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A Time to Live and a Time to Die: Heterotopian Spatialities and Temporalities in a Pediatric Palliative Care Team

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ABSTRACT

The death of a child creates especially poignant feelings and extreme stress, distress, and devastation for family members and healthcare providers. In addition, serious or long-term illness forces a reconstruction of our experiences with time and space. In this paper, we report on a long-term ethnographic study of a Pediatric Palliative Care Team (PPCT). Using the concepts of spatiality and temporality; Deleuze's concepts of smooth and striated spaces; Innis's concepts of space and time biases; Foucault's concept of heterotopian space—places with multiple layers of meaning; and a related concept of heterokairoi—moments in time with multiple possibilities—we consider how the PPCT constructs and reconstructs meaning in the midst of chaos, ethical dilemmas, and heartbreaking choices.

Facing our own mortality or that of a loved one forces us to encounter uncertainty, confusion, despair, and the bewildering loss of agency over our own bodies and lives. In addition, serious or long-term illness forces a reconstruction of our experiences with time and space (Morgan & Thomas, 2009). The death of a child creates especially poignant feelings and extreme stress, distress, and devastation for family members and healthcare providers.

Palliative care—care targeted to symptom and pain management with the aim of improved quality of life at or near the end of life—has the reputation of being synonymous with death and dying and hospice care. In actual practice, palliative care is appropriate for any patient with a serious or life-threatening illness and can be provided in a hospital setting, as well as in a hospice or home setting (Pantilat, Anderson, Gonzales, & Widera, 2015). Whether in a hospital, home-based, or outpatient, palliative care frequently utilizes a long-term collaborative interdisciplinary team-based approach, preferably within a family centered perspective (Davis, 2010; Remke & Schermer, 2014). Palliative care typically supports the patient and his/her family through the end-stages of their disease and sometimes through the bereavement process. Palliative care addresses, in addition to symptom management, the emotional, social, and spiritual aspects of the experience for patients and families, which results in preservation of the inherent humanness of the patient and family (Davis, 2010; Egan & Labyak, 2001).

A child's suffering from a critical illness goes against shared cultural beliefs and forces us to renegotiate the way we understand justice and morality, the present and the future (Stroebe, Schut, & Finkenauer, 2013). Healthcare teams in pediatric palliative care are responsible for not only providing treatment consistent with the biomedical model of healthcare, but also for co-constructing new meanings of humanness and quality of life with patients and their families. The uncertainty surrounding the context of children's palliative care requires staff to help families navigate life and death amid high levels of ambiguity.

In this research, we are studying communication and discourse within a Pediatric Palliative Care Team (PPCT) in a children's hospital, part of a large regional healthcare system in the Southeast. We report on a long-term ethnographic study of the PPCT, and in this analysis, we use the concepts of spatiality and temporality; Deleuze's concepts of smooth and striated spaces; Innis's concept of space and time biases; and Foucault's concept of heterotopian space (Foucault, 1972, 1979, 1984)—places with multiple layers of meaning—to consider how the PPCT constructs and reconstructs meaning for children and families. This research adds to the scholarly conversation about end-of-life care as we answer the myriad of calls for providing pediatric healthcare providers with better information on compassionate communication at the end-of-life. It also adds to the conversation on healthcare spaces and temporality.

Literature review

Contextual issues in pediatric palliative care

Western culture paints a good death as one in which the dying person and his/her family is aware and accepting of, and prepared for, the death; occurs at the end of a long and happy life; is free of pain; and maximizes personal agency, dignity, and bodily integrity until the end (Cipolletta &

Oprandi, 2014; Frith, Raisborough, & Klein, 2013). Given this understanding, it makes sense that a good death for children is incomprehensible.

A child's death does not occur at the end of a lengthy life, and, as we will explain shortly, the experience of time shifts for children with a terminal prognosis. In addition, hospitalized children experience a childhood through their immature interpretive lenses, sometimes seeing healthcare providers as frightening strangers, other times seeing them as more parental than their parents, for instance, more instructive or authoritarian. Even with the best efforts of modern children's hospitals to make their space child-friendly, hospitals can be isolating and frightening places for children, different from the rest of their world in terms of conventional expectations around everyday things such as clothing, eating, communicating, and playing (Bluebond-Langner, 1978). In addition, a child's death trajectory can be confusing and uncertain. In the context of a serious or life-limiting medical condition for a child, the wide array of treatment options available for patients, mixed with the uncertainty of a child's prognosis, and America's taboo attitudes toward death and dying, there are increasing complexities for families and healthcare teams. This contextual space is made all the more tumultuous by the wide range of experiences and decisions: for instance, whether or not to use life sustaining treatment or to withdraw or discontinue treatments, procedures, or machines. Experiences in the hospital bound from crises to acceptance. A multitude of moral issues arise in this context, including parental and patient autonomy, futility of medical intervention, incorporation of the unique characteristics of the patient and his/her entire family in the decision-making process, and balancing comfort care with cure (Feudtner & Nathanson, 2014; Jones, Contro, & Koch, 2014). Families of children with life-threatening illnesses face gut-wrenching decisions among multiple treatment alternatives, including life prolonging treatments, such as intubation and artificial breathing vents, organ transplant, heart-lung bypass machine (ECMO–Extracorporeal Membrane Oxygenation), and kidney dialysis; or comfort care. As PPCTs are most likely to be involved in cases that are medically complex and reflect uncertain prognoses (Doorenbos et al., 2013), the balance between patient autonomy and medical guidance is especially precarious under their care (Roeland et al., 2014). Parents, too, lose their role identity as they experience powerlessness and loss of agency over their children (Bluebond-Langner, 1978). Thus, the complexities of the PPCT environment require healthcare staff to negotiate their interactions within differing medical spaces and to help families navigate life and death amid high levels of uncertainty, complexity, and turmoil. Finally, a child's death raises difficult and frequently unanswerable questions about the nature of life and death for both the children and their families.

