Attitudes Toward the Use of Voice-Assisted Technologies Among People With Parkinson Disease: Findings From a Web-Based Survey

People with Parkinson's report favorable attitudes towards the use of Voice Assisted Technologies: findings from an online survey

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Abstract

Background: Speech problems are very common in people living with Parkinson's, limiting communication and ultimately affecting their quality of life. Voice assisted technology in health and care settings has shown some potential in small-scale studies to address such problems, with retrospective analysis of user reviews reporting anecdotal communication effects and promising usability features when using this technology for people with a range of disabilities. However, there is a need for research to establish the users' perspectives of the potential contribution of voice assisted technology for people with Parkinson's.
Aim: To explore attitudes towards the use of voice assisted technology for people with Parkinson's.
Methods: A survey was approved for dissemination by a national charity, Parkinson's UK, to be completed online by people living with the condition. The survey elicited respondent demographics, Parkinson's features, voice difficulties, digital skill capability, smart technology

usage, voice assisted technology ownership and usage, confidentiality and privacy concerns. Data was analyzed using descriptive statistics and summative content analysis of free text responses.
Results: Of 290 participants, 79% (229/290) indicated that they or others had noticed changes in their speech or voice due to symptoms of their condition. Digital skills and awareness were reported on 11 digital skills, such as ability to 'find a website you have visited before'. A high number, 72% (209/290) reported being able to perform at least 10 of these 11 tasks. Similarly, of the 71% (205/290) participants who owned a voice-assisted device, most of them (166) used it regularly, with 31% (52/166) reporting that they used the technology specifically to address needs associated with their Parkinson's. Of these 166 users, 55% sometimes or rarely had to repeat themselves when using the technology. When asked about speech changes since they started using it, 25% noticed that having to repeat themselves less, and 15% perceived their speech to be clearer. Of the 290 respondents 91% were not concerned, or only slightly concerned, about privacy and confidentiality.
Conclusions: Having been added to the homes of Western society, domestic voice assist devices are now available to assist those with communication problems. People with Parkinson's report a high digital capability, albeit those who responded to an online survey. Most have embraced voice assisted technology and find it helpful and usable. Speech and language therapists may have a virtual ally, already in the patient's home to support future therapy provision.

Key Words

Parkinson's; Voice assisted technology; Speech and Language difficulties.

Introduction

Globally, there are over six million people diagnosed with Parkinson's (PwP) and it is currently the fastest growing neurological disease worldwide [1]. Early presentation includes tremor, stiffness or rigidity, slow movement, impaired balance, poor coordination and speech problems [2]. Although it usually affects people aged over 50 years, it can also affect younger people [2].

Problems with speech occur in 90% of PwP [3], at some point in their condition, and include: monotonous tone, reduced pitch and loudness, variable rate, imprecise consonant production and an unclear 'breathy' voice ([4]; [5]). These speech symptoms are caused by issues with muscular control over the speech mechanism which can be classified under the umbrella term of 'dysarthria'[6]. PwP have an abnormal perception of loudness levels to guide the correct production of volume in their speech [7], so that an individual will feel that they are shouting when speaking at a normal level. Recalibration of the internal perception of volume and effort is one of the goals of speech and language therapy [8]. The impact of speech problems is wide, affecting activities of daily living, mood and self-identity [3].

Early speech and language therapy (SLT) intervention is important to address communication issues [8] but only a little over half of all PwP have contact with a therapist (52% in the UK [9]; 59% in Australia [10]). Given the extremely high rates of this population who experience voice changes or are dissatisfied with how they communicate [11], this rate of access to SLT is alarmingly low. Lee Silverman Voice Treatment (LSVT®) is the gold standard approach provided by SLT for improving vocal loudness in PwP (which is often the primary concern). Despite its benefits, LSVT is resource intensive; requiring significant personal and professional time investment, and self-directed motivation to practice largely repetitive exercises [12]. Often the intensity and effort required to finish a program of LSVT outweigh the perceived benefits. PwP report that practicing on their own can be difficult, they feel self-conscious, overburdened and doubtful about the effectiveness of carryover from therapy sessions to everyday situations [13]. The limited access to SLT and resource intensity of clinical services warrants exploration of alternative methods to support PwP to communicate effectively.

