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# Child's Play: The Role of Play in Mitigating the Fear of Death Among Pediatric Palliative Care Team Patients, Families, and Caregivers

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## ABSTRACT

Terror Management Theory (TMT), derived from Ernest Becker's *The Denial of Death* (1974), maintains that humans are motivated by the desire to overcome our fear of death by constructing meaning and significance in our lives in various ways, including making light of our mortality. In this paper, we examine the role of play as seriously ill children involved with a hospital-based palliative care team live out what may be the remainder of their lives. We question the function that play has, if any, in mitigating the fear of death among dying children and their caregivers. We explore formal and informal manners of therapeutic play among children and adults occurring in moments of terrible stress, pain, and the looming threat of death. We draw on playful representations of death from popular culture and from extended field research conducted with a pediatric palliative care team in a large regional children's hospital caring for seriously ill children and their families, as patients, families, and caretakers struggle to make sense of their suffering, fear and loss.

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For children and careworn adults in search of a welcome reminder that anything is possible, play is an essential mechanism to explore the plastic intersection of bodies, desires, consciousness, and the material world (see Bratton, Ray, Rhine, & Jones, 2005; Landreth, 2012; Malchiodi, 2006). Play can even deliver us from fear and pain when we are threatened by death and overwhelmed by grief. Play falls under the same social category as fantasy, or pretense, in which we navigate the tension between real and not-real (Bateson, 1956). Fantasy, says Laing (1961), is a unique mode of experience, as we conjure up imaginary worlds and immerse ourselves in personal fantasies. Groups construct fantasy worlds as well, claims Laing (1961), especially when engaged in untenable situations, and while groups sometimes collude to deceive themselves or others that their fantasies are reality, there is no such collusion among seriously ill children save for, perhaps, extended hopes for miraculous cures. In times of play, all players know that these playful fantasies are temporary and fleeting. Play, whether by children or by adults, solitary or

communal, mediated or imagined, sanctioned or sandlot, grants players, in glad moments of temporary respite, the power to remake and redeem the world. Play leads to greater social and emotional growth in children, gives children the opportunity to develop creativity and imagination, and helps children develop physically, cognitively, and emotionally (Milteer & Ginsburg, 2012). Through play, Bretherton (1989) notes, children “deliberately blur the boundary between reality and pretense” (p. 399), and various types of play serve important socialization functions for children (Denzin, 2010); for instance, children play make-believe house, doctor, fireman, mommy, daddy, to try on adult roles, social hierarchies, and emotional functioning (Bretherton, 1989).

In this paper, part of a larger ethnographic project examining the juxtaposition of popular culture and pediatric palliative care, we interrogate the role of play as terminally and seriously ill children live out the potentially short time that remains for them and their families. In addition, we question the function that play has, if any, in mitigating the fear of death among dying children and their caregivers. We explore formal and informal manners of therapeutic play among children and adults occurring in moments of terrible stress, pain, and the looming threat of personal extinction. We draw examples from cultural realms and from extended field research conducted in conjunction with a Pediatric Palliative Care Team caring for seriously ill children and their families, in a large regional children’s hospital, as patients, families, and caretakers struggle to make sense of their suffering, fear and loss. The ethnographic data results from over 200 hours in the field via multiple methods of data collection over 10 months of fieldwork, including detailed field notes of 30 weekly rounds meetings with team members and 28 other interactions and field visits with and between Pediatric Palliative Care Team (PPCT) members, patients, and families. We conducted 7 semistructured interviews and one focus group with team members; we interviewed 8 parents of pediatric patients and one patient over 12 years old. Patients of the PPCT ranged in age from newborn to teenage; their diagnoses ranged from congenital disorders, birth traumas, and cancer, to brain injuries, automobile accidents, and severe burns. We also studied the PPCT team members: team leader, chaplain, multiple nurses, music therapist, patient and family liaison, physician, and social worker. All patients, families, and team members who were observed and interviewed provided informed consent, and the pediatric patients we interviewed provided assent. This study was conducted under the oversight of both the hospital and university IRBs.

