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## How Medical Students Make Meaning of Uncertainty through a Novel Pediatric Psycho-Oncology Rotation



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### **GOOD PRACTICES**

### How Medical Students make Meaning of Uncertainty Through a Novel Pediatric Psycho-oncology Rotation

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#### **Abstract**

Purpose: Feelings of uncertainty about one's professional identity are experienced regularly by those training to be healthcare providers, but the inability to cope with these feelings can be associated with negative outcomes for both students and patients. Medical school is an important time when future physicians must learn to tolerate feelings of internal (personal) and external (patient) uncertainty. We present the impact of a novel pediatric psycho-oncology and narrative medicine elective on medical students' ability to cope with—and embrace—feelings of uncertainty in their education.

Methods: Third- and fourth-year medical students on a 2-week elective rotation were tasked with structuring their own time as they shadowed pediatric oncology patients, keeping a narrative of their experiences. A retrospective qualitative analysis of 120 student journals was performed to identify recurrent themes within the narratives.

Results: Students often initially described feelings of intrusiveness and awkwardness as they were thrust into a new role, as well as a sense of helplessness as they watched the struggles of cancer patients unfold from the bedside. Ultimately, however, these negative emotions evolved into feelings of empathy as they learned to understand a patient's unique story and struggles. Narratives demonstrated that students were able to make meaning of their uncertainty by adopting new perspectives and behaviors to support patients and their families.

Discussion.: Thematic analysis of narratives revealed that placing medical students in an unstructured clinical situation focused on humanistic care was an effective strategy for learning to cope with uncertainty.

Keywords: Medical student, Uncertainty, Narrative medicine, Medical education, Pediatric oncology

### 1. Background

### 1.1. Uncertainty in medicine

ncertainty is inherent in healthcare, and feelings of uncertainty are felt regularly by both patients and providers [1]. For a patient, feelings of uncertainty about a prognosis may manifest as anxiety and doubt, while uncertainty in a provider may look like frustration or preoccupation with a particularly difficult case. Even if uncertainty could be reduced through years of experience and rigorous study, no medical decision will be made without some element of uncertainty [2–4]. Medical

training is a critical time for future physicians to learn to develop a tolerance for the unknown [5], but there is still much to be studied about exactly how students cope with feelings of uncertainty in their training, and how these feelings evolve with more clinical exposure [6,7].

Developing an understanding of how students deal with uncertainty is important because many poor outcomes in both medical training and practice are linked to the inability to cope with uncertainty. An intolerance of uncertainty among physicians leads to increased stress, higher rates of burnout, and worse outcomes for patients [3,7–11], yet there is a lack of exposure to uncertainty in medical

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education [12]. Medical sociologists suggest that our current medical education system makes students less comfortable with feelings of uncertainty by training them to memorize facts and avoid ambiguities [4]. When students learn this way, they will be more likely to seek quick solutions, make assumptions, and experience premature closure bias in real clinical scenarios, which has been described as "the very antithesis of humanistic, individualized patient-centered care." [2] An alternative educational approach is offered by the practice of narrative medicine.

### 1.2. Narrative medicine

Every patient has a story. The practice of narrative medicine enables providers to make meaning and develop empathy for a patient's unique story. Use of narrative-based medicine skills, namely the ability to "recognize, absorb, interpret, and be moved by the stories one hears or reads," [13] enables a provider to understand illness from a deeper, patient-centered perspective rather than simply viewing illness as a disease process [14]. Therefore, engaging with patients through their narratives has the potential to inform clinical practice.

Reflecting on a patient's story, as well as generating one's own narratives through creative writing, can similarly help medical students communicate more compassionately, learn to make clinical decisions, and foster personal and professional identity growth [15–19]. The process of reading and writing about patients serves as a means for students to empathize with another's illness experience; particularly in simulated settings, medical students trained in these techniques are more effective at counseling and communicating with patients [20–23].

Despite evidence that training in narrative medicine techniques can help increase student empathy and communication skills, we still do not know the complete scope of its benefits for medical education [24]. Little is known about whether the benefits of training students to recognize and reflect on a patient's narrative translate from the classroom to a clinical setting. Our study hopes to provide insights about the emotional processing, professional growth, and identity formation that occurs when students are removed from the traditional rotation to be immersed in a patient's story.