Technology can offer a range of opportunities to support PwP during this process of home-based practice, by structuring activities, adding gamified elements to increase enjoyment, and provide positive reinforcement and feedback. For example, improved engagement and enjoyment was described by users, in vocal loudness exercises conducted with a digital game [14]; an innovative crowdsourcing approach was explored to provide real-time, human feedback on speech for PwP, who uploaded structured speech samples via an app [15]. Participants could then use a practice area in the app, based on feedback received, to direct their home-based practice (e.g. focus on volume using a decibel meter; focus on pacing using a metronome). Further work showed promising results for the use of a head worn wearable device (Google Glass®) as a volume training

tool at home and an assistance device in social settings with cues to increase volume [16]. The glasses displayed real time feedback of volume, using a thumbs up symbol for positive reinforcement when a pre-set target was achieved. When discussing Google Glass, PwP explicitly described the benefits of the voice interaction functionality, to access technology. Even those with pronounced speech difficulties found success with the voice interaction [17]. Whilst this work on technology assisted SLT for PwP seems promising, it is only now emerging as an area of research and studies to date only explore the interventions with small numbers of participants. Through this work we explored the opportunities for widely used, off-the-shelf voice assisted technologies (which implement voice interaction) in supporting PwP.

"Voice assistants" are software agents installed in devices such as phones, computers or tablets, or on purpose-built speakers [18]. They are capable of interpreting human speech and, depending on the command they receive, can complete different tasks (e.g. tell the time or the weather, send and read text messages, make phone calls, set alarms, play music, and control various connected devices) [18]. Currently, one in five homes in the UK own a voice assisted speaker, a figure which is predicted to rise significantly in coming years [19]. As many as 40% in the US own one [20]. As such, these voice-assisted technologies are growing in popularity and are becoming pervasive. The older population (60+) make up around 20% of smart speaker ownership, with almost 60% of these consumers using the device every day [21]. The Amazon Alexa® is the market leader across all age groups [21]. Voice assisted technology (VAT) offers hands-free access and naturalistic voice interaction: a beneficial means of interacting with the device for those with physical disabilities or lower levels of technology literacy [15]. As such, recent years have seen an emergence in research in the health and care space, which is exploring the role of VAT in supporting people within these demographics.

A living-lab study was conducted with older adults aged between 64 and 89 [22] to explore older people's interactions with a voice assistant (Google Home) and several connected smart home devices. Participants were asked to perform several relevant activities (e.g. ask for information, control lights, fans and a TV) and were interviewed about their experiences. The authors noted high levels of acceptance with the smart home technologies amongst older adults, and in particular described the value they found using voice command as an input, describing how participants enjoyed interacting at their own pace, without being 'judged' or 'hurried'. Similarly, the design of an adaptive system (ALADIN) is described, to help people with physical disabilities use smart homes [23]. The VAT system was "self-learning" and adapted to each user's command preferences, after being trained through a series of short sessions. This work shows promise in particular for participants with speech difficulties, as the system adapts to impaired speech patterns (e.g. people with dysarthria taking more pauses between phrases).

Several studies have explicitly explored the opportunities of the leading VAT (Amazon Alexa) to support people with disabilities, largely focusing on analysis from public reviews (posted on the

Amazon store). For example, 284 reviews were thematically analyzed from people discussing disability and found recurrent themes relating to feelings of empowerment, as well as reporting success from people with speech difficulties [24]. They concluded that whilst very promising, usability issues, such as unintended access to the technology from children and privacy concerns, can have serious implications for health applications in the home. They also recognized the need to consider disease state in technology skill development to reduce frustrations. Similarly, 346 Amazon reviews by people with cognitive, sensory or physical disability, were analyzed, finding high levels of acceptance amongst users, reports of users considering the device as a companion, as well as increased reported independence in the user [25]. The authors also explicitly discussed reviews from users with speech difficulties. A total of 13.6% of the reviews were by someone with a speech impairment and 74.2% of their comments were around positive experiences with the technology, indicating success with being understood by Alexa. Interestingly 2% of users mentioned specifically that it helped them "to talk slowly, clearly, and loudly" which is highly relevant to our work with Parkinson's, where this is often the main aim of SLT. There were similar findings in a study of the challenges and opportunities for IoT for PwP [26]. Approximately 50% of the participants were already using Alexa in their homes, and similar reports from a participant with speech difficulties described speaking in a slower, clearer voice to enhance his ability to interact with Alexa [26]. This effect is interesting and potentially significant for speech improvement, justifying further investigation.

Relating to this, the extent to which people with dysarthria (the motor speech disorder experienced by PwP) interacted with three specific VATs (Siri, Google Assistant and Amazon Alexa) was investigated [27]. They used the TORGO database [28], consisting of available recordings of people with dysarthria, and found 50–60% accuracy of phrase recognition. What was not controlled for in this paper was how well the VATs worked in correlation with the degree of dysarthric speech (i.e. did it work better with a moderate level vs severe dysarthria, or was the presence of any dysarthria, even a mild one, a cause for issue). In addition, the speech samples were standardized in nature and recorded in labs, and thus did not represent the naturalistic interactions with the VATs that one would carry out in everyday life. Finally, the above study did not account for disease specific origins of the dysarthria, which could in themselves have different factors which account for the intelligibility levels in the speech samples.

