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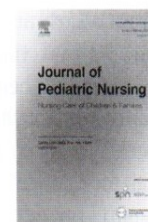

Factors impacting pediatric registered nurse attitudes toward caring for dying children and their families: A descriptive study

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ABSTRACT

Purpose: The purpose of this study was to gain knowledge of the educational preparation and attitudes of registered nurses at a southeastern pediatric hospital toward caring for dying children and their families.
Design and methods: A descriptive study with two independent samples was used to examine the attitudes of registered nurses at a pediatric hospital in southeastern United States. Participants completed the Frommelt Attitude Toward Care of the Dying Scale, Form B, a 30-item survey. Descriptive and inferential statistics were used to analyze data.
Results: One hundred and thirty-two registered nurses participated in the study. Results indicated a statistically significant difference in attitudes toward caring for dying pediatric patient scores in registered nurses working in the hematology/oncology and intensive care units compared to the other units ($p = 0.0017$; 95% CI: 2.39–10.12).
Conclusions: This study described the educational preparation and attitudes of registered nurses who care for children who are dying and their families. Additionally, pediatric end-of-life care is complex and is further influenced by experiences and attitudes. Future research is needed to identify educational needs to care for pediatric patients and their families at the end of life.
Practice implications: Findings from this project indicated end-of-life care education should be integrated into undergraduate curricula. New nurse graduates who are entering the workforce should receive education on end-of-life care, especially if they are entering into a pediatric specific organization. Healthcare organizations should include end-of-life care education as part of the orientation process and annual competency process.
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Introduction

In the United States (US), approximately 53,000 children die annually and another 400,000 live with a life-threatening illness (National Hospice and Palliative Care Organization [NHPCO], 2018). Of those children, many deaths occur in the hospital setting (Centers for Disease Control and Prevention [CDC], 2020). These statistics demonstrate the need for nurses to receive education and advanced skills to adequately care for these patients at the end of life (EoL). End-of-life is defined as "patient care before death, either while undergoing curative treatment or after deciding to focus on comfort rather than cure" (American Association of Critical-Care Nurses, 2022). With the current nursing shortage, nurses responsible for providing high quality, EoL care to dying children and their families are often new graduate nurses (Mazanec et al., 2020).

Registered nurses receive education and training to care for the patient holistically. Patients who are at the EoL require complex, specialized care that routinely includes counseling for their families (Fristedt et al., 2021). End-of-life care is a component of palliative care referring to the "support and care given during the time surrounding death, which can be days, weeks, or even months" (Fristedt et al., 2021). Without adequate knowledge, skills, and abilities surrounding EoL care, nurses report feelings of uncertainty about death and dying

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issues. Such nurses may avoid palliative care tasks or assignments, further impacting the provision of high quality, EoL care for pediatric patients and their families (Zahran et al., 2022).

The care of children at the EoL has been reported as inconsistent, especially prior to 2017, when two landmark reports were published, "A Call for Change" and "When Children Die" (O'Shea et al., 2017). These reports provided a national description of the problem of the lack of consistent care practices across the continuum of care, from the acute care setting to the home or hospice setting for children and their families. Discussions prompted a call to provide palliative and EoL care for children and their families so that physical, psychosocial, emotional, developmental, and spiritual needs could be met in a timely manner, which had been lacking prior to the report (O'Shea et al., 2017). As a result, *Clinical Practice Guidelines for Quality Palliative Care* was created. Following additional recommendations and guidelines from the American Academy of Pediatrics, hospice and palliative care curriculum competencies were developed for schools of medicine and nursing (O'Shea et al., 2017). Even with the construction of palliative and EoL care materials, dissemination has been reported as inconsistent and requiring both human and fiscal resources.

Preparation of undergraduate nursing students

There are noted inconsistencies in the total number of hours of EoL care education in undergraduate nursing curricula nationally and internationally, leading to a knowledge and practice gap (Croxon et al., 2018; Fristedt et al., 2021; O'Shea et al., 2017; Zahran et al., 2022). These inconsistencies have led to new graduates and practicing nurses feeling unprepared when providing EoL care (Bergstrasser et al., 2017; Fristedt et al., 2021; Welborn, 2017). When nursing students transition into practice, new nurses have reported not understanding their role in providing palliative care for patients as well as having a poor outlook while caring for this patient population in general (Fristedt et al., 2021; Paul et al., 2019). To improve these negative associations with EoL pediatric care, there is a need for all nurses to be taught to deliver high quality EoL care. However, due to the lack of EoL care education offered in undergraduate nursing curricula and the delay of EoL content integration into the undergraduate curricula, the responsibility often falls on healthcare organizations to provide this critical education to new graduate nurses and to practicing nurses.

