Conceptualization of the experience of exoskeletons in home hand rehabilitation after stroke

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INTRODUCTION

Optimizing an individual's rehabilitation after stroke by integrating therapy into daily life beyond the necessarily limited time spent in formal, clinic-based visits has been the goal of a wide array of home-based technologies.[1] Of the 15 principles of neurorehabilitation identified as underpinning therapies promoting functional recovery after stroke, [2] fully two-thirds describe a strategy of *practice*: massed, spaced, variable, task-specific, goal-oriented, etc. In rehabilitation of the hand after stroke, unassisted task practice is effective in individuals with mild impairment who have some finger extension ability [3, 4], however moderately to severely impaired individuals find task practice frustrating and fatiguing [5], an experience that impedes adherence to a home practice regimen. To reduce patient burden and corresponding disincentive, the conventional clinical approach has been to limit practice to tasks that can be achieved using compensation. However, this strategy may inadvertently curtail recovery.[6] Exoskeleton technologies, both passive mechanical and, increasingly, robotic, provide assistance via forces applied to the hand that facilitate practice characterized by proper, biomechanical alignment and assistance completing movements that would otherwise be impossible to carry out. A recent Cochrane review of electromechanically assisted, upper extremity training after stroke rated the evidence for effectiveness as high [7], an affirmation that supports implementation of these technologies in the home to provide people recovering from stroke greater opportunity to leverage them in their practice programs.

Beyond the essential demonstration of effectiveness, multiple factors need to be considered in the implementation of existing hand exoskeleton orthoses and in the on-going design and evolution of next-generation systems. An accurate mapping of user needs to the functionalities a technology delivers, and the ability to measure user satisfaction with technology once placed in use, are crucial to the support of therapeutic outcomes, as well as to progressive improvement of rehabilitation technologies [8, 9]. Very little is known about the factors associated with successful integration of currently commercially available, hand exoskeleton orthoses, into the personal therapeutic practice of people with stroke. Further, the additional functionality inherent in robot-supported hand orthoses increases the challenge of measuring the relation between device characteristics and the needs of stroke user communities. A systematic review (SR) of subjective measures used to evaluate robotic assistive or rehabilitative technology (A/RT) found that none of the 31 studies examined used an instrument specifically tailored to robotics and only eight studies used any instrument whose validity and reliability had been assessed. [10] This finding led to the development of the PYTHEIA, an instrument designed to capture subjective, user-reported outcomes for specifically robotic AR/T. [11] The PYTHIA has been shown to be a valid and reliable instrument in its original, Greek-language version. It has not yet been tested with English-speaking users or with the specific contexts of hand exoskeletons, stroke, or home-based rehabilitative practice.

The overarching goal of the current study is to better understand and measure the factors that lead to hand exoskeleton acceptance and promote adherence to beyond-the-clinic task practice after stroke. We report the conceptualization phase of our work to adapt, revise, or expand the constructs of the PYTHEIA to fit the hand exoskeleton home-based practice use case and stroke stakeholder population.

METHODS

Design

Our assessment design replicates the systematic procedures [12] used to develop the PYTHEIA. These procedures encompass four main stages: Conceptualization (focus of this paper), Design, Testing, and Revision. The constructs and items of the PYTHEIA, [11] served as the point of departure for interviews with stroke hand exoskeleton stakeholders to explore points of convergence and divergence. Interviewees provided informed consent and received a stipend of $25 in appreciation of their time and effort. The study was approved as exempt by the MedStar Health Institutional Review Board.

Table 1. Highlights of Participant Feedback on PYTHEIA Robotic A/RT Satisfaction Themes

