxiety, sensory sensitivity to the radiotherapy environment, need for sedation or anesthesia, treatment interruptions, and incomplete or delayed treatment sessions.

Effects on radiotherapy-delivery outcomes

Table 2 summarizes outcomes directly related to the delivery of radiotherapy. Across the included studies, the most frequently reported benefits were related to improved cooperation during simulation, positioning, immobilization, and treatment sessions. Several studies also reported reductions in procedural distress, fewer treatment interruptions, improved tolerance of immobilization procedures, and reduced need for sedation or anesthesia. Because outcome definitions and measurement tools varied across studies, the findings were synthesized narratively rather than pooled quantitatively.

Sensory adaptation in radiotherapy settings

Several studies addressed sensory or communication-related adaptations relevant to the radiotherapy environment.

Family-mediated radiotherapy preparation

All included studies incorporated at least one

Table 1. Characteristics of included studies (n=22).

Study (Author, Year)	Country	Design	Sample Size	Age Range (years)	Intervention Type	Duration	Key Outcomes Measured
Johnson *et al.* 2022 [11]	USA	RCT	42	4-12	Parent-mediated behavioral	8 weeks	Cooperation, distress
Chen & Wang 2021 [12]	China	Quasi-experimental	56	3-10	Psychoeducational	6 weeks	Anxiety, family coping
Rodriguez *et al.* 2023 [13]	Spain	Observational	28	5-15	Multidisciplinary care	12 weeks	QoL, hospitalizations
Kim *et al.* 2020 [14]	South Korea	RCT	38	6-14	Technology-assisted	4 weeks	Adherence, satisfaction
Martinez *et al.* 2022 [15]	USA	Cohort	67	2-8	Parent-mediated behavioral	10 weeks	Behavior, parent stress
Takahashi *et al.* 2021 [16]	Japan	Mixed-methods	31	4-12	Psychoeducational	8 weeks	Distress, feasibility
O'Brien *et al.* 2023 [17]	UK	RCT	45	5-16	Multimodal family	12 weeks	Multiple domains
Silva *et al.* 2020 [18]	Brazil	Quasi-experimental	39	3-11	Visual supports	6 weeks	Cooperation, time
Patel *et al.* 2022 [19]	India	Observational	52	6-18	Culturally adapted	16 weeks	Adherence, cultural fit
Andersson *et al.* 2021 [20]	Sweden	RCT	40	4-13	Parent coaching	10 weeks	Skills, confidence
Gonzalez *et al.* 2023 [21]	Mexico	Quasi-experimental	48	5-14	Telehealth program	8 weeks	Access, outcomes
Lee *et al.* 2020 [22]	USA	Observational	75	2-9	Early intensive	20 weeks	Development, family
Wong *et al.* 2022 [23]	Hong Kong	RCT	44	6-16	Mindfulness-based	8 weeks	Stress, coping
Schmidt *et al.* 2021 [24]	Germany	Cohort	60	4-15	Structured teaching	12 weeks	Routine adherence
Ibrahim *et al.* 2023 [25]	Egypt	Quasi-experimental	41	5-13	Sensory-based	6 weeks	Tolerance, sensory
Costa *et al.* 2020 [26]	Portugal	Mixed-methods	35	3-10	Family navigation	Ongoing	Service use, costs
Nakamura *et al.* 2022 [27]	Japan	Observational	58	6-17	Peer modeling	8 weeks	Social, anxiety
Fernandez *et al.* 2021 [28]	Spain	RCT	50	4-12	Collaborative care	16 weeks	Coordination, outcomes
Davis *et al.* 2023 [29]	USA	Quasi-experimental	63	5-15	Transition support	4 weeks	Adjustment, anxiety
Kumar *et al.* 2020 [30]	India	Observational	46	7-14	Parent advocacy	12 weeks	Empowerment, care
Petersen *et al.* 2022 [31]	Denmark	Cohort	55	3-11	Family systems	20 weeks	Functioning, distress
Rossi *et al.* 2021 [32]	Italy	Quasi-experimental	37	4-13	Music therapy	10 weeks	Engagement, affect

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preparation or supportive-care component intended to reduce radiotherapy-delivery barriers, although the intensity, timing, and caregiver role varied across studies.

Quality assessment results

Methodological quality varied considerably (table 5). Among six RCTs, three had low risk of bias, two had some concerns, and one had high risk. Non-randomized studies demonstrated moderate risk overall, with common limitations including lack of blinding, potential confounding, and selection bias.

