


# The Experience of Children With Neuroblastoma and Their Parents During Single-Room Isolation for $^{131}\text{I}$ -Metaiodobenzylguanidine Therapy: A Qualitative Descriptive Study

Journal of Pediatric Hematology/  
Oncology Nursing  
2022, Vol. 39(5) 304–316  
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Hematology/Oncology Nurses  
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DOI: 10.1177/27527530211068749  
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## Abstract

**Background:** Administration of  $^{131}\text{I}$ -metaiodobenzylguanidine ( $^{131}\text{I}$ -MIBG) for neuroblastoma requires hospitalization in single-room isolation and limits caregiver physical contact due to the child's radioactive burden. Though used for decades, there is a dearth of research on the experiences of children and their parents while isolated. **Methods:** This qualitative descriptive study evaluated the experience of children with neuroblastoma undergoing single-room isolation for  $^{131}\text{I}$ -MIBG therapy and their parents. Ten nurses, nine parents, and five children were interviewed; transcripts were analyzed applying a conventional content analysis approach. **Results:** Child themes included overall experiences ranging from positive to negative; emotional stress was common; symptoms were common but mostly managed; the children were adequately prepared for isolation; and audiovisual technology and entertainment helped. The indwelling urinary catheter was a source of emotional stress and/or pain for several children. Parent themes included I thought it was going to be a lot worse; it gets better with time; feeling concerned and overwhelmed; prepared as much as you can be; and you feel like you're not alone. **Discussion:** Findings suggest that children and parents would benefit from additional coping support interventions to address emotional distress. Efforts should be made to identify other sources of technology or room designs that can maximize the child's sense of connection with parents and healthcare professionals. Additional research is needed to examine the impact of this isolation experience on the long-term psychological outcomes of children and parents.

## Keywords

Metaiodobenzylguanidine (MIBG), child experience, pediatric, emotional distress, radiotherapy

## Introduction

Neuroblastoma, a cancer of the sympathetic nervous system, accounts for 6% of pediatric cancer cases in the United States and is the most common extra-cranial tumor in children (Rufini et al., 2015; Siegel et al., 2020). While outcomes for children with low-risk neuroblastoma are promising, relapse is common for patients classified as high-risk (Pinto et al., 2015; Whittle et al., 2017) and their estimated five-year survival is 46% (Coughlan et al., 2017). Accordingly, approaches for treatments are based on risk, with patients at high-risk receiving more intensive multi-modal therapy including induction (chemotherapy and surgery), consolidation (high-dose chemotherapy, autologous hematopoietic stem-cell rescue and radiotherapy), and postconsolidation

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(immunotherapy regimen) therapies (Coughlan et al., 2017; Pinto et al., 2015).

$^{131}\text{I}$ -metaiodobenzylguanidine ( $^{131}\text{I}$ -MIBG) is a radiotherapy that has been used as a primary and adjunctive therapy in clinical research trials for patients with newly diagnosed high-risk neuroblastoma and relapsed or refractory neuroblastoma (Breneman et al., 2018; Sharp et al., 2016). When  $^{131}\text{I}$ -MIBG is administered, the children are hospitalized in single-room isolation, typically in a dedicated lead-lined room, for four to six days due to the child's radioactive burden and risk of radiation exposure to caregivers (Rufini et al., 2016). Because  $^{131}\text{I}$ -MIBG is almost entirely excreted in urine, placement of an indwelling urinary catheter is standard during hospitalization for bladder protection and safety of the children's caregivers (DuBois et al., 2015; DuBois & Matthay, 2008).

As a result of radiation precautions, usual hospital practices are disrupted; visitors are generally not allowed and caregivers must limit physical contact with the child until the child's levels of radiation decrease. Parents often stay in a separate room with video monitoring or a leaded glass window (Agrawal et al., 2018). Due to the risk of exposure caring for patients over time, nurses are limited to as few as 30 min per day with the children. Thus, parents take on responsibilities such as draining the urinary catheter bag, administering oral medications, and providing hygiene care (Sharp et al., 2016).

Even though this radiotherapy has been used for over three decades, there is a dearth of research on the experiences of children and their parents during single-room isolation. Authors of discussion papers and publications outlining  $^{131}\text{I}$ -MIBG program development suggest the children and family experience heightened stress and anxiety related to the admission and isolation (Chu et al., 2016; Lessig, 2009). In addition to being separated from others, the children's usual comfort items such as a favorite blanket or toy may be restricted from the room due to risk of contamination (Shusterman et al., 2011). The children may also be affected by symptoms from treatment. While  $^{131}\text{I}$ -MIBG is often well tolerated, nausea and vomiting can occur from acute radiation gastritis in the first hours to days of treatment (Agrawal et al., 2018).

