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Article abstract

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## Childhood Worldings of Brittle Bone Disease: A Portrait in Five Triptych Research Poems

Brenda Cleary, Franco Carnevale, and Argerie Tsimicalis

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*This paper offers a collection of found poems offering insights into representative worlds of children living with dis/abilities, chronic hospitalizations, and the ethical dilemmas surrounding their perioperative care. The collection represents the sum tota poetic crystallization of a multiyear ethnography focused on the ethical experiences of the childhood osteogenesis imperfecta community as encountered in a specialized North American pediatric OI clinic. The collection deliberately bridges multiple separate (yet deeply connected) worlds of children, clinicians, and family members to reveal their interdependence and yet preserve each individual's distinct viewpoints.*

**Key words:** children with dis/abilities; found poetry; osteogenesis imperfecta; brittle bone disease; ethical dilemmas; perioperative care

Poetry, as perhaps no other written form, demonstrates the profoundly interrelated nature by which a phenomenon co-arises by its collective parts. Found poetry wherein research documents are abbreviated and combined to produce concise representations of data offers a particularly useful means of preserving and presenting research insights within their multifaceted and emotionally evocative context. The purpose of this paper is to offer the childhood studies community a collection of found poems offering insights into representative worlds of children living with dis/abilities, chronic hospitalizations, and the ethical dilemmas surrounding their perioperative care. The collection represents the *summa totalis* poetic crystallization of a multiyear ethnography focused on the ethical experiences of the childhood osteogenesis imperfecta (OI) community as encountered in a specialized North American pediatric OI clinic. The collection deliberately bridged multiple separate (yet deeply connected)

worlds of children, clinicians, and family members to reveal their interdependence and yet preserve each individual's distinct viewpoints. The collection is divided into five triptychs: The Ethical Community; Solitude; Culture; Decisions; and Hidden Struggles. Each triptych is composed of three poems examining these research themes from diverse interlocking vantage points within the community of care to highlight their dynamic interplay.

### Background of foundational study

The complete collection of found poetry shared here is derived from research conducted at the Shriners Hospitals for Children®—Canada in collaboration with VOICE—Views On Interdisciplinary Childhood Ethics Research Group at McGill University. The research aims to promote a stronger recognition of the voices of children with OI

and their desire to participate in matters of importance to them (Wang et al., 2022). Culture, hospital protocols, and clinicians' ability to engage with children play an important role in whether or not children are fully heard in clinical settings. The question then becomes: How might children's complex values, ethics, and preferences be made visible (and actionable) to adults who care for them during their chronic hospitalizations? (Wang et al., 2022).

## Thinking and feeling with poetry

While the collection of poetry offers a considered response to this question, it refuses any clear answers. In a previous coauthored methodology paper, "The Poetics of Brittle Bone Disease," we discussed the slow, intentional creation process of the found poems and situated qualitative themes within the greater discussion of childhood bioethics (Cleary et al., 2022). Much like how one would cut up pictures in a magazine to make a collage, different parts of research interview transcripts were cut and pasted to compose these found poems. In this case, the first author intentionally hand-cut pieces for each of the found poems from our research team's extensive interviews with children with OI and their siblings, families, and clinicians and accompanying research field notes (Wang et al., 2022). Each word, line, space, and punctuation mark was painstakingly selected to communicate emergent research themes within their emotive matrix and contained by the aesthetic logic of poetry (see Figure 1). In this article we share all of the created poems to be engaged directly as the works of literature that they are.



Figure 1. A simple diagram showing the poems in progress during the stages of composition.

As opposed to the secondary abstractions of more traditional research, the poetic form allows readers to directly immerse themselves in a felt push-and-pull of contradicting forces within a child's experience of hospitalization. These poems are offered as tools to think about, feel, and companion the unseen struggles children face in their attempts to enact their values. Through intercalating the voices of multiple adult care providers, readers are invited into multiple layers of felt difficulty, paradox, uncertainty and pathos, inherent to navigating childhood bioethics. The layering of multiple vantage points in the triptych format reveals the tesseract (see Figure 2) of forces in the hospital ecosystem interacting at micro, meso, and macro levels to support or thwart children's inherent agency. This collection of found poetry offers a clear, integral, and simultaneous line of sight into the heart of this emergent ethical dilemma, yet neither dictates readers' interpretations of it nor captures the composing author's

point of view. Thinking and feeling with poetry, as such, is not an innocent act but one laced with ambiguity and conjecture. Readers find here not a sanitized set of idyllic poems but one that is at times grotesque, transgressive, and vulnerable.