Spatiality and temporality

Spatiality

Postmodern scholars conceptualize space as consisting of social structures, or "social space" (Allen, 1999, p. 258), and argue pure spaces free from social influence are simply an illusion (Lefebvre, 1974/1991). All spaces are instead seen as relational, ideological, and hegemonic (Allen, 1999). Within this view, while "place" refers to a physical location, "space" or "spatiality" refers to the meanings constructed around, represented by, and produced within, a specific physical place and time (Allen & Hardin, 2001; Foucault, 1972). Space is subjective and socially constructed (Durkheim, 1976; Lefebvre, 1974, 1991; Shields, 2006), and, suggests Foucault, is formed through discourse (Foucault, 1972). Deleuze's concept of nomadic space is also relevant to this study. Nomadic space (e.g., temporary work spaces), suggests Deleuze, is "smooth" and heterogeneous and, in contrast, "State" (e.g., official) space (e.g., government or banks) is "striated" and homogeneous. Nomadic, or smooth spaces, are relational, undifferentiated, and dependent on environmental contexts for meaning. Striated spaces are measurable spaces that are delineated by consistency, hierarchy, walls, and enclosures (Marcussen, 2008). In this paper, we will be examining the PPCT in the context of smooth and striated space.

Temporality

Just as spatiality refers to the meanings attached to spaces, temporality refers to the meanings attached to time. We order, organize, control, and experience our lives temporally (Adam, 1992; Morgan & Thomas, 2009). While we live our lives as a continuous, ongoing process, we experience and make sense of our lives in a nonlinear manner, often attaching meaning to events retrospectively, and understanding past events in light of present ones—and vice versa (Freeman, 1998; Mensch, 2010; Riessman, 2015). We experience time spatially—we move through time (Bergson, 1955), and we experience time in motion (Protevi, 1994), as the past, present, and future co-exist and influence each other, and are communicated and represented in and through each other (Bergson, 1955; Heidegger, 1962; Mensch, 2010; Parmentier, 2007). Time can be experienced as intense or it can be invisible (forgotten) (Pritchard, 1992). We also experience time personally, historically, and socially through obligations, choices, actions, anticipations, and expectations (Durkheim, 1976; Mensch, 2010; Parmentier, 2007). One's experience of time is related to language, beliefs, and customs (Innis, 2008). Time is also related to power, as historically, people in power maintained their power by being able to control the experience of time (Innis, 2008). Finally, time is represented symbolically (Parmentier, 2007) and is measured exterior (externally) to us (in relationship to the sun or moon, for instance), and interior (internally), as the body itself is a chronograph—our body clocks tell time in synthesized and coordinated rhythms (Adam, 1992; Protevi, 1994). In this sense, time is an embodied experience.

Space and time biases

Space and time cannot be separated, as space is experienced temporally and time is experienced spatially. Innis (2008), in his scholarship on space and time, considers their interrelationship with each other and with culture. Innis suggests that social factors interact with ecological and historical factors to construct and modify specific spaces. He also proposes that institutions (or systems) tend to be either bound (biased)

toward time or toward space. While there is a space and time interplay, suggests Innis, the two are inversely related in that if an institution has a stronger bias toward time, it will have a lesser bias toward space. Space-bound institutions are ones that are organic, mutable, and variable. Biases of space, suggests Innis, are the work of networks primarily interested in winning territory through channels of distribution. Time-bound institutions are ones which are more rigid, durable, and lean toward a long-term, more stable trajectory. Time-emphasizing institutions tend to be more hierarchical than space-emphasizing institutions, and have a commitment to preservation. Innis also notes that both types of biases are essential for functioning (Di Norcia, 1990; Innis, 2008; Mullen, 2009) and claims that "in Western civilization a stable society is dependent on an appreciation of a proper balance between the concepts of space and time" (Innis, 2008, p. 64). Space is dynamic, changes over time, and is constructed through communication, within an environmental and temporal context (Mullen, 2009). Innis notes that the ability to effectively move (utilize space) at the right time (utilize time) is the mark of a healthy culture (2008). In the context of this paper, we will examine the PPCT from the understanding of space and time biases.

Heterotopias and heterokairoi

Foucault's (1984) concept of "heterotopia" is a derivation of "utopias,", spaces of perfection. The prefix "hetero" refers to differences, and "topia" refers to spaces, thus, a "heterotopia" is a space of differences. Heterotopias, according to Foucault, are spaces that hold multiple layers of meaning across different times and experiences. Scholars have conceptualized spaces such as hospital settings as heterotopias because they span different positionalities (relational, cultural, and experiential standpoints), such as joy and grief, birth and death, wellness and illness, warmth and sterility, memory and existence, the beautiful and the repulsive, reality and unreality, and the ephemeral and the eternal (Bleakley, 2013; Wright, 2005). We suggest creating a related term, heterokairoi, to refer to multiple positionalities of time within a heterotopian space. As we've mentioned, time is experienced spatially—we move through time, spend time, and take time. Kairoi (plural of "kairos") refers to moments of possibility or opportunity—"the right moment"—says White (1987, p. 13); a "kairos of the postmodern" (Geiser, 2013, p. 90). Thus, as we use the term, heterokairoi means moments of possibility within multiple meanings. In our context, the juxtaposition of these two terms refers to the myriad of meanings of spaces and times that make up the liminal space of the PPCT as it simultaneously constructs notions of care and cure, life and death, hopelessness and hope, and home and hospital.

Healthcare spaces and medical time

Health crises, both chronic and terminal, require us to negotiate and experience our temporality and spatiality in the context of healthcare spaces and healthcare timetables (Charmaz, 1991; Morgan & Thomas, 2009). Foucault (1973) was one of the first scholars to critique modern medicine for treating healthcare as a spatially constrained phenomenon, positioning illness within the body and restraining the patient and the physician within a closed medical space. Foucault's (1973) analysis of healthcare spaces distinguishes between places of disease and spaces of relationships between the body, the self, and the experience. Long-term care for chronic and critical illness transforms a medical place into an environment of experience and feelings (Bleakley, 2013). Hospital spaces are controlled by the physicians; patients give up control when they enter the hospital (Frankenberg, 1992).

