Using Wearable Devices to Mitigate Bias in Patient Reported Outcomes for Aging Populations

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Abstract. Wearable devices are increasingly used in health monitoring due to the provision of objective and longitudinal measures of physiological functions. The purpose of this work was to assess variability of perceived functionality for autonomic function, sleep, and physical activity, compared to objective physiological measures collected via device sensors. Further, this work assessed disparities between healthy aging populations and those with confirmed neurodegenerative conditions (e.g., Parkinson's Disease (PD)). 30 participants ($n = 20$ PD; $n = 10$ control) wore a smart tracker to collect objective features for autonomic function, sleep, and activity. Further, all participants completed daily questionnaires to depict perceived physiologic functionality. While previous studies note the importance of patient reported outcomes (PROs), these may be subject to variability. PROs of the control group were higher than sensor-based values across all functions; where sleep and heart rate yielded statistical significance ($p = 0.002$; $p = 0.012$; respectively). Conversely, PROs of populations with PD were significantly lower for sleep quality, heart rate, and activity ($p = 0.018$; $p = 0.009$; $p = 0.007$; respectively) compared to sensor-based values. Finally, significant differences ($p << 0.01$) were present for all functions between groups. Although PROs are commonly used to monitor health, digital health systems should be used to increase reliability and accuracy via the collection of objective sensor-based measures.

Keywords: Digital Biomarkers · Neurocognitive Assessment · Wearable Devices · Parkinson's Disease

1 Introduction

Given the pervasiveness of digital technology in everyday life, mobile and wearable devices provide clinicians (e.g., epidemiologists, neurologists, physicians,

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and other healthcare personnel) the opportunity to collect, analyze, and interpret new and complex sensor-based health datasets [1,2]. These devices and their capabilities yield an expansive assortment of objective symptom-specific information (e.g., digital outcome measures) acquired via mobile device sensors (e.g., wearable accelerometers, gyroscopes, and optical sensors) [3–5]. The provision of this objective data is imperative to aid in the mitigation of individual subjective bias and allow for the accurate evaluation of neurocognitive functionalities (e.g., motor function, autonomic function, and sleep) necessary in patient monitoring, disease diagnosis, and subsequent rehabilitation [6].

Currently, the monitoring of a patient's thoughts and opinions with respect to short-term changes commonly come from patient reported outcomes (PROs) [7]. These PROS are also commonly used as a measure for improved disease management, as the individual is able to recognize and interpret their condition, symptoms, and triggers [8]. However, as individuals age, their perceived neurocognitive functionalities (e.g., motor, sleep, and autonomic functions) may become reliant on changes in their cognition, the memory of past experiences, and/or sensory experiences in the body [7–9]. Further, as these individuals age, there is a noted susceptibility increase for various neurodegenerative conditions (e.g., Parkinson's Disease (PD), Alzheimer's Disease, and dementia [10–13]) that may affect changes in the way individuals perceive their neurocognitive functionalities. This concept is expressed using the stereotype embodiment theory, which suggests that beliefs surrounding culture leads to self-definitions that may influence perceived functioning and health (e.g., such that if you are deemed 'healthy' you embody the perceived notion that you are comprehensively healthy, and vice versa) [14,15].

The objective of this work was to assess the variability of perceived functionality for autonomic function, sleep, and activity levels, for aging populations, in comparison to objective physiological measures collected using wearable device sensors. Further, this work was extended to assess disparities between healthy aging populations and individuals with confirmed neurodegenerative diseases (e.g., individuals with PD).

2 Related Work

Although PROs are regularly used for monitoring a patient's thoughts and opinions with respect to short-term changes, there are no well-defined criteria on what these PROs actually entail, in the perception of the individual [7,8,16]. Exploratory analyses have shown that high physical activity PROs is associated with a minimized progression of symptoms for individuals with neurodegenerative conditions [17] and rate of perceived exertion was found to increase with heart rate (HR) and maximal oxygen consumption during exercise (VO2) among older adults [18]. However, other review studies have provided mixed results between traditional objective markers and PROs [9].

