

ORIGINAL ARTICLE

“Communicating Lily’s Pain”: A reflective narrative commentary about co-creating a resource to provoke thinking and change about assessing and managing the pain of children with profound cognitive impairment

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Abstract

This paper draws together about 20 years of research work and discovery and the development of a resource about pain assessment and management in children with profound cognitive impairment. The animation tells the story of an imagined child called Lily and the skills her mother uses and the challenges that her mother faces in assessing and managing Lily's pain. The animation is built on stories drawn from qualitative research findings, conversations while in clinical practice and with members of the general public, parent advisers and other sources. Most of the “evidence” came from stories shared by parents and healthcare professionals. This paper draws on some elements of socio-narratology and is predicated on the basis that stories are important and they can act on and with us. By using an animation to tell Lily's story, the intention was to communicate research findings to a wider and more diverse audience than the typical readership of an academic journal. The intention was to act in and on people's consciousness about children's pain and to strengthen relationships and create bonds between clinicians, parents, and children in pain to make their dialog more social, connected, and meaningful. All three of us—the researcher, the writer, and the animator—have been marked and “re-shaped” by our work related to creating Lily; we have learned more about children like Lily and their mothers, and we have learned more about ourselves and our humanity. This animation is still a story in progress, a story ‘in the wild’, a story (and a resource) we would like you to re-tell and share. The story of Lily's pain aimed to change the lives of parents and children and professionals. Our hope is that you can be part of that change.

KEYWORDS

animation, assessment, child, developmental disabilities, intellectual disabilities, pain, profound cognitive impairment

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1 | PROLOGUE

The introduction of most research papers positions the work in the context of specific epidemiological factors or definitions of the “problem” being considered or relates the topic to other published work. This paper is strongly informed by a reflective narrative (or story-based) perspective¹ and, thus, it adopts a somewhat different approach from a typical scientific paper.

Put simply, the core aim of this paper is to tell the story of the co-creation of a resource (an animation and information sheets) which aspires to enhance the practice of pain assessment in children with profound intellectual disabilities or cognitive impairment.

This paper, like most good stories, starts with the introduction of a character. In this paper, this character is Lily, who is an imagined, but very real—to me at least—child. Lily and her mother feature in an animation (*Communicating Lily's Pain*¹). Lily was created to try and reach out and “touch” people, to help them appreciate the challenges that parents and clinicians face when assessing and managing the pain of a child who is profoundly cognitively impaired. Lily exists because of the children and parents I have met and worked with as a researcher and as a children's nurse. Where evidence comes from my research work,^{2,3} this work had gained ethics approval. Where the work was part of engagement and consultation, I worked ethically, for example, gaining permission from the people I engaged with to weave their words and ideas into my work, and as needed, I gained permission from gatekeepers; however, formal ethics approval for this type of work is not required within the United Kingdom.

I have had many conversations with parents about their children's pain, both as a researcher and as a clinician. Like other health professionals, I have a whole host of stories in my head about children I have cared for, many of them children like Lily. Lily has become a real child through seemingly endless hours of analyzing transcripts, through countless conversations with nurses, doctors, physiotherapists, teachers, other professionals, and members of the public. I have carried a child such as Lily in my consciousness for years. She finally emerged, co-created from a mess of ideas with the help of a writer and an artist who have little direct experience of children like Lily but who absolutely understood the essence of what I wanted to portray and share with the wider world.

Arguably, Lily was created by the writer, the artist and I working together, but every pen stroke, every word, every nuance has been informed by the lived-and-shared experiences of parents who, on a daily basis, care for children like Lily. The emphasis in this paper is on creation in the widest sense of the word and how creativity can be inspired, buoyed, endorsed, critiqued, challenged, stretched, and magnified when working with people outside of our usual frame of reference.