### 1.3. Study introduction

Based on these realities, our research sought to address the question: "Can an elective in pediatric psycho-oncology and narrative medicine help medical students make meaning of—and even learn to embrace-uncertainty?" We analyzed journals kept by medical students on a two-week elective rotation in pediatric psycho-oncology. Students were given no formal training in narrative medicine, but were instead instructed to develop a journal capturing their responses to clinical interactions. While the journals were a requirement for completion of the rotation, the retrospective analysis of these written reflections provided better understanding of how immersion directly into a patient's story affected the students' education experience and perceptions of uncertainty. Initial analyses suggested incorporating narrative medicine can be used to increase empathy in students [25].

### 2. Methods

### 2.1. Overview

Our goal was to understand the reactions of third and fourth-year medical students as they were exposed to children undergoing cancer treatment and to the families caring for them. As opposed to the typical rotation structure which pairs students with teams of residents and attendings, this rotation was designed so that students were assigned a panel of patients to check in with directly and follow daily. Students were encouraged to focus on their personal emotional experiences—as well as those of the patient and family—rather than analyzing medical data. Those who chose to take the elective met with the course director before starting to review the goals and expectations of the rotation. Student responsibilities included documenting their experiences while shadowing a variety of encounters in both inpatient and outpatient settings. A majority of the rotation was spent following the same 2-4 pediatric patients for an extended time during their inpatient stays. The course director assigned students to patients so various stages of treatment could be seen. Students kept confidential electronic journals to record their observations and insights, which were submitted to the course director at the end of their rotation.

In total, 120 student journals from third and fourth year medical students were collected over an 11 year period (2008–2019). The journals varied greatly in size (word counts ranging from 769 to 13,295, or approximately 4–24 pages) and in content. Since students had reduced clinical duties while on the rotation, the focus of the writing was to be less on the diagnosis, medications, and treatments, and more on the interpersonal interactions and their

reactions to the daily occurrences. Instructions provided to students read: "Through the journal, the student will communicate what he or she has learned about how patients and families deal with a cancer diagnosis, but also with the positive and negative aspects of the medical system they need to navigate for a cure. The length, content, style, and format of the journal is left up to the student." Journals were stored in a secure server managed by the institution.

### 2.2. Procedure

Before analysis of the student narratives began, the course director—who did not take part in the analysis—removed all student names and assigned a random code number to each journal. All personal identifying student or patient information was redacted. For anonymity, researchers did not know who the journal was written by, the year it was written, or the identities of the patients or their family members.

A qualitative approach was taken to analyze the journals for recurring themes. The course director was not involved in the narrative review because he was familiar with the journals as well as the students and patients that were discussed in them. A faculty member with expertise in qualitative research and a team of four pre-clinical medical students were given training in narrative interpretation to conduct an initial review. Techniques for narrative inquiry similar to those described by Petty (2018) were employed to generate codes from the raw data in the journals and turn them into common codes [26]. The first 40 journals, randomly arranged and therefore not chronological, were read by all team members to identify major concepts and ideas in the writings. Coding sheets were used by each team member to identify examples of patient coping, family coping, system functioning, student reactions, student growth/insights, and overall student impression within the narratives. The research team then met to compare findings and reach agreement on common themes that appeared within and between journals.

### 2.3. Analysis

Once clear themes were observed and saturation was reached, meaning that no new themes were identified, the remaining 80 journals were analyzed to develop a deeper understanding of the identified themes. Specific attention was given to comparing and contrasting insights related to the uncertainty expressed by the students, as well as how these

interactions may have influenced the student's professional growth or identity formation as a future physician.

### 3. Results

### 3.1. Overview

Students generally arranged their journals in one of two ways: by date, so that the narrative progressed chronologically, or by patient, so that the narrative progressed as a summary of key events. The overall organization of the journal had little influence on the presence of personal insights or emotional reflections.

Writing styles varied greatly among the journals, and were more predictive of whether the student would provide unique insights about the rotation. For example, some students wrote in a succinct style reminiscent of a medical note. When students chose to report on the facts rather than reflect on their experiences, the journals included fewer insights about their uncertainties or professional growth. Journals that were more emotional in nature—those in which students more freely discussed their excitements, doubts, and anxieties—were more likely to include themes that revolved around personal uncertainty and growth as a healthcare provider.