PYTHEIA Themes	Relevance	Summary Feedback, Home-use Hand Exoskeletons After Stroke
Complexity, Effort	Highly Relevant	• Donning and tensioning the main issues
Device Dimensions	Highly Relevant	• Bulk reported to impede optimal use
Device Weight	Highly Relevant	• Hemiparetic hand sensitive to even minimal additional weight
Needing Help to Use	Highly Relevant	• Donning and adjusting (tensioning) issues universal
Security (Feeling Protected, Confident)	Relevant/ Needs More Exploration	• Perspectives diverged: relevance affirmed by clinicians, advocates, engineers; denied by persons with stroke
Comfort Using Around Others	Relevant/ Needs More Exploration	• Perspectives diverged: relevance affirmed by clinicians, advocates, engineers; denied by persons with stroke
Sufficiency of Existing Functionalities	Relevant/ Needs Refinement	• Learnability, reliability, proper match of device to user's stage of recovery • Difficulty differentiating training functions from assistance functions;
Adaptability to Everyday Life Environments	Needs Refinement	• No use beyond the home or clinic reported or envisioned • Hand exoskeletons intrinsically small and portable • Conflation of "adapt" and "compensate" in stroke recovery context
Exoskeleton-related Improvement to Everyday Life	Needs Refinement	• Training vs. assistance the primary use, perceived improvements in everyday life longitudinal and retrospective • Indirect vs. direct assistive technology (AT)
Ease of learning Exoskeleton Functions: All functions and those of most concern to the individual	Needs Refinement	• Guidance needed in clearly understanding the immediate (e.g. training) function of devices versus instrumental use to improve function and performance of activities of daily living (ADL) • Functions of robotic devices more numerous and easier to enumerate than those of passive devices, easier to distinguish basic from more advanced
Feeling of Autonomy Using Exoskeleton	Less Relevant/ Needs Refinement	• Usual AT focus is autonomy in ADL; less relevant given very tangential use for ADL assistance • Personal control inherent in facilitated home training synonymous with autonomy, but connection not readily made
Security (Safety)	Not Relevant	• Universal lack of concern rooted in small size

Participants

Participants were identified by referral from clinical, research, and industry partners. Though we ultimately seek to identify use factors for specifically robotic hand exoskeletons, we also recruited persons with experience using passive mechanical exoskeletons, across experimental (research), clinical, and home-based contexts. Passive hand exoskeletons, actuated by springs or elastic bands, are similar in appearance to robotic ones, perform similar basic functions, but are more widely distributed than are next-generation, robot-controlled devices that leverage motors, pneumatics, or hydraulics for actuation. Informants included: two hand robotics research engineers; two occupational therapists, one with research as well as clinical experience of hand exoskeletons, passive and robotic; two consumer advocates, individuals who support clients (both clinicians and individuals/families with stroke) using commercially available devices; five individuals with stroke whose pooled experience included passive and robotic, as well as research and commercial, products; and three family members supporting individuals using hand exoskeletons at home after stroke. Participants were located on the Eastern Seaboard of the United States. Consumer participants received clinical services ranging from those easily accessible in their local communities to those provided at major, regional, stroke rehabilitation centers.

Procedure

We conducted in-depth, semi-structured interviews, 60-90 minutes in length, with 14 individuals either in person or by phone. Interviews were audio-recorded and unfolded across two segments. The first segment elicited spontaneous narratives of individuals' experience of stroke and hand exoskeleton-based therapy in their own homes or in a simulated home setting in the case of one robotic technology still early in development. The second segment guided informants through the items of the PYTHEIA, asking them to reflect on how each item aligned with their personal experience of hand exoskeleton use. The PYTHEIA itself is administered in two parts. Part A presents 15 items focused on individuals' overall experience of a robotic A/RT. Confirmatory factor analysis mapped these items to the latent variables of *ease of use* and *fitness for use* consonant with Davis' foundational work on technology acceptance [13] grounded in theory of reasoned action.[14] Part B of the PYTHEIA facilitates adaptation of the assessment to heterogeneous technologies through an additional five items (four reiterated from Part A and a fifth focused on reliability) that drill down on the individual functionalities of a system. Part B provides the flexibility to evaluate as many functionalities as deemed appropriate to the technology under assessment. Interviewees provided their perceptions of the important individual functionalities in the hand exoskeletons they used prior to exploration of Part B items. The interview guide was updated after each interview to reflect new perspectives and carried forward to subsequent participants. Interview audio files were imported to NVivo12 qualitative data analysis software, for transcription, iterative annotation and memo creation, and coding.

Analysis

We used an Interpretative Phenomenological Analytic [15] approach wherein the narrative of each participant was evaluated as a discrete unit and then connections across cases subsequently made. The items of the PYTHEIA, as thematically reflected in the Interview Guide, served as initial codes. Novel themes introduced by participants but not reflected in the PYTHEIA were also captured. In this paper we present our findings on the mapping of PYTHEIA themes to hand exoskeleton stakeholders' experience.

