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Understanding Pediatric Trainees' Response to Child Death and Implementing Needs-Based Processes to Improve Bereavement, Resilience, and Wellness

Study Purpose and Rationale

Nearly 40,000 infants and children die in the United States each year, the majority of which occur at tertiary healthcare centers.[1] These deaths take a significant emotional and psychological toll on parents, siblings, and healthcare providers. In 2000, the American Academy of Pediatrics (AAP) set forth guidelines regarding child death and the role of Pediatric Palliative Care in order to assist patients, families, and healthcare providers through these challenging clinical encounters.[2] After the publication of these guidelines, the Accreditation Council for Graduate Medical Education required training programs to establish curricula related to terminal conditions, end of life care, and death of patients.[3] Since this time, residency training programs have adopted both formal and informal instruction related to pediatric death, however the majority of the curricula focuses on patient and parent communication and symptom management via modules, role playing, and traditional lecture series.[4–6] Additionally, trainee-focused seminars on death, dying, and bereavement have been developed and implemented at many training programs. The establishment of these educational initiatives is likely beneficially for trainees, however the effects have not been critically studied.[7,8] While training programs have worked on implementing knowledge-based curriculum as well as strategies for resilience, there is minimal research that focuses on the emotional and psychological impact of pediatric death and dying on trainees. Additionally, the current studies that do exist regarding resident experience with patient death have used quantitative methodology.

The goal of this study is to build on existing literature by evaluating the effect of patient death on pediatric trainees using qualitative methodology. We feel that using qualitative methodology would provide a deeper, more accurate understanding of trainee experiences. We hope to use this information to develop much needed interventions and resources to support residents. We believe that it is critical to the mental health of resident physicians to further study and evaluate this topic.

Study Design and Statistical Analysis

This will be a two-part study. The objective of the first part of the study is to evaluate the experience of patient death on pediatric trainees using qualitative methodology. We will conduct interviews with pediatric trainees at Columbia University Medical Center (CUMC) with regard to their experiences with caring for a dying patient, their perceptions of current curriculum and support systems around this area, and the possible need for the creation of other resources to address the gaps in education. We will also provide a quantitative questionnaire to residents to get a baseline understanding of the frequency of these clinical encounters. The second part of the study will utilize the key themes that emerge from this study to develop an intervention to assist pediatric trainees during and after these challenging clinical experiences.

Data will be coded by independent reviewers in an iterative fashion to generate codes. As new data is collected, codes will be revised in an iterative fashion and applied to the whole data set.

At the end of the data collection, coded responses will be ranked in order of frequency of responses in the text. These codes will be translated into broad themes that may provide insight on the views of residents who have experienced patient death.

Study Procedure
No procedures will take place during this study.

Study Drugs / Medical Devices
No study drugs will be used.

Study Questionnaires
Please see a copy of the qualitative interview questions below. The quantitative questionnaire is currently being developed as we determine which descriptive statistics we would like and if we hope to collect pre-intervention data. The survey will be delivered to residents via Qualtrics.

Study Subjects and Recruitment
As previously stated, this study will include pediatric residents at CUMC. Residents will be invited to participate via email. An information sheet (attached) will be used to provide participants with more information about the study. Agreement to participate in the study implies consent.

Confidentiality of Study Data
Interviews will be held in a private room with just the participant and investigator conducting the interview. Participants will be asked not to reveal any identifying information while being interviewed and audio-recorded. Interviews will be conducted on an encrypted, password-protected mobile device. These data files will be transferred to a password-protected computer in a secure MC domain on an encrypted drive with access granted only to the investigators. Upon transfer, the files will be permanently deleted from the mobile device. Transcribed interviews will also be stored on a password-protected computer in a secure MC domain on an encrypted drive with access granted only to the investigators. No identifying information will be collected.

Participants will not be asked any private or identifying information on the survey. The survey will be conducted using Qualtrics, a secure database for collecting and storing data.

Potential Conflict of Interest
No conflicts of interest exist at this time.

Location of the Study
This study will take place at CUMC. Interviews will be held in a private room.

Potential Risks
Risk of participation in the interview process is minimal. We will minimize risks by not collecting any identifiable information in the interviews. All data collected will be stored in an encrypted password-protected database and will be disposed of at the conclusion of the study.

Potential Benefits
There are no immediate benefits to the residents participating in the study. However, the results of this study may be used to further develop the pediatric residency curriculum particularly as it pertains to coping with patient death in the pediatric population.

