Ethical Robot Design Considerations for Individuals Suffering from a Neurodegenerative Disease

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***Abstract*—Neurodegenerative disorders such as Alzheimer's disease, Parkinson's disease, and amyotrophic lateral sclerosis impose significant burdens on individuals and healthcare systems globally. These disorders induce cognitive, motor, and functional impairments that hinder daily activities. Intelligent Assistive Technologies, which include robots to handle routine tasks or facilitate socialization, show promise in supporting individuals with those disorders, aiming to enhance their quality of life and independence. However, ethical considerations are paramount in the development and deployment of assistive technologies. We discuss three key ethical dimensions: privacy safeguards, nonmaleficence and beneficence, and supporting autonomy and community.**

***Index Terms*—Elderly care, dementia, Alzheimer's, neurodegenerative disease, assistive care, assistive technologies, robotics**

I. Introduction

According to data from the World Health Organization (WHO) and the United Nations (UN), by 2030, one in six people in the world will be over age 60 [1], [2], [3]. This burgeoning elderly population constitutes a vulnerable group susceptible to neurodegenerative diseases and digital exclusion [4]. It is estimated that approximately four million Americans are currently diagnosed with Alzheimer's disease. The prevalence rate is about 7 percent for those aged 65 and older, with risk doubling every 5 years after the age of 65 [5]. Neurodegenerative disorders encompass a broad spectrum of persistent and progressive conditions, such as Alzheimer's disease (AD), Parkinson's disease (PD), amyotrophic lateral sclerosis (ALS), Huntington's disease, multiple sclerosis (MS), and others [6]. These conditions share a common characteristic: the gradual decline of neuronal function, which results in a progressive degeneration within the brain and nervous system [4].

II. Challenges for individuals with degenerative diseases

Individuals grappling with neurodegenerative diseases confront an array of formidable obstacles that significantly impede their capacity to engage in everyday activities [7], [8]. Among the shared tribulations are far-reaching repercussions on cognitive functions [9], [10], motor proficiency, memory retention, and communication [11], [12], [13], [14], [15]. Even tasks as basic as dressing, preparing meals, and remembering appointments can evolve into monumental challenges, eroding the independence and the overall quality of life. As these diseases advance, the ability to navigate familiar surroundings, employ technology, and partake in social interactions can also be profoundly compromised.

Memory impairment presents another pervasive concern, causing difficulties in recalling vital tasks, appointments, and even recognizing familiar facial expressions. Erosion of motor skills is another difficulty, given that these ailments often signal a decline in motor functions, rendering elementary tasks such as typing, manipulating a mouse, or handling small objects increasingly difficult. Concurrently, cognitive regression [16] adds a further level of complexity, as tasks requiring complex decision-making, problem-solving, and multitasking become overwhelming. Furthermore, individuals might grapple with visual and auditory impairments, thus amplifying the complexity of using interfaces that depend on these senses. The challenge of dealing with disorientation and navigation is also of note, with challenges in spatial awareness and orientation impacting both physical settings and digital interfaces [17]. The introduction of assistive technologies can provide support for people with impairments.

III. Technological landscape

Intelligent assistive technologies (IATs) utilize a variety of robots and sensors, coupled with machine intelligence methods, to support elderly and subjects with disabilities [18], [19]. In assistive living, they aim to reduce caregiver strain and empower individuals through assistance designed to foster self-reliance rather than dependence, adhering to the ethical principles of beneficence (compassion) and non-maleficence (avoiding harm). This involves effective task execution, communication, trust, and empathy [20].

IATs hold potential for aiding aging-in-place among cognitively impaired adults, offering an alternative to caregiver-dependent living. In addition to their aims to enhance well-being, and ensure safety and independence [21], they can also address socio-psychological issues, promoting social interaction and reducing distress, and can assist with daily tasks both indoors and outdoors [22].

Socially assistive robots can aid communication, mitigate sensory loss impacts, and reduce isolation. For instance assistive robots such as MATY [23] can improve quality of life by promoting routine and communication with loved ones. Further, serious video games, especially in virtual reality, have shown potential in stimulating individuals with Alzheimer's disease [24], [25]. Safety and independence measures also play a role in facilitating daily tasks, as seen in projects like ISR-AIWALKER [26], MindMate [27], and COGKNOW [28].

IV. Ethical guidance and considerations

With current advancements and the promise of future progress in assistive technology, we delineate the core ethical considerations: 1) ensuring privacy safeguards, 2) upholding the principles of nonmaleficence and beneficence, and 3) nurturing autonomy and fostering a sense of community.

