

## Enhancing care for young people with MD: Addressing the human elements of progressive illness

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### INTRO

- Most young people with MD regularly attend medical clinics
- It is important to make sure this experience has a positive impact on people's lives beyond the biomedical benefits
- This study aims to explore and improve the human aspects of care, and how these are addressed in healthcare practices

### METHODS

- *Participants:* 30 families and 34 clinicians took part in the study across 2 Ontario hospitals
- *Clinic observations:* 44 clinic visits of 30 families were conducted over a 3-year period – notes were taken on interactions between staff and families, clinic processes, and the physical environment
- *Clinician dialogues:* 15 'dialogues' were conducted with the clinicians – these consisted of discussions regarding how human aspects of living with MD were/were not attended to in the clinic, and how this might be improved



There is a **mismatch** between the importance clinicians place on the **human aspects of care**, and what **actually happens in clinics.**



### KEY FINDINGS

1. *Clinic processes:* Timing of sessions was set by biomedical goals based on best practice standards, rather than human-focused care.
2. *Clinician-child/family interactions:*
  - i) Most interactions were conducted with parents or other caregivers.
  - ii) Children and families often directed discussions towards human aspects of care, while clinicians often prioritised biomedical care.
  - iii) Negative emotions expressed by children or other family members were often avoided by clinicians.
3. *Staffing Allocations:* Most staff were traditionally from more biomedical professions vs. more human focused professions.

### RECOMMENDATIONS

Establish integrated clinic processes to consider human focused care, e.g:

- Increase flexibility of clinic length, frequency and focus
- Create opportunities for the child and family to have separate time with clinicians so all can contribute to care decisions
- Allocate physical space and time for discussions of difficult or emotional topics
- Shift staffing to have a greater focus on human care
- Continue process of reflexively analysing clinic practices and processes

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