

# Assistive technology in everyday living – A user survey of people with Parkinson’s disease

Joanna A. Muras<sup>a</sup>, Emma K. Stokes<sup>b,\*</sup> and Vinny Cahill<sup>a</sup>

<sup>a</sup>*Distributed Systems Group, Department of Computer Science, Trinity College Dublin, Ireland*

<sup>b</sup>*Department of Physiotherapy, School of Medicine, Trinity College Dublin, Ireland*

**Abstract.** The aim of this study was to explore the individual circumstances of people with Parkinson’s disease, as well as their ideas and opinions about assistive technology that may be used for daily living. A self-reported, user survey was designed. The results of the study were derived from a postal survey of randomly chosen members of the Parkinson’s Association of Ireland. Analysis was conducted on data from 59 people. According to the survey results the majority of the participants reported problems with mobility (88%), fatigue (54%), and getting tired fast (70%). Problems with mobility included changing location (59%) and body position (51%–53%). Thirty four and twenty five percent of respondents described their physical strength and flexibility, respectively, as ‘poor’ or ‘very poor’. For 81% of participants it was important to be able to contact someone in a case of a fall. The results of this study indicate a possible underutilisation of assistive technologies and technology by people with Parkinson’s disease. In addition, the study identifies areas in which there is a demand for assistive technologies.

**Keywords:** Physical difficulties, mobility, activities of daily living, fatigue, Parkinson’s disease, self-reported survey

## 1. Introduction

Parkinson’s disease (PD) is one of the most common neurodegenerative disorders [5]. Its symptoms include tremor, rigidity, gait disturbances and postural instability. Impairment of these functions influences the performance of everyday tasks and decreases quality of life [9]. PD progresses over time and only its symptoms can be treated [17]. To date there is no treatment for the disease itself. Currently the most effective method of minimising the impact of PD is pharmacological treatment with some surgical options also being available [23]. However, different types of treatments such as physiotherapy and occupational therapy, can be also beneficial for people with PD and improve their quality of life [8,15,21].

To increase independence in daily living, in parallel to the treatments mentioned above, assistive tech-

nology (AT) may be used. AT is ‘any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customised that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities’ [1]. Traditionally AT has enabled people to remain independent longer and reduce the cost of their healthcare as well as the burden for their caregivers [20]. Due to significant technological developments, AT has the possibility of empower users through information about their condition e.g. insulin pumps, and other technologies to measure biological parameters. In addition, AT can be used to support people in their environments and ultimately AT can augment assisted living [12,16]. Other emerging technologies such as robotics are useful in mediating exercise interventions in people with neurological disability [7,11].

The range and variety of AT being developed and researched as well as those commercially available is growing. To date, knowledge about the use of AT by people with PD is limited [19]. In addition, to design and manufacture AT to support people with PD requires an identification of their needs. To this end,

---

\*Address for correspondence: Dr. Emma K. Stokes, Department of Physiotherapy, Trinity Centre for Health Sciences, St. James’s Hospital, Dublin 8, Ireland. Tel.: +353 1 8962127; Fax: +353 1 4531915; E-mail: estokes@tcd.ie.

this study engaged the user community to investigate their problems and AT used or perceived to be relevant in everyday living.

## 2. Method

This study employed a self-reported user survey methodology. The study was approved by the Research Ethics Committee, Trinity College Dublin.