Approximately one in three students openly discussed their own personal insecurities or worries regarding the rotation near the beginning of the journal, and only about one-third of these revisited this theme at the end of the journals to talk about how these feelings had changed as a result of the rotation. Therefore, only about one in every ten students explicitly addressed their own personal growth in terms of how they became more tolerant of uncertainty.

In addition, a significant proportion of students spent time discussing the uncertainties of the patients or the parents they were shadowing and did not mention their own uncertainties. Therefore, writing about what they observed in the patients or parents evidenced a growing sense of empathy toward others even if these reflections did not involve their own uncertainties. Ultimately, about one-half of the journals were written as simple summaries of the student's day, and the other half focused more on student's personal emotions or reactions.

A general pattern emerged in how students documented feelings of uncertainty and the growth that it caused. Initial uncertainties—which students either observed in patients and parents, or that they felt based on their presence in this new setting—often led students to document in their

narratives about feelings of intrusiveness and inadequacy. Whereas most students often seek ways to be helpful in the clinical environment even when there is no clear role for them, uncertainties can lead to feelings of helplessness. Over time, however, as students developed relationships with patients and family members, those feelings of uncertainty about their role led them to find new ways to connect with patients. Select journal entries highlight progression of student willingness and ability to embrace uncertainty.

### 3.2. Uncertainty makes students feel intrusive or awkward

Part of the design of this rotation, in addition to exposing students to the difficulties of the patient's journey, was to remove them from the comfort they have come to know from shadowing physicians and residents in the hospital. The initial journal entries of many students described how they felt like an outsider jumping into a family during an extremely sensitive time. This was especially true for students paired with recently diagnosed patients, as the emotions were still unfamiliar and uncensored. Students feared that they would be unwanted or that they would make the family's struggle worse than it would have otherwise been. As one student put it bluntly:

"I just sit, and try not to make things worse with my presence - I feel like I fail." — Journal 070

Others felt awkward in specific situations, because of unfamiliarity with how to interact at such sensitive times:

"I saw her unbraiding her hair which came out in clumps. As a teenager for which appearance is of utmost importance I can imagine how difficult it must be undergoing such drastic changes. I struggled with ways to respond to awkward moments of silence." — Journal 120

"I was markedly uncomfortable as I watched [his] father sob, helpless to offer comfort beyond a sympathetic look." — Journal 099

Even for students who do not experience these intense reactions, their first few meetings with patients were often peppered with doubts. This rotation demands significantly more face-to-face time with patients compared to others in their clinical years, so sitting in a room with patients for hours without a designated activity can cause quite a bit of stress for students already worried about saying something that may cause offense or discomfort.

They quickly realized the need for balance between speaking up to learn from the families while not speaking so much as to be a disturbance:

"I really enjoyed hearing stories about [the patient's] interests and life. However, it was so hard to control the urge to ask questions about his cancer. I'm so curious as to what he thinks of it, how he has dealt with it, how it has changed his life, and in what ways has life remained the same ... I hesitate to ask these questions though, as cancer seems like such a personal and emotional diagnosis. I think I want to have more of a relationship with him before I ask the tough questions." — Journal 050

How students responded to feelings of uncertainty over the following days influenced how well they were able to connect with the patients and their families. Those that were able to overcome these thoughts were more likely to convey confidence in their writings about their relationship with the families they shadowed. Others spent the entire two weeks feeling as if they were an unspoken "burden" on the family, and their journals tended to have more negative themes.