Pediatric nursing

Pediatric nursing is a rewarding career, but it also presents unique challenges regarding children who face life-threatening illness, suffering, and death. Many nurses caring for children who are dying have limited expertise with death and dying and varying comfort levels regarding EoL care (O'Shea et al., 2017). Historically, nurses are taught that their main role is to preserve life, especially with pediatric patients who have not yet experienced many years of life. However, as the primary care provider on the healthcare team, this role is reversed when a child is dying, which may lead to personal strife, unfavorable attitudes about caring for this population, and anxiety (Fristedt et al., 2021). Nurses' attitudes toward death are essential in the delivery of high-quality care at this vulnerable time (Zahran et al., 2021).

End-of-life care for the pediatric patient must be of the highest quality to alleviate physical, psychological, and existential suffering of the patient and their families (Fristedt et al., 2021). National initiatives and incentives support and advocate EoL care for children, but evidence demonstrates that nurses are both unprepared for this type of care and express confusion regarding their role in EoL care (National Hospice and Palliative Care Organization, 2018; American Nurses Association, 2016). This can create emotional distress and internal conflicts for the nurse as they attempt to navigate the physical and psychosocial needs of the patient who is at the EoL (Bergstrasser et al., 2017).

New graduate pediatric nurses

End-of-life care is never an easy environment to navigate, however, there is an unsettling feeling that compounds EoL care when the patient is a child (Bergsträsser et al., 2017). When new nurse graduates are faced with their first EoL experience in practice, a complex situation is more complex due to a lack of curricular content (didactic and clinical) in schools of nursing (Rees et al., 2020). Clinical reasoning skills are formed through exposure to clinical situations and knowledge of that situation. As a novice with a lack of exposure to EoL care, the new graduate nurse is often less confident and has less skill than a more experienced nurse in the same EoL situation (Fristedt et al., 2021). A lack of ability to cope with the phenomena of death and concerns about psychosocial issues related to caring for a dying child and their families have been reported by new graduate nurses (Croxon et al., 2018).

Increasing end of life care knowledge, skills, and attitudes through education

To bridge the gaps between undergraduate nursing curricula, the new graduate nurse, and practicing nurses with limited or no EoL experience, educational programs have been developed on EoL care. Education, the largest barrier in delivering EoL care, decreases healthcare delivery obstacles while increasing and improving attitudes of nurses (Blaževičienė, Laurs, and Newland, 2020; Rees et al., 2020). Therefore, it is imperative that all nurses who care for children and their families at EoL receive comprehensive education on pediatric EoL care (Rees et al., 2020).

Modules focusing on conversations on EoL care topics have been created and supported through online education and simulation with a positive response from participants (Thompson et al., 2018). The modules, simulations, and implemented talking points, expand insight into the needs of staff and set new guidelines for EoL education requirements during onboarding of new hires. Implementation of nursing education on care of the dying patient resulted in an increase in students' attitudes on average by 52.2% (Berndtsson et al., 2019).

New nurse residency programs have been used to incorporate EoL care content. The End- of-Life Nursing Education Consortium (ELNEC) was developed to bridge the gap for nurses with limited clinical experience and varied didactic curriculum content (Mazanec et al., 2020; Rees et al., 2020). The ELNEC meets the AACN CARES competencies and offers online Undergraduate, Graduate, CORE, Critical Care, Pediatric, and Geriatric curricula (AACN, 2016; Mazanec et al., 2020). Nurse residency programs which have integrated the ELNEC- Undergraduate Curriculum successfully reported a positive change in clinical practice one month after participating in the program (Mazanec et al., 2020).