As we've said, as space is a construct of our social world, so is time. Living through chronic illness requires a restructuring of our experience with time and the meanings we give to time, constructing disease and treatment-specific markers of time (Charmaz, 1991; Riessman, 2015). The experience of illness can distort time (Pritchard, 1992), and Pritchard (1992) suggests that sick time is "time of a different kind, where other rules apply" (p. 85). For children with a terminal prognosis, the experience of time moves from an infinite phenomenon to a temporally bound one. Thus, children's viewpoints move from the future—dreaming of what will be—to the present—focusing on one day, one hour, one moment at a time (Bluebond-Langner, 1978). In fact, for those with a serious illness, future time is ambiguous or uncertain (Morgan & Thomas, 2009; Riessman, 2015) and concerning and frightening (Morgan & Thomas, 2009). Serious illness can be experienced as an interruption or slowing down of our timeline (Charmaz, 1991; Moola & Norman, 2011; Morgan & Thomas, 2009; Riessman, 2015). Medical time is staged or episodic (Morgan & Thomas, 2009), as, for instance, a cancer diagnosis necessarily depends on stages, as do treatments. Temporality also figures into hopes and dreams related to illness and health—terminally ill patients and family members grieve the loss of an imagined future (Moola & Norman, 2011); hopes include a future without illness or treatment (Morgan & Thomas, 2009); one's temporal perspective influences perceptions of hope versus hopelessness (Davis, 2010); and, time to ill children is understood in terms of what s/he will miss from this life (e.g., friends or family members, school, or television shows) when s/he dies (Bluebond-Langner, 1978). Further, help seeking is related to temporality—patients frequently wait until symptoms have "taken over" their time before they visit healthcare providers (Morgan & Thomas, 2009). As with other resources, time represents power—the person with the most power can keep other people waiting. A physician's time, for instance, is represented by urgency, busyness, rushing, and long hours. Hospital time—experienced differently by the doctor, nurse, patient, and family—is scheduled and regulated. A patient's time, in contrast, is represented by waiting, a reality reinforced by the first thing encountered upon entering a doctor's office—the waiting room (Frankenberg, 1992). In fact, says Frankenberg (1992), "medicine is a waiting culture" (p. 1), as patients wait for appointments, treatments, and results.

In this paper, we adopt the postmodern conceptualizations of spatial and temporal theory; Foucault's idea of heterotopias (and the related term, heterokairoi); Deleuze's ideas of smooth and striated spaces; and Innis's concepts of space and time biases, as theoretical frameworks to understand how discourse within pediatric palliative healthcare constructs patient experiences through the interplay of space and time.

Throughout this paper, we use the terms "space" and "time" in alignment with this understanding of the social construction of place and time.

Study objective

Pediatric palliative care is a rich environment in which to study space and time; for it is here that multiple meanings of caring and curing converge and contrast. The overall objective of this long-term ethnographic project is to understand the socially constructed and communicative experience within the PPCT. For this paper, we examine the discursive environment within the PPCT to understand how space and time in this context of children's serious, chronic, and life-threatening illnesses are constructed, interrelated, and experienced.

Methods

Study design

This is an ethnography utilizing multiple methods of data collection over 10 months of fieldwork at a PPCT in a children's hospital, part of a regional healthcare system in the Southeast.

Data collection

From August 2013 through June 2014, the first and second authors functioned as observers-as-participants, observing a total of 30 weekly rounds meetings with the interdisciplinary PPCT and 28 other interactions and field visits with and between PPCT members, patients, and families. We conducted multiple interviews and one focus group with PPC team members, and interviewed 11 parents of pediatric patients and one patient over 12 years old. In addition, we had many informal "hallway" conversations with PPCT team members, patients, and families throughout the course of our fieldwork. We took detailed field notes of our observations and audiotaped and transcribed the interviews. Our time in the field—completing close to 200 hours of field work—allowed us to reach data saturation.

All patients, families, and team members who were observed and interviewed provided informed consent, and the pediatric patient we interviewed provided assent. This study was conducted under the oversight of both the hospital and university IRBs. The PPCT members each provided consent at the outset of the project (the research project was conducted at their invitation), and family members and patients were invited to participate by the social worker, nurse, or physician and consented once by the person recruiting them and again by the lead author.

Study population and sample

We studied the PPCT members—team leader, chaplain, nurse, music therapist, patient and family liaison, physician, and social worker—as well as PPCT patients and their families. Patients of the PPCT ranged in age from newborn to young adult; their diagnoses ranged from congenital disorders, birth traumas, and cancer, to brain injuries, automobile accidents and severe burns. Some were in the hospital for the first time

and some had been in the hospital multiple prior times. Some were in the hospital multiple times during our time in the field, while others were in once. The average length of hospital stay was 28 days, but patients are characterized by multiple and frequent admittance. The PPCT works with multiple "floors" (departments), so the patients varied between rehabilitation, pediatric intensive care (PICU), neonatal intensive care unit (NICU), cardio-vascular intensive care unit (CVICU), general pediatrics, and the hematology/oncology floor. Many patients moved between multiple floors while in our study. All of the parents who agreed to be interviewed for the study were biological mothers and fathers, but some patients under the care of the PPCT during our time in the field were under the care of grandparents or foster parents or were wards of the state.

Our sample was purposive, in that we sat in on all team meetings for the duration of the fieldwork, shadowed team interactions with families and patients as we had consent and availability, and interviewed parents (and one patient) as we were given consent. Most patients were too young or too ill to consent to be interviewed. We interviewed all team members.

Analysis

All interviews were transcribed verbatim and, for the current analysis, coded using a discourse analysis approach. The overarching intention of discourse analysis is to provide an understanding and interpretation of meaning from both the micro (verbal and nonverbal communication) and the macro (social practice and context) levels of discourse simultaneously (Silverman, 1993). Discourse analysis attends to meaning construction by understanding discourse as rhetorical situations in which both the interpersonal and cultural levels of discourse jointly construct meaning (Davis, 2016; Manning & Kunkel, 2014; Murdoch, Poland, & Salter, 2010).

