

A photo-narrative intervention protocol for clinicians and parents of children with severe neurological impairment in the PICU

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ARTICLE INFO

Keywords:

Pediatric
Neurological impairment
Intervention
Humanistic care

ABSTRACT

Background: Children with severe neurological impairment (SNI) have central nervous system conditions that result in medical complexity and lifelong caregiver assistance. When children with SNI are admitted to the pediatric intensive care unit (PICU), their parents/families may experience elevated stress due to poor communication with clinicians.

Methods: To address this, we created a photo-narrative intervention designed to facilitate parent-clinician communication. The intervention asks parents/families to share 3 photos with captions that inform clinicians about their child's well-being and quality-of-life. The steps include: 1) learning about photo-narratives; 2) deciding on a story; 3) selecting photos; and 4) identifying the broader context. Clinicians receive a companion guide on how to use the photo-narrative. In this pilot randomized controlled trial, N = 40 parent/family caregivers of children with SNI and their child's PICU clinicians will be randomized to receive the photo-narrative intervention or usual care. Participants will complete study surveys at enrollment and the child's PICU discharge; intervention-arm participants will also complete semi-structured interviews at discharge. The primary aim is to describe: 1) feasibility, assessed by the recruitment (approached/enrolled) and completion (intervention completion/intervention-arm) rates; and 2) acceptability (recommend the intervention/intervention-arm). We also will evaluate proof of concept by comparing changes in parent self-reported stress, perceptions of therapeutic alliance, and effects on stigma, resilience, benefit-finding, and respect as well as clinician self-reported empathy and perspective-taking.

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<https://doi.org/10.1016/j.conctc.2025.101455>

Received 24 December 2024; Received in revised form 23 January 2025; Accepted 10 February 2025

Available online 11 February 2025

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Discussion: This study will evaluate the feasibility and acceptability of a novel photo-narrative intervention designed to improve caregiver stress and communication. Findings will guide the development of future multisite studies.

Clinical trial registration: NCT06208332.

1. Background

Children with severe neurological impairment (SNI) have static and/or progressive central nervous system conditions resulting in motor and cognitive impairment and medical complexity [1,2].

Common diagnoses include congenital and chromosomal conditions and severe epilepsy syndromes. Over 75% of children with SNI are assisted by technology at home such as gastrostomy tubes and respiratory supports [3]. Although children with SNI make up <1% of the pediatric population, they account for >25% of pediatric intensive care unit (PICU) admissions at children's hospitals in the United States and approximately 50% of PICU deaths [4–6].

Family caregivers, including parents, of children with SNI have highly demanding roles that result in increased stress and diminished well-being [7–9]. In recent studies among parents, nearly half had poor psychosocial health due to the economic, emotional, and social/family impact of their child's condition [7,10]. Although stress among parents of children with SNI is multifactorial, studies suggest that threats to parent psychosocial well-being are heightened during their child's critical illness and exacerbated by communication challenges with their child's clinicians [11]. Specifically, parents report communication challenges that result from not being believed about their child's well-being with clinicians who only see their child in their worst health and rotate frequently. [11,12] Parents also report additional burdens from stigma related to misperceptions about their child's quality-of-life [13–15]. A key aspect of communication is therapeutic alliance, which includes the sense of mutual understanding, caring, and respect important for compassionate patient/parent-clinician relationships [16]. Decreasing parental stress and bolstering parent perceptions of therapeutic alliance with their child's PICU clinicians are key to improving care and communication during critical illness among children with SNI [17]. The importance of these aspects of care, along with enhanced humanistic care that focuses on the whole patient as a person, have been underscored in recent national studies [18].

One promising strategy to facilitate parents' feeling heard about their child's health and quality-of-life are photo-narratives [19–21]. Photo-narratives further humanistic care by enabling patients and family caregivers to formulate, synthesize, and share stories from their perspective. Photo-based methodologies have been successfully used among parents and children with developmental and learning disabilities [22], children with palliative care needs [23], and those with neurologic injuries [24], where they have improved perceptions of well-being, de-stigmatization, respect, and therapeutic alliance, and also prosocial behaviors in clinicians [25–28]. This paper describes the protocol for a pilot randomized controlled clinical trial of a photo-narrative intervention for parents of children with SNI and their child's PICU clinicians.

