

Wellness and ‘responsive caring’ for children with cerebral palsy and their families

Research Summary

What was the purpose of this study?

The purpose of this study was to understand the wellness needs of young people with cerebral palsy (CP) and their families and how to address these needs in outpatient clinical care. We did this by observing clinic visits and talking to children, families, and clinicians.

What were the study methods?

Observations of clinic appointments: The study took place during the COVID 19 pandemic. A researcher observed 14 in-person or virtual outpatient clinic appointments with children with cerebral palsy and their families.

Interviews: We interviewed five children, eight parents, and seven clinicians to explore their views of what constituted wellness and ‘good’ care within the observed clinical appointments and more generally.

Clinician Dialogues: We conducted three virtual dialogues with the physician clinic leaders to explore emerging findings, discuss ‘what worked’ or not in clinical

care and training, and explored areas for change in practice and education

Key Findings: From Addressing Wellness to ‘Responsive Caring’

Our analysis suggested that adequately addressing family needs requires integrated and flexible care processes that do not separate care into ‘wellness’ versus ‘medical’ priorities. We called these integrated practices ‘responsive caring’.

Responsive caring:

- Partnered with families to maintain a broad focus on child and family needs, priorities, resource access, and life circumstances.
- Co-explored what to do and what was best in each unique situation. Clinicians’ humility was inherent to effective partnering.
- Required clinicians to sometimes let go of their medical priorities and/or to address these priorities through a commitment to ‘really listen’ to families’ challenges and priorities.

Responsive Caring Example - Clinic Observation

Nicole[doctor] asked, “As a family, a year into the pandemic, how are you coping? With work, school -with everything?” Dan [parent] said, “It comes in waves. Right now, it’s okay.” He added that the “times were stressful.” ...He worried, “we’re not doing enough to push [him] forward... you feel like a disaster parent.” ...Nicole gave Dan a supportive smile and began to carefully explain how some of the behaviours they spoke about were normal behaviours at that age. Dan looked relieved. She added that some of what he described was also concerning and it was worth checking into to see what was going on. She added, “But you guys are doing a great job!” Dan thanked Nicole twice, “I really needed to hear that.”

From a Parent Interview

"I keep running notes on my phone of the checkups at [Hospital 1]. Then I keep the neuro ones for [Hospital 2] separate. And we [parents] will just kind of go through if there's anything that we need to bring up, like - have we noticed anything since the last checkup that is a concern we should mention... Sometimes I'll also ask my mother... Just in case, sometimes I'm so close to it maybe I don't see what others are maybe noticing."

Challenges to Responsive Caring

Fragmented Health System

Within the broader health care 'system', services and supports for families were fragmented and multiple which created ongoing stress and additional work for both families and clinicians. There was no central repository of knowledge or navigator - an issue for families that also impeded the abilities of clinicians to support families. Parents were often placed in the position of having to take on the role of navigator which required time and money, and could be emotionally exhausting to maintain.

Child surveillance is a burden for families

Families vigilantly monitored their children's symptoms and progress to be able to accurately report to clinicians. Parents described the burdens of taking copious notes across different medical appointments, and the burdens of needing to communicate between healthcare professionals. Constant scrutiny of functional abilities can insidiously influence family life, how parents see their child, and affect how the child sees themselves.

Implications/Next Steps

The study findings are being applied in two ways:

1. Clinicians are implementing lessons learned in Bloorview clinics to better support families, including in the training of developmental pediatricians.
2. We are conducting further research to develop recommendations for clinical training and improved care.

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