## **Terror management theory**

This paper is informed by Terror Management Theory (TMT; Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyon, 1989), which is based on Ernest

Becker (1973)'s detailed investigation into the human desire to overcome our uniform fear of death by constructing personal bulwarks of meaning and significance that allow us to effectively deny the power of death to erase us all. A social psychology theory, TMT has been used to explain human cognition and motivation in the face of mortality salience, or awareness of death. Research into TMT has discovered relationships between mortality salience and a wide range of identity and motivational factors: For example, the meaning of life (Taubman-Ben-Ari, 2011), cultural validation (Pyszczynski, Greenberg, & Solomon, 1999; Taubman-Ben-Ari, 2011), death-denying thoughts (Pyszczynski et al., 1999), reactions to terrorist threats (Miller & Landau, 2005), reactions to horror films (Sullivan, Greenberg, & Landau, 2009), television programming preferences (Taylor, 2012), functioning in close relationships (Van Tongeren, 2013), and sports team affiliation (Dechesne, Greenberg, Arndt, & Schimel, 2000), among much else. Relevant to this paper specifically, the use of humor has been found to be a defense mechanism against mortality salience (Hackney, 2011; Leese & Koenigseder, 2015). In this paper, we propose to broaden the parameters of Terror Management Theory to encompass ludic-based communication and symbolic ritual as a therapeutic barrier against the early onset of terminal illness, childhood suffering, and the unbearable loss of a child.

### **The illusory nature of play**

In the realm of the PPCT, woe, despair, and doom are palpable vectors scaring the daily routines and topographies of all who find themselves in their care. Here, body snatchers—virulent germs, impossible cancers, and childhood killers—take their full limit of human flesh. Cold machines substitute for one-time reliable organs and autonomic systems that could once be counted on to work unceasingly without fail. Frail, beautiful children are condemned to live Frankenstein's nightmare as body parts are harvested and replaced in difficult, dangerous surgeries that too frequently have unintended outcomes. Ravaged by accidents, intentional acts of cruel violence, and the deadly poisons of chemotherapy and radiation, killing friendly and enemy cells alike, these hospital floors are where childhood ends.

Nevertheless, the PPCT space is alive with all sorts of beguiling, transformative play. Like other dedicated spaces reserved in whole or in part for children (school, rec rooms, day care, the nursery), here, even when routines are ordered by fear, pain, and death, children and their guardians take the time to lose themselves in idle play. The play of PPCT patients is not concerned with exploring the meaning of imminent death. Unlike so many fictional realms that allow children to play with and anticipate the death of the people, creatures, and things they love, as with an endless list of ugly-cry Disney films, *Old Yeller* (1957), *Bambi* (1942), *The Lion King* (1994), and sad, signal children's stories, *The*

*Giving Tree* (1964), *Charlotte's Web* (1952), and *The Velveteen Rabbit* (1922), for example, here, patients and their allies engage in symbolic rituals and theater that serve as reminders of lives conducted outside the hospital walls and a time when bodies were not yet infected, broken, or in the final stages of treatment.

Becker (1973) calls play “creative illusion” (p. 190), referring to the dream worlds and rituals we create to overcome death. Intentionally, as directed by trained therapists and spontaneously, as family and the patients themselves make up games and diversions of their own invention, play allows patients and their families to forget serious illness and terminal prognoses and focus instead on what it means to be fully incarnate in a child's body. For example, the PPCT members provide a 9-year-old suffering from a serious spinal disorder with a Nerf basketball and a net attached to the wall by plastic suction cups. “She's a jock,” they explain, using the title of a skilled player with an able body to eclipse the image of seriously ill child more dead than alive. No matter the havoc disease may wreak on the body, with an orange sponge ball in hand and a bucket to be made, the girl rejoins her best self and scores.

The palliative care social worker talks about “cancer perks,” those benefits their pediatric patients receive that provide some welcome counterbalance to their diagnoses, prognoses, and painful treatments. One legendary perk was footballs signed by the Carolina Panthers on one of their regular visits to the children's hospital.

“Cancer perks, you know, meeting famous people. We have a lot of that kind of stuff for people who are here—the Charlotte Knights come and visit, Sir Purr comes and visits. We have [Ryan] Seacrest Studios [in the lobby of the children's hospital], and a lot of bands are coming to visit. The cast of *Lion King* was here yesterday.”

When celebrities and star athletes call, everyone gets the red-carpet treatment.

The social worker April (all names are pseudonyms) describes a seven-year-old boy with cystic fibrosis as a “cute kid and so sweet. He likes to make new girlfriends.” April flirts with him, toying with the notion that, in some other realm where a healthy boy makes time with his favorites, this flirtatious romance would take place. Playing up romantic attraction serves to create a pipedream, howsoever temporary, that projects the patient and his special friend well beyond hospital space and time. Feigned romance offers an embraceable future when this child, still alive as a young man, no longer consumed by Death, lives on with April as his love interest.