2. Methods

2.1. Study design: pilot randomized controlled clinical trial

We will perform a single-site, phase II randomized controlled clinical trial of a psychosocial behavioral health photo-narrative intervention to assess feasibility and acceptability among parents of children with SNI and their PICU clinicians at a single academic quaternary pediatric center [29]. Both parents and multidisciplinary PICU clinicians will be surveyed pre- (enrollment) and post- (discharge) intervention; intervention-arm participants will also complete semi-structured interviews (Fig. 1). This study has been approved by the Seattle Children's Hospital Institutional Review Board. The trial is registered at [ClinicalTrials.gov](https://clinicaltrials.gov) (NCT06208332) and is funded by The National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD K23HD107232) and The National Palliative Care Research Center's Kornfeld Scholars Program.

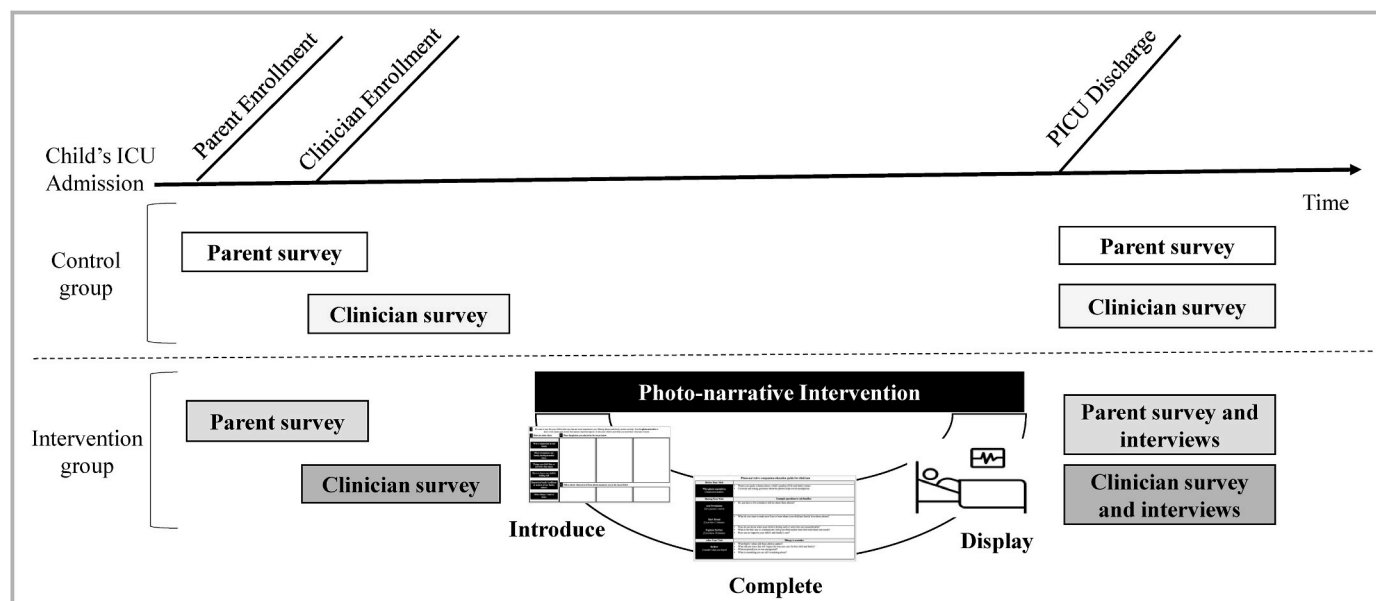


Fig. 1. Study schema.