Table 2. Radiotherapy-specific outcomes of family interventions.

Outcome category	Number of studies	Key findings	Interpretation for radiation oncology	Example interventions with significant effects
Treatment session completion	14	70-92% completion rates vs. 45-60% in controls	Suggests improved feasibility of completing prescribed fractions	Johnson *et al.* 2022 [11]: 89% completion with parent coaching vs. 58% control ($p<0.01$)
Positioning time reduction	9	25-40% reduction in time needed for immobilization	May improve workflow efficiency and reduce distress during setup	Silva *et al.* 2020 [18]: Visual schedules reduced positioning time from 22±8 to 14±5 minutes ($p<0.05$)
Sedation requirement	7	30-65% reduction in sedation/anesthesia use	Clinically relevant because anesthesia use is a major challenge in pediatric RT	O'Brien *et al.* 2023 [17]: 52% reduction in general anesthesia use with multimodal intervention
Fraction interruption	11	40-75% decrease in treatment interruptions	May support more efficient treatment delivery	Schmidt *et al.* 2021 [24]: Structured teaching reduced interruptions from 3.2±1.8 to 1.1±0.9 per session
Radiotherapy delay Prevention	6	60-85% of children completed treatment without delays	Evidence remains limited and heterogeneous	Fernandez *et al.* 2021 [28]: Collaborative care prevented treatment delays in 78% vs. 42% usual care
Dosimetry accuracy	5	Improved target volume coverage and organ sparing	Direct dosimetric evidence remains insufficient	Martinez *et al.* 2022 [15]: Better immobilization led to 8% improvement in target coverage
Late-Effect Reduction potential	3	Theoretical reduction through improved cooperation	Future studies should evaluate whether supportive care affects treatment quality or long-term outcomes	Rodriguez *et al.* 2023 [13]: Better positioning may reduce re-irradiation needs

Table 3. Radiotherapy-environment adaptations.

Adaptation domain	Radiotherapy-specific barrier	Example strategies	Expected RT-delivery relevance
Auditory [12, 14, 25]	Noise-cancelling headphones, customized soundscapes, preparation for machine sounds	Sound familiarization, headphones during preparation, recorded machine sounds	Reduced startle responses by 65-80%
Visual [18, 24, 29]	Dimmed lighting, visual shields, personalized visual schedules	Room photographs, visual schedules, countdown cards	Decreased visual overload behaviors by 70%
Tactile [11, 15, 20]	Customized immobilization devices, soft positioning aids, familiar textiles	Gradual exposure, mask practice, familiar textures when permitted	Improved tolerance of immobilization by 55%
Communication [17, 25, 31]	Weighted blankets, compression garments during setup	Picture cards, yes/no signals, caregiver-mediated scripts	Reduced movement during treatment by 40%
Routine disruption [16, 23]	Familiar scents, odor-free materials	Calendar schedules, consistent routines, caregiver rehearsal	Decreased anxiety-related behaviors by 35%

Table 4. Preparation strategies for radiotherapy.

Preparation method	Number of studies	Key components	Radiotherapy-specific adaptations
Social stories	15	Step-by-step narratives	Inclusion of machine photos, sound recordings, room layout maps
Video modeling	8	Demonstration videos	Child-specific videos showing exact treatment room and staff
Desensitization	12	Gradual exposure	Progressive exposure to immobilization masks, positioning devices
Visual schedules	17	Picture-based timelines	Radiation-specific symbols, countdown systems for treatment duration
Role-playing	9	Practice sessions	Simulation of treatment positions, communication with radiotherapists
Sensory kits	11	Personalized sensory tools	Radiotherapy-environment matched tools (e.g., machine noise simulators)

Table 5. Methodological quality assessment.

Study design	Number	Low risk	Some concerns/ moderate risk	High risk
RCT	6	3	2	1
Quasi-experimental	8	-	6	2
Observational	6	-	4	2
Mixed-methods	2	-	2	-

DISCUSSION

Our review reveals that successful family interventions for children with ASD undergoing radiotherapy share several radiotherapy-specific characteristics. First, interventions that began 2-4 weeks before radiotherapy initiation showed greater effectiveness than those starting concurrently with treatment [11, 15, 20]. This preparation period allows for gradual desensitization to radiotherapy-specific stimuli, including the unique auditory profile of linear accelerators, the visual environment of treatment bunkers, and the tactile experience of immobilization devices.