In summary, there is some evidence that VATs are already beginning to improve the lives of older people and people with disabilities, and clear potential for the technology to support people with speech impairments. Furthermore, VATs may even be unexpectedly acting as a prompt for improving the speech of some users [24]-[26]. However, these studies provide only anecdotal evidence, highlighting a need to conduct systematic research which will explore if and how people with different levels of speech impairment engage with VATs.

In this work we investigate the opportunities for VAT to support SLT outcomes for PwP. We focused on exploring the ownership and acceptance of VATs amongst the Parkinson's community, and their usability for those with speech issues. In addition, to further explore possible barriers to the adoption of VAT to the wider Parkinson's community, we also wanted to explore any privacy and security concerns that PwP might have surrounding these technologies. We aimed to answer three questions.

Within the UK-based Parkinson's community;

1. What is the level of basic digital skills?
2. What is the knowledge and experience of existing VAT?
3. What are the reported effects of VAT upon speech and language?

In so doing, we build a foundation of knowledge for further research, development and implementation of VAT for PwP

Methods

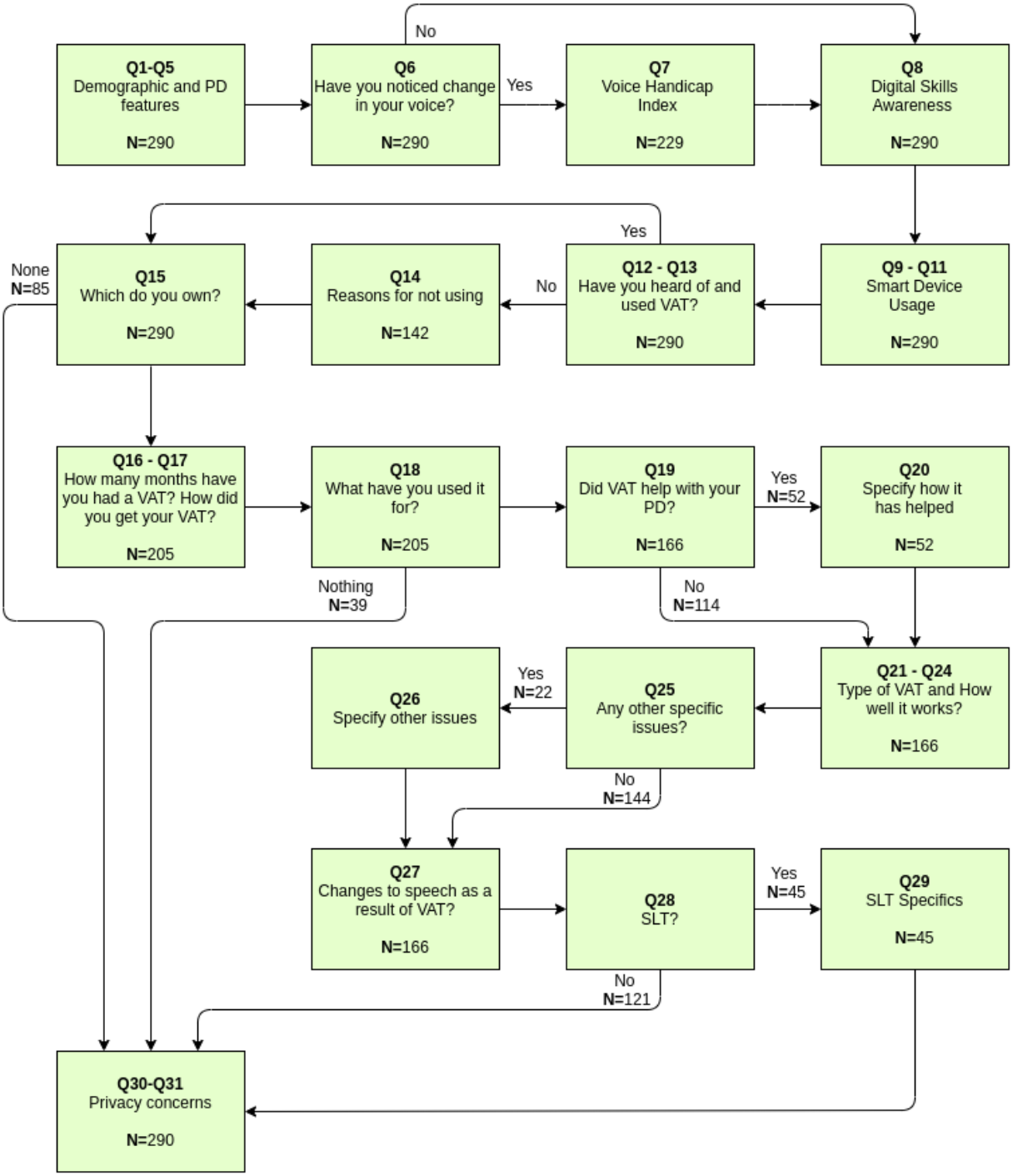
Survey Design

Taking a descriptive observational approach, we developed a survey, using Qualtrics, an online platform. The survey was based upon a review of the literature in Parkinson's speech and voice difficulties, and digital technology usage [26, 29, 30]. It was pilot tested with six academic staff at two UK Universities. Following amendment, it was further piloted with 44 Patient and Public Involvement (PPI) volunteers, accessed through Parkinson's UK. Volunteers were sent a link for the survey which they completed online, and they were asked to provide feedback on the survey with any suggestions for improvement. The PPI feedback resulted in amendments to the flow of the survey, removal and addition of questions, improving clarity and improving format.