Research regarding the experience of children in single-room isolation for other reasons (e.g., infection prevention) is also limited. Much of the research was conducted over 20 years ago and few studies included perspectives of the children (Alvarez et al., 2020; Austin et al., 2013). However, findings from studies with adult and pediatric patients in isolation for infection prevention (protective precautions or transmission precautions) suggest emotional distress is present (Alvarez et al., 2020; Austin et al., 2013; Gammon & Hunt, 2018). Children with cancer, autoimmune disorders, and infectious diseases have expressed sadness, loneliness, and fearfulness, and their parents have expressed anxiety, stress, and

loneliness while isolated for infection prevention (Alvarez et al., 2020; Austin et al., 2013). Yet, isolation for infection differs from  $^{131}\text{I}$ -MIBG therapy in that caregivers are permitted to be at the children's bedside without time restrictions. Consequently, findings from research of isolation for infection may have key differences. For example, reduced time in the room during  $^{131}\text{I}$ -MIBG therapy could impact nurses' detection of behavioral cues of pain or nausea in children who are hesitant or have less ability to articulate discomforts.

Thus, the aim of this qualitative study was to describe the experience of children undergoing  $^{131}\text{I}$ -MIBG therapy and their parents. We sought to identify the emotional stressors and symptoms experienced by children during single-room isolation and the actions that assisted with coping. We also evaluated the parents' experience, preparation for their child's isolation, and actions identified as supportive.

## Methods

### Setting and Sample

This qualitative descriptive research was conducted at University of Chicago Comer Children's Hospital.

Eligible subjects included English-speaking children with neuroblastoma admitted for  $^{131}\text{I}$ -MIBG therapy, parents/guardians acting as caretakers during the therapy, and pediatric inpatient oncology nurses. Children between the ages of 4 and 18 years old were included. Children under the age of 4 years old were excluded, but their parents were still eligible for participation. Nurses were included if they provided care to a child who received pediatric patient  $^{131}\text{I}$ -MIBG therapy within the past three weeks.

A projected sample size of 30 (10 each of children, parents, and nurses) was anticipated to be sufficient to obtain information-rich data (Hennink et al., 2017) and to allow for maximal variation in participant attributes (Patton, 2014). Multiple perspectives were included to obtain a more complete understanding of the patient and parent experience and to triangulate findings (Patton, 2014). Nurses were included because along with parents, they provide the most direct care to the children during isolation (Shusterman et al., 2011). Nurses assess and intervene for patient symptoms and emotional distress, and offer support to parents during the admission. As such, nurses' clinical perspectives were important to comprehensively address the study aims.

### Procedures

Institutional Review Board approval was obtained, IRB14-1192. The  $^{131}\text{I}$ -MIBG research nurse recruited parents and children during a scheduled outpatient appointment prior to admission for  $^{131}\text{I}$ -MIBG therapy. Parents and nurses provided consent, and upon parental permission, assent was obtained from the children.

**Table 1.** Participant Interview Guide Sample Questions.

Participant	Sample Interview Questions
Nurse	Please tell me about your recent experience caring for a child in single-room isolation for MIBG therapy. While caring for this child, did he/she experience any symptoms/physical distress? If yes, please explain. While caring for this child, did he/she experience any emotional distress? If yes, please describe. Have you cared for other children receiving MIBG therapy? How were they similar/different?
Parent Interview 1	How did you prepare for this treatment? Tell me about the day of the MIBG infusion. What happened each time you went in the room with your child? How did you feel being your child's primary caregiver? What were you and your nurse responsible for in caring for your child? How would you describe your child's understanding of the treatment? How would you describe your child's experience of the treatment? What emotions did you feel throughout this experience? Is there anything that has been helpful for you during this experience? We are asking these questions so we can inform doctors and nurses more about how to help children with neuroblastoma who are going through MIBG therapy. What do you think we should tell them?
Parent Interview 2	Was caring for your child during this therapy different from other inpatient treatment stays? How so? Tell me about the discharge process. Did you feel prepared to take your child home? What was it like at home managing your child's care with the radiation restrictions? Were there any challenges for you to provide care to your child? Please explain.
Child (age 4–7 years)	(Using a photo of the MIBG room) Do you recognize this room? Tell me what you remember about this room. What was it like? What things did your mom and dad do to take care of you during MIBG? Nurses? What feelings did you have while in the room? During your treatment, did you feel hurt/pain (use words suggested by parent)? Nausea/upset stomach? Did anything else make you not feel good? For each, if yes: When? Where? From what? Did anything help to make it feel better? Was there anything that helped you while you had to be in this room?
Child (age 8 and older)	Did you do anything to get ready for going to the hospital for MIBG? Tell me about the room you were in for therapy. What was it like? What things did your mom and dad do to take care of you during MIBG treatment? Nurses? During your treatment, did you feel hurt/pain? Nausea/upset stomach? Did anything else make you not feel good? For each, if yes: When? Where? From what? Did anything help to make it feel better? What feelings did you have while in the room? Was there anything that helped you while you had to be in this room? Suppose someone you know found out that he/she has neuroblastoma and needs MIBG therapy. What would you tell him/her about it? If you needed MIBG therapy again, is there anything you would want done differently?

