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Abstract

This study examines the impact of digital rehabilitation on stroke survivors and their families. It proposes a platform leveraging family resilience as a framework to provide resources and community-building opportunities. Addressing issues identified in the literature and by stroke survivors, the platform aims to improve recovery and well-being by empowering survivors to play an active role in their treatment.

Keywords: cerebrovascular disease (CVD), stroke, digital platform, recovery, family, rehabilitation.

1   Introduction

Stroke is a leading cause of death and severe, long-term, disability around the globe. Annually, approximately 15 million people suffer from stroke worldwide, and it represents a serious health problem in the Western world (Camak, 2015). Stroke patients frequently experience physical limitations, reduced capacity to perform daily life activities and limited work performance (Camak, 2015). In addition, a stroke may provoke feelings of anxiety, depression, personality changes (Medeiros *et al.*, 2020). Moreover, the immediate impact of a stroke on survivors also affects their family and social sphere (Camak, 2015).

Stroke recovery requires a broad spectrum of resources, including specialized medical care, physical, speech, and occupational therapy, psychological assistance, and support networks at home (e.g., family caregivers) (Malik *et al.*, 2022). Survivors grappling with daily tasks often need aid, shifting responsibilities to family or caregivers, thus reshaping family dynamics and increasing care obligations (Camak, 2015). Thus, caregivers and family members also endure stress, anxiety, and uncertainty. Support networks, stroke education, and resources available for caregivers play a pivotal role in lessening strokes' immediate impacts and nurturing family resilience during tough times. This highlights that a successful intervention for stroke survivors should put their whole social sphere at the center.

While digital contributions to stroke prevention, treatment, and rehabilitation are common, most of this literature is centered on the patient or stroke survivor and does not consider their families. Furthermore, this family support network is a *sine qua non* for a successful rehabilitation process. The aim of this research project is to explore the challenges of designing, implementing, and scaling a digital intervention for stroke survivors and their families.

2   Previous work

Physical, occupational, and speech-language therapies are key to regain functionality and independence after a stroke (Verma *et al.*, 2022). There are, however, many barriers to quality rehabilitation care, hence the importance of developing new digital technologies to close this gap. Caregivers and families of stroke survivors also require support to adequately adapt to new household dynamics.

Digital interventions and technologies have benefited stroke care by facilitating early access to treatment, decreasing costs, empowering patients, and enabling personalized treatment (Verma *et al.*, 2022, Silva and Schwamm, 2021), and have the potential to increase access to post-stroke rehabilitation. Several studies have demonstrated efficacy of remotely supervised or self-administered telerehabilitation, yielding positive outcomes and high rates of patient and caregiver approval (Silva and Schwamm, 2021, Quique *et al.*, 2022). The impact of these rehabilitation interventions on family and caregivers is unclear due to concerns about limited digital access (e.g., Wifi, Internet-connected devices), digital literacy, unstable housing, and insufficient social support. While digital health interventions have the potential in addressing stroke inequities, they must be thoughtfully designed to address potential barriers (Silva and Schwamm, 2021).

3   Conceptual framework: Family resilience

In the domain of care coordination, the theories of family resilience, drawn from social work and family therapy, offer valuable insights. These theories, emphasizing a family's innate capacity to manage stress collectively, provide a framework for understanding how families cope with crises (Henry *et al.*, 2015, Walsh, 2016). Family resilience theory can inform the design of collaborative technologies aimed at assisting families in adapting to disruptions caused by strokes and subsequent rehabilitation. Leveraging the Family Adaptive Systems (FAS) framework, we categorize challenges and practices across four key subsystems: Emotion, Control, Meaning, and Maintenance. Through empirical investigation, we aim to elucidate how digital artifacts interact with these subsystems and inform the design of future technologies. Our focus is on exploring how digital interventions can support families in managing immediate impacts and long-term consequences, including permanent disabilities and occupational loss. By addressing these challenges, our research seeks to enhance care coordination and bolster family resilience in the face of stroke-related stressors.

4   Methodology and design challenges

This project adopts a Design Science Research (DSR) methodology, utilizing the DSRM process model with six steps: problem identification, objective definition, design and development, demonstration, evaluation, and communication. Focus groups with stroke survivors and their caregivers, along with online surveys with medical professionals, are conducted during steps I and II. A prototype of the proposed digital platform is developed and tested with the *Afasia Vital* community during step IV, with results compared against defined objectives before evaluation in step V. The digital platform, tailored for stroke survivors and their support groups, aims to provide access to rehabilitation resources and facilitate community engagement, accessible through a Spanish-language website. Key features include a web-based system for cross-device accessibility, usability considerations for users with aphasia, organized rehabilitation resources, and community-building spaces. Challenges in design and development include addressing emotional and occupational support needs, ensuring usability across diverse user groups, and validation with medical personnel and the target audience, while also considering contextual factors like device capabilities and environmental conditions. Overcoming these challenges is essential to ensure the platform's utility and effectiveness.

5   Potential contributions and future work

This project intends to introduce the framework of FAS into Information Systems literature, marking its inaugural inclusion and emphasizing its role in bolstering caregiver collaboration amidst health crises within familial contexts, particularly concerning stroke. It seeks to address challenges articulated by participants, aiming to explore its potential application in the development and testing of future technologies. Additionally, the project aims for a transformative impact on the community by tackling medical and social challenges encountered by stroke survivors and their caregivers. Through the provision of a digital platform, access to rehabilitation resources is facilitated, while encouraging engagement from caregivers, relatives, and therapists. This platform is designed to promote treatment adherence, support long-term recovery, and empower both survivors and their families, through the provision of online rehabilitation resources and the establishment of support groups.

Following the DSR approach, the project will transition into phase III, where emphasis will be placed on the design and development of the artifact. This phase entails the selection of an appropriate software platform and the formulation of an information model for rehabilitation resources, prioritizing the reinforcement of community functionalities and the enhancement of usability. Input from stroke survivors, caregivers, therapists, and neurologists will remain integral. Phase IV, demonstration, will ensue, followed by phase V, evaluation, which will center on the analysis of the introduced FAS framework and the identification of gaps in available rehabilitation resources, with a specific focus on resources catering to Spanish speakers. These evaluations are anticipated to catalyze the adaptation or development of new rehabilitation resources, contributing to the overarching goals of the project.

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