The final version of the survey consisted of 31 questions in four sections (see multimedia appendix 1): 1) Six questions on demographics and Parkinson's features to elicit the profile of respondents. 2) Voice Handicap Index (VHI): We wanted to collect information on participants' voice symptoms and the impact these had on their lives. As such, we used a validated instrument, the VHI [29]. The VHI is a voice outcome measure that has been used widely in voice research with various clinical and healthy populations and specifically with the Parkinson's population. It is validated with good psychometric properties. It assesses physical, functional and emotional impact of voice difficulties; 3) Digital skills and awareness: Digital skills were assessed through an adaptation of The Tech Partnership's Basic Digital Skills framework [30]. Re-use permission was granted. This framework consists of asking respondents which of 11 digital tasks they would be able to complete if they were asked. These digital skills cover areas including Managing Information, Communicating, Transacting, Problem Solving and Creating. For example, a "Managing Information" digital skill is "Find a website I have visited before". This instrument

collected detail on digital ability; 4) Smart device usage: There were 3 questions about smart device usage providing further detail about digital access and familiarity. To find out about VAT specifically, there were 20 questions around usage, ownership, support for Parkinson's features, problems with usage, VAT impact on speech, and security concerns. Responses were in both free text and checkbox format. The survey used display logic to direct participants to relevant questions, therefore different numbers of participants answered some questions (see figure 1).

Figure 1. Survey Flow Diagram. Starting at top left, the diagram shows elements of the survey with skip logic to avoid unnecessary questions such as Voice Handicap Index which applies to respondents who notice a change (Q7). Numbers of respondents to each element are given. The final element elicits security concerns (bottom left).


Q1-Q5
Demographic and PD features
N=290
Q6
Have you noticed change in your voice?
N=290
No
Yes
Q7
Voice Handicap Index
N=229
Q8
Digital Skills Awareness
N=290
Q9 - Q11
Smart Device Usage
N=290
Q12 - Q13
Have you heard of and used VAT?
N=290
Yes
No
Q14
Reasons for not using
N=142
Q15
Which do you own?
N=290
None
N=85
Q16 - Q17
How many months have you had a VAT? How did you get your VAT?
N=205
Q18
What have you used it for?
N=205
Nothing
N=39
Q19
Did VAT help with your PD?
N=166
Yes
N=52
Q20
Specify how it has helped
N=52
No
N=114
Q21 - Q24
Type of VAT and How well it works?
N=166
Q25
Any other specific issues?
Yes
N=22
Q26
Specify other issues
No
N=144
Q27
Changes to speech as a result of VAT?
N=166
Q28
SLT?
Yes
N=45
Q29
SLT Specifics
N=45
No
N=121
Q30-Q31
Privacy concerns
N=290

Study Population and Recruitment

Following peer review, the study gained ethical approval from the Institute of Nursing and Health Research ethics committee at Ulster University. Participants were presented with details about the study on the welcome page. Participants were made aware that all data was anonymous and would be used in research. Informed consent was achieved by providing participants with information about the study, its purpose, length of time to complete, data storage and anonymity. Consent was indicated through submission of responses. Parkinson's UK disseminated the survey by emailing it to their research support network from 15th March until 30th April 2019. We included PwP of any age and at any stage of disease. The sample size was based upon the number required to obtain 90% confidence and +/- 5% margin of error in estimating proportions: exact calculation N=289.

Analysis

The study used a mixed methods approach. Quantitative data was analyzed using the statistical package, IBM-SPSS (v26) [31]. Descriptive statistics, such as frequency, standard deviation, and mean were used. Summative content analysis was used for the qualitative free text responses [32]. Responses from each free text question were collated into a spreadsheet and separately analyzed by two researchers to identify themes. Any disagreements were resolved through discussion until a decision had been made on the final set of themes. Frequency counts were then provided, with number of responses relating to each theme available for the analysis.

Results

The survey received responses from 320 respondents. Partially completed survey responses, which did not include completion of the final mandatory question, were excluded. This resulted in the exclusion of 30 respondents, providing a total of 290 fully completed surveys for analysis.