This paper draws together an extended timeline of work and discovery about children like Lily, parents like Lily's mother and the clinicians who care for them. Some, but by no means all of the time, I

frame myself as a narrative researcher; I am certainly someone who has been interested in and immersed in stories for as long as I can remember. As a researcher, I have triggered, possibly provoked people to tell stories which I have listened to and with, attended to and learned from. I have read about narratives and have been influenced by Arthur Frank's writing; in particular, his work on generosity^{4;p25} which explores the importance of stories and dialog for both people who are ill and the doctors and nurses encountering and caring for them. Frank's book on generosity was a catalyst to my thinking about and with people and it made me even more sure that the stories we tell each other can be enriching and lead to better understanding of each other and our situations. Another important influence was his book on socio-narratology, which unravels and reveals much about stories and the ways that stories affect and can improve our lives by “enhancing human companionship”.^{1,p203}

This paper tells of a journey taken to tell a story through an animation that requires people to pause, listen, attend, and reflect. In its own small way, it is an attempt to improve the assessment of pain for children with profound cognitive impairment. Frank notes that stories “act in human consciousness” (p14), and stories have capacities, such as being able to “act to make life social” (p20). Although I did not know it at the time, my journey started with a somewhat fuzzy desire to act in and on people's consciousness about children's pain and to strengthen relationships and create bonds between clinicians, parents, and children in pain to make life and dialog more social, connected, and meaningful.

This is a co-authored paper but, like many stories, it is narrated in the first person by the first author (BC), who weaves in the ideas and words of the other authors (JM and RY) and of our parent advisors. All these voices are essential to the story arc; without these voices being shared the story (and this paper) has less capacity to engage and inform.

2 | TROUBLE: A BREACH IN THE EXPECTED

Trouble is central to all stories; trouble is a breach in what is expected;¹ trouble creates uncertainty and although we can never “get rid of uncertainty”^{5,p50} usually, we can manage it to a degree. In this paper, the trouble is a child in pain; more particularly, a child with very limited capacities to communicate their pain. Trouble is also evident in the challenges that confront parents and clinicians in managing that child's pain. Even when pain is part of a child's everyday life, some pains breach what is expected, reasonable, previously experienced and/or managed. It is these episodes of pain that constitute the trouble that is the heart of this story.

Children like Lily, who have complex healthcare needs and who are profoundly cognitively impaired (have severe intellectually disabilities or profound and multiple learning disability), experience pain from a wide range of sources. Typically, their burden of pain is high; the episodes of pain are frequent, persistent, and significant,^{6,7} and increase across their lifetime. Research shows that, all

¹<https://www.edgehill.ac.uk/communicatinglilypain/>

too often, many of these children receive inadequate assessment and treatment^{8,9} potentially reflecting a “double whammy” of high clinical uncertainty² and low confidence¹⁰ and/or knowledge levels. Unlike some other areas of children's pain research and management, these children tend to have been overlooked, with the body of pain research described as “small [and] slow moving”.¹¹ The evidence-base that does exist is inconsistently embedded within practice.¹²

Despite this, parents manage their children's pain with expertise borne out of experience.^{3,13} When pain spirals out of control or a new pain occurs, parents turn to clinicians for assessment of their child's pain; and, among many questions, they need answers about the cause and implications of the pain, and they want their child's pain managed. These answers are not always forthcoming. Sometimes health professionals and parents are caught up in different stories; communication can seem impossible as attention is tuned to different facets of the child's needs. Stories told by parents reveal their desire to be listened to and for conversation to be engaged and productive; Frank^{14,p16} makes the point that conversation (dialog) requires openness:

Dialogue opens when both are willing to become caught up in that other's story, letting go of what has been their own story, at least provisionally.

The animation is one means by which we hope that parents and professionals can become caught up in each other's stories.

3 | THE JOURNEY TO TELLING LILY'S STORY

An unexpected opportunity led me to a meeting with a professional writer (RY), who frequently uses his creative writing skills to help health professionals connect and communicate through words and ideas. For me, working with a writer to help me tell Lily's story opened up a whole range of opportunities. Despite having worked narratively, interpretatively, and qualitatively for years and being open to the nuances in the data I handle, I am framed by my nursing and health background. I am framed by the expectations of how I should write, communicate, and inform. A professional writer is driven differently and his lack of preconceptions about the pain that children such as Lily experience means that his starting point, preconceptions, and the connections he made with the material I shared were very different to mine. Not necessarily better, clearer, or more visceral—although they often were—but I soon learned that writers are really good at asking questions and digging for authenticity. Working with a writer triggered me to explore and explain my work in a way I was not used to. He challenged me to go deeper and work differently into exploring my data (stories from parents, professionals, and others), asking questions such as what colors came to mind when I recalled a particular story or what struck me as important to share from another story.

