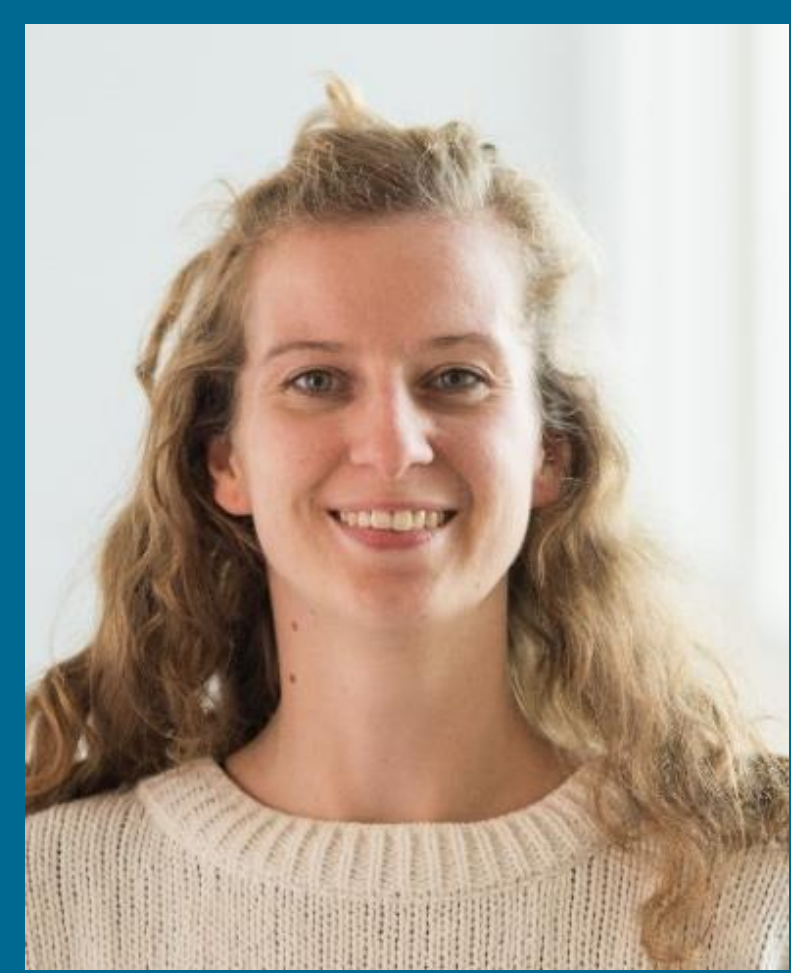


Mobility, Stability, Adaptability: The challenges of walking for people with Hereditary Spastic Paraplegia

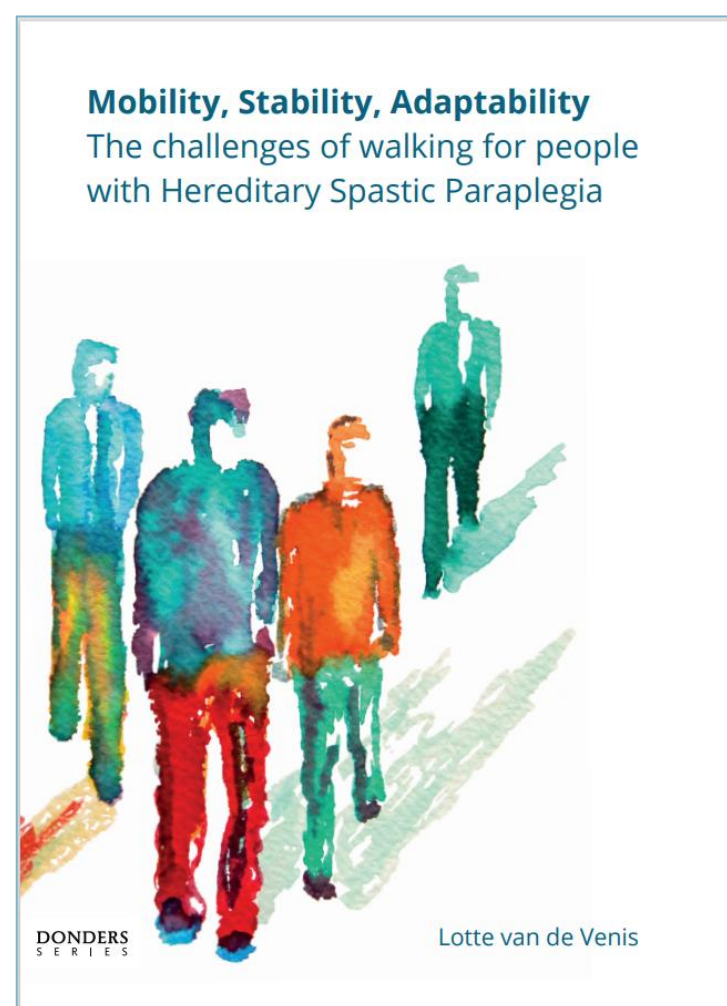
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Rationale