“I hear you're going on a Make a Wish trip!” April says as she pops into Sean's room.

“I'm going to swim with the dolphins,” Sean says shyly, the tips of his ears turning pink.

“You know, I've swam with dolphins,” April says. “I'll have to bring you my pictures of me swimming with dolphins.”

“Cool!” Sean replies.

“In one of the pictures I’m petting a dolphin, and in the other one, I’m kissing a dolphin!”

“Kissing! Gross!”

Sean returns from Florida’s Marine Park with a picture of him kissing a dolphin. “I wonder if we kissed the same dolphin?” he asks April.

She grins and ruffles his hair. “You’re so cute! Am I your girlfriend?”

He fidgets and pulls away, a smile at the corner of his lips giving him away.

## **The communal nature of play**

Just as play benefits us as individuals, providing a fluid stage where we can find release conjuring up absorbing chameleon realities, play also allows us to build virtual communities of collective engagement and fashion powerful bonds with others. Via play, imaginative relief from the workaday world arrives as either a solitary pleasure or shared communion. We immerse our monastic selves in a challenging sudoku, a jumble of Legos, a fidget spinner, a triple-decker novel or long-term craft project that calls us to take up clacking needles, loom, or brush and concentrate our full attention on the complex task at hand. When we dance at the club on Saturday nights, spell out YMCA in full body contortions during the seventh-inning stretch, or line up for the Electric Slide at a grand marital celebration, music urges us to move, registering most forcefully when dance floors, stadiums, and wedding halls are packed cheek-to-cheek and we wiggle and bop as part of a dynamic, writhing mass. Adrift in the kinetic commotion of sound, flesh, and light, dance unfetters the body from the prosaic exercise of deadly, robotic routine. This type of corporeal play brings us to a conscious awareness of the vitality of our own bodies and those of our companions.

This feeling of infectious camaraderie even bridges the gap between health care providers, patients, and families, as the PPCT social worker points out:

“We had one family, the day we got the consult, the dad was wearing a sweatshirt from [my alma mater], so I got all excited. I spent a month while she was in the hospital bonding with the family.”

These sorts of instant foxhole connections are routine on the team. There is always time for small talk with patients. Neither patients nor care providers can stand to remain rigidly fixed on dire discussions of hard treatments and long-shot odds for a better future. Yet, small talk on the floor is more than a communicative lubricant easing everyday encounters with others. Here, small

talk is a communicative transaction that celebrates the little things that carry an enormous charge of positive energy and glad affect when adrift in an endless reservoir of loss and suffering. Bonds forged over university logos and other trivial commonplaces are a welcome reminder that life continues beyond the walls of the institution. When care providers, patients, and their families share affective bonds created over the course of lives, as with favorite sports teams and our beloved alma mater, the spark of connection is palpable.

It may be the case that playful daydreaming is most frequently represented in the iconic figure of the quixotic solitary dreamer cut loose from the world, wholly engrossed in his or her private fantasy, as, for instance, with the animated Dreamworks Studio logo that showcases a drowsy young dreamer nestled in a crescent moon that kicks off each screening of a Steven Spielberg matinee idyll. Nevertheless, despite the more regular depiction of the dreamer as a marooned isolate, it is corporate dreaming that speaks most powerfully to the benefits of fantastic invention. Lennon's "Imagine" (1971) articulates the claims for group play with far greater economy than any scholarly essay, offering a powerful plea for the collective power of dreamers in the memorable chorus. In shared play, we aren't the only ones, as concerted, creative, and harmonious effort vanquishes anomie and we collaboratively summon up something better. To experience the maximal affective charge, certain forms of play require that we find ourselves linked together by an interconnected limbic and nervous system channeling communal passion at full capacity. Play is shared transport for allied troupers.

When a Nerf-ball-playing patient hits nothing but net, everyone in the room joins in a loud, spontaneous cheer. Just as, when the social worker flirts with her young charge, everyone in attendance smiles as part of a loving conspiracy, happy to share in the knowledge that even the sickest among us can relish the coy joy of a libidinal rush. These petite rituals may be momentary evasions of sad destinies, but they also provide the welcome shock of mutual recognition that comes with the shared eruption of ordinary epiphanies. With the exchange of a tossed ball, a shared joke, or a sly wink, play endows all of us with the collective ability to upstage and revolt against institutional decorum, doctor's orders, and the forward progress of implacable disease.