### 2.1. Survey instrument design

The phase prior to the design of the user survey involved a systematic review of the literature to establish what AT may be available for use by people with PD. Articles for the review were compiled from a number of sources. Searches were performed in the databases of PUBMED, CINAHL, AMED, ScienceDirect and ACM Digital Library. AT databases were also reviewed and included ABLEDATA,<sup>1</sup> assistivetech.net,<sup>2</sup> assistireland.ie,<sup>3</sup> and Microsoft Accessibility.<sup>4</sup> This information in conjunction with the clinical experience of one of the researchers (ES) was employed to design the first version of the user survey. The World Health Organisation International Classification of Functioning, Disability and Health (ICF) provided a framework for describing activities and participation within the survey instrument i.e. mobility, activities of daily living etc. [25]. The initial version of the user survey was revised based on feedback from physiotherapists and occupational therapists working with people who have PD and further pilot studies of the survey instrument were conducted with people with neurological disorders from the Irish Wheelchair Association (IWA).<sup>5</sup>

### 2.2. User survey

The first part of the user survey consisted of a questionnaire to be completed by the person with PD and it aimed to explore participants' individual circumstances and their views on the AT that they use for daily living. The questionnaire consisted of single and multiple-choice questions and Likert rating scales. This first part of the survey was designed to gather general informa-

tion about the participants, e.g. age, gender, diagnosis and place of living, as well as more specific information about difficulties in daily living and the types and usability of AT used during specified activities of daily living.

The second part of the user survey aimed to explore participants' ideas and opinions about AT and their features. This part of the questionnaire consisted of open-ended questions only. This approach enabled participants to give more details about their views and experience.

### 2.3. Data collection

A survey of people with PD was conducted by post. The following inclusion criteria were used: (1) diagnosis of PD; (2) ability to fill out the questionnaire independently; (3) age 18 or over. One hundred survey sets were delivered to a support group for people with PD (PALS),<sup>6</sup> which is a branch of the Parkinson's Association of Ireland, where they were sent to 100 out of 200 PALS members all over Ireland. Address labels were chosen at random, therefore participants recruited ranged from newly diagnosed to these with Advanced disease. Each survey set contained information about the purpose of the research, a consent form, and the questionnaire as well as a stamped envelope with return Address to facilitate and encourage participants to fill out the questionnaire and send it back. The overall response rate during the data collection period (August, 2006 – November, 2006) was 59%.

### 2.4. Analysis of data

Quantitative data were coded and inputted into Excel where descriptive statistics were computed, Chi-squared and Fisher's Exact tests were employed to consider the relationships between categorical data. The qualitative data was reviewed by two researchers independently. Responses to open questions were reviewed by two researchers independently. They were categorised and themed separately and any disagreement between the categories of answers was resolved by discussion.

<sup>1</sup><http://www.abledata.com>.

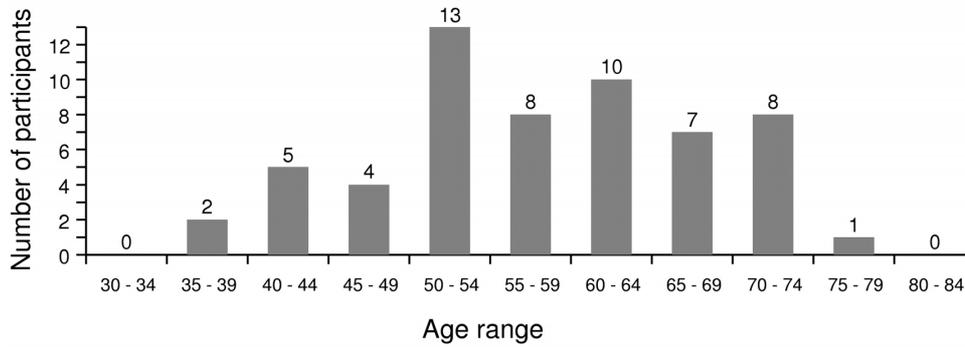
<sup>2</sup><http://assistivetech.net>.

<sup>3</sup><http://www.assistireland.ie>.

