

Physical Therapy Interventions for Those with Spinal Muscular Atrophy Compared to Standard of Care Guidelines

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Background and Objectives

Spinal Muscular Atrophy (SMA) is an autosomal recessive genetic disorder that results in weakness and decreased function and presents with phenotypic variation impacting prognosis. Medical care for those with SMA has changed significantly as disease-modifying therapies (DMT) have impacted prognosis and functional outcomes. Therefore, identifying current physical therapist (PT) practice patterns to optimize education of peer professionals and best care for patients is critical. This survey examined current PT practice alignment with standard of care (SOC) guidelines, and barriers and facilitators to care. We hypothesized that practice recommendations would vary from SOC guidelines and would also vary based on familiarity with SOC and after DMT.

Methods

- Pediatric PTs working with patients with SMA were recruited by e-blast, email and public posting on PT and SMA related websites.
- Participants completed a REDCap cross-sectional survey. Demographics, knowledge of SOC, implementation of interventions, and barriers and facilitators to successful application were captured.
- Practicing PT recommendations for strengthening, aerobic exercise, stretching, standing, and balance, were compared to SOC guidelines.
- Data was analyzed using descriptive statistics, chi-square, binomial tests and correlations (SPSS 20) to examine factors associated with PT provision and facilitators and barriers associated with implementation.

Results

Participants:

- Of 356 respondents, 190 completed surveys.
- 82% of survey respondents report direct PT care of those with SMA (N=156).
 - State of practice, years in practice, education, and practice setting varied, with more PTs working in the Midwest and more treating children in outpatient settings.

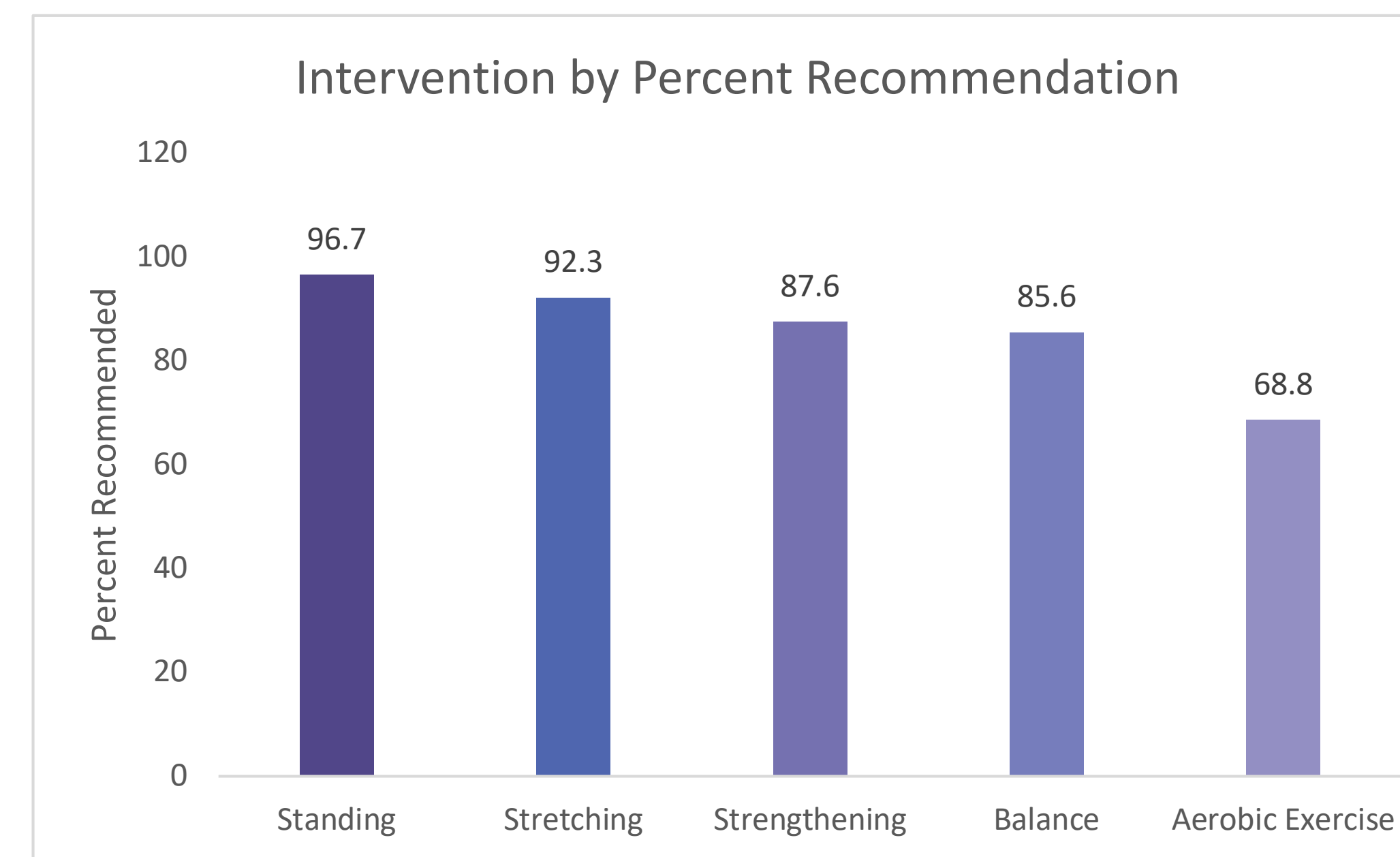
Familiarity with SOC guidelines:

- 48% of PTs reported familiarity with the 2007 SOC guidelines.
- 53% of PTs reported familiarity with the 2016 SOC guidelines.
- SOC familiarity was associated with change in practice ($p < .001$), with 98% of PTs reporting an influence on their practice choices.

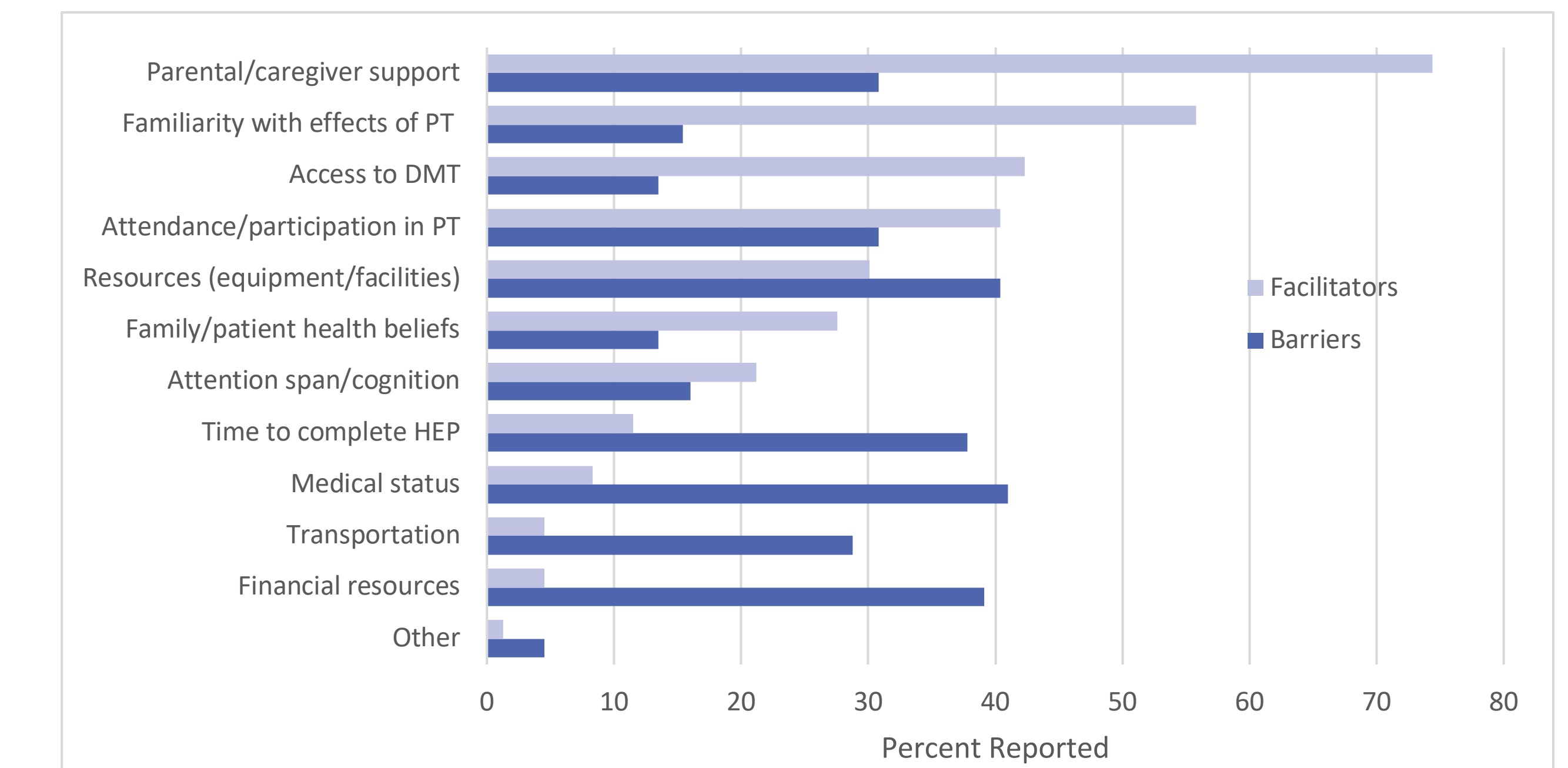
Changes in practice patterns for patients on DMT:

- Significant increase in both frequency $X^2(2, n=70)=55.4$ and intensity $X^2(1, n=79)=7.9$ recommendations after DMT ($p=0.007$).
- Post-DMT, PTs recommended increases in:
 - Exercise $X^2(1, n=79)=27.9, p < 0.001$
 - Balance $X^2(1, n=77)=15.9, p < 0.001$
 - Stretching $X^2(2, n=77)=65.5, p < 0.001$
 - Standing $X^2(1, n=78)=3.3, p = 0.07$

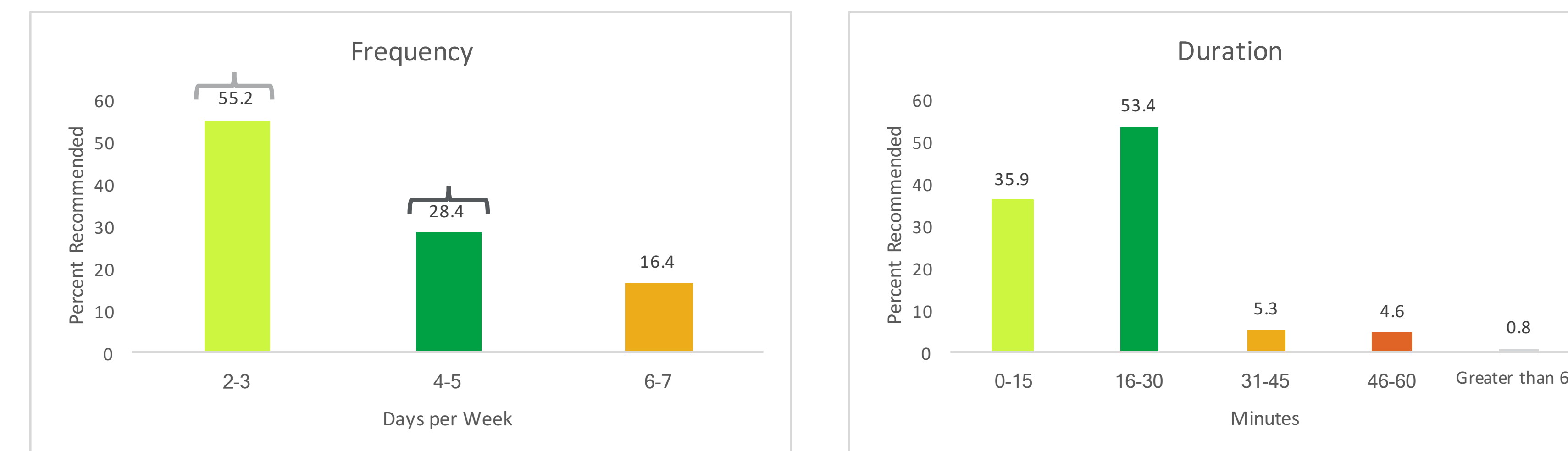
Results



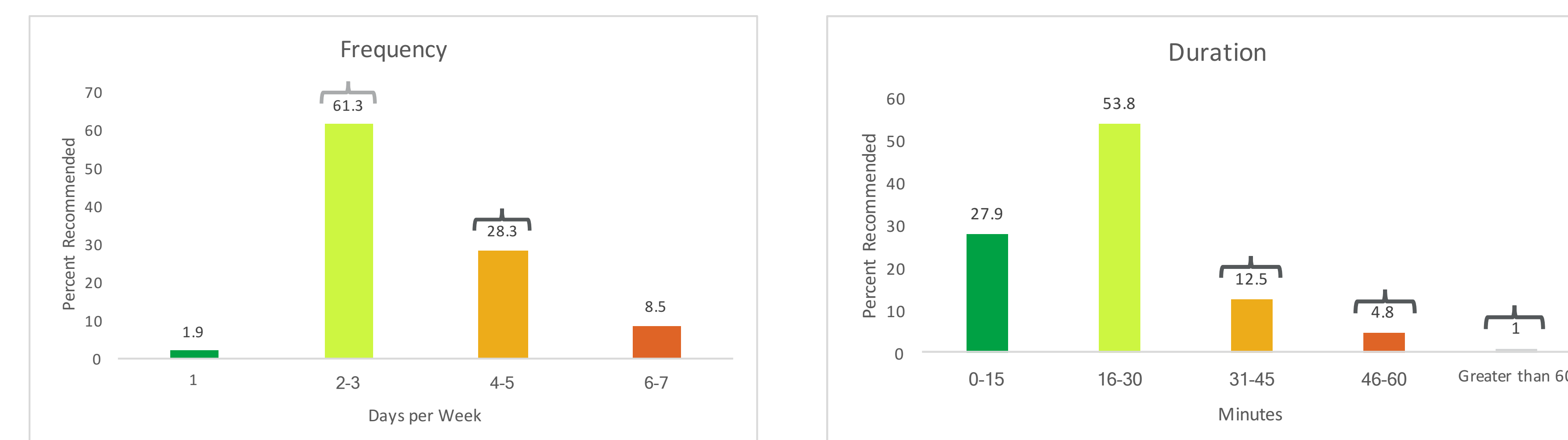
Barriers and Facilitators to Progress



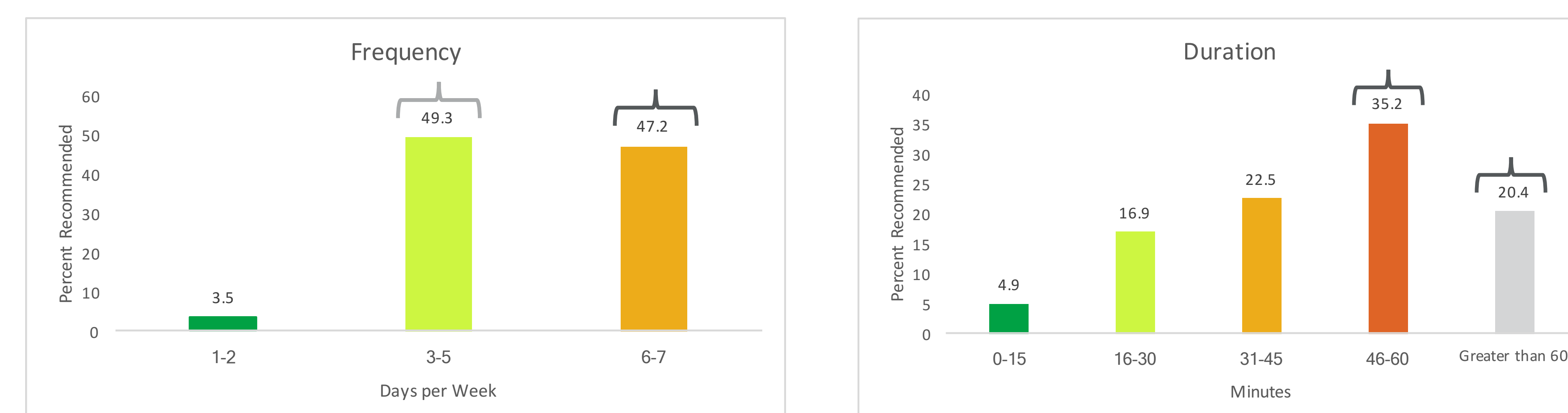
Strengthening



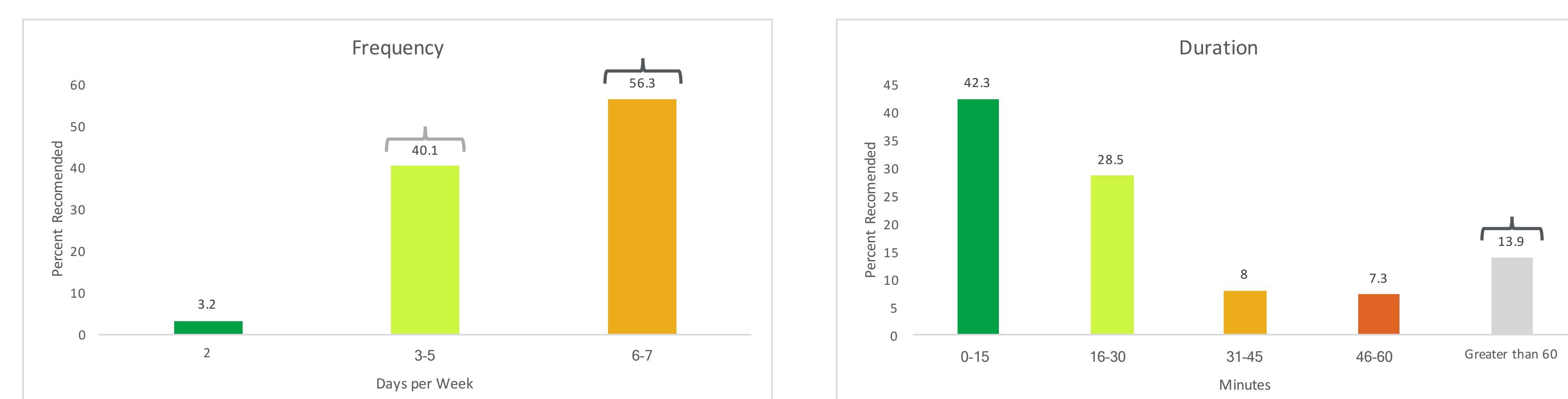