### 3.3. Uncertainty results in feelings of helplessness

In addition to the uncomfortable feeling of being intrusive, many students reported a sense of help-lessness at some point on the rotation, in large part brought on by uncertainty of their position and of the outcomes for the patient. While difficult, these reactions enabled students to get a glimpse of what it is like for the patients and their families who are perpetually reminded of the lack of control they have over their lives. Some students experienced anxiety even before entering the patient's room, as they read through the chart and realized how serious the child's condition was. Emotions surrounding a cancer diagnosis are intense, and the burden of this reality can be felt even by those outside of the child's family:

"I felt helpless and wished so deeply that this was not happening to her and her family ... The raw fear of death was the most overwhelming to me as a student, with little to offer at this point. I couldn't imagine how terrifying the experience was with a diagnosis but no insight yet into the prognosis, treatment, or plan." — Journal 098

The natural response of many students in these situations was to try to find a way to help, and when they had to simply wait and worry with the family, their sense of powerlessness was heightened:

"[She] was still crying when she was taken to the recovery area. Again, I was lost for words — didn't know how to comfort her. She was crying out for her mom and I could not help her. In that moment, it seemed as if she had regressed to childhood ... She stopped crying for a while but when the nurse left us alone again, she once more cried out for her mother. Am I so lacking in skills that I cannot console her even for a little while?" — Journal 104

Students were therefore forced to grapple with both the uncertainties of a cancer diagnosis and their own role confusion. Both of these aspects expose students, who normally seek to find worth in being helpful members of the care team, to feelings of helplessness.

Students expressed two general types of reactions. Some indicated that these experiences left them feeling inadequate, while others sought new ways to help, defined new roles for themselves, and learned to connect with patients in ways they never had before. Students who were more adaptive under situations of stress were more likely to demonstrate a positive learning experience throughout the course of the rotation.

### 3.4. Uncertainty leads to empathy

Shadowing patients—and seeing firsthand the hardships, suffering, and resilience of these children who are fighting for their lives—is emotionally taxing for many students. A natural response of students is to feel sorry for the patients and their families who must live this reality every day. Especially when students begin to build a relationship with the patient or their families, the weight of the diagnosis becomes a little more real.

"Frustrated was the emotion I felt today because of my inability to do anything for them. Frustrated that I couldn't take away their pain, I couldn't stop their side effects and I couldn't do much more than sit there. Frustrated because they have to experience this." — Journal 088

But the sense of feeling sorry for a patient often gives way, over time, to empathy. This develops from students becoming a part of the patient's story: dealing with the very real frustrations of waiting, being a companion in times of boredom or distress, and even experiencing the simple joys of floor bingo games and music therapy sessions. Their own feelings of awkwardness or helplessness are often overshadowed by the respect and appreciation they develop for the patient and family. The continuity of spending a significant amount of time, over several

days, with the same patients, enables a personal connection that increases the family's trust in the student, and likewise the student's investment in the family. These interactions often serve as a reminder of the humanistic side of medicine that attracted them to the medical profession in the first place, and are a major focus of the students' narratives.

"It seems that I had become more withdrawn and cynical than I had thought towards the patient experience in the first few years of medical school. I had taken on the thought process that all that matters are my grades and my learning, when in actuality real people and real families are going through unimaginable struggles while I complain about trivial things. I'm so grateful for the patients I met during these two weeks because not only did they teach me about the hospital system and patient experiences but they allowed me to shed that selfish notion I had begun to live with and truly embrace why I wanted to become a doctor to begin with ..." — Journal 054

Students were thankful for these experiences, which reminded them to recognize the patient behind the diagnosis and to combat the loss of empathy that inevitably afflicts many students as a result of the stresses and demands of clinical rotations. The challenges they observed in two weeks made many contemplate their future patient interactions and how their actions, even as medical students, can have large impacts on the lives of their patients.

### 3.5. Uncertainty helps students make meaning of their experience

This rotation in pediatric psycho-oncology took students out of their comfort zones. On a typical rotation, much of a student's attention is on learning the technical aspects of medical care—disease processes, medications, and procedures. Being propelled into the unfamiliar life of a pediatric cancer patient reminded students the value of recognizing medicine's personal side:

"I think it's important for us to think about how what we say as physicians impacts our patients in a very real and profound way. And I think that the more in tune we are with the needs of our patients and their families, the better we can share information in an effective and meaningful way." — Journal 017

Seeing medical care from the patient perspective gave students an awareness of patient struggles not always evident on other rotations. As they simultaneously faced their own worries regarding professional roles, relational boundaries, and personal doubts, students were able to find meaning in their experience by reconnecting with the humanistic side of medicine that is often "lost" in the clinical years. They sat by bedsides for hours and learned to bond with kids who were struggling. They validated the frustrations and emotions of distraught fathers. They experienced the fallout when a provider ignores a mother's requests, and conversely how much less nerve-racking the day can become when the provider takes the time to address her concerns. Even when students were unsure whether their experiences were directly going to help them become better doctors, having a patient at the center of their learning was still extremely beneficial:

"When I'm talking to these parents and these kids I'm always trying to think of how this information will help me to be a better doctor, and I don't always feel like it will. I don't always think they're telling me anything terribly profound that I didn't know before, but hopefully just by actually listening to them and by caring what they have to say—whatever it relates to—I'm helping them just by lending and ear, and hopefully helping to prepare myself, too, for something unknown down the road for me." — Journal 004

Many students took the opportunity to reflect in their journals on what they believe makes a good doctor, based on their observations and the conversations they had with the families. Being honest, while also being able to connect with families and provide reassurance when the news is undesired, was central to many of the students' findings. For those who discussed how the lessons of this rotation affected their professional growth as future physicians, an overwhelming theme was the importance of understanding a patient's story and unique struggles, and letting that story inform clinical practice.

In addition to finding meaning in the experience by connecting with patients and appreciating the qualities that patients most value in a physician, students were able to learn how to contend with their own feelings of uncertainty. Though not all students discussed themes of personal doubt or insecurity, those that did outlined the importance of addressing the uncertainty when you can, and accept it when you cannot. As one student summarized the experience:

"I personally have experienced a wide range of emotions during this past week. I have felt helpless at times when parents have so many questions unanswered, and I cannot give them the answer they are looking for. This has motivated me to go home each night and read as much as I can on the patient's illness or the potential diagnoses in question. This way I can have an active role in the education process, but also I gain a more complete understanding why certain decisions are made and procedure/tests are done. But, I have realized and accepted that I still cannot have all the answers. Even physicians with significant experience and expertise must consistently work for these answers, sometimes still in the end unable to understand everything associated with a particular patient. We are human and also feel helpless when inevitably all possible therapies and attempts to promote health have failed in some situations. However, working through these emotions has helped me grow as an individual currently and while learning my limits throughout medical school." —Journal 051

### 4. Discussion

Uncertainty surrounds a cancer diagnosis. For pediatric cancer patients and families, nearly every stage of treatment brings about new uncertainties: "When will we officially find out the diagnosis?" "How much longer will we have to wait for the procedure?" "What will we do if it is a relapse?" "Will I survive this?" As medical students on this rotation were matched with patients and learned firsthand how families learn to deal with these stresses, they struggled with new uncertainties of their own. One of the goals of this rotation was for students to make meaning of the complicated emotions that came from navigating a new and different role where they must live through experiences with patients and families. For many students, the added component of watching families cope with their worries intensified their own questions and emotions. Taking this novel elective gave students an intimate glance into the demands placed on individuals when a healthy child becomes a sick patient: lifestyle changes, loss of independence, and a total reliance on the healthcare system. It also allowed students to build relationships with the patients and their families. Essentially, students were able to make meaning of a situation that evoked great uncertainty through entering the patient's narrative and watching it unfold as they sat by their bedside.

As with any rotation, this experience in pediatric psycho-oncology was meant to help prepare medical students for their future careers. This study sought to understand whether immersing medical students in the patient experience on this rotation—and causing them to recognize and reflect on a patient's narrative in a highly uncertain environment—helped them grow in the embracing of uncertainty that could benefit them in other clinical situations. They were no longer working in a

classroom setting with simulated encounters and hypothetical scenarios, and they were not on a rotation that had them follow residents or attendings with little input into the patient's care plan. From analysis of major themes in their journals, we found that this rotation helped many students tolerate uncertainty and better empathize with the pediatric patients and families undergoing the stress of intense cancer treatment.

Possibly the most notable finding for many students, as they documented in their journals, was the revelation that they can still help patients without directly helping to treat their cancer. By crafting a new role for themselves as therapeutic "friends" and helpers, they came to see their presence as beneficial and accept that not all members of the medical team need to be involved in managing treatments and making diagnoses. Parents were especially likely to express gratitude for the non-medical contributions that the student made to their child's time in the hospital, helping some students realize that they may have made a greater difference in this role than in their traditional one. As students reflected on all of the trials and difficulties that patients and parents were going through, they were reminded that uncertainty is part of life as a medical provider and even when it could not be eliminated, it could be embraced for the sake of their patients they are there to serve.