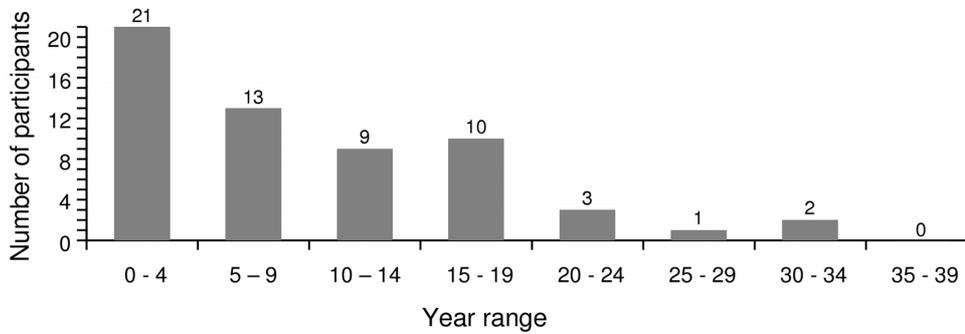
<sup>4</sup><http://www.microsoft.com/enable/at/>.

<sup>5</sup><http://www.iwa.ie>.

<sup>6</sup><http://gofree.indigo.ie/~pdpals/>.



(a) Participants' age



(b) Disease duration

Fig. 1. Distribution of participants' age and their disease duration.

### 3. Results

#### 3.1. General characteristics

A total of 59 (25 men and 34 women) people with PD participated in the study. One person failed to report the year in which they were born and for that reason data from 58 subjects was used for characterisation of the participants' age, age of diagnosis and duration of disease. The mean participants' age was 58 years (range 35–77 years; SD ±10 years), mean age of diagnosis was 49 years (range 20–67 years; SD ±11 years) and mean time since diagnosis of PD was nine years (range 1–33 years; SD ±8 years). The distribution of participants' ages is illustrated in Fig. 1(a) and time of disease duration is illustrated in Fig. 1(b).

Half (51%) of the 59 respondents lived with their spouse or partner, a small proportion (7%) lived with their children only, and almost a quarter (24%) lived with their spouse/partner as well as their children. The rest of the participants lived alone (12%) or with other people including parents and siblings.

#### 3.2. Limitations, functions, and activity restrictions

##### 3.2.1. Self-reported condition

In Table 1 self-reported ratings of participants' memory, vision, hearing, quality of speech and physical condition are illustrated. The functions and senses listed above were ordered from the highest rated (on top) to the lowest. Hearing, memory, and vision were the highest-rated. The lowest-rated functions were flexibility, quality of speech, and physical strength. A quarter (25%) of the participants rated their flexibility as 'poor' or 'very poor'. The term 'flexibility' was used in this survey as opposed to the rigidity associated with PD as this is a commonly used lay term that incorporates both the rigidity that may be experienced by people with PD and general flexibility. The pilot revealed no difficulties with the use of this term. Quality of speech was reported as 'poor' or 'very poor' by 27% of the respondents. Physical strength was reported as the most common problem. One third (34%) of the respondents reported it as 'poor' or 'very poor' and only one fifth (19%) as 'very good' or 'excellent'.

Table 1  
Overall self-reported ratings of participants' condition

Function or sense	Excellent	Very good	Good	Poor	Very poor
Hearing	15%	27%	47%	8%	2%
Memory	12%	32%	37%	19%	0%
Vision	9%	22%	53%	16%	0%
Coordination	2%	18%	61%	18%	2%
Flexibility	4%	19%	53%	23%	2%
Quality of speech	7%	19%	47%	27%	0%
Physical strength	5%	14%	47%	32%	2%

Table 2  
Management of self-care tasks

Task	Eating/drinking	Using bathroom	Washing	Dressing
Managed without difficulty	69%	66%	64%	53%
Managed with difficulty	24%	21%	26%	25%
Assistive device used	2%	3%	2%	2%
Help needed occasionally	5%	7%	3%	19%
Help needed all the time	0%	3%	5%	2%

