

Family Partnership in Continuing Medical Education: A Collaborative Experience

Catherine Diskin, MB, BCH, BAO, MSc, MRCPI,^{a,b,c,*} Kate Robinson, MFA,^{d,*} Rishi Agrawal, MD, MPH,^{e,f}
Deiren Masterson, BA,^g Cara Coleman, JD, MPH,^{d,**} Eyal Cohen, MD, MSc, FRCPC^{a,b,c,h,i,j,**}

Caregiver and patient involvement in clinical education is described by those involved hoping it can inform clinical practice through conversation, prompting learning and reflection.¹ Over the past year, a seminar series exploring the clinical care of children with medical complexity (CMC) was designed and delivered. Each stage of this seminar series, from conception to writing this manuscript, was rooted in a partnership between clinicians and families. Typically, activities of continuing medical education do not involve a codelivery model. Dialogic education, rooted in nonhierarchical conversation, incorporates patient experiences to deepen learners' perspectives and values through reflection.¹ We hope that by sharing our novel experience as educators who incorporated some aspects of dialogic education to inform and encourage other clinician-family partnerships in education. There is a purposeful breadth of authors in this manuscript. The coprimary and cosenior authors are experienced family leaders who were seminal in the design and implementation of Collaborative Conversations with Families to Advance the Clinical Care of Children with Medical Complexities and Disabilities (C6) and contributed extensively to every phase of this manuscript's development.

Children with medical complexity and neurodisability have multiple

and often characteristic comorbidities that can be challenging to manage.² The existing body of literature does not provide a sufficient evidence base to guide care practices for many children with multisystem comorbidity.³ To address this knowledge gap, we involved clinicians and families in a prioritization study that identified numerous gaps in clinical knowledge for the care of CMC and neurodisability.⁴ Study participants prioritized clinical topics and research questions in which considerable equipoise exists in clinical practice. Table 1 highlights the top 10 clinical topics prioritized in this study³ as adapted for this seminar series. With the prioritization study completed, we considered how to build momentum to develop a community of practice. In partnership with Family Voices, a national family-led organization of families of children and youth with special health care needs and disabilities, we created a seminar series.

THE GOAL: FAMILY PARTNERSHIP CODESIGN AND IMPLEMENTATION OF IN CONTINUING MEDICAL EDUCATION

The C6 virtual and interactive series was designed to stimulate conversation among clinicians, family members, and researchers on challenges in the clinical care of CMC and neurodisability. The primary aims of the seminar series were to: (1) build on the prioritization project

^aDivision of Paediatric Medicine, Department of Paediatrics, and ^dLearning Institute, The Hospital for Sick Children, Toronto, Ontario, Canada; ^bDepartment of Paediatrics, ^eInstitute for Health Policy, Management and Evaluation, and ^fEdwin S.H. Leong Centre for Healthy Children, University of Toronto, Toronto, Ontario, Canada; ^cChild Health Evaluative Sciences, SickKids Research Institute, Toronto, Ontario, Canada; ^gFamily Voices, Lexington, Massachusetts; ^hDivision of Hospital-Based Medicine, Department of Pediatrics, Ann & Robert H. Lurie Children's Hospital of Chicago, Northwestern University Feinberg School of Medicine, Chicago, Illinois; ⁱSection of Chronic Disease, La Rabida Children's Hospital, Chicago, Illinois; and ^jCanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Ontario, Canada
*Contributed equally as co-first authors.
**Contributed equally as co-senior authors.

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Address correspondence to Catherine Diskin, Black Wing 8227, Division of Paediatric Medicine, The Hospital for Sick Children, 555 University Ave, Toronto, ON, M5G 1X8, Canada. E-mail: catherine.diskin@sickkids.ca

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TABLE 1 The Top Clinical Topics Prioritized for Research by Clinicians and Families

1	Neuroirritability and pain
2	Child mental health ^a
3	Disorders of tone
4	Polypharmacy
5	Sleep
6	Aspiration
7	Behavior ^a
8	Dysautonomia ^b
9	Feeding intolerance

Session 1 explored the prioritization study and session 10 considered the next steps in advancing research focused on children with medical complexity. We also included an additional session on shared decision making.

^a Combined as a single session.

^b Partly included with neuroirritability and pain.

and stimulate conversation among clinicians, family members, and others on challenges in the clinical care of CMC and neurodisability; (2) share learnings on clinical topics prioritized, focusing on areas where considerable equipoise exists in practice; and (3) foster a community of practice focused on improving care for CMC and neurodisability via shared practice and potential future research collaboration.