He was interested in words, responses, the drama of the events, how things unfold, things that could be said, and things that were not amenable to language. Although some aspects resonated with the way I work narratively, they were also different. Stories and writing are his job and he is less constrained by the conventions and practices that imbue my practice as an academic researcher and writer. He explained that one of the requirements for good writing is for him to approach the project “as an innocent”. I could see that innocence was a good starting point although, arguably, no-one arrives at a story about chronic pain as an innocent; we all bring some preconceptions, some life experiences and expectations. And, although the scenario of parents managing the pain of a profoundly cognitively impaired child was unfamiliar to him, he carries with him pain stories from when he was a child:

When I was 4, I pulled a kettle over my head, then spent years having skin grafts (part of my chest still looks like bacon, 50 years on). I'd have painful injections into the tissue and the reward for this was a cheap boiled sweet. I remember thinking, “it's not worth it”. Those early experiences of pain are still raw and visceral. Following an accident later in life, as I looked down on my leg, weirdly bent at the mid-shin, I remember thinking, “this is familiar”. Pain is a subject that is close to my heart, as well as my leg and my chest.

We talked about the challenges of communicating to a wider audience and accepted that it is both inherently difficult to talk about and disquieting to listen to and/or watch pain stories unfold. The writer's initial reflections about pain were on the elusiveness of pain:

You can't see, hear, examine or compare it. While everyone knows what pain is, no one can truly empathise as every pain is unique. Our gut-reaction is to change channels to something less disturbing. The world of children in relentless pain is so dark, profound and deeply private, it is almost unbearable. Added to that, the language we use to express pain is so woefully inadequate, it's almost absurd.

Working with a writer opens up opportunities that are outside of mainstream health funding; their understanding of what buttons to push in terms of artistic funding can be the difference between a convincing application and one that fails to meet the criteria. As a starting point for collaboration, we applied to a theatre company to explore and communicate the trouble that lays at the heart of children's pain. The application was successful and resulted in a week's residency working with 30Bird,² a company that creates interdisciplinary performances through collaborative practice. Working

²<http://www.30bird.org>

together with the director, producer, and technicians generated new conversations with people with no specific pain or health background, requiring me to explain the core challenges for and experiences of children like Lily and her parents. This sharpened and refined my thinking. We created “The Mother of All Pain”, an immersive sound and light installation, in which a fractured soundscape (including quotations from my research, sounds, and audio extracts from parent-driven videos) played in a blacked-out studio lit only by tiny spinning lights. We aimed for the installation to create an eerie sense of disconnection and movement that portrayed the uncertainty, loss and pain of the children and their parents.¹⁵ The entire experience would never have happened had the writer not had the specific skillset to pitch the bid in the first place and the imagination to weave the words, sounds, and performance together. Our different disciplinary experiences and perspectives were key to co-creation. The performances of *The Mother of All Pain* were successful in that they provoked a visceral response, evoking stories to be shared and communicating the essence of parents’ stories in a powerful and haunting way.

4 | CREATING A STORY THAT RESONATES AND REVEALS TRUTHS

“The Mother of All Pain” was evocative but it was never going to reach a wide audience, so we spoke to our parent advisors, and they concluded that we should create something to inform and educate parents and professionals. They agreed an animation would bring together the power of the spoken word and the moving image. Together (researcher, writer, illustrator/ animator and parent advisors) we worked to co-create an animation that would represent a compelling, accessible narrative that would resonate with both parents and clinicians and reflect the pain of children like Lily. We hoped that the final result would tell a story that makes people think and help clinicians learn about pain communication and engaging with parents of children like Lily. We knew that even with the support of the visual element it would be difficult selecting the right words for the script, as so much of pain communication, especially with children who cannot use language or signs, occurs without words. As the writer noted:

What interests me, as a writer, is that much of the communication happens between the lines: the writhe of a torso, the dart of an eye, it’s all “in” there, if only we knew the key. It’s a language issue, how do we translate the curve of a spine into a precise location that the clinician requires to isolate the pain? How does the mother’s metaphor, “she’s like a rabbit in the headlights” translate into a practical solution that an anaesthetist can grapple with? How does a child who can’t speak tell us where it hurts, when her body, language and society as a whole all refuse to cooperate? How can we, the allies, understand?