Therefore the aim of digital health technology (e.g., wearable devices) is to increase both the accuracy and reliability of PROs by combining it with objective measures, thus yielding higher diagnostic and prognostic values while also reducing individual variability and/or bias [19–22]. With the use of wearable devices, the collection of vital health related data can occur both opportunistically and longitudinally via the implementation of inherent device sensors [23,24]. These wearable devices allow for an objective evaluation of neurocognitive functions (e.g., sleep and autonomic function) that are imperative to the monitoring of aging populations, especially those with neurodegenerative conditions [6]. Digital features from these devices relate to health-related monitoring (e.g., for the assessment of autonomic functions [25]), in tandem with the utilization of on-device accelerometers and gyroscopes (e.g., to aid in the assessment of physical activity and sleep) [26]. Although previous works have utilized wearable technology for the increased reliability of patient reported outcomes of healthy aging populations (e.g., for sleep and physical activity [27,28]) further work across comprehensively representative populations is necessary to capture objective disease-related symptoms and inform big data applications [29].

3 Methodology

This pilot study included thirty individuals between the ages of 50 and 85. The population was split into two groups, (a) those with a clinical diagnosis of PD ($n = 20$) and (b) age-matched healthy controls ($n = 10$). In this pilot, slightly less than half were male ($n = 13$ or 43.33%) with nine being from the PD population, and four being from the age-matched control population. Participants of the PD group were recruited for an IRB-approved study via advertisements, referrals by physicians and clinicians, and organized therapeutic programs. Age-matched health control populations were also recruited via advertisement from groups including spouses/caregivers of the clinically affected population in addition to preceding research work in this setting. In the Western world, early-to-mid 60s is the mean onset age for clinical diagnosis of PD [30]; therefore, recruitment for this study was limited to persons who are 50 years or older from the aforementioned groups.

3.1 Wearable Device Monitoring

The wearable device chosen for this study was the Fitbit Charge 5 fitness tracker. This consumer activity tracker was chosen as several reviews examined the validity and inter-reliability of Fitbit activity trackers in both the laboratory setting and free-living environments, while demonstrating the high accuracy of physical activity measures including steps, distance traveled, and energy expenditure [31–33]. All participants were instructed to wear the device for a total of 4 weeks. Participants wore this wearable device on their non-dominant hand continuously for the duration of this study (e.g., only taking the watch off to charge). Individuals were instructed to charge the device daily when they were sedentary/inactive, but not sleeping (e.g., as the collection of sleep data was imperative to the outcomes of this work).

Data from the device accelerometer and optical sensors were used for the collection of physical activity, sleep, heart rate, and breathing features. While the Fitbit software development kit (SDK) allows for the programming of these devices to access raw sensor measurements, the devices themselves use this data to compute a number of physiological parameters such as sleep quality, step count, calorie burn, metabolic rate, activity levels, that were used to calculate the normalized score of each functionality (e.g., sleep, breathing, heart rate, and physical activity).

3.2 Patient Reported Outcomes

Each participant was given a commonly administered questionnaire for aging populations. Questions included information regarding general health information, medical diagnoses, and respective disease stage, as well as any related symptoms (e.g., an individual's feeling in general, energy levels, activity levels, pain, sleep quality, medication schedule, etc.) as depicted in Tables 1 and 2. In addition, the PDQ-39 (e.g., a fixed questionnaire regarding the quality of life for individuals with PD) was administered to gain an understanding of mobility, activities of daily living (ADLs), emotional well-being, social support, cognition, communication, bodily discomfort, and their perceived stigma of PD [34]. Questionnaires depicted in Tables 1 and 2 were administered to accompany and confirm diagnoses provided by medical practitioners. Further, all participants were administered a daily questionnaire to assess autonomic functions, sleep, and physical activity as listed in Table 3. This questionnaire used the Borg Rating Scale to assess the rate of perceived exertion [9], Likert Scales for the rating of all other functions, and additional questions regarding perceived factors that may have affected functional quality. All daily questionnaires were scheduled (e.g., participants were alerted using push notifications for the completion of mobile-based daily questionnaires) for participants to maintain compliance. All participants completed the daily questionnaire at the end of each day (e.g., before bed) such that all responses were related to the previous 24 h.