Following interpretive research conventions, the initial analytical process was ongoing throughout the fieldwork phase through analytical notations coupled with the field notes, analytical conversations with the co-authors, and conversations with PPCT members. After multiple passes through the data in an open coding stage, we decided to use the lens of space and time as sensitizing concepts for this analysis. In the subsequent stages of coding and analysis, we closely examined our notes and transcripts with an eye out for discursive elements and categories that were representative of these concepts. Our analytical process went through the following stages:

(1) Initial engagement with the data concurrent with field work.
(2) Transcription of field notes and interview tape recordings.
(3) Open coding to examine the data for meaning, narrowing down sensitizing concepts, and specifically attending to the interpersonal levels of communication and the social and cultural contexts.
(4) Constant comparison coding utilizing the sensitizing concepts and further refining the categories and analysis.
(5) Final analysis and discussion: relating the categories to the theoretical foundations.

Excerpts from the interview transcripts and field notes from the team meetings (or "rounds") are used to support the findings. The excerpts from the rounds come from extensive hand-written field notes but do not represent a transcripted recording. In addition, we note that the field notes from the rounds represent three different types of reporting that go on during "rounds.". The first is that of technical, factual information using medical jargon. The second is more informal language, such as the use of humor or other depreciating, metaphoric, or colloquial communication to help the healthcare providers cope with depressing situations and distance themselves from the emotion-laden situations in which they are involved. The third type of language used in meetings is language that helps providers emotionally connect with their patients and families. Our field note excerpts report on all three types of language but in some cases, we edited the field notes to protect patients' anonymity. This paper does include some diagnostic or descriptive information for patients or families, but in many cases, such information was omitted to protect patient confidentiality and anonymity.

Findings

Members of the PPCT move in and out of spaces and times of confusion, chaos, uncertainty, and fear, as patients and families frequently find themselves in difficult places, and move through hard times, such as these. Yet, PPCT members also move in and out of spaces and moments of peace, comfort, and care. These very different sorts of experiences are not necessarily separated in time or space, and are even experienced simultaneously. In our analysis, we identified four overarching meanings of space and time in the PPCT: spaces and times of living and dying, spaces and times of chaos and ambiguity, spaces and times of home and hospital, and spaces and times of presence. We note two issues in reading these findings: space and time are fundamentally and experientially interrelated; and the same spaces and processes can be experienced differently depending on the identity of the people in a given space at a given time.

Spaces and times of living and dying

Spaces and times of injury, disease, pain, and suffering

The PPCT works with the sickest of the sick patients in the children's hospital and supports traumatized parents and families. The PPCT space is a virtual space in which team members work across departmental, disease, treatment, and situated borders. It is the severity of the patient's condition or impact on the patient or family's quality of life that defines the space. Also relevant is that the PPCT does not exist as a space until (such time that) the patient's primary hospital physician invites them in. Thus, it is a forbidden space until the moment of entry. Team members describe their patients' and families' situations as being "sad," "unrepaired," and "shocky," and discuss situations that are surreal and in flux.

> [FIELD NOTES FROM TEAM MEETING]: He's a 9-day-old, has a renal dysfunction and a big clot, may be has a clotting disorder,

his kidneys have taken a hit and we're very worried about their recovery. Parents were completely shocky, mom was tearful and not looking at us. You could tell dad wasn't taking in anything.

Spaces and times of treatment and cure

Housed within a major medical center whose central purpose is clinical, the PPCT is clearly located within a space of disease, treatment, cure, and pain. Medical discourse constructs the hospital as a curative space, evident in one mother's explanation as to why her family relocated from Puerto Rico to this hospital—the possibility to cure her daughter's illness exists only in this specific space, and everything else comes second to cure. In fact, the parents quit their jobs and removed their other children from school in order to come to this hospital to try to save their daughter's life.

> "Our doctor [in Puerto Rico] told us that we needed to come here. I have a sister-in-law in [state 1], a sister-in-law in [state 2], and we thought about moving there because we have family and they can help us. But the doctor said no. She said that the doctor my daughter needed was [at this hospital] and this was the place where we needed to go."

Frequently the desperation for a cure is palpable.

> [FIELD NOTES FROM TEAM MEETING]: She's had a bone marrow transplant. They've been flying all over the place trying to find someone to cure her.

Another parent describes different healthcare teams interacting with her daughter as they try to identify the source of her daughter's chronic pain and treat her illness. The language used describes much activity—doing, trying, calling, bringing, and changing.

> "They always explain to us everything that she is going through. Changes in the medication. [They] are going to do this, [they] are going to try that. [They] are going to call the oncologist, but if they see something happening in the kidneys… …they [call] the specialist for that organ. And just like that, they bring more people."

Medical jargon reinforces the clinical aspects of the space, and to parents, it can seem as if they are speaking a foreign language. The following quote is from an interview with another parent:

> "This was very early in _____'s hospitalization. We had one of the cardiologists that came in and he's so smart, but sometimes it, he's just one of those that's so smart that it was hard for us to understand what he was really trying to tell us sometimes."

Crowded spaces and times

While the interprofessional approach can be perceived as facilitative for curing, it can be seen as a hindrance to caring. In interviews, mothers give detailed descriptions of visits from different groups of doctors who crowd and stand but do not acknowledge the personhood of the patient or parent, almost as if personhood is intruding on the clinical space rather than the other way around.

> [INTERVIEW WITH MOTHER]: "Well generally they do their rounds. They come in and sometimes they bring the whole team with them, the nurse practitioner and everything. And sometimes it's like 6:00 A.M. and you're just lying there in bed [trying] to

sleep. And then they just all smile at you and nod their head and you're like, 'Okay?'

