

Original Article

# 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.*

*Corresponding Author : [dhwaj.Maheshwari@gmail.com](mailto:dhwaj.Maheshwari@gmail.com)*

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**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.

## 1. Introduction

The world is experiencing a silent crisis in neurological wellness. Over one in three people worldwide – more than 3 billion individuals – live with a condition that affects motor function or mental health [1]. One of the related diseases is Parkinson's disease. Parkinson's disease, characterised by tremors, illustrates a particularly destructive aspect of what these disorders can do to human mental and physical health, progressively stripping an individual of the capacity to carry out routine activities such as eating and drinking. Research suggests that over 75% of patients experience a range of challenges arising from tremor, particularly in the food domain [2, 3]. These patients also experience considerable social stigma, often being reluctant to eat in front of others for fear of the embarrassment caused by visibly shaking hands, and caregivers may share in this sense of shame. In this sense, the challenge is not merely physical; it is a medical condition translated into a social one. The sample population addressed

in this study includes patients with Parkinson's Disease Dementia (PDD), Parkinson's Disease Mild Cognitive Impairment (PDMCI), and essential tremor, with an emphasis on how the burden imposed on patients and their families could be reduced through technological intervention. The relevance of this topic is reflected in recent cross-sectional studies in regions such as Saudi Arabia, which indicate a direct correlation between physical impairment and elevated rates of clinical depression and social isolation among patients with Parkinson's disease.

This is an urgent social issue, as available solutions are either inaccessible or carry a medicalised look and feel that adds to the stigma surrounding the illness. For technology to be considered and used consistently, it should avoid stigmatising the user and should support assistive dignity, allowing the user to feel like a full member of society rather than a patient. The issue is deeply influenced by cultural



factors, particularly in societies where communal dining is a cornerstone of social cohesion and family identity. In many Middle Eastern and South Asian cultures, the sharing of a meal is a symbolic gesture of belonging within the family; the inability to do this without assistance can produce a sense of shame or loss of face for the entire family. Cultural expectations placed on able-bodied patriarchs or matriarchs can exacerbate the psychological toll on families and caregivers, as the patient feels they have transitioned from provider to burden – a transition made more visible by the bulky, medicalised look of current assistive devices, which often clash with the traditional attire of ordinary social settings.

The main objectives of this study are to analyse the effectiveness of active three-axis stabilisation in targeting the coherent, multi-directional tremors associated with neurological disorders – specifically the stabilisation of pitch, roll, and yaw – and to examine the effectiveness of real-time motion monitoring through Inertial Measurement Units (IMUs) in delivering a more responsive user experience than traditional, passive weighted utensils. A further goal is to design and validate a prototype, the Stable Spoon, that fulfils both high-tech functional requirements and a mainstream, inclusive design intended to minimise the device stigma that hinders patient adoption of assistive technology.

This study is guided by the following research questions: (1) How effectively does active three-axis stabilisation address the coherent, multi-directional tremors (pitch, roll, and yaw) associated with Parkinson's disease? (2) How does real-time motion monitoring via Inertial Measurement Units compare to passive weighted utensils in delivering a responsive user experience? (3) What design features are necessary for an assistive utensil to be both functionally effective and socially acceptable to users?

This paper begins with a review of existing interdisciplinary practice, covering both the effectiveness of robotic-based rehabilitation and multimodal therapy and the usability of wearable devices such as Google Glass. The technical development of the Stable Spoon is then outlined in the Methodology section, describing how micro-controllers and micro-actuators are incorporated into the spoon head to keep it level against the erratic movement of the handle. The paper provides the theoretical and empirical foundation for the physical prototype, explaining why its mechanical features were chosen and how the design addresses the emotional and physical issues identified in the existing literature on Parkinsonism.