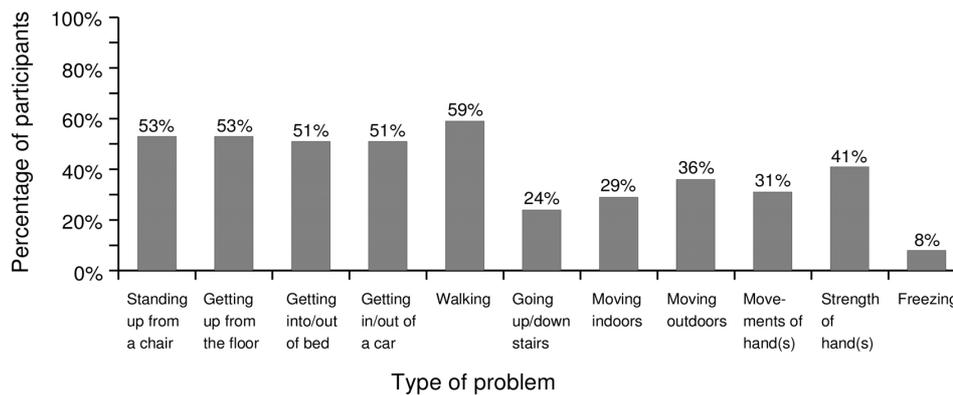


Fig. 2. Problems with mobility.

### 3.2.2. Mobility

Only 12% of 59 respondents reported that they did not have any problems with changing body position and transferring from one place to another. Problems noted by the other respondents (88%) are illustrated in Fig. 2. More men (92%) than women (85%) reported problems with mobility. The most common problem for both genders was walking and the majority of the respondents (59%) found it difficult. Half of them (51%–53%) had problems with changing body position including standing up from a chair, getting up from the floor, getting into/out of bed, and transferring in/out of a car. Thirty six percent of the respondents had problems with moving outdoors and they were more common than difficulties with moving indoors (29%). Going up/down the stairs was a difficult task for a quarter (24%) of the participants. A few respondents (8%) reported 'freezing' as a problem in daily living. Strength

of the hand(s) was a problem for 41% of the respondents and hand movements were reported as a difficulty by one third (31%) of them.

### 3.2.3. Tasks of self-care

As reported in Table 2, two thirds of the participants (64%–69%) said that they did not have any difficulties with most self-care tasks and were able to do them without any ATs. These tasks included going to the bathroom, washing, and eating or drinking. A quarter (21%–26%) found tasks of self-care difficult or needed more time to accomplish them but still managed on their own. Dressing rather than the tasks mentioned above was the most common problem with one fifth (19%) of the respondents needing help from their caregivers. Only two to three percent of the respondents used an AT.

Table 3  
Management of household tasks

Task	Washing up	Prepare meals	Clean house	Carry objects	Laundry	Shopping
Managed without difficulty	63%	44%	45%	42%	50%	49%
Managed with difficulty	18%	23%	19%	16%	11%	12%
Assistive device used	4%	0%	0%	0%	2%	0%
Help needed occasionally	7%	16%	12%	19%	11%	4%
Help needed all the time	2%	11%	14%	14%	16%	25%
Not managed	7%	7%	10%	9%	11%	11%

Table 4  
Management of self-care tasks depending on condition

Problems with	Task	Eating/drinking	Using bathroom	Washing	Dressing	Number of participants
Flexibility and strength	Managed without difficulty	1	2	1	0	9
	Managed with difficulty	6	4	7	4	
	Assistive device used	1	0	0	1	
	Help needed occasionally	1	2	0	3	
	Help needed all the time	0	1	1	1	
Strength	Managed without difficulty	6	7	7	4	8
	Managed with difficulty	2	1	1	2	
	Assistive device used	0	0	0	0	
	Help needed occasionally	0	0	0	2	
	Help needed all the time	0	0	0	0	
Flexibility	Managed without difficulty	2	1	2	1	4
	Managed with difficulty	1	0	0	2	
	Assistive device used	0	2	1	0	
	Help needed occasionally	1	0	0	1	
	Help needed all the time	0	1	1	0	

