

**PROJECT TITLE:**  
Advance Care Planning Conversations: Perspectives from Families of Individuals with Cerebral Palsy

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**RATIONALE**  
**Advance Care Planning (ACP)** helps parents of children with chronic health conditions understand their child's diagnosis and prognosis and use that knowledge to anticipate and discuss future health, developmental states, and treatment options and prepare in case of severe illness. Although the Canadian Paediatric Society views early discussions about **ACP** as the standard of care for any child with a chronic life-threatening condition, **ACP** has not been routinely integrated into the care of children with cerebral palsy (CP).

**OBJECTIVES**  
To explore attitudes, knowledge, preferences and willingness to engage in ACP among families of individuals with CP.

**METHODS**  
**Cross-sectional descriptive study**  
**Participants** - Family members (n=86)  
• Recruitment via newsletters, websites, twitter, and social media - shared by 3 provincial community CP organizations (CP-NET, ThreeToBe/PAL, OFCP)



**Data collection & outcome measure**  
• Online adapted anonymized survey: Parent Perspective on Advance Care Planning Questionnaire<sup>5</sup>  
• 4 Key Sections: Characteristics of the Family & Individual with CP, Understanding of CP, Knowledge of ACP, Decision-making Preferences.

**Data Analysis**  
• Descriptive statistics, chi square, content analysis

**PARTICIPANT CHARACTERISTICS**

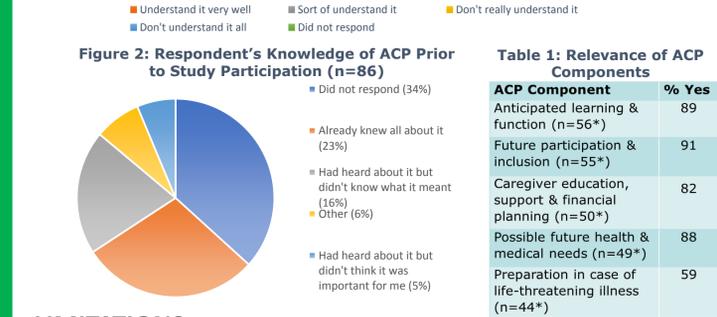
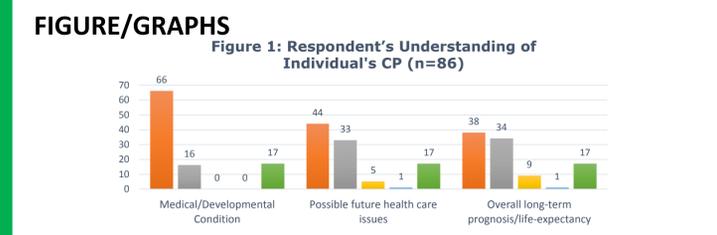
Survey Respondent		Individual with CP	
<b>Mean Age</b>	48 yrs (range 23-81 yrs)	<b>Mean Age</b>	15 yrs (range 2-54 yrs)
<b>Relationship</b>	<b>n=86</b>	<b>Type of CP</b>	<b>n=86*</b>
Mother	67 (78%)	Spastic	51 (59%)
Father	14 (16%)	Mixed Tone	17 (20%)
Other (sibling, foster parent, grandmother)	5 (6%)	Ataxic	9 (10%)
		Dyskinetic	3 (3%)
		Other/Not sure	6 (7%)
<b>Family Income</b>	<b>n=83*</b>	<b>GMFCS Level</b>	<b>n=81*</b>
> \$100,000	24 (29%)	Level 1	13 (16%)
\$50,000 - \$100,000	31 (36%)	Level 2	14 (17%)
\$25,000 - \$50,000	16 (19%)	Level 3	18 (22%)
< \$25,000	12 (14%)	Level 4	18 (22%)
		Level 5	18 (22%)
<b>Education Complete</b>	<b>n=86</b>	<b>Medical Technology</b>	<b>n=77*</b>
College/University	63 (73%)	Yes	35 (45%)
High School	20 (23%)		
<b>Stress Level</b>	<b>n=86</b>	<b>ICU Admission</b>	<b>n=69*</b>
Very high/high	47 (55%)	Yes	46 (67%)
Average	31 (36%)		
Very Low/Low	8 (9%)	<b>Born in Canada</b>	<b>n=85*</b>
		Yes	57 (85%)

\* Note that not every respondent answered every question

# Families who have a child with cerebral palsy feel Advance Care Planning is an important topic to discuss with their child's health care provider



- RESULTS**
- Knowledge of CP is high; knowledge about possible future health care issues and overall long-term prognosis and life expectancy is less certain (Fig 1).
  - Almost half of respondents had not heard of or had little understanding of ACP (Fig 2).
  - Most stated that ACP was a relevant topic that they would like to discuss with their child's health care providers (HCP) (44/56; 79%) and most components of ACP were relevant (Table 1).
  - Regardless of GMFCS level, many felt that preparation for severe illness was an important topic to discuss with their HCP (17/26; 65%); only a minority had had these discussions (3/25; 12%).
  - Many respondents had thought about their child's risk of dying (29/45; 64%); very few had spoken about it with their child's HCP (9/29; 31%).
  - Most felt that conversation about ACP should be initiated and guided by a HCP.



- LIMITATIONS**
- A decreasing number of responses to questions as the survey progressed - may be attributed to survey design issues, technical challenges, topic sensitivity, and/or lack of perceived relevance of item to some respondents.

- CONCLUSIONS**
- Not all families want to discuss all aspects of ACP but many believe it is an important topic to address.
  - HCP should be aware of the different components of ACP and raise the topics with families in a gentle and compassionate way to gauge receptivity.

- NEXT STEPS**
- Multivariate analysis underway to explore underlying child or family characteristics that may be associated with a family's willingness to engage in conversations about ACP.
  - Work with partner organizations (CP-NET, ThreeToBe/PAL, OFCP) to share findings with families of children with CP.
  - Phase 2 - direct engagement with families, front line clinicians and practice leaders to gather feedback and co-design ways of integrating ACP into the routine care for individuals with CP.

**REFERENCES**

1. Kolarik RC et al. *J Palliat Med* 2002
2. Hammes BJ et al. *J Palliat Med* 2005
3. Lotz JD et al. *Pediatrics* 2013
4. Lyon ME et al. *J Adol Health* 2014
5. Liberman DB et al. *Pediatrics* 2014