2.2. Eligibility

Parent caregivers will be eligible if their children are: 1) admitted to the PICU at Seattle Children's Hospital (SCH); 2) aged 6 months-25 years; 3) have SNI, defined by Allen et al. [1] including permanent static or progressive central nervous system injury resulting in motor/-cognitive impairment and medical complexity; 4) have an expected PICU length of stay >1 week; and 5) have a life expectancy >4 weeks (based on the PICU team's clinical perspective). Caregivers will be excluded if they: 1) are not the child's identified parent/legal guardian; and/or 2) if they are not English- or Spanish-speaking. Inclusion and exclusion criteria will be confirmed with the child's PICU team prior to approach.

For clinician eligibility, all licensed physicians, nurses, advanced practice providers and respiratory therapists in the PICU will be able to participate. We will recruit 1–3 clinicians per enrolled parent/child. Parent caregivers and clinicians will only be eligible once; they will not be able to participate in a subsequent hospital admission.

2.3. Recruitment and consent

Prior to study launch, we will present to PICU leadership and staff for study awareness as well as the hospital's social work department. Three days per week the study team will review the daily PICU census, verify eligibility via the child's electronic health record review, and communicate with their PICU team. We will approach eligible parents after 24 hours in the PICU in-person or by phone and if they are interested in learning about the study, conduct a consent conference either in-person, phone, or by videoconferencing and complete informed consent documentation. Parent caregivers will be given time to review the study consent form and decide about participation. They will also be given copies of their signed consent materials and a one-time \$50 incentive at enrollment.

Clinician recruitment will take place at the time of parent enrollment via emails to their PICU team containing study information sheets. For clinicians, completing study surveys will confirm consent. All participants will be able to skip any questions they do not want to answer and withdraw from the study at any time. Participation will be voluntary. For those who decline participation, we will record the reason for decline. We anticipate adequate enrollment within 2 years of study launch but will extend enrollment another 6 months if needed.

2.4. Randomization

Parent caregiver participants who provide informed consent will be randomized along with their corresponding clinicians in a 1:1 ratio to either the photo-narrative intervention or usual care control groups following completion of the parent's baseline (enrollment) survey. The randomization group will be the primary predictor of interest. Group assignment will be determined using computerized random numbers with variable block sizes and stratified by language (either English or Spanish). Due to the nature of the intervention, participants and study staff will be aware of their assignment making blinding infeasible.

2.5. Sample size

Accounting for our expected attrition and missingness based on previous studies in the same parent caregiver and PICU clinician participant populations, we will plan to approach 57 parents total to reach our target sample size of $N = 40$, the 95% confidence interval will be an enrollment feasibility of 0.57, 0.80. With $N = 40$ ($n = 20$ in the intervention-arm), the 95% confidence interval for intervention feasibility and acceptability values of 70% will be 0.40, 0.89. As noted above, the sample size is not intended to provide definitive assessment of the performance of the intervention (which will be the aim of future appropriately powered studies). Instead, our approach will be to explore

proof of concept by evaluating the magnitude of effect size and trends in expected outcomes.

2.6. Study timepoints and procedures

All parent and clinician participants will complete surveys at enrollment and the child's PICU discharge; intervention subjects will also complete 30-min semi-structured interviews. All study survey data will be stored on our secure, internal Research Electronic Data Capture (REDCap) [30] system, a cloud-based HIPAA compliant secure electronic data management platform. Four contacts will be made either by phone or email to parent caregiver and clinician participants to complete surveys. All surveys and other study materials will be created with an appropriate reading level (Flesch-Kincaid reading grade level 6), formatted for ease of use, and have contact information for the study staff clearly visible. Study surveys will be administered online through REDCap and will be completed in-person on study iPads or sent via secure email or text invitation to participants with an individual anonymous link. Paper surveys will also be available for participants who prefer this format.