### 3.2.4. Household tasks

In Table 3, participants' problems with household tasks are illustrated. A minority of subjects had problems with washing up and preparing meals. Sixty three and forty four percent of survey respondents, respectively, managed to do the tasks listed above without difficulty. Eighteen and twenty three percent, respectively, experienced some difficulties but still could manage on their own. Nine to eighteen percent of survey respondents could not do them or needed the help of other people all the time. Sixty three percent of the subjects reported that they did not have any problems with doing washing up. More respondents had difficulties with preparing meals. Forty four percent could do it on their own without any problems, 16% occasionally needed other people to help them, and 7% could not do the task at all. The most common, according to the survey respondents, were difficulties with doing shopping, carrying objects, and doing laundry. Fifty-eight to sixty-one percent of the participants could complete these tasks on their own and 23%–36% could not do them or needed assistance all the time. Cleaning the house was also a significant problem among the survey respondents and a quarter (24%) of the participants could not manage it. More respondents, in general, found household tasks more difficult than tasks of self-

care. Less than five percent of subjects always needed other people's help with self-care tasks, in comparison to 9%–36% of participants who needed another's help all the time or could not do household tasks at all.

### 3.2.5. Physical strength and flexibility

Thirty three and twenty five percent of the survey participants, respectively, reported their physical strength and flexibility as 'poor' or 'very poor'. Table 4 illustrates the relationship between physical strength, flexibility and number of people who had problems with self-care tasks. All eight subjects who reported problems with physical strength but not flexibility could manage self-care tasks such as eating/drinking, using bathroom, and washing on their own and without any use of AT, whereas some participants that reported problems with flexibility as well as those with a combination of flexibility and physical strength tended to use the help of other people to complete these tasks. As reported in Table 5, none of the participants who reported problems in both physical strength and flexibility could manage household tasks without any difficulty, whereas, some respondents with other conditions could do it. In addition, more people in this category could not complete household tasks at all.

Table 5  
Management of household tasks depending on condition

Problems with	Task	Washing up	Prepare meals	Clean house	Carry objects	Laundry	Shopping	Number of participants
Flexibility and strength	Managed without difficulty	0	0	0	0	0	0	9
	Managed with difficulty	3	3	4	1	2	1	
	Assistive device used	2	0	0	0	1	0	
	Help needed occasionally	2	3	2	1	2	0	
	Help needed all the time	0	2	0	3	0	4	
Strength	Not managed	2	1	3	4	3	3	8
	Managed without difficulty	4	2	2	1	3	2	
	Managed with difficulty	2	2	1	2	0	1	
	Assistive device used	0	0	0	0	0	0	
	Help needed occasionally	0	0	1	3	1	1	
Flexibility	Help needed all the time	1	3	3	1	3	3	4
	Not managed	0	0	0	0	0	0	
	Managed without difficulty	3	2	1	1	1	1	
	Managed with difficulty	0	0	0	0	0	0	
	Assistive device used	0	0	0	0	0	0	
	Help needed occasionally	0	1	1	1	1	0	
	Help needed all the time	0	0	1	1	1	2	
	Not managed	1	1	1	1	1	1	

Table 6  
Problems with mobility depending on condition

Problems with	Strength and flexibility	Strength	Flexibility
Standing up from a chair	7	5	4
Getting up from a floor	7	4	4
Getting into/out of bed	8	4	4
Transferring in/out of a car	6	3	3
Walking	7	4	4
Going up/down stairs	3	0	3
Moving indoors	5	1	2
Moving outdoors	4	1	4
Movements of hand(s)	5	1	2
Strength of hand(s)	5	1	2
Number of participants	9	8	4

As illustrated in Table 6, most respondents who reported problems with flexibility but not physical strength ( $n = 4$ ) had also problems with mobility. Fewer participants who reported problems with physical strength only ( $n = 8$ ) had problems with changing body position or moving around in comparison to other groups. A statistical analysis of the relationships between users' ratings and tasks of self-care, household tasks, and problems with mobility was not noted.