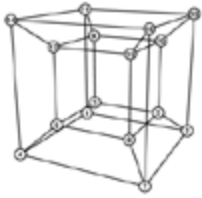


Figure 2. A tesseract is offered as a metaphor for the collection of poetry's ability to portray multiple visible and invisible dynamics and points of view simultaneously (Petrov et al., 2022).

## The collection

The collection revolves around repeated use of the triptych: a work of art divided into three pieces but presented as a single unit. The triptych served a classical format of European art from the Middle Ages onward that, without overt explanations, invokes the patriarchal Euro-Western lineage of many ideas framing modern clinical care. The following five triptychs, Ethical Community, Solitude, Culture, Decisions, and Hidden Struggles, each offer readers possibilities for a more wholesome picture of what the vast interiority of children might include. The founding study communicated the need to include children in medical decisions and discussions of import to them lest they suffer unnecessary duress (Wang et al., 2022). The collection of poems, on the other hand, may offer some insight into the child's mind and heart so as to encourage greater efforts to elicit their perspectives and inspire more child-centric practice.

"The Ethical Community," the initial triptych, flanks an extensive presentation of children's suffering in silence with an image of their resilience on one side and the clinical community discussing possibilities for a better way of including children in perioperative processes on the other. It is followed by the triptych "Solitude," which evokes how children with dis/abilities have embraced a creative and lively solitude within their experiences of social othering and alienation. "Culture" assumes the center of the collection and grounds the poetry in an awareness that cultural forces can serve as a source of strength for children and families, as well as a heavy inertia deterring positive evolution in models of clinical care. "Decisions" reveals children's own solutions to bioethical dilemmas and portrays forces preventing those solutions from being operationalized. For instance, the poem "Parent Patient" allows readers to feel alongside the paralyzing fear of parents that prevents them from enacting the kind of collaboration children ask for in "A Child's Response." "Hidden Struggles," the final triptych, invites readers into the subjective struggles of the human beings who offer childhood clinical care and the young human beings who receive it, specifically, the struggle of a surgeon against his patriarchal training, the tension between the natural ability to relate to children versus the lack of it, and the resistance of dis/abled children against discrimination at large. The final triptych alights an empathy for all the actors who have crossed the stage of our minds as we wrestle with the literary work. In the ensemble, readers experience the interconnectedness of seemingly individual struggles and the interdependent nature of their positive solutions. Above all, readers experience the richness of children's "inner universe" and the importance of authentically listening, responding, and including children in their clinical care.

*Triptych 1: The Ethical Community*

We begin our explorations with the following triptych, *The Ethical Community*, which challenges adult readers to consider the ethical dimensions of bridging their solitudes with those of children. The triptych first introduces clinicians and hospital administrators in “Art Allows Us to Connect.” These (primarily) adult voices are drawn from individual interviews and a large panel discussion focused on improving the inclusion of children in medical decision making. “Operations By Surprise” is drawn exclusively from children’s interviews. The two poems draw attention to the is/ought tension in clinical care: the gap between what is currently operational clinical practice and what is envisioned as a more ideal manner of delivering care. In this case, readers see the stark contrast of a stoic child silently enduring hospitalization against the possibility of eliciting vivid disclosures of children’s own needs, preferences, and ethical values with an improved bedside approach. While the silence of children is not explained, readers are invited to invoke their empathy to ponder what this marginalization might feel like for a child facing surgery. Readers also see that children experience acute concern for their families during their own surgical procedures. The last poem, “Crazy Strong,” names the subjective presence of a researcher bearing witness through her field notes and draws heavily from an interaction of a physiotherapist’s interruption of her interview to conduct a clinical assessment. The excerpt was selected to highlight the strength children develop in bridging the is/ought divide. The poems synergize to elicit greater respect for children’s courage and philosophical depth and the love that steadies families in difficult times. Readers are invited to become allies to children in their journey.

**Art allows us to connect**

You know they are tough decisions:

“It wouldn’t be good to amputate too early because it was thought that there would be a better result if you kept your two feet.”

Art allows us to connect.

When a child doesn’t speak, it doesn’t mean that they are not engaged.

Some contexts facilitate expression while others suppress it.

Give them a little space to draw how they are feeling

and show where their pain is.

Their inner universe is rich and alive.

Artemaking is one vehicle to enter a child’s world,

reveal what was hidden or unknown,

and visualize what is going on inside their head.

