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Commentary

Ethical issues in the equitable virtual delivery of pediatric chronic pain care

Mica Gabrielle Marbil and Kathryn A. Birnie

Many healthcare services were provided virtually during the COVID-19 pandemic (Killackey et al., 2021). Despite the ongoing demand for virtual pediatric chronic pain treatment, there is limited research guiding this practice (Birnie et al., 2021). The research that does exist often excludes equity-seeking groups (Birnie et al., 2022); consequently, present virtual care practices risk underserving minoritized populations. In response to recent discussions surrounding equity in research (Hood et al., 2022; Janevic et al., 2022), this commentary situates virtual care ethics within overlapping equity issues to emphasize necessary work towards ethical and equitable pediatric pain care. As such, it focuses primarily on virtual care ethical considerations of particular relevance to equity-seeking groups. The authors are most familiar with ethical guidelines that govern Canadian psychology (e.g., Canadian Psychological Association [CPA], 2017); however, references draw from various disciplines and loci with many shared ethical principles and values, and can be contextualized accordingly.

Virtual care, ethics, and equity

Virtual care comprises any remote interaction (i.e. encounters that are not in-person and rely on any form of digital communication or information technologies) between patients and health professionals to facilitate care (Shaw et al., 2018). Although virtual care usage has increased since the COVID-19 pandemic, even after easing public

health restrictions (Shaver, 2022), effective virtual care implementation for pediatric chronic pain is challenging without guidelines to inform health professionals and policymakers (Birnie et al., 2021). While both in-person and virtual care have been shown to be viable and effective for pediatric pain management (Fisher et al., 2022), published work to date comparing remote delivery of one treatment to its equivalent in-person counterpart is generally limited to demonstrations of feasibility and acceptability (e.g. Kashikar-Zuck et al., 2022; Hale et al., 2023), with little information available to assess the efficacy of virtual relative to in-person care.

Virtual care ethics for pediatric chronic pain (e.g. Henderson et al., 2012) have minimally focused on youth in equity-seeking groups (e.g. racialized, lower socioeconomic status), despite the disproportionate impact of chronic pain on these populations (Craig et al., 2020). Recruitment from tertiary pain clinics in most research is intrinsically biased by socially maintained inequities, which can involve age, gender, and race (Crombie & Davies, 1998). Furthermore, discussions of equity in virtual care (e.g. Budhwani et al., 2022) are not always integrated within ethical contexts. We believe that equity is inherent to ethical care and herein outline considerations for ethical and equitable virtual pediatric pain management.

Informed consent

Informed consent is necessary for ethical care (Chaet et al., 2017; Keenan et al., 2021). Patients must be informed of benefits and risks, given the opportunity to fully participate in decision-making, and have this decision documented (CPA, 2017), thereby facilitating patient autonomy. However, with research underrepresenting equity-seeking groups, who are both more vulnerable to chronic pain and underserved by healthcare services (Latimer et al., 2018; Craig et al., 2020), the current understanding of virtual care's benefits and risks is inadequate. This adversely impacts individuals' ability to be truly informed when providing consent.

In considering virtual care as a treatment option, health professionals should be cognizant of the many factors that influence patient and caregiver preferences, and guide discussions of consent to ensure that these are appropriately addressed therein. For example, in-person care might be preferred over virtual care more generally (Terrell et al., 2021) or for certain aspects of multidisciplinary pediatric pain treatment (Ruskin et al., 2023). Importantly, virtual care implications are not equal. For some, it increases accessibility by removing travel costs associated with in-person services (Terrell et al., 2021); for others, it is a barrier to quality care. Families with lower income might have less access to technology or possess challenges with digital literacy needed for virtual care (Lindsay et al., 2023). Virtual care is not universally defined by insurance companies, complicating financial reimbursement where such health service models apply (Henderson et al., 2012). Moreover, other factors, such as language differences, can increase difficulty with virtual engagement and communication (Lindsay et al., 2023). One review identified virtual care's lack of cultural or contextual relevance for Indigenous peoples, compounded with mistrust in the health system and low access to internet and technology resulting from intersectional health disparities (Budhwani et al., 2022). In general, pain management preferences for minoritized groups are infrequently examined, and better understanding of inequity in pediatric pain management has been deemed a priority (Eccleston et al., 2021). Therefore,

it is important to clarify how virtual delivery might impact a patient's individual circumstance to best ensure they and their families are properly informed when providing consent.