### 3.2.6. Fatigue and tiredness

A common problem among the participants was fatigue and getting tired fast. As reported in Table 7, 36% of the subjects said that they had ongoing fatigue 'frequently' and 18% declared it 'all the time'. More participants reported getting tired fast. 58% of the subjects got tired fast 'frequently' and 12% 'all the time'. For the purpose of analysis purposes we assumed that

Table 7  
Problems with getting tired and fatigue

Condition	Never	Rarely	Frequently	Always
I get tired fast	14%	16%	58%	12%
I have ongoing fatigue	33%	13%	36%	18%

Table 8  
Number of participants who reported tiring fast in relation to fatigue

Condition	I have ongoing fatigue	I do not have ongoing fatigue
I get tired fast	29	9
I do not get tired fast	0	16

participants had some condition (fatigue/tiredness) if they reported it 'always' or 'frequently'. As illustrated in Table 8, all participants who reported ongoing fatigue reported also getting tired fast. However, not all participants who reported getting tired fast reported also ongoing fatigue.

Table 9  
Percentage of participants who had problems with mobility

Condition	I have ongoing fatigue	I do not have ongoing fatigue
I get tired fast	93%	78%
I do not get tired fast	N/A	81%

As reported in Table 9, problems with mobility (78%–83%) did not tend to depend on participants' condition; however more respondents with ongoing fatigue reported using AT or assistance of other people for mobility (48%) than the subjects who did not report ongoing fatigue (28%).

A significant difference was noted in the relationship between those reporting 'getting tired fast' and the presence or absence of ongoing fatigue – all those who reported ongoing fatigue also reported getting tired easily whereas only 1/3 of those who did not have ongoing fatigue reported tiring quickly (X-square 26.37,  $p = 0.000$ ). This did not differ across gender.

Categories of assistance and fatigue were collapsed to yield a  $2 \times 2$  table, presence/absence of ongoing fatigue and independent/require assistance. No significant relationships were noted between fatigue and the use of assistance in the following tasks of self-care were noted – going to the bathroom, washing or dressing. However, for eating/drinking, those who reported not requiring assistance reported ongoing fatigue in significantly greater numbers ( $p = 0.002$ ).

Seventy per cent of respondents who reported that they were independent in preparing meals also reported ongoing fatigue, whereas 76% of those who sought assistance did not report ongoing fatigue ( $p = 0.002$ ), these results i.e. more fatigue is those not using assistance are consistent for all other household tasks except paying the bills – doing laundry ( $p = 0.004$ ), doing shopping ( $p = 0.002$ ) and carrying objects ( $p = 0.000$ ), washing up ( $p = 0.02$ ), house cleaning ( $p = 0.01$ ).

### 3.3. Assistive technologies

#### 3.3.1. AT in self-care and household tasks

As illustrated in Tables 2 and 3 only a few participants (up to two per task) used AT to help themselves in self-care or household tasks. Because the use of only very few AT was reported it is difficult to derive any conclusions about their usage. However, rather than AT, the survey respondents (5%–33%) used the assistance of other people to help them in activities of daily living.