2.7. Measures

Primary outcomes will include: 1) feasibility defined as >70% enrollment (enrolled parents/total approached) and completion (parents completing intervention/total randomized to the intervention), and 2) >70% acceptability of the intervention (parents likely or very likely to recommend the intervention to others/total randomized to intervention). Demonstration of feasibility, acceptability, and proof of concept are standard in psychosocial intervention design translational pathways, and necessary prior to future multisite clinical trials [29]. Secondary outcomes will include proof of concept defined as more improvement in the post-intervention scores adjusted for baseline scores between intervention and usual care control groups of parent stress and perceptions of therapeutic alliance. Additionally, we will determine outcomes by evaluating post-intervention scores in clinicians' prosocial behaviors including self-assessments of empathy and perspective-taking. The study measures included in the surveys to assess these secondary outcomes are shown in Table 1. Intervention-arm parents and clinicians will also complete 30-minute semi-structured interviews following surveys to assess feasibility, acceptability, impact, and areas for improvement. Table 2 shows semi-structured interview questions. We will also collect parent demographics on surveys including age, sex, race/ethnicity, socioeconomic status, marital status, and social supports. Clinician characteristics collected via surveys will include discipline, years in practice, experience with SNI patients/families, previous care for the study patient/family, and previous exposure to the photo-narrative. We will also collect information about how long they cared for the patient during the study period.

Relevant demographic and clinical information about the child will also be obtained using the child's electronic health record including age, sex, race, ethnicity, caregiver role, diagnoses, medical technology, psychosocial services in the PICU (spiritual care, social work, palliative care, child life) as well as the number of emergency department, acute care, and PICU admissions in the prior year and health status determined by the pediatric risk of mortality score (PRISM III) [31], pediatric logistic organ dysfunction (PELOD) [32] score, and the Functional Status Score (FSS-ICU) [33]. These data will be recorded in a case report form by the study team in REDCap.

2.8. Safety of subjects

Since this study has the potential to elicit psychosocial distress, a protocol has been developed to address any concerns that arise. This protocol includes access to mental health resources through social work for parent caregivers and employee health services for clinicians.

Table 1
Outcome measures.

Domain/Measure	Details
Parents	
Psychosocial outcomes	
Perceived Stress Scale (PSS)	10-item measure of the degree to which participants appraise their situation as stressful; 5-point Likert scale (range 0–40); scores 14–26 moderate and >27 high levels of stress
Neuro-QOL Stigma Short-Form	8-item measure of stigma associated with neurologic illness; 5-point Likert scale; higher scores suggest more perceived stigma
Benefit Finding Scale	14-item measure of areas of personal growth; 5-point Likert scale (range 10–49); higher scores suggest more benefit finding
Connor Davidson Resilience Scale (CD-RISC 10)	10-item measure of self-perceived resilience including approaches to personal problem-solving and adversity; 5-point Likert scale (range 0–40); higher scores suggesting greater resilience; measure has strong reliability and validity
Communication	
Human Connection Scale (HCS)	16-item measure of sense of fondness, mutual understanding, caring, and trust with clinicians; 4-point Likert scale (range 16–64); higher scores suggest greater therapeutic alliance
Climate of Respect Evaluation in Intensive Care Units (CORE-ICU)	21-item measure of 3 domains of respect as perceived by patients/surrogates in the ICU; 5-point Likert scale; higher scores on overall (range 7–42) and respectful behaviors (range 10–60) suggest greater respect, and lower respect on the disrespectful behaviors subsection (range 4–24)
Clinicians	
Prosocial behaviors	
Empathic Concern Subscale	7-item subscale of the interpersonal reactivity index that measure of the degree of feelings of sympathy and concern for others; 5-point Likert scale; range 0–28; higher scores suggest more empathetic concern
Perspective-taking Subscale	7-item subscale of the interpersonal reactivity index that measure of the tendency to adopt the psychological point of view of others; 5-point Likert scale; range 0–28; higher scores suggest more perspective-taking

Additionally, the study has a data safety and monitoring committee that includes two external senior researchers with expertise in palliative care research who will meet every 12 months during the study period to review and evaluate any safety concerns.