Space and time to decide

Within this space of treatment and cure, there is a time to recover, a time to wait, and there is a time to decide—whether or not to discontinue life prolonging care and whether or not to accept what appears to be an inevitable death. Sometimes it takes a long time to get to this decision point. Death is the absence of space and time, yet sometimes, time stretches interminably while waiting for death to come, both for the families and staff. Sometimes the conversation to decide hangs, unvoiced, at the edge of the care-cure line. As one team member said in a team meeting, "they are holding two competing beliefs at the same time, hoping and accepting death at the same time." Deciding to remove life support first requires the removal of one of those competing beliefs. Parents have to choose between "keeping on" and "coming to a point" of decision. In interviews, the nurses tell us they are emotionally drained by not knowing when to "push" parents into a space and time to decide to be "done," and to "stop." Parents are agonized over knowing when it is "time." Once the time to decide to discontinue treatment is reached, there is no going back.

> [FIELD NOTES FROM TEAM MEETING]: DOCTOR: It's the elephant [in the room] no one wants to talk about. No one will bring it up to them. I can't say to Dad, 'you know we're done, don't you?' That's a conversation I have in my head but how do you bring it up?
>
> NURSE: She felt that if he said that he would never leave, if she said that it would never happen.
>
> SOCIAL WORKER: She just needed Dr. ____ to have that conversation and just say it's okay, it's ok to stop. There's always a doctor to say there's something else we can do.

In this case, we suggest that time holds primacy over space, as the PPC space does not become the space to make these difficult decisions until it is deemed to "be time" to make the decision.

A space and time to die

The PPCT is most definitely a space in which death looms large. Death sometimes arrives too swiftly for parents' ability to come to terms with the prognosis, but sometimes it creeps much too slowly to bear. Prognosticating about the approach of the end of life, and the pace at which it may come, is something the PPCT does. The number of months, weeks, days, hours, and minutes to death is predicted, estimated, reported, and acted upon by a myriad of medical professionals within and outside the PPCT. Death is both fast and slow at the same time and waiting is interminable, but members of the PPCT do not presume to know the exact time that death will come. They have stories of cases in which a person "hung on" longer than expected, or "let go" or "went more quickly" than had been expected. They may account for such variances using biological, relational, or spiritual explanations. Being the timekeeper of death changes the nature of the time and space in which these encounters take place, in myriad hegemonic and relational ways.

> [FIELD NOTES FROM TEAM MEETING]:

> SOCIAL WORKER: Got consulted for end-of-life support. The family thought he took forever to die.
>
> DOCTOR: It took over a week. They wanted us to speed it up, we couldn't.

To families experiencing the PPCT space, the future is here, now, and it is unimaginable. At the same time, the future can lie down the road in wait with presumed bad intent for those who approach.

> [INTERVIEW WITH MOTHER]: "It's, (long pause) Yeah, yeah, um…a really hard realization that I know that in the back of my mind I've known that this is how the disease progresses and this is what was in our future but (long pause) you know, living it is a different thing. And now it's here."

Spaces and times of chaos and ambiguity

Sudden spaces and times

No parent plans to end up in the Emergency Department, or the PICU, or in the NICU with their newborn baby. Nothing prepares a parent to hear their child has a life limiting prognosis. No training teaches parents how to navigate and negotiate any healthcare system, especially one as complex as an interdisciplinary pediatric hospital. A parent's first foray into the PPCT space is one of confusion and uncertainty, and the experience is disorienting. The initiation is sudden and shocking. For this mother, this moment occurred after waking up from her emergency C-section:

> "So when I woke up I'm just looking around [and] I see all these lights and people. I say, 'Where are my kids? Are they alright? Are they okay?' And [the doctors] are asking me, 'Are you alright?' I said, 'I'm fine! Are my babies okay?' They told me that they were premature but they were going to be okay. [Baby One], she is fine. Everything is fine with her. But [Baby Two], she has some brain issues. She is having two types of bleeding in her brain. She has a [level three brain bleed] on the left side, I think, and she has a [level four brain bleed] on the right side. And she has a large amount of fluid right in the middle of all of that."

This mother's story is similar to that of many other mothers under the care of the PPCT, where a person enters into this space and finds her child bound to a physician's care. As another mother explains, "We never knew she had a heart problem. We never saw it in the ultrasound. So we didn't find that out until she got [to the hospital]."

However, it is not necessary for a diagnosis to occur at birth for a patient to become a member of this space, and have a disorienting reaction to the bad news. A teen-aged patient explained she was admitted to the hospital when she experienced flu-like symptoms and severe fatigue. Despite the severity of her symptoms, it wasn't until physicians at the hospital said, "we need to take a bone marrow sample" (a diagnostic test to identify Leukemia and certain other types of cancers, among other conditions) she felt the threat of a serious diagnosis.

These moments of entry to the healthcare space are important, not just because they are the point where the patient receives a diagnosis, but because they are the point of a dramatic shift in the hospital space, where individuals are suddenly transformed from temporary visitors to semi-permanent members, captives, even. With the utterance of

certain words—brain bleed, heart problem, leukemia—the hospital suddenly becomes the lived space in which patients and families (re)negotiate their understanding of who they are. The diagnosis discursively gives shape to the social structure of pediatric palliative healthcare and the subject positions (Foucault, 1972) of patient, parent, and physician that are lived out in this space.

Interrupted space and time

The sudden diagnosis of a critical or life-threatening illness is an interruption of the family's story, and the child's own story. For parents of a newborn baby, receiving news of such an illness is a particularly poignant interruption in what they imagine for him or her, and what they imagine the days and weeks will be like as a family. Within the trajectory of a serious illness, even the slow recuperation of a child with a disability can be interrupted with a new diagnosis or health crisis. Family plans and dreams are interrupted and cancelled; time is never in a parent's control.