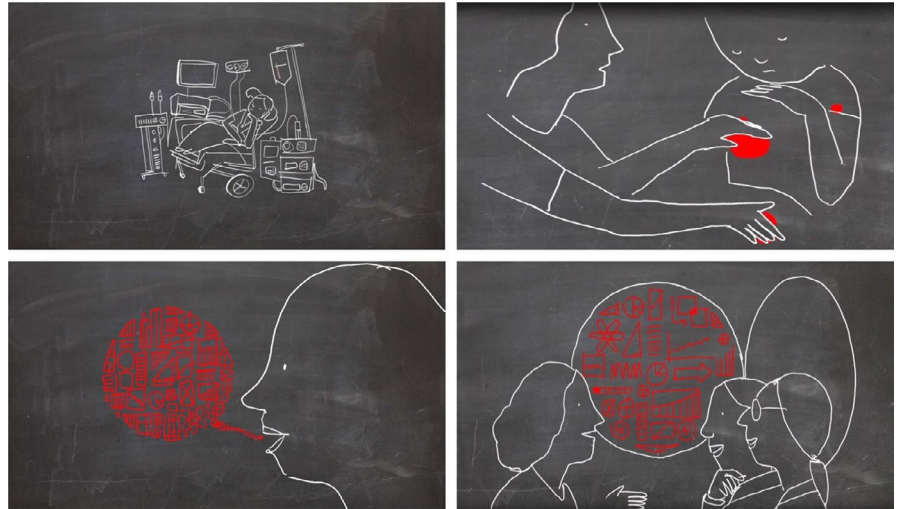
The parents were clear that the script should be based on the quotes from interviews, for example, from my previous research work³ and from informal conversations and engagement with parents, as these represented authentic lived experiences; this was also important to me as I felt that grounding the animation in evidence from research would add to its credibility.

The initial scripts or storylines were developed from quotes selected from both consultation work and work linked to previous research studies^{2,3} that reflected typical parent experiences such as “I can see in her face [that she’s in pain], but the doctors aren’t always convinced”, and “sometimes they [health professionals] just don’t listen to me, I know his pain, they need to trust me, help us, we need to work together to get things right”. Triggered by these, the writer started to draft ideas for a story arc, script, and suggestions for visuals (such as red dots representing the child’s pain). Neither of us quite knew what we expected from the initial drafts, although we agreed that “The Clear Clinician” and “The Friendly Parent” scripts felt a bit too arty. Engagement with our parent advisors suggested that in the first script the clinician felt remote and disengaged and in the second script the mother felt too disempowered and eager to please. We used their feedback to help shape and refine the script and to make the middle and end sections less metaphorical. As we continued to collaborate, we edged our way towards something that felt right. We knew we were telling a story, but we did not want it to be a work of fiction. As the writer noted, “the last thing you want is a parent saying, ‘that would never happen’ because in that moment, the illusion is shattered”.

Our story arc reflected a mother explaining how she knows when her child is in pain, how she can usually manage the pain fine, but turns to clinicians when the pain is new or getting worse. She explains that the best clinicians reach out to her expertise and listen, look and learn from her and how, joining forces, parents and clinicians can work things out. This simple message was a distillation of the core messages that parents had shared with me and that resonated strongly with our parent advisors. The script started by introducing the child we had tentatively called Lily and positioned her as being loved and beautiful but requiring care for her complex needs. This positioning reflects nearly every interview I have undertaken with parents, as parents always start by talking about what is special about their child before talking about their child’s needs. Our parent advisors provided feedback that this was “absolutely the right place to start”. When we reviewed the script it was clear that it also incorporated the key capacities of stories (e.g. trouble, character, point of view, suspense, inherent morality, resonance, and truth telling) indicated in Frank’s work on socio-narratology.¹ We also included potential prompts for the visuals, as we can see in this extract from the start of the script:

This is Lily.
(A childish drawing of a happy little girl)
She’s wonderful, and beautiful, and I love her to bits
(She has a balloon)
But she’s not like other kids

FIGURE 1 Selected images from “Communicating Lily’s Pain” animation



(Lines are scratched on the balloon, so it becomes a medical drip. Lily’s body shrinks a little and distorts).