Purpose and aims

Research to date has focused on methods to educate nursing students on adult EoL content. There is a paucity of research exploring education for practicing nurses, especially on EoL pediatric content. To address this gap, the purpose of this study was to gain knowledge of the educational preparation and attitudes of registered nurses at a southeastern pediatric hospital toward caring for dying children and their families. The primary aims of this study were to: (1) describe the level of experience and preparation of the registered nurses caring for pediatric patients and their families at the EoL and (2) describe the attitudes among registered nurses caring for EoL pediatric patients and their families.

Methods

Design, subjects, and setting

This was a descriptive study with two independent samples from a large urban pediatric hospital, in the southeastern United States. The

hospital employs approximately 740 registered nurses in a 222-bed facility offering services in behavioral health, neuroscience, emergency care, hematology-oncology, surgery, cardiac care, intensive care, outpatient clinics, and telehealth.

The two independent samples were composed of the following: a) registered nurses working in the hematology-oncology units (inpatient and outpatient) and intensive care units (ICU) and b) registered nurses working in all acute care units, float pool, and Nursing Professional Development. Inclusion criteria for the study were registered nurses employed at the pediatric hospital in the following positions: 1) staff nurses in the inpatient acute care units, intensive care units, hematology-oncology units (inpatient and outpatient), acute and intensive care float pool, 2) nurse directors of the acute care units, intensive care units, and clinics, and 3) nurse educators in the Nursing Professional Development Department. Institutional Review Board approval was obtained from the hospital where the study was conducted prior to study implementation.

Data collection

A convenience sample of all registered nurses who met inclusion criteria ($n = 394$) was recruited for the study via email through the hospital's intranet system. The email consisted of a letter of invitation describing the study and asking nurses to voluntarily complete an electronic survey. An electronic platform was used to house the survey and it was set up by the researchers to collect data anonymously and without IP address tracking, further ensuring anonymity. The survey was open for six months, October 2020 to April 2021, with reminder emails sent out every two weeks.

Instrumentation

Demographics

A nine-item researcher-developed demographic survey was used to collect demographic data. Data included age, gender, unit employed, highest degree obtained, previous education on death and dying, previous experience with terminally ill children, and previous and present experience with loss.

Frommelt attitude toward care of the dying scale, Form B

The Frommelt Attitude Toward Care of the Dying Scale, (FATCOD) was developed to assess nurses' attitudes toward caring for dying patients and their families (Frommelt, 1991). FATCOD Form B (FATCOD-B), the revised version of the FATCOD includes the assessment of attitudes of individuals of various professional backgrounds, fields of study, and societal roles. (Frommelt, 2003). For this study, the FATCOD-B was used and modified with author permission to replace "patient" with "child." The tool is a 30-item instrument using a 5-point Likert scale ranging from (1) strongly disagree to (5) strongly agree. Fifteen statements are positively worded and 15 are negatively worded. Scores range from 30 to 150 with higher scores indicating a more positive attitude toward caring for patients at the end of life (Frommelt, 2003). Reliability was reported as Cronbach's alpha of 0.81 and content validity index of 0.92 (Mastroianni et al., 2015; Wang, Li, Yan, and Li, 2016).

Data analysis

Descriptive statistics in the form of means, percentages, and ranges were conducted for the demographic data and the registered nurses' responses to the FATCOD-B. Inferential statistics in the form of independent sample t-tests were used to compare the means of two independent groups. For reporting of data, results were divided into two groups: 1) hematology-oncology units (inpatient and outpatient) and intensive care units (ICU) and 2) "other" units; consisting of all acute care units, float pool, the emergency department, and the Nursing Professional Development Department. The hematology-oncology and intensive care units were grouped because these units have a higher census of terminally ill patients; therefore, the grouping of these units provided more consistent participants. Data analysis was performed with Statistical Analysis System (SAS) 9.4. Software and statistical significance was set at $p \le 0.05$.

Results

Demographics

A total of 132/394 (34%) registered nurses responded to the survey. The majority identified themselves as female ($n = 125$; 94.7%) and 28–35 years old ($n = 43$; 32.58%). Most participants reported having a bachelor's degree in nursing ($n = 93$; 70.45%) and being employed on a critical care unit ($n = 81$; 61.83%). Even though responses indicated that a specific course on death and dying had not been taken previously, responses indicated that material on the subject had been included in other courses taken ($n = 78$; 59.09%). Most of the participants ($n = 124$; 93.94%) noted having cared for terminally ill persons and their family members previously. Similarly, many participants ($n = 75$; 57.25%) reported losing someone close to them within the past year but were not dealing with an impending loss at the time of the survey ($n = 113$, 85.61%). Table 1 provides participant demographics and experience with death and dying.