Demographics and Digital Skills

A total of 116/290 (40%) respondents were female, 174/290 (60%) male; the most represented age group was 65-74 (121/290; 42%), followed by 55-64 (96/290; 33%). The majority of respondents (237/290; 81.7%) were based in England, with 25 (8.6%) based in Scotland, 17 (5.9%) in Wales, and 11 (3.8%) in Northern Ireland. Respondents were asked to specify how many years it had been since their diagnosis. A total of 284/290 (98%) respondents had been diagnosed with PD for at least 1 year. The mean years since diagnosis was 6.35 (SD: 5.55).

Respondents were asked to select which symptoms of PD they experienced. Slow movement was the most commonly experienced symptom (227/290; 78%) followed by writing changes (223/290; 77%). Of particular relevance to this study was speech changes, which was the third most

commonly reported symptom at 67% (194/290). Additionally, 79% of respondents (229/290) indicated that themselves or others had noticed changes in their speech or voice due to their Parkinson's and this group of 229 then were asked to complete the VHI. The VHI consists of three parts; each part provides 10 statements regarding speech difficulties and their impact on physical, functional and emotional domains. Respondents are asked to respond to each statement with a score between 0 (Never) and 4 (Always), indicating how often they experience each difficulty. Example statements are "My voice makes it difficult for people to hear me" and "My voice problem upsets me". Higher scores indicate more severe vocal difficulty. Each section has a minimum possible score of 0 and a maximum possible score of 40. The minimum possible score for the entire VHI is 0 and the maximum possible score is 120. Table 1 provides an overview of the mean scores for each VHI section, and for the overall VHI.

Table 1 – The great majority of respondents 79% (229/290) indicated changes in their voice due to PD. The table shows their VHI scores: a score over 11 is regarded as abnormal.

Section	Mean Score (Standard Deviation, Maximum, Minimum)
Function	16.06 (7.67, 37, 0)
Physical	16.09 (6.78, 34, 0)
Emotion	14.04 (8.70, 38, 0)
Total	46.19 (21.08, 108, 1)

Scores for each statement were analyzed. In the Function section the top rated items were "*People have difficulty understanding me in a noisy room*" (mean 2.31; SD 0.94), "*My voice makes it difficult for people to hear me*" (mean 2.07; SD 0.78) and "*People ask me to repeat myself when speaking face-to-face*" (mean 2.00; SD 0.86). Of the 229 respondents, 3 people scored 0 in this section. In the Physical section the top-rated items were "*The clarity of my voice is unpredictable*" (mean 2.19; SD 0.91) and "*The sound of my voice varies throughout the day*" (mean 2.13; SD 0.89). In this section, 4 people scored 0 and they were not the same as the 3 respondents who scored 0 in the function section. In the Emotions section the top-rated item was "*My voice problem upsets me*" (mean 1.80; SD 1.18). In this section, 8 people scored 0, 2 of them scored 0 in part 2, and 1 scored 0 in part 1.

The Digital Skills questionnaire consisted of 11 items (for example, "use a search engine to look for information online"). Participants were asked to select yes if they could complete the skill, or no if they could not. Of the 290 who completed the questionnaire, 72% or more were able to complete the task for 10/11 of the items. The highest rated skill was "Use a search engine to look for information online" as 283/290 (98%) of respondents were able to complete it, closely followed

by “Find a website you have visited before” (280/290; 97%) and “Send a personal message to another person via email or online messaging service” (275/290; 95%). “Create something new from existing online images, music or video” had the lowest number of participants indicating they would be able to complete it (132/290; 46%).

In summary, as many as 79% of respondents indicated that they or others had noticed change in their speech or voice due to Parkinson’s. The respondents rated themselves as digitally competent with at least 72% being able to complete 10/11 digital skills.

Smart Device Usage

Respondents (290) reported how familiar they were using technology such as smartphones, computers, tablets and laptops. Over half (163/290; 56%) indicated that they were very familiar, 112/290 (39%) indicated that they were somewhat familiar; only 15/290 (5.2%) indicated that they were unfamiliar with the use of these devices. Respondents (290) were asked how often they use technologies such as smartphones, computers, tablets and laptops. The vast majority (272/290; 94%) indicated daily usage, 4/290 (1.4%) indicated weekly, 5/290 (1.7%) monthly, and 9/290 (3.1%) indicated they never used these devices. A total of 266/290 (92%) respondents indicated that they own a touch screen device, such as a smartphone or tablet.

The respondents were asked about ownership of VAT. A total of 85/290 (29%) said that they did not own a VAT and were directed to the last 2 questions of the survey, as the rest of the survey was concerned with ownership. The remaining 205/290 (71%) responded to questions about how long they owned their device and how they had gained one. The respondents owned their VAT for a mean of 23 months (range 0 - 84 months), with 70% (144/205) owning it for 24 months or less.