[INTERVIEW WITH MOTHER]:

MOTHER: With her new diagnosis everything that happened with her, I mean we actually were readmitted for IV hydration. We came in on Friday and were supposed to go home on Tuesday.
    INTERVIEWER: Wow. So it's been 2 months and you thought it was going to be maybe a couple days.
    MOTHER: She was not tolerating her tube feedings so they switched her from a G to a G-J. Um, underwent anesthesia and everything has spiraled down-hill since.
    INTERVIEWER: Oh my gosh. Have they ever told you how long she's going to be in?
    MOTHER: About 3 more weeks.
    INTERVIEWER: At what point did you know that it was going to be a long-term thing? Right away?
    MOTHER: Oh no. Um, after the anesthesia they said that we would be here until Wednesday, and then it was Thursday, and then they just stop telling us when it was going to be.

To some families under the PPCT's care, time is timeless:

[INTERVIEW WITH SOCIAL WORKER]: We have these rugs in some of the elevators that say 'Have a pleasant Wednesday' or whatever day it is and I walked onto the elevator with one family and they said, 'Oh, it's Wednesday.' I never thought about the value of those rugs before until that family said that. They said 'We've been here for so long. We have no idea what day it is. We're not even sure it's today.'

A space and time of uncertainty

In the PPCT space, diagnoses are ambiguous and prognoses are stated in terms of probability rather than certainty. Side effects are unexpected. In unfamiliar surroundings, hearing unfamiliar jargon, facing an unfamiliar role of patient, life of the PPCT patient and family is one of unanswered questions and confusion. These field notes from a team meeting tell a story of the fear and uncertainty of a very young child who is in the hospital with serious injuries from an automobile accident in which her parents were also severely injured.

[FIELD NOTES FROM TEAM MEETING]: Now there's a big concern they still haven't really talked to her, nobody has told her what's going on with her body. She's anxious and scared.

MUSIC THERAPIST: When I had my session with her, there was some brain injury behavior. I wonder if she's processing things normally. It made me a little concerned if we were to tell her things if she could express what she needs to express.

DOCTOR: She has a subdural hematoma. Maybe she has some ICU delirium, but if you didn't know what's going on, if your body wouldn't do what you wanted it to do and you didn't know what was going on…

Possibly one of the worst aspects of the uncertainty inherent in the PPCT space is the lack of understanding of what's happening inside one's own, or one's child's, body. Not knowing what illness or injury they have, not knowing how to make it better, and not even knowing how to feel about it is an excruciating experience.

[INTERVIEW WITH MOTHER]:
INTERVIEWER: "How is she doing now?"

MOTHER: "She's awake. She's different than she was and we're trying to figure out what that is, if that's all the thrashing around and stuff like that if that's a neurological thing or if she's in pain and we can't figure out what the pain is. So, it's difficult that she can't talk to figure out what's going on with her. She has those very expressive eyes, but it's just learning what those signals are."

Some families wonder if life will ever be the same, while others anticipate a future very different from what came before. Interestingly, the uncertainty provides them with a liminal space in which they can discursively reframe the meaning of the experience—in the absence of meaning, the parents can fill in the blanks for themselves.

[FIELD NOTES FROM TEAM MEETING]: She said [she's] looking forward to [the transplant surgery] next week when we get the organ [for transplant]. She's come to believe the [wait for the transplant] time will be short. She's taking evidence of his decline to reframe it to something hopeful, more comfortable. I suspect a lot hangs on that. There are so many unknowns. It is a scary thing. The waiting and not knowing. Lack of control.

With a seriously ill child in the family, the future is not only uncertain; it is frequently unthinkable. Simple temporal markers like birthdays and holidays can be turned into triggers of crisis, sadness, hopelessness, and fear. In the following case taken from field notes of a team meeting, the parents wish they were at the end of the PPCT journey, but are instead at the "end of their rope." Time is "spinning" and they can't catch it. They are "waiting for the drop"—afraid of what is ahead of them. For other families, time is "on hold" while they are waiting to "get through" this crisis. In the PPCT, time toward the future moves slowly, sometimes imperceptibly, as decisions, situations, life itself, hinge on test results and a host of unknowns.

[FIELD NOTES FROM TEAM MEETING]:

SOCIAL WORKER: He is a little less sedated. So he's restless. That's hard for parents to watch. They are really pinning their hopes on him getting a heart by Dad's birthday. What happens if

he doesn't get it by then? They are feeling like they're at the end of their rope. They're tired.

CHAPLAIN: Mom and Dad have good images. Mom is at the top of a roller coaster. She's clicked her way up, she's at the top. Dad's on a merry go round. It's spinning. It has to stop before he can get on. They're both in the in-between thing.

Spaces and times of impotence

Being unable to "fix" one's child's problems is a horrifyingly powerless feeling for a parent. Witnessing agitation, pain, and suffering without being able to alleviate it is a difficult struggle for families and for PPCT staff.

[FIELD NOTES FROM TEAM MEETING]: MUSIC THERAPIST: The nursing staff is struggling. It's a very fine line in keeping him comfortable but not overly awake. He's grabby. He'll grab at things. He's got a restraint on his hand. I've been doing soothing music for relaxation. Yesterday it made him more restless. He asked me to stop. He's coughing and gagging. He gets really upset. The parents are always trying to settle him down, help him calm. But he can't be fully sedated. It wouldn't be good for him. He doesn't look comfortable much of the time. It's hard to keep him at that edge. He's really awake. He doesn't sleep much. He's in and out. He'll sleep for short bursts. Which I'm sure it is exhausting for the parents. He was grimacing yesterday, looked like he was going to cry. He looked like he felt miserable.

Spaces and times of home and hospital

Permeable boundaries between home and hospital

Hospitals leak into homes and homes leak into hospitals. For PPCT patients, the boundaries between home and hospital are permeable—space spills over. One of the instances of permeability is in the concept of home. Certainly, a hospital is not a home. However, as families with very sick children move in to the child's hospital room, this room becomes their home-away-from-home. Personalized toys and pictures from home decorate the room. Further adding to the blurring of boundaries, some rooms are designated as family rooms—rooms for family members to sleep overnight close to their ill children but not in the same room— much as a mom and dad might sleep in their bedroom down the hall from their child. Older children who are in-and-out of the hospital with chronic and long-term disorders frequently keep the same room when they return. If they are physically able, they can play video and other games to maintain a semblance of childhood.