All consents and assents were obtained just prior to the interview. Parents were interviewed in a room separate from their child, just prior to the child's hospital discharge. Parents were interviewed again in person during a follow-up outpatient appointment two to three weeks later, or by phone, if their child's follow-up care occurred at another institution. The children provided assent and were interviewed in-person at the follow-up appointment two to three weeks following therapy once radiation restrictions were lifted. Parents were present in the room with the children during the interview and were coached prior to the interview to refrain from contributing to the discussion. Nurses were recruited by flyer and email following the admission of a patient for <sup>131</sup>I-MIBG therapy and were interviewed in-person no later than three weeks from caring for a patient. Subjects were compensated for

their participation in each interview with a \$20.00 gift card and personalized letter of thanks. Experienced PhD-prepared qualitative researchers, not involved in the clinical care of the patients, conducted the interviews and took field notes. The interviews were audio recorded, transcribed verbatim, and checked for accuracy by study personnel.

### Measures

Five semi-structured interview guides were developed for this research for interviewing (1) children ages 4–7 years old, (2) children 8 years old or older, (3) first parent interview during hospitalization, (4) second parent interview within three weeks of hospital discharge, and (5) staff nurses (see Table 1 for sample questions). Prior to

initiating the study, we consulted three oncology staff nurses with experience caring for children receiving  $^{131}\text{I}$ -MIBG therapy. They reviewed the interview guides, provided feedback regarding content and clarity of the questions, and made recommendations for additional questions. Additionally, we consulted with certified Child Life Specialists to incorporate child-friendly methods of conducting interviews and to adapt our interview guides for children of varying stages of development.

The research team developed child, parent, and nurse demographic instruments. Child information included age, gender, race/ethnicity, whether the child's neuroblastoma was relapsed/refractory, and whether this was the child's first  $^{131}\text{I}$ -MIBG treatment. Parent items included age, race, gender, race/ethnicity, marital status, occupation, highest education, whether the child's neuroblastoma was relapsed/refractory, and whether this was a first  $^{131}\text{I}$ -MIBG treatment. Nurse demographics included gender, race/ethnicity, nursing experience, nursing education, nursing specialty certification, primary shift worked, and number of patients receiving  $^{131}\text{I}$ -MIBG treatment in the past 6 months.

### Analysis

Transcripts of the interviews were analyzed for key concepts using conventional qualitative content analysis (Hsieh & Shannon, 2005) and N-Vivo 12 qualitative software. Study team members (CL, KL, and AK) independently coded a subset of transcripts and then met to review and come to a consensus upon initial themes and subthemes. All subsequent interviews were coded independently by the principal investigator (CL) and another team member (KL or AK). Bi-weekly meetings occurred to discuss new themes/subthemes and to resolve discrepancies in coding. Matrices were created to examine themes within and across participant groups.

### Results

Five children, nine parents, and 10 nurses participated in an interview. Eight parents completed a second interview after their child's radiation restrictions were lifted. Participant demographic, clinical, and professional information is provided in Table 2. The children who were interviewed ranged in age from 6 to 12 years old and were all admitted for their first  $^{131}\text{I}$ -MIBG admission. The parents were primarily married females with a child with relapsed/refractory neuroblastoma. For six parents, this was their child's first experience receiving  $^{131}\text{I}$ -MIBG. The participating nurses had a wide range of pediatric oncology experience (5 months to 35 years) and reported providing care for one to three children who received  $^{131}\text{I}$ -MIBG in the past 6 months. Six nurses described caring for a patient

**Table 2.** Participant Demographics (Child  $n = 5$ , Parents  $n = 9$ , and Nurses  $n = 10$ ).

	Median (IQR) or $n$ (%)
<b>Children (<math>n = 5</math>)</b>	
Age (years)	7 (6, 8)
Gender: Female	3 (60)
Race: White/Caucasian	5 (100)
Ethnicity: Not Hispanic/Latino	5 (100)
Neuroblastoma: Relapsed/refractory	4 (80)
First MIBG treatment	5 (100)
<b>Parents (<math>n = 9</math>)</b>	
Age (years)	34 (34, 37)
Gender: Female	7 (78)
Race: White/Caucasian	9 (100)
Ethnicity: Not Hispanic/Latino	9 (100)
Marital status	
Married	7 (78)
Divorced/separated	2 (22)
Highest education	
High school/GED	3 (33)
Associate degree	2 (22)
Baccalaureate degree	3 (33)
Master's degree	1 (11)
Child's Neuroblastoma: Relapsed/refractory	8 (89)
Child's first MIBG treatment	6 (67)
<b>Nurses (<math>n = 10</math>)</b>	
Female gender	9 (90)
Race: White/Caucasian	8 (80)
Race: Asian	2 (20)
Ethnicity: Not Hispanic/Latino	10 (100)
Nursing experience (years)	4.5 (2.5, 22)
Pediatric oncology nursing experience (years)	3.5 (2.5, 13)
Highest nursing education: Baccalaureate	10 (100)
Nursing specialty certification	2 (20)
Shift	
Day shift	7 (70)
Night shift	3 (30)
Number of MIBG patients in past 6 months	
One	6 (60)
Two	3 (30)
Three	1 (10)

during the first day of single-room isolation. No new themes were identified for the last two subjects or more per group (child, parent, and nurse).

