“Applied Clinical Humanities: Exploration of Childhood Osteogenesis Imperfecta Bioethics”

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complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

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Abstract

“Applied clinical humanities: exploration of childhood Osteogenesis Imperfecta bioethics”

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Osteogenesis Imperfecta (OI) is a rare genetic disorder resulting in deficient or defective type 1 collagen and impacting 1 in 15,000 people in North America (National Institutes of Health 2019). The resulting weakness of bones and connective tissues, separated into distinct diagnostic categories according to severity (van Dijk et al. 2015), leads to physical limitations (Tsimicalis et al., 2016), acute and chronic pain (Nghiem et al., 2017), fear of accidents, and multiple quality of life concerns (Dahan-Oliel et al., 2016; Tsimicalis et al., 2016). The challenges children with OI face across the biopsychosocial spectrum remain little documented. With no cure, OI treatment involves treatments that improve bone fragility, but greater efforts are needed to optimize overall quality of life (Dwan, Phillipi, Steiner, & Basel, 2016). As most funded scientific studies focus on medical outcomes of OI, little research, let alone creation of knowledge mobilization artifacts, have been produced to address varying ethical concerns arising in the OI community such as social isolation (Tsimicalis et al., 2016), feelings of ‘otherness’ (Siedlikowski et al, 2020), description of oneself as a ‘mutant’ (De Carmoy, 2004); being frequent recipients of larger societal discourses about genetic screening (Dogba et al., 2014), selective pregnancy termination (Coors & Townsend, 2006), and disparaging messages related to disability (Coors, 2014). This study used open ethnodramatic interviews to explore children's desire for participation in their healthcare, hospital-to-school transitions as well as inclusivity in their school settings.

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Contributions of Authors

Brenda Cleary (MScN) is a community artist, community health nurse and trainee of the VOICE research program (VOICE: Views On Interdisciplinary Childhood Ethics) and the Shriners Hospitals for Children®-Canada. Brenda Cleary authored the , designed this study, drafted the ethics protocol, collected the data, authored these manuscripts, illustrated these stories and is submitting this work for consideration as a Masters' thesis to University of Concordia. This work is neither published nor considered as part of any other academic program. Ms. Cleary would like to gratefully acknowledge the support of the following individuals in producing this work:

Dr. Warren Linds (Committee, PhD) is an Associate Professor at Concordia University and Director of Human Systems Intervention Graduate Program in the Department of Applied Human Sciences. Dr. Warren Linds reviewed and offered feedback on the penultimate version of both drafts, approved the final drafts and guided my inquiry into arts-based research generally and ethnodrama specifically as a field of research. Dr. Linds personally instructed me in autoethnography as a field of research and facilitated connections with the greater arts-based research community that helped secure a strong enough methodological foundation to advocate for this first of its kind arts based study approved by the McGill Faculty of Medicine and Health Sciences.

Dr. Argerie Tsimicalis (Committee, RN PhD) is an Associate Professor at the Ingram School of Nursing, McGill University, and holds the inaugural Nurse Scientist position at the Shriners Hospitals for Children®-Canada. Dr. Tsimicalis offered extensive support, liaising, revision guidance, editing and general low-flying angel activity related to all versions of each manuscript.

Dr. Andrew Ryder (Committee, PhD) is an Associate Professor at Professor & Interim Chair of the Concordia Department of Psychology and a Core Member for the Centre for Clinical Research in Health. Dr. Ryder has assisted navigating the cultural shift of the past 5 years of expatriating to Canada, navigating higher education and research, encouraged my love of health humanities and intercultural health care, and held space for my retraining and debut of my clinical career as an Inuit community health nurse at the pandemic's onset. Thank you for your patience.

Dr. Franco Carnevale (RN, PhD Psychology, PhD Philosophy) is a full professor at the Ingram School of Nursing, McGill University, and Principal Investigator of the McGill-based VOICE research program (VOICE: https://www.mcgill.ca/voice/). Dr. Franco Carnevale approved the final drafts of both articles to be submitted for publication, offered regular bioethics workshops to VOICE trainees on myriad topics and reviewed the first version of both drafts offering global feedback.

Kelly Thorstad, MSc(A)N, PHCNP, Director of Nursing and Patient Care Services / Nurse Executive, Shriners Hospitals for Children-Canada assisted to coordinate patient participation in the project and nurse collaboration for on site data collection. Nurse Thorstad approved the final draft of both manuscripts for publication.

Dr. Frank Rauch (MD) is Professor in the Department of Pediatrics, McGill University, and Clinician-Scientist and Director of the Biomedical Clinical Laboratory, at the Shriners Hospitals for Children®-Canada. Dr. Rauch approved this study to take place in the bisphosphonate day clinics and pre-operative surgical wards under his supervision and approved the final draft of both manuscripts for publication.

Jenny Wang RN, VOICE trainee, assisted to format the School of No-Fun and No Play as a disability support to the primary author and helped with many dexterity intensive tasks.

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Introduction:

Osteogenesis Imperfecta (OI) is a rare genetic disorder resulting in deficient or defective type 1 collagen and impacting 1 in 15,000 people in North America (National Institutes of Health 2019). The resulting weakness of bones and connective tissues, separated into distinct diagnostic categories according to severity (van Dijk et al. 2015), leads to physical limitations (Tsimicalis et al., 2016), acute and chronic pain (Nghiem et al., 2017), fear of accidents, and multiple quality of life concerns (Dahan-Oliel et al., 2016; Tsimicalis et al., 2016). The challenges children with OI face across the biopsychosocial spectrum remain little documented. With no cure, OI treatment involves treatments that improve bone fragility, but greater efforts are needed to optimize overall quality of life (Dwan, Phillipi, Steiner, & Basel, 2016). As most funded scientific studies focus on medical outcomes of OI, little research, let alone creation of knowledge mobilization artifacts, have been produced to address varying ethical concerns arising in the OI community such as social isolation (Tsimicalis et al., 2016), feelings of ‘otherness’ (Siedlikowski et al, 2020), description of oneself as a ‘mutant’ (De Carmoy, 2004); being frequent recipients of larger societal discourses about genetic screening (Dogba et al., 2014), selective pregnancy termination (Coors & Townsend, 2006), and disparaging messages related to disability (Coors, 2014). Unfortunately, healthcare providers and other children or adults may perpetuate, exacerbate, or contribute to these ethical concerns by underestimating or disregarding children’s competencies due to their status as minors or misconceptions about disability (Dogba et al., 2013; 2014; Siedlikowski et al, 2020; Hill et al., 2022). In an analysis of children’s agency, Montreuil and Carnevale (2016) found that children’s voices and agential capacities were often undervalued by healthcare measures intended to protect their best interests.

Despite the imperative of the provision of child-centered pediatric care early investigations confirm the marginalization of OI affected children in clinical settings and scant publications capture the children’s perspectives of their OI care ought entail (Dahan-Oliel et al. 2016; Nghiem et al. 2016; Tsimicalis et al. 2016; Dogba et al. 2013; Carnevale et al. 2015; Söderbäck et al. 2007). Efforts to capture that critical childhood perspective are presently ongoing at Shriners Hospital for Children where a 3-phase study is being conducted via arts practice-based research in conjunction with the VOICE: Views On Interdisciplinary Childhood Ethics working group (led by Dr. Franco Carnevale), the Shriners Hospital Pediatric Ethics Committee/Advisory Councils and this Masters Thesis housed by the INDI department of Concordia University. Findings from the first two phases have revealed that hospital practices, often secondary to a lack of resources, can promote negative moral experiences for children by thwarting their desire to be actively involved in their own care (Wang et al. 2018; Montreuil & Carnevale, 2016). Art-based methods were emphatically identified by patients with OI (many of them talented artists themselves) as a means to voice their needs, desires, and improve the quality of their life during hospital stays and in the community beyond (Wang et al. 2018). This study was thusly initiated to begin to map the gap between hospital policy and the state of child centered care using collaborative ethnodramatic play memorialized in children's storybooks. Notably, children in this study pinpointed the centrality of inclusivity in their school environment and located the need from hospital care to extend to include hospital to school transitions. The ethnodramatic script and accompanying manusscript, The Hospital of Unhappy Surprises, encompasses children's views on how “bad” hospitals can be transformed into “good” ones. The script is currently under review for production and filming by the International Marionette Arts Centre in Montreal's puppet theatre company to be made available as a pre-operative resource for children. The children's book “The School of No Play and No Fun” similarly details children's views on how “bad” schools can be transformed into “good” ones with the collaboration of hospital and school staff. It is being developed into an ebook to be made freely available on international OI channels. Thank you for reviewing the two following creative works and their accompanying research exegesis as a submission for consideration of a Masters of Social Science in the INDI department of Concordia University.

The School of No Fun and No Play: Learning How to Create Able-ing Environments from Children with Osteogenesis Imperfecta

1. Introduction

The worlds of children are largely dominated by the work of schooling, including lessons, homework, socialization, principals, reading intramurals, friends and teachers, which all form the rhythm of a healthy child's schooling life. Yet, what about children with medical complexities associated with a rare disease, such as osteogenesis imperfecta (OI)? How do children with OI navigate the competing demands of schooling, medical interventions and lengthy recuperation periods? While children's school and health care systems remain largely separate, both systems have enduring impact on the well-being of children. The confluence of medical complexity and disability, as evidenced by OI-affected children, pose unique opportunities and challenges to affected children requiring sustained support and understanding from the school environment (Tsimicalis et al., 2016). Eurowestern conceptualizations of childhood often stress the child as the object of adult moral action in need of assistance, as opposed to the subject of their own rich moral lives (James & Prout, 2003). Little attention has been paid to the moral agency of disabled children, both individually and collectively, and their power to effect their own well-being (Davis, 2017). A sense of peer acceptance remains a primary determinant of successful hospital to school transitions drawing questions as to how to harness the power of childhood cultures to create inclusive, school environments for disabled children (Chatzitheochari et al., 2016; James & Prout, 2003; Vanclooster et al., 2018). There is much to be learned from the stories children imagine about how they would transform an exclusive school environment into an inclusive one. Hence, the purpose of this study was to collaboratively create a storybook with OI-affected children to illuminate exclusive and inclusive school environments and children's concepts of transformational change.

1.1 *Use of Storytelling to Promote Inclusivity*

Despite the steady rise in children with disabilities, there remains a pronounced lack of representation of disabled children in available children’s literature and television (duPaul et al., 2018; Götz et al., 2019). The lack of positive representative role models for disabled children reflects the marginalization of disability at a social level. Cameron and Rutland (2006) demonstrated that children’s interaction with stories, featuring students with disabilities, proved effective in creating a more inclusive classroom even when socialization with disabled children was not available. Hence, the early equitable integration of disabled persons into childhood school environments could be meaningfully enhanced by such literature and other media portrayals.

The United Nations Convention on the Rights of Disabled Persons and the Rights of the

Child both reference the importance of equality of experience between disabled and non-disabled persons in integrated school environments. To ensure this equitable experience, the United Nations recommends provision of school services to support disabled children's sense of belonging in the community through individualized support measures and sensitive environmental design (United Nations, 2006). Realizing these recommendations, unfortunately, is compromised when few resources are delegated to creating inclusive environments reinforcing poor school experiences for disabled children relative to their healthy peers (Lum et al. 2017). For instance, parents of children affected with OI may not always be able to enroll their child in a school that would best nurture that child's gifts and talents. Rather, these parents may need to choose schools based on the presence of an elevator and the teacher's willingness to instruct a disabled student (Dogba, 2013). Due to the physical limitations associated with their bone fragility, these children often opt to cultivate their intellectual gifts and talents at high levels, allowing them to excel in many academic, extracurricular, and vocational activities including fine arts (Ablon, 2003; Tsimicalis et al., 2016). Globally, the OI community is replete with critically acclaimed artists who celebrate their community, through myriad art forms: music, theater, visual arts, storytelling, YouTube and other social media. Through these means, the OI community, at large, engages with the work of changing the story of deficit, limiting stereotypes and pejorative attitudes that too often perfuse their social experience (Tsimicalis et al., 2016).

1.2 *Ethnodrama: Storytelling as Research*

Children with OI, especially those with the severe subtypes, share a parallel experience with many diverse, medically complex childhood population experiencing repeated hospitalizations (Arundel, 2015). The severity of OI extends from a mildly elevated risk of fracture to severe limb deformations requiring lifelong wheelchair use (Tauer et al., 2019). Regardless of the presentation, children affected with OI experience wide ranging biopsychosocial impacts, and ethical harms, that may touch every aspect of their school experiences (Wang et al., 2019; Tsimicalis et al., 2016; Cleary et al., 2020). Ethnodramatic storytelling invites participants to theatrically co-create a representative story of their hopes and experiences with the help of an expert facilitator (Taylor et al., 2017). The methodology seeks present empirical findings in ways that engage the empathic and ethical intelligences to collaboratively reflect upon and change recurrent social issues (Taylor et al., 2017). By utilizing a medium that reflects on what "is" and has the flexibility to imagine what could be, the ethical harms experienced by children and their proposed unique solutions to them can be illuminated in ways that are accessible to other children and other non-academic audiences.

2 Methods

2.1 *Theoretical Frameworks*

This practice-based study drew from three interrelated frameworks: moral experience, social constructivist, and ethnodramatic storytelling. Moral experience, firstly, is defined as the way in which an individual experiences their values either supported or thwarted and illuminates what moral harms may be needed to be addressed in a given environment (Hunt & Carnevale, 2011). Inspired by research demonstrating that children are significantly more ethically sophisticated than stage-based developmental models predict, the core concept of moral experiences in this study strives to examine how children's moral convictions and values specifically are enacted and responded to in a hospital setting (Carnevale, et al., 2017).

According to social constructivism, knowledge is not absolute but rather a human cultural product (Thomas et al., 2014). The social constructivist theory further posits professional knowledge users, as active problem solvers, purposefully translate new knowledge into existing systems of meaning within their sociological contexts. As such, the union between knowledge and social processes emphasizes action and interaction with social change (Thomas et al., 2014). From this vantage point, the dynamism of children's moral landscapes, a complex confluence of subjectivity and external forces, comes into view preserved in the nuance, emotive and evocative creative forms chosen for the study within a framework that empowers positive change.

Ethnodramatic storytelling is a novel methodology created by the artist-researcher and is related to “fiction as research” and theater of the oppressed traditions. In the well-known Theater of the Oppressed praxis developed by Boal (2006), “spect-actors” (audience members)work with theatre facilitators to transform on-stage oppressive scenarios into liberating scenarios. This is done by making plot suggestions or changing place with actors themselves to transform the outcomes of familiar oppressive life circumstance (Boal, 2006). Such experimental theater games at the bedside may allow participants to express their insights and direct experiences anonymously through fictional storytelling, permitting these insights to be woven together, drafted and illustrated by the artist-researcher into a final story. By representing research insights as fictional stories, readers and content creators alike can explore the context of the narrative as they experience it, arrive at their own conclusions of what the story means and what may be possible in the "real" world based on these reflections (Leavy, 2017). The specific choice of generating fictional stories accessible to children achieves the aim of centering children's voices in both research design and possible child-centric modes of dissemination.

2.3 *Study Design, Purpose and Setting*

Following institutional ethical approval, a practice-based research study was conducted to collaboratively create an ethnodramatic story wherein a "bad" school was transformed into a "good" one for children with OI. In this way, children identified what they experienced as moral harms and moral goods in their school environments as well as enact their agency to effect transformational social change. This study was part of a three-phase ethnography seeking to understand the moral experiences of children with OI during hospitalization and in their community (Wang et al. 2019, Cleary et al. 2019). The last phase of this ethnography entailed creating resources to promote children's positive moral experiences (present study and others forthcoming). The study was conducted at a university-affiliated, not-for-profit, bilingual, paediatric orthopedic hospital located in Montreal, Quebec, which specializes in the treatment of children with OI.

2.4 *Sample and Recruitment*

Purposive and maximum variation sampling were used to recruit participants who were: either OI affected children or youth or their siblings (either affected or not affected) under the age of 18. See Table 1 for inclusion and exclusion criteria. Families were approached by a non-authoritative person unrelated to the study to invite them to participate. If they agreed to meet with the researcher, they were explained the study and informed consent and assent form was obtained. A sample size range of 8-12 was estimated to generate enough separate storylines from the children to combine into one narrative without sacrificing precise creative contributions from individual participants.

