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Résumé de l'article

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ACTES DE COLLOQUE / CONFERENCE PROCEEDINGS

How 'Ought' the Best Interests of Children be Considered in Medical Decision-making?



Zoe Ritchie^{a,b,c}, Micaela Forte^{a,b,c}, Maxwell J. Smith^{a,b,c}, Jacob Shelley^{a,b,c,d}

Résumé

Ce résumé rend compte de la conception et du déroulement d'un atelier collaboratif basé sur des cas concrets et d'un panel sur la manière dont nous « devrions » prendre en compte le meilleur intérêt des enfants dans la prise de décision médicale, présenté virtuellement lors de l'atelier et du forum communautaire de la Société canadienne de bioéthique - Canadian Bioethics Society, en mai 2023.

Mots-clés

meilleurs intérêts, prise de décision, capacité, enfants, soins de réadaptation, soins aigus

Abstract

This summary reports on the design and proceedings of a collaborative case-based workshop and panel on how we 'ought' to consider the best interests of children in medical decision-making, presented virtually at the Canadian Bioethics Society - Société Canadienne de Bioéthique Workshop and Community Forum in May of 2023.

Keywords

best interests, decision-making, capacity, children, rehabilitation care, acute care

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Our team was pleased to join attendees at the Canadian Bioethics Society - Société Canadienne de Bioéthique Workshop and Community Forum held virtually on May 15-18, 2023, to lead a collaborative workshop on the use of the best interests of the child standard in children's healthcare. Our workshop focused on exploring the normativity of this standard in medical decision-making through challenging case studies and a panel with expertise in childhood ethics, youth engagement, family and pro-bono law, and clinical ethics.

In medical decision-making, capable patients have a right to make autonomous decisions. Yet, this principle is often challenged if the patient is a child. In our workshop we classified children under the definition used by the United Nations Convention on the Rights of the Child in reference to persons under the age of 18 (1). However, the perspectives presented in our workshop also incorporated a more expansive conception of a 'child' that includes social and relational aspects of participation in their environments as central to their identity as 'children' (2). Children are often assumed to lack the capacity to make medical decisions, but this assertion is inconsistent with the majority of provincial statutes in Canada, which do not define an age with regard to the capacity to make medical decisions (3). When a child is deemed incapable (by assumption or by a more formal judgement of their capacity), responsibility for decision-making is assigned to the child's substitute decision maker (SDM), often a parent or guardian, who is charged with making treatment decisions on behalf of the child. Several provincial statutes that cover the responsibilities of an SDM, including the Ontario Health Care Consent Act (HCCA), do not make any distinctions if the incapable person is a child (4). The Act outlines an SDM must consider the incapable person's values and beliefs, their prior expressed wishes with respect to the treatment, the person's condition and well-being, risks and benefits of the proposed treatment, and whether an alternative treatment could be beneficial, among other factors. The interpretation of these provincial statutes, with respect to children, can present an ethical challenge in how we hold an SDM accountable to this obligation of considering the beliefs, values, and expressed wishes of their child in a best interests calculus.

Despite the best interest standard being the prevailing ethical principle in pediatric ethics (5), the standard has faced criticism for being vague, applied inconsistently, and subject to abuse wherein clinicians, SDMs, and legislative bodies can manipulate interpretations of what is or is not in the patient's 'best interest' based on factors that may not centre on the patient (6-8). With respect to common law precedent in Canada, cases that have made express reference to the standard often vary in their interpretation of how its use motivates, justifies, or explains decisions regarding children's participatory rights (9). As Erica Salter describes, "We have encumbered the 'best interest' language with substantial inconsistency and obscurity. The 'standard' has become so diluted that it does no real heavy lifting and can offer no real guidance to families, decision makers, or health care professionals." (8). The ubiquitous nature of these criticisms was the catalyst for the creation of a collaborative research study between the Faculty of Law and the Faculty of Health Sciences at Western University, supported by the Canada Social Sciences and Humanities Research Council (SSHRC), interim results of which we shared throughout the workshop.

Our workshop was split into two parts. In the first stage, we presented attendees with original case studies involving a child and a medical decision that engaged with (a) COVID-19 vaccination, (b) prosthetics, and (c) treatment of anorexia nervosa.