Privacy and confidentiality protections will be maintained in accordance with regulatory and institutional guidelines. Data will only be accessible to the study team. We will only collect the minimum amount of data necessary for sample demographics and data will be analyzed after it is de-identified and reported in publications in aggregate. The photos that are a part of the photo-narrative intervention will not be shared beyond the study.

2.9. Data management

Data will be reviewed at weekly study team meetings to ensure completion and compliance with regulatory policies. Data will be de-identified and linked via a participant identification number to a study key. During interviews, the study team member will take notes and repeat back a summary to participants for further clarification and/or elaboration. Audio-recordings will be professionally transcribed and de-identified prior to being uploaded into Dedoose [34], a HIPAA-compliant cloud-based qualitative software program, for analysis.

2.10. Intervention description

The photo-narrative is a structured behavioral intervention based on photo-elicitation and photo-voice methodologies [19–21]. Based on a stepwise, iterative, stakeholder-inclusive intervention design process,

the content, format, and implementation were informed by a formal usability testing approach with cognitive interviews and intervention refinement among 3 cycles of 5 parents and their child's corresponding PICU clinicians [35]. Briefly, the photo-narrative is comprised of a series of steps that include: 1) learning about photo-narratives, 2) deciding on a story; 3) selecting photos, and 4) identifying the broader context. These steps provide parent participants with the rationale, examples, and ways to describe the meaning of their photo-narrative. Prompts are provided that include common palliative care concepts such as: 1) who is important in our family; 2) what strengthens us during difficult times; 3) how we know our child is feeling well; and 4) any family traditions or cultural considerations that are important. Parents can also select another topic if they prefer. Once 3 photos are selected, participants create brief captions to go with each photo to convey their story and ensure that clinicians reviewing the photo-narrative understand what each photo means to the parent/family.

Once the photo-narrative is complete, it will be placed at the child's bedside in the PICU along with a clinician companion guide that walks clinicians through the steps to engage in the photo-narrative with families. The clinician companion guide consists of 4 parts: 1) understanding the rationale; 2) asking parents' permission to ask questions about the photos; 3) a list of example questions regarding parental values and medical decision making for their child (e.g., What do you want to make sure I see or learn about your child and family from these photos?); and 4) reflection questions to prompt clinicians to consider something new or unexpected they learned and to solidify how they will use this information in the child's PICU care.

Table 2
Semi-structured interview questions.

Domain	Parents	Clinicians
Photo-elicitation		
Process	What was it like selecting photos of your child? Why did you pick the photos you did?	What was it like reviewing the photos with the parent? What is the optimal time to talk about photos with parents?
Content	What else would you have liked to share? How did it feel to share the photos?	What did you learn about the patient or family? What other topics would be helpful?
Context	What would be the best time to complete an intervention like this? Should the photos be updated? Where should photos be placed?	How do you envision this impacting clinical care? Communication with the family? Decision-making?
Intervention		
Effectiveness	What was it like sharing photos of your child? Do you think the photos had any impact or changed the way you or your child were treated? If so, in what way?	Do you think you were impacted at all by seeing the photos of your patient? Do you think this impacted your clinical care, and if so, in what ways?
Improvement	Was there anything you didn't like about the tool? How could the tool and the process for sharing photos be improved?	Was there anything you didn't like about the tool? How could the tool and the process for sharing photos be improved?

2.11. Intervention delivery

The photo-narrative intervention will be administered after randomization to the intervention-arm by the study team and can be completed all at once or broken into 4 steps. Photos will be printed by the study team and/or bedside nurse and entered into the photo-narrative to be displayed at the child's bedside in the PICU. Parents will be encouraged to discuss the photos with PICU clinicians caring for their child. We will also send electronic copies of the completed photo-narrative to the parent and corresponding PICU clinicians participating in the study via secure email.