### **The immortalizing nature of play**

For the very sickest children, the PPCT makes exceptions that are not available for children who are expected to survive and carry on with their lives after a short period of care in the hospital. In this fashion, breaking its own rules, and making exceptions for some patients, the institution formally observes the anarchic nostrum that "rules are made to be broken." Older

children can play video games in their rooms for a near-unlimited duration, as no one enforces the kind of strict time limits common to monitored game play at home or school. Hospital staff help a young girl construct a make-believe nail salon in which all visitors receive “manicures.” The music therapist provides drum sets for interested teens and brings every child his or her favorite music. The children can play their own music, sing along, or simply listen to the therapist’s performance.

These playful activities remind children and their families that they may be seriously ill, many are dying, but they remain, at their core, children, still alive and still playful—death is not all that matters. They are kids to the end. Play in the hospital helps create a reassuring preserve for children and their parents, each of whom are scared and stressed, in need of a preserve where they can find relief. PPC team members, allies all, make a constant rhetorical effort to look beyond a patient’s impending death to see the personhood, the child herself, the human being beneath the tubes and machines and medical charts. Dr. Long always asks the parents when she first meets them, “Tell me a little bit about your child. Tell me what she was like before she came into the hospital.” When the parents tell the story of their child before he or she was claimed by disease and the hospital, the child is reincarnated.

In team meetings, providers remind themselves of the childlike nature of their patients. They lead with the personhood and follow with the patienthood:

“He is a 2-week old baby. Cute as can be. Adorable. Curly hair.”

“She’s a sweet little girl. She loves to play with her toys.”

“This 2-year old little girl was born at 24 weeks’ gestation. She is on a trach and vent. After heart surgery, she was running around her playpen, pulling the vent around behind her.”

Parents also remind themselves that their very sick children are, in fact, children first. Their fantasies revolve around practicing life, rather than preparing for death.

“They got a full head of hair,” the mom tells us about her prematurely born twin girls. “They had hair at birth.”

“Is it long enough to put a bow in?” we ask.

“I can put one in, a real teeny one,” she says, “but they’re not ready for that right now. When I’m able to put clothes on them, then I can put little bows in there.”

“What are you looking forward to most, when you take them home?” we ask.

“I’m ready to play with them, do their hair, dress them real nice,” she answers with a smile. “And just love them. I just want to love them.” She pauses and swallows. “I’m just ready for them to come home so I can get in practice with both of them.”



## The demonstrative nature of play

In the children's hospital, too, play can be a diversionary tactic against the unending demands of hospital life and miserable unhappiness that comes with harsh side effects and brutal illnesses. Here, even the very young grow world-weary and tired of their captivity. Play is a bolster against the *weltschmerz* that accompanies lengthy therapeutic residence:

The doctor reviews the next case. "This is a four-year-old, here for a bone marrow transplant. He's starting to have complications with his chemotherapy. He's not a happy camper." She looks around the room. "He's really cute, but does not like to interact with people."

The music therapist interjects. "I'll come in with a peace offering. I'll pop in and ask him, 'Want to hit on a drum?'"

The nurse laughs. "That will give him an outlet."

The music therapist's live music repertoire is diverse: folk, classical, opera, bluegrass, gospel, pop, rock, and rap. If the child asks for it, she can play it. By using familiar music, holding the child's hand to enable her or him to play the instruments and encouraging the child to vocalize as she sings, she bridges home and hospital and, frequently, helps the child, at least temporarily, channel pain and sadness into an embodied experience that is not connected with treatments or the usual smorgasbord of invasive therapies. "Music," she says, "is not threatening," as the child bangs his drum, sways with the music, and plays along.

Play spirits captives tethered by IVs and ventilators out of their immediate surroundings into imaginative acts of radical decontextualization. The walls will tumble; but, in turn, play entails the fabrication of a more desirable alternative to take the place of the tedious confines that constitute the concrete purgatory of hospital routine, ceaseless pain, and looming death. In this regard, play is a form of transport that carries the players away. In other arenas, enthusiastic players are often cautioned not to get carried away, as someone could get hurt, but here, the exact opposite is true.