2.5 *Interview Guide and Props*

Story development through collaborative, improvisational, ethnodramatic play and Boalian theater games followed from a semi-structured interview guide and selection of props to help maximize children's engagement, discussions and creative choices. The interviewer was a nursing graduate student with experience as a children's community artist. The interview guide consisted of the following:

(1) Imagine a terrible school: What is it like?

(2) Imagine the best school in the world: What is it like?

(3) Can you tell me a story of how a terrible school becomes a good school?

Some children chose to consult and comment on different facets of the ethnodramatic story, as opposed to other children who created one themselves according to their preferences. The interview further incorporated the children's preferences for prop options of using puppets, collaborative graphic storyboarding, and/or directly consulting on anonymized children's stories. The puppetry and graphic storyboarding involved the use of "triggers" by suggesting a plotline of a bad school being transformed into a good one (Carter & Ford, 2013). Fourteen puppets were available and included: finger puppet family members, finger puppet animals, a dragon, ballerina, a patient, a nurse, a physician, and more generic large sized puppets. The variety of puppet characters made available to the children encouraged maximum imaginative, open-ended, exploration of the child's conceptions of "good" and "bad" as well as the transformative process between the two (Carter & Ford, 2013). A simplified interview guide was created to permit children to govern not just the creative process but also the spatial dynamics of staging the puppets and videorecording to afford them a greater sense of power and agency within the interview process (Bird & Donelan, 2020; Carter & Ford, 2013; Elwood & Martin 2000). For example, children decided whether or not they wanted to film the puppet play, animate the puppets or perform voiceovers. **The interviewer guide**

also offered instructions for one participant who preferred graphic storyboarding as opposed to the use of puppetry. The participant directed the artist-researcher to draw a cartoon storyboard for an imagined plot using the same improvisational manner used with puppets. Three participants opted to comment on anonymized summaries of children's stories concretely.

2.6 *Data Collection*

The interviewer explained the interview process to the children and their parent(s) and collected the data in the child's private hospital room or in an open format, outpatient clinic behind a semi drawn curtain (See Table 2). Parents were welcome to stay for the duration of the interview. The interview guide and props guided the interview and the interviewer adjusted according to children's preferences, engagement, and capacities. Children were invited to invent fictions combining "good" or "bad" school characteristics. For children uncomfortable with imagining a complete story, the researcher would act out school characteristics mentioned by other children as "good" or "bad" and welcomed the children's input (e.g. if the characteristics were right/wrong and what characteristics should be changed). For all children, the interviewer regularly paused to allow time for children to develop, integrate and build the storyline into a fluid and iterative fashion. The one-time interviews lasted from 15 to 65 minutes, varying with participants' age, interest and discussion topics. During the course of recruitment and data collection, one youth participant requested to meet the interviewer again to help collate the children's anonymized fictions during their prolonged hospitalization. They met a total of 3 times. Interviews were audio-recorded and professionally transcribed within 48 hours and films, where applicable, were uploaded on the server and reviewed as needed for data analysis. After each interview, observations, field notes, and reflections were also transcribed.

2.7 *Data Analysis as Ethnodramatic Story Development*

Ethnodramatic storytelling was the collective creative practice, data source, and analytical technique used for the study. This technique was iterative, inductive, and continuous over the course of data collection and analysis. After each interview, the data from observations, field notes, transcripts, artwork from graphic storyboarding, and puppet videos were consolidated. The interview guided was updated to offer new potential storylines and probes of “good” and “bad” school characteristics that were shared with remaining participants. Key texts were tabulated, categorized per topic, and analyzed to understand characteristics defining a “good” or “bad” school environment. Summaries were created and key ideas were presented to one youth participant who helped create the full fictional story with the researcher. All characteristics defining a “good” or “bad” school environment expressed by the children, and how to effect transformational social change were included in the final story. Details such as name, place and personal attributes of characters were changed for plot coherence and to preserve anonymity. The researcher proceeded to draft the story according to the specifications of the participants and continuity of plot structures detailed in the critical reflection below.

3. Results

3.1 *Sample Characteristics*

Of the 13 children approached for study, two declined, and 11 children, ages 6 to 17, consented or assented to participate. There were no children who withdrew. (See Table 2 for full sample characteristics). Two of the participants had severe presentations of OI requiring permanent wheelchair use, five had less severe presentations suffering primarily from an elevated risk of fracture. The remaining four participants were unaffected siblings.

3.2 *The School of No Play and No Fun Summary*

The resulting children's book called "The School of No Play and No Fun" was collaboratively produced with the 11 participants. This 1,600-word fiction is available as supplemental material. The fiction offers trenchant insight into how child and adult cultures can converge to effect the kinds of support medically complex children themselves report needing. A brief overview of the children's' book and a critical reflection is as follows:

The book begins with two siblings, a less severely affected Maria and a severely affected wheelchair-bound Mikey, arriving at their new school only to discover there is no wheelchair ramp, the bathrooms are tiny and there is no room for Mikey to maneuver his wheelchair in class around his classmate’s desks (Figure 1). Coach Meanie Weenie, the head-master, is an overly enthusiastic physical education teacher. The teachers forbid all children to play outside and permit only games that carry an elevated risk of fracture be played. Children sit in classes and regurgitate boring information. Children who are “disobedient” are turned into turtles by their teachers (Figure 2). Maria and Mikey take refuge in each other and their imaginary friends, actively hide from the school bullies, and try to avoid the pushing and shoving that ensues in the classroom (Figure 3). During gym class Maria sits on the sideline forlorn unable to join high fracture risk activities that other forms of children play. Mikey, however, refuses to sit on the sidelines and speaks out, declaring that he is capable of doing many activities but not the ones allowed in gym class. He is punished for speaking up and turned into a turtle (Figure 5). In his new transformed state, Mikey can communicate with the other turtles. The turtles explain the school was cursed by an OI affected girl just like him who spent so much time in detention that her bitterness and sorrow bewitched the school.

Mikey learns of a way to break the curse. He leaves for the forest and avails of the animals to make a magic potion capable of lifting the curse (Figure 6). The potion comprises of calm, a sense of humor, confidence, determination, community acceptance, a sense of play and love. The forest animals and Mikey travel underneath the school. They discover a river of tears flowing from a weeping door. As they approach the door, the witch begins throwing dodgeballs. The animals surround the witch in a loving, warm and fuzzy circle and throw roses in return. As the witch experiences a sense of love and belonging, she transforms into a grown woman. She subsequently assumes the leadership of the school. She makes the school socially inclusive and with a wave of her wand invites an occupational therapist from the hospital to transform the school into one that is wheelchair accessible (Figure 7). The wizard occupational therapist (the "physiowizard") mandates the creation of a wheelchair friendly built environment with bright colors, a soft playroom, large bathrooms, an elevator and many adapted play opportunities. The physiowizard teaches a special class to the students on how to welcome the children to their school, so OI affected students can experience a genuine sense of love and belonging. The children are concerned about others who suffer from OI throughout the world and invite them through a magic portal to come to the special school. The story ends with the children going to play outside in the snow and the children in wheelchairs can participate because special skis have been fitted for them (Figure 8).

3.3 *Critical Reflection*

Throughout the ethnodramatic story, the importance of physical play to the child affected with OI was highlighted. Being excluded from opportunities for play or having an assumed, nonexistent, physical capacity for activities was a major source of injustice felt by the participants. Dodgeball, monkey bars, and rope climbing were among the unsafe activities shared but sled hockey and dancing were safe activities suggested by Mikey, the more severely affected character. One participant mentioned that the simple considered act of allowing a friend of her choice to stay with her during non-adapted activities, spared her from isolation and the stigmatization experienced by Mikey and Maria. Another participant, who did not report experiencing those same accommodations, appeared visibly upset by the detail of sitting on the sidelines during physical recreation in the story. The constraints on their physical bodies appeared to heighten the importance of freedom of mind and creativity integrated into their school assignments. Children who consulted on the developing plot reported appreciating opportunities for “complete freedom” and “choice” in academic assignments, as many commented on the incomprehensible or otherwise boring information learned in school. Notably bullying was increased in the story for older children and “pushing and shoving” was reported as an unsafe activity in the school due to fracture risk. Mikey’s outburst against the injustice in the gym was amplified with similar commentary from other study participants who emphasized their physical and mental *abilities*, rather than disabilities.

The ethnodramatic story also revealed children’s insight into school culture: negative leadership created ineffective classrooms and negative student experiences. Yet, the participants noted that the source of the adverse leadership was a sense of unhappiness amongst leaders themselves who, much like the children, required a sense of love, support and belonging. Mikey, the main character, expresses an affinity with the natural world making a potion comprised of the participants’ sources of resilience. Inclusive leadership was demonstrated in the story by specifically casting a central character, the school principal, as an individual who intimately understood affected children from the vantage point of her own lived experience. The transformed witch's first acts of leadership included rejecting normalcy, as reflected in an un-adapted built environment, and interrogating disabling institutional processes to create an empowering school culture. An environment of acceptance, happiness and understanding created a social culture that potentiated changes in the built environment to reflect the needs of wheelchair users and adapted for high fracture risk students.

The ethnodramatic story also highlighted the positive experiences enjoyed by one participant whose occupational therapist "sensitized" her classmates of her needs before her school arrival. As a result, the participant enjoined her peers in creating a culture that would be safe and welcoming for her. The participant credited this intervention, and her long-standing team of care providers, with her early successful integration into the academic environment, positive self-concept and prevention of bullying in her social environment. The school leadership had even taken personal responsibility to fitting her wheelchair with skis so she could go outside and play in the snow with other students.

4. Discussion

An ethnodramatic study was conducted with 5 children living with OI and their 6 siblings to devise a story about their preference for inclusivity in mainstream school settings. Children's desired school location revealed they preferred an integrated environment instead of a "special" school. Their preference echoes the greater disability rights movement for greater social integration of disabled students at large to optimize social membership, emotional well-being and educational achievement (Ballard & Dymond, 2018). Nevertheless, integration brings challenges of painful barriers and stigmatization (Cleary et al., 2020; Wang et al., 2020; Dogba, 2013). The story, mediated by puppets and graphic storyboarding, illuminated how disabled children hold sophisticated recommendations for effective school leadership, adapted built environments, varied peer microsystems, catalyzing transformational solutions and a possible school-hospital liaison model to support their well-being. This creative approach permitted a fullness of children's dialogic, visual and creative modes of expression to facilitate trenchant means of understanding, interpreting and re-presenting children's perspectives (Hodgins, 2017; Carter & Ford, 2013). The built environment in the story showcased the immediacy of exclusion encountered by wheelchair-bound and high-fracture risk students. Navigating small spaces between desks with a wheelchair, inappropriate use of recreation equipment, and walking through densely packed narrow hallways were varying examples identified by the children showcasing the dangers of their school-built environments. In the literature, particularly for female identified wheelchair-bound participants, there is a long-standing otherization inherent in bathroom design (Slater, 2018). Children's conceptualization of a just environment necessitated an inclusive design for wheelchair accessibility, a safety fracture management plan, and a new playground equipped with soft areas and low monkey bars. Despite the clear importance of inclusive design of built spaces, children's sense of place is also a product of co-constituting peer and adult relationships.

Children with complex health care needs are 3.8 times more likely to repeat a grade, and relative to their healthy peers, parents report 4.6 times more likely to suffer from low social confidence (Lum et al. 2019). Chronically hospitalized children undergo prolonged school absences that create not just a disjointed social experience but a difficult academic one as well (DuPaul et al 2018), and this impact also extends to their siblings; (Tsimicalis et al., 2018). Despite well substantiated adversity in the social environment, these students do not receive significantly more academic or psychological support than their healthy peers (Lum et al., 2019). As seen in the story, villain teachers frustrate individual choices, allow bullying and do not accommodate affected children’s needs. One chronically hospitalized participant specified that bad teachers alternate between “really hard” lessons and speaking in unintelligible gibberish.

Teachers have expressed feeling ill-prepared to accommodate and anticipate the needs of a chronically ill child, nor how to differentiate between the health impacts of the disease and the child’s normal academic function (Tresman et al., 2016). These elements of the story highlight the need to create inclusivity beginning with the preparation of disability-inclusive teachers capable of encouraging medically complex children’s highest academic flourishing. The fiction created by the children further highlighted variable childhood cultures that exist in response to, or distinct from, teachers and other adult characters. In the “bad school” for instance, older students mirrored the attitude of their teachers and appeared physically and relationally aggressive. In contrast, younger students appeared frightened and submissive in response to an authoritarian teacher in the classroom (Shaw, 2013). Among these younger students, poor classroom leadership can compound peer stigmatization of complex care needs. Such stigmatization can include fears about contagion and worries about associating oneself with an individual who is “different” resulting in feeling ignored, otherized, isolated or rejected at school among (DuPaul et al 2018; MacArthur et al., 2014).

Bullying, sadly, is a prominent aspect of disabled children’s social experience. These children are 2 to 3 times more likely to experience both relational and physical bullying compared to their healthy peers (Hernandez et al., 2017; Lum et al., 2019). Sixty percent of disabled students report frequent bullying compared with 25% of all other students (Hernandez et al., 2017; Lum et al., 2019). Bullying undermines a sense of self and agency in children and is thus implicated in negative life course outcomes that extend well into adulthood (Chatzitheochari et al 2016; Powell et al., 2019). Perceived peer support, by contrast, is both a coping mechanism and predictor of mental health, academic success, rehabilitation adherence and positive life course outcomes (Canberry, 2019; Chatzitheochari et al 2016).

The ethnodramatic story seems to suggest that by collectively engaging young children in a prejudice-reduction and welcoming process, with the support of leadership, can create a welcoming school culture that embraces the complex health care needs of children (Birtel et al., 2019; Cameron

& Rutland, 2006; DeMatthews, 2020). Clearly, the transformation of inclusivity must embrace teachers, students and leadership alike. Supportive leadership in the school environment can transform both the built environment obstacles of disability oppression and the social exclusions, such as bullying, that give rise to the private emotional obstacles of internalized oppression, particularly bullying (Hernandez-Saca & Cannon, 2016). This ethnodramatic story highlights the importance of supportive and warm leadership, which allows classroom peers to emulate and better shift peer microsystems towards much needed inclusivity. Childhood cultures can co-emerge, in response to the leadership of children, to foment institutional initiatives and adapt them to structure their own unique social world (Davis, 2017). Leadership to effect concrete accessible activities and adaptations to the built environment provide tangible demonstrations of this work towards an intangible paradigm shift. In effecting change, leaders become a role model for children demonstrating how to resist and challenge marginalization in their classrooms and society at large (DeMatthews, 2020). The character of the witch offers unique insight into the way in which children conceptualize where school leadership goes wrong. Specifically, the transformation of the witch from an unhappy girl that replicates cultures of disabilism into a capable woman leader that disrupts cultures of a disabilism within the education system she leads (DeMatthews, 2020). Indeed, the ethnodramatic fiction demonstrates that inclusive leadership of adults also brings about the leadership of children in turn.

4.1 *The Hospital-School Liaison as Catalyst for Inclusivity*

The ethnodramatic story suggests that the skillful interfacing of clinical and school environments can also co-catalyze a school culture capable of understanding and accommodating the needs of this special population (Canberry, 2019). Coordination between schools and heath care systems is a woefully underutilized, and powerful opportunity to effect positive change in the life of the medically complex child (Vanclooster et al., 2018). Common characteristics of hospital led interventions in the school setting have included supporting parents to become more effective advocates for their children, making presentations to staff, and promoting a supportive peer environment (Carberry, 2019). The ethnodramatic story does not directly reference parental liaising but instead suggests that there is a clear and needed role for hospitals in supporting schools in creating peer presentations and leadership sensitization. With sufficient skillful support, the “happy ending” of an “abling” environment may very well be within reach for medically complex children with disabilities. The enduring absence of evidence-based guidelines to structure hospital to school transitions for medically complex children is a further glaring knowledge and knowledge translation gap (Carberry, 2019). Extrapolation of some school transition programs or validated assessment tools derived from research with certain chronically ill children, such as the well documented successes in pediatric oncology, may not translate to the specific needs of different medical populations pointing towards the need for further research (Elam et al. 2019; Bruce et al. 2012). As increasing populations of medically complex children continue to enter the school setting research into cost-effective coordinated hospital to school transitions and specific validated tools for children with OI and other populations are imperative.