## **2. Review of Literature**

### **2.1. Sociocultural Stigma and Degenerative Diseases**

The social stigma surrounding Parkinson's disease and other degenerative conditions in the elderly forms an important part of the sociocultural landscape. In South Asian

and Middle Eastern contexts, where families place great value on maintaining an image of a healthy household, motor dysfunctions such as Parkinson's disease are often misinterpreted as a sign of weakness in the whole family. A cross-sectional study in Saudi Arabia highlights that the high rate of depression among Parkinson's disease patients is not merely a biological byproduct but also a reflection of cultural stigma imposed on affected families.

In many regions, communal eating is a central ritual of social bonding; when a person cannot hold a spoon steadily, they often withdraw from gatherings, which can bring shame to the family's name and place a heavy burden on the caregiver. This social stigma is compounded by a lack of public awareness, leading to a phenomenon in which elderly patients are kept out of sight to preserve the appearance of a healthy household, deepening isolation, depression, and other emotional difficulties.

### **2.2. Managing Stigma Through Technology**

Emerging research suggests that technological intervention can help counter the social embarrassment associated with Parkinson's and related conditions. Rather than acting as a cold mechanism, modern robotics and assistive tools designed with human-like traits can help lower patient stigma. This burden is carried not only by the patient but also by caregivers; an assistive device that allows the patient to perform tasks independently shifts some of this burden away from the caregiver. The key to managing this stigma lies in the transition from purely functional aids toward modern, sleek, and non-medical-looking robotics. Stabilised utensils designed with this principle have a strong chance of lowering the stigma associated with eating in public, allowing the patient to remain engaged with their social community while keeping their clinical condition private – preserving both social standing and self-esteem.

### **2.3. The Role of Assistive Technology**

Assistive Technology (AT) for Parkinson's patients spans a wide range, from wearable sensors such as Google Glass [4] to complex robotic rehabilitation systems such as Tymo [5] and walker systems [6]. General resources compiled by patient organisations catalogue this range of devices and their intended uses [7-10]. The effectiveness of such technology is well documented: it has been observed to improve balance, reduce the fear of falling, and improve quality of life for both patient and caregiver by reducing the care burden. However, the application of such technology is severely limited in practice. Most high-tech solutions, such as VR-based rehabilitation or advanced robotic platforms, remain confined to healthcare environments because they are expensive and complex. Wearables such as Google Glass also suffer from usability problems, including poor speech-recognition performance in speech-impaired patients and unnecessarily complex navigation systems that patients with degraded cognitive abilities may struggle to use.

## 2.4. Research Gap

Three-axis active stabilisation devices remain expensive and inaccessible, requiring high-tier engineering to produce. Most existing studies focus on doctor-grade robotics that are too costly for home use or too bulky to carry outside. Several prior projects have proposed self-stabilising spoon prototypes that address multi-directional tremor (pitch, roll, and yaw) using embedded sensors and micro-actuators [11-17], but these efforts have largely emphasised technical feasibility over affordability, everyday aesthetics, and the emotional stigma that shapes whether a patient is actually willing to use the device. Existing research does not sufficiently examine the emotional stigma created by the appearance of assistive devices themselves, and this gap forms the basis of the present study. This research aims to address these gaps by developing the Stable Spoon (SS), a prototype with a three-axis corrective-response stabiliser that uses micro-actuators and inertial measurement units to provide a self-stabilising device for Parkinson's patients – moving beyond the price barrier that makes current technology inaccessible, and balancing technical performance with a design that minimises social embarrassment.

## 3. Materials and Methods

The research design employed was a qualitative, explanatory design, grounded in the first-person experience of participants and the meaning they attach to that experience. Food spillage was treated not only as a pragmatic object of study but also as a social and emotional one, connected to notions of dignity, visibility, and mealtime among older adults with Parkinson's. The study was conducted virtually and in person across India and the United Arab Emirates, regions where cultural attitudes toward communal food intake give particular prominence to the issues under study. The final sample comprised three Parkinson's patients and one caregiver, all between the ages of 50 and 70. Participants were selected purposively based on specific criteria, chiefly the experience of tremors disrupting food intake, and snowball sampling was used, with already-sampled participants helping to identify further potential participants from the same target population.