It is morally important to be authentically heard.

The child’s voice is needed to know their best interests.

Give them a little space to draw how they are feeling and show where their pain is.

If the concept of ethics is where you draw the line,

art is not traditionally part of the guidelines  
to let them know that they are being heard.

So

Nurse...

Parent...

Doctor...

I know it's scary and intimidating

to create this world from zero.

Instead of using the world that is already there...

awareness is an important first step in creating change...

Attunement to a child's voice is the work of everybody:

A shared vision.

A shared culture.

A paradigm shift.

Equip them with the power.

Do you like to dance?

Child: No. I like to make (others) dance.

Can you help me?

### **Operations by surprise**

My dad, to keep track for us, he tattoos himself.

Every time you fracture he gets a tattoo?

Participant: Yes.

Surprise!

Spine fracture having bent the rods.

Pain.

Both femurs broken.

Waiting a long time.

Humiliation.

Nobody told me it was going to be like this.

Pain and immobilization.

Unable to wash.

I stink.

Surprise operations that really really hurt.

My dad, he didn't tell me because he didn't want me to regret it if something happened.

I black out.

Restless nights.

You're worried about your mom who has to take care of you?

So much pain.

Surprise! Stuck in your bed.

Doing your business in the bed.

I stink.

Can I go outside?

Please?

[his sister fed him spoonfuls of food while his head was immobilized by screws]

It's in the process of healing.

Is it discouraging? A little.

They don't listen to us.

My parents don't speak English.

The doctors only really speak English.

I didn't feel ready to go back home.

Nobody tells them what's happening.

Surprise!

Yeah, I would say it's them [the staff] that make the decisions. C'est la vie.

We can talk about it but it's gonna happen. It's gonna happen. It doesn't matter how it's announced or introduced. It changes nothing.

When you get an operation you just want to lay back and do nothing.

When you're going through difficult situations you try to get yourself out of it.

But with an operation you have to just let things pass. It just takes the time it takes.

I feel tired

But...

OI isn't...?

Participant: No.

My condition, apart from the operations, doesn't really take up much space in my life.

Interviewer: No? You don't have the feeling that it keeps you from doing things?

Participant: No.

### **Crazy strong**

[I didn't know if I should stop the interview

or stop reading the story...or??

Playing is the heart of the child's world in mind and in body.]

So, you're a tennis player?

...Your sister is the dancer...right?

[She drew a picture of herself in a tutu.

She drew a picture of the constellation of Hercules hanging inside her heart.

She seemed to hide her face for a moment...

bury it behind her pillows... tearing up...

The villain of their story took away the children's ability to play,

left them sitting on the bench alone watching others move with their bodies freely.]

Physiotherapist (interrupted us): Left hand last one. Keep trying. Squeeze as hard as you can, more and more and more; okay, good work.

Look at how strong you are. That's crazy...



*Triptych 2: Solitude*

The selection continues with an exploration of the nuanced nature of children's solitude as a source of strength, imagination, and fruit of the suffering imposed by othering. While no two children are alike, this triptych offers us a window into this aspect of a hidden world that is both a source of creative rapture and sorrow. OI-affected children and youth transcend the struggle of stigmatization and the solitude it entails through rich imagination, perseverance, physical play, and a deep sense of solidarity with other children. By understanding their unique concerns, we can better help them thrive according to the values and concerns that are important to them. Artmaking is one tool many OI-affected children and youth use to express themselves to others and an instrument of resistance against limiting social narratives of dis/ability.

**In my little bubble**

In my little bubble,

I'm really good.

When you go to the hospital, do you play games that involve the people around you, or are the activities only for you?

Child: Only for me.

I don't really make direct ties with other people.

I alone think about things. I look out the window and I imagine myself.

Do you feel different from other kids at school?

Yes.

I don't have friends.

I feel so different from other people.

But

I don't feel the need to have friends.

*I isolate myself*

**Mine, just mine**

There are so many things in their lives over which they have no control.

But I do all the things; whatever I want and I can, I do it:

- My puppet that I want to make
- Crayons, or pastels, or markers
- Sled hockey allows me to skate and play hockey

- Making origami
- Drawing in the hospital
- To have the nonverbal expressed
- Watercolours or acrylics?
- Making dolls

Participant: Yeah, and I modified it.

Interviewer 2: In your head.

TA-DA!

(laughs)

It's beautiful!