Of those who own VAT (205), 49.3% (101/ 205) bought it for themselves and 17.1% (35/ 205) received it as a gift and 2.9% (6/ 205) were recommended VAT by a healthcare professional. Other sources (30.7%; 63/205) include; pre-installed on a smart device (47/63; 75%), provided for work or study access (8/63; 12.5%) and other general comments (8/63; 12.5%).

Respondents who owned VAT (205) were asked what they had used the technology to do. For this question, participants could select more than one response. The most popular responses were: To request information (131/205; 64%), to play music (92/205; 45%) and to set a reminder (67/205; 33%). The “other” category was selected by 30% (62/205) and free-text responses included: dictating messages and text (58%; 36/62), creating a shopping list (6%; 4/62), setting a timer (5%; 3/62), controlling the home environment (5%; 3/62), answering questions (5%; 3/62), miscellaneous (21%; 13/62). Of those who owned a VAT, 19% (39/205) had not used it and they were directed to the last two questions in the survey as the remaining questions were about usage. Therefore 166 respondents answered the next set of questions.

Voice Assisted Technology for Parkinson's support

A total of 166 respondents were asked if they had used VAT to help with their PD. A total of 52/166 (31%) reported that voice assistants were helping them with aspects of their PD. Most responses focused around utilizing speech-to-text functions (63%; 33/52) to cope with symptoms such as *"tremor, which makes typing difficult"*. There were specific mentions about how VAT had helped respondents to practice their speech (13%, 7/52) for example *"Voice meter to practice voice levels"* and *"Low Volume speech. I have to concentrate to say 'Alexa' loud enough"*. Other respondents used the technology to set medication reminders (8%; 4/52), for accessing entertainment such as listening to music (6%; 3/52) and to communicate with other people through calls (8%; 4/52).

When queried about the type of VAT respondents used, 46% (76/166) used only mobile VAT, 30% (50/166) used only a standalone device and 24% (40/166) used both.

How well do Voice Assistants work?

Table 2 provides an overview of how well voice assistants function for participants. Participants were asked how well the VAT works in general, and specifically how well they feel the VAT understands their voice.

Table 2 - How well VAT works for participants, and how well it elicits meaning in their speech

How well does the VAT work for you?		**How well do you feel the VAT understands your voice?**	
It always works for me	12.0% (20 / 166)	**I never have to repeat myself**	4.2% (7 / 166)
It works most of the time	43.4% (72 / 166)	**I rarely have to repeat myself**	13.9% (23 / 166)
It works about half of the time	10.2% (17 / 166)	**I sometimes have to repeat myself, but it works most of the time**	36.7% (61 / 166)
It works some of the time	31.3% (52 / 166)	**OK, but I often have to repeat myself**	26.5% (44 / 166)
It never works for me	3.0% (5 / 166)	**I usually have to repeat myself**	9.6% (16 / 166)
		I always have to repeat myself	9.0% (15 / 166)

Participants were asked to explain their answers, with 144/166 providing further explanation via a free-text box. A total of 36.1% (52/144 respondents) agreed that the device/technology misinterpreted what they had asked, which could cause frustration, for example, *"I find that it often misinterprets what I say so I spend a lot of time correcting it which is very frustrating"*. More common problems related to Parkinson's and specifically with speech were also mentioned (19/144, 13.2%) such as *"Sometimes Alexa does not hear me - because of my Speech problem with Parkinson's"*; *"Due to stumbling over words/ stuttering/ low gravelly voice misunderstands me"*; *"Sometimes my voice is too quiet for Siri"*. Several participants noted that intonation or accent (9/144, 6.3%) affected this technology, for example, *"I have a Scottish accent and so some voice technology does not understand my accent"*. Other responses were related to the fact that participants did not use the technology frequently 9.0% (13/144), that they were in an early 'training phase' of using the technology (4.9%, 7/144), or that there were general technical issues (4.2%, 6/144).

Of 166 respondents, 12.0% (20/166) who have used VAT reported other specific issues while using VAT. Misinterpretation of what participants had said was one of the main issues reported (30%, 6/20). For example, *"Misunderstood words and proper nouns".* Grammar was also cited as a problem for 15% (3/20) of participants, for example: *"Always inserts capital letter. Correcting it is not easy"*. In addition, there were (30%, 6/20) responses which specifically discussed technical restrictions of the technology itself and how this could cause issues. Some of the participants (15%, 3/20) however highlighted that some positive speaking behaviors might be arising through issues with the technology, for example: *"have to speak slowly and clearly"*; *"Having to talk louder"*; *"Making my voice clear".* Another (5%, 1/20) reported concerns over the privacy of their personal information.

Speech changes as a result of VAT

Respondents with Parkinson's were asked about changes in their speech as a result of using VAT. Table 3 provides an overview of responses from 166 who use VAT and from PwP who recorded speech changes as a symptom they experience. The most common response was *"I have not noticed any change in my speech"* (52.4%, 87/166 overall, 42.6%, 71/166 of PwP with speech changes), and the least common response was *"Confidence in my speech has decreased"* (6.6%, 11/ 166 overall, 9.3%, 15/166 of PwP with speech changes). As many as 25% (42/166) of participants who had identified speech changes reported that VAT asks them to repeat less.