3.3 Feature Normalization

The standardization of wearable device collected feature values and patient reported outcomes is necessary as part of this work as many of the collected features differ distinctly (e.g., as they come from standardized questionnaires/tools with varying ranges and units). This normalization utilized Z-scores as depicted in Eq. 1; such that Z results from x (i.e., individual scores), μ (i.e., the mean of the population) and σ (i.e., the population standard deviation).

$$Z = \frac{(x - \mu)}{\sigma} \tag{1}$$

Z-scores are measured as standard deviations with relation to the mean. These Z-scores can be either + or −, where a positive Z-score indicates a value greater than the mean, a negative Z-score indicates a value less than the mean, and a Z-score of 0 indicates a value equal to the mean.

Table 1. General medical history questionnaire [35].

Answer Type	Question
(Multiple Choice/ Open Answer)	How old are you?
	How do you identify?
	What is your highest level of education?
	Are you currently employed or retired?
	What industry are/were you employed?
	Do you have a clinical diagnosis of any neurological conditions?
	If yes, have you been diagnosed with PD?
	If yes, in what year was your diagnosis?
	If yes, in what stage of Parkinson's Disease are you?
	If yes, please describe your first noticed symptoms? (e.g., shaky or smaller handwriting)
	If yes, when did your symptoms first become noticeable?
	Have you received a clinical diagnosis of any additional neurological condition? (e.g., dementia or stroke)
	If yes, what other condition(s)?
	If yes, when were you diagnosed?
	What is your medication schedule for your diagnosed condition(s)? (e.g., medication name, dosage, and timing for each listed condition)

Table 2. Questionnaire regarding symptom-specific effects of Parkinson's Disease [35].

Answer Type	Question (How often during the last month have you had...)
(Likert Scale 1–5) (1 = Never) (2 = Occasionally) (3 = Sometimes) (4 = Often) (5 = Always)	Issues and/or concerns with your Short Term Memory (e.g., what you had to eat for breakfast)?
	Issues and/or concerns with your Long Term Memory (e.g., the date of children's birthdays)?
	Issues and/or concerns with your Fine Motor Function (e.g., writing your name)?
	Issues and/or concerns with your Gross Motor Function (e.g., going from a sitting position to a standing position)?
	Issues and/or concerns with your Balance/Stability (e.g., standing still in an upright position without support)?
	Issues and/or concerns with your Word Finding (e.g., expressing words you want to say when you wish to say them)?
	Issues and/or concerns with your Attention (e.g., the ability to maintain focus on a specific thing)?
	Issues and/or concerns with your Judgment (e.g., the ability to make decisions considering many possible outcomes)?
	Issues and/or concerns with your Reasoning (e.g., the ability to consciously apply logic)?
	Issues and/or concerns with your Problem Solving (e.g., the ability to find solutions to complex problems)?
	Issues and/or concerns Following Conversations?
	Issues and/or concerns Reading (e.g., difficulty in following the information on the page)?
	Issues and/or concerns with your Speech (e.g., having quiet or effortful speech)?
	Poor Energy Levels (e.g., the ability to complete normal physical activities without being tired)?
	Poor Sleep Quality (e.g., restless, duration)?
	Bodily Pain (e.g., bodily aches, muscle or joint pain, headaches)?
	Issues and/or concerns in your Social Engagement (e.g., spending time with family and friends)?
	Issues and/or concerns with your Sensory Function(s) (e.g., touch, vision, hearing, taste, and/or smell)?
	Issues and/or concerns expressing your Emotions (e.g., your natural state of mind based on current circumstances, mood, and/or relationships)?

Table 3. Daily questionnaire regarding patient reported outcomes of sleep, autonomic function and activity.

Question	Function	Scale
How did you feel in general today?	Overall	(Scale of 0–10; 10 being the best)
What was the quality of your sleep last night?	Sleep	(Scale of 1–10; 10 being very high quality)
What affected your quality of sleep last night?	Sleep	(Mark all that apply)
What was your breathing capacity today?	Breathing	(Scale of 1–10; 10 being very high capacity)
What affected your breathing capacity today?	Breathing	(Mark all that apply)
What was your rate of perceived exertion today?	Heart Rate	(Borg Rating Scale of 0–10; 10 being maximal physical exertion)
What caused your rate of perceived exertion today?	Heart Rate	(Mark all that apply)
What was your activity level today?	Activity	(Scale of 1–10; 10 being very active)
How many active minutes did you have today?	Activity	Number of active minutes
What activities did you participate in today?	Activity	(Mark all that apply)

Following feature normalization both perceived and sensor-based aggregated scores were formed. Aggregated perceived functional scores were calculated from normalized response data from daily surveys found in Table 3. Aggregated sensor-based functional scores were calculated from normalized physiological parameters retrieved from Fitbit Charge 5 fitness tracker found in Table 4.