### Child Experience

For the children's experience, several themes emerged: an overall experience ranging from positive to negative;

emotional distress was common; symptoms were common but mostly managed; the children were adequately prepared for isolation; and audiovisual technology and entertainment helped. Theme descriptions with exemplar quotes are provided in Table 3.

*Child Overall Experience: Ranging From Positive to Negative.*

While the circumstances for the children to be in single-room isolation were similar, their experiences were wide-ranging, from positive or acceptable, to negative. A mother who described her child's experience as positive stated, "I think he got a break from parents, and nurses, and doctors. This is probably a vacation for him. Yeah, he really has not had a single complaint." Participants describing an acceptable experience used words such as "fine" or "pretty fair." Negative experiences described by children ranged from "boring" to sharing that everything about the experience was "terrible." Parents and nurses described the children's overall experience as dependent upon different factors, including the child's personality; age and development; interests; state of health; and past experiences with hospitalizations, medical devices, and medications. One parent best summarized this idea:

I know every kid, different ages, and boy, girl, they're probably all gonna have different experiences in there. It's hard to say that our experience was—we do things one way, and that's gonna—it's not universal at all. One thing that is universal is the patient experience. You're stuck and isolated in a bed for several days in a row.

As such, parents and nurses commonly identified separation as a challenging part of the children's overall experience. When asked what it was like to be alone in the room one boy stated, "It was wearying. [I] wasn't used to it." A mother similarly explained that her daughter was used to having treatments, but was not used to being away from her parents:

It's a scary thing for a child to have to go through, especially one that's sick. They're afraid to be alone. They don't like being secluded. They've been shut off from everybody for so much. This is a big thing. This kind of blows it out of the water.

Several parents and nurses described a child's experience as improving over time. Parents described a turning point for their child as restrictions were lifted, such as a door was allowed to remain open or parents could stay in the room longer. "Once those doors open you see a totally different kid." Likewise, nurses identified that the first hours to days of single-room isolation posed the greatest challenges for the children.

Descriptions of the children's overall experience were generally consistent. However, a variation by subject group and two cases of divergence between parent and child dyads was identified. Parents and nurses more often described the children's overall experience as acceptable or positive, but also shared challenging aspects of the single-room isolation. For example, though one nurse described a child's experience as overall "okay," she simultaneously recognized that being alone and "stuck in the room" was difficult for the child. The children more often described their overall experience negatively and at times described a positive aspect of the admission (e.g., using the walkie-talkies). None of the children described their overall experience as positive. Further, a divergence was present for the two children described by their parents as having an overall positive experience including "easy" and "probably a vacation for him." These two children described their experience in single-room isolation negatively, stating it was "terrible" and like being "stuck in a cage."

*Emotional Stress was Common.* Most of the subjects described negative emotions or displays of emotional stress by the children during isolation (see Table 3 for themes and code exemplars). Fear and anxiety were most often described. Similar to the child's overall experience, the extent of the emotional stress ranged substantially, from no fear or anxiety, some emotional stress but easily distracted, moderate anxiety and/or fear, to children who were "very anxious" and one child who was "very angry." Behaviors of children expressing anxiety and fear included crying, not sleeping or eating, irritability, and trying to get out of bed.

Anxiety was often attributed to separation, but was also described in response to hospitalization in general, an unknown treatment, taking "icky" tasting oral medications, or experiencing symptoms. The urinary catheter was a source of emotional stress for three children. Two children were described as having fear/anxiety related to the catheter, with guarding of the device and limited movements in bed; for one of these children, the fear was attributed to painful bladder spasms that resolved with pharmacological treatment. The third child was described as "very angry" by the catheter's presence, as she did not fully understand prior to admission that the catheter would remain inserted for most of the hospitalization. In contrasting past patients, two nurses described differences in emotional stress exhibited by child age, "the lesser the age ... the more fear is there." Notably, the two parents who denied seeing emotional stress in their child are the same parents who described their child as having an overall positive experience, which was divergent from the child's negative description.