RESULTS

Themes underlying PYTHEIA items were condensed according to participant feedback, sorted according to initial understanding of their relevance to hand exoskeleton technologies, and major points summarized. (See Table 1.) Four satisfaction criteria identified within the PYTHEIA were highly relevant to hand exoskeletons. Participants related that the dimensions (bulk) of an exoskeleton sometimes impeded the grasping tasks it was supposed to facilitate. Weight was highly relevant to individuals with stroke given that the hemiparetic hand is very sensitive to even minimal additional weight. Complexity and effort, as well as need for help, related to difficulty experienced in donning and tensioning orthoses, particularly if the affected hand was the individual's dominant hand. Only one PYTHEIA theme, Security (Safety) was deemed not relevant. Some participants noted that they felt an initial uncertainty given the ungainly appearance of exoskeletons, but reservation with respect to their safe use was denied. This finding stands in contrast to a theoretical concern noted by Chen et al. relative to unsupervised use of robotic technologies in the home after stroke.[1] The small size hand exoskeletons nullified users' apprehension. In contrast, a common complaint was that the device did not exert enough force to efficiently open and close the hand versus exerting excessive force that might be injurious.

Two themes, the feelings of security and confidence promoted by exoskeleton use, and the level of comfort a person experienced using their device in various social contexts (family/friends, community, at work) were perceived relevant by clinicians, engineers, and client advocates but irrelevant by persons with stroke. The literature supports the former perspective.[1] Notably, only one of the devices studied had a stated assistive use case. Consequently, use outside the home, apart from consultations with one's OT, was not reported. More exploration of these variant perceptions is needed.

Three PYTHEIA themes were of ambiguous relevance and categorized as needing more refinement. The adaptability of a device to everyday life environments was not meaningful to consumer participants. They structured their exoskeleton-mediated practice for home and did not perceive a need to do it elsewhere. The abstraction of adaptability proved generally problematic. We observed conflation of the concepts "adapt" and "compensate" among some participants with stroke. Other participants talked about adapting their hand to the exoskeleton and vice versa. The theme of exoskeleton-mediated improvement in everyday life introduced confusion around the instrumental and ultimate outcomes exoskeletons target. Exoskeletons' focal purpose is to facilitate practice, the goal of which, in turn, is to achieve functional recovery. This instrumentality was hard for individuals to keep in mind and they focused on the improvement they were observing in their function versus how great a facilitator of home practice the exoskeleton might have been. The same confusion occurred in examining the relevance of how easy it was to learn the exoskeleton's functions. This was an area where the value of Part B of the PYTHEIA was very clearly demonstrated, guiding individuals to very clearly define the functions of their exoskeleton so they could evaluate them. It also became apparent that the functions of a robotic exoskeleton are more numerous and easier to rank from basic to advanced than are those of a passive mechanical exoskeleton.

Finally, the theme of autonomy was initially confounded with needing help to don and tension the exoskeleton. Participants associated autonomy with performance of ADL, creating confusion as the use case of the device is training, not assistance. That said, autonomy was highly valued in one's ability to guide one's own program of recovery. Autonomy was classified as a less relevant construct unless specifically tuned to the training context.

DISCUSSION

Use of hand exoskeletons for home-based training after stroke provides a clear example of the theoretical difference between rehabilitative and assistive technology, demonstrating that the device use case is essential in developing a meaningful assessment. Cowan et al.[16] distinguish direct versus indirect assistive technology (AT). A technology used to further rehabilitation is indirectly assistive. It assists with therapeutic task performance that, in turn, facilitates functional gains that enable better performance of ADL. Direct AT is technology that restores function by compensating disability, and directly enabling ADL. The same technology can, of course, be used to support both outcomes. The criteria for evaluating the technology, however, will be grounded in a specific use case. We expect that the mapping of PYTHEIA themes to user experiences would have been different had the single device with stated assistance functionality been the focus of inquiry versus on the periphery.

CONCLUSIONS

A clear differentiation of rehabilitation versus assistive uses of hand exoskeletons is essential to their meaningful assessment. Among the implications of this finding is a corresponding need to design the assessment instrument so as to make the evaluation context, rehabilitation or assistance, readily apparent.

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