However, it is important to acknowledge that while many students openly talked about the uncertainty that they felt, not all students discussed these themes. For the students who chose not to journal about their personal or emotional reactions, and who simply summarized the day-to-day happenings of the rotation, there was little discussion on the theme of uncertainty. Students were all subjected to similar situations, and there is evidence to support the assertion that they all experienced uncertainty, but nearly half of the journals did not contain evidence of this theme. Therefore, we cannot conclude that every student learned to embrace uncertainty simply through participating in this rotation or the narrative writing process. Despite this limitation, we were still able to understand how this rotation helped many students productively embrace uncertainty from those who chose to write about such topics.

### 5. Limitations and suggestions

### 5.1. Long term development

Research by Nevalainen et al. (2010) concluded that for medical students, exposure to uncertainty

over time leads to understanding that one is incomplete, and this results in the acceptance that he or she is only good enough for his or her current level of training [6]. Students reportedly learned to cope effectively with negative feelings, such as the fear of making mistakes and the confusion related to the inexactness of medicine, over long periods of time. In our study, we found that the impact of the brief experience was impressive, but we did not see considerable growth or shifting of mindsets in students. This is likely because the rotation lasted only two weeks, and there were no follow up surveys or journaling. Prompting students to write about their perceived professional development may also enable better data collection on their personal development as a clinician.

### 5.2. Lack of follow up

We required no follow up journaling of students after they left the rotation, nor did we collect information at the completion of the rotation, so we do not know whether their experiences affected their choice of specialty, how they interacted with their future patients, or even whether the rotation had any lasting effect on them at all. This limitation could be remedied by following students for years after the rotation ends, and periodically inquiring about the lasting effects of their rotation experience. Further studies are underway to elucidate if and how this rotation affected students longitudinally.

### 5.3. Journal entry limitations

More than half of the participating students chose to narrate their journals as simple summaries of their day rather than focus on their personal emotions or reactions, and those students were also less likely to discuss their professional growth or lessons learned. We therefore cannot conclude whether these students truly gained any transferable skills from the experience, whether they simply chose not to write about these things in the journals, or whether it was too distressing to expound on the experiences they had witnessed. The lack of discussion on the topic could be due to the absence of a specific journal prompt for each day, such as a reminder to "describe how you felt, rather than simply what was going on." Additional pre-rotation instructions to students on the purpose of the narrative approach may also have resulted in more data to suggest how the rotation influenced their ability to make meaning of uncertainty. While this is a limitation of such open-ended requirements for the student journals, we recognized the importance

of giving students the freedom to express themselves in their writing, even if it did not assist in all aspects of the narrative research.

### 6. Conclusions

Teaching students to develop a tolerance for uncertainty will require a culture change in medicine beyond a two-week elective rotation; however, exposing students to situations that make them uncomfortable is a start. Through the analysis of written narratives, it is clear that many of the students who participated in this novel pediatric psycho-oncology rotation were forced to address uncertainty in a new way for the first time and puzzle out its meaning.

A clear benefit of this rotation was the shifting of their mindset to consider narrative medicine as an important component of clinical practice. This rotation adjusted the lens through which medical students perceived the medical field and forced tough questions upon them. Intentionally exposing students to situations of uncertainty in their medical training, as was done on this rotation, would be a safe and effective way to help students learn early in their career to deal with uncertainty and embrace the unknown, because that is an aspect of medicine that will never go away: "As we move further into the 21st century, it seems clear that technology will perform the routine tasks of medicine for which algorithms can be developed. Our value as physicians will lie in the gray-scale space, where we will have to support patients who are living with uncertainty — work that is essential to strong and meaningful doctor-patient relationships." [11].

### Ethical approval

The Penn State Institutional Review Board evaluated this work and deemed it as exempt from needing IRB approval. This study did not have any funding source. Informed consent and HIPAA Authorization was waved by the Penn State IRB, as no patient health information was used and all medical student information was de-identified.

### Other disclosures

None.

### Conflicts of interest

None.

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