1) Safeguards for Privacy: IATs hold immense potential to improve the lives of persons with dementia (PwD) and elderly. However, their deployment raises critical ethical considerations. People with diminished cognitive capacities might not be able to provide informed consent for collecting personal data required to train IATs. Obtaining proxy consent from caregivers or utilizing advance directives becomes crucial.

Example: John, a senior resident in an assisted care facility, may ask the assistive robot to retrieve his wallet from his private room. As the robot carries out the task, it has the potential to inadvertently capture sensitive personal information, such as financial statements or health related information, that may be visible within the room. This raises concerns as fetching personal belongings without appropriate safeguards can compromise the person's privacy and confidentiality of sensitive information. Unconditional and non-consensual surveillance and access should be monitored and avoided whenever possible.

It is crucial to design systems with robust security features that protect patient data, prevent unauthorized access, and adhere to federal and local policies on data handling in healthcare setting [29]. The security and privacy of any collected data are critical. Privacy supporting technologies, such as federated learning [30], offer a promising solution, allowing data to remain on the client's device, thereby reducing the risk of data leaks.

2) Nonmaleficence and beneficence: Ensuring that IATs do not cause harm, such as social isolation, increased dependence, or adverse mental health effects, is paramount in their design and deployment for PwD [31]. Thorough testing, continuous monitoring, and involving caregivers, family members, and medical professionals are necessary to mitigate these risks [32]. Furthermore, IATs should be designed to be transparent, explainable, and understandable, making it easier for caregivers and healthcare professionals to assess the potential impacts of these technologies on the users [33].

Integrating ethical considerations from the onset and throughout the development process will help ensure that IATs are safe and actively promote well-being.

In designing IATs, the focus should be on enhancing the autonomy, quality of life, and daily functioning of PwD. These technologies should complement human care, fostering positive interactions and a supportive care environment. Including PwD and their caregivers in the design process is essential to ensure that IATs are tailored to their needs and preferences. Emphasizing user-centered design, customization, and adaptability will make it possible to develop IATs that can cater to diverse cognitive and sensory abilities [34]. By actively involving users, caregivers, and healthcare professionals in the decision-making process and fostering collaboration among researchers, engineers, and clinicians, we can ensure the ethical design and evaluation of IATs.

3) Supporting autonomy and community: IATs should incorporate a multisensory approach, adaptability, personalization, and emotion recognition technologies. Integrating multisensory stimuli into IATs can enhance interaction and foster well-being for PwD, catering to their varied cognitive and sensory capabilities. Emotion recognition, which leverages physiological signals from wearables [35], [36] and facial expressions [37], can provide insights into the emotional states of PwD. By combining auditory and visual cues, IATs can effectively discern emotions like anger, happiness, and surprise. Customizing IATs to individual requirements, accounting for cultural nuances, and providing families with training on their usage are essential steps. Through the integration of these elements, IATs can support both PwD and their caregivers, promoting autonomy and social well-being.

Introducing humanoid robots might involve "implicit deception" as they can give a false sense of human-like companionship. The ethical implications of this should be carefully considered and balanced against the potential benefits [38]. Ultimately, the development and implementation of IATs for PwD should be carried out with utmost respect for their autonomy and rights, ensuring that the technology truly serves their best interests. Measures should be taken to support general well being while supporting autonomy wherever possible.

Example: Emma, a resident showing early signs of dementia, may request her medication through a fetch robot. However, due to her condition, she may struggle to remember if she has already taken her medication or may refuse to take it altogether. This raises concerns about Emma's autonomy and her decision-making capacity. With impaired memory and judgment, Emma may not be able to make responsible decisions regarding her medication intake.

Striking a balance between the assistance provided by care robots and preserving autonomy is vital. Caregivers and developers must ensure that the design and implementation of care robots respect preferences, values, and individual needs. Users should have the ability to fine-tune their interactions with the robots, allowing them to retain control over their care and maintain a sense of autonomy.

Example: if James, a resident with Parkinson's disease, requests a knife through a fetch robot, this should raise concerns about safety due to his motor symptoms and the potential risk of injury. The fetch robot should prioritize safety and prevent residents from accessing objects that could pose a risk to themselves or others [39] while not overriding their autonomy. For instance, the robot could ask James why he needs the knife and if he could instead use something else.

V. Conclusions

Neurodegenerative diseases present formidable challenges for individuals' daily lives, impacting cognition, motor skills, and independence. The rising aging population amplifies these issues, requiring innovative solutions. IATs offer hope, but ethical concerns are integral to their successful implementation. Incorporating these ethical dimensions will foster the creation of IATs that respect the dignity of their users, empower and improve their lives, reinforcing their sense of agency and connection to their communities.

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