Case A considered COVID-19 vaccine decision-making between divorced parents who disagreed on whether vaccinating their 13-year-old child was in his best interests based on (mis)information about the vaccine one parent found to be compelling on the internet. Case B considers the cultural context of a family when selecting a prosthetic leg, who interprets their child's best interests as favouring aesthetic appearance over the child's expressed preference for functional properties. Case C considers a 17-year-old patient with anorexia nervosa whose parents are seemingly dejected from conversations about her treatment as her clinical team is divided on whether to accept her refusal of treatment for her eating disorder. The case studies were developed in collaboration with subject matter experts from Western University and Holland Bloorview Kids Rehabilitation Hospital, whose Clinical Bioethicist and Manager of Youth Engagement, Dolly Menna-Dack, conceived and wrote Case B (prosthetics). We used breakout rooms to facilitate dialogue and debate in smaller groups before coming together for discussions among the entire group.

In the second stage, we hosted a panel with five scholars engaged in academic and clinical discourse on the place of the best interests standard concerning decision-making in children's healthcare. Panelists included Dr. Franco Carnevale (Ethicist and Professor, McGill University), Lee Ann Chapman (Lawyer Pro Bono Ontario, Family Legal Health Program, The Hospital for Sick Children), Dr. Claire Houston (Assistant Professor, Faculty of Law, Western University), Dolly Menna-Dack (Clinical Bioethicist and Manager of Youth Engagement, Holland Bloorview Kids Rehabilitation Hospital), and Dr. Randi Zlotnik Shaul (Director of the Department of Bioethics, The Hospital for Sick Children). Questions that emerged from earlier discussions of the case studies were submitted by attendees using our virtual chat options and presented to panellists by moderators.

The collaborative nature of the workshop and panel produced several key insights on how our attendees engage with the limitations and strengths of the best interests of the child standard in pediatric decision-making. Our attendees agreed this is a complex and critical topic that engages specialties across children's healthcare in unique ways. One idea expressed as underexplored in discussions on best interests was normative distinctions between considerations of past, present, and future interests and a child's ability to differentiate between interests that may or may not be more significant in different temporal periods of their lives. For instance, in Case B (prosthetics) some attendees disagreed on how we should, or even if we should, take seriously the parents' future concerns about their child. Specifically, the concern of her not being accepted in a marriage if her prosthetic is more visible ended up being an intriguing discussion point among the group, especially as the patient herself clearly expressed her present interest in the functionality of the prosthetic to allow her to play sports and have fun.

Another insight was that attendees shared uncertainty in assessing what influence cultural or religious values held by parents should have in guiding substitute decision-making. In our case studies, attendees frequently communicated the importance of recognizing that our medical system often does an inadequate job of eliciting children's moral attitudes and values about healthcare decisions that affect them. This theme also emerged in our panel discussion where panelists reflected on the importance of cultivating a climate of relational safety and trust with children in healthcare settings. Efforts to do so, they discussed, can optimize the abilities of children to engage with thoughts, feelings, and when appropriate, discussions or decisions, with family members and healthcare professionals about their medical treatment against a background of the aspects of their lives they deem morally significant. Recognizing the importance of parents in shaping the social norms that will define a child's approach to thinking, feeling, or sharing what is important to them was also an insight described as meaningful for several attendees.

Attendee feedback indicated that incorporating a multitude of perspectives from different care spaces (e.g., acute, rehab) and fields (e.g., clinical ethics, family law, medicine) into the workshop was executed well and deepened their insights on the best interests standard. As moderators, we likewise found that attendees' own fields of study and experiences enriched the level of dialogue throughout the three hours. Following the workshop, attendees also shared that they enjoyed the chemistry between panel members and wished the panel had lasted longer. We are exploring future opportunities to re-convene this panel of experts to delve into a more specific discussion about the application and use of the best interests standard.

As our research project at Western University is ongoing, we were fortunate to have a well-attended workshop that highlighted several questions for further inquiry, both in our study and beyond. Some of these questions include: 1) Does the best interests of the child standard have the normative strength to do the "ethics work" we assume it does to guide clinical practice? 2) When it comes to best interests, is it prudent to avoid conflating bioethics with law, and vice versa? 3) How can current discourse on the best interests of the child standard be enriched by lenses and conceptual understandings adopted by other fields such as disability studies and rehabilitation sciences? 4) How do we consider the utility of the mature minor doctrine? Ought we use it? Why or why not? How are conceptions of maturity and capacity conflated in these conversations? These questions reflect the important dynamics this area of inquiry produces for future interdisciplinary exploration.

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Conflicts of Interest

None to declare

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