- Hereditary spastic paraplegia (HSP) is a rare, inherited movement disorder marked by progressive bilateral spasticity, muscle weakness, and proprioceptive loss of the lower extremities. Over 90 genetic subtypes (SPG) have been identified.
- Clinically, HSP is classified as pure or complicated, depending on additional symptoms such as ataxia, epilepsy, or cognitive impairment.
- HSP significantly impacts daily functioning and societal participation, due to disabling gait impairments, fear of falling, and falls.



Objectives

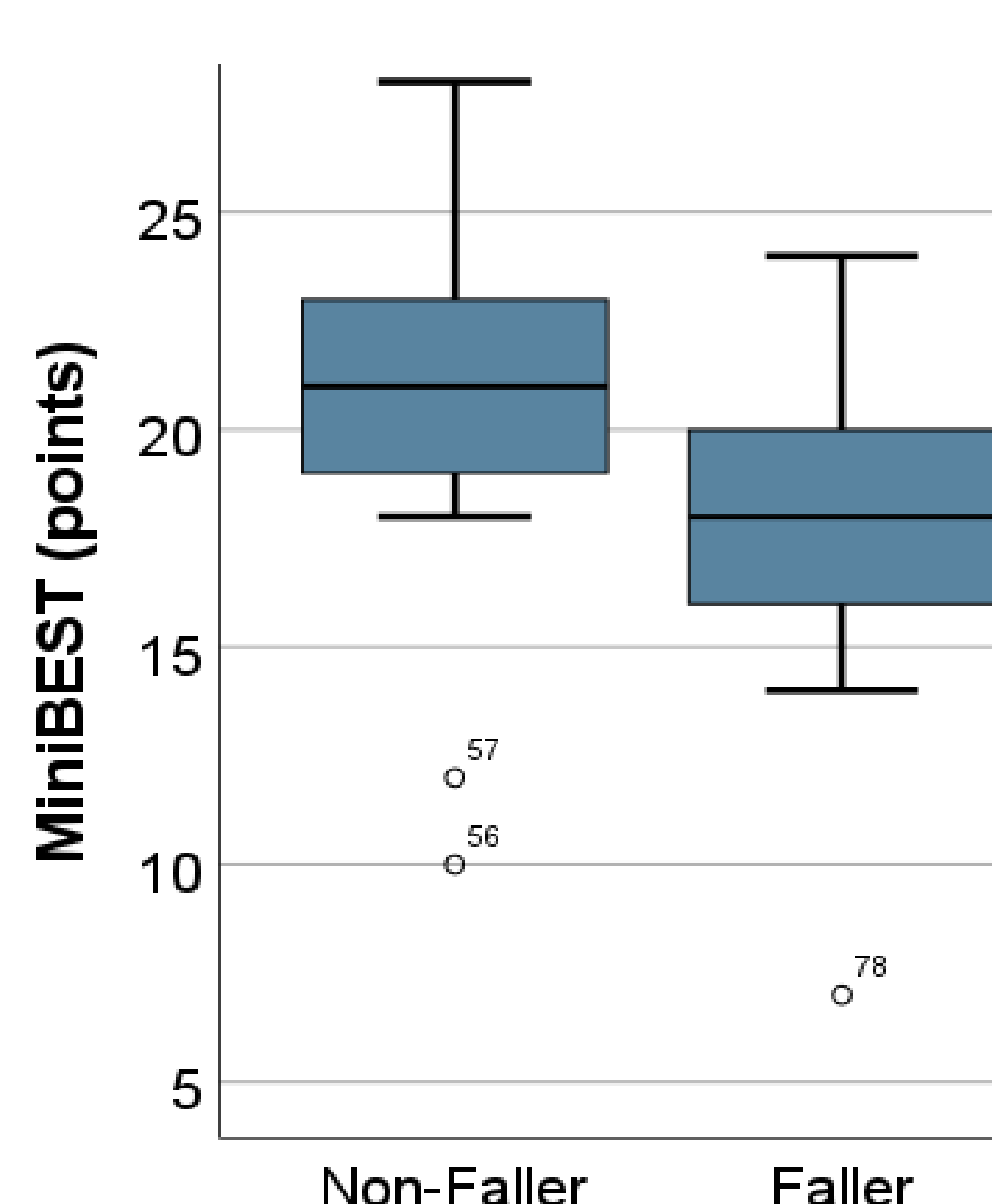
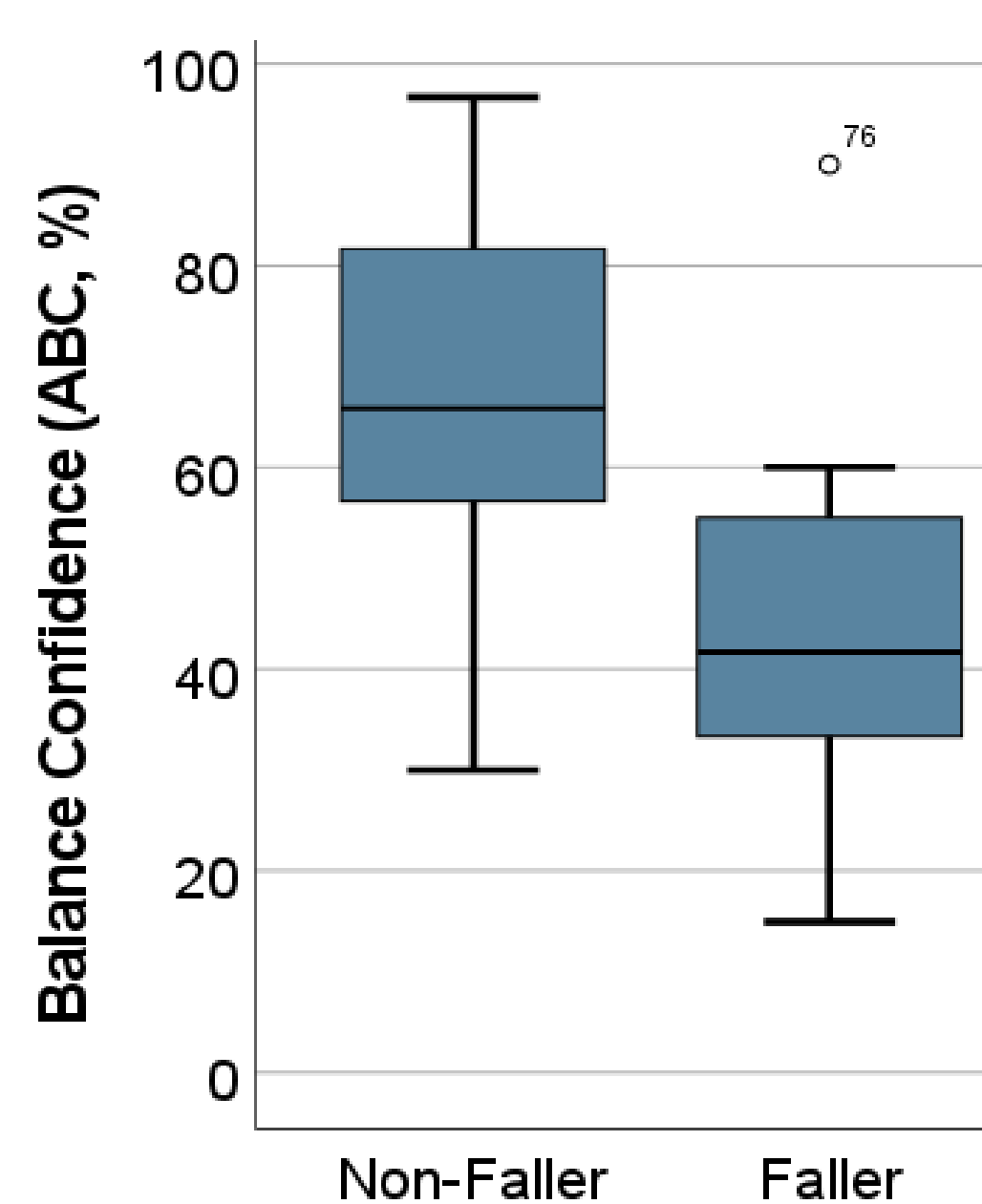
- Why does this person with HSP walk like this; what drives the excessive trunk movements?
- How do I assess if he is at high risk of falling?
- How can I effectively train his balance and gait problems?