To laugh at situations that are a bit difficult

They said [my leg] it was like Robocop!

[Explaining the prosthesis]

I just write poems,

stories,

to have the nonverbal expressed,

Couplets... Haiku...

I want to audition for television

to be...

a comedian [!]

Interviewer: So, you like to make art at the hospital?

Participant: Yes.

I just like the thought of me creating something, and it's just like, mine, it's just mine, nobody... else's

### **In my imagination**

In my imagination,

me and my friends have this universe

we actually *become*.

I play

the costume is on in your head.

When I sleep at night, or when I rest, I like to think about them:

my dreams.

It's like this regeneration potion

but they couldn't control it because they haven't unleashed it yet,

and so they go, "Well, my God! We have powers!!"

Interviewer: The parents couldn't control it?

They couldn't control their powers.

They didn't know the powers

..... in my dreams.

Interviewer:

What do you like most, when you have complete freedom or when they...?

Participant: Complete freedom.

That's when my imagination goes...

(makes sound reminiscent of rocket soaring)

### *Triptych 3: Culture*

The third triptych, Culture, brings into view the forces of culture at work in the ethical community: both the microculture of family and hospital and the headwaters of colonial paternalism either opposing or synergizing with them. We see children's awareness of identity in the poem "Family Culture," which references the work of caring, young patients' positive response to childcentric environments, and their engagement with family traditions. In these poems we see the ways in which adults charged with their care come together like a patchwork quilt that wraps around the children as best they can. Children with brittle bone disease want us to know that they are not as fragile as we may think and are aware of the social dynamics driving their care. "Creating a Culture" intercalates the voice of a surgeon talking about leading by example with the voices of children aware of the impact of workplace culture on the quality of their care. In this poem children name the power of generating "good" (i.e., responsive and inclusive) hospital culture as how they believe all children facing operations can best be served. The triptych ends with "The Surgeon's Scarring," which offers readers a rare glimpse behind assumptions of paternalism to show

how surgeons grapple with the ethical dilemmas inherent in their work.

### **Family culture**

Every wedding that happens in our family, my grandma folds 1001 paper cranes, and um, folds 1001 paper cranes and makes them into, like, our family crest.

As a family

those are the happiest moments.

[Traditions hold the world together.]

My mother is always there.

She always comes.

She's closest to me.

She knows more than your father?

Yes... she gives him a list of things to do.

They want the best for me.

She's always there.

She always comes.

Interviewer: Do you go out together after treatment to eat somewhere or something like that?

Father

Yeah, we usually do.

Interviewer

That's fun. What kind of food do you like?

Father

Everything. (Laughs).

If you fold 1001 paper cranes, then the gods will grant you your wish.

### **Creating a culture**

The way is by example.

It was like, just like the atmosphere, it's like, it wasn't really a hospital, even though it was, just how, kind of peaceful, calm, all the things you associate with a home that you've been to for a while.

She enjoys coming here a lot better.

We love the breakfasts

playrooms...

bright colours.

I could tell everybody in the hospital was close, they all knew each other, there was a real sense of community.

Are you able to teach that to your residents? To your fellows?

If I could have one magic power?

It would be for transformation...

to replicate the good hospital.

### **The surgeon's scarring**

Do we scar them for life?

Do I bypass the parents to inform the child?

Informed consent is mandatory for adults.

Parents forbid me from telling the child.

Traditionally, children were viewed as possessions of their father and not beings in their own right.

So where is the cut-off?

Where is that transition, ethically?

What am I supposed to be obliged to tell that child?

What does a [5-year-old] understand about 2%?

How much input does the child have?

A [5-year-old] doesn't see the bigger picture.

We can't afford for him to be 18 and say, oh, now I want the surgery.

Should we be including the child in the whole decision process [?]

It may just confuse them?

I think that you have to listen to your child and try to figure out what's what, but if the child doesn't have the competency to take the decision,

if they don't understand the bigger picture...

Maybe the assumption is that they're not mature enough to see the bigger picture.

.....but maybe they do.....

How do you consider that?

When the [5-year-old] tells me he doesn't want surgery,

I know that no matter how you're going to look at it,

it's... a... horrible... decision...

We don't give him the light of day.