2.12. Control group

Participants randomized to the usual care control arm, including parents and clinicians, will complete the same study measures at the same timepoints as intervention subjects. Usual care available to both study arms will consist of standard supportive care provided for all patients in the PICU including an assigned social worker. Additionally, referrals to child life, chaplaincy, palliative care, and art-, music-, developmental-therapy can be requested by the parent or PICU team. Participants in this group will not receive any interim contact or instruction outside of the study team follow up for discharge survey completion. However, the study team will be available and contact information will be provided for any study related questions.

2.13. Data analysis

Our primary outcomes will be feasibility and acceptability of the photo-narrative intervention. To evaluate feasibility, we will calculate the percent enrolled (enrolled parents/total approached) and the percent completion (parents completing intervention/total in intervention-arm). To evaluate acceptability, we will calculate the percentage of intervention parents likely or very likely to recommend the intervention to other parents on post-intervention surveys. We will use a benchmark of >70% for feasibility and acceptability based on previous studies examining psychosocial interventions among seriously ill children and their parents [36–38]. Feasibility and acceptability will also be assessed qualitatively through semi-structured interviews with parents and clinicians in the intervention-arm. Audio-recordings of interviews will be analyzed using content analysis by the study team [39]. Briefly, a primary and secondary reviewer will use an inductively developed coding matrix to identify and organize topics discussed in parent and clinician interviews. The study team will discuss topics in a series of meetings to review findings, discuss plans for dissemination of results, and to determine actionable next steps in regard to further intervention refinement and implementation concerns.

We will also explore proof of concept by summarizing outcome changes in each study arm using means, medians, standard deviations, and inter-quartile ranges, together with linear regression modeling comparing therapeutic alliance scores post-intervention at discharge in intervention and usual care control arms, adjusted for baseline scores. Potential covariates will be examined for potential confounding and interaction, and include: 1) child age, length of illness, and illness severity (both based on objective measures and parent report of their perception of their child's health at the time of survey completion on a 0 = worst health to 10 = best health scale); 2) parent age, sex, race/ethnicity, socioeconomic status, marital status, and social supports; and 3) clinician characteristics (discipline, years in practice, experience with SNI patients/families, previous care for the study patient/family, and previous exposure to the photo-narrative). We will use a similar approach for evaluating between-arm differences in discharge scores for other secondary outcomes of stress, stigma, benefit-finding, coping, and resilience. We expect to find better mean score change in the intervention-arm compared to the usual care arm, for both parent-reported outcomes and prosocial behaviors in clinicians.

3. Discussion

We have designed the photo-narrative intervention to address the unique needs of children with SNI, their parents, and their PICU clinicians. Through this pilot randomized controlled clinical trial we will assess feasibility and acceptability of the intervention as well as proof of concept in decreasing parental stress and increasing perceptions of therapeutic alliance at a single site. Although photo-based methodologies have been used in previous studies, this is one of the first to focus on the PICU context for children with SNI. Prior to designing an appropriately powered randomized controlled clinical trial, we need to determine feasibility and acceptability. Information from this pilot study will be used to inform future multisite randomized controlled clinical trials.

In creating this study protocol, we made several decisions to reflect the specific needs of parents and families of children with SNI through adaptations to the photo-narrative intervention. Specifically, we will include completion of the photo-narrative with a study team member to help with printing the photos and placing them within the photo-narrative template, as we learned through our intervention refinement process that parents wanted this support [35]. We also will plan to place the completed photo-narratives in the PICU rooms at the child's bedside in addition to sending them electronically to parents and clinicians, as we have learned that both are important modalities to increase access and availability of the intervention. Finally, we will include example questions clinicians can use to inquire about the photo-narrative in the clinician companion guide to facilitate discussion, as we have learned that some clinicians benefit from this additional information [35]. Ultimately, we recognize that having a simple, flexible intervention that is tailored to the needs of children with SNI, their parents/families, and PICU clinicians is essential to an intervention that can be disseminated and standardized in the high-acuity, fast-paced PICU environment.

