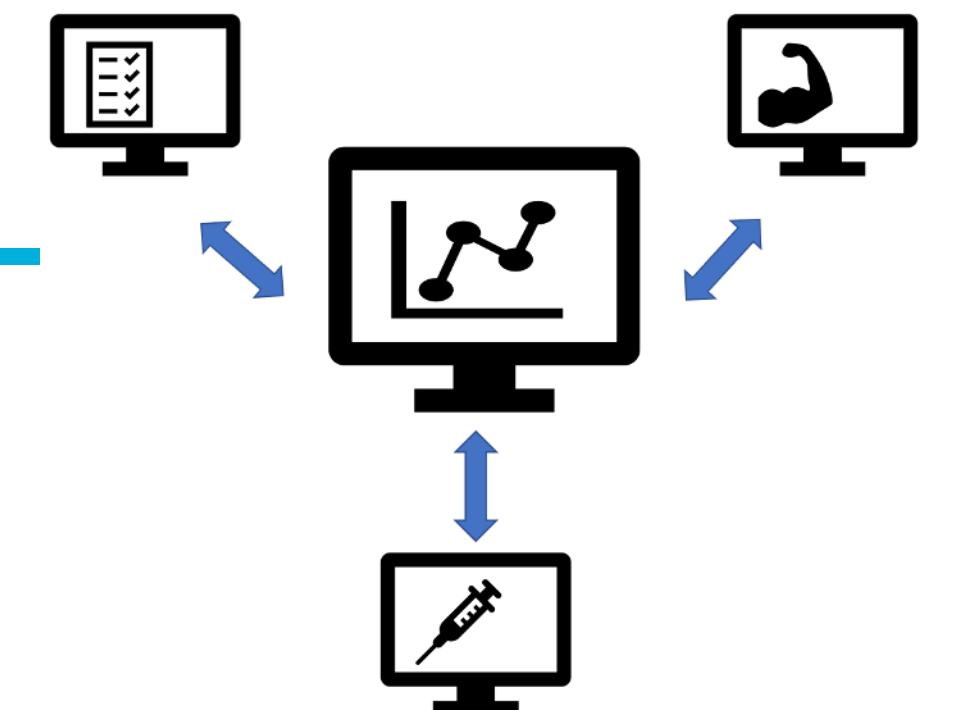


Smoothing the waves of spasticity: the value of personalized monitoring

Aiming for neap tide by using a monitoring approach

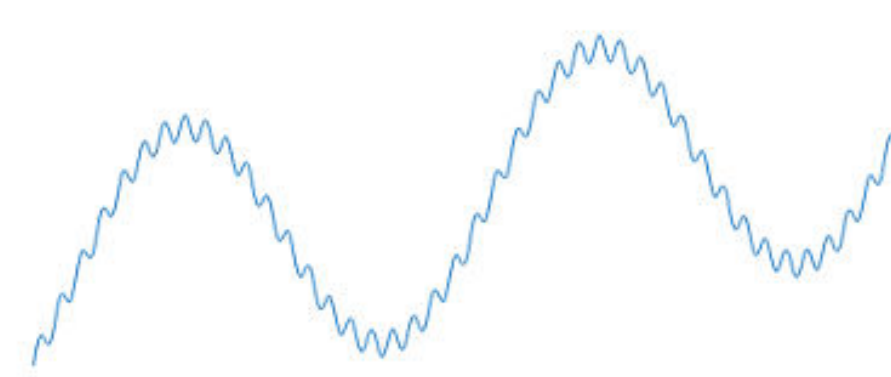
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Introduction

Spasticity is characterized by gradual changes and temporary fluctuations caused by personal, environmental and treatment factors (wearing on and off).



'Some days I am walking with difficulty, but the next day people see me walking and wonder why is she unfit to work? There is nothing wrong with her. This is very frustrating and difficult to deal with' (participant¹).