4.2 *Strengths and Limitations*

This study contributed to the scant research available, from the child's perspective, as to what they need to flourish in an inclusive school. Above all, this child-centric design generated an ethnodramatic story to disseminate these insights broadly to adult knowledge users and their child peers completing the arc of child centric research design, knowledge translation and representative children's media for the global OI community. The book may be used as a means of fostering the critical peer support and demonstrating approaches to transformative leadership critical to this inclusive environment. Art-based approaches, including the participatory ethnodrama technique that generated our data, are an appealing and empirically validated method that resonate with children's ways of knowing and an appropriate means of engaging a variety of children's voices (Carter & Ford 2013). This study presents a novel ethnodramatic praxis that generated translatable knowledge in how school environments can engender positive moral experiences for children. Nevertheless, common quandaries of arts-based research surfaced: the question of difficulty in accessing children for sufficient time and language barriers placed the researcher in typing the final draft of the story and filling in gaps left by the informal conversation wherein all participant storylines were concatenated by the researcher and a central participant. While the use of ethnodramatic storytelling generation facilitated anonymous insight into the children's perspectives, the method offered only sporadic insight as to whether the fictional stories were tethered to their individual experiences. The representation of characters in the story itself proved a double-edged sword. On one hand, the study produced a meaningful work of literature by, for, and about disabled children that diversified common lack of representation through the central heroic role of a wheelchair bound child and the presence of a female villain and leader (Götz et. al, 2019). On the other hand, it perpetuated problematic tropes of male heroes capable of using their intelligence and skill to make change and "beautiful" female heroines relying on the use of magic to accomplish meaningful action (Götz et. al, 2019).

5 Conclusion

Traditional social models of disability focus on the material, structural determination of disability and have little focused on the process of social-emotional disablism imposed by the adverse synergy of material and social exclusion (Hernandez-Saca & Cannon, 2016). The ethnodramatic story highlights the interdependent and co-arising nature of physical accessibility, effective leadership and social-emotional well-being for OI affected children. The story highlights how the collective self-efficacy and agency of children sculpts and informs the institutions with which they interact in contrast to the preponderance of emphasis on the ways in which adult institutions sculpt and inform children (Davis, 2017). The “School of No Fun and No Play” further teaches us that children have not only sophisticated preferences for their academic environments but also cast themselves, and clinicians who support them, as protagonists in the work of social change. They see themselves as strong, resourceful, resilient, visionary and capable despite the disability, incompetence and fragility inscribed on their bodies by various social scripts (Scully, 2012). In all, the tremendous progress marked by the ratification of the United Nation convention on the rights of disabled persons in 2006 is still contrasted by major lags in the full inclusion of disabled children in school settings (Powell, & Pfahl, 2019). While the research methods engaged fiction to imagine ideal solutions to creating abilifying academic environments, we must continue to move to make this imagined transformation a living fact for vulnerable students. Questions remain as to how to effect a welcoming childhood culture, populated and scaffolded by supportive adults, that a fortunate few of this study’s participants seemed to enjoy.

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Declaration of interest statement:

We have no conflict of interests to declare.

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Table 1. Inclusion and Exclusion Criteria for Child Participants

Inclusion	Exclusion
• 3-17 years • Is a current child OI patient diagnosed with any of the OI* OR • A sibling of a child receiving treatment by the multidisciplinary healthcare team at the study site	• Over 18 years • Not diagnosed with OI or sibling of affected patient • If any team member suggests that participation in the study may be harmful to the child • Does not speak French, English, or Spanish

Table 2. Child Study Participant (n=11) Characteristics and Overview of Interview Locations and Modality

Gender	Male	5
	Female	6
Age	3-5 years	0
	6-11 years	4
	12-17 years	7
Diagnosis	Mild form of OI	4
	Severe form of OI	2
Participant	Child with OI	6
	Unaffected Sibling of a Child with OI	5

Study Site	**# of Participants**	**Interactions**
Outpatient clinic	6	• 5 plot consultations (patient & sibling; 2 affected siblings; 1 individual) • 1 individual semi-structured cartoon storyboarding interview
In-patient Room	5	• 5 puppet mediated ethnodramatic interviews
TOTAL	**11**	

Note. Diagnosis categories based on Shapiro, Glorieux, & Sponseller, P. D. (2014). Osteogenesis imperfecta. Elsevier, Amsterdam.

Supplemental Materials

Examples of Story Illustrations

Figure 1. No room for Mikey to maneuver his wheelchair in class

Figure 2. “Disobedient” children are turned into turtles by their teachers

Figure 3. Maria and Mikey take refuge in each other and their imaginary friends, actively hide from the school bullies, and try to avoid the pushing and shoving that ensues in the classroom environment.

Figure 5. Mikey punished for speaking up and turned into a turtle

Figure 6. Mikey leaves for the forest and avails of the animals to make a magic potion capable of lifting the curse (Figure 7).

Figure 7. With a wave of their wands the physiowizard and witch create an accepting and supportive environment, with bright colors, a soft playroom, large bathrooms, an elevator and many adapted play opportunities. The physiowizard teaches a special class to the students on how to welcome the children to their school, so OI affected students can experience a genuine sense of love and belonging (Figure 7).

Figure 8. The story ends with the children going to play outside in the snow and the children in wheelchairs can participate because special skis have been fitted for them (Figure 10).

The School of No Play and No Fun

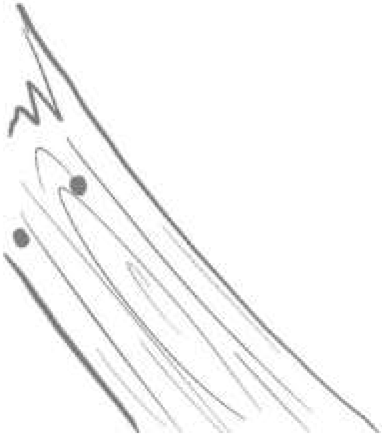
An Adventure in Osteogenesis Imperfecta

Written and Illustrated by Brenda Cleary & The Children of Shriners Hospital edited by Argerie Tsimicalis

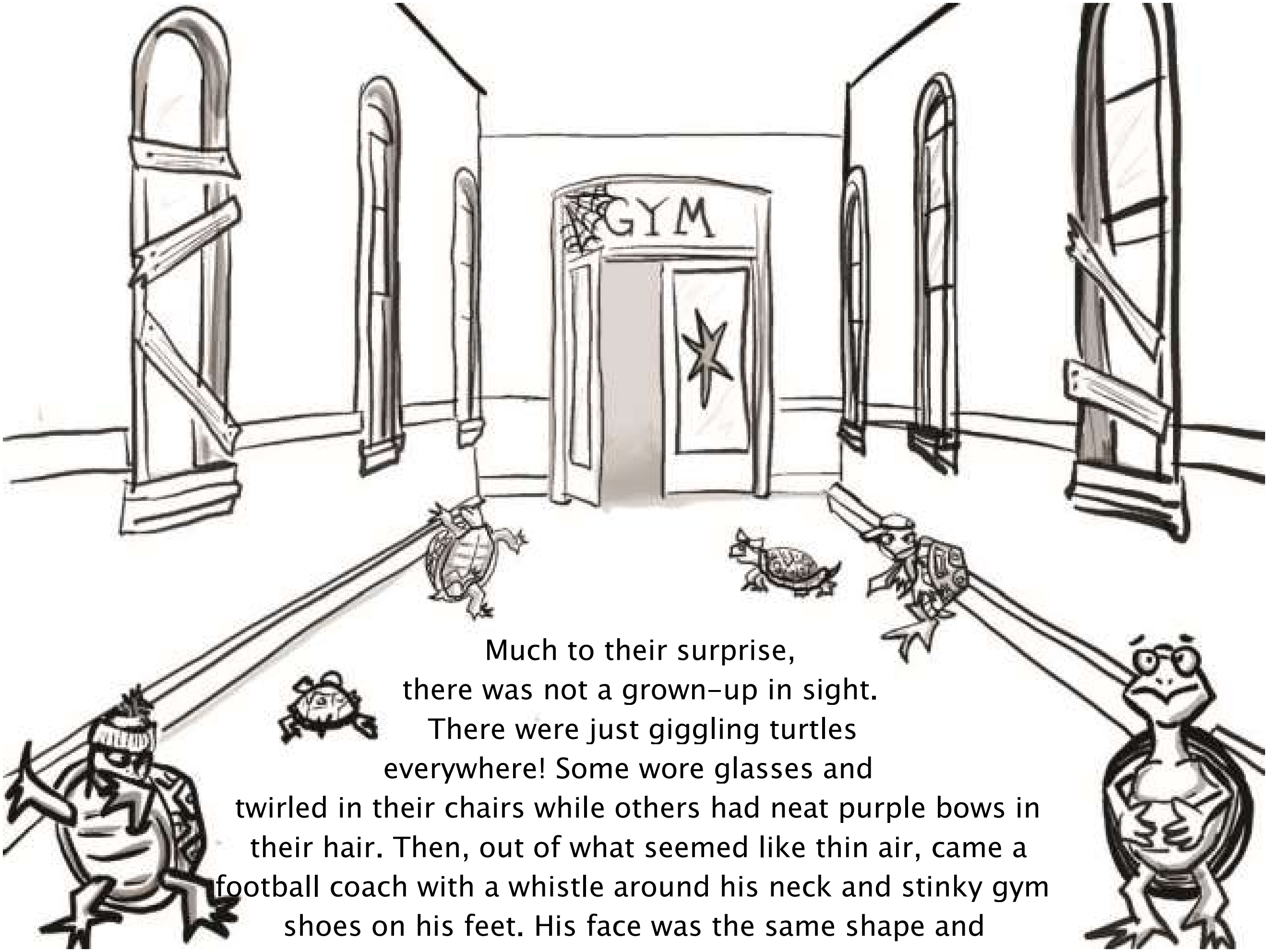
This children’s story was collaboratively written with patients affected by osteogenesis imperfecta (OI), a bone disease known for causing deformity and elevated fracture risk, at the Shriners Hospitals for Children® – Canada. Children were invited to invent a story wherein a “bad” school transforms into a “good” school, thereby revealing the complex values and preferences these children hold. We believe that by understanding the perspectives of children our communities can better serve them.

We gratefully acknowledge the support from the Henry Luce Foundation, Tunis Shriners, The McGill Nursing Collaborative, the Newton Foundation, and Scotiabank® in supporting the ongoing ethnography that inspired this book. Brenda Cleary was further supported by the Chang Family Bursary Fund, the McGill Faculty of Medicine Research Bursary, Réseau de Recherche en Santé Buccodentaire et Osseuse Masters Fellowship, and the First Lady Helen Lemieux Internship Program, “Research- Straight to the Heart”, Shriners Hospitals for Children®. Dr. Argerie Tsimicalis was supported by the Fonds de Recherche Québec-Santé (Quebec Medical Research Council) under the Chercheur-Boursier Junior 1 Award. The project took place as part of the McGill VOICE Project: Views on Interdisciplinary Childhood Ethics led by Dr. Franco Carnevale.

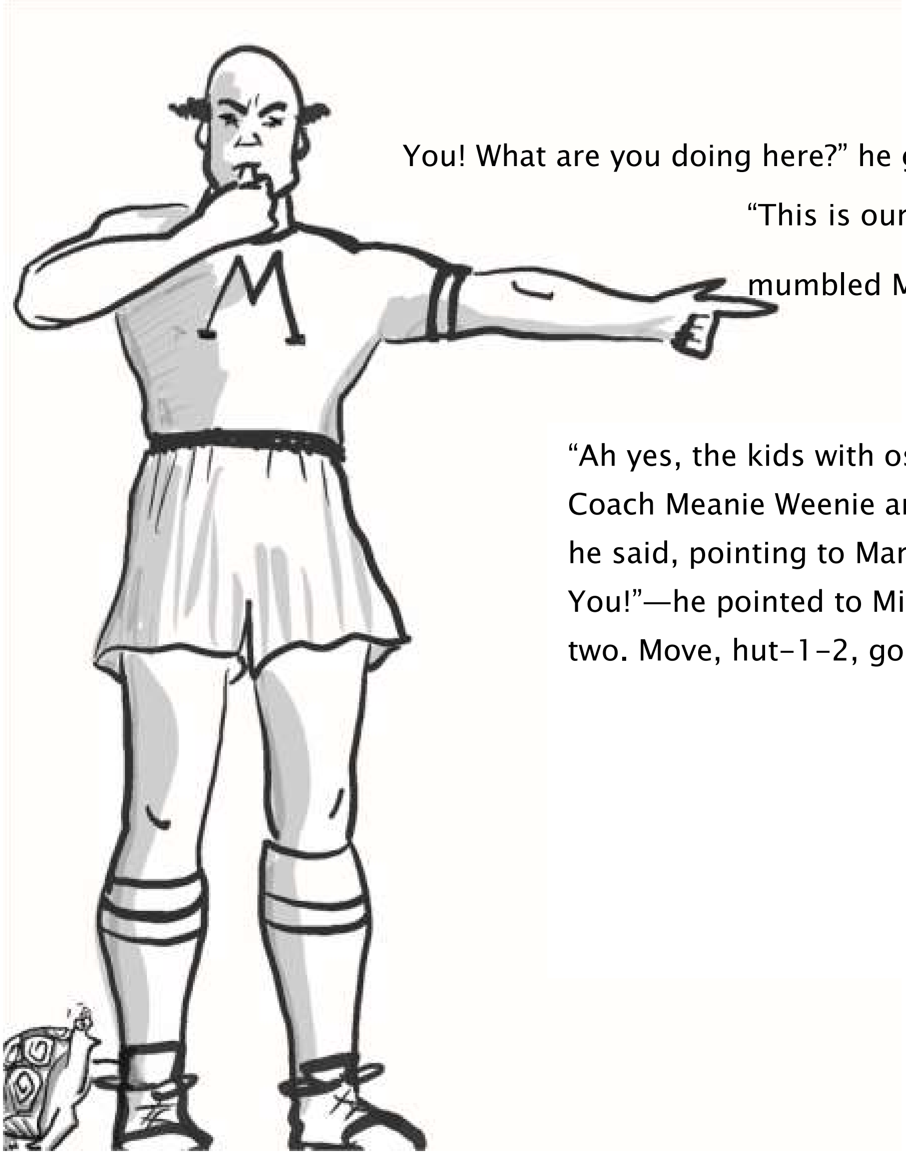
In a city not too far from this city and a place not too unlike this place, Maria and her brother Mikey couldn’t tell if the building in front of them was a haunted house or their new school. They pulled back the vines on a sign that read, “The School of No Fun and No Play.”



There was no ramp for Mikey’s wheelchair, so Maria struggled to help her brother up the front steps before he wheeled his way inside.



Much to their surprise,
there was not a grown-up in sight.
There were just giggling turtles
everywhere! Some wore glasses and
twirled in their chairs while others had neat purple bows in
their hair. Then, out of what seemed like thin air, came a
football coach with a whistle around his neck and stinky gym
shoes on his feet. His face was the same shape and
colour as a terribly cooked beet.



You! What are you doing here?" he growled.

"This is our first day at school. We are new,"

mumbled Maria

"Ah yes, the kids with osteogenesis imperfecta. I am Coach Meanie Weenie and you will report to me. You!" he said, pointing to Maria. "Report to classroom three. You!"—he pointed to Mikey—"Report to classroom two. Move, hut-1-2, go!"