Aerobic Exercise



Standing



Stretching

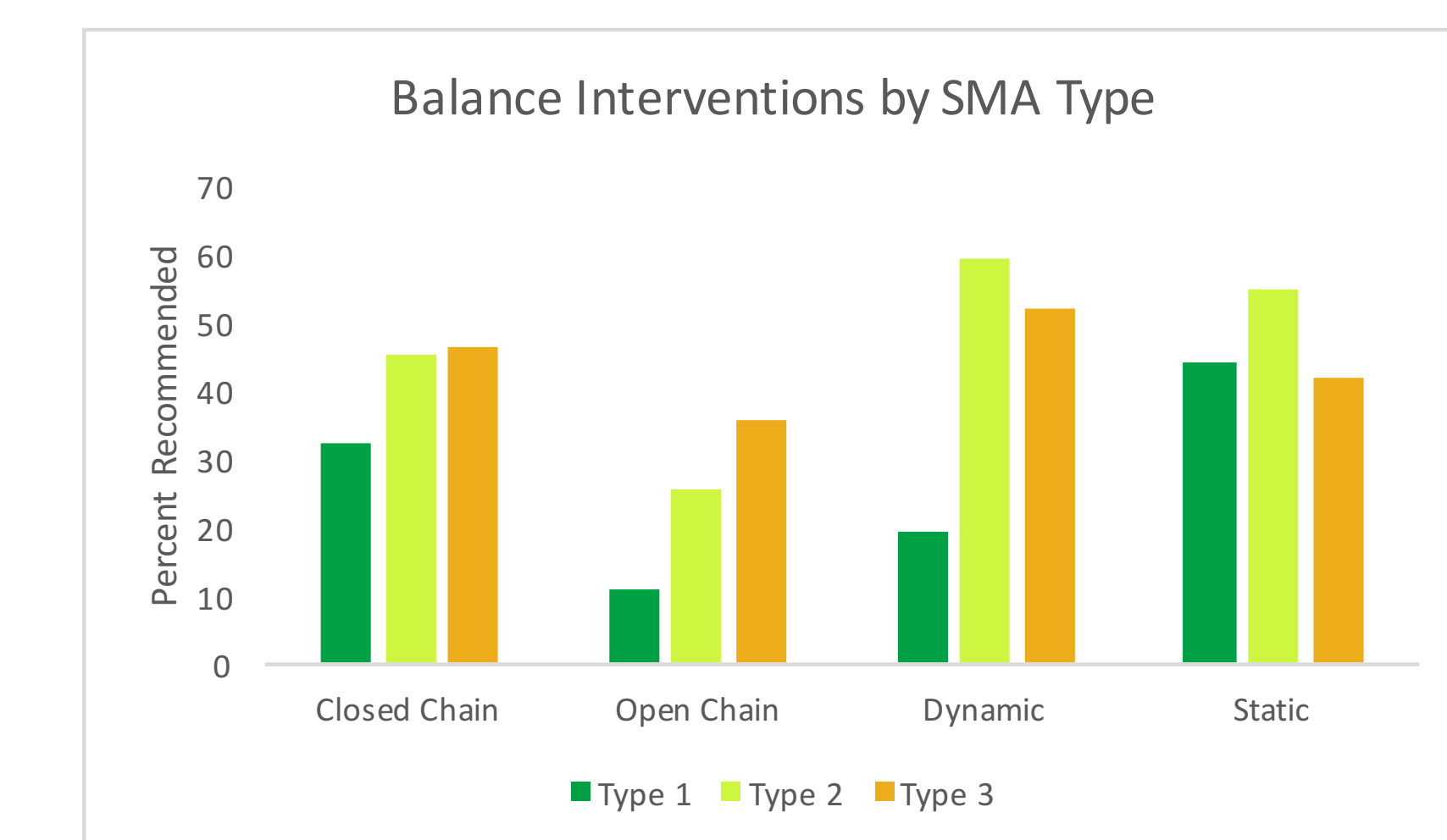


Balance

Recommendation meets SOC guideline

Minimal:

Optimal:



Conclusions

- Although a majority of PT recommendations matched SOC guidelines, actual familiarity with SOC guidelines was only reported by slightly more than half of respondents.
- While a majority of PTs make recommendations for 5 key interventions (strengthening, aerobic exercise, balance, standing and stretching) that match SOC guidelines, more education is needed on specific intervention parameters, including: stretching duration recommended to improve length, as well as aerobic exercise duration and implementation.
- Interestingly, while the SOC only addresses balance interventions for those with Type 3, PTs also recommend static balance activities for those with Type 1 and dynamic activities for those with Type 2.
- Familiarity with the SOC significantly influences plan of care.
- PT practice recommendations for exercise, standing and balance increase post-DMT.
- Most common facilitator (caregiver support) and barrier (medical status) to progress were identified.
- Limitations:
 - Questionnaire design and responder bias, as well as small sample size may limit generalizability of results

Clinical Relevance

- This data provides a rich resource on how PTs implement 5 of the interventions described in the SOC into their plan of care and how specific parameters match or vary from SOC guidelines.
- These findings can guide educational initiatives for therapists as well as further inform SOC and best-practice rehabilitation management. However, more research is needed to understand the feasibility and efficacy of actual implementation of the 5 PT interventions.