Working with the animator (JM) now began in earnest and although we had suggested visual prompts, his visual sensitivity, imagination, skillset, and his emotional response to the script resulted in a series of evocative sketches. He was moved by “learning how doctors and families try to read the pain of children who are unable to communicate” and he wanted to convey the complexity of that challenge through his drawings. In the same way that the initial scripts had not been quite right, some of the initial drawings of Lily needed refining to reflect the context of a child with complex healthcare issues more accurately. We engaged with our parent advisors to get a sense of their response to these early sketches, and he drew on my feedback about where his preliminary visuals either worked or needed changing to ensure a sense of authenticity. He also incorporated some of his own family experience, and with consent from Gemma, he shares his story for this paper:

My adult experience of children with complex disabilities is very limited. When I was a lot younger, my cousin Annabelle was born with cerebral palsy, and died around the time I went to secondary school. My memories of Annabelle are very sketchy, and I know she could communicate to some extent. However, I tried to keep her in mind when creating the character of the child in the animation, remembering her position, her chair and her features. I hadn’t thought of Annabelle in many years, so it was lovely to be able to look back and bring her to life in drawing and to learn of some of the things that Annabelle and her mum Gemma would’ve been experiencing.

His idea to use a black background and chalk as the basis for the animation was inspired by the blacked-out performance of *The Mother of*

All Pain, creating a connection with that work. He was also compelled to create something “delicate” and sensitive:

It was also a challenge to give the visuals the same sensitivity and warmth of the script and the research. Rather than my usual animation style which could have been a bit too cartoonish this required something more delicate. I tried to do this by using simple lines, and a more traditional frame-by-frame style.

The animation was coming together; it was becoming more compelling, and the story arc we had imagined was working. Communicating via an animation is very different to communicating via academic papers or presentations. The script was composed of around 250 words; much of the message lay in the way in which the images added depth and meaning and filled the gaps without the need for language. This was achieved through an animation composed of roughly 1400 hand-drawn frames; this was an intense, manual and analog process (see Figure 1 for examples of images). The animator notes that he became “totally immersed in the making of Lily’s Pain” and he hopes that this “helped to create an immersive experience for the viewer too”. The writer reflected that the “incredibly labor-intensive style of animation with every frame hand drawn.... mirrors the diligence of the parents” in caring for their children.

Hours of work later, we had the final silent animation, but we still needed a voiceover. Although we had considered working with a celebrity, which could have resulted in greater publicity, our parent-advisors guided us to have the voiceover performed by a parent with lived experience. We invited one of the WellChild Parent Ambassadors, whom I knew through my work with WellChild and who I anticipated would bring her own experience and a genuine warmth to the narration. The final part of the jigsaw was in place when she agreed to do the voiceover; the animator provided support and guidance to her when she performed the script in a studio near her home.

5 | GAINING PERSPECTIVE AND COLLABORATING WITH PARENT ADVISORS

Engaging with experts by experience and securing public and patient involvement and engagement (PPIE) including children and their parents¹⁶ is now considered to be a fundamental practice within health research, service development and policy,¹⁷ even if some researchers view it with cynicism and ambivalence.¹⁸ For me, the benefits of engaging with parents always outweigh the challenges, as their insights and lived experience ground my research and its outputs. I also believe that good PPIE (e.g., respectful, authentic, collaborative, responsive, engaging) can have benefits for those participating. It is a clear means by which parents can shape practice, policy, inform knowledge, or in this case, develop a resource for informing, teaching and guiding other parents and professionals.