Alternative Therapies
Pediatric residents may choose not to participate in this study, or leave the study at any time.

Compensation to Subjects
Subjects will not be compensated for participating in this study.

Costs to Subjects
Subjects will not incur any additional costs as a result of participating in the study.

Minors as Research Subjects
This study does not involve the participation of minors.

Radiation or Radioactive Substances
This study does not involve radiation or radioactive substances.

References

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2. Siden, H. & van Breemen, C. Palliative Care for Children. *Handb. Palliat. Care* **106**, 231–246 (2012).
3. ACGME Program Requirements for Graduate Medical Education in Pediatrics ACGME Program Requirements for Graduate Medical Education in Pediatrics Common Program Requirements are in BOLD. (2017).
4. Wilson, P. M., Herbst, L. A. & Gonzalez-del-Rey, J. Development and Implementation of an End-of-Life Curriculum for Pediatric Residents. *Am. J. Hosp. Palliat. Med.* **35**, 1439–1445 (2018).
5. Flint, H., Meyer, M., Hossain, M. & Klein, M. Discussing Serious News. *Am. J. Hosp. Palliat. Med.* **34**, 254–257 (2015).
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7. Serwint, J. R. *et al.* "I Learned That No Death Is Routine". *Acad. Med.* **77**, 278–284 (2002).
8. Berger, A., Meyer, R., Herron, S., Villar, R. & Bagatell, R. When Children Die: A Seminar Series for Pediatric Residents. *Pediatrics* **110**, 348–353 (2004).

Pediatric Resident Response to Patient Death – Interview Guide - SAMPLE

1. Tell me about the experiences you have had taking care of children who were at the end of life or who passed away.

2. What went well during this experience? What were the biggest challenges when taking care of this child? What resources did you utilize?

3. How did you cope with caring for a child at the end of life? How did you cope with the loss of a patient?

4. Have you attended a funeral / memorial service for a patient that has passed away? If so, tell me about the impact this had on your experience with losing a patient.

5. What is your impression of the current resources the pediatric residency program has in place? What have you found to be the most helpful / least helpful, why?

6. What initiatives or resources do you think would better help you, and other residents, feel supported through these difficult encounters? Why would those be helpful?

Columbia University Medical Center Information Sheet

IRB Protocol Title: Pediatric Resident Response to Patient Death
IRB Protocol #: AAAS4868
Principal Investigator: Divya Lakhaney, MD
Phone Number: (212) 342-3656
Participation Duration: June 2019 – May 2021
Anticipated number of research participants at this site: 25

Introduction
We are asking you to take part in a research study. The study is being conducted to better characterize how pediatric residents cope with the loss of a patient and to assess the current resources in place to help with these challenging clinical encounters. We are asking that you allow us to conduct a 30- minute interview with you. Interviews will be audio-recorded. After the interview we will ask you to fill out a short questionnaire.

Risks
There is minimal risk to taking part to this study. No identifiable information will be collected. Data collected through the interview and survey will be stored in a secure location using secure data programs (password-protected computer or Qualtrics software).

Benefits
There is likely minimal direct benefit to you for in participating in this study. However, the information collected in this study may help improve the current initiatives and resources in place for pediatric residents who experience the loss of a patient.

Alternatives
You can choose not to participate in this study.

Confidentiality
Interviews will be recorded on a secure, encrypted mobile device. The recordings will be used to ensure accuracy of your responses during data analysis. Recordings will not include any identifying information. The audio-recordings will be transcribed for accuracy. Audio-recordings and transcriptions will be stored electronically on a password- protected computer and destroyed after publication. The post-interview questionnaire will not include any identifying information. It will be stored in a locked office and destroyed after data analysis and publication.

The following individuals and/or agencies will be able to look at, copy, use, and share your research information: the investigator, Columbia University Medical Center and other medical professionals who may be evaluating the study, Authorities from Columbia University, including the Institutional Review Board ('IRB'), & the Federal Office of Human Research Protections ('OHRP').

Whom do I call if I have questions or problems?

If you have any questions or concerns about this study, you may contact Dr. Divya Lakhaney at (212) 342-3656. Taking part in this study is your choice. You can decide not to take part in or stop being in the study at any time for any reason. If you have any questions about your rights as a research subject, you can contact the Institutional Review Board at 212-305-5883 or visit the website at http://www.cumc.columbia.edu/dept/irb/info.html. A copy of this information sheet will be mailed or given to you.