Why does this person walk like this?

Excessive trunk movements are common in HSP, often aiding foot clearance and step length. As foot placement and ankle strategies are frequently impaired, individuals may recruit hip strategies involving the trunk. Video analysis of 86 people with HSP showed that increased trunk movements are associated with reduced balance capacity. Therefore, these trunk movements may also serve as a compensatory balance strategy.

How do I assess fall risk?

- 33 persons with HSP, 15 of them identified as fallers, performed clinical and instrumented assessments of balance and gait.
- The Activities-specific Balance Confidence (ABC) scale and the Mini-Balance Evaluation Systems Test (MiniBEST), demonstrated potential for identifying individuals with HSP at high fall risk.
- None of the instrumented assessments differed between fallers and non-fallers



How can I train balance and gait?

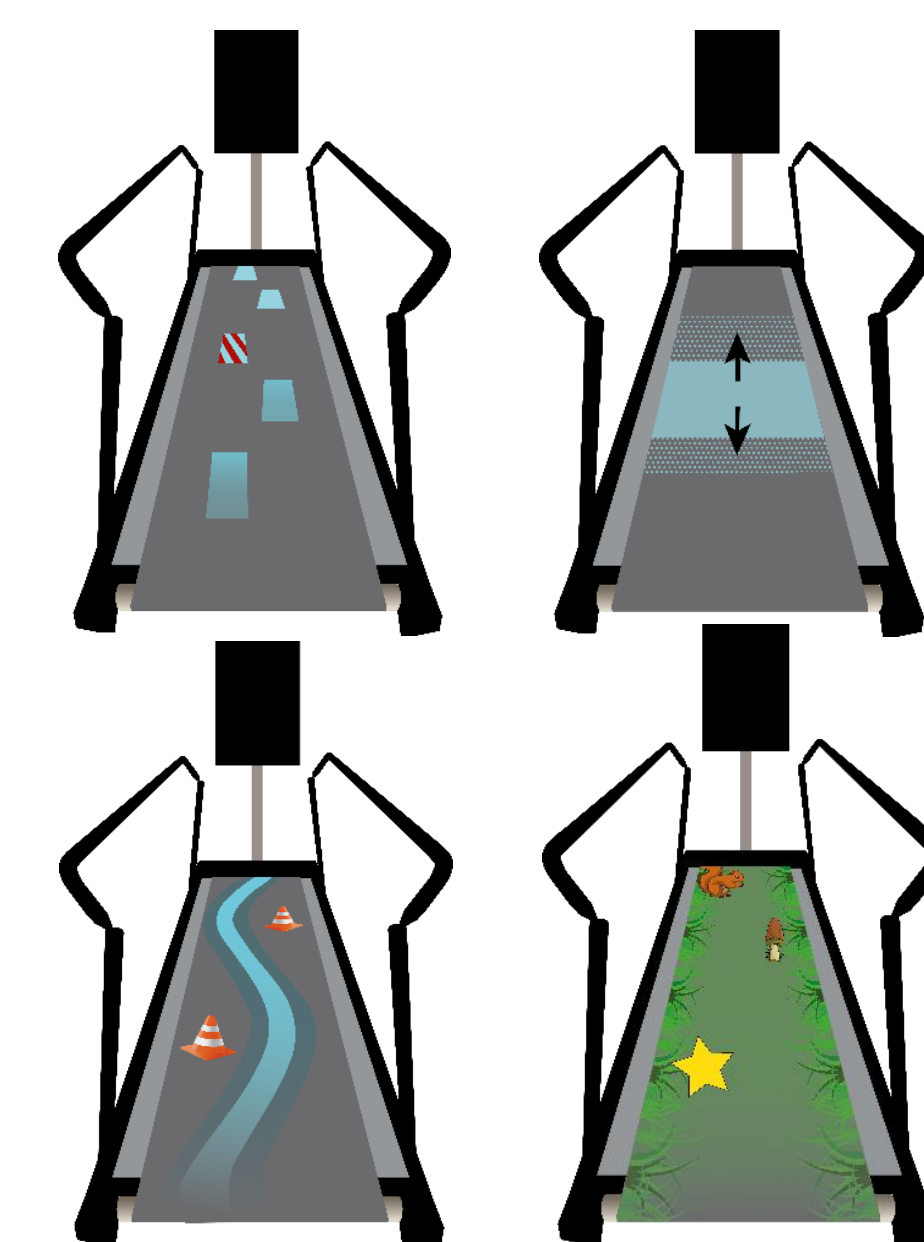
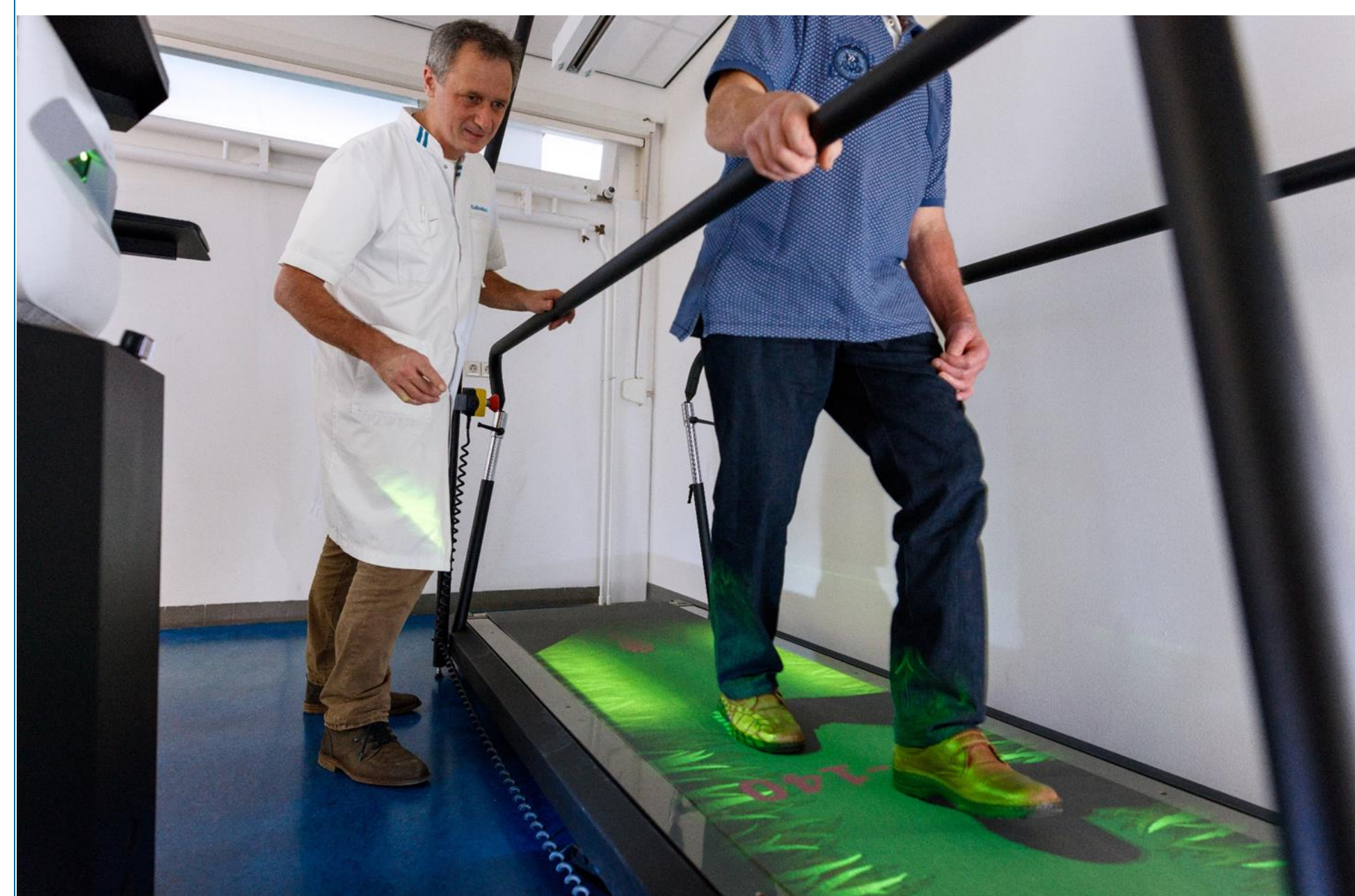
Impact of physical activity and stress

