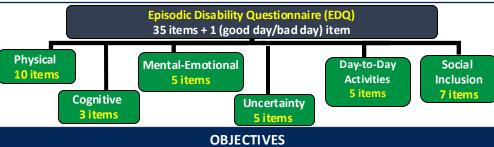
Advancing Measurement of Episodic Disability: Assessing the Sensibility, Utility and Implementation Considerations of an Episodic Disability Questionnaire with Older Adults Living with Complex Health Needs

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INTRODUCTION

- >1/3 of older adults experience multi-morbidity, leading to disability; defined as the multidimensional health-related consequences of health conditions (Gontijo et al. 2019).
- Patient reported outcome measures (PROMs): self-reported questionnaires that can be used to describe, predict or evaluate a change in health outcomes (Churruca et al. 2021)
- Derived from the HIV disability questionnaire (HDQ), the Episodic Disability Questionnaire; generic PROM assessing presence, severity and episodic nature of disability (0'Brien et al. 2024)
- The Episodic Disability Questionnaire may show promise for use with older adults with complex health needs, however its properties are unknown.



- 1. To assess sensibility (face and content validity, ease of use, format) of the EDQ with older adults with complex health needs.
- 2. To explore utility of the EDQ for use in clinical practice from the perspectives of older adults with complex health needs.
- 3. To identify implementation considerations for administration and communication of scores from the perspectives of older adults with complex health needs.

METHODS

Study Design: Multi-methods cross-sectional study.

Study Setting: St. Michael's Hospital Academic Family Health Team (SMHAFHT). Inclusion Criteria: Community dwelling older adults living with complex health needs, age ≥65

years, receiving care from the SMHAFHT, able to understand, read and speak English.

Data Collection: In person – home (n=10) or SMHAFHT clinic (n=1).

- **EDQ:** Electronically or paper-administered.
- Sensibility Questionnaire: Feinstein (1987) face, content validity, format, ease of usage.
- **Demographic Questionnaire**
- **In-person semi-structured interview:** Sensibility, utility, implementation considerations.

Data Analysis: Interview transcripts: Group-based directed content analysis of interview, Questionnaires: Median, 25th & 75th percentiles, Sensibility Questionnaire: EDQ was sensible if ≥80% of items had a median score of ≥5/7, and no items had a score of ≤3/7 (0'Brien et al.2022)

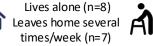
RESULTS

Participant Characteristics (n=11)

Median age: 83 years

Women (n=6)

Men (n=5)



Uses mobility aid indoors (n=8) Uses mobility aid

outdoors (n=9) Common health conditions: Diabetes (n=4), Osteoarthritis (n=5)

Highest presence (78/100) & severity scores (38/100) in day-to-day activities domain

Highest episodic score (33/100) in **cognitive** domain the EDQ (n=9)

EDQ Key Findings:

Interviewer observations:

Participants required ++ Median time ~ **12 mins** to assistance to complete

complete

Sensibility Findings:

Questionnaire:

- EDQ demonstrated face and content validity, was easy to use with community dwelling older adults with complex health needs:

100% of items had a median score of $\geq 5/7$, and no items had a score of $\leq 3/7$.

Interview:

- The EDQ is simple, comprehensive and captured episodic nature of disability.
- Participants highlighted the importance of the mental-emotional health domain in capturing their health challenges.

..the questions helped me identify the health issues that I need to look at ...helped me to honestly admit the disabilities I have." (P13)

"Mentally I'm having problems. And I think they (healthcare providers) should look into my mental state a lot..." (P1)

Implementation Considerations Interview Findings:

Mode, Timing and Location of Administration:

- Preference to complete EDQ verbally and for similar mode of administration in the future (n=8).
- Preference for administration during their medical appointment (n=5).

Communication of EDQ Scores:

- Preference for wanting their EDQ scores (n=5)
- Preference for printed report of EDQ scores in conjunction with a conversation with HCP (n=6).

Utility Interview Findings:

Participants found the EDQ could:

- Provide a full picture of their health challenges to HCPs.
- Guide assessment and treatment planning for their HCP.
- Foster conversation between patients and their HCPs.
- Foster self-awareness of their disability and help track their health fluctuations.

"...I talk more better than I can read to understand." (P4)

DISCUSSION

- The EDQ demonstrated sensibility and utility for use in older adults living with complex health needs.
- Participants had a preference for interviewer administration of EDQ and had difficulty understanding questions. Administration and communication of scores should be tailored to the individual.
- Strengths: Multi-methods of data collection, strong conceptual frameworks and engaging older adults in community to inform process.
- **Limitations:** Limited transferability of findings to the population at large or care settings.
- Future work: Explore clinicians perspectives on the EDQ, establish strategies to facilitate the uptake and usage of the EDQ in this population, and exploring the application of the EDQ to other populations.
- Clinical Takeaways: Expand on mental-emotional health domain, tailor application to specific patient, discuss results with patient