In promoting equitable decision-making encounters, it should also be recognized that familial structures and norms (e.g. cultural) vary in the roles of youth, caregivers, and other members in a pediatric patient's circle of care, who might all have distinct preferences in decision-making (Unguru, 2022). People involved in the consent process may vary from family to family, and such encounters should be navigated with care that is personalized to the individual. Overall, virtual care decisions should appropriately involve individuals in a youth's care team and address, as much as applicable, relevant sociocultural factors that impact care.

Competence

Competence can include knowledge, training, personal feelings of competence, and comfort delivering care remotely (Chaet et al., 2017; CPA, 2020). However, one study revealed that only 28.1% of Canadian and Dutch therapists delivering virtual care received training in telerehabilitation services (Giesbrecht et al., 2023), and minimal information describes whether health professionals are trained for equitable virtual care delivery. Notably, little is known on culturally adapted virtual interventions for pediatric care and if such modifications to treatment based on group characteristics are more appropriate than tailoring care to the individual (Willis et al., 2022). To ensure evidence-based, quality care, health professionals must undertake appropriate training for remote treatment provision, including cultural humility (Crawford & Serhal, 2020). Health professionals should be able to navigate virtual care when faced with the realities of health disparities, such as varying levels of digital health literacy, differences in technology access, and accessibility concerns. For example, diverse youth with chronic pain and caregivers require straightforward and helpful communication from health professionals (e.g. teaching and demonstration; Birnie et al., 2022), which would be facilitated by proper training in both virtual and multicultural care.

Privacy, confidentiality, and licensure

Maintaining privacy and confidentiality virtually is critical (Chaet et al., 2017). Health professionals should consider patient factors (e.g. patient discomfort in disclosing and receiving private and confidential information in their home environment; Curfman et al., 2021), and ensure patients' awareness of privacy risks. However, minoritized groups (e.g. lower socioeconomic status) might not have the resources (e.g. private space, adequate technology) necessary for ethical delivery of remote treatment, hindering equitable accessibility and sustainability of virtual care (Willis et al., 2022).

Lastly, as in psychology, licensure for both in-person and virtual services might be jurisdictionally confined. Health professionals should provide alternatives if services would be discontinued or transferred (CPA, 2017, 2020), the effects of which might be particularly impactful for clients in equity-seeking groups who already experience barriers to care (Craig et al., 2020).

Summary and recommendations

An overarching theme in virtual care is to offer it as a choice for patients. Youth with pain and caregivers have a desire for more involvement in treatment decisions (Birnie et al., 2022), but are often excluded from these conversations (Bui & Lima, 2021). One approach to address this is shared decision-making, which enables patients and health professionals to collaboratively decide on treatment given existing evidence and patient preferences (Makoul & Clayman, 2006; MacKenzie et al., 2023).

While remote delivery benefited many during the pandemic (D'Alessandro et al., 2020), researchers must examine virtual care with attention to diverse perspectives to ensure its ethical and equitable delivery. Unfortunately, the recurring underrepresentation of many equity-seeking groups in virtual care research mirrors health inequities that impact pain (Craig et al., 2020) and perpetuates a

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false and harmful narrative of equality (Janevic et al., 2022). Albeit virtual care might narrow inequities for some, it remains unclear how it impacts others already disadvantaged (e.g. with multiple intersecting minoritized identities). Therefore, more inclusive and equitable approaches are needed to inform our research and practice surrounding virtual care.