## The humanizing nature of play

Among the most important communities that coalesce in and through play are charmed coalitions comprised of children and their adult guardians. The ultimate purpose of such couplings may be to prepare the young for their future roles, but shared play is one of the primary exchanges enabling children and adults to enter into one another's worlds as collaborative equals. Play builds familial bonds (Milteer & Ginsburg, 2012). In addition to providing an occasion for democratic nonconformity and rule breaking, think of what happens when our kids dress up for Halloween and we shepherd them from

house to house calling on strangers to pay sweet tribute or else: Play bonds caregivers and children. As a nurturing best practice, we expect able and committed mothers, fathers, and loving attendants to play an instructional role with responsive youngsters. If they are to be worthy of the title, caregivers for children must step down from the lofty heights from which children are often regarded and enter the carnival of play on hands and knees as equals with their tiny, squealing charges. On this ideal ground, the vile command *no* is never voiced; in this judgement-free zone, all petitions are successfully heard and relationships of enduring strength are forged. Here too, the reasons why children must play are made manifest; early play strengthens the formative ability to think and act creatively. If the serious play of more mature and able dreamers can rework the world with muscular aplomb, it is because children accessed and practiced their model powers early on in development. And, when play is conducted absent any commitment to the future, as with kids whose time left alive is counted in days or hours, play is its own reward for children who forget their place and for care providers who can also lose themselves in a make-believe moment that is richer and more enduring than the abject reality of place and condition that has been momentarily superseded. Escape is traditionally condemned as the vacant pursuit of pleasure, but here escape carries the connotations we apply when the unjustly condemned make their way to freedom.

And, while cooperative play pays unique benefits to coalitions conjoined in make-believe, there are powerful individual payoffs as well. Whatever woeful mistakes and shameful missteps have tainted previous actions in the disparate worlds of our everyday lives, in the realm of play each of us is recast. Recall, for instance, the marvelous goodbye in *The Godfather* (1972) when Vito Corleone dies the perfect death playing a shambling, harmless ogre in a sun-dappled California garden. Scant seconds before the evil Don is felled by a bad heart or other worn-out organ, the Godfather shares a Hallmark exchange with his toddling grandson as they join together in the favorite game of almost any plucky child: Monster. One of fiction's most diabolical characters finally gets what's coming and our most salient memory of the legendary puppet master is that of a playful patriarch who loved children well. This is a miracle of transubstantiation as a foul man of great and total evil is remade and departs the stage as everyone's Pop Pop.

Drew is a 12-year-old boy who is in the hospital for surgery related to a congenital disorder. He is nonverbal but seems to be in pain when Susie, the music therapist, comes in to see him to, as she puts it, "normalize the environment." And, while those words might seem impossibly stilted, therapeutic claptrap wholly unsuited to the plight of Drew and his family, Susie is an able conductor who knows the score.

"What kind of music do you like?" Susie asks Drew.

“He likes gospel and bluegrass. And country.” His mom answers for him.

Susie reaches into her music cart and begins pulling out instruments. Drew smiles and raises his head. Susie hands him a small drum.

“Would you like to play the drum?” she asks. She gently puts her hand over Drew’s and guides him to lightly tap. They do that for a few minutes. She reaches back in her cart and pulls out a guitar.

Drew beams at her, grinning from ear to ear. He sits straight up in his bed.

“What should I sing?” she asks. “How about ‘I’ll Fly Away?’”

Drew smiles as she begins to strum the chords to the gospel song. She begins singing and he rocks his body in accompaniment, joining in with vocalizations.

I’ll fly away, oh glory, I’ll fly away.

In the morning when I die, hallelujah by and by,

I’ll fly away.

Susie places the drum in Drew’s lap and his mom helps him tap along to the song, the three of them singing together, Drew becoming noticeably more jovial and good-humored, flying away in his mind even as his body is bound to the bed.

As we’ve discussed, play is a means of escape from pain and fear, as death and suffering are cast from consciousness. Playing music, for instance, creates a safe space for sick children, as melody and rhythm and the energy mustered up to sing and play let the body and mind transcend enervating pain and illness. Sometimes, however, humanizing transcendence happens not by ignoring death or denying the claim death has upon the living, but rather calling a halt to the fight and finding release in what is to come: a sad, painful descent that closes with a child’s untimely end.

Play is not a con where strong desires and wayward fantasies lead us astray. Play is not aligned with false consciousness, bad faith, or other critical terms that denote a disastrous combination of flawed judgement and self-deception. Unlike a con, where so-called “victims” are preyed upon by able frauds, in play everyone knows the game is rigged. Players can easily slip in and out of the special ground we designate for play and play can inspire us to be at our most creative and resilient on and off the pitch. Like the Danse Macabre, we know how this song will end. And when Drew finds a moment of solace playing “I’ll Fly Away” with his mother and therapist, it is likely that, for a boy raised in the faith who loves the promise of gospel music, he knows just where he’s going.

## The humorous nature of play

Some heartbreaks and misfortunes are too hard to address head on, too tragic to face squarely or directly; these situations call for the sideways, gimlet glance of black humor.