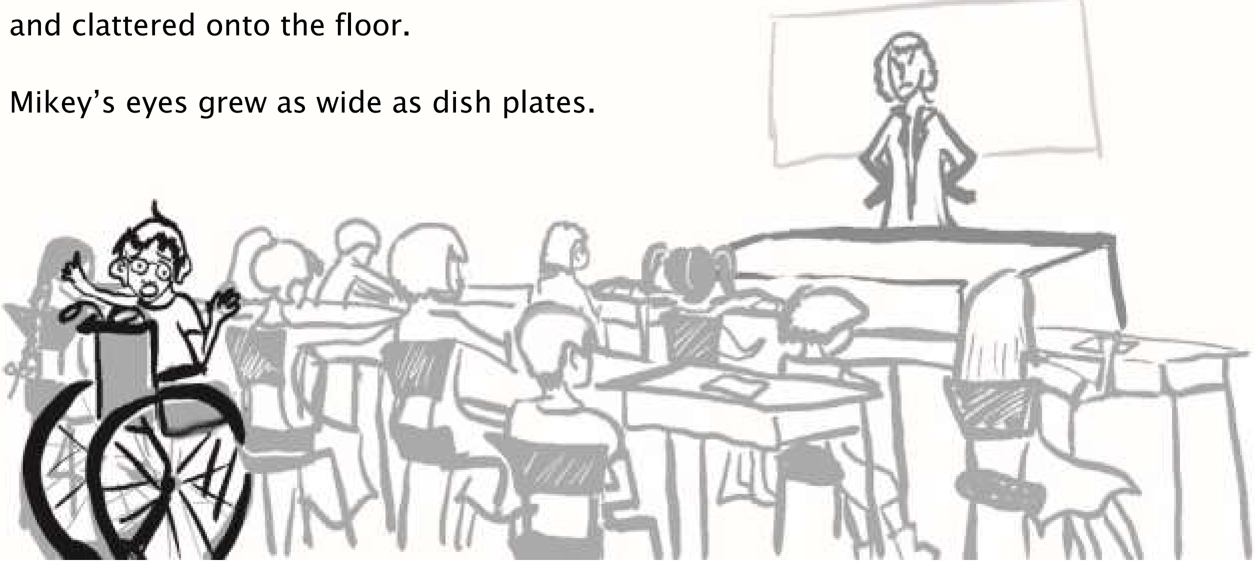
.

Off the kids went their separate ways as baffled as could be.
Mikey wheeled his way past a teeny, tiny bathroom and into a teeny, tiny classroom barely big enough for him and his wheelchair. Everyone was learning their multiplication tables and Aesop's Fables but not in a fun way like at his old school. The children sat hunched over their books, writing in teeny-weeny neat little lines while the teacher spoke gibberish.
One of the girls gazed outside at the falling snow. She looked as though she was about to burst into tears! "Teacher," she said. "We haven't gone outside to play in years!"

"Quiet!" the teacher snapped.

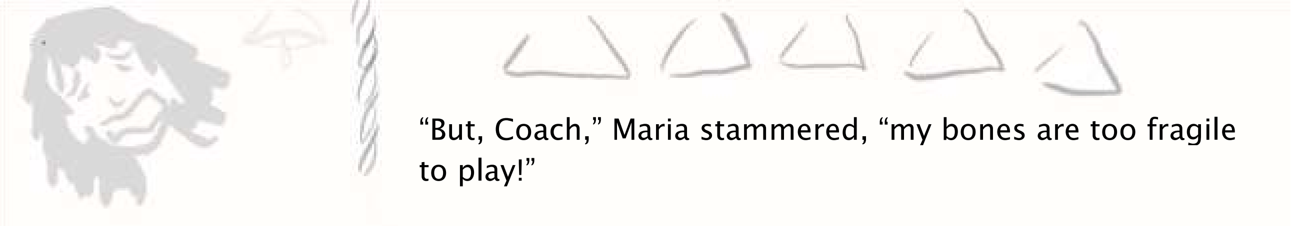
Then, with a poof and a flash and a little puff of ash, the girl was turned into a turtle and clattered onto the floor.

Mikey's eyes grew as wide as dish plates.



Things weren't going much better for Maria. The older kids were terribly mean. They picked on each other and even pushed each other around in the hallways. Maria sat in her corner with her imaginary friends and thought about her escape. Nobody knew about her OI; they couldn't tell that she was affected by it.

Coach Meanie Weenie arrived at the door and blew his whistle. "All students report to the school gym! It's mandatory dodgeball day."



“But, Coach,” Maria stammered, “my bones are too fragile to play!”

The other students laughed at her as they marched into a gym that had nothing but high monkey bars and baskets of rain-coloured dodgeballs.
Maria knew such games would be too rough for her fragile bones. She resigned herself to watching alone on the sidelines, but Mikey had had enough.

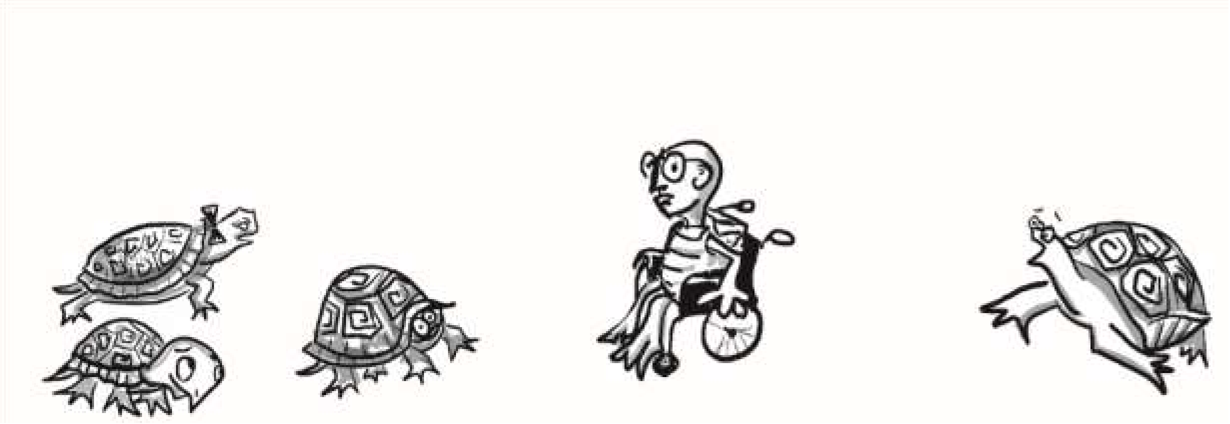
“Coach Weenie, we all need to play! You can’t just order kids around and only have your way! I might be in a wheelchair, but I still dance, play sled hockey and ski! I can do just about anything I try, but dodgeball and tall monkey bars just aren’t good for my OI.”

The coach snorted and took out his magic whistle …

ZAP! ZAM!!! ZOOF!!!!

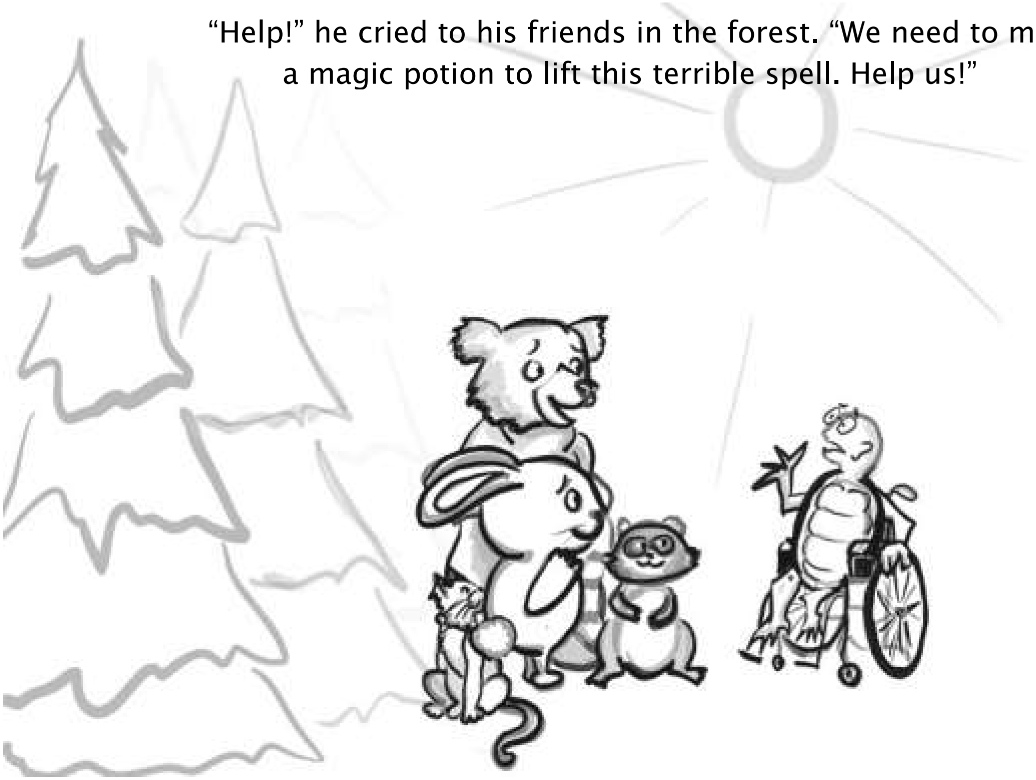
With a poof and a flash and a little puff of ash, Mikey was transformed into a little turtle on a tiny wheelchair. He rolled into the corner towards the other turtle children. That's where he finally learned the true story of the school's curse.

The turtle children told Mikey that many years ago a little girl, spunky and full of life, wasn't allowed to play either. Her bones broke easily and every time she spoke out about her right to play, she was given hours and hours of permanent detention. Her sadness began casting a cloud of no-fun black magic over everyone. Thus was born the School of No Play and No Fun! She was still there now giving orders to Coach Weenie and keeping all the children who rebelled trapped in turtle bodies and under her terrible spell.



Mikey was as scared as could be, but he knew he could do something to help. His wheelchair made him speedier than others, so he wheeled away into the low-hanging sun that shone so bright it made the snow sparkle in the cool winter light.

“Help!” he cried to his friends in the forest. “We need to make a magic potion to lift this terrible spell. Help us!”



The softest and cuddliest animals of the forest began to mix a magic potion in a tiny crystal bottle. They added a dash of don't-give-up-ness and a healthy sense of play, the power of longtime friends and grownups who accept you any which way, a splash of confidence, a little bit of calm, a little sense of humour to deal with things that go wrong, the ability of mean opinions to slide off one's back, confidence in one's self and helpers to help you stay on track. They mixed it with sunshine and birdsongs and the beautiful heavens above, but the ingredient above all the rest has always been and always will be … love. When all was said and all was done, they passed Mikey that tiny, little bottle filled with the most powerful magic in the world.

Mikey expressed his thanks, but he knew much more was needed. “I can’t do this alone. I still need your help,” he pleaded.

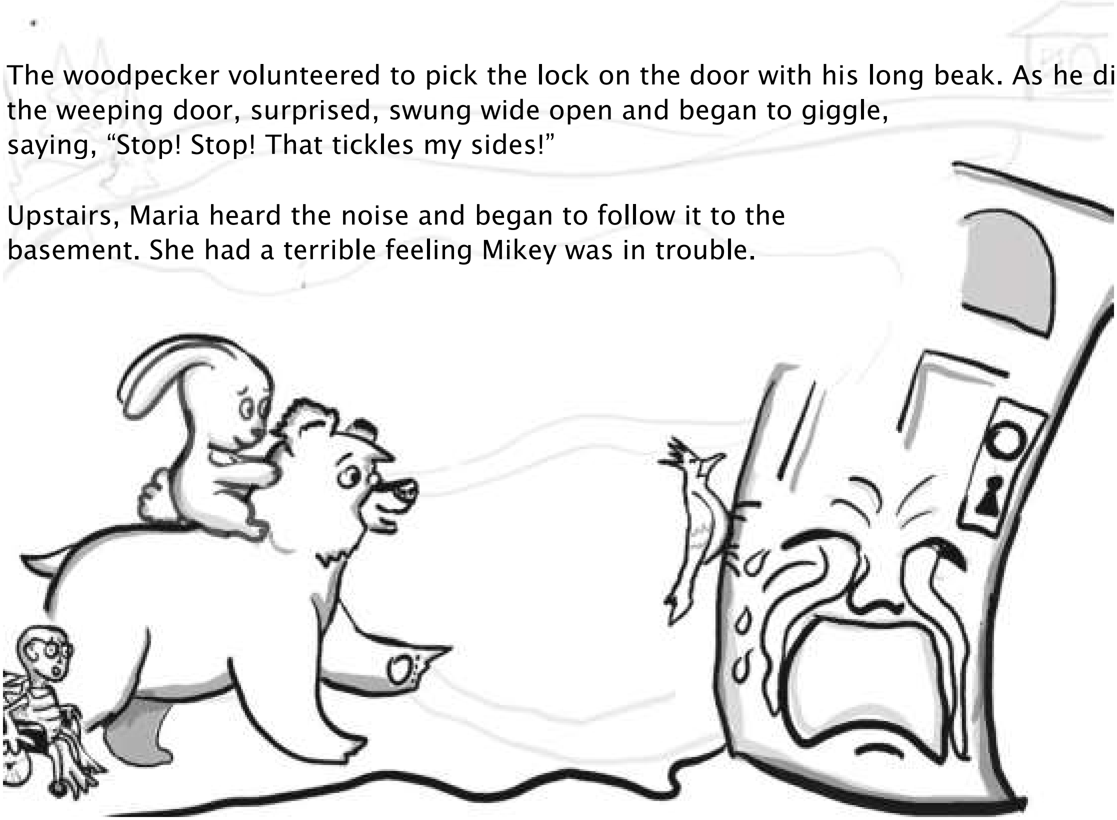
Off they went following Mikey through a maze of tunnels beneath the school: deeper and deeper and steeper and steeper. At long last, they reached a great blue door with a face that wept a river of tears.

“We’re here!” said Mikey. “Onward! We’ve arrived!”

All the brave cuddly creatures rallied at his cry. They came close and peeked through the keyhole and at last caught sight of that terrible witch who had bewitched the school

The woodpecker volunteered to pick the lock on the door with his long beak. As he did, the weeping door, surprised, swung wide open and began to giggle, saying, “Stop! Stop! That tickles my sides!”

Upstairs, Maria heard the noise and began to follow it to the basement. She had a terrible feeling Mikey was in trouble.

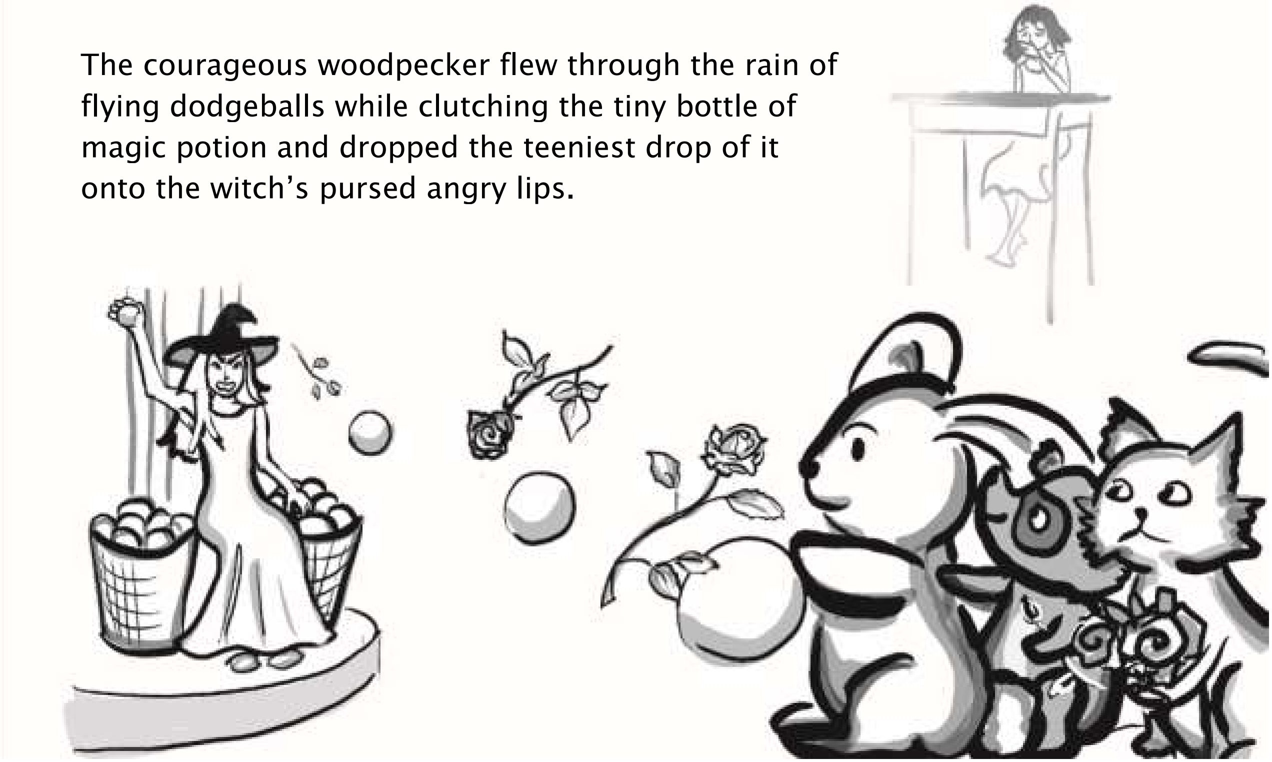


“Somebody is laughing in my school?” said the witch as she slowly turned around to see Mikey and the animals. “What are you doing here?” The witch reached for a large basket of extra-hard grey dodgeballs and began throwing them at the animals to scare them away.

