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# Outcomes of a caregiver-inclusive approach to providing assistive technology: A mixed-methods study

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# Background

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- In 2013, 40 million family caregivers in the US provided care to adults with unpaid contributions estimated at \$470 billion (Reinhard et al., 2015).
- 55% of caregivers feel **overwhelmed** (American Psychological Association, 2012).



# Background

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- Given the rapidly aging population and issues associated with caregiver burnout, reducing caregiver burden is critical
- Two systematic reviews have suggested that assistive technology (AT) has the potential to reduce caregiver demands (Mortenson et al. 2012; Marasinghe, 2016)
- A pilot RCT we conducted revealed AT improved AT user performance and reduced caregiver burden (Mortenson et al. 2013)



# Objective

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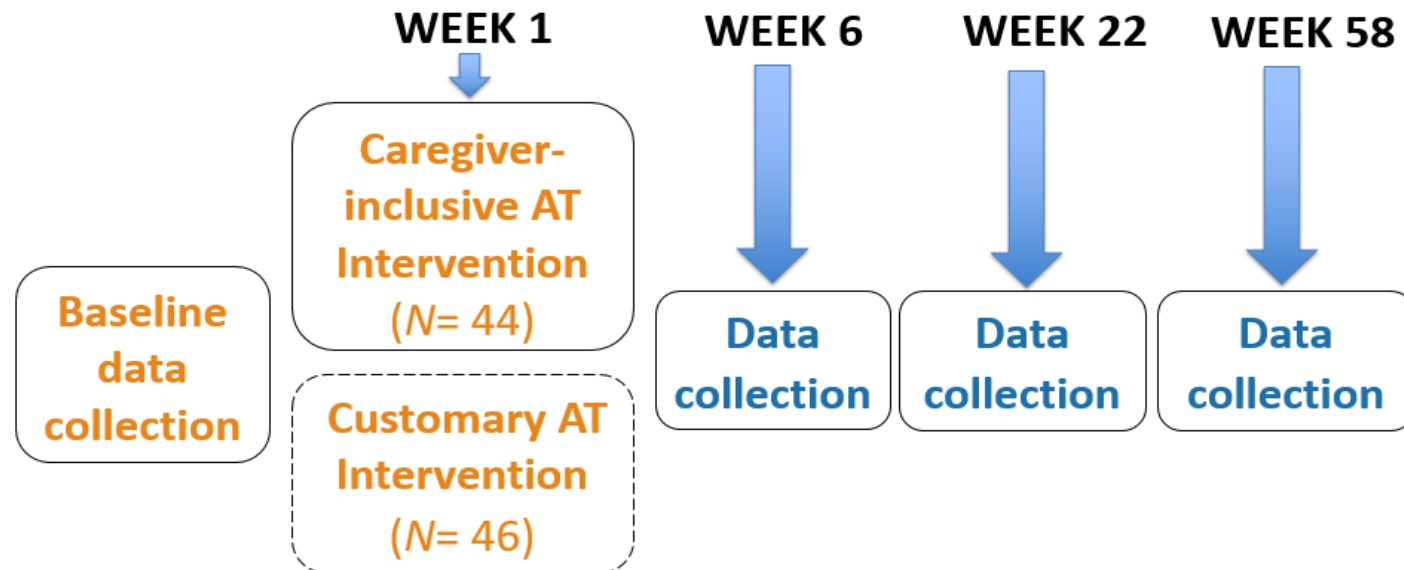
To determine if a caregiver-inclusive approach to AT provision decreases family caregivers' burden and increases care recipients' abilities to perform activities.



# Methods

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- RCT, mixed-methods in 3 Canadian sites (Demers et al. 2016)
- Inclusion criteria: Dyads with a family caregiver who provided unpaid assistance >4 hours/ week for >1 month to a person over 55 years old with a mobility limitation



# Experimental Intervention

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The Assistive Technology Provision, Updating, and Tune-Up (ATPUT) intervention consisted of five components:

1. Working collaboratively with the care recipient and family caregiver, problematic activities were identified and prioritized;
2. The care recipient's daily activities and social participation were assessed in the home and community;
3. Human assistance and AT being used at the time were reviewed;
4. The therapist made recommendations for changes in assistance and AT;
5. An ATPUT Personal Plan was negotiated by the occupational therapist with the care recipient and caregiver. This could include recommendations for AT, financial assistance to repair or acquire new AT, receipt of AT in a prompt manner, training, and additional follow-up visits.