Although the development of the Lily's Pain resource was not a research study, I was keen to continue to collaborate with a group of (WellChild Family Tree³) parents whose children have exceptional health needs. This group consists of a core of parents who I had worked with for various projects and studies over many years; some of the parents had contributed to an advisory panel for a prior pain study.^{2,3} We worked with this fluid group of parent advisors (mothers and fathers) from the inception of the project and developed an agreed plan for how and when they would contribute their ideas and critique our work. I knew that their lives as parents caring for child with profound cognitive impairment were busy, sometimes fraught and full of challenges (as well as rewards), so I wanted to ensure that they did not feel under pressure to engage with me, so WellChild's Head of Family Services acted a conduit to the parents. The parents were clear that they preferred to work remotely as this meant that they were able to respond to our requests at a time that suited them, and which fitted in around their family routine and their child's care. Our agreed consultation plan focused on engagement with parent advisors at the following timepoints: (1) prior to making the decision to create an animation to determine if an animation could be a valuable resource and the broad purpose of the resource; (2) at first good draft of the script; (3) at first good draft of the story board; (4) at pre-final version of the animation; and (5) during dissemination. Each of these timepoints were seminal moments to the development of the animation.

We engaged with our parent advisors via short surveys comprised of focused open and closed questions that created opportunities for mothers and fathers to provide feedback on the things they liked and things that needed to be changed or considered further. We asked our parent advisors questions such as "Does the script resonate with your experiences?", "How could we improve the visuals in the storyboard?", "Do you think that the script/storyboard are likely to work for both intended audiences (parents and professionals)? If not, what could we change?" We also asked

about the focus being on a mother and child rather than a father and child. This was important as, although most research evidence has been built on engagement with mothers, we knew from our wider engagement work that there are many fathers dedicated to caring for their child with complex healthcare needs, and pain-related decisions are often made jointly between mothers and fathers. The final decision was made by our parent advisors, who agreed that the animation could not represent everything. One of the parent advisors—a father—agreed that it was "reasonable" for the main parent character to be a mother.

Our parent advisors also guided us on language, the focus of the message, whether the voiceover should be done by a celebrity, an actor, or a mother with lived experience, the need to emphasize the mother's skill in assessing her child, whether the choice of Lily as the child's name was appropriate, and ideas for the title of the animation. Feedback about the final version of the storyboard was emphatic about it "resonating with me, powerfully". Our initial concern that an animation might be at odds with conveying an authentic portrayal of a child's pain and the mother's distress was set aside by parents who noted that it reflected their reality:

This is exactly what we are dealing with right now and normally I don't think graphics like this get it right, but this really has, well done!

We valued positive feedback as it helped us feel we were heading in the right direction but, even more than this, we valued parent feedback that suggested we had got things wrong and/or needed to rethink things. One mother's feedback on an early version on the storyboard led to an important revision in one part of the storyboard:

I like the whole thing [storyboard], but on first watch – when the mum picks the child up at the end of page 4 and Lily stays on the chair, I thought the child had died – obviously not, but not sure if anyone else thought of that.

At key points, we also engaged with around 90 professional stakeholders (eg, children's pain nurse specialists, pediatricians) face-to-face at conferences and pain study days and remotely by email via pain networks. This engagement aimed to ensure that the storyline, visuals, and feel of the storyboard resonated with them. We gained positive feedback from these stakeholders who were keen to see the final animation.

6 | LETTING THE STORY OUT INTO 'THE WILD'

Once the animation "Communicating Lily's Pain; parents and professionals working together" was completed, we also co-created two information sheets (one for parents and one for health care

³<https://www.wellchild.org.uk/supporting-you/connecting-families/>

professionals) which provide more detailed information, advice, and guidance on assessing pain. The animation and leaflets are all free to download (<https://www.edgehill.ac.uk/communicatinglilypain/>). Our work now turned from creation to dissemination and evaluation. Dissemination is the point at which the resource goes public, becomes part of the universe of knowledge and the stories it generates are "out in the wild" and outside of the control of the original creators. The three core collaborators were responsible for creating the story of "Lily's Pain" and, although it was based on the stories of parents and our collaboration with parents, we were aware that stories can be interpreted in different ways. We knew that arts-based methods, such as our animation, are synergistic knowledge-translation strategies.¹⁹ We wanted our animation to inspire the people who viewed it; we understood the power of stories to teach. Frank^{1, p25} notes that:

The storyteller speaks, but the story teaches – a complex synergy.

