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Designing Dignity: Unpacking Shame, Stigma, and Challenges Around Public Eating for People with Parkinson's Disease

Dhwaj Maheshwari*Dubai International Academy, Emirates Hills, United Arab Emirates*

Abstract

This study is based on three Parkinson's patients and one caregiver and investigates the social, emotional, and functional challenges associated with eating while living with Parkinson's disease. Tremors related to Parkinson's disease and other disorders affect a significant number of people worldwide, significantly impacting independent mobility and quality of life. The issue is particularly important within South Asian and Middle Eastern families, where dining together is central to social participation. While assistive devices exist, most focus narrowly on improving motor function, are under-researched from a social standpoint, and carry considerable stigma in public settings. This study investigates how tremor-related eating difficulties influence dignity, independence, and social participation, while also examining the limitations of existing assistive device technologies. A qualitative research design was employed, involving structured interviews with three Parkinson's patients and one caregiver, alongside a comparative analysis of assistive utensils currently on the market. Three key findings emerged: eating-related tremors create significant social stigma and embarrassment in public, which often discourages participation in public dining or family bonding; existing assistive devices only partially address these challenges due to limitations in affordability, usability, and spill prevention; and dignity and social acceptance were found to be equally important as technical performance in determining whether users would adopt assistive technologies. The Stable Spoon is presented as a design proposal for a three-axis stabilising assistive utensil designed to reduce food spillage while maintaining affordability, usability, and dignity-centred design principles. The study contributes to existing research by highlighting the importance of addressing both the emotional and functional dimensions of developing assistive technologies for individuals with Parkinson's disease.

Keywords: assistive technology, dignity, dining, Parkinson's disease, stigma