**Table 3.** Exemplar Quotes for Themes and Subthemes Related to the Child's Experience.

Theme	Subtheme	Illustrative quote	Respondent characteristics
Child's overall experience	Fine/acceptable experience	It was fine. I mean it wasn't as bad as I thought it would be.	Child, 7 years old
	Negative experience	It's like I'm stuck in a cage. Cuz in the bed, it felt like I'm stuck in a cage forever.	Child, 6 years old
	Positive experience	He's had fun the whole time.	Mother, child's first treatment
	Improving over time	I think at that time it was a very anxious situation, but she ended up being fine.	Nurse, 5 years pediatric oncology experience
Emotional stress	Angry	That she had to be woken up every four hours to take medicine that tasted like motor oil. That she had a catheter. Yeah, she was really upset about that, just that she didn't have control about what was happening. She was really angry ... Yelling, refusing to take medicine, trying to rip the catheter out, throwing things	Mother, child's first treatment
	Anxiety	She was just very, very anxious the second I walked in. You could tell she was missing her mom ... She was crying. When I got there, she was trying to get out of bed.	Nurse, 5 months pediatric oncology experience
	Fear/concern	... any of our oncology kids, just fear, just scared and need their mom.	Nurse, 2.5 years pediatric oncology experience
	Withdrawn/depressed	It's different. I mean, you go through this in the hospital. You're sitting in bed. You've got a catheter in. Your mom and dad can't come in the room very much. Everyone's wearing suits. It's different. Then you get home, and you're like, "Oh I'm home. This is great. Oh, wait, there's all this other stuff I still can't do" ... It's not scary, like the hospital stuff can be scary. This is—my take, looking at her, was it was more depressing.	Father, child's first treatment
	No emotional stress	He was totally happy to be playing that Xbox.	Mother, child's first treatment
Symptoms	Fatigue	Otherwise, any other side effects that I've noticed, really, after we go home she might be a little more exhausted or tired from it.	Father, child's second treatment
	Nausea and/or vomiting	The first time around she got sick and threw up, so we had to call radiation safety for that, because she threw up over the side of her bed.	Mother, child's second treatment
	Pain/discomfort	My back hurt for the first couple of days	Child, 8 years of age
	No symptoms	I don't know if you interviewed [his other nurse] but for my shifts, the two shifts I had him, he had no issues, no anything.	Nurse, 26 years pediatric oncology experience
Child comprehension of isolation and treatment	Pain improved	... he was having pains, like chest pains and left arm pains. He'd been having that for about three weeks before we came in ... About halfway through the treatment, he just didn't have pain anymore.	Mother, child's first treatment
	Understands	She hears everything, and she can understand it. In that sense, I'm happy. She got to talk to everyone, and everyone asked her if she had any questions, feel free to ask. If you come up with anything, feel free to call.	Mother, child's first treatment
	Does not understand	We should have spent more time with [her] on the catheter because we talked to her about it,	Father, child's first treatment

(continued)

Table 3. (continued)

Theme	Subtheme	Illustrative quote	Respondent characteristics
Preparation of child for therapy	Informational	and she saw it, but that was a traumatic surprise for her. I've explained to him what MIBG is and what it does, and what iodine with MIBG is and does. Basically, the way I explained it to him was the MIBG is driving the car. It's taking the iodine where it needs to go.	Mother, child's second treatment
	Physical	The weeks leading up we got his bed moved to a location that's still in our bedroom but he can be in his own bed, and entertain himself. We'll tell him we're gonna go outside and hang out with the animals while he stays inside. Just giving him little moments of time by himself.	Mother, child's first treatment
Supportive interventions for the child	Entertainment/games	They would, like I said, make a game out of the walkie-talkie. They made a game out of the isolation by saying that this patient had received super power infusions and they didn't wanna take away her super power so they couldn't be too close. She needed all of the super power that she could get. By making a game out of what she had received and why they couldn't be so close to her, I think helped her a lot. She thought it was fun that she was a super hero cuz she had gotten super powers.	Nurse, 3 years pediatric oncology experience
	Visualization/communication with others	But she [mother] knew that if he would reach out, "Hey," all he needed was to have Mom say, "Right here," and that's all he needed for his emotional support, just knowing she was right there watching him.	Nurse, 2.5 years pediatric oncology experience
	Hospital staff—nurses	A comfort for him are nurses that we've had. They go in and they talk to him. They ask how he's doing, if there is anything they can do, if he needs anything. That right there shows him they care. That's a comfort. He feels safe ... I think that has also made that transition to this treatment different, because he has confidence—he has comfort with the nursing staff. He feels safe.	Mother, child's second treatment
	Hospital staff—child life	Child life's been awesome with the number of times that they've—they can't physically go in the room or play with her, but I don't know how many trips and missions they ran and came back with more things, and more things, and more things. That's been helpful keepin' her busy with that type of stuff.	Father, child's second treatment
	Hospital staff—radiation safety	They were really good at not making it seem like she's this scary thing now that we can't be around ... They're really good at explaining it's not because something bad is going on. It's because the medicine is only meant for you.	Mother, child's first treatment
	Parent engagement	The parents were great, and they were very supportive and very present, so that helped.	Nurse, 5 years pediatric oncology experience

*Symptoms Were Common but Mostly Managed.* Symptoms reported included pain, nausea/vomiting, and fatigue. The majority of interviewees reported pain/discomfort or nausea and vomiting was present

during hospitalization. All parents and children reported at least one symptom. Nurses did not always recount a child with symptoms and acknowledged that while symptom-free for their shift(s), the child

may have had symptoms at a different point in the hospitalization.

**Pain.** Of the three children who reported pain, two described mild discomfort from the indwelling urinary catheter and one reported arriving to the hospital with back pain that went away in “a couple of days.” Nurse and parent reports of a child’s pain during hospitalization were convergent and included discomfort from the urinary catheter ( $n = 4$ ) and parotitis ( $n = 1$ ) that resolved with sour candy. Pain from the urinary catheter ranged from mild “feeling funny” or “tender” to more moderate pain from bladder spasms. Pain from spasms was reported to resolve with pharmacological treatment. Parents of the four children who arrived with disease pain described substantial improvement or complete relief of the pain following treatment. One child’s mobility improved as disease pain resolved, allowing independent ambulation at home.