The C6 seminar series ran between September 2021 and June 2022 (with 10 total sessions). Although initially intended to be 1-hour seminars, given the large volume of questions in the initial session, we extended the sessions to 90 minutes to facilitate an extended panel discussion. A total of 1729 individuals registered to participate and 1023 individuals attended at least 1 seminar. Registrants reflected the interdisciplinary team that cares for CMC, including advanced practice nurses (20%), pediatricians (19%), social workers (8%), rehabilitation therapists (including occupational therapists and physiotherapists) (7%), registered dietitians (2%), psychologists (2%), child life therapists (2%) family members including paid, and unpaid family leaders and youth (8%). Six percent of registrants did not provide additional

information and the remaining registrants (26%) included a variety of other professionals, such as family physicians, physician assistants, and researchers. Family members had the highest conversion rate from registration to participation (68%).

Although the C6 seminar series was aimed primarily at providing continuing education for a clinician audience, it was anchored in partnership with families; family leaders were involved in every phase, including designing, delivering, and refining the seminar series. Family involvement in the education of clinicians has the potential to improve patient-clinician partnerships.⁵ Although family involvement is common in clinical education, it is typically anchored in specific sessions that aim to inform learners about their experiences.⁶ Reported benefits to learners include increased empathy and understanding of illness experiences and improved communication with patients and families.^{5,7} Broader family and patient participation in clinical education and continuing medical education (eg, design and evaluation of teaching) is less common.⁸ The codesign model adopted by the organizers of the C6 seminar series represents a novel approach to continuing medical education, and the learnings are valuable to others designing and delivering continuing medical education.

The challenges identified by the organizers of the C6 seminar series include managing power differentials and needing for both training and compensation for patients.⁵

KEY LEARNINGS FROM THE DELIVERY OF C6 SEMINAR SERIES

Early Partnership Informed Successful Partnership

Partnership with Family Voices began when designing the C6 seminar series, before grant

application, with the formation of a leadership committee that included 3 clinicians and 2 family leaders. Early involvement was pivotal in many ways, including creating a shared understanding of the aims of the C6 seminar series so that an outline of what a seminar might look like was developed. This shared understanding underpinned the relationship between organizers. It allowed us to understand what was important when considering the essentials of organizing a seminar series, including recruiting diverse family leaders, preparing family leaders that an experienced family-led organization can provide, and remunerating families for their expertise. We deliberately used the term “family leaders” to refer to families or youth throughout the series to convey their pivotal role in the seminar and mitigate potential power hierarchies.

Deliberate Structuring of Seminars Reflected Meaningful Collaboration With Families and Clinicians

Each session was framed as a collaboration between family leaders and clinicians. At the opening of each session, we acknowledged that the seminars were large and virtual, with discussions involving lived examples that may resurface a variety of reactions and offered resources for clinicians, patients, and families. Two family members began each session by sharing their lived experiences with the topic, including their perspectives on diagnosis, management, and their impact on the child and his or her family. A presentation by the clinical experts followed and a moderated panel discussion between the family leaders and clinical experts followed the presentation. The family leaders reflected on the clinical experts’ talk before audience members’ questions or comments were considered.

National and international medical experts delivered short didactic lectures exploring the 7 prioritized clinical topics. Additional sessions included an opening session focused on the prioritization study, another explored shared decision making, and the final session considered how to move family partnership in research and clinical care forward. The leadership committee wanted the seminar series to reflect interdisciplinary care, a critical component in delivering holistic care to CMC with neurodisability. Medical experts were invited to nominate a second expert from a complementary discipline to participate (eg, for a discussion on feeding problems, a gastroenterologist partnered with a dietician). Family Voices recruited 2 family leaders to participate in each session. Family leaders participated in seminars related to their experience caring for a child with the topic under consideration. For example, family leaders involved in the session focused on irritability had first-hand knowledge of caring for a child with pain and irritability.

Reflecting the coleadership model, sessions were facilitated by either a clinician or family leader. Family leaders and clinicians received equal billing on all communications promoting the series, again emphasizing the shared conversation space we wanted this seminar series to occupy. The deliberate introduction of family leaders at the beginning of a session and again at the start of a panel discussion ensured that all the conversations were rooted in the family perspective. When the seminar series launched, family leaders had 10 minutes at the seminar's outset series to present their experience. As the series evolved, it became clear that the family leaders needed more time to share pertinent details of a

particular experience. The time allocated to family leaders was expanded to 15 minutes.

Valuing Family Leaders' Expertise is Essential

"Family leaders have vast experience managing their child's health and navigating health care systems. Many also have the experience of providing a great deal of clinical care in their homes and see themselves as partners in the clinical care of their child. For example, my son is medically complex and sees specialists in 3 states. My husband and I make decisions about his care every day, managing and administering medication while managing his port access and administering intravenous medications and fluids intermittently for several days-weeks at a time. Like most family leaders I've met, we see ourselves as equal partners with clinicians in his clinical care. We simply have different expertise" (K.R., family leader, reflection on seminar series).