Digital ethnography and semi-structured interviews were the two methods used to collect information. Digital ethnography involved interpreting and analysing the online space as a system: the researcher monitored the presentation, pricing, aesthetic production, and ratings of assistive eating devices on Amazon and eBay. The interview guide served as the main research instrument for the semi-structured interviews, in which participants discussed food spillage, social dining, and their perception of assistive devices, in particular stigma and usability. Four interviews (three Parkinson's patients and one caregiver) were transcribed and analysed. The second data source was a market analysis of 10–15 assistive cutlery products, analysed using a comparison table (weight, shape, materials, cleaning, visibility, and price)

alongside public reviews discussing comfort and usage. Data was collected over three to four weeks and analysed using a thematic approach, coding repetitive patterns from interview transcripts and digital ethnography notes around recurring ideas such as food spillage, stigma, independence, dignity, and usability. The correlation between product characteristics and their emotional and social implications was examined using a feature-meaning matrix, supported by triangulation across three sources of evidence: interview data, product analysis, and online observations. Data was cleaned and analysed manually to maintain close engagement with the findings. Given the exploratory scope and small sample size of this study, data saturation in the formal sense was not claimed; findings are presented as indicative of recurring patterns across participants rather than as an exhaustive account of the Parkinson's patient experience.

Given that the elderly demographic affected by Parkinsonism or tremor-related conditions constitutes a vulnerable population, careful attention was given to the ethical aspects of the research. This study's procedures for participant recruitment, informed consent, and data handling were reviewed and approved by [name of school/mentor programme ethics process] prior to data collection. Informed consent was obtained from all participants before interviews were conducted, and participation was entirely voluntary, with participants informed of their right to withdraw or decline to answer any question at any time without consequence. Pseudonyms were used throughout the study to protect participants' identities, and all interview transcripts and research data were stored securely. For digital data, only publicly available information was used, and no identifiable usernames or screenshots were included in the research. As the sole researcher on this project, care was taken to avoid over-interpreting participants' accounts through a purely technical lens; regular check-ins with a research mentor were used to review interview framing and interpretation, given the vulnerability of the participant population and the researcher's position as a non-clinician.

## 4. Analysis

At the outset of this analysis, it is important to note that four participants (three Parkinson's patients and one caregiver) were interviewed; to protect confidentiality, the names used throughout this section are pseudonyms.

### 4.1. Sociocultural Stigma and the Emotional Experience of Dining

The interviews showed that one of the most significant impacts of Parkinson's disease was the emotional experience associated with eating in public. Participant A described eating with visible tremors as “extremely embarrassing,” while Caregiver A said that many individuals with Parkinson's avoided restaurants or social gatherings out of fear of being judged or stared at. Participant B similarly described feeling embarrassed and self-conscious when eating

in public places. These responses demonstrate that food spillage is not simply a physical challenge but a socially visible event that affects confidence, identity, and willingness to participate in public and social life.

These findings support the literature review's account of stigma and social isolation as common experiences among Parkinson's patients, an issue that is especially significant in South Asian and Middle Eastern contexts, where social dining plays a central role in family bonding and social interaction. The market analysis conducted further supports this theme, as both the GYENNO Steady Spoon and GYENNO Bravo Twist are marketed around independence, confidence, and a non-medical appearance. This marketing suggests that manufacturers recognise stigma as an important consideration for users, although it does not prove that the products eliminate it; reducing embarrassment and preserving dignity should therefore be considered a design priority in their own right.

#### ***4.2. Physical Challenges and Functional Limitations of Existing Assistive Devices***

The interviews showed that participants faced difficulties controlling utensils, lifting food, carrying drinks, and swallowing during periods when symptoms worsened. Participant A and Caregiver A emphasised the importance of Parkinson's "on" and "off" periods, explaining that a patient may function normally at one moment and struggle significantly at another. Participants also described adapting their behaviour by eating more slowly – adaptations that show people are already compensating for solutions missing from products currently on the market.