In looking askance at the worst, play sometimes takes on the specific form of a beleaguered and combative humorous response. Most early philosophers believed joking to be something that should be avoided—Plato said humor was an irrational emotion. Today, most scholars and psychologists claim humor is an adaptive defense mechanism that allows the beleaguered to cope with difficult situations (see, for instance, Fox, 2016; Mirivel, 2014).

Gallows or black humor makes light of death and helps health care providers and others who work with dead bodies cope with the stress of their jobs, and those who are dying cope with the stress of their failing condition. Frankl (1959/2006) observed the “grim sense of humor” (p. 16) that prisoners in Nazi concentration camps had, one of the many ways they maintained “the last of the human freedoms—to choose one’s attitude in any given set of circumstances” (p. 66). While not equivalent spheres, hospital wards for the terminally ill and concentration camps are places where finding any measure of hope requires special reserves of agency. Black humor becomes, then, a protest that allows us to offer the honest affirmation that we are, indeed, up against an unyielding enemy but, no matter how bad things are going, with hope long since abandoned, we mock our doom.

Laughter and ironic joking is a way of dealing with our awareness of mortality (Becker, 1973) by providing us with a sense of control over our reactions to death, even though we can’t control death itself (Hackney, 2011). Just as play, too, helps children overcome adversity, improves resilience, and lessens depression and anxiety (Burgdorf, Colechio, Stanton, & Panksepp, 2017; Milteer & Ginsburg, 2012), so do many types of positive emotion (Lyubomirsky, King, & Diener, 2005; Philippe, Lecours, & Beaulieu-Pelletier, 2008) and positive communication (Davis, Dollard, & Vergon, 2009; Davis, Mayo, Picora, & Winberley, 2012). In fact, while all types of play are essential for children to develop socially, emotionally, cognitively, and physically (Miltier & Ginsburg, 2012), at the corporeal level, laughter and other manifestations of positive emotions cause desirable chemical changes in our bodies that reduce stress hormones and boost the immune system (Brod, Rattazzi, Piras, & D’Acquisto, 2014). No matter how we elect to operationalize play and humor, people feel better, cognitively and physically, when they make light.

With no hope and under impossible pressure, the joke is also on the jesters who dare to poke fun. The nurse says, “We’re walking on eggshells. We’re told not to mention end-of-life care to these parents. I come to work to help this child die. We’re trying to do the best we can. We’re giving 100%, and in the futile cases, it’s draining.”

I nod sympathetically. “What do you do to take care of yourself?” I ask.

She responds quickly. “Make inappropriate jokes.”

Another nurse chimes in, “What uplifts everyone is when we get an update that’s not a funeral arrangement after the child is discharged.”

Such moments are not confined only to knowing, jaded experts who have seen it all. Patients too can find humor an acid balm when they can sink no lower. A teenage patient with leukemia uses gallows humor as a face-saving device in the brave attempt to overcome the social embarrassment of her treatments: “It was really hard at first to do all the therapy and with my chemo going on, sometimes it’s like, gotta bring a puke bucket with me” (laughing).

Thus, black humor is efficacious when more tempered instances of play fail to call up nurturing fantasies of health, hope, or a miraculous return home. Black humor is the last vestige of play, the last life ring in reach to buoy spirits in situations that are increasingly hopeless, a final, hapless attempt to play when “it’s not dark yet, but it’s getting there” (Dylan, 1997).

### **The limited nature of play**

In the dialectical union of life and death, we understand that death only holds meaning with reference to life, and vice versa—life’s significance hinges on the foreknowledge of our death. Everyday activities become sanctified when contrasted with their absence. Thus, a Thanksgiving feast is exalted to greater heights than usual when a family brings dinner to the ward when a son is unable to be discharged from the hospital for the holiday. For the family, this meal feels akin to taking communion as bread is broken and shared. Never again will turkey and the trimmings carry such significance. Somewhat different in tone from the usual anarchic fun we consider play, this performance marks the last time all the family will gather together to enact their holiday roles in one another’s company. The ritual will be repeated again and again in the future, but this run is coming to a close.