Recommendations for ethical and equitable virtual care research and implementation involve engaging relevant, diverse end users as early as possible (Janevic et al., 2022); including evaluative measures for virtual care (Chuo et al., 2020); and adopting elements of the digital health equity framework, which considers digital influences in health and their interactions with social factors (Crawford & Serhal, 2020). In practice, this framework could help us understand how digital health literacy, alongside attitudes and beliefs, impacts the uptake of virtual care by equity-seeking groups (Crawford & Serhal, 2020), informs treatment decisions, and could support modifications for virtual care, as identified by diverse youth with chronic pain (Birnie et al., 2022). Recommendations of best practices for equitable and inclusive virtual pediatric chronic pain management for health professionals have previously been made available, and include using the home environment as an opportunity for more culturally inclusive practices and non-stigmatizing healthcare interactions (e.g. Birnie et al., 2022). These adaptations can be amplified by health professionals ensuring their own digital health literacy and cultural humility, and providing diverse supports and resources during virtual sessions.

The relevance of virtual care is clear, but important research and practice gaps persist, especially for equity-seeking groups. Understanding how to improve virtual care to address inequities is critical for its successful integration within the health system to suit patient needs.

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Book review

Empowering children through imagination to overcome pain

Jana Kaoussarani

Amarante C (2023). *The Dream Machine*.
Tellwell Talent, 126 pp. ISBN 978-0228846529
(Paperback: \$16.00 USD).
www.amazon.com/Dream-Machine-Candace-Amarante/dp/0228846528

It goes without saying that everyone is likely familiar with the concept of a time machine: a hypothetical invention that allows traveling through time and experiencing past or future events. Such an idea has been explored in books and movies for centuries, driven by people's desire to change their present by correcting their past through time travel. However, we all know too well that instead of focusing on changing what has happened (or what will happen), a more realistic perspective would be to deal with present, undesirable events such as injuries and illness. This is particularly true for hospitalized children who experience a lot of pain. The book, *The Dream Machine*, suggests alternative, distracting ways for hospitalized children to deal with their acute and/or chronic pain by allowing their imagination to flourish upon being immersed in the story, enabling them to better tolerate pain.

The Dream Machine is an illustrated children's book designed to help children aged five years and older, as well as their parents, to learn to deal with acute and chronic pain. The story mainly revolves around Skylar, an 8-year-old ski enthusiast and prodigy, who broke her femur in a ski accident. The story also involves Skylar's 16-year-old sister, Ashling, who often deals with broken bones as she lives with a severe type of osteogenesis imperfecta, a chronic condition that makes one's bones very

fragile and weak causing them to break often (www.niams.nih.gov/health-topics/osteogenesis-imperfecta). Skylar is devastated upon hearing the most dreadful news: she will not be able to practice her favorite sport for some time due to her broken femur. Ashling tries to cheer Skylar up by playing a game called the dream machine. Ashling had invented this game when she was younger as a way for her to deal with her many broken bones; she believes the game can also help her younger sister. In that alternate world, Skylar's dreams come true, her imagination runs wild, and she learns to deal with the pain of her injury. The game distracts Skylar from the pain she feels in real life while being transported to an imaginary world. Courage, perseverance, and human connection are powerful themes embedded throughout this light-hearted book.

The *Dream Machine* has 126 pages, of which the first 60 pages (divided into 7 chapters) pertain to the story itself, followed by 30 pages detailing useful information (e.g. how casts work, recovering from broken bones, how X-rays work, how to cope with pain) for parents with unwell children. A further 12 pages of educational activities are included. Although complex medical concepts are introduced, they are explained concisely using simple language. For example, Ashling describes her disease (osteogenesis imperfecta) in simple terms as a condition that affects the bones making them more fragile. She also explains the different types of this disease, hers being a severe type III. Of note, *The Dream Machine* was edited by Dr. Argerie Tsimicalis, a nurse scientist at the Shriners

Hospitals for Children–Canada, ensuring credibility of the medical information provided.

When the story shifts to the dream machine's world, the color palette changes from less saturated, dull blue surroundings (as is the case in this hospital setting) to many vibrant hues of lively and intense colors, allowing the reader to better follow the sequence of events. Following the story, there are multiple pages of information that range in breadth and depth from detailed explanations on osteogenesis imperfecta, hospital procedures, and techniques to advice for parents of children dealing with pain. To further charm young readers, the book includes a dozen pages of fun, educational activities such as coloring, mandalas, spelling practice, a search and spell, a word search, and origami. Overall, this book provides a comprehensive and engaging experience, with the story and supplementary sections catering to both parents and children. I have to say though that reading *The Dream Machine* pre-publication on a screen made it feel a bit long, but I am certain the feeling would be different holding a hard copy.