Table 4. Daily sensor-based smart tracker values from Fitbit Charge 5.

Smart Tracker Value	Function
Minutes Asleep	Sleep
Minutes Awake	Sleep
Time in Deep Sleep	Sleep
Count of Deep Sleep Intervals	Sleep
Time in Light Sleep	Sleep
Count of Light Sleep Intervals	Sleep
Time in REM Sleep	Sleep
Count of REM Sleep Intervals	Sleep
Average SPO2 Score	Breathing
Lower Bound SPO2 Score	Breathing
Upper Bound SPO2 Score	Breathing
Resting Heart Rate	Heart Rate
Time in Heart Rate Zones	Heart Rate
Daily Heart Rate	Heart Rate
Active Zone Minutes	Activity
Caloric Burn	Activity
Sedentary Minutes	Activity
Lightly Active Minutes	Activity
Moderately Active Minutes	Activity
Very Active Minutes	Activity
Step Count	Activity

3.4 Statistical Analysis

All normalized patient reported outcome measures and sensor-based scores were analyzed between groups using both ANOVAs and post hoc t-tests for statistical analysis.

4 Results

The depiction of perceived neurocognitive functionalities between PD populations and age-matched healthy control populations, is reported via normalized scores from the patient reported outcomes questionnaire for sleep, autonomic functions (e.g., breathing and heart rate), physical activity, in addition to how the individual feels in general. Average Z-scores for these perceived functional areas are shown in Fig. 1. This figure depicts that age-matched healthy controls have a higher average perceived functionality score across all functions (e.g., an individual's feeling in general, sleep, autonomic functions, and physical activity) compared to those with confirmed PD diagnosis.

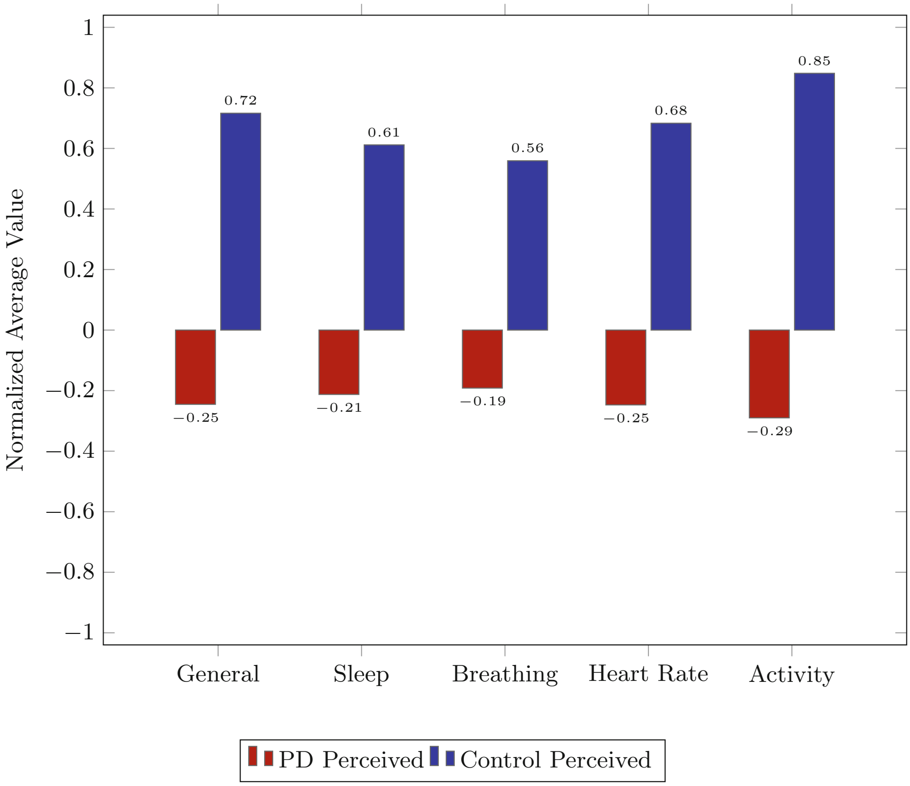

Fig. 1. Normalized perceived scores across overall functionality, sleep, autonomic function, and physical activity between healthy aging control populations and PD populations

Figure 2 presents both normalized perceived and sensor-based functional scores across sleep, autonomic functions, and physical activity between healthy aging control populations and PD populations. Figure 2 depicts that control populations have higher average scores for both perceived functionality and sensor-based features across all areas when compared to those with a confirmed PD diagnosis. Further, this figure shows that healthy age-matched populations perceive their functionality across all categories to be higher than sensor-based scores, whereas PD populations perceive their functionality to be worse than sensor-based scores for sleep, heart rate, and physical activity.