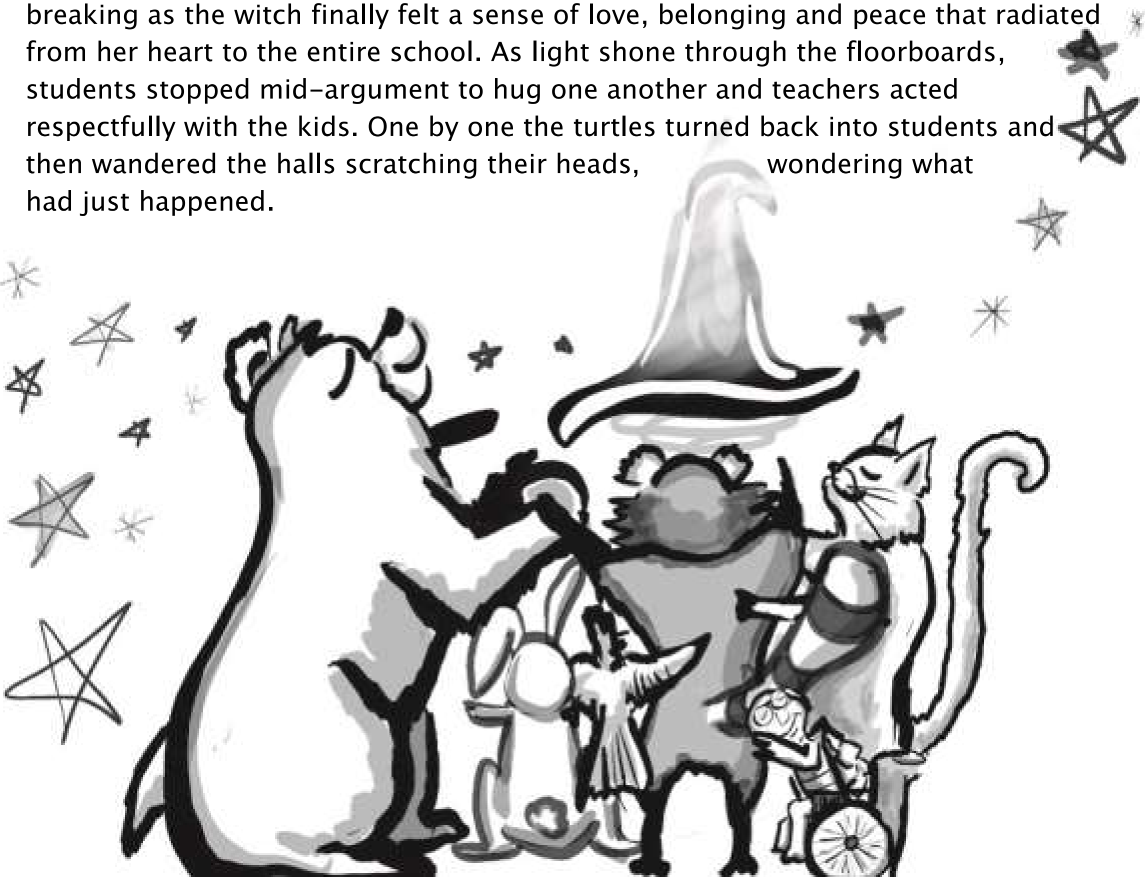
The animals had brought beautiful blooming roses that they launched at her in return.

“I hate you all! Go away! None of you ever let me play!” said the witch as she threw more dodgeballs at the animals.

The courageous woodpecker flew through the rain of flying dodgeballs while clutching the tiny bottle of magic potion and dropped the teeniest drop of it onto the witch’s pursed angry lips.



The forest animals surrounded her in a great furry and feathered hug. The witch transformed into a sad little girl, then into a fully grown-up good witch. The spell was breaking as the witch finally felt a sense of love, belonging and peace that radiated from her heart to the entire school. As light shone through the floorboards, students stopped mid-argument to hug one another and teachers acted respectfully with the kids. One by one the turtles turned back into students and then wandered the halls scratching their heads, wondering what had just happened.



The door of sadness transformed into a smiling, giggling yellow door of gladness, and its light shone on Maria as she walked through it saying, “This school still isn’t safe for me, my brother or any other child with OI!”

“Yeah!” Mikey chimed in, “your classrooms and bathrooms aren’t big enough for my wheelchair. Nobody understands what I need to be safe, and your gym has no games I can play!”

“Oh me, oh my, we all three have OI!” said the now-transformed witch. With a wave of her wand, she conjured an elevator door and a hospital physio-wizard stepped out onto the floor. He made the rooms bigger and brightened the walls. He built a soft squishy playroom and widened the halls. The bathrooms became big enough for a game of baseball! For all the students upstairs, he taught a special class about how to welcome students with OI.

“How do you like your new school now?”
“I’m so grateful,” said Mikey. Thank you! It’s really nice. But, you see, I want these things for every kid with OI, not just me!”
The good witch and physio-wizard looked at each other and smiled as a portal appeared and began to whirl. Out of it, other OI-affected children began to twirl. Why they came from every corner of the great wide world: every kind of boy and every kind of girl!

They piled into the elevator, now comfy and wide, wheeled through the hallways and finally made it outside.
Amidst all this magic, the snow piled high to their knees, the children lunged forth with great joy. For the good witch and wizard made sure every wheelchair was fitted with skis.

The Ethical Imagination of Children with Osteogenesis Imperfecta: What Children's Stories Teach Us about Transforming Hospital Care

Children's hospitals have been likened to a complex "place ballet" of relational, spatial, emotional and social actions that facilitates children's healing (Crooks et al. 2018, 32-37; Water et al. 2018, 146-153). Theater, as a mode of research and educational art, can render visible the corporeal, cognitive, normative, expressive and silencial elements of this bodily dance navigating the social field of a children's hospital (Bourdieu 1991, 13–14; LeGrow et al. 2014, 327-335). Medically complex children, disadvantaged by pejorative Western childhood narratives, often arrive in clinical settings under resourced of social resources and material independence (Bourdieu 1991, 13–14**;** Montreuil & Carnevale 2016,503-511**;** James & Prout 2003, 11-83; D'Amico 2016, 528-545; Mykitiuk 2015, 373-382). If children's hospitalizations were enacted as a theatrical play, the child actors would likely be delivering *few* lines: an ironic contrast to policies promoting their role as leading protagonist in children's hospitals (Cavet & Sloper 2004, 613-621; LeGrow 2014, 327-335; Koller 2017, 2657-2668; Coyne 2008, 1682–1689; Ruhe et al. 2014a, 775–782; Ruhe et al. 2014b, 44–54). The passivity inherent in children's socialization within some children's hospital settings contrasts landmark research suggesting that children are significantly agential, morally sophisticated and capable of understanding complex medical information reflected in clinical practice (Montreuil & Carnevale, 2016; Coyne 2008,1682–1689; Coyne & Gallagher 2011, 2334–2343). Hence, the purpose of this practice-based study was to collaboratively create an educational theatrical play, wherein a "bad" hospital was transformed into a "good" one, with frequently hospitalized children living with osteogenesis imperfecta (OI). The play, thusly, would become a map not only of the ethical harms experienced by these hospitalized children but also a roadmap to their radical transformation.

An "Is-Ought" Tension and Its Consequences

The stage-based developmental models that often undergird children's hospitals policies and procedures engender significant ethical problems in clinical practice (James and Prout, 2003, 7-74; Bluebond-Langner 1980, 221-281; Carnevale et al. 2007, 11-17). In essence, children with unique experiences and potentialities can be reductively sorted into age categories that then circumscribe what they supposedly can, and are thus permitted, to participate in (James and Prout, 2003, 7-74; Bluebond-Langner 1980, 221-281; Carnevale et al. 2007, 11-17). These policies, procedures and practices contradict current Canadian recommendations that children should participate in discussions, decisions and actions related to their health care (Coughlin 2018, 138-146). Pediatric residents are often inadequately prepared to render surgical assent and families, in turn, decide on medical issues without consulting their wards (Bester, & Kodish 2017, 17-19; Coughlin 2018, 138-146; Firdouse et al. 2017, Tait and Hutchinson 2018, 211-212; Nickels et al. 2016, 298-304). The resulting processes may leave children suffering undue duress and subject to varying interpretations of their best interests without their input (Wangmo et al. 2017, 11-20; Bester, & Kodish 2017, 17-19; Firdouse et al. 2017, 859-863; Heath, 2007, 403-417). Theater is an ideal medium through which to educate clinicians and families on children's solutions to the "is-ought" tension between health care's ideals of child centric practices and their less-than-ideal implementations (Coughlin 2018, 138-146; Mayne et al. 2016, 673-687; McCabe 1996, 505–516; Millum 2014, 522–538).

An Educational Ethnodrama on Children Living with Osteogenesis Imperfecta

Ethnodrama, a type of arts-based methodology, seeks to educate and promote avenues for social progress by producing vivid theatrical accounts of research data; provoking an aesthetic, intellectual and emotional response within viewers (Saldana 2008, 195-207). The performance of health ethonodrama fosters a multi-layered, reflexive mirroring of the stakeholders that create the clinical environment revealing the unspoken tensions, and emotive experiences hidden in plain sight (Bird & Donelan 2020, 218-235). For instance, Bray and colleagues used participatory ethnodrama to showcase children's perioperative anxiety and marginalization, their desire to both express these feelings, and actively participate in medical decision-making (Bray et al., 2019, 1964–1973). Osteogenesis imperfecta is a rare genetic defect in the collagen synthesis and metabolism resulting in a range of symptoms, varying from life-threatening to a moderately elevated risk of fracture (Tauer et al. 2019, 74-79). At an early age these children are faced with clinical decisions that will impact their identities, moral experience and experience of chronic pain, wheelchair use, and physical appearance for the rest of their lives (Rohani & Shaliamini

2015, 183; Water et al. 2018, 146-153; Tauer et al. 2019, 2019, 74-79). Children living with OI, when denied participation in decisions with such lifelong implications, express a felt moral harm and suggest that their healthcare providers provide them with opportunities for artmaking to better access their thoughts and feelings in these stressful moments (Wang et al. 2019, 2-10). Such research insights inspired this participatory puppet-mediated ethnodrama to better understand these children's ethical concerns, open the opportunity to play with their own solutions to these issues in theatrical space and collaboratively create an educational performance to kickstart the collective moral labour necessary to act on children's insights into how to effect positive change.

Research Context of Present Study

The ethnodrama was housed within an overarching three-phase focused ethnography spearheading knowledge generation and knowledge translation processes regarding children's ethical concerns, harms, moral experiences, and moral agency during hospitalization for OI treatment (Cleary, 2020; Wang et al., 2019). The first two phases identified children's desire to participate in their care, self-expression through art, the importance of inclusive hospital-to-school transitions, and how to better make room for children's voices during their hospitalizations (Cleary 2021a, 1-20; Cleary 2021b, 1-20; Wang et al., 2019). The last phase of this ethnography entailed creating arts-based resources, namely a play, poetry and children's books, to promote children's positive moral experiences crystallizing children's rich and nuanced ethical concerns as well as the factors that support or thwart their moral agency within the school system and hospital's respective socioecological contexts (Cleary, 2021a, 1-20; Cleary 2021b, 1-20).

The Labour of Script Writing

Finding Co-Authors

This study represents the first of its kind of arts-based research at the affiliated school of nursing and specialized pediatric orthopedic hospital. Much of the ethical approval process involved promoting the possibility that theater could itself form a powerful research process and educational instrument. A small committed core of individuals successfully saw the decidedly out-of-the-box approach for medical research through the ethical review board of both institutions. Hospital staff unrelated to the study approached OI patients under the age of 18 to invite them to participate in the project and the artist-researcher then reviewed guardian consent and specialized pediatric assent forms in detail. The inclusion of siblings who did not necessarily live with osteogenesis imperfecta was unplanned yet crucial to the success of the project. These children had journeyed significantly alongside their siblings who lived with the disease, cultivated keen insight into hospital systems and possessed their own poignant experience of being peripheral in the care of their family member.

In all, thirteen children were approached for study. Two refused and 11 children, aged 6 to 17, agreed to participate in the study (Table 2). There were no study withdrawals. Two participants had severe forms of OI, and five had less severe forms of OI and the remaining four participants were siblings without the disease. The study was capped at 11 participants based on the **practice wisdom** arising from the 17 years of children's community arts experience of the artist-researcher so as to be sufficient to secure enough separate storylines to optimally collate into one narrative without sacrificing details from individual contributions (Paton & Linnell 2019, 289-298).

Classic tenants of theater the oppressed, wherein scenes of oppression are played for audiences who experience them and the audience is engaged to imagine alternative just endings, were reinterpreted so as to allow for ethnodramatic play in the child's private room or behind a semi-drawn curtain in an open-format clinic where the children received their regular bisphosphonate treatments **(**Boal 2000, 21-50**).** Children imagined a bad and good hospital and the positive transformation between the two environments and was enhanced with the children's choice of puppets, narration and staging. In this way children could portray their lived experiences through a fictional story without the vulnerability of self-disclosure. Several of the participants did opt to self-disclose how the fictional stories they acted out reflected their adverse moral experiences privately to the interviewer.

The artist-researcher carefully explained the process, which entailed first a brainstorm of a hospital characteristics mentioned as "bad" or "good" and then acting them out in front of the children behind a portable puppet theater. The interviewer regularly pausing to inquired whether the evolving characters were correctly representative of the child's direction or if changes were needed. Children were invited to combine the "good" or "bad" characteristics into an improvisational story. During the puppetry interactions, children were given a choice of staging and if they wanted to film the improvised puppet play, act or perform voice overs affording them a greater sense of power over the interview process (Carter & Ford 2013, 95–107; Elwood & Martin 2000, 649-657). Four children opted to weigh in on anonymous plot summaries from other children's ethnodramatic play to discuss what they would add or change.

Data Analysis as Fiction Writing

One seventeen-year-old participant living with the disease reviewed all summaries and notes from the four plot consultations with the researcher and collated all relevant details, changing only some character details for continuity. The researcher verified that no elements of the analyzed plots had been omitted working with the central participant until their hospital discharge. The researcher transposed remaining participant contributions who had specified how preoperative process "ought" to be done and supplemented the story with themes emerging from the earlier stages of the focused ethnography for completion and coherence of a script for a play (Redvall 2009, 22-26; Wang et al., 2019; Cleary et al., 2020c, 1-67). The resulting 4,000 word, two act play with four scenes, entitled "The Hospital of Unhappy Surprises" is available as supplemental material together with classroom activities related to its presentation and analysis. A brief overview of the ethnodrama is summarized and a critical reflection as follows:

The Hospital of Unhappy Surprises Summary

The ethnodrama features two co-protagonists: Angie, the younger sibling of Dario, an older child with OI. In the first act, Angie who does not have OI fractures her leg and is bought by ambulance to the emergency room. The hospital is colorless, has long wait times and no nurses are available. Two robot parents, characterized as passive and mechanical as per children's descriptions of "bad" parents, consent to a surgical procedure without telling the children. They then awkwardly reassure Angie, before abandoning her in the emergency room with her brother Dario for a long, lonely wait. Dario shares his wisdom about just letting the experience pass. Suddenly, Nurse Mona, who previously worked at the "Hospital of Unhappy Surprises", arrives on a magic carpet with the children's imaginary friend, a large unicorn, to spirit them away to the colorful "Magic Hospital" where Nurse Mona is now happily employed. The Magic Hospital has a large playroom, accessible parking and good working conditions for the nursing staff. The nurse directly communicates with the children's imaginary friend letting them know a better hospital experience awaits them, which is staffed by a happy Dragon surgeon and his hospital staff.