In terms of story themes and emotions, *The Dream Machine* showcases different themes as the story progresses and highlights many challenging events and emotions in an athlete's career, especially when experiencing an injury that entails pain and mental stress. Courage, perseverance, determination, representation of women in sports, as well as the importance of coping mechanisms and family support are the main underlying themes. Predominantly, family support and a healthy connection between siblings, as the one between the two sisters, are repeatedly portrayed. Also, all sorts of emotions are disclosed as Ashling continues to manage her chronic pain while helping Skylar overcome her acute pain. Skylar is portrayed as being terrified and feeling excluded after her accident; she will not be able to practice the sport she adores and compete with her team in the next ski season. Feeling sad and angry, Skylar does not know how to deal with her disappointment, and she is very aware of the fact that it will take her months to get back to the same mobility she had before the incident. This is when the dream machine comes to the rescue.

The illustrations created by Dave Reed are simply fascinating. My favorite is that of a landscape filled with candy, along with its colorful rainbow waterfall, sweet marshmallows, popsicles, and chocolate toppings, all complementing each other in a joyous manner. The characters in the book are a combination of humans (e.g. Skylar, Ashling, the physician) and cartoon like creatures (e.g. Skylar's stuffed animals that come to life while playing the dream machine, riding a gigantic eagle). More importantly, the illustrations are more than just decorative; they intertwine with the narrative and help better understand the themes and concepts explored. The vibrant colors bring the story to life, becoming more saturated as the characters are immersed into the dream machine, thereby amplifying the fantastical aspect of the storyline. The cartoonish style, soft lines, and fine details give the artwork a dream-like feel, which draws young readers into the story's universe. The characters' expressive faces and body language allow for a deeper understanding of the story. The artist does an appreciable job illustrating the various ambiances and backgrounds. The images' style and colors provide readers with a multisensory experience. Personally, I felt completely immersed in the story and fully enjoyed the adventure.

The story takes place in the Canadian city of Montreal, a culturally diverse environment where many cultures coexist. People with different ethnicities are shown, demonstrating either an intentional effort for inclusion and diversity by the author or perhaps a mere representation of the multicultural background of the Montreal cosmopolitan area. Foremost, part of the story includes Irish folklore, as evident from illustrations of a leprechaun character. Additionally, Muslim women are portrayed in the field of medicine as practicing healthcare professionals, negating the unfounded image of the oppressed veiled Muslim woman. Skylar's doctor is pictured wearing a hijab, a head covering worn by Muslim women to express their religious beliefs.

As an athlete myself, this book speaks to me on so many levels. I, too, have experienced many injuries and setbacks in my main competitive sport (artistic gymnastics) that I have practiced for more than a decade. I speak from experience and can

confirm that, even now at the age of 18, the psychological dread of being incapable of executing certain elements in gymnastics has lingered with me longer than any physical injury. I know exactly how Skylar feels as I have dealt with acute pain myself. Thinking back to my earlier days, I would have liked to play a game like the dream machine to learn to manage my pain and truly believe that tomorrow would be a different reality. This virtual concept can help not only young athletes suffering from an injury, but also children experiencing all sorts of pain. The healing power of the imagination cannot be undermined.

The Dream Machine is a captivating, must-read children's book that explores the power of imagination and resilience in the face of adversity while providing educational content for children

and parents. This book can be appreciated by young children (aged 5 and up) and by parents of sick children. As American fantasy and science fiction writer Patricia A. McKillip once said: "*Imagination is the golden-eyed monster that never sleeps. It must be fed; it cannot be ignored.*" (www.goodreads.com/quotes/503997). This quote beautifully complements the essence of *The Dream Machine*, reminding us that embracing our imagination can make adverse life events just a tiny bit more bearable.

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