Table 3 - Changes to Speech as a Result of Using Voice Assisted Technology by the overall population and by respondents who experience speech changes as a symptom of PD

Changes to your speech as a result of using your voice assisted technology (% agree / strongly agree)		
	Overall	**With Symptom: Speech Changes**
I have not noticed any change in my speech	52.4%	42.6%
The voice assistant asks me to repeat myself less than when I first started using the technology	23.5%	25%
I feel my voice is clearer	14.5%	14.8%
I feel my voice is louder	12.0%	13.0%
Confidence in my speech has increased	10.8%	13.9%
Other people ask me to repeat myself less than when I first started using the technology	8.4%	10.2%
Confidence in my speech has decreased	6.6%	9.3%

Privacy and Confidentiality issues

All 290 participants responded to questions relating to privacy and confidentiality issues associated with the use of VAT. A minority of respondents (9.3%; 27/290) were very concerned, 34.5% (100/ 290) were slightly concerned, and 56.2% (163/ 290) were not concerned at all. Respondents who did have privacy and confidentiality concerns were invited to provide further information about these concerns, with 87/290 (30%) responding in free text. Of these, the biggest concern from participants was related to the possibility that they could be 'hacked' (26.4%; 23/87): such as *"Being spied on and hackers"*. The second most discussed concern was related to the storage and misuse of personal data (23%; 20/87): for example, *"The surveillance potential in these devices is alarming. Information could be used to my detriment - health insurance for example"*. Another theme that was widely commented on was the fact that devices were 'always listening' and how this might be used for surveillance purposes (15%; 13/87): *"If the voice control technology is permanently active then you have a 'Big Brother' situation"*. Finally, there were general comments regarding privacy (10%, 9/87), e.g. *"TV documentaries have shown that Amazon can collect information on users of Alexa, so they have no privacy"*; security (9%, 8/87), and confidentiality concerns (5%, 4/87).

In summary, 205/ 290 (71%) participants owned VAT, 166 of them used their VAT device and a further 52/ 166 (31%) participants reported using VAT to help with their Parkinson's. Of the 166 participants, 55% never or only sometimes had to repeat themselves when using VAT. When asked about speech changes since using VAT, as many as 25% noticed that VAT asked them to repeat less when compared to when they started using it and 15% noticed that their speech was clearer. Of the 290 respondents almost 91% were not concerned or only slightly concerned about privacy and confidentiality.

Discussion

Principle Findings

The purpose of this study was to understand the attitudes and experience of PwP towards VAT and to investigate their digital capability. Specifically, we were interested in any reported changes to speech and language through the use of VAT. We found that the majority of respondents reported change in their speech or voice due to Parkinson's with almost 80% indicating this symptom. Interestingly a large proportion (71%) of participants owned VAT, with almost a third using VAT to help with Parkinson's symptoms. Of particular interest is that a quarter of participants using VAT reported that it asks them to repeat less since they started using it.

The participants in this study could be considered representative of PwP, in agreement with other studies, by the proportion experiencing speech changes and the nature of their symptoms [11]. On average they reported a moderate voice impairment as measured by the VHI [29], emphasizing the impact on quality of life and supporting the need to explore solutions. The top rated items in the VHI indicate issues with volume, clarity and predictability of voice, all of which may be a challenge when communicating with VAT, however recent studies have found that participants report putting in extra effort to optimize their speech when interacting with the device [26]; [24]. Future research is needed to fully explore the impact of VAT usage on speech in Parkinson's.

This survey explored digital skills, capabilities, and found the majority of respondents were capable of completing most of the basic digital skills. The task which the least respondents indicated they could complete was creating something new from existing online images, music, or video. Nevertheless, a task of this nature is beyond the complexity of VAT interaction. Overall, this level of basic digital skills, technology familiarity, usage, and ownership, indicate a community in which the majority are actively embracing technology. Similarly, high rates of ownership and adoption of technology with older adults were found in a recent study [33]. This is a welcome result for technology developers, as this ultimately reduces the barriers to uptake of novel solutions for the Parkinson's community, whom our findings have indicated as digitally capable.

Results from this survey provide a positive outlook towards the knowledge and experience of existing VAT, with a high level of ownership and usage, showing a readiness to engage with new technology. There were similar findings in a study exploring the internet of things for support in PwP [26]. The accessibility features of voice activation for individuals who may be experiencing manual dexterity difficulties could be contributing to this positive attitude amongst PwP [26]. However, we do need to be cautious in our interpretation as this self-selecting group may have responded because of their familiarity with VAT.