**Nausea and/or Vomiting.** Six children were reported to experience nausea and/or vomiting. Four children had a single episode of emesis that resolved with treatment, one child had nausea and vomiting “the whole time,” another child experienced nausea only, which parents reported to be usual with any hospitalization. Parent responses of nausea and/or vomiting were consistent with the children. Only three nurses reported a child who experienced nausea or vomiting during their shift(s).

**Fatigue.** Three children were described by parents as fatigued, ranging from “a little more tired” to “really tired.” One child was described as having lost strength and mobility, attributed to bed-rest. No children or nurses described fatigue as a symptom.

*The Children Were Adequately Prepared for Isolation.* The majority of interviewees described the children as prepared for the experience and provided examples of how the children were prepared. Methods to prepare the children most often included providing information in a developmentally appropriate manner and answering questions. Physical preparation was also described, such as getting to see the treatment room in the hospital in advance and changing sleeping arrangements at home before treatment (child sleeping in bed by self, separate room). One parent described preparing her child to be by himself in the weeks leading up to treatment, “We’ll tell him we’re gonna go outside ... while he stays inside. Just giving him little moments of time by himself.” No participants described themselves/a child as “not prepared” for the single-room isolation, however, some parents described a child as not fully comprehending aspects of the hospitalization (e.g., the urinary catheter).

*Child Support: Audiovisual Technology and Entertainment Helped.* The children, parents, and nurses described

supportive actions as actions that decreased the children’s sense of separation from others and distracted the children from the situation. An electronic device often enabled this support.

**Visualization/Communication With Others.** The majority of participants described electronics as a helpful method of visualization and communication with parents/caregivers at the hospital and others were unable to be present. The electronics included a monitor in the child’s room, walkie-talkies, and tablets for video chat. One parent stated the walkie-talkies were a “life-saver ... because when she couldn’t see us, she knew that she could at least talk to us whenever she wanted to.” The technology in the room was also positively described by children, including “cool” and “I love the walkie-talkies in that room.” While all parents and children appreciated the technology available, two parents and one nurse expressed a need for additional capabilities for the children to see parents at all times. In addition to the electronics, nurses and parents identified having someone in the child’s room or visible to the child through an open door as helpful, especially if the child was displaying emotional stress.

**Entertainment/Games.** Activities such as video games, movies, and coloring books, were described by all subject groups as helpful in supporting the children. The tablets were especially helpful as they allowed the children to play games, watch videos, and communicate with family. When asked if anything made a negative experience better (e.g., being scared), three children described the “stuff” or devices they had in the room. One child reported nothing made the negative experience better.

*Additional Sources of Support. Hospital Staff.* Parents also described support coming from nursing staff, especially those who know their child well, and radiation safety staff who helped to calm or distract the child during isolation. While child life specialists were unable to be in the room with the children, they were acknowledged for providing games or toys specific to the child’s interests. Two nurses described their own actions to support a child, such as staying in the room a little longer earlier in the shift to calm a child who was upset.

**Parent Engagement.** Parents and nurses described the important role of the parent in creating a positive experience for the children. Engaged parents were described as being ever present for the child: communicating with technology, coming into the room when their child was upset, and sitting outside the room when the door could be opened. The parents often orchestrated support, providing the child new surprise activities throughout the stay, and offering small comforts from home (favorite foods, special linen). One nurse stated, “I’ve never



experienced any of these patients where their parents were not 100,000 percent [involved] in their care.”

### Parent Experience

Themes regarding the experience of parents were identified from parent and nurse interviews. Themes and sub-themes included: I thought it was going to be a lot worse; it gets better with time; feeling concerned and overwhelmed; prepared “as much as you can be”; and parental support “you feel like you’re not alone.”

**Parent Overall Experience: I Thought it was Going to be a lot Worse and it Gets Better With Time.** Two themes were identified in the parents’ description of their overall experience. Five parents reported their experience as being better than what they anticipated, using words such as “went smoother” or “better” than they thought. Other parents inferred that the idea of the treatment was scarier than the actual event. “I could say that going into it was far more scary than actually being in it. Going through the experience wasn’t that bad.” Five parents described their experience as improving over time. Three of these parents identified the first day or two of isolation most difficult “it gets better with time. I think the first couple days are the most strenuous.” The parents also described developing a routine, which made the experience eventually easier.

**Feeling Worried, Overwhelmed.** Concerns related to the admission were present for the majority ( $n = 7$ ) of the parents and contributed to the parents’ overall experience. “Fear of the unknown” was expressed—not knowing how their child would do during treatment, being new to the institution/entrusting their child’s care to a team they didn’t know, and taking on additional responsibilities of the child’s care. One parent stated, “I was really worried about the urine part, but it turned out to be fine.” Concerns regarding exposing the child to radiation or the circumstances of the child’s need for treatment were also described. One parent shared, worrying about “Will this work?” and “What if I can’t console my child?” Four of the parents also described feeling “overwhelmed” going into the experience. “... we were also very overwhelmed. This is my child and this is what we’re going to do to my child. What we’re doing to my child can harm me.” Two nurses described the visible “emotional toll” or “stress” of treatment and separation on a parent.