At the Magic Hospital, the children are served a magic sauce, which is drunk by the whole hospital community. The magic sauce is designed to help keep people happy and calm and be kinder to one another. The children's real parents arrive and their children express concern for the parents' wellbeing, embrace them and serve them magic sauce in beautiful mugs but there isn't quite enough for a second serving. Angie and Dario are shown a vision of what happens in hospitals without magic: they would have been seen by a robot physician more concerned with going on vacation than taking care of his patients. The robot physician in the vision misdiagnoses Angie with merely a broken ballet slipper and painfully grabs her injured foot despite her protest. The physician appears annoyed and announces he will operate.

The parents offer to protect Angie in the magical blanket that would keep her safe from knowing the details of surgery but she refuses. The parents slowly start turning into robots as the dragon surgeon helps determine, with the input of parents and other members of the interprofessional team, who and how should the medical information be explained to the children. Dario, in this case, was not hospitalized but wanted to know information about his previous medical experiences. As such the dragon surgeon explains the procedure to Dario children and the parents assist brokering medical information to the younger child Angie as they are completely turned into robots. The Dragon surgeon concludes and asks about the children's further concerns and verifies their understanding of the procedures. Angie screams and points to her robot parents now malfunctioning and going mildly beserk in the background. The hospital administrator leaps into the frame and explains that the magic sauce is running dry and it has to be regenerated by everyone working together to do pre-operative admissions "right." Nurse Mona and the gives Angie a "bogeyman inventory", so she can draw out her fears and a series of common hospital "boogeymen" are reviewed. In this case, Angie's greatest fear is that her hospital gown might be too small. Angie gives her drawing to Nurse Mona who understands, asks questions, and brings her a properly fitted gown. Nurse Mona shows the children some of the tools and devices that will be used in the surgery. In all, the preoperative process is slowed down enough to allow the children to process their emotions, discuss their thoughts and feelings with adults and render assent. The surgery is then carried out, sensitively, as Angie understands that something positive will result as she now understands her risks and benefits as a "pizza pie chart" which the robot parents, now slowly becoming human again, help explain.

Angie's successful surgery is celebrated. The hospital administrator interjects that children are needed to help transform gloomy children's hospitals everywhere. The play ends with the hospital administrator entreating all staff, parents and children in the work of making all hospitals a great place for children. Children are given microphones by the hospital administrator, Humpty Dumpty, to distribute to other children stranded in "pre-op". The siblings fly off in the dawn prepared to help other children everywhere.

Critical Reflections

The Hospital of Unhappy Surprises is a composite of children's plots and insights and an aesthetical interpretation of their perspectives. In the "bad hospital", the rushed, rude and abstracted robot doctor represents suggestions from three participants who stated that "bad" doctors do not "put their patients first" and do not "get to the heart" of the issue, (which was represented as a misdiagnosis in the play) and are unavailable due to chronic vacationing. Participants of early elementary years expressed that "mean" physicians override patient dissent, only speak to parents and generally "aren't very nice." Another participant confirmed this negative experience from her own life story. As she became more mature, she became angry with this pattern, started to manage her own care and, like Dario, chose to speak directly to the clinicians. She further mentioned that language barriers alienated her parents from hospital care, which was represented by the Morse code spoken by the robots. Notably nurses were not mentioned in the "bad" hospital narratives as protagonists. Two participants clarified their take on the systemic causes of suboptimal care: bad hospitals had poor nurse-patient staffing ratios that resulted in long waiting times. However, the participants may have been reluctant to share any adverse experiences of nursing care as the interviewer was also a nursing graduate student.

The insensitivity of the robot surgeon was counter posed by the passivity of the robot parents derived from participants stating that "bad parents" would be disengaged, superficially reassuring children and siblings, and then abandoning them during the perioperative process.. Another participant stated that being separated from her parents while they looked for parking was a negative experience. Having access to a magic carpet that allowed the story characters to park near the hospital entrance instantaneously contributed to the features of a "good" hospital. All participants confirmed their preference for colorful and clean environments, good working conditions and the avoidance of stressful surprise operations.

The story originally ended with OI being magically cured for everyone in the whole world by a friendly and kind doctor. This version, however, precluded participants' suggestions who offered plot progression and construction after the central participant's discharge. The other participants offered direct feedback to improve peri-operative and surgical assent processes. These contributions were shown in a slow, sensitive, way in depicting how children desire assent and surgical procedures to be carried out. Notably, the risk-benefit analysis was a desired component of pre-operative information and optimally explained through a "pizza" pie chart, instead of an abstract percentage, reflecting a manner of inclusive communication with children. The slower perioperative process allowed for "emotional processing" with family members (including siblings) and included opportunities for children to express care for their parents. Younger participants expressed more concern about separation from parents while older participants increasingly expressed concern for their families' well-being during hospitalization. The children, as patients, preferred to work with their parents or directly with the clinicians to discuss sensitive medical information. This suggestion was derived from a youth participant and his sibling without OI preferring to discuss medical information with their parents instead of "someone they had just met" during the perioperative process. The "bogeyman inventory" was derived from two twins living with OI who expressed concern that clinicians may not always think about what the children might be afraid of. They recommended clinicians incorporate varying strategies to ask children directly about their fears and concerns. Participants expressed the importance of showcasing the "superpowers" of the story. These superpower messages entailed ensuring Angie, the main character, had a choice in where or how she received care; had her dissent weighted; and reinforced the importance of transforming "bad" hospitals to good ones to benefit all children. Two other sibling participants, one living with OI and one who did not, did concede that there was a place for benign paternalism in life threatening decision making wherein they would trust their parents and might not want to know the details of the surgical planned care.

Discussion

If we have the heart to listen the "Hospital of Unhappy Surprises" can teach viewers what children living with OI most need from the adults who care for them and transport them back into the world of children. The theatrical play offers a rich and multi-leveled account of how children perceived their therapeutic landscapes and preferences for built environments, ethical perioperative care, optimal organizational and communication dynamics. The study sought to illuminate in depth and specificity what causes moral harm to children living with OI, how they would transform these sources of harm, and actively participate in their hospital care in order to bring these insights into the classrooms of future healthcare providers. For instance, children clearly prefer spaces that were clean, well-cared for, brightly coloured, had good food and included adapted play areas (Rollins 2009, 201–11; Koller & McLaren 2014, 451-464). Furthermore, children reiterated findings previously reported by Rollins and colleagues (2009) on the importance of interconnected hospital staff members to create a similarly emotionally warm and bright environment (201–211).

Nurses, portrayed in “The Hospital of Unhappy Surprises”, were never villainized by the children. Now, the children may have had a reticence to critique the interviewer who was also a nursing graduate nurse or indirectly their nurses who were providing care at the study site. However, the collaborative storyline of the children revealed how they experienced the absence of sufficient nurses as a form of hardship. The absence of nurses left the children feeling isolated for long periods of time and being unable to move freely. Dario and Angie children experienced increasing amounts of anxiety imagining what will happen to them without sufficient medical information to allay their fears echoing similar findings in the literature (Wangmo et al. 2017, 11-20). Nurses establish close relationships with hospitalized children as evidenced by Nurse Mona’s ability to speak to children’s imaginary friends in the play. Nurses professionally serve as the individual who reliably listens and carefully explains medical information to families in varying hospital settings (Bray et al. 2012, 1964–1973; Corsano et al. 2013, 294–304; Swallow et al., 2009 49-59). The children, in the present study, wanted nurses to leave understaffed hospitals and favored their transfer to a healthy work environments. A scoping review of factors related to nurse burnout found that pediatric nurses are particularly helped by high levels of organizational support and that this in turn, improves the quality of care for children (Buckley et al. 2020, 9-11). The important role nurses play in the story suggest they influence significant positive contributions to illuminating and resolving dilemmas caused by prevailing medical decision-making practices that may exclude children and inflict unnecessary distress (Carnevale et al. 2017, 268-284; Koller 2017, 451-464).

The Hospital of Unhappy Surprises storyline extended myriad parallel child-driven study findings about what helps and harms children during the perioperative and surgical processes that must form part of future child health professional's training. There is potential for children's preferences to be honored outside the decisive viewpoint; addressing the dehumanizing experiences of uncaring surgeons who do not really listen to children; optimizing the direction of medical communication towards parents; or avoiding complex use of language that marginalizes children (Bray et al. 2019, 1-20). Notably, children living with OI in the study mirrored reports from hospitalized children at large stating that adult communication designed at reassuring their emotional state actually had the effect of shutting down satisfactory exploration of their feelings and truly alleviating what was causing the child to worry (Bray et al. 2019, 1-20; Wangmo et al. 2017, 11-20). Such behavior was included in what constituted a "bad" hospital. The study, furthermore, corroborated literature demonstrating that children have morally sophisticated preferences, systems of meaning and an ethical calculus that takes into consideration matters of importance to them (Carnevale et al 2017, 268-284). Our study indicated that children themselves are helped by exercising their ability to care for the people who care for them including their parents, siblings and nurses. The children demonstrated a felt solidarity and concern for the welfare of other children in similar circumstances across the world. This study contributed to the research needed to pinpoint what provokes children's anxiety in the perioperative process and how best to alleviate their distress. Similar to other findings, children do not wish to be left alone in the hospital in the hands of strangers, rushed through preoperative preparations, dehumanized, ill-informed, or have their dissent weighted (Bray et al. 2012, 1964–1973; Carnevale et al. 2017, 268-284; Koller 2017, 451-464; Wangmo et al. 2017, 11-20). Children living with OI rarely wanted to be completely uninvolved in the surgical decision or, as other research has demonstrated, involved so late in the process acquiescing to the surgical procedure is expected thus rendering their participation merely symbolic (Bray et al. 2012, 1964–1973). These results on the whole seem to indicate that children experience themselves as resilient, competent and that adults ought not underestimate their coping abilities (Rollins 2009, 201–11; Wangmo et al. 2017, 11-20).

Clearly, a child's hospitalization is a psychosocial event for the entire family system and the dynamic: the effectiveness of parental coping is one strongly correlated factor in the child's experience (Burns-Nader et al. 2014, 6–18). As found in this study, children confirmed that their parents, particularly mothers, were best positioned to broker information about the upcoming procedure and felt many medical staff were “strangers” (Buckley & Savage 2010, 2879-2887). Children’s concepts of uninvolved “bad parents” were represented by robots who passively left the child at the hospital and “good parents” were sensitive, involved and helped them process their feelings and understand medical information. This approach contrasts the rationale of excluding children from medical processes in the name of “protecting them from unsettling feelings” and champions children’s right to be informed about upcoming procedures(Montreuil & Carnevale 2016, 503-511; Bluebond-Langner 1980, 221-281; Hudson et al. 2019, 13-17). Parental understanding and skill in navigating the healthcare system is a significant factor in children's coping and experience of distress (Burns-Nader et al. 2014, 6–18). Our findings suggest that for some children, parental skill in navigating the healthcare system ought to include strategies for effectively brokering medical information to their younger children and facilitating older children’s management of their own care. Indeed, these parents are “experts” in knowing their children’s experiences and how various clinical and non-clinical approaches can affect them favorably or unfavorably; yet, may not be adequately prepared for the commonly implied role of clinical interlocuter to accompany substitute decision making (Trowbridge & Mische-Lawson, 2014, 640-658; Bowyer, 2016, 63-69; Montreuil & Carnevale, 2016; Coughlin 2018, 138-146).

The study similarly demonstrated children’s aversion to working with strangers in lieu of parents (Rollins 2009, 201–11). Furthermore, children are acutely sensitive to the suffering of their families who worry about them during procedures and desired to be able to care for their parents as much as parents care for them (Carnevale 2017, 268-284). The "magic sauce" of kindness and calm is an adaptation of art-as-object interviews wherein children envisioned a magic potion that would not only soothe their parents but also help staff have better days and soothe distraught parents. Offering children opportunities to express their care and concern for their families during peri-operative preparation was indicated in our study as part of the shift away from children being treated as objects of adult moral action and acknowledge their subjectivity within their own morally rich landscape. Lastly, our study pointed to the important place of sibling relationships in the childhood world of OI and the clear way in which siblings share each other's pain and experience of chronic hospitalizations similar to siblings of other chronically hospitalized children (Gerhardt et al. 2015, 750-804). More research is needed to clarify these dynamics in the OI community and may draw from the experiences of these other sibling populations of chronically ill children.

Strengths & Limitations

The ethnodrama generated keen insight into children's perspectives on the varied moral malaises in "bad" OI care and their suggestions for its transformation by leveraging the liminal space between fiction and reality to explore how children themselves would solve these ethical dilemmas in an emotionally safe manner (Rollins 2009, 201–11; Koller & McLaren 2014, 451-464). Offering innovative choices for the "good" to "bad" storytelling technique respected the heterogeneity of children and aligned with best practice recommendations for flexible child-centered approaches that minimized power relations between researcher and participant (Carter & Ford, 2013, 95–107). Surprisingly, while controversy exists over what range of ages for which puppetry is an effective interview modality, this study demonstrated sustained engagement, enjoyment and effectiveness for the youngest and oldest participants in the study ages 6 and 17 respectively (Epstein et al. 2008, 49–56). Above all, this study makes the unique contribution of generating and disseminating research results, in the form of a performative piece, that is accessible to both adults and children completing the arc of a study design by, for and relevant to children. The relatively small sample size and maximum flexibility of the theatre of the oppressed technique, offered the benefit of in-depth improvisational playmaking that revealed the moral dimension at work beneath daily clinical operations.

The concept of "truth" as an ethical issue in arts-based health research remains elusive: whose truth is being told and how do actors in that environment and factors in the child impact the telling of that story? These questions endure in this, and many, forms of practice-based research. The optimal flexibility of our study design in the end significant emphasis on researcher subjectivity in interpreting how to represent various child viewpoints aesthetically and authentically (Cox & Boydell 2016, 83-91). Availability of subjects for limited time periods in the clinic and sudden social distancing practices due to COVID-19 halted further efforts to finalize the ‘‘interpretive authority’’ over how to collate and symbolize all children’s contributions to the final script (Driessnack 2005, 415-423). Nevertheless, although the co-created nature of practice-based work commonly implicates researcher subjectivity in improvising storylines with children, every effort was made to ensure children were “driving” the plot and catalogued children’s creative choices were represented in the final collated play. This care could not, however, account for how "triggers" of choice of puppets, easily identified as a doctor or nurse, offered may have potentially constrained the narratives of the children (Carter & Ford, 2013, 95–107).

Conclusion

Theatre reveals to us that our actions are in essence a performance and that the script can be reimagined and the story we tell can be retold in ways that create justice, connection and fulfilment of our values. The lifelong implications of surgical procedures make the transformation of perioperative care to engender participation and sensitivity to children all the more an urgent component of health professionals training (Bray et al., 2012, 1964–1973). The hospital holds an important sociological significance and are the locus of positive or negative aesthetic associations, emotional feelings, interactions and attachments that develop and impact the identity of care users and performers dialectically (Rohani & Shaliamini, 2015, 183). As a teaching tool, the fluid, intersubjective and unfolding nature of this ethnodrama captured these co-constituting relationships and represents a significant to mapping the human geography of the clinical environment so that future healthcare professionals may successfully navigate the ethical dilemmas experienced by medically complex children (Bray et al., 2012, 1964–1973; Carnevale et al. 2017, 268-284; Earle et al. 2006, 270-282; Gibson et al., 2016, 1397–407; King et al., 2018, 1829-1841; Wang et al., 2019). From the liminal space between fiction and reality, this collaborative ethnodrama emerged as an educational centerpiece to locate problematic practice and voice children’s alternative vision for a moral future (Raynor 2019, 691-710). Its affective pedagogy allowed for greater attunement to the needs of children by allowing them to “think, feel and matter” in research not only by/about them but also accessible to other children (Ehret 2018, 53-71; Raynor 2019, 691-710). In all, The Hospital of Unhappy Surprises allows us to see what part we adults may play in the suffering of children living with osteogenesis imperfecta and awakens the empathy, and humility, to follow the children's lead towards a new moral horizon.