Play functions like a demotic version of Negation. Negation, as developed by Theodor Adorno and Max Horkheimer of The Frankfurt School, refers to the ability of the highly cultured to conceive of worlds other than our present after time spent in deep contemplation with uncompromising works of abstruse literature and other High Modernist productions (1987/2007). In this rarefied pursuit, cultivated aesthetes parse complex works of forbidding difficulty as they ruthlessly interrogate the failure of traditional arts and settled aesthetic norms to lead ordinary folk to recognize their compromised state in a broken, irredeemable world. In contrast to Negation, the recondite work of the game aesthete, play offers anyone, no matter how poorly educated or intellectually immature, a way out. On the egalitarian playground, we can imagine alternative possibilities to the present, as autonomous agents at play

in the boundless liberty of infinitely malleable space. In positing that anywhere is better than here, play upholds the utopian charge of the Frankfurt School to say *no* to things as they are. And, unlike the work of Negation which can only be carried out by the intellectually worthy and properly credentialed, play is never hierarchical or meritocratic when undertaken to flaunt or ignore the ruthless press of things as they are. Anyone is free to play and play allows anyone to be free.

While play is an independent refuge open to all, it is vital to point out those moments when the work of imagination fails short. It may be advisable to excuse play for failing to reach the apex of cultural erudition and refined agency demanded by The Frankfurt School, as not all of us have the requisite intellectual bona fides required to make sense of inordinately difficult works of art, but even with that proviso, play is not a sphere of interaction without fault lines and limitations. Play may be a space where anything is possible, but that does not mean playful engagement carries no risk. Likewise, playing with death comes at a cost.

Music therapist Susie stands by the bedside, strumming her guitar softly as two aides give a sponge bath to the girl in the bed. At 15 years old and under total care since birth, Teresa is used to being bathed, but still seems agitated at the aides' attention. Teresa's mom is at the foot of the bed, watching. She will be providing care for Teresa when they go home on Monday.

Susie is singing one of Teresa's favorite songs.

The song is interrupted. "She needs to be suctioned," Mom says, noticing the faint cough and slight purple hue of Teresa's face. Susie backs away from the bed as an attentive mother leans in and suctions the trach.

The aides don't miss a beat; they step in as soon as the airway is clear. They towel dry Teresa off and ever so gently pull a t-shirt over her tracheostomy tube. They help Mom lift Teresa out of the bed and place her on Mom's lap as they both settle in a chair. The aides change the bed as Susie resumes her song. In her lap, Mom holds Teresa, now almost as big as she is.

You are my sunshine, my only sunshine

You make me happy when skies are grey.

You'll never know, dear, how much I love you

Please don't take my sunshine away.

No matter how often we stress the healing and transcendent powers of play on the ward, the moment always comes when a medical emergency will interrupt. When death comes in the last instance, there is nothing more that can be done. As with both "I'll Fly Away" and "You Are My Sunshine," these songs and all play on the ward are undertaken with the poignant knowledge that each and every moment of joy and spirited abandon may be temporary.

In terrible harmony with all the medical devices crammed into every room and corridor, each of which adds its own unique beep and blip to the hushed cacophony of the hospital floor, the clock is ticking.

Two weeks later, Mom takes Teresa home for the holidays. Teresa dies the day after Christmas.

In positing that play is a fabricated amalgamation fashioned as both an amplification and alteration of the routine experiences of everyday life, we want to call attention to how play inescapably draws from the elemental materials and social practices that subtend and organize our collective and individual lives, even when the aim of play is to pretend that what's inescapably real (pain, treatment, institutionalization) does not exist. Like kids making mud pies out of the dirty muck at their feet and bald children doing their "hair" in hospital rooms now chic salons, all players use the materials and practices near to hand to construct individual and collaborative fancies. For that reason, play has to be conceptualized as an extension of the particular niche in the grander social order that each of us calls home. Play cannot be conducted without some dependent relationship on the worlds that preexist and, to some degree, necessarily determine the bounds and course of our imaginations. At the same time, as with inspired children who can whip up delectable pastries out of the wet dirt, play allows us to do almost anything with the constituent elements of the material and social realms that sustain us as individuals and linked collectives.

You would expect that, children being children, young patients would manage to create playgrounds within medical space—playing doctor or nurse with a PICC-line, for instance. But we didn't see that. The medical accoutrements, we suspect, are much too real and threatening to be toyed with. Thus, play has to be physically brought into the hospital space, through the aegis of music therapists, generous jocks, recording artists, and tired parents, nearly all of whom are desperately ready to slough off constant worry and just play with their kid. The same is true for the medical staff, who also grow weary of the constricting roles defined for themselves and their sick charges. Children with bodies physically exhausted from treatments and illnesses, with tempers and personalities long since frayed by a constant diet of pain and unending medical attention, have to be coaxed to play. Parents and staff have to remind themselves and their children that they can all be young at heart. They have to be given explicit permission to play. But, once permitted, play they do, and fleeting moments of joy enliven the bleak desert of illness, pain, and endless treatments. When the players can be enticed to play, these instances of diverting escape always mean as much to the caregivers and attendants as they do to the children themselves.