#### *Triptych 4: Decisions*

Although making space for the voices of children is the work of everyone in the hospital ecosystem, habits can get in the way of that. Children have plenty of suggestions for how to make the hospital better for them. Children know exactly what helps them during their hospitalizations and we can hear their suggestions in the following poems. Above all, they do not want to be surprised by upcoming surgical procedures. The following triptych shows multiple forces at play in peri-operative decision-making processes. For instance, "Parent Patient" draws from clinician interviews and demonstrates how parents are often so overwhelmed with the prospect of children's upcoming procedures that they displace their children's participation in medical decision making. "A Child's Response" derived exclusively from child interviews proposes that children and parents work as a team. They also suggest that physicians use appropriate means to communicate with children so that they can understand these procedures and render their assent. These poems open with a poetic exploration of the question "Do we listen to children to appease their emotions or to ensure that they are authentically heard?" This question frames the call and response structure of the second and third poems by invoking a critical ethical dimension to the way in which adults listen to children.

#### **Do we listen to children to appease their emotions or to ensure that they are authentically heard?**

Do we listen to children to appease their emotions or to ensure that they are authentically heard?

Participant: Mama...

Mother: What, my love?

Participant: It hurts.

Nurse: I know it's scary and intimidating.

Don't be afraid.

Participant: I am afraid.

Why do we listen to children?

Is it to soothe their emotions, or to make sure they are authentically heard?

I have to start to trust more in myself but. She doesn't know how.

Most children are talked over and not talked to.

It impacts children when they are suddenly offered that space.

Children need support in terms of making that experience more common.

Child: Yes, the doctor told me it was a little dangerous..... that I could be...

[pause]

Paralyzed.

I didn't know how it was going to finish, and I was a bit scared, but at the end I decided to do it, because I knew it was the best for me.

**Parent patient**

That's our perception.

As a medical team, do we impose the way that we think or not?

Is it ethical to impose a treatment on a child?

Well, the law tells you yes, it is.

.....<<<<<<<[[[[their parents.....they are frozen]]]]>>>>>>>.....

they are so afraid to make the wrong decision,

so they don't make the decision.

My values and my approach

are themselves an ethical question.

Where do you draw the line?

.....<<<<<<<[[[[ their parents.....they are frozen]]]]>>>>>>>.....

they are so afraid to make the wrong decision,

so they don't make the decision.

They say,

“I would like my kid to be aware.

He has to understand what is going to happen...” It is not up to me to decide.

I am going to influence that patient’s approach toward his kid

[I mean]

The parent’s approach.

We will take that away from you.

We will make the decision.

You know, I catch myself just talking to the parents and the kid is just sitting there the kid is just sitting there.

My values and my approach

are themselves an ethical question.

### **A child’s response**

Child: Even in the best hospital parents have the final say.

I don’t think it would be too scary if somebody was to ask for my permission.

But I know why they didn’t tell me about this.

They didn’t want me to feel like I made the wrong choice if anything bad happened.

Can you tell me what’s going to happen?

If you don’t want to do something and your parents say you have to

I would back them up and say it’s not all about you; I’m also here.

There’s a risk

You are not the only person alive.

It’s not all about you.

I’m also here

[He seemed to trust that his parents would listen]

If it’s like life or death,

I would not want to know.

It would be scary. I would be scared



But  
I would want to know.  
I would say no.  
If you show me the light out of it.  
Yes,  
bad things that could happen,  
but  
the worst thing is when it's too quick to know what's happening.  
Not everyone is attuned to hearing children's voices and communicating with them.  
Fractions? yeah. I learned that last year, not really anymore.  
Oftentimes grownups use numbers [to explain medical information]; it doesn't always work with children.  
Maybe. How do you say... a pie?  
Kind of like cut it up in 100  
to show chances of winning or losing.  
Tell me something good would come out of it, like, yeah. Like if I could be able to walk, run, and play and do things that other people can do.  
Tell me what's going to happen, what my condition is step by step, almost.  
{Surgeon: Parents should talk with their children,  
families should talk to other families,  
it's better if it's a group decision}:  
Less stress,  
Slowly,  
yeah, slowly,  
yeah, so they can process.  
Have parents step it through instead of someone brand new.  
Somebody is less likely to be shy with their parents as opposed to with a stranger  
or someone that you met like once four months ago  
[who can't] get to the heart of the problem.