Frommelt attitudes toward care of the dying scale, Form B

To review, the hospital units were categorized into two groups. Group one consisted of hematology-oncology units (inpatient and outpatient) and intensive care units (ICUs). Group two consisted of all acute care units, float pool, and the Nursing Professional Development Department.

Concerning attitudes toward caring for the dying pediatric patient and their family, analysis showed the total mean score for nurses on the hematology-oncology units and ICUs was 126.6 (SD 9.10). For nurses working on all other units and the Nursing Professional Development Department, analysis showed the total mean score for nurses was 120.3 (SD 12.83). Table 2 provides the mean attitude toward dying patient score by groups.

Noting that a higher score is synonymous with a more positive attitude in caring for patients at EoL, the differences in mean scores between the two groups were compared. On average, there was a statistically significant difference in attitudes toward caring for dying pediatric patient scores in nurses working in the hematology-oncology/ICU units compared to the "other" units. The parameter estimate between groups was also higher for nurses who work in the hematology-oncology/ICU units versus those nurses working in the "other" units. The data are provided in Tables 2 and 3.

Discussion

Care of dying patients and their families, including children, is a core function of a nurse. Without adequate preparation, gaps in knowledge, skills, and the abilities of nurses (new graduate and practicing) to perform essential functions in EoL care will continue to grow and impact the quality of care for these patients and their families. As this research has evaluated the attitudes and preparedness of nurses caring for children at end of life, insight has been gained on the specific needs of nurses in this area. With a better awareness of the knowledge and skill gaps present, organizations can begin to adequately prepare nurses working with this vulnerable population.

Educational preparation of registered nurses: death and dying

In the present study, the majority of participants reported they had not taken a specific course on death and dying, but they had received

Table 1
Demographic characteristics of study participants & attitude toward care of the dying patient (n = 132).

Characteristics	N	%
Age	132	
18–22	2	1.51
23–27	38	28.79
28–35	43	32.58
36–45	22	16.67
46–55	17	12.88
56–65	10	7.57
Sex	132	
Male	7	5.30
Female	125	94.70
Unit Employed		
Hematology/oncology units and ICUs	87	
Pediatric Intensive Care Unite (PICU)	14	10.61
Neonatal Intensive Care Unit (NICU)	35	26.52
Cardiac Intensive Care Unit (CICU)	8	6.10
4 West (hematology/oncology inpatient unit)	22	16.79
Hematology/Oncology Clinic (outpatient)	8	6.10
Other	44	
5 Center (acute care)	7	5.34
3 Center (acute care)	8	6.10
6 Center (acute care)	14	10.61
Emergency Department	12	9.16
Float pool	1	0.76
Nursing Professional Development Department	2	1.52
Highest Degree	132	
Associate Degree	18	13.64
Bachelor's degree	93	70.45
Master's degree	19	14.39
Education beyond Master	1	0.76
Other (please specify):	1	0.76
Previous Education on Death & Dying	132	
I took a course in death and dying previously.	40	30.30
I did not take a specific course on death and dying, but material on the subject was included in other courses.	78	59.09
No information dealing with death and dying was previously presented to me	14	10.61
Previous experience in dealing with terminally ill children	132	
I have cared for terminally ill persons and their family members previously.	124	93.94
I have had NO experience caring for terminally ill persons and their family members previously.	8	6.06
Previous experience with loss	131	
I have no previous experience with the loss of someone close to me.	56	42.75
I have lost someone close to me within the past year. Please specify (husband, wife, significant other, mother, father, child)	75	57.25
Present Experience	132	
I am presently anticipating the loss of a loved one.	9	6.82
I presently have a loved one who is terminally ill (life expectancy 1 year or less)	10	7.57
I am not dealing with any impending loss at the present time.	113	85.61

the material on death and dying in other courses (59.1%). This finding mirrors the current literature. The lack of education surrounding death and dying content and integrated, versus included, curricular content on death and dying are the largest barriers to providing appropriate EoL care (Mazanec et al., 2020; Rees et al., 2020).