Our dissemination has occurred through social media, conferences, via the WellChild website, through contact with parents and professionals, via study days and through informal conversations. "Lily's Pain" is being used in induction sessions about children's pain within hospitals and in teaching sessions in universities. It has also occurred through academic papers,¹⁵ thus closing the circle which started at academic dissemination. We gained endorsement for the resource from the Royal College of Nursing in the United Kingdom.

We have encouraged feedback via a simple evaluation survey on our webpage and also received direct feedback from parents and professionals via email etc. Almost all of the feedback has been positive (<https://doi.org/10.25416/edgehill.13554632>); typical comments suggest that it is an "eloquent testimony," and has "provoked an emotional response" from parents. One comment was:

Oh, this has well and truly left me in tears. Here's a video that actually confirms what us parents have known all along... "we just know." I can relate to this on so many levels. I'm going to share it with my daughter's palliative care team at the hospice so they can use it in their teaching. Thank you so much for sharing this

Healthcare professionals have also responded positively, for example:

As a children's nurse of 30 years I am experienced in this area but feel that this video says it all in a few minutes and in a lovely thought-provoking and appropriate way.

Some feedback has suggested disappointment that the animation was not more detailed or directive or longer (it is 2.26 minutes long).

We agree that the animation does not provide specific detail, although with a tiny budget we had insufficient resources to create something that would be a detailed teaching tool. Our aim had always been to provoke people to think with and about Lily's story. We wanted healthcare professionals to examine their conscience and ask themselves if they could do more or act better. We hoped that watching the animation would help parents feel that their experience and expertise were important and that it would support them to continue to be their child's pain advocate.

7 | CONCLUSION

Using an animation as a means of complementing academic research findings aimed to communicate to a diverse audience using an arts-based approach. We hoped that it would generate discussion and provoke meaning making for the viewers. Our animation was one way of telling the story of children like Lily and her mother. This animation worked with the stories that parents had told me and we shared them as a way of both honoring their stories and also a way of asking other people to care about and learn from Lily's story. Lopez²⁰ writes:

The stories people tell have a way of taking care of them. If stories come to you, care for them. And learn to give them away where they are needed.

I believe that everyone involved in creating Lily, whether through the initial research, the immersive soundscape, or through the animation and information leaflets, has been touched by the experiences of children like Lily and their parents. The writer reflected that these parents are "ordinary and extraordinary" and that their stories (within the research data) reveal:

The years of sleepless nights and the small practical important decisions that bit by bit, improved the life of their child. Thousands and thousands of hours compressed into one weary expression, softened with kindness and the fluent knowledge of their craft...I look up to those parents. They are veterans of love.

We have all been marked and "re-shaped"²¹ by our work related to co-creating Lily and by the opportunities to learn from each other's disciplinary approaches, perspectives, and insights. Our hope is that, in a small way, this contribution to the body of work about noncommunicating children like Lily will communicate something important about their pain. Although the animation and the information sheets will not change (until they are revised), they are dynamic starting points for new stories to be told and shared "in the wild". Our hope is that the story of Lily's Pain will help to change the lives of parents and children and professionals. Our hope is that you can be part of that change.

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AUTHOR CONTRIBUTIONS

BC, RY, and JM conceived and co-created the animation and resource with the support of the WellChild Families. BC conceived and wrote the first draft of the paper with core contributions from RY and JM.

DATA AVAILABILITY STATEMENT

Data from the original research studies is available only on request due to privacy/ethical restrictions.