**Prepared as Much as you can be.** All parents described preparing for  $^{131}\text{I}$ -MIBG therapy through information. Sources of information included hospital-based informational materials and training with staff, websites, social media, and other parents with a child who received  $^{131}\text{I}$ -MIBG therapy. While parents in our study said they were intellectually or “mentally” prepared for this

hospitalization, they did not always feel emotionally prepared. When discussing hospital-based training, one parent described this additional need “Preparing yourself from a mother’s standpoint, it really didn’t cover that.” The parents did not identify what more could have been done to prepare them for this aspect of hospital admission. One parent described being prepared “as much as you can be” and another started “... they did as much as they could ... I don’t think anybody can really be prepared for that.”

All nurses affirmed that the parents of their most recent patient were prepared to take on the additional responsibilities. The nurses offered examples of parents initiating care, asking for clarification or troubleshooting, and reminding the nurse of the child’s needs. Three nurses described challenges with past caregivers who needed ongoing prompts to complete their responsibilities or who demonstrated a lack of knowledge regarding the treatment, risks, and associated responsibilities. One nurse described her perspective regarding the parent’s emotional state and preparedness for  $^{131}\text{I}$ -MIBG:

This mom seemed well prepared and understanding what was going on. I’ve seen others that are a little more emotional about it, a little more nervous about it. Sometimes I think it’s more the level of functioning of the parents than—intellectual level, that they understand it a little better.

**Parental Support: You Feel Like You’re not Alone.** The parents described multiple sources of support, both external to and within the hospital setting. External sources of support included friends and family and social media groups. Seven of the nine parents described family and friends as being helpful—assisting with care of the child’s siblings at home, partnering with a parent to provide care of the child during  $^{131}\text{I}$ -MIBG therapy, calling with offers of help and messages of spiritual support, and reminding the parent of need for self-care. One mother stated:

We have a huge support group back at home of people that are willing to take care of the other kids on just a phone call. People that are willing to bring stuff to the house, activities ... They let us know every day—the phone goes off and it’s just a little note of, “Hey, I’m praying for you. Do you need anything? Can I help in any way?” which is huge ... I think that it’s comforting to know that you’re not by yourself. This isn’t you in a room. Your child’s in a room, and you’re all by yourself, that there are people pulling for you. There are people advocating to God for you. That was huge for us.

Social media similarly provided a source of comfort to parents, providing them messages of emotional and spiritual support, and allowing them to connect with other

parents of children with neuroblastoma. One parent stated, “Every night I would update the Care page. Then every morning I’d read all the comments and then you see how many people are praying ... It’s a relief. You feel like you’re not alone.” Another parent described his experience connecting with another family on Facebook and watching their daughter’s infusion live prior to his child’s infusion, “you know what, after seeing that, and this girl was younger than [our child], it was very uneventful and not really that big of a deal ... It took a lot of the stress off of my shoulders.”

Hospital staff, including nurses, radiation safety personnel, physicians, and child life specialists were identified as supportive to the parents. Nurses were most frequently mentioned by parents; their supportive actions included coordinating and reinforcing care responsibilities; checking in on the parents, intervening if the child became upset; and providing a break/encouraging parental self-care. One mother stated, “Whether it’s the doctors, the nurses, Child Life, they always come in and they always see how you’re doing ... Really, that helps a lot. It makes you feel not as alone, going through all of this.” Conversely, two parents noted situations where they did not feel as supported by staff, one parent perceived apprehension of some nurses to enter the child’s room and another parent described feeling isolated by the location of the room, experiencing delays in reaching staff at night as a result. One nurse described how she supported a parent:

The mom had the 2:00 in the morning one [medication], and she said, “Do you mind,” she said to me can I just be in the anteroom, she just wanted that support, which was fine. The dad was very independent. Different personalities. He just did his own thing, did it appropriately, but mom I think just wanted that. I just stayed with her in the anteroom and she did everything fine. She just wanted to know someone else was there.

## Discussion

This qualitative descriptive study evaluated the experience of children undergoing  $^{131}\text{I}$ -MIBG therapy and their caregivers. Our findings suggest that the children’s overall experience and expression of emotional stress varied widely, from a satisfactory experience and minimal emotional stress to a negative experience and substantial stress. For most children, symptoms of nausea/vomiting and pain were present but managed. Similarities among the children included adequate preparation for the physical separation, and support via audiovisual technology and play activities.