On the varied hospital wards and units where all are called to confront and endure the very worst, in the ER, the OR, ICU, NICU, the morgue, quarantined rooms, and on the PPCT, the monstrous exists and there is

good reason to be very fearful. At these moments when we are confronted with a dread diagnosis, a code blue, or a resigned physician who has done all she knows to do for our child, words and imagination fail. Play and hearts are halted.

Contrast these moments of real, abject horror with all the times, since childhood, that we have prepared for the worst. I think now of watching a group of elementary school girls tenderly bury a dead worm under a memorial of pebbles on the playground. As each added their small stone to the burial mound, they talked about how the worm deserved a nice funeral. Each of those girls will someday, some much sooner than others, bury their own dead and say farewell. Signal crises will lead most of us to temporarily shut down the free play of the imagination to attend to grave matters of consequence in the here and now, but play will have prepared us for these encounters and nearly all of us return to play more quickly and with greater avidity than might initially seem feasible following a tragic misfortune.

## Conclusion

As we have shown, consistent with Terror Management Theory, the staff of the PPCT and the children's hospital, alongside parents and allied caregivers of seriously ill children, use playful activities and humor to help pediatric patients deal with their fears of death. Even though, as Rich (2002) suggests, play provides seriously ill children a needed break from medical experiences and an opportunity to temporarily forget how closely death looms, eventually reality must be faced. Thus, play in the PPCT is not about collusion, denial, or false fantasies. Rather, it provides a temporary respite from relentless needle sticks, bad news, and embodied pain. Play and humor provide fragments of palpable illusion that allow patients, families, and health care providers to momentarily forgo terminal despair and the anguish that comes with a pressing death; play lets them take a stand against death and turns their attention away from the impending end and toward brief moments of enchanting interaction and whimsy. These diversions can be more efficacious and beneficial than any surgical or pharmacological intervention and are one of the few remedies available when medical options are exhausted. Apart from these individual benefits, play and humor are also communal activities that build bonds and soften the blow of tragedy for all who lament. Grief, sorrow, and suffering can leave us shattered and alone; laughter brings families and colleagues together. Finally, play and humor offer sick children one last reminder that their lives matter and that, alive to the final moment, patients are still fully human, truly human amid a maelstrom of pain and anger, fear and dismay. Whenever patients and their attendants play, there is still life left on the balance sheet.



For the young, the healthy, the strong, playing with death empowers fantasies that we can control our eventual demise. For those whose mortality looms large, playing with death is a brave charade. The game is always a counterfeit simulation. No one is incapable of recognizing playtime as a bracketed respite where ordinary rules and conventions are temporarily suspended. Once we reach a very early stage in psychological development, we know magical thinking is of no particular efficacy during the regular hours of operation that circumscribe of our daily worlds, but all who play well exit ritual fantasies with privileges and allowances of genuine value. Play is alchemy; it grants participants the possibility of remaking the world, themselves, and like-minded others who elect to join together in an arbitrary union. Play grants participants the freedom to make up their own conventions and slough off the cold-iron constraints—including those ordering life and death—that suture the entwined realms of the material, corporeal, and social worlds.

Play is a springboard for human action and invention; it stretches and strengthens the limits of consciousness in analogous fashion to what long hours in the gym do for the body. To claim the world for play is not to argue that the symbolic mastery exercised in lucid dreaming ever allows for the immediate or direct reordering of real world constructs. Death will come, but in the meantime, play allows us to make the best of whatever we have in the here and now.

I step on the elevator and push the button to the sixth floor. “Sixth floor,” the voice says. I pause. I ride up three extra floors just to hear it again. “Ninth floor,” the voice says. It is the voice of a child—literally. A small child’s voice, it could belong to one of the young patients, playfully announcing each stop. For the elevator that takes new arrivals and the already committed to the PPCT, the hospital engineers have removed the usual adult voice that duly intones the arrival of each floor and replaced it with the sweet voice of a child. With a child at the helm, the elevator that carries passengers to the last stop is now a ride and not a cold, metallic box that shuttles the sick up and down. Suddenly I become aware of the child’s presence in the elevator with me. “Eighth floor,” the small voice declares—announcing the floor, the space, the frame. This is a place for children. Despite everything we know to the contrary, this is a place for play.

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