By the same token, home is not the hospital. However, with a sick child at home, sometimes it must be hard to distinguish between them. Children are sent home with critical medical devices—tracheostomy tubes, gastrointestinal tubes, and dialysis machines, and parents are trained on their proper use before discharge. Life with a seriously ill child at home is a different world. There is a "new normal," transformed into new markers and boundaries. In this clinical space, healthcare providers serve the important function of normalizing the patient's condition, but normal inevitably involves providing clinical care at home. Understanding what a diagnosis means beyond the immediate hospital space is increasingly important as medical advancements in life-prolonging technologies expand the spatial boundaries of healthcare beyond the hospital. Through the utilization of long-term treatments such as tracheostomies and gastrostomy tubes, a patient's illness persists, requiring care outside of the hospital. The

mother in the following interview quote discusses this when talking about her fears of leaving the hospital.

"He's holding steady right now. He may go home, [but] we're going home with all kinds of new equipment and this is a totally new experience… …He hasn't really had any problems with [his disease]. He's in a wheelchair but we've lived quote unquote, a 'normal life.' And this is just, for me especially, knowing that we're going to be taking all this equipment home and everything and our routine is going to totally change, it's really hitting home. Life is going to be like this now and we have to think about this all the time now."

In this case, the healthcare space moves with them from hospital to home, and the mother realizes everything will be different at home from what it was at a different point in time. The child returns home, still a patient.

Spaces and times of relationship or separation

There is also a distinction between family and strangers, but this distinction is blurred in the hospital setting. Children are taught to not talk to strangers, for instance, and to not allow strangers to remove their clothing or touch their bodies. Family secrets remain private, and stoicism is the publicly presented face. In the hospital, people who are initially strangers see, touch, and hear many otherwise private things. Families can become estranged as medical crises strain emotions and flare tempers, but sometimes crisis brings estranged families together. Nurses become like family as they care, comfort, and grieve for their patients and with their families. Acts of caring as a family member would create a space that blurs the boundaries between the patients, families, and healthcare providers. This mother describes her interactions with the nurses who perform the role of surrogate mothers.

"There are some ladies [that] have been [like my baby's] step-moms. They've been with her from day one. They know all about her. The reason that they have become my good friends is because they take very good care of my daughter. They know what she likes, what she doesn't like. You know, how a mom should be."

In the too-frequent and tragic circumstance of a child being removed from a parent's care because of abuse or neglect, or when a child is in the hospital as a result of a parent's abuse or neglect, the hospital staff becomes very protective; almost parental, toward the child.

[FIELD NOTES FROM TEAM MEETING]: Mom is insisting on taking baby home with trach vent and G-tube but seems very nonchalant when nurse tells her everything that is involved with the child's care. And she lives in a part of the state that will not be able to provide her with around the clock nursing care. They are afraid Mom's decision-making is clouded by charges Dad could face. They wonder if this is appropriate to bring this up to Mom.

If the child is under the legal guardianship of the state or foster care, the parent's parental rights may be terminated and he/she may be unable to see the child as she/he is dying. In the following case, the mother had limited ability to see her baby while she was in the hospital and the nurse filled in for the mother at the moment of death.

As ___ the baby was in the hospital, the mother could occasionally see her baby, she couldn't at all when she was in the foster home… . There are issues with a history of substance abuse, fighting reality; fighting the final decisions. Mom wasn't there

when she died; she died with a nurse holding her lovingly when she died in the hospital.

Spaces and times of presence

Looking to the future

One of the ways the PPCT helps patients and families move through a chaotic present into their uncertain future, is by helping them identify what's ultimately important to them. Sometimes these are big picture desires, but other times PPCT members support families to find the small things which would make their situation more bearable now. When stresses are high, the time-horizon becomes very short. Many patients and families who are followed by the PPCT say they're taking things a day at a time, an hour at a time, or even a minute at a time. Sometimes the future seems interminable, but other times the parents wish for more time. Sometimes the future goals involve the unthinkable—preparing a funeral for one's child, but other times the future goals involve a renegotiation of the concept of "normalcy" in the present, involving clinical spaces and ongoing treatment. Members of the PPCT help patients and families navigate their futures through discussions with patients to learn about their hopes and expectations, their concerns or fears, to find out what questions they have—what puzzle pieces they might be searching for—and to find out what would or would not seem to them to be an acceptable quality of life for the future. These conversations are important because they help provide clarity. Movement toward a future goal may mean simply eating something, getting some sleep, or making one phone call. Sometimes it involves letting children be children. The chaplain relays a story of their patient elevators—the voice announcing floors is the voice of young patients. "It changes the space of the elevator," he says.

Other times moving into the future requires making decisions. While the PPCT is well equipped to have conversations with patients and families about important subjects, such as what would or would not be an acceptable quality of life, movement on these big-picture issues happens in its own time. Sometimes the patient or family can take their time, or they may find themselves at a point at which a decision must be made.

[FIELD NOTES FROM TEAM MEETING]: CHAPLAIN: She wants more time, she'll come to a decision if she has more time and space. It seems like she was pushing it down the road. She may be getting overwhelmed by all the input. She's clearly articulated that living like this permanently would not fit. On the flip side, all we have is more time.

There are different levels on which there is movement toward the future. Members of the PPCT create a relational space in which patients and families voice their hopes and expectations for the future. This space might occur through conversational moments; these are safe spaces in which they are suddenly able to imagine a desirable future, able to move into another space—negotiable and future-oriented.