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Figures

Figure 1. Child with OI converses with other characters in ethnodrama

Figure 2. Close up of Melissa & Doug Puppet Theater used for research process (Item 2530, www.melissaanddoug.com)

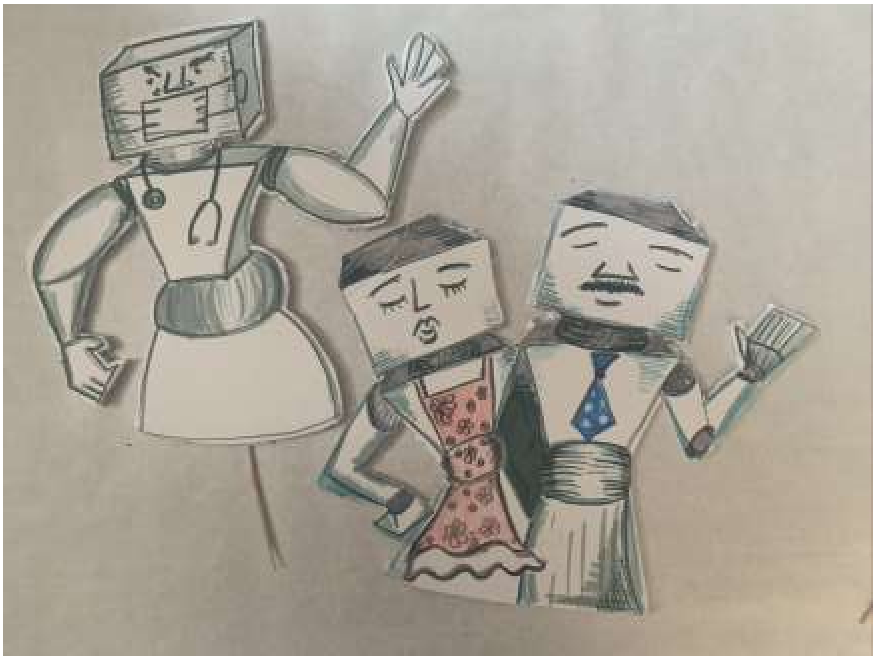


Figure 3. Robot Parents and Surgeon personify children's feelings of dehumanizing treatment during their care

Figure 4. Close up of Humpty Dumpty hospital administrator, risk/benefit pizza, mug and hospital props. Puppets include Melissa & Doug Dragon Puppet (Item # 30360, www.melissaanddoug.com) and FUN 365 School Learning Aid Puppet (Item # 58/1007, www. https://www.fun365.orientaltrading.com).

Supplemental Material

Interview Guide:

(1) Imagine a terrible hospital: What is it like?

(2) Imagine the best hospital in the world: What is it like?

(3) Can you tell me a story of how a terrible hospital becomes a good hospital?

Preparation for Workshop

Narrative exercise homework:

Consider the following section of script (with extra space between lines). Writers keep a different "script within a script" to track notes and ideas about the world the characters inhabit: what they think, their background, their motivations, who has power, their values, their secrets etc. Students are encouraged to write this second script, the motivation and beliefs that cause character's speech and actions, on top of different sections of the play as homework before seeing the full piece. All students must come to the presentation of the play prepared to present their different segments of the "metascript" to further understand the motivations of the characters as well as identify different sociocultural, historical and political influences detailed in the readings on the practices of childhood medical decision making.

Assigned Reading

Please complete the mandatory foundational reading on consent and assent and choose three articles from the remaining list. Please write a 600 word synopsis and reflection of all your chosen readings and what you most learned from them

1. Mandatory:
    - Heubel, F., & Biller-Andorno, N. (2005). The contribution of Kantian moral theory to contemporary medical ethics: a critical analysis. *Medicine, Health Care and Philosophy*, *8*(1), 5-18.

2. Choose:
    - Excerpts from The Passion of the Western Mind - Understanding the Ideas that Shape Our World View by Richard Tarnas
        - Jean Jacques Rousseau
        - Kant
        - Locke

And/or (student choice)

    - Excerpts from Fass, P. S. (Ed.). (2013). The Routledge history of childhood in the western world. Routledge.

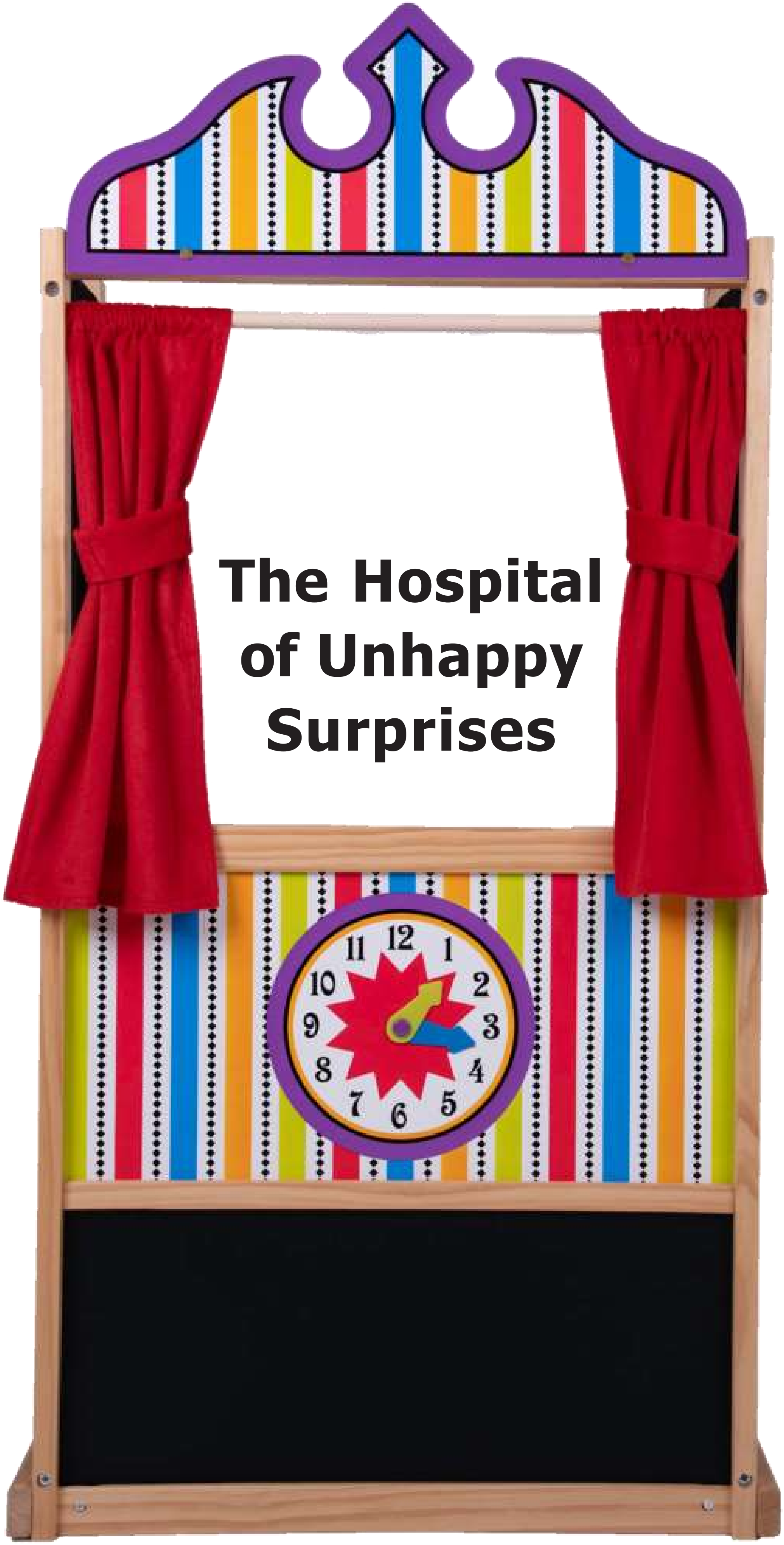
3. Choose:
    - Navin, M. C., & Wasserman, J. A. (2019). Capacity for preferences and pediatric assent: Implications for pediatric practice. Hastings Center Report, 49(1), 43-51.

And/or (student choice)

    - A Relational Ethics Framework for Advancing Practice with Children with Complex Health Care Needs and Their Parents by, Franco A. Carnevale PhD, Gail Teachman & Aline Bogossian

4. Choose
    a. Reynolds, J. M. (2017). "I'd rather be dead than disabled"—the ableist conflation and the meanings of disability. *Review of Communication*, *17*(3), 149-163.
    b. Barnes, C. (2012). Understanding the social model of disability. *Routledge handbook of disability studies*, 12-29.

The Hospital of Unhappy Surprises



Act 1 Scene 1

Scene opens with Angie being picked up by an ambulance from a school theater. Narrator pauses to allow puppet improvisation.

Narrator: It was a terrible day at the school play for Angie had twisted her knee and broken another bone during her dazzling debut. Angie was not just any little girl but a courageous one: independent and unafraid of exploring the world around her. Her very best friend in the whole world was her brother Dario who lived with osteogenesis imperfecta. Every time he broke his bones she felt as if she had broken one of her own. But this time she really had. With a zip and a splash and nearly a crash an ambulance whisked her away. The clown paramedics struggled with her frilly costume tutu of which there was much ado and as they were about to pull away!

Angie: “Oh no you don’t! Not without my brother!”

Brother mounts ambulance

Narrator: So away they went quite a pair with a frilly tutu, stretcher and wheelchair. The ambulance zoomed and vroomed past strange looking trees and funny birds and purple bees and at last they pulled into a very strange hospital called The Hospital of Unhappy Surprises.

Ambulance pulls up to a gray colorless hospital whose windows anddoor look like a sad face.

Narrator: People were spilling out of the waiting room, it had gray walls and lots of gloom and not to mention the smell. The food was the worst and where was the nurse? A glowing sign gave her number in line which was not one bit less than 500 bazillion and ninety point 9!

Puppets act out dismay as a clock prop’s hands move in circles over and over.

Hours passed and she was feeling sad but just then robots who looked just like mom and dad appeared. They were not at all mom and dad and really quite weird. They creaked and they squeaked and…

Robot Parents: “You’ll be just fine try not to whine and do what the doctors say. This is your preop admission we’ve made the decision. You’ll be staying here and we are leaving to go to the hotelbed to stay… .”

Robot parent pats Angie’s head in a glitchy manner and wheel away. Children look at each other, look at the camera perplexed and puppet scream in unison. Clock hands twirl interspersed with close ups of the children looking increasingly bored and exasperated

Narrator: Angie was given the hospital gown that was too small and left alone with her brother in a very strange place for hours of terrible waiting. There was nothing on the walls and nobody in the halls and so she waited and waited in bed. They had no idea what was going to happen in the OR the next day and if it was the right thing at all. They knew one thing for sure that whatever was going to happen it would happen by surprise.

Clock hands twirl with ticking sound growing louder

Angie: Dario I’m scared. What’s happening???

Darío: “I don’t know Angie (shaking his head) I’ve been here to this hospital dozens of times and I never know…You just have to let it pass! I am sure our parents made the right decision for you and the doctors know what they are doing.”

Angie: But that’s not ok! How come we are the only ones that don’t know what’s happening when we are the ones it’s happening to??? Besides those are not our parents. They had bolts and screws and funny robot voices and metal hands. This place is not a hospital it is clearly a madhouse."

Narrator: The two children looked at each other not knowing what to say just waiting and waiting and waiting and waiting and not knowing not knowing not knowing not knowing! Until a troubled sleep fell over them both.

Clock hands twirl with ticking sound growing louder

Know: The children tossed and turned in the great black night waiting for whatever terrible unhappy surprise would pass.. Hours passed and just as dawn was about break they heard a knock on the door and a spunky nurse wearing brightly colored scrubs tiptoed into the room.

Nurse Mona enters from offstage consulting with the imaginary Unicorn friend to find the children in the dark room

Angie and Darío: “ Who are you!?!?”

A match is lit and we can see her face.

Darío: “ Nurse Mona!!!”

Nurse Mona: “Shhhh!!!! Be very quiet I’m going to get us out of here”

Behind her trailed the unicorn carrying a magic carpet and a beautiful multicolored box. They are singing and speaking amongst themselves inaudibly in the shadows. Matches are periodically illuminated and we can see the fiasco of getting everything on a magic carpet.

Nurse Mona: (whisper) “Hop on kids! Next destination the magical volcano!”

Imaginary Unicorn dances and high-fives nurse Mona

Narrator: And off they went flying into the deep blue night sky lifting higher and higher away from the gray city and its frowning city buildings. the sky and the stars became more and more colorful and the beautiful box began to sing songs about kindness, comfort and calm. All the worry of the waiting and the not knowing began to melt away as they flew straight through the night and into the light of day…..

Scene ends with backdrop of the starry sky with planets and comets zooming….A Unicorn Only Accessible Parking Spot sign is seen zooming by where they park and arrive to the magical hospital

Act 2 scene 1

Scene opens at the top of magical volcano upon which there is a shiny happy hospital that is brightly colored. A babbling brook of hot cocoa flows in front of it. As the magic carpet touches down the colorful box begins to giggle and laugh and nurse Mona opens it revealing two jumping eggs: one purple and one white.

Nurse Mona: "Don't worry…These are special eggs that sense when magic is growing near… You'll see!"

The eggs continue to giggle and bounce up and down the unicorn is clearly happy to be home

Angie and Darío: " Where are we!?!?"

The purple egg begins to crack open revealing a happy Dragon in a white lab coat wearing a pink stethoscope. The white egg covered in tiny little fractures begins to expand and grow a bowtie, crown around his neck and funny duck legs. A white cloud of smoke curls up behind them and a glittering multicolored hospital <u>with a giant playground</u> rises from the top of the mountain.

Humpty Dumpty: "Welcome to the hospital on top of the magical mountain! I am Humpty Dumpty your hospital administrator."

Dr. Pepe: "And I'm Pepe the Dragon your friendly head hospital physician!"

Nurse Mona: "I knew you would be much happier here…I left that terrible hospital to come work here on the mountain and rescue children stranded in preop."

Darío: "I remember you nurse Mona! You were my favorite nurse I worried about you in that hospital too. You did everything nice and slowly so I was ready for it and stopped when I asked you to. Gee whiz you were my only friend in that terrible terrible place."

The unicorn nods vigorously

Nurse Mona: "Of course I remember you Darío. How could I possibly forget and leave you behind there ever again? Here drink this."

Nurse Mona dips two mugs into the river of hot cocoa and passes them to the children. Unicorn acts as a comical foil throughout their time on the mountain according to the creativity of the puppeteer

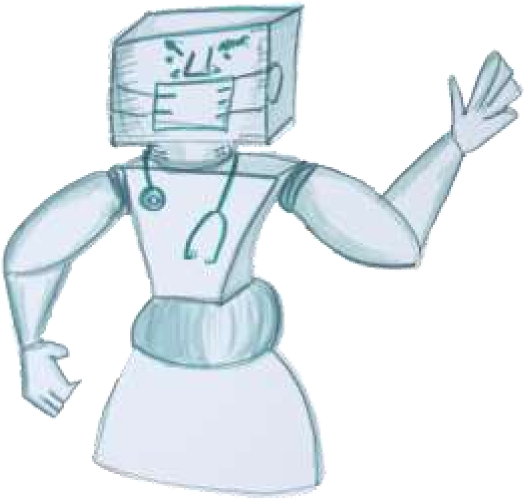
Nurse Mona: “This special magic runs freely in the heart of the volcano. It’s pure liquid kindness, happiness and calm.”

Angie: “This is the most delicious thing I have evertasted!”

Children slurp their drinks happily

Nurse Mona: “Its not only delicious…. Its very important! Just look what happens when it runs dry”

Nurse Mona dips her mug into the river of hot cocoa and pours it out on the ground. It swirls into a rainbow and becomes a jeweled mirror that the nurse holds up. It reflects a scene where each character is reflected as a worse version of themselves:



Robot Dr.: “what another patient? I don’t have time for this. You have clearly broken your ballet slipper. It will NEVER work again. Let me see that!”

Robot doctor reaches for her broken ballet slipper.

Angie: “No! No!”

Robot Dr.: “Let me see your broken slipper now!”

Dr. persists and the two wrestle

“It’s my foot that’s broken not my…….Youch!!’” Dr.: “Assistant!” He yelled.

Angie: In the room zoomed a robot assistant.

Carrying a tray of scary pokey things. The Dr.and his assistant spoke a robot language incomprehensible to Darío and Angie with just mom and dad.

Robot Dr.: (improvised robot speech) “Okay let’s operate….I want to get this over with and get back to the beach.”

Robot Dr. smiles haughtily while twiddling his sunglasses and towel around his shoulders.

Act 1 scene 2

Scene opens as the mirror swirls back into a rainbow and disappears into a poof of smoke. The Unicorn is crouching in the corner and hiding her eyes.