According to the National Council of State Boards of Nursing (NCSBN, 2022), the average age of registered nurses in the US is 52 years of age (2022). Among study participants, registered nurses aged 28–35 years of age (32.6%) were the majority of respondents followed by those

Table 3
Simple linear regression analysis of association between FATCOD Score and Unit.

	Estimate	SE	95% CI	*P* value
Units (Hem-ICU vs. Other Units)	6.26	1.95	2.39–10.12	0.0017

Note. n = 132, *3 missing data; p-value: significant at ≤0.05 level.

aged 23–27 years of age (28.8%). These findings align with other studies noting that new graduate nurses are likely to be caring for pediatric patients and their families at the EoL (Croxon et al., 2018; Fristedt et al., 2021; Mazanec et al., 2020; O'Shea et al., 2017). These age ranges of participants indicate that they were in the young adult stage, age 19 to 40 according to Erikson, and likely to be new graduate nurses or nurses with five years or less of clinical experience (Cherry, 2021). This finding is important to note because schools of nursing are just beginning to integrate curricular content on death and dying following the endorsement of the AACN CARES document in, 2016. However, as our findings reflect, content integration takes time and curricular outcomes will not be seen in graduates for many years (Mazanec et al., 2020). Furthermore, registered nurses who have been practicing for more than five years are likely to have never received formal content or training on EoL care. New graduate nurses and nurses with no exposure to EoL care curricular content should be taught this content. Although EoL care is the responsibility of the entire healthcare team, providing support for all nurses to receive EoL education can improve patient outcomes and alleviate negative attitudes (Mazanec et al., 2020).

Registered nurses with more clinical experience will have progressed further through the five stages of the Skill Acquisition Model and will display increased confidence and accuracy in their actions in clinical situations (Benner, 2001). As nurses age, it is plausible that they will have more personal life experiences to integrate into their nursing practice. These experiences, clinical and personal, affect nurses' attitudes about death, dying, and EoL care (Fristedt et al., 2021). Study results indicated that most participants (93.9%) had cared for terminally ill persons (children) and their family members previously. These findings are in contrast to the literature, indicating that most new graduate nurses will not have cared for a pediatric patient and their family at the EoL (Mazanec et al., 2020; Rees et al., 2020). The current study found that only a small group of participants (6.1%) reported having no experience caring for terminally ill persons (children) and their family members. This is again in contrast to the current literature.

Attitudes toward caring for dying children

Attitudes surrounding death, dying, and EoL impact the delivery of care that nurses provide (Zahran et al., 2022). The current study noted that registered nurse attitudes toward caring for dying children and their families or children and their families at the EoL were higher in the units that provided care to this patient population on a regular basis. The current literature provides a mixed perspective on what impacts nurse attitudes toward caring for patients at the EoL. The literature is even more sparse concerning nurse attitudes and caring for pediatric patients and their families at the EoL. Registered nurses with more clinical experience, specifically more than ten years, have been noted to have more positive attitudes toward EoL care (Fristedt et al., 2021). Additionally, nurses working on units, such as surgery and oncology,

Table 2
t-test comparing attitudes toward dying patient score by groups.

		Units			
		Hematology-Oncology/ICU	Other Units		
		N = 85	*N* = 44	*t*-value	p
Attitude Toward Dying Patient Score	**M**	126.60	120.30	2.88	**0.0053**
	SD	(9.10)	(12.83)		

Note. *n* = 132, *3 missing data; Hematology-Oncology/ICU = (*n* = 85); Other Units = (*n* = 44); p-value: significant at ≤0.05 level.

who care for adult patients at the EoL are reported to have more positive attitudes toward caring for EoL patients (Fristedt et al., 2021). The current study found that nurses working on the hematology/oncology and intensive care units had statistically significant higher scores on the FATCOD-B. These higher scores indicated more positive attitudes when caring for pediatric patients at the EOL. The concept of clinical experience affecting attitudes toward caring for EOL patients are somewhat in alignment with the current study findings as participants most likely had less than five years of experience as a nurse but worked on a unit that routinely provided care to pediatric patients and their families at the EoL. Attitudes surrounding caring for patients at the EoL have been noted as positively impacted through EoL education, either while in nursing school, enrolled in a nurse residency program, or ongoing staff development (Frommelt, 2003; Mastroianni et al., 2015; Mazanec et al., 2020). These findings mirror the current study as the majority of participants (89.39%) reported having death and dying material as part of a course or as having taken a course on death and dying.