Provided free assistive technology to participants and did not restrict the number of visits.

# Methods

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- Quantitative data:
  1. Care recipients: Functional Autonomy Measurement System (SMAF) (Desrosier et al., 1995).
  2. Caregiver: Caregiver Assistive Technology Outcome Measure (CATOM) Part A and Part B. Part A measures AT specific burden and Part B measures overall burden. (Mortenson et al., 2015)
- Qualitative data: Semi-structured interviews analyzed thematically with a 5-step process (Braun and Clark, 2005).



# Demographics

- No significant differences between experimental and customary group demographic characteristics

| Care recipients at baseline         |              |           | Caregivers at baseline             |              |           | Interviewed caregivers (N=27) |
|-------------------------------------|--------------|-----------|------------------------------------|--------------|-----------|-------------------------------|
|                                     | Experimental | Customary |                                    | Experimental | Customary | Qualitative                   |
| Age (Yrs)                           | 75           | 75        | Age (Yrs)                          | 63           | 67        | 63                            |
| Sex (Female)                        | 57%          | 52%       | Sex (Female)                       | 57%          | 64%       | 67%                           |
| Years of Education                  | 13           | 13        | Relationship (Spouse)              | 61%          | 76%       | 67%                           |
| Marital status (Married)            | 68%          | 78%       | Years helping recipient            | 7            | 7         | 6                             |
| Length of functional problems (Yrs) | 6            | 4         | Avg hours/ wk providing assistance | 29           | 22        | 20                            |



# Intervention Differences

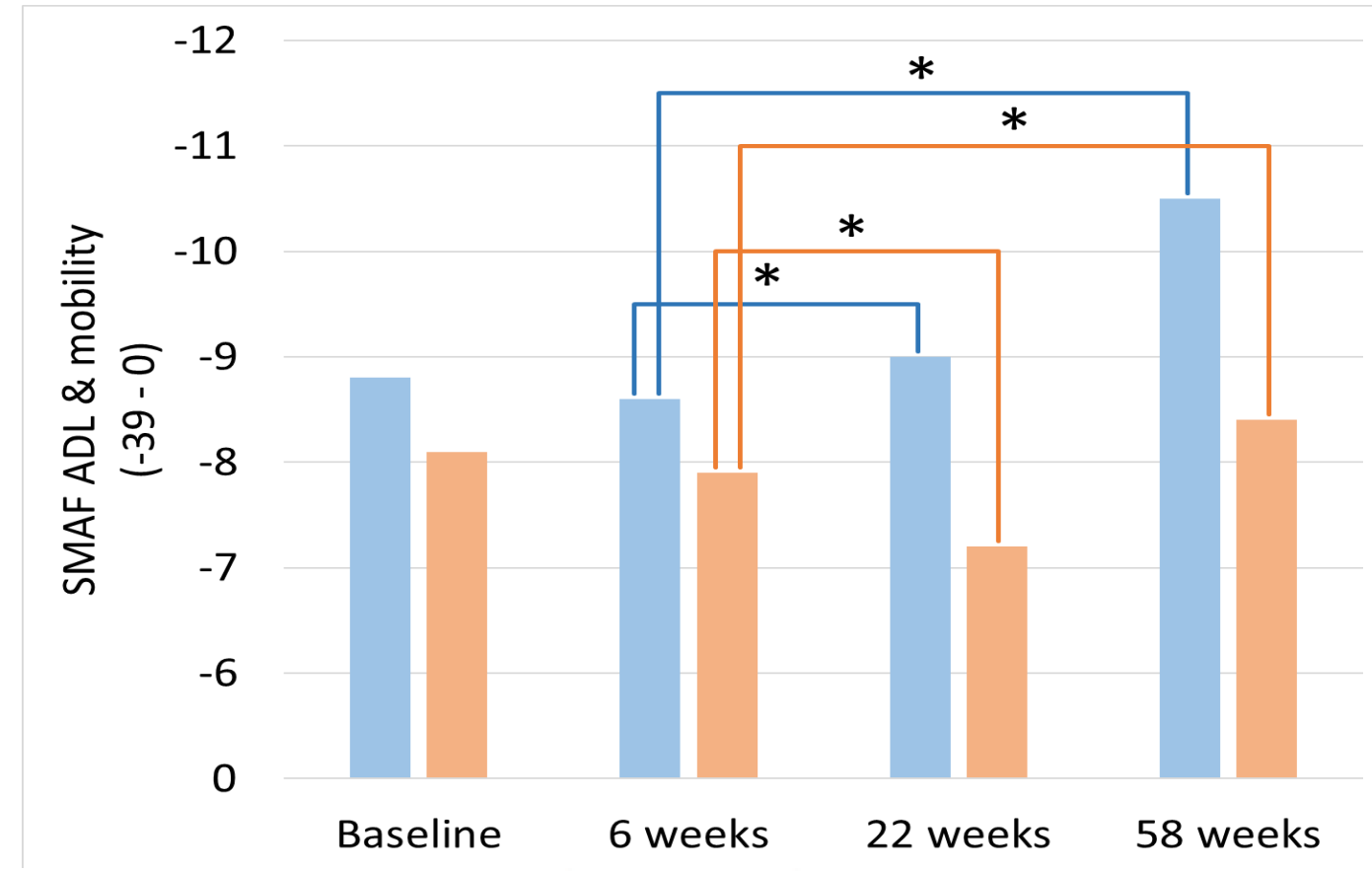
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The experimental group:

- Received more AT devices to assist with problematic activities compared to the comparison group
- Had significantly higher percentage of problematic activities targeted by the provision of AT
- Received significantly more visits

Treatment fidelity: an average of 93% of the steps comprising the experimental intervention were completed by occupational therapists.

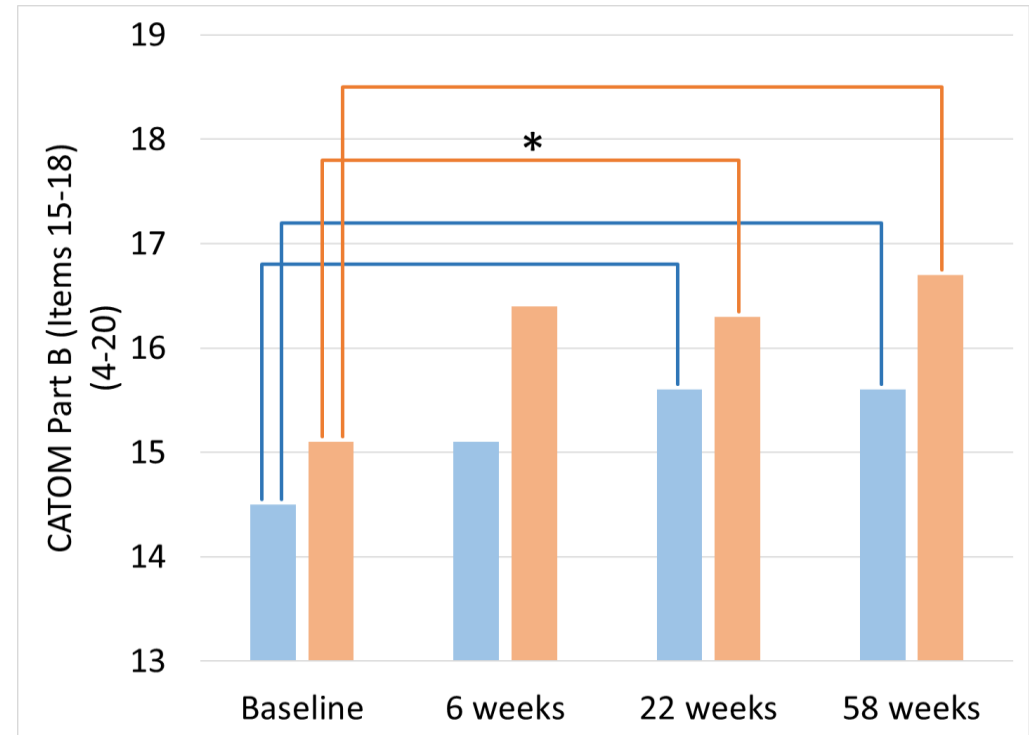
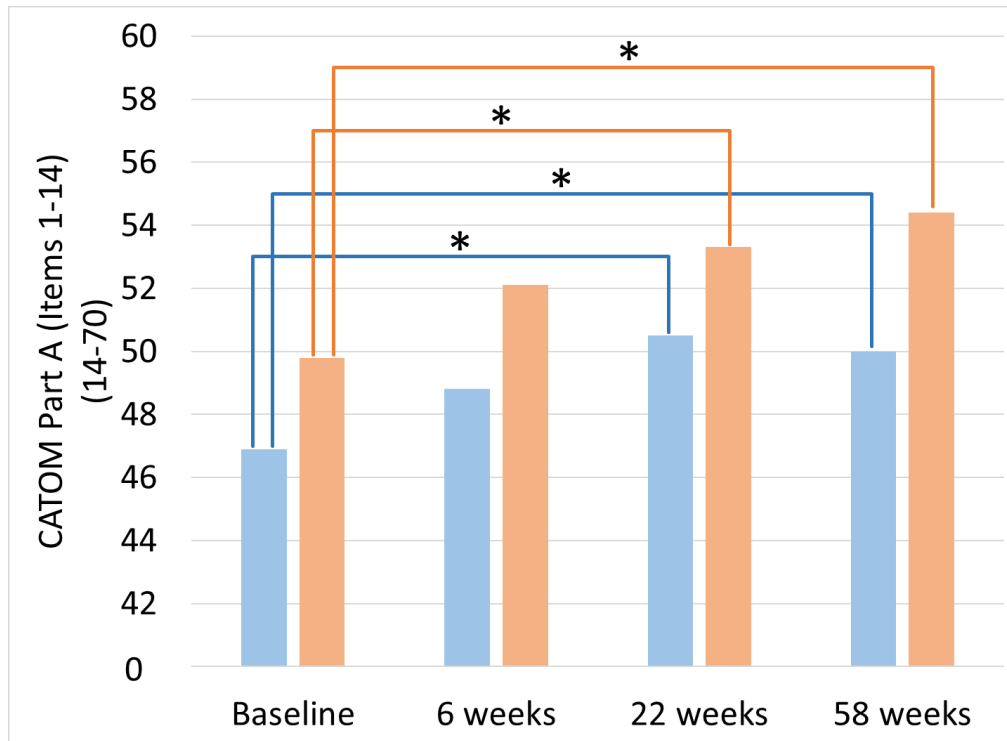
# Quantitative Results: Care recipients