Angie: (Gulp) So you mean… That’s what was waiting for me down there??

Dario and Mona look at each other sheepishly, turn back to her and nod

Angie: (Gulp) So you mean… (Pause…. Children and Unicorn Puppet scream!!!)

Angie’s parents, now freed from their robot form, walk on stage.

Parents: “Don’t worry my love it was only a bad dream. We are here now and we will not leave you alone.”

Angie and Darío: “Mom! Dad!”—I was so afraid you were turned into robots in that terrible hospital!” YAY!!!!

The children run to their parents for an embrace and then excitedly run to the babbling brook of magic sauce and bring their parents steaming mugs

Darío: “We were so worried about you! Here have some of this pure liquid kindness and calm

to take care of youwhile we are here in the hospital.”

The children run back to their parents for an embrace and eagerly watch them to take joy in helping their beloved mom and dad. The parents begin to drink the drink and slurp happily making little comments about how lovely and delicious the magic sauce is and make happy butt wiggles of joy.

Parents: *Umm.. Slurp! Delicious! Oh! How lovely! Splendid I say! Grand! Ooof!*

Gone so soon? I would love a bit more !

The Magic Unicorn, mute and ever comical, makes a grand show of taking the mugs to refill from the magic river and can squeeze only a few drops for the parents' mugs. It's the audience's first glimpse that something might be wrong atop the magic mountain but the scene continues anyway. The parents are served their tiny drops which are painstakingly consumed and fade into the background.

Dr. Pepe: "Now Angie I need to examine your foot for a moment with the help of my butterfly-flower technology. This flower needs to flutter around your leg three times and apply its extra special petal technology to check and make sure the bone is healing well. If your bones need help healing it will share petal magic with them right where the fractures are. The procedure shouldn't hurt.

Angie: "Slow down!! I'm still scared! I know this hospital looks pretty and shiny and new and fun but it's still a scary place for a kid!!"

The unicorn rallies behind Angie to hold her hand.

Dr. Pepe: "Of course Angie. It's normal to be scared. . I am so sorry to have rushed through! I clearly got ahead of myself. Sometimes we doctors are so busy we do that.

Pepe the Dragon puts his big paws over his eyes and shakes his head… clearly embarrassed

Here…

Pepe the Dragon reaches into his white coat pockets and starts to fumble around

Here…Ermm. At the magic hospital…

Then draws out a box of markers and a clean sheet of paper labeled "bogeyman inventory".

…we have invented the bogeyman inventory. We realize that not everything is easy to say out loud especially things that might be scary or embarrassing! We will give you a moment to draw out what might be scary about being here and give it to the grown-up of your choice."

Dario wheel over, clearly interested in the conversation. The two siblings turn to one another to whisper about all the scary things in the hospital and periodically consult the unicorn. The Unicorn acts out the comical implications of each scenario as each child pops up into the camera frame in classic puppet theatre style. Nurse Mona is seen wearing reading glasses, ferverishly noting and inventorying each boogeyman and checking that they are each labeled and *hanging in the boogeyman closet (like Too Small Gown Goon etc. etc.)*

Darío: “Poky things!”

The unicorn grabs his butt and runs away as Nurse Mona checks and sees the “Captain Blind Needle: Pokes over and over” (a pirate with patches on both eyes) is swinging his syringe sword, is hung up and safely stowed away

Angie: “Being alone while mom looks for parking!”

A tumbleweed blows past the unicorn and western saloon music cues. Nurse Mona checks and sees a Saguero cactus labeled “Parking Desert” is hung up and safely stowed away

Darío: “Bad food!”

Unicorn holds her nose as Nurse Mona checks and sees a a walking ball of stinky green mush in clown shows labeled “Hospital Mush Monster” is hung up and safely stowed away.

Angie: “Surprise operations”

Unicorn leaps out of her fuzzy suit as a skeleton and then her fuzzy suit jumps over skeleton and the skeleton jumps back in the fuzzy suit each looking at the other and becoming so scared that they play this brief “leap frog” game. Nurse Mona checks and sees a 1960s style spy in a khaki duster and fedora. Only his bobbly eyes are visible in the black space between the two. Nurse Mona checks the label “Agent Ambush” and makes sure he is hung up and safely stowed away.

Darío: “Being alone because there’s no nurses”

Nurse Mona sighs, makes eye contact with the unicorn and shrugs her shoulders and holds out her hands as if to say “I got nothin’”

Angie: “Not being listened to when you say no!”

The Unicorn lassos the robot doctor off his beach chair. Music “Domo Arigato Dr. Roboto” cues. Nurse Mona grabs the enormous pair of hot pink ear mufflers with long eyelashes he is wearing from off stage and handcuffs them to the closet hanger. She puts them in a special “maximum security” section of the boogeyman closet where “Mistress Ear Muffler” is kept under lock and key.

Angie and **Darío:** “And things you adults could never dream of!”

Narrator: In the end Angie drew a picture of a too small hospital gown that showed her gangly legs. She passed it to nurse Mona who instantly understood and brought her a specially designed hospital tutu for the procedure, which of course, fit like a magic glove. The “Too Small Gown Goon” was forever captured and placed in the boogeyman closet where it would never

Nurse Mona: (wiping sweat from her brow) “Do you have any other questions or concerns?”

Angie nods her head and looks side to side her head and makes a funny face.

Angie: You guys are really great and I am glad you are going to fix me up but……I just met you like 5 minutes ago!

Dr. Pepe: "….. and you might want to talk about the procedure with your parents?"

Angie nods her head and looks a little guilty

Dr. Pepe: "…No trouble at all my dear I am glad you said something.."

The parents kneel down to her level with the unicorn alongside holding a sparkling "magic blanket"

Parents: "You know Angie we *can* take care of you and figure this all out *for* you if you just let us wrap you inthis magic care blanket."

Angie: "Sometimes I might want a magic blanket but not today, today I think I can be afraid and still….*(pushes away blanket)*…. Can you tell me what's happening mom and dad?"

The parents stand up and begin to move a little bit like robots but not so much as to be obvious

The unicorn gives them a quizzical look

Darío: "Dr. Pepe can you tell me what's going on? I've had this done a million times and nobody at the hospital has ever talked to me directly."

The unicorn nods vigorously

Nurse Mona: "Here Angie and Darío why don't we move this closer so you can see the butterfly technology of our magical hospital while you guys talk."

Narrator: "So, nurse Mona drew the butterfly nice and close so she could see it's pretty pretty wings and goofy bespectacled eyes. And the two children talked and talked until…"

The parents and the doctor are shown in two frames side by side. Mona and the Doctor flip through drawings with Dario and are engrossed in conversation. The little butterfly-flower Angie and her parents talk together as the parents move more and more like robots Nurse Mona and the unicorn sit together and seem satisfied by the conversation

Act 2 Scene 2

Darío: "I get it!"

Angie: "I …. I… I…. don't….!"

Angie points to her parents who, upon close up with the camera, have been turned back into robots. The camera turns back to her and she screams and hides behind the unicorn who acts frightened and then pretends to be brave.

Humpty Dumpty: "Hold on!"

Mr. Humpty Dumpty peers at the robot parents assessing their robotification and leveling his spectacles.

Humpty Dumpty: "Oh no… This isn't good

Angie and Darío: "Did somebody leave the boogeyman closet unlocked?!?

Children look at each other, look at the camera perplexed and puppet scream in unison.

Angie and Darío: "Not again!!?

Robot Parents: "You'll be just fine try not to whine… You'll be staying here and we are leaving..

Robot parent moves to pat Angie's head in a glitchy manner but Angie ducks and a jerky spark is seen flying off the robot's elbow

Humpty Dumpty: "It's the magic sauce…. It's been running low lately.. If we don't learn to manufacture it real quick the magic sauce will run dry and there will be nothing but Hospitals of Unhappy Surprises….. Everywhere!!!"

Robot Parents(background): "You'll be just fine try not to whine….. You'll be staying here and we are leaving..

Robot parent continues to glitch in the background

Humpty Dumpty: You all play a critical part in saving the day!"

All: "Who me!?" How?? I'm just…..

Puppets bumble around looking incredulous. The two children, nurse and Dragon ask in bewildered semi-unison. The unicorn coos and the Humpty Dumpty puts his hands on his "hips." Even the robot parents awkwardly cock their heads to one side and their jaws drop

Robot Parents (background): This is your preop.... This is your preop..

Humpty Dumpty: "Just a kid? Just a nurse? Just a parent? A doctor? Yes all of you. You must all work together to save the power of our magicmountain and …(looks at increasingly glitching robot parents) quickly!!!! We have to do pre-op right!! Right away!!"

Nurse Mona: "Where do we start??"

Humpty Dumpty: "Bogeyman inventory?"

Nurse Mona: "Check"

Humpty Dumpty: "Heart Monitor?"

Robot Parents (background): Try not to whine.... Try not to whine.... Try not to whine.... Try not to whine....

Nurse Mona: "You mean.... The machine?"

Humpty Dumpty: "Yes.... The magic one!"

Nurse Mona: "Ah!"

Nurse Mona holds up her finger and runs offstage only to return wheeling a vitals machine that has a large painter's palette on a tube strapped to a pole and a large rectangular screen hanging off a strap.

Nurse Mona: "Here!"

She passes Angie the art palette which she starts to play with but hesitates to put the strap to hang over her neck.

Angie: "I don't know what this is....!"

Angie starts to put the strap over her neck as Mona explains.. A heart with an anxious emoji is shown in the center of her chest

Nurse Mona: "It's the magic heart monitor.. You can draw how you feel and it lets grownups know what's going on in your heart

Angie: "Oh ok....!"

The anxious emoji rings (think the sound made by a flash of shiny white teeth in a gum commercial) and a happy, peaceful emoji is shown in the center of her chest as she doodles in the air in the delighted way of a fully engrossed solitary child

Humpty Dumpty: "We are forgetting something"

Nurse Mona: Kids would you like to see and feel the butterfly flower technology?

Angie and Darío nod vigorously. And they wave at the flower who waves back and lands on their noses. A delightful butterfly dance ensues. The heart monitor emoji registers from anxious to tickled pink.

Humpty Dumpty: "Now.."

Nurse Mona: (interrupting) "What about the parents? Doctors don't always explain things in a way kids understand!"

Darío: "Yeah! Mom and dad always can…er.. could..before…

Dario looks over forlorn at his robot parents who are now standing slack-jawed with their forearms *dangling side to side from their awkwardly positioned upper arms. They make creaking sounds, spark and repeat in the back ground clips from Act 1. Particularly the phrase "made the decision"*

Darío: "You've got to help us help mom and dad!"

Mona matter-of-factly reaches into her deep scrub pockets and draws out a steaming pizza pie dripping in cheese. She cuts a small sliver.

Humpty Dumpty: "Nurse Mona are you cutting the cheese???

Nurse Mona: No silly! (eyeroll)) Children asked to have things explained in a way they understand and most every kid understands pizza!

The river starts to bubble.. Humpty Dumpty leaps up in joy.

Humpty Dumpty: "It's working! I don't know what that is but we need more of it!"

Angie: "It's a chance pie! I want to know: what are my chances to dance again?! The chance the surgery doesn't work?! I need to know too! I want the biggest slice!"

Angie nods and her robot parents (now not sparking but still frozen) nod their heads and blink in unison with a beeping sound… The little transformation shows that they are becoming human again.

Nurse Mona: Here Dr. Pepe help them.

Angie places a slice of the pizza pie in the robots hands who can't quite hold it yet so it is stabilized by the unicorn's tail. The large pizza pie she gives to Pepe to hold

Dr. Pepe: "This is the big piece… It represents all of the good things that can possibly happen. And this…

Camera zooms in on little slice which parents can now hold together. The parents on either side point to it. Parents show a little more that they are becoming human again.

….is the tiny sliver that represents the things might not go according to plan. As you can see it is very tiny as our high tech butterflies are quite that good. Does that make sense?"

Angie: (nods mumbles and shrugs)

The river starts to bubble but then audibly peters out.. Humpty Dumpty looks at the stalled flow.

Humpty Dumpty: "Angie and Dario I know it's really hard to do sometimes but….. There is only one way that the magic from the world of children can flow and take root in the often unmagical world of grown-up robots. Do you know how that is?"

The two children look at each other and shake their heads. Humpty Dumpty reaches into his in deep blue polka dot pockets and draws out two child size megaphones.

Humpty Dumpty: "By speaking up!!!"

He passes the megaphones to the two children

Angie and Darío in unison: “That’s allowed????

Palms megaphones and try to figure out which side is which

Angie and Darío in unison: Speaking up????”

The earth begins to shake and the mountain rumbles in the background.
The unicorn jumps up and down joyfully.

Humpty Dumpty: “Yes! You have to be a part of the process.”

The earth begins to shake and the mountain rumbles in the background. The unicorn jumps up and down joyfully scarfing up the small slice of pizza with the help of his tail. Angie and Dario gobble up the large piece happily as the parents at first, still robots, walk normally to Angie and Dario and kneel down smoothly and slowly. They are restored to their humanity but still are shown only in grey scale.

Angie: (with megaphone) I understand and I think something good will come out of it so bring on the butterfly!

The river continues to bubble but appears stronger. The parents start turning to pastel colors.

Dr. Pepe: “Okay good Angie great. Can we start? Is it okay if I touch your foot?”

Darío: “Mom and dad!! You are coming back!!!

Mom: “We think this is the very best thing sweet heart. We all are here for you but what do you think?”

Angie: I.. I… (stammering)

Nurse Mona: We are here for you Angie!

Narrator: And because she trusted herself, and she trusted her parents who trusted Pepe wholistened and helped make her feel safe and understood. She overcame her fear and nodded. She grabbed her microphone and bravely said

Angie: “I’m ready…!”

Humpty Dumpty: “Eureka!!! It’s working! The magic sauce it’s regenerating!”

The parents turn to full color as they embrace their two children once more. The magic sauce begins to bubble, and ariver of glittering lava emerges in the foreground of the scene. Butterfly flowers bloom along its bank as its flow emerges. Dr. Pepe’s (surgical) butterfly flower grabs the river with her *wingtip and braids it into Angie's broken foot where it seems to dissolve. She carefully daubs her foot a magic paintbrush and it sparkles and becomes whole again.*

Dr. Pepe: All better…!"

Narrator: "The bright flower twirled and swirled with his little pocket of magic and paintbrush and both her foot and bedazzled red ballet shoes glittered as never before. She was all better and both her and her brother danced together with delight. Everybody was about to sayTHE ENNNNN…"

Act 2 Scene 2

Humpty Dumpty: "Hold on!"

Humpty Dumpty reaches an arm through the closing curtains,straightens his crooked bowtie and wiggles his body and, again, levels his spectacles.

Humpty Dumpty: "Ahem!"

Humpty Dumpty takes his cane and pokes back at the "The End" sign threatening to descend on his head. The characters look a little peeved at the interruption of their bliss.

Humpty Dumpty: "I didn't come all this way just to have you dance off into the sunset! You have to spread the magic far and wide into other hospitals around the world. There are gray and unhappy hospitals everywhere that need your help! Are you with me?"

Humpty Dumpty excitedly reaches into his coat pockets unloading a small mountain of megaphones. The unicorn, children, and nurse Mona all work together to stack them onto the magic carpet. The Unicorn wears one as a hat.

Angie and Darío in unison: "Aye aye captain!"

Humpty Dumpty: "You have work to do!

Dr. Pepe: Bravo…!"

Darío: "We are going to make this right right away!"

All salute Dario and Pepe claps his hands

The children reach up to the Unicorn offering her hat/megaphone by tilting her head, Pepe offers a bouquet of magical flowers, Mona bottles a jug of magic sauce, and Humpty Dumpty passes them a blank bogey man inventory

Angie and Darío in unison in the megaphone: "There will be no more hospitals of unhappy surprises!!

The heart monitor begins to radiate a glowing rainbow as Angie says Yipeeee! A clear strand of rainbow slips from her megaphone through the clouds and touches down on the gray gray city and the gray gray hospital. A little bit of color could be seen far far away. The sound of magic sauce bubbling in the heart of the mountain could be heard.

Narrator: "And away they went. Into the deep blue sky back into the gray gray world with the secret of making magic alive in their hearts and a mountain of megaphones to give to children everywhere. The end. Or is it the beginning?"