Respondents were asked how they obtained their VAT. A very small proportion (2.9%) of respondents indicated that they were recommended such technology by a healthcare professional, suggesting that an increased evidence base with regards to the potential benefits of VAT for PwP, combined with closer communication with healthcare professionals, may be required. Future research should consider the current knowledge and experience of speech and language therapists of using VAT.

Almost a third of our participants used VAT to help with their Parkinson's symptoms. A small number of these reported that VAT had helped them to successfully practice their speech, by concentrating on increasing their volume or clarity as to be understood by the device, which is similar to findings from other recent papers [24]- [26]. It is important to recognize that there may be a misconception that VAT is not an option for PwP who experience speech changes, yet VAT is offering some participants the encouragement to speak slower and louder. Perhaps the opportunity for unlimited attempts, with clear indicators of success and the absence of frustration from a communication partner makes this technology an attractive option. Such preliminary positive findings indicate the need for further research into how VAT can work for people with speech difficulties, as well as support and perhaps improve speech difficulties in PwP.

Participants using VAT were asked about speech changes as a result of using this technology. A quarter of those respondents experiencing speech changes noted that the VAT asked them to repeat themselves less than when they began using the technology. This suggests that out-of-the-box VAT use may actually improve speech. Whilst we need to be cautious in this interpretation—it is possible that there are other reasons for being asked to repeat less: increased familiarity with the technology, increased awareness of the most reliable voice commands, the VAT can improve voice recognition rather than speech improving—this finding warrants further research.

One note of caution is that 9.3% of respondents with speech changes indicated a decrease in confidence in their speech since using VAT. It is not certain that this decline in confidence is a direct result of VAT rather than a progression of Parkinson's, however, this result brings to light the possibility that repeated unsuccessful engagement with VAT may be detrimental to confidence, and that usage by PwP should be monitored, particularly in the early stages of use. Coyne et al (2017) found that users were frustrated when VAT didn't understand their voice due to speech impairments [24]. Future work should ensure that speech recognition can be as accurate as possible

for individual speakers with speech impairments to ensure that their confidence is strengthened and not eroded.

Nevertheless, a notable portion of respondents with speech changes did indicate that they felt their voice was clearer (14.8%), louder (13.0%), that their confidence in speech had increased (13.9%) and that other people ask them to repeat themselves less than when they started using the technology (10.2%). Whilst these changes were noticed by a minority of respondents, they do provide some promise that VAT may provide therapeutic benefit to PwP. It is interesting to consider the possibility that speech improvements reported by participants were experienced beyond the voice interaction with VAT. It is widely recognized that there are problems for PwP with maintenance and generalization of speech improvements from therapy tasks into everyday contexts [34]. The potential for VAT to improve social participation warrants further investigation.

Privacy and confidentiality concerns with VAT are a current topic of significant discussion within the media and academia [35]. The results from our survey indicate that the majority of respondents were not seriously concerned with regards to privacy and confidentiality. However, over one third of respondents did have slight concerns, and 9.3% were very concerned. Specific concerns were around the potential for hacking, misuse of personal data and surveillance potential. This prevalence of concern is similar to that found in another study, in which 7% of participants reported privacy concerns as a reason for not using such devices and concluded that these concerns influence likelihood to use the device and trust in commercial companies [36]. Interestingly, research has found that individuals might be more likely to share data for the benefit for their care and others [26], [37] . In order to maximize the uptake of these technologies, and benefit from the immense potential offered for patients' health, further efforts must be made to reassure, promote clear privacy-friendly default settings in companies and educate potential users about privacy and confidentiality concerns.

Limitations

The survey was advertised and distributed electronically. Therefore, it is logical to assume that respondents primarily consisted of self-selecting PwP who are already actively engaging with technology. Nevertheless, this method of distribution facilitated the collection of a higher number of responses than would have otherwise been possible. Another potential limitation with this study is that there is the possibility that PwP who are familiar with VAT may have been more likely to engage with the survey than those who have no experience with VAT. This is a limitation of any survey which focuses on a particular subject.

Conclusions

Many PwP recognize that they are experiencing voice and speech changes due to their condition. This group of participants report some promising effects on their speech symptoms when using VAT, however this needs further investigation. This is the first study to systematically explore

experiences of using VAT by people with speech difficulties. The next step will be to investigate Speech and Language Therapists' current professional use of VAT and to consider their professional opinion of VAT as a potential useful support for speech improvement. More research is needed to trial out-of-the-box VAT for speech and communication difficulties in PwP and explore the potential generalization effects that might occur in other non-technology mediated speaking contexts.

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Conflicts of Interest

None declared.

Abbreviations

PwPD: People diagnosed with Parkinson's Disease
SLT: Speech and Language Therapy
LSVT®: Lee Silverman Voice Treatment
VAT: Voice assisted technology
PPI: Public and patient involvement
VHI: Voice handicap index

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