During Covid-19 lockdowns, an online survey among 58 people with HSP in the Netherlands, revealed that:

- 74% had reduced levels of physical activity, associated with increased muscle stiffness, pain, physical fatigue, and balance and gait impairments.
- 43% experienced increased psychological stress, resulting in increased muscle stiffness, pain, and mental fatigue.
- Sufficient levels of daily physical activity have a positive impact on the severity of spasticity-related symptoms.

Move-HSP trial

- What is the effectiveness of 10 hours gait-adaptability training?
- Five-week, randomized clinical trial, with a cross-over for the waiting-list control group, 36 persons with HSP participated.
- Usual care continued; including PT and spasticity treatments.
- C-Mill: an augmented reality treadmill, where visual projected act as step targets or obstacles to elicit step adjustments:



- High adherence to the training (99,7%) and positive feedback.
- Following 5-weeks of gait-adaptability training, improvements on the obstacle subtask, and several secondary outcome measures on balance and gait capacity were found.
- However, gait-adaptability training did not result in greater improvements compared to usual care.

Next steps

People with HSP may benefit most from a multimodal program combining strength, stretching, balance, gait, and cardiopulmonary training. The RE-TRAIN-HSP RCT, will evaluate this approach using a personalized, app-based program (Physitrack), with remote physiotherapist support. The year-long program aims to promote long-term behavior change and functional improvement.

