When doctors and parents disagree: Ethics, paediatrics and the zone of parental discretion

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The Federation Press, Leichardt, NSW
ISBN 978-1-76002-059-0, pp. 261, paperback, NZ$ 83.66

Cometh the hour, cometh the book! Parents are becoming increasingly active in the medical care of their children. With the help of "Dr Google" they are diagnosing their children (Bouwman, Teunissen, Wijburg, & Linthorst, 2010) before they have even visited their local GP. With access to online medical information, advice from global social media communities and a high degree of educational attainment, parents are taking a stand to get the very best assessment and treatment for their children. Parents are becoming experts and why not?

But what happens when the wishes of parents go against the medical advice from their child's doctor? How can the autonomy of parents be preserved, the knowledge of clinicians honoured and the best interests of children maintained? This timely publication, funded by the Australian Research Council and authored by members of the Children's Bioethics Centre addresses just that problem: what is to be done when parents and doctors disagree?

Within hours of this book falling into my hands it had circulated around our Paediatric Intensive Care Unit and a number of the staff had ordered copies. This is a hot issue and the conceptual framework, *Zone of Parental Discretion* (ZPD, not to be confused with the work of Vygotsky) is an ethical tool that balances the child's wellbeing and the parent's right to make medical decisions for their child.

ZPD shifts the focus from what is in the "best interests" of the child, to "will the parent's decision cause probable harm to the child?" (p. 17). Parents are entitled to make treatment decisions for their child, but that ethical entitlement ends when they make decisions that might result in suffering, injury or death. The zone of parental discretion is the area of parental decision making that is "good enough" for the child, but may not be perceived by the medical team as being the "best" for the child. However, the treatment decisions (advocated by the parents) that fall outside of the zone of parental discretion and will harm the child are overruled by the medical team. It is at this point when doctors and parents disagree, that second opinions, clinical ethics consultations and, ultimately, the rule of law, are implemented to secure a decision. This is also a critical stage for social work to intervene.

What are the implications of this text for those of us who are health social workers? We often act as a bridge between the medical team and the family, and we recognise the dominant weight of the health system. Hence we advocate for parents and often communicate their perspectives and opinions to the medical team, or provide forums to build engagement and collaboration. We take a position in the parent and doctor relationship that requires us to understand the perspective and motivations of both parties. Taking a step back and surveying the whole picture can engender a conflicted response, especially if the harm to the child appears to be perpetuated by the medical system rather than from the parent's decision making. The role of the health social worker is key in this process, maintaining the relationship, keeping communication open and clearly articulating the way forward. The ZPD provides us with a helpful ethical tool and possibly, as we consider the zone of parental discretion, we might also reflect on the zone of doctor discretion.

This text is an excellent teaching resource on health ethics. Expertly covering the evolving doctor and parent relationship, so eloquently penned by Antolovich (chapter 3), and also provides an informative set of case studies to illustrate the ZPD framework that will be helpful for medical, nursing and allied health staff. Cases range from parental refusal of treatment, to parent-led requests for genital cosmetic surgery for an adolescent. Each of these cases provide material for ethical discussion that would provoke stimulating debate amongst students and health practitioners. As Delany comments in her concluding chapter, ethics education should equip students to "perceive *moral dimensions*", "*provide information* about ethical concepts", "*motivate* clinicians to prioritise the moral dimensions of a clinical situation" and "instil a *level of persistence*." This book hits the mark on all those fronts.

Essential reading if you are an allied health professional who regularly engages in complex decision-making with families. It is skilfully produced by experienced paediatric clinicians and bio-ethicists. I particularly appreciated the informative structure, each chapter is introduced with an editor's summary and helpful links to other chapters. It should be remembered that this is written from a dominant medical discourse position and would be enriched with the voices of parents who might provide an alternative view on this framework.

Technology is transforming the work of human experts (Susskind & Susskind, 2015) and changing the parent–doctor relationship, this publication is a timely and helpful resource for clinicians struggling with empowered and informed parents. Parents are raising the bar as they become more informed and this, in turn, challenges their doctors, and social workers, to step up and in turn lift our own expertise and professionalism.

Reviewed by **Andrew Thompson** University of Auckland

References

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