Practice implications

Staff education

Nurses are the primary providers of EoL care for pediatric patients and their families. However, there is a paucity of research exploring education (content, integration in undergraduate curriculum, post-graduation) for nurses, especially on EoL pediatric care. Despite the limitations of this study, the findings provided valuable feedback and identified knowledge gaps present within an organization, specifically with new graduate nurses. New graduate nurses are noted to have little to no EoL experience or curricular content as they transition to bedside care; therefore, hospital administration should consider optimizing educational resources related to EoL care (Mazanec et al., 2020; Zahran et al., 2022).

Findings from this project indicate that improvements to the new nurse orientation are needed. New nurse residency programs have had success incorporating the ELNEC- Undergraduate Curriculum (Mazanec et al., 2020). Additionally, an ELNEC-Pediatric option is available and recommended for the study setting. Additional practice recommendations include EoL content specific to the pediatric patient and their family in preceptor training, nurse annual competency training, and interdisciplinary team training for those members who care for children at the EoL (Drach et al., 2021).

Implications for nursing education

Preparing nurses to care for dying patients and their families presents an ongoing challenge for nursing education, especially for pediatric patients and their families. In 2016, the AACN endorsed the CARES document outlining 17 essential palliative care competencies. These competencies should be achieved by all undergraduate nursing students prior to graduation. However, it will take time and resources before all schools of nurses are able to meet this outcome (Mazanec et al., 2020). A recommendation for nursing education is for schools of nursing to integrate the ELNEC-Undergraduate Curriculum into established curricula to bridge the current gap in EoL content. Graduate programs could incorporate the ELNEC-Graduate Curriculum and review the NCP Clinical Practice Guidelines for Quality Palliative Care. Additionally, high-fidelity simulation or the use of standardized patients is recommended as a safe learning environment for students to experience EoL care for pediatric patients and their families, particularly the communication aspect of EoL care (Campbell et al., 2020; Fielding et al., 2022; Tamaki et al., 2019).

Limitations

Several limitations of this study are acknowledged and are taken into consideration. A convenience sample was used from a single pediatric hospital in the southeastern US, which may not be nationally representative. Study results are impacted by a low participant response rate and a predominantly female sample. Registered nurses who are more comfortable with self- reporting their attitudes about EoL care may have been more likely to participate, which could bias results. The comparison groups were created based on the similarities with respect to assumed exposure to caring for dying children and their families. There was a disparity in size between the groups, which may have influenced the outcomes of the study. Additionally, participants came from a range of experience levels. All factors limit the generalizability of the study findings.

Another limitation of this study is that there was no data gathered to determine level of experience and no statistical comparison between attitudes toward caring for dying children and nurses based on those years of experience. This information could have provided useful data regarding new graduate readiness to provide EoL care. Results may have given insight to additional needs of experienced nurses working on various units within the organization. Study findings warrant further research to include a larger, more diverse sample and inclusion of additional institutions to explore and compare attitudes toward EoL care.

Conclusions

This study described the educational preparation and attitudes of registered nurses who care for children who are dying and their families. The results highlighted the importance of ensuring all pediatric staff have or receive education to prepare them to provide high quality EoL care. Furthermore, study results showed that pediatric EoL care is complex and is further influenced by experiences and attitudes. Future research could identify specific educational needs to care for pediatric patients and their families at the EoL and additional influences on nurse attitudes surrounding EoL care. Through this additional research, improved EoL care can be provided to pediatric patients and their families and nurses can benefit from less emotional distress as they have a deeper understanding of a multifaceted topic.

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CRediT authorship contribution statement

Dianne N. Richoux: Conceptualization, Methodology, Investigation, Writing – original draft, Visualization, Project administration. **Benita N. Chatmon:** Writing – original draft, Supervision, Project administration, Methodology. **Alison H. Davis:** Writing – original draft, Validation, Supervision. **Brittany Sweeney:** Data curation, Writing – original draft.

Declaration of Competing Interest

The authors declare no competing interests.

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