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REFERENCES

1. Frank AW. *Letting Stories Breathe: A Socio-Narratology*. University of Chicago Press; 2010.
2. Carter B, Simons J, Bray L, et al. Navigating uncertainty: health professionals' knowledge, skill, and confidence in assessing and managing pain in children with profound cognitive impairment. *Pain Res Manag*. 2016;2016:8617182. doi:10.1155/2016/8617182
3. Carter B, Arnott J, Simons J, et al. Developing a sense of knowing and acquiring the skills to manage pain in children with profound cognitive impairments: mothers' perspectives. *Pain Res Manage*. 2017;2017:2514920. doi:10.1155/2017/2514920
4. Frank AW. *The Renewal of Generosity: Illness, Medicine, and How to Live*. University of Chicago Press; 2004. <https://press.uchicago.edu/ucp/books/book/chicago/R/bo3645911.html>
5. Rovelli C, de Finetti B. *There are Places in the World Where Rules are Less Important than Kindness*. Allen Lane; 2018:45. <https://www.penguin.co.uk/books/318/318988/there-are-places-in-the-world-where-rules-are-less-important-tha/9780241454688.html>
6. Breau LM, Camfield CS, McGrath PJ, et al. The incidence of pain in children with severe cognitive impairments. *Arch Pediatr Adolesc Med*. 2003;157(12):1219-1226. doi:10.1001/archpedi.157.12.1219
7. Jayanath S, Ong LC, Marret MJ, et al. Parent-reported pain in non-verbal children and adolescents with cerebral palsy. *Dev Med Child Neurol*. 2016;58(4):395-401. doi:10.1111/dmcn.12943
8. Genik LM, Pomerleau CA, McMurtry CM, et al. Pain in children with intellectual disabilities: a randomized controlled trial evaluating caregiver knowledge measures. *Pain Manag*. 2017;7(3):175-187. doi:10.2217/pmt-2016-0049
9. Barney CC, Andersen RD, Defrin R, et al. Challenges in pain assessment and management among individuals with intellectual and developmental disabilities. *Pain Rep*. 2020;5(4):e821-e921. doi:10.1097/PR9.0000000000000822
10. Petigas L, Newman CJ. Paediatricians' views on pain in children with profound intellectual and multiple disabilities. *Brain Sci*. 2021;11(3):408. doi:10.3390/brainsci11030408
11. Genik LM, McMurtry CM. Reflections and considerations for knowledge translation efforts on pain training for caregivers of children with intellectual and developmental disabilities. *Pediatric Pain Letter*. 2020;22(2):21-24. http://ppl.childpain.org/issues/v22n2_2020/v22n2_genik.pdf
12. Yamada J, Squires JE, Estabrooks CA, et al. The role of organizational context in moderating the effect of research use on pain outcomes in hospitalized children: a cross sectional study. *BMC Health Serv Res*. 2017;17(1):68. doi:10.1186/s12913-017-2029-2
13. Kruithof K, Willems D, van Etten-Jamaludin F, et al. Parents' knowledge of their child with profound intellectual and multiple disabilities: an interpretative synthesis. *J Appl Res Intellect Disabil*. 2020;33(6):1141-1150. doi:10.1111/jar.12740
14. Frank AW. "How Can They Act like That?": Clinicians and patients as characters in each other's stories. *The Hastings Center Report*. 2002;32(6):14-22. doi:10.2307/3528129
15. Carter B. Animating children's pain research: using arts-based approaches to disseminate knowledge and mobilise emotions. *Nurs Stand*. 2020;35(10):4. doi:10.7748/ns.35.10.48.s31
16. Molloy EJ, Mader S, Modi N, et al. Parent, child and public involvement in child health research: core value not just an optional extra. *Pediatr Res*. 2019;85(1):2-3. doi:10.1038/s41390-018-0245-z
17. Reynolds J, Beresford R. "An Active, Productive Life": Narratives of, and through, participation in public and patient involvement in health research. *Qual Health Res*. 2020;30(14):2265-2277. doi:10.1177/1049732320961053
18. Boylan AM, Locock L, Thomson R, et al. "About sixty per cent I want to do it": Health researchers' attitudes to, and experiences of, patient and public involvement (PPI)—A qualitative interview study. *Health Expect*. 2019;22(4):721-730. doi:10.1111/hex.12883
19. Rieger K, Schultz ASH. Exploring arts-based knowledge translation: sharing research findings through performing the patterns, rehearsing the results, staging the synthesis: exploring arts-based knowledge translation. *Worldviews Evid Based Nurs*. 2014;11(2):133-139. doi:10.1111/wvn.12031
20. Lopez B. *Crow and Weasel*. HarperPerennial; 1993.
21. Lapum J, Ruttonsha P, Church K, et al. Employing the arts in research as an analytical tool and dissemination method: interpreting experience through the aesthetic. *Qual Inq*. 2012;18(1):100-115. doi:10.1177/1077800411427852

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