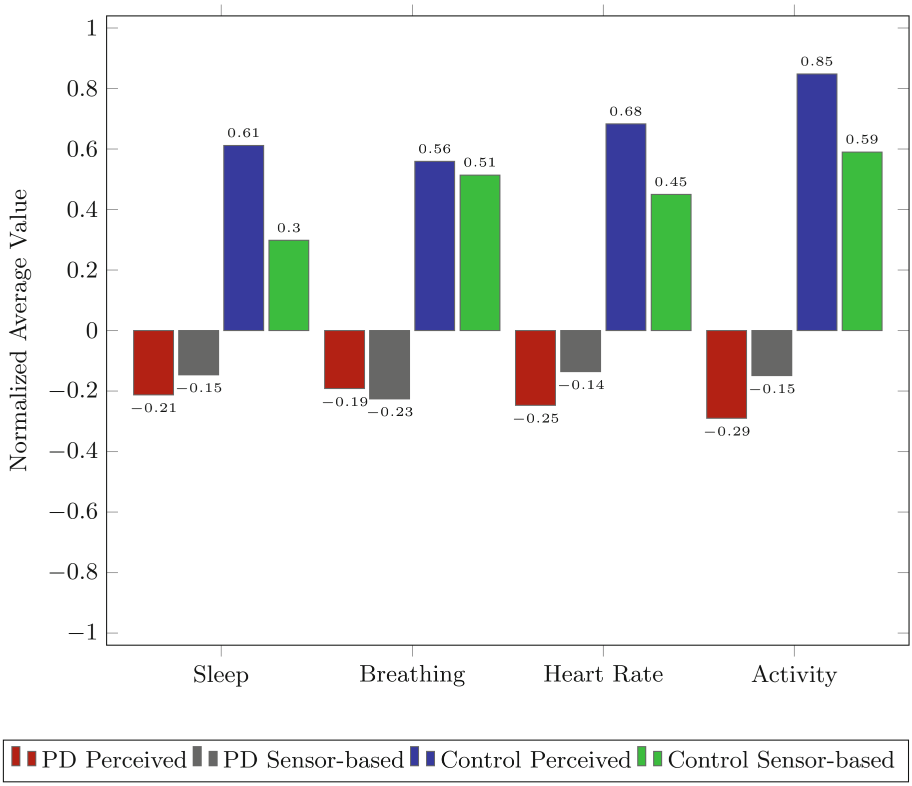

Fig. 2. Normalized perceived functionality and sensor-based scores across sleep, autonomic function, and physical activity between healthy aging control populations and PD populations

5 Discussion

Although PROs are commonly used to track a thoughts or opinions of the patient regarding short-term changes it is presumable that these thoughts and opinions have a high reliance on cognitive processes, memory of past exercise experiences, in addition to felt experiences in the body [9]. Further, it is noted that these patient reported outcomes may be negatively impacted in individuals with neurodegenerative diseases [7,8]. This concept is further depicted using the stereotype embodiment theory, which suggests that beliefs surrounding culture leads to self-definitions that may influence perceived functionality as it relates to health (e.g., such that if you are deemed 'healthy' you embody the perceived notion that you are comprehensively healthy, and vice versa) [14,15]. The stereotype embodiment theory perspective may be observed in Fig. 2 as the PD population's overall perceived scores for sleep quality, heart rate, and physical activity are significantly lower ($p = 0.018$, $p = 0.009$, and $p = 0.007$; respectively) than sensor-based normalized values. Conversely, the age matched healthy control population's overall perceived scores across all functions (e.g., sleep, breathing, heart rate, and physical activity) are higher than sensor-based normalized values; where sleep and heart rate are significantly higher ($p = 0.002$, and $p = 0.012$; respectively). It is noted that the PD population's overall perceived score for breathing is higher than sensor-based normalized values, as depicted in Fig. 2; however, it is also expressed that there is not a significant difference between these scores given this population.