Preparation focused on delivering sessions with educational value. Family Voices has experience preparing family leaders to reflect on their experiences, learning, and expertise. Leaders from Family Voices guided family leaders in distilling life-altering and sometimes traumatic experiences into salient examples with pertinent details. Because family leaders understand the nuances of how challenging it can be to formulate and deliver this type of lived experience presentation, this process was adopted to maintain authenticity by having peer-led preparation for patients and families as opposed to faculty-led.^{5,9,10} Family leaders tailored their stories to align with learning objectives and the clinical expert presentations. They succinctly shared intense and scary experiences while highlighting

lessons learned and implications for future research and systems change.

Although the series was designed to incorporate support for family leaders, we still underestimated the time needed for this important activity. We were flexible as series leaders and found this time. However, we suggest that 3 hours of peer-led support time be made available to family leaders in the future per session.

Focus on Relationship Building Between Clinicians and Family Leaders

Clinicians and family leaders participating in each session were introduced virtually at least 4 weeks before each seminar. Family Voices facilitated these 1-hour informal meetings. Family leaders and clinicians were encouraged to discuss what the seminar topic meant to them and what was important about the topic from their perspective and ask each other questions. These informal, lightly facilitated conversations provided the space for comfort and connection among the presenters to emerge. A huddle also preceded each session with the 2 clinical experts, the 2 family speakers, and the C6 leadership committee. They further expressed ideas and cocreated specific objectives for the session. Resources that clinicians were using in preparation for their talks were shared. These expectations were shared with clinicians and family leaders in their invitation to participate. Clinical experts often edited or revised their didactic talks to incorporate the perspectives of family leaders. Family leaders reflected on what clinicians were speaking to, often incorporating that within their stories. This natural symbiosis between clinicians and family leaders facilitated the achievement of learning objectives in a way that

reflected true patient- and family-centered clinical practice.

“Taking the time to connect family leaders and clinicians helped build relationships that improved the colearning and collaboration of the seminars, with clinicians changing their slides, the family leader’s highlighting stories that fitted with didactic presentations, and their familiarity with each other contributed to the panel discussion flow” (K.R., family leader, reflection on seminar series).

Clinical lead C.D. reflected on the seminar series: “One key takeaway for me is that at the outset, we, as clinicians said, ‘families need the preparation,’ the reality is that providers did too. Working with family leaders to deliver this seminar series required time, to get to know each other, understand different perspectives including that of the audience however the investment delivers.”

The novelty of the C6 seminar series extends beyond its design, involving partnership and exchange between clinicians and family leaders. Seminar delivery differed from a patient or family telling a story followed by an academic medical discussion because family leaders were part of the academic medical discussion and dialog. For instance, if a presenter discussed treatment A versus treatment B, the family partners would indicate what aspects of that decision would be necessary for their experience.

Feedback from participants on the seminar series highlighted the spontaneity, volume, and quality of exchange that occurred in the Chat and extended question-and-answer section. We wonder if the Webinar format of Zoom afforded anonymity, which encouraged a sense of nonhierarchy/equilibrium that we sought within the seminar participation itself, and, by

extension, addressed that conversation about “management of power-differentials” that surfaced as an identified challenge.

Focusing on the relationship between clinicians and family leaders yielded benefits for the leadership committee. “I found working on the C6 seminar series to be purposeful. Bringing parents/family caregivers and clinicians together has a deep professional and personal resonance for me. The inspiration, openness, and opportunity to be creative with this amazing team of families and clinicians was career-influencing” (D.M., communications and operations specialist, reflection on seminar series).

“Looking back, we can confidently say that the involvement of family leaders in C6 improved the quality of the C6 seminar series. While family leaders knew this before the series, our experience has taught us that such family partnership in education is not dissimilar from family-centered care except that the recipient is a health care provider in a learner role rather than a patient and their family” (E.C., clinical lead, reflection on seminar series).

Success requires investment in a relationship-building, idea-sharing, and respectful partnership so that all involved share a common goal that ultimately results in an improved outcome. “Communication takes time and a willingness to be vulnerable. Communication is the secret sauce for successful family partnership” (K.R., family leader, reflection on seminar series).

We hope that sharing our experience will inspire others to create new and meaningful ways to engage with families to enable the extension of the mantra of “nothing about us, without us” into educational activities regarding

complex care, childhood disability, and other areas of clinical pediatrics as well.

FUTURE DIRECTIONS

We hope that future projects continue to develop a community of practice that includes family and clinical partners focused on CMC, considering the known research gaps, and working toward addressing them.

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ABBREVIATIONS

C6: Collaborative Conversations with Families to Advance the Clinical Care of Children with Medical Complexities and Disabilities
CMC: children with medical complexity

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