Focusing on the present

To find this future space, they have to step back into their past because in order to imagine their future, all they have is their own experiences from which to draw. Finally, in that last moment, moving into the future requires turning their attention to the present moment—here and now. In order to take a step forward, we have to be able to balance in the present moment before we step into midair. Patients and families live moment to moment, hour to hour, day to day, as they fit the puzzle pieces of their lives together. This takes us back to Kairos—that opening, that moment which opens to allow them to step into time for a moment of clarity, enough time to figure out where they are and where they are going. Sometimes that requires dealing with the present—what they need right now, to get them through the day. Other times it requires acknowledging they do not have more time; acknowledging the moment is now, this is the moment that's important or relevant or necessary. Sometimes families have to "pull themselves together" so they can make the necessary decisions. Of course, then, in making themselves ready to decide, they have to be willing to shift within, to, in essence, become a different person than they were the moment before. It's a different reality moment by moment and what controls that reality is what's happening in the medical space. These are not moments that stand still. In fact, focusing on one thing—versus another—in the present changes the space.

While healthcare spaces remain primarily biomedical clinical spaces focusing on disease and physical cures, there are times when the PPCT transforms this space into smooth spaces—heterotopia—with multiple meanings. Curing is always the backdrop to the hospital space, but the presence of the PPCT adds layers of relating, living, and dying to the space. Time stands still in these moments, even as the future looms menacingly large. During these times, the PPCT space holds a present time orientation as PPCT team members are, literally, present with their patients and families as they help the families maintain their focus in the present moment. Sometimes, remembering the past—what the child was like before he/she got sick—distresses the families; and thoughts about the future can be hurtful as well. PPCT staff help the families accept where they are and what is happening, and support them in their current situation.

[INTERVIEW WITH CHAPLAIN]: I meet people where they are. Make myself available to journey alongside them. The vast majority accept the offer, and allow me to do so. That ends up taking a variety of different shapes. The relationships unfold in different ways. Once they realize that I'm respectful of who they are and their needs, boundaries, expectations and so forth. My focus is certainly helping people to adapt. Helping children and their families to adapt to what they're experiencing. Whether it be in the middle of their health crisis, or their chronic illness, or whatever it is that they're facing and whatever that involves.

Conclusion

Foucault's (1973) analysis of healthcare spaces distinguishes between places of disease and spaces of relationships between the body, the self, and the experience. Pediatric palliative care represents a uniquely diverse space and time—heterotopia and heterokairoi—which allows notions of care and cure, life and death, hopelessness and hope, separation and connection, to co-exist and overlap. In the hospital, sometimes time seems to stand still, other times it moves forward too quickly,

yet other times it is invisible and forgotten. In the end, the PPCT offers a presence to the patients and families because the present is all they have.

Space and time in the PPCT space is multilayered—truly heterotopia and heterokairoi—offering more than one space at a time, as one moment moves to the next moment, and the only way to move forward is to pay attention to multiple moments, yet pausing in that one present moment. Heterotopias and heterokairoi imply the present is both simple and complex at the same time. The PPC team members are with patients and families in the present moment, sometimes holding their hand as they lead them through the chaos, other times sitting with them in silence as chaos reigns, in all moments helping the families discern when is the right time to decide and do what needs to be done. In all of these moments, the PPC team lets themselves, patients, and families be present with what and where they are. Sometimes, they let time stand still; other times they must move time forward. Presence, then, is a space within the multilayered confusing space in the hospital, and it is experienced in moments in which patients and families are more in tune with themselves, reality, the world, God, others. Being the parent of a seriously or terminally ill child is excruciating as one faces physical, emotional, and spiritual pain; a rupture of his/her personal, familial, and cultural narrative; and agonizing life and death uncertainties on an hourly basis. In a world in which a child's future lifespan is counted and measured in hours and days, it is a struggle to know when to push forward and when to let go. Space and time within the PPCT raises many philosophically and morally difficult questions. There is a time to move from cure to care; a time to move from fighting death to accepting death; a time to move from living to dying; and a time to move decisions from continuing care to preparing for death. The PPCT is also a space and time of uncertainty and ambiguity—certainty is interrupted by uncertainty, which morphs into the dismay of a new certainty. In the PPCT space, the lines between home and hospital, family and caregivers, blur. Chaos and agency vie for control, and parents (and staff) face the agonizing reality of impotence in the face of a loved one's pain and suffering. Connections and separations come and go, and—through it all—team members, patients, and families find some moments of meaning, comfort, and hope.

The hospital constructs an institutional space and time that is linear and hierarchical – a linearity of time and striation of space, as experienced by the institution and its representatives and imposed on its patients and families. The hospital institution has a time-bias; founded on tenure and structure and long-term trajectories and, ultimately, attempts at immortality and permanence. The PPCT, however, is in its own space and time. It is a smooth space, ever changing and in flux; it is a liminal space and time, lingering between the spaces and times to live and die; it has a space bias as it redefines every space in which it enters. The PPCT space is nomadic; it infiltrates–it enters spaces across all corners, rooms, and hallways of the hospital. In essence, the PPCT moves into a territory and, once there, changes the space. Sometimes the space becomes less stressful, more comforting. Other times, the space becomes grief-filled as the PPCT presence reinforces a diagnosis families and patients would rather deny. The PPCT's message overshadows the linearity of time, understanding that for many of its young patients, there is no time left. It is an immediate and present-moment time, a space for presence, a space for lengthening time by lengthening the present.

We think we are born into a fixed place and time but in reality, space and time are smooth, continually changing, evolving, and interacting. Just as our spaces begin to settle in, time shifts. The limits of mortality overshadow our previously anticipated future, as the patterns of our lives are interrupted by tragedy and decay. The PPCT navigates space and time in the midst of death, helping patients hold on to that precarious balance between the two. At the appropriate time, they variously construct for their patients, families, and themselves, spaces for treating, curing, playing, being, and dying. When the time is appropriate, the PPCT lets children and families linger in childhood as long as possible, by configuring the space to facilitate play, relationships, and humanness. At the same time, it gives more than a passing nod to the future time about to be lost through activities such as legacy building and memory making. Finally, when it is time, the PPCT provides a safe space to die and grieve. It is this interplay of space and time that makes the PPCT space within the hospital space a space of timelessness, time standing still in the midst of the chaos, pain, and grief.

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