Challenges in spasticity management are:

- Measuring patient-relevant outcomes → functional impact and adjustment of treatment plan
- Prolonged structural data sampling → differentiate between structural changes and treatment effects
- Incorporating shared-decision making, shared goal setting and self-management → active patient participation

Objective

To support personalized spasticity management by developing an online monitoring tool that is feasible and useful for patients and healthcare professionals, and that incorporates patient-relevant outcomes

Material and Methods



Patient-relevant outcome (PRO)

Qualitative interviews:

- The perspective of patients with HSP on spastic paresis¹
- The perspective of patients with Stroke on spastic paresis²

Survey:

- Experienced complaints, activity limitations, and loss of motor capacities in patients with pure HSP³
- Identifying healthcare needs, expectations, utilization, and the experienced treatment effects in patients with pure HSP⁴

Incorporation PRO in online tool

→ Online spasticity monitoring tool (app and webbased)

Feasibility of online tool

Mixed methods study:

- Online monitoring of focal spasticity treatment with botulinum toxin in people with chronic stroke or hereditary spastic paraplegia: a feasibility study⁵

Results

Patient-relevant outcome (PRO)

- Experiences → Involuntary contractions, muscle cramps and stiffness; Impact on everyday life; Psychological and social consequences; Continuous adaptation
- Needs → Information from expert professional; Active participation in treatment; Coaching, Adequate timing of medication

Incorporation PRO in online tool

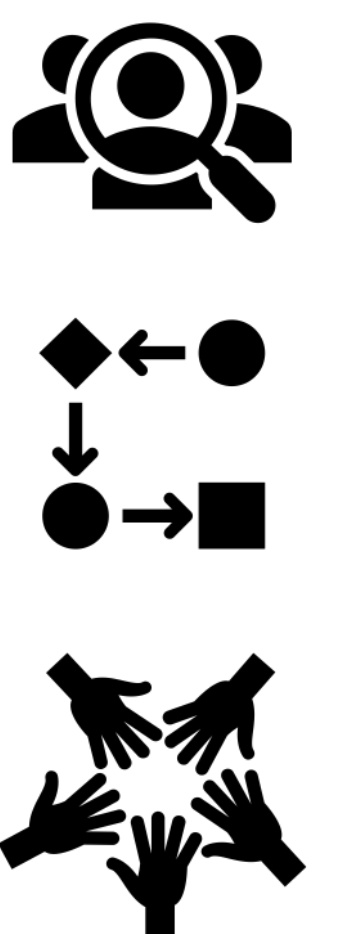
- Stiffness, muscle cramps, pain, fatigue, number of falls, satisfaction with gait and arm function were incorporated

Feasibility of online tool

- Feasibility →
 - Quantitative:
% recruitment success CVA:HSP = 39:76
Median adherence CVA:HSP = 20:63
 - Qualitative:
Provides insight in course spasticity; Contribution to shared-decision making varied; More helpful in an early stage

Discussion

- Monitoring should be tailored
 - Use personalized, tailored outcome measures
 - Involvement of relevant healthcare professionals
- The process of monitoring should be optimized
 - Incorporation of monitoring in daily (work)routines
 - Training in use of the online tool
- Patient participation should be improved
 - Coaching of patient in adapting to consequences of spasticity, and obtaining skills in selfmanagement, and shared-decision making.
 - Education of healthcare professionals regarding shared-decision making and implementation of online monitoring.



Conclusion

- Next to classical symptoms, non-motor consequences of spasticity are important PRO.
- Online monitoring of spasticity is more feasible for people with HSP than for people with Stroke.
- It provides relevant insight in the individual course of spasticity, and may support shared-decision making.
- Important facilitators for using an online monitoring tool by patients and healthcare professionals are: Adequate user selection, focussed timing of use, tailoring to individual needs, integration in daily routines, incorporation of tool in electronic patient files.

¹ Stumbling, struggling, and shame due to spasticity: a qualitative study of adult persons with hereditary spastic paraplegia, *Disability and Rehabilitation* 2019; ² Experienced consequences of spasticity and effects of botulinum toxin injections: a qualitative study amongst patients with disabling spasticity after stroke, *Disability and Rehabilitation* 2020; ³ Experienced complaints, activity limitations and loss of motor capacities in patients with pure hereditary spastic paraplegia: a web-based survey in the Netherlands. *Orphanet J Rare Dis.* 2020; ⁴ Healthcare needs, expectations, utilization, and experienced treatment effects in patients with hereditary spastic paraplegia: a web-based survey in the Netherlands. *Orphanet J Rare Dis.* 2021; ⁵ Online monitoring of focal spasticity treatment with botulinum toxin in people with chronic stroke or hereditary spastic paraplegia: a feasibility study. *Journal of Rehabilitation Medicine* 2023