It is not surprising that most children in our study used negative terms to describe their experience; hospitalized children with cancer report social isolation, physical

burden from treatments, interruptions/inconveniences, and negative surroundings (Linder & Seitz, 2017). This negative experience is undoubtedly heightened by the additional restrictions placed on family members’ ability to be near the children during  $^{131}\text{I}$ -MIBG therapy. The variability of emotional stress the children expressed is consistent with past research that suggests cancer-related distress is affected by many factors, including characteristics of the individual child and the social and medical environment (Bakula et al., 2019; Bemis et al., 2015; Linder & Seitz, 2017; Monti et al., 2017; Trentacosta et al., 2016). Hospital design (e.g., layout, accommodations, lighting, and appearance of rooms and other spaces) has been associated with child and parent experience, including decreased anxiety in children and greater restorative experiences for children and parents (Cartland et al., 2018). Congruently, one parent in our study identified the location of the patient room as further isolating them from nursing support. Chu et al. (2016) successfully piloted parental presence in the child’s room during  $^{131}\text{I}$ -MIBG therapy, without excessive radiation exposure to parents or healthcare professionals. Multi-site research is warranted to examine how room and unit design (proximity of parent accommodations, presence of windows, décor, technology, etc.) may improve the parent and child experience during single-room isolation.

Two children in our study, who were perceived by their parents to have had a positive overall experience, described a negative experience. Poor agreement between parents and children regarding the child’s symptoms and psychological stress has been described in the pediatric oncology population (Mack et al., 2020; Tomlinson et al., 2021). Reasons for disagreements are multifactorial, and can include parent characteristics (e.g., parents’ own health), child characteristics (e.g., gender), differing perceptions or expectations, ability to observe the symptom/distress, and lack of communication, among other reasons (Mack et al., 2020; Tomlinson et al., 2021). It is likely that because the parents in our study did not see signs of emotional stress, the children were presumed to have had a positive experience. Our findings suggest parents and nurses may benefit from coaching on how to engage a child in conversations about their emotional state, to better identify children who require further intervention.

The indwelling urinary catheter was a common source of discomfort and/or emotional stress and was a difficult aspect of hospitalization for a younger child to comprehend. There is insufficient literature regarding urinary catheter-related pain and bladder discomfort in children. In adults, catheter-related discomfort can be distressing and contribute to agitation (Bach et al., 2020). Reduced catheter size and balloon volume are proposed to improve tolerance to the indwelling catheter (Bach et al., 2020; Zugail et al., 2019). Because this device is

considered standard of care to reduce radiation exposure during  $^{131}\text{I}$ -MIBG therapy, research of interventions to prepare children for the ongoing presence of the catheter and to reduce discomfort is needed.

Devices that allowed connection with others or provided distraction (i.e., walkie-talkies, tablets, and video games) were commonly described as supportive for the children in our study. Gaming and mobile technologies have become increasingly popular in pediatric oncology research, and are found to provide enjoyable play experiences and have physical and psychological benefits for hospitalized children (Carrion-Plaza et al., 2020; Jurdi et al., 2018). Different types of technology should be explored for use with children during  $^{131}\text{I}$ -MIBG therapy. For example, a multiplayer modality may increase the child's sense of connection with others (Jurdi et al., 2018). Virtual reality has also emerged as a promising intervention for improving the emotional, cognitive, and physical well-being of patients with cancer (Zeng et al., 2019; Tennant et al., 2020). Feasibility and usability of virtual reality for  $^{131}\text{I}$ -MIBG therapy should be explored, as less available physical support from adults may be a barrier to use for this often-younger population.

The majority of parents in our study reported feeling worried and overwhelmed prior to their child's hospitalization. They found education and social support helpful, but identified a need for further emotional preparation. In a meta-analysis that included research with parents of children with cancer, educational, social/structural support, and emotional regulation interventions were shown to reduce parent stress and anxiety (Dounnik et al., 2017). Healthcare professionals should systematically incorporate more emotional self-care interventions for parents in preparation for and during single-room isolation, as increased parental distress is associated with increased child distress and poorer child quality of life in pediatric cancer (Bakula et al., 2019; Bakula et al., 2020).

### Study Limitations and Strengths

Limitations of this research include recruitment from a single center and a small sample of children who were participants. Due to the number of children outside the eligible age range for this study and the number of children receiving follow-up care out of state, we were unable to obtain our desired sample of child participants or interview all parent-child dyads. Still, a redundancy in themes in each participant group was achieved, likely due to our use of focused interviews and the concrete nature of information shared by the children (Hennink et al., 2017). Our study does address two limitations of past single-room isolation research: failure to include children in the research and conducting interviews with

participants months after the child's isolation occurred (Alvarez et al., 2020; Austin et al., 2013). Our findings are strengthened through our procedures that included data and investigator triangulation (Patton, 2014).

### Conclusion/Implications

This research is a first step in understanding the experience of children undergoing  $^{131}\text{I}$ -MIBG therapy for neuroblastoma and their caregivers. Because the universal experience for the children is the time they must spend by themselves in a hospital room, the children, parents, and nurses consistently described supportive actions as actions that distract the children from the situation and decrease their sense of separation. Nurses have an important role in supporting the children and their parents during isolation and have opportunity to further integrate coping interventions into their care. Ongoing research efforts should be made to identify additional technology or room design that can maximize the children's sense of connection with others.

### Acknowledgments

This research was funded by a J. Patrick Barnes Research Grant, The DAISY Foundation. We would like to thank Catherine Vincent for her mentorship and Caitlin Rocha, Jennie Ott, & Jennifer Loewy for sharing their clinical expertise.


### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the DAISY Foundation (grant no. JPB-2014-54-A).

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