[End of Interview]

### *Triptych 5: Hidden Struggles*

The final triptych, Hidden Struggles, reveals the process of perioperative decision making and unseen struggles therein, specifically, the struggle of a surgeon against his training, the tension between the natural ability to relate to children versus the lack of it, and the struggle of disabled children against discrimination at large. In “A Bit Fatherly” transcripts from an interview with a surgeon show an individual somewhat regretfully reviewing how large the sociological forces are that dictate medicine and how he is sadly “father(ly).” The poem “Innate or Learned Skills?” showcases two approaches to working with children from the transcript of a nurse performing clinical care with a child in the room versus a story recounted by one of the participants about his medical care in another hospital. In this brief poem the contrast in the bedside manner is evident and readers are turned to the question of whether these skills can be taught, learned, and enacted at a greater scale. The question of social change is raised again in the final poem, “The Hardship Was Not a Medical Problem,” in which children’s fight against discrimination and their commitment to integrity in the face of injustice is clear. We see in this triptych social change in the psyche of healthcare providers grappling with social norms, the granular change of sensitive micro-decision making with children, and the need for a more compassionate world both in spirit and in literal, concrete change to built environments. The poetry makes visible these hidden struggles so that their solutions can also emerge.

#### **A bit fatherly**

The concept of ethics is where you draw the line.

My approach, sadly, is a bit like a father.

That has nothing to do with medicine: it is the approach of society.

What we believe is best for the child

is sociology..

It is an institution...

Residents tell me, “Oh, you’re like a mentor to us.”

The way is all by example.

That has nothing to do with medicine: it is the approach of society.

You give them a false hope that, yeah yeah, they’re part of the decision, but in fact,

they don’t know,

they don’t know best.

It’s something that you realize in getting older.

My approach, sadly, is a bit like a father.

**Innate or learned skills?**

Nurse: You want to leave with that on?

Participant: No.

Nurse: Okay, you decide: yes or no?

Participant: Yes.

Nurse: You want to pull it off? Go ahead.

Participant: No, you do it... OOOOOH, Owwww.

Nurse: Don't touch; it's done. Look! You see?

vs.

« There were doctors I didn't like there [at the other hospital]. Interviewer: Why? Participant: Because they were a little mean. Interviewer: What did they do? Participant: Every time I asked them to stop touching my leg. They didn't listen. Me, I don't like that. »

**The hardship was not a medical problem**

It's physical and social barriers;

The hardship was not a medical problem.

It's physical and social barriers;

.....The teachers were not nice.

.....bullies.

.....The doctors were a little bit mean.

He wished that he would not feel so much pain when others made fun of him.

Stigmatization:

that was the hardship.

I did not live with the sense of being different;

children in my school were sensitized.

They started saying what would and would not work for me

[so I wouldn't have to].

Still,  
I would like there to be ramps instead of steps,  
bigger bathrooms.  
If I could change the world?  
Kindness.  
I would just make everyone a bit kinder.  
It's hard work  
to throw roses in return for rocks.

### Final thoughts

Childhood perioperative decision making involves determining the “best interests” of the child and making decisions accordingly. Nonetheless, clinicians and families can exclude children from the very conversations that define those best interests. In so doing, hidden concerns, preferences, and what children need most to flourish through hospitalizations might never enter clinical care plans. Child patients may be left feeling bewildered, abandoned, and unheard in already unfamiliar hospital settings. The poems reference children experiencing “operations by surprise” when they may have clear ideas for how to create perioperative processes that engender a sense of safety and positive lived experiences for all. Chronically hospitalized children, such as those living with brittle bone disease, often develop complex strategies to navigate medical decision making despite prevailing societal notions of their fragility. Disseminating children’s expertise, as done in this collection, challenges assumptions that children are but passive recipients of adult care. Eliciting perspectives and solutions from children, as a collective practice, must form the fulcrum of any movement toward more child-centric models of care.

Poetry, however, is too nuanced an art form to stop at a mere directive. The collection does not allow readers to point a finger at the supposed ignorance of adults who need to “get with it” and update their practice. In the words of the poet Naomi Shihab Nye, the poetry collection allows readers to relate with “[sorrow] till your voice catches the thread of all the sorrows and you see the size of the cloth” (Nye, 1995, p. 21). Parents and clinicians have their sources of bewilderment and moments of felt powerlessness. By offering insight into the interwoven threads of all these actors’ interlocking vulnerabilities an all-encompassing compassion is evoked. Reaching for professional reflexivity necessary to address the potential deficiencies of the past becomes emotionally safe in the warmth of this compassion. Without giving marching orders, the poetry points to the ways in which all actors, whether facing or brokering difficult medical decisions, need to be individually resourced in order to engage the work of social change and fully support children’s inherent agency. The children’s voices presented in this collection of poetry seem to indicate that change is possible.

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