Additionally, we recognize that the intention of the photo-narrative intervention in sharing information from parent perspectives about their child's baseline health and quality-of-life is an important part of addressing stigma in this population [12,14,15]. While this is crucial to improving care for children with SNI and enabling parents to feel heard and understood about their child's well-being, we recognize that this is a multifaceted, complex problem and that multiple approaches are likely needed [40–42]. However, we are hopeful that this intervention can have some impact on clinician attitudes and behavior change imperative to improving care for this unique population of children and families in ways that are essential to furthering humanistic care [18].

Notably, there are limitations to this study. It will be conducted at a single site which may impact the diversity of the sample and generalizability. The comparator group of usual care will limit our ability to differentiate impacts of the intervention as opposed to other 1:1 attention controls. Additionally, some parents already place pictures of their child at the bedside in the PICU and there is also a risk of contamination given the limited number of total PICU clinicians at SCH. These issues were raised during our study design process and ultimately it was felt that they would make detecting a difference in our proof of concept outcomes even more difficult and thus only make the study stronger. We will collect information from parents in both the usual care and intervention arms about other photos and signage about their child that they placed at the bedside during the study to inform our analyses. Finally, the assessment of intervention impact at the time of the child's PICU discharge limits our ability to detect durable effects. Despite these limitations, we will be able to determine feasibility and acceptability, which are necessary prior to systematically implementing the intervention to determine efficacy and eventually effectiveness.

The findings from this study will be used to develop a multisite randomized controlled clinical trial of the photo-narrative for children with SNI, their parents, and PICU clinicians. It will inform decisions surrounding the intervention format, delivery, and assessment. At the conclusion of this pilot trial, we will be able to determine whether

applying this version of the photo-narrative intervention is feasible, or if additional modifications are needed. This study will provide insights into conducting psychosocial behavioral intervention research among parents of children with SNI and their clinicians in the PICU, which is necessary to better understanding and addressing the humanistic care needs of this population through supportive interventions.

CRedit authorship contribution statement

Jori Bogetz: Writing – original draft, Conceptualization. **Elsa Ayala:** Writing – review & editing. **Jordan Anderson:** Writing – review & editing. **Liz Morris:** Writing – review & editing. **Krysta S. Barton:** Writing – review & editing, Conceptualization. **Miranda C. Bradford:** Writing – review & editing, Conceptualization. **Chuan Zhou:** Writing – review & editing, Conceptualization. **Joyce Yi-Frazier:** Writing – review & editing, Conceptualization. **R. Scott Watson:** Writing – review & editing, Conceptualization. **Abby R. Rosenberg:** Writing – review & editing, Conceptualization.

Language statement

In this paper we use the term severe neurological impairment because it describes a specific population of children with medical complexity that has been well-defined in existing research literature. We recognize that this is an imperfect term and that it may not be the preferred term for some people.

Data availability

No data were used for the research described in this paper.

Declaration of generative AI and AI-assisted technologies in the writing process

The authors did not use AI technologies for any work described in this manuscript nor in manuscript writing.

Financial disclosure

This study was supported by The National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development K23HD107232 PI: Bogetz and The National Palliative Care Research Center's Kornfeld Scholars Program. Dr. Bogetz has received grants for unrelated work from The Cambia Health Foundation, The Seattle Children's Research Institute, and The Lucile Packard Foundation for Children's Health. Dr. Yi Frazier and Dr. Watson have both received grants for unrelated work from the National Institutes of Health. Dr. Rosenberg has received grants for unrelated work from the National Institutes of Health, the American Cancer Society, Arthur Vining Davis Foundations, Cambia Health Solutions, Conquer Cancer Foundation of ASCO, CureSearch for Children's Cancer, and the National Palliative Care Research Center. The opinions herein are those of the authors and not necessarily their funders.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to thank Blyth Lord and our Parent Advisory Group for partnering in review of this study and its materials. We thank The Treuman Katz Center for Pediatric Bioethics and Palliative Care and the Palliative Care and Resilience Program. Finally, we are grateful to the

children, families, and clinicians who generously shared their perspectives with us to inform this research.

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