Subsequently, Fig. 2 depicts the difference in objective measures between PD populations and healthy age-matched control populations. In this pilot study all functions (e.g., sleep, breathing, heart rate, and physical activity) differed significantly ($p << 0.01$) between groups. As individuals with neurodegenerative diseases may present with functional deficits across each of the following areas of neurocognition: motor, memory, speech, language, executive function, sensory, behavioral and psychological, sleep, and autonomic functions [6,36], the collection of accurate and sensor-based features using digital health technology is imperative for the assessment and monitoring of each functional area of neurocognition.

As there are significant differences in perceived functionalities and sensor-based normalized values across groups, the importance of using digital health technology (e.g., wearables) to increase the reliability and accuracy of patient reported outcome data is imperative [20,22]. The combination of PROs with objective digitally collected features should remain a main focus in the assessment and monitoring of health outcomes for all groups.

5.1 Limitations and Future Work

One of the main limitations of this pilot study results from the population size and breakdown. Future work should incorporate the collection of a larger dataset with respect to both diagnosed healthy control populations in addition to the inclusion of additional neurodegenerative diseases (e.g., amyotrophic lateral sclerosis, dementia, and Huntington's disease) and their stages. This would then allow for the separation of groups on the basis of disease presence and respective stages in a fine-grained classification approach. This is necessary for both the assessment of perceived functionality and sensor-based scores as they relate to representative aging populations. Further, this work only explores a subset of neurocognitive functions as they relate to digital health technologies (e.g., wearable devices and smartphones). Additional work with respect to wearable devices, utilizing electrodermal activity sensors for the assessment of stress and behavior [25,37] would expand wearable monitoring efforts to include more functional areas of neurocognition. Expanding this work to include additional IoT devices, such as smartphones, would also allow for the expanded analysis of more functional areas of neurocognition [38]; via the comparison of PROs found in Tables 1 and 2 with objective, digitally collected features. Finally, the work presented in this pilot study should be extended to include the assessment of function-specific (e.g., autonomic function and sleep) benefits from a diverse set of clinically relevant therapeutics (e.g., pharmacological, medical, physical, speech, occupational, etc.).

Subsequently, with the collection of more digitally-collected, objective features across larger populations with respect to therapeutic protocols, machine learning methods could be used in the translation of this data into actionable knowledge [39,40]. While previous research has focused on assessing different motor systems using a number of wearable sensors placed on different body parts [41,42], advances in machine learning provide opportunities to measure motor symptoms using a smaller number of sensors (e.g., wearables worn on a wrist) [43]. Specifically, supervised machine learning for the purpose of prediction and classification of various diseases, and the provision of personalized healthcare decisions in response to prediction and classification (e.g., as they relate to a patient's ability to perform ADLs, the severity of symptoms, symptom progression, response to medication and other interventions, and their overall quality of life) is necessary for these aging populations given the increased susceptibility to neurodegenerative diseases (e.g., PD) [10,44,45]. However, future work regarding the development of robust machine learning models relies on an expanded dataset of adequate quality (e.g., one that comprehensively represents aging populations) [29,46].

6 Conclusions

Although PROs are commonly utilized in practice for the monitoring of an individual's thoughts or opinions (e.g., with respect to short-term changes), the aim of digital health technology should be to increase both the reliability and accuracy of these PROs by combining it with objective digital outcome measures from mobile-based devices. This work utilized wearable devices to assess disparities between healthy aging populations and those with confirmed neurodegenerative diseases by comparing patient reported outcomes and sensor-based features across functional areas of neurocognition. As there were significant differences both between groups (e.g., healthy aging populations and those with confirmed neurodegenerative diseases) and between feature types (e.g., patient reported outcomes and sensor-based features) it is confirmed that mobile devices should be utilized in tandem with PROs for increased reliability and accuracy. As these wearables not only allow for the collection of objective features, both opportunistically and longitudinally, while requiring minimal interaction from the individual in the collection of vital health information, further advocacy for their use in these contexts should be seen. With the further integration of these wearable devices in neurocognitive digital health assessment systems, all future efforts should aim at improving the overall quality of life for aging populations by expanding personalized medicine.

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