The market analysis showed similar shortcomings across available devices. Both spoons offered strong technology but remained expensive and dependent on batteries and electronic maintenance, and neither device completely prevented food spillage during severe tremors. The GYENNO Steady Spoon is lightweight but expensive, while the GYENNO Bravo Twist is also expensive and requires charging and maintenance. Participants indicated a preference for lightweight utensils that would be easier to hold and grip. Together, the interview findings and product analysis reveal a clear functional gap in current market products and point to the need for a more effective stabilising utensil, such as the Stable Spoon.

#### ***4.3. Device Acceptance, Dignity, and Quality of Life***

The third theme identified was the importance of device acceptance and dignity. Participants consistently stated that they would be more likely to use an assistive device if it blended into everyday life without attracting attention or raising social stigma. Caregiver A explained that devices such as walkers are socially accepted because they are common and familiar, whereas specialised Parkinson's utensils may make users feel self-conscious in public precisely because they are not a normalised assistive device. Participant B likewise stated

a preference for a utensil that looked ordinary rather than like medical equipment standing out in a crowd.

The product comparison shows that both market products attempt to reduce stigma through modern, non-medical designs, but at the cost of high prices, charging requirements, and maintenance demands. Interviewees repeatedly emphasised that independence and confidence should come paired with affordable prices and emotional comfort, and that reducing food spillage would improve their willingness to dine socially with family, increasing both confidence and family bonding. This indicates that dignity is one of the most important measures of assistive technology success, and that a device improving both independence and self-confidence can significantly enhance overall quality of life.

A table comparing the two market products discussed in this section is presented in Appendix A.

### **5. Conclusion**

This study examined the social, emotional, and functional challenges experienced by individuals with Parkinson's disease in relation to eating and food spillage. Through a combination of literature review, market analysis, and semi-structured interviews, three key themes emerged. First, eating difficulties create significant social stigma and embarrassment, often leading to reduced participation in public dining situations.

Second, existing assistive devices only partially address the physical challenges associated with tremor, leaving important gaps in affordability, usability, and spill prevention. Third, dignity and social acceptance were identified as critical factors influencing whether individuals are able or willing to adopt assistive technology into daily life.

These findings directly informed the development of the Stable Spoon design proposal. Participants consistently expressed the need for a solution that is stable, lightweight, affordable, and socially accepted. By combining a three-axis stabilisation system with a user-friendly, non-medical design and a digital interface, the Stable Spoon is proposed as a prototype expected to improve independence and potentially reduce caregiving burden and enhance quality of life, although these outcomes were not measured in this study.

Future research should involve larger participant groups and further testing to evaluate the effectiveness of the prototype in real-world settings. Beyond the device itself, these findings carry a practical implication for the wider field: manufacturers of assistive eating devices should weigh affordability and everyday, non-clinical appearance as core design requirements, not as secondary concerns layered on top of technical stabilisation. Caregivers and occupational therapists working with Parkinson's patients may likewise benefit from involving patients more directly in the selection

of assistive devices, so that dignity and social comfort are treated as part of the decision alongside functional performance.

This study also faced several limitations. Recruiting participants with Parkinson's disease proved challenging, resulting in a relatively small sample size that may not fully represent the experience of the wider Parkinson's community. Product testing and user validation also took significantly longer than expected due to logistical constraints within the United Arab Emirates, limiting the extent of testing possible within the project timeline. Finally, access to literature was restricted, as many relevant papers and case studies required paid subscriptions, reducing the number of sources available for review and comparison. Despite these limitations, the combination of interviews, market analysis, and literature

review provided meaningful insight into the social and functional challenges associated with Parkinson's disease and informed the development of the Stable Spoon prototype.