■ Experimental intervention ■ Customary intervention

(Mortenson et al., 2018)

# Quantitative Results: Caregivers



■ Experimental intervention    ■ Customary intervention

No significant difference between groups, but caregiver burden decreased in both.

(Mortenson et al., 2018)

# Qualitative Results

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- 3 themes were identified:
  1. A partial piece of mind
  2. Working together
  3. Overcoming barriers

(Mortenson et al., 2017).



# A Partial Piece of Mind

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- Shift in caregiving labor to a monitoring role:

*“I’m still around... I have to be there, just in case something happens.”* – Son taking care of his mother who no longer needed help bathing

- AT may alter the provision of caregiving from direct physical assistance to supervision (Pettersen et al., 2005).
- Also identified reduced stress and ATs may improve the caregivers’ sense of security (Starkhammar and Nygård, 2008)

# Working Together

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- Caregivers' sense of collaboration during the intervention process to receive ATs:

*“[The OT] was very, very good, and she really answered all our questions. ... [She] questioned whether I was worried at times or if it [caregiving] affected me psychologically” -*

Caregiver whose husband has mobility challenges

# Overcoming Barriers

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- Wait times for service providers is a barrier to AT:

*“[The first visit] was a little bit too late. ... That stuff really would have been needed in, you know, the very first week that it happened” -*

Caregiver, whose mother had fractured her foot

- Another barrier that was identified was lack of funding



# Conclusion

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- No significant between-group differences
- Caregivers burden in both groups decreased despite decreasing functional independence of the care recipient over time



# Conclusion

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- Lack of clear differences may be explained by:
  1. Unanticipated engagement of caregivers by therapists providing customary care
  2. Lack of sensitivity of outcome measures
- Combined with qualitative data, suggests a multi-factorial AT interventions can reduce caregiver burden, but access may be problematic for some individuals

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