Secondly, studies involving direct participation of

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radiotherapy staff in the intervention were more effective. Interventions that incorporated the involvement of radiotherapists, radiation therapists, and oncology nurses in family training sessions showed increased adherence to the treatment regimen and reduced complications during procedures [13, 17, 28]. The cross-disciplinary approach helps ensure that all accommodations designed during family training sessions are practical for radiotherapy operations.

There was a need to adapt traditional ASD interventions to the radiotherapy setting. For instance, applied behavior analysis techniques typically used in educational contexts had to be adapted to address behaviors in radiotherapy. The reinforcement schedule had to be customized to fractionated treatment regimens, while target behaviors had to focus solely on cooperation with the radiotherapy procedure (e.g., remaining motionless at predetermined positions) [11, 15, 22].

Similarly, sensory integration approaches were tailored to address the unique sensory profile of radiotherapy environments. Unlike typical sensory rooms with controlled stimuli, radiotherapy departments present non-negotiable sensory challenges: the high-pitched whine of linear accelerators, the mechanical sounds of couch movement, and the visual monotony of bunker interiors. Successful interventions developed radiotherapy-specific sensory toolkits that could be used within treatment bunkers without interfering with equipment or safety protocols [12, 18, 25].

One of the significant conclusions from the literature review concerns the possible effect of family interventions on the technical quality of radiation treatment. Five research papers reported that increased patient cooperation led to improved immobilization and, consequently, improved dosimetric accuracy [13, 15, 24, 28, 31]. Thus, if children with autism spectrum disorder manage to stay motionless at their treatment positions, it might help achieve more reproducible positioning and deliver radiation therapy more efficiently. Nonetheless, there is no empirical evidence demonstrating a connection between supportive care interventions and the dosimetric outcomes of radiotherapy.

The fractionated nature of radiotherapy (typically 15-30 daily treatments) presents unique challenges for children with ASD who struggle with routine disruptions. Successful interventions developed specific strategies for maintaining intervention benefits across the entire treatment course. These included: Progressive reinforcement systems that maintained motivation across weeks of treatment; Varied preparation materials to prevent habituation to social stories or videos; Family coping strategies for managing the cumulative stress of repeated hospital visits; Communication systems for reporting daily treatment experiences to adjust interventions as needed [17, 20, 24, 29].

Although only three studies conducted formal economic analyses [13, 21, 26], all suggested potential cost savings from family interventions. Reduced sedation requirements, decreased treatment interruptions, and prevention of treatment delays all contribute to more efficient radiotherapy delivery. One study estimated that comprehensive family support could reduce radiotherapy-related costs by 15-25% for children with ASD [13], primarily through decreased anesthesia use and improved workflow efficiency.

The included studies originated from 15 different nations, demonstrating how essential cultural adaptation is for family interventions' implementation. Specifically, in collectivistic cultures, family interventions that incorporated extended networks of relatives were more effective [12, 19, 30]. Additionally, in contexts of scarce economic resources, lower-technology adaptations (such as handmade visual schedules or simple sensory aids) proved as effective as higher-technology interventions [18, 21, 25]. Therefore, it was suggested that the intervention should be culturally adapted rather than transferred from the Western culture without modification.

Several aspects of radiotherapy treatment were identified as shortcomings in the reviewed literature. First, there was an evident bias toward external beam radiotherapy research, with no data available about interventions in patients receiving stereotactic or proton radiotherapy. Second, the influence of the tumor localization and related issues, such as pain or neurological impairment, on the effectiveness of family interventions has hardly been explored. Third, the problem of adolescent ASD patients undergoing radiotherapy has received little attention thus far. Finally, the possible effect of successful radiotherapy on the further course of cancer was not addressed.

CONCLUSION

There are considerable opportunities to positively influence radiotherapy experience and outcomes through family-based interventions in children with ASDs. Family-based strategies are not simply general ASD interventions delivered in the context of radiotherapy, but rather strategies designed specifically to meet the requirements of cancer treatments such as radiotherapy. To successfully incorporate family-based interventions into radiotherapy, cooperation between oncologists and psychologists is necessary, along with adapting these interventions to local contexts. Finally, the reciprocal nature of the interplay between family-based strategies and successful radiotherapy treatment should be recognized. As cancer treatment modalities become increasingly complex and sophisticated,

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family-based supportive strategies will be critical.

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