## Conflicts of Interest

The author declares that there is no conflict of interest regarding the publication of this paper.

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## Appendix A: Comparison of Publicly Available Products

Table A1. SWOT comparison of the GYENNO Steady Spoon and GYENNO Bravo Twist, compiled from market analysis and public product reviews

|                      | PRODUCT 1 – GYENNO Steady Spoon                                                                                                                                                                                                                                                                                                                                                                        | PRODUCT 2 – GYENNO Bravo Twist                                                                                                                                                                                                                                                                                                                                                                 |
|----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Strengths</b>     | <ul style="list-style-type: none"> <li>• Uses active stabilization technology to reduce tremors during eating</li> <li>• Helps users eat more independently with less caregiver support</li> <li>• Lightweight and portable design makes it easy to carry</li> <li>• Interchangeable spoon attachments improve usability</li> <li>• Modern and non-medical appearance reduces social stigma</li> </ul> | <ul style="list-style-type: none"> <li>• Combines spoon and fork functionality with interchangeable heads</li> <li>• Ergonomic grip improves comfort for elderly users</li> <li>• Compact and travel-friendly design</li> <li>• Helps reduce hand tremor effects during eating</li> <li>• Encourages greater independence during meals</li> </ul>                                              |
| <b>Weaknesses</b>    | <ul style="list-style-type: none"> <li>• Very expensive for many middle-income or elderly households</li> <li>• Requires charging and electronic maintenance</li> <li>• Limited customization for different tremor intensities</li> <li>• Technology may feel complicated for elderly or less tech-savvy users</li> <li>• Does not fully eliminate food spillage during severe tremors</li> </ul>      | <ul style="list-style-type: none"> <li>• Stabilization performance is weaker compared to premium assistive utensils</li> <li>• Battery life may not support long-term continuous use</li> <li>• Limited availability in many countries</li> <li>• Cleaning and maintenance may be difficult because of electronic components</li> <li>• Still expensive for lower-income households</li> </ul> |
| <b>Opportunities</b> | <ul style="list-style-type: none"> <li>• Can integrate AI-based tremor adaptation for personalized stabilization</li> <li>• Could expand to forks, cups, and other adaptive utensils</li> <li>• Increasing awareness about Parkinson's creates larger demand</li> <li>• Can partner with hospitals and rehabilitation centers</li> </ul>                                                               | <ul style="list-style-type: none"> <li>• Can be redesigned with stronger stabilization motors</li> <li>• Potential integration with smart monitoring systems</li> <li>• Growing elderly population increases market potential</li> <li>• Opportunity to improve waterproofing and durability</li> </ul>                                                                                        |
| <b>Threats</b>       | <ul style="list-style-type: none"> <li>• Cheaper competitors or DIY alternatives may reduce market demand</li> <li>• Dependence on batteries reduces reliability during power issues</li> <li>• High manufacturing cost may limit accessibility in developing countries</li> <li>• Users may prefer traditional weighted utensils because of simplicity</li> </ul>                                     | <ul style="list-style-type: none"> <li>• Rapidly advancing assistive technology market increases competition</li> <li>• Technology failure during use may reduce user trust</li> <li>• Simpler low-cost utensils may appeal more to some users</li> <li>• Economic conditions may reduce spending on assistive devices</li> </ul>                                                              |
| <b>Key Takeaways</b> | <ul style="list-style-type: none"> <li>• Successfully improves independence and confidence during meals</li> <li>• Sleek design helps reduce stigma linked to assistive devices</li> <li>• High pricing and dependence on electronics limit accessibility</li> <li>• Scope for a simpler and more affordable alternative</li> </ul>                                                                    | <ul style="list-style-type: none"> <li>• Focuses on flexibility and portability for daily use</li> <li>• Supports dignity and independence for people with tremors</li> <li>• Reliability and battery limitations remain concerns</li> <li>• Opportunity for a more durable and affordable redesign</li> </ul>                                                                                 |