Article Summary

Evidence-Based Neuroethics for Neurodevelopmental Disorders

Racine, E., Bell, E., Di Pietro, N.C., Wade, L., and Illes, J.
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NeuroDevNet and the Neuroethics Core

NeuroDevNet is a Canada-wide, multidisciplinary research network dedicated to accelerating the understanding of neurologic conditions that affect children, with a specific focus on cerebral palsy (CP), autism spectrum disorder (ASD), and fetal alcohol spectrum disorder (FASD). Questions related to human values and respect arise from the research; they call for a practical and flexible ethics approach responsive to the wide range of issues and stakeholders involved. The Neuroethics team at NeuroDevNet has adopted a pragmatic neuroethics framework to achieve this goal.

Pragmatic Neuroethics for Neurodevelopmental Disorders

A distinct feature of a pragmatic approach to neuroethics is an openness to different ethical approaches, taking into account their consequences. The approach also allows for integration of stakeholder perspectives and aims to apply current evidence to guide and inform best practices in ethics. There are three fundamental aspects to the pragmatic approach of the Neuroethics Core:

1. Bringing the voice of people affected by neurodevelopmental disorders to the foreground of research;
2. Shifting the ethical perspective from the individual to a broader view of the complex interactions of genetics, social contexts, and disability;
3. Providing a platform for the integration of social science and biomedical research.
Case Examples

- **Healthcare Delivery in CP**: A recent pilot study showed that young adults with CP face a number of challenges with ethical implications during medical consultations. Through a pragmatic neuroethics lens, the Neuroethics Core is able to provide evidence-based recommendations to enhance ethics in healthcare delivery for this population. This work may also translate to the ASD and FASD groups.

- **Neonatal Neurological Decision Making**: There is high potential for misunderstanding and conflict in such discussions, particularly regarding end-of-life decision-making. A better understanding of diagnosis and future outcomes in the neonatal context is needed.

- **Alternative Therapies**: The use of alternative therapies can generate ethical dilemmas, particularly in the care of children. The voice of stakeholder perspectives must be heard to i) inform policy on alternative therapies in routine clinical care, and ii) to develop guidelines for delivery of these therapies.

- **Identity, Integrity, and Personhood**: Personal accounts from individuals with autism provide a better understanding of their self-identity. Including patient perspectives in the conduct of research helps to respect their values and social diversity.

Conclusion

The Neuroethics Core of NeuroDevNet is addressing the challenges of CP, ASD, and FASD in pragmatic and innovative ways. Within the four initial areas of focus – healthcare delivery, neonatal neurologic decision-making, alternative therapies, and identity – the Core is poised to align human values with cutting-edge research to improve treatment and understanding of neurodevelopmental disorders.