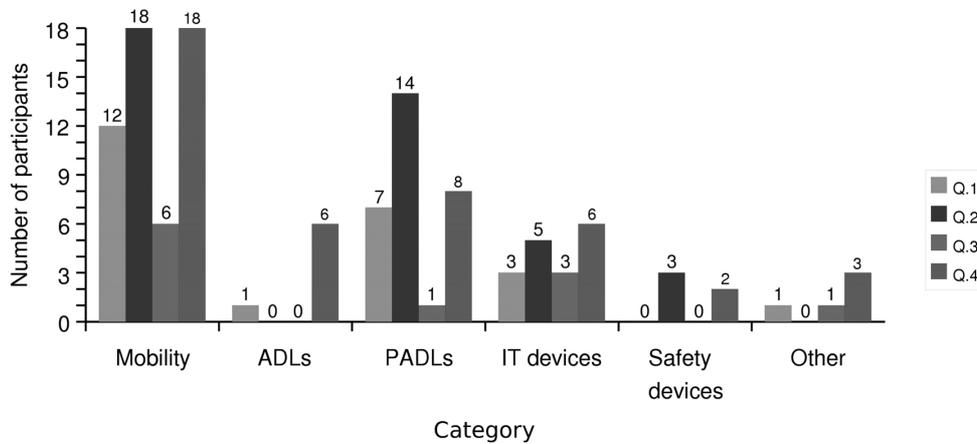
#### 3.3.2. Mobility aids

More than one third (39%) of the 59 survey respondents said that they used assistance for mobility. As reported before, more men (92%) than women (85%) tended to have problems with mobility and it may be for that reason that more men (44%) than women (35%) used assistance for mobility. The most popular form of assistance was a cane (19%). Twelve to fifteen percent of the subjects used other people's help, walkers, and manual wheelchairs. Only a few of them (2%–7%) used other AT to move around. These included tripods, crutches, scooters and AT to transfer in/out of bed. There was a difference in use of wheelchairs depending on gender. More women used manual (18%) as well as powered wheelchairs (6%) compared to four and zero percent of men, respectively.

#### 3.3.3. Memory aids

One third (34%) of the 53 participants who answered the question said that they used an AT to help their memory. Of note was that 54% of 59 respondents reported problems with their memory. The most common problem was the remembering names of people (42%). Less than one third of the respondents (29%) could not remember the location of the objects and less than one quarter had problems with remembering what they did yesterday (20%) and last week (24%). Seventeen percent of the participants reported that they found it hard to remember about medication intake and 12% could not remember the names of objects. Few people mentioned that they were forgetting to eat their meals (7%) and did not remember other people's faces (3%). The most common memory aids were paper notebooks (19%) and mobile phones (15%). The majority of their users (19%–21%) found them 'very helpful' or 'helpful'. 13% of the participants used an alarm clock or timer to remind them about scheduled tasks or appointments. Four percent of them found this kind of memory aid 'helpful' and nine percent 'very helpful'. The most common reason for not using AT to help memory was 'no need to use them' and 53% of all participants responded in this way. Some of the participants responded that they did not have sufficient information about technologies to help their memory (15%) and 11% of them had never heard of such technologies.

In the survey the events about which respondents wanted to be reminded were investigated. The most commonly used memory aids were for scheduled appointments (30%) and taking medication (26%). One fifth (18%–21%) of the subjects used memory aids to remember shopping lists and things to do. Less than



ADLs = Activities of daily living  
 PADLs = Personal activities of daily living

Fig. 3. ATs reported in answers to open-ended questions.

half of the participants (41%–43%) reported that they did not use any assistance, but thought that a technology to remind them about things to do, medication and scheduled appointments could be useful. One third (33%–34%) said that reminders of the location of objects and how to do various activities could be useful for them.

#### 3.3.4. Personal alarms

The majority (89%) of the 54 subjects who answered the question did not use any personal alarms. The reasons reported were absence of perceived need (65%), lack of sufficient information about existing technologies (22%), and prohibitive cost of AT (2%). In addition, it was reported by participants that the technologies were too complicated to be used and there was a lack of sufficient education in their use (2%). A number of respondents used automatic phone calls (6%) and voice messages (2%) as personal alarms and found them helpful.

In the survey the importance of events for which an alarm should be triggered was also investigated. Most of the respondents (81%) said that it was 'very important' to them that someone was informed if they had fallen and could not get up. It was also 'very important' to 71% of the participants that their next of kin be contacted automatically if they have medical condition and need to contact someone but are unable. Only 14% of participants (18% of men and 12% of women) reported that it was not important to them for contact to be made with someone if they had a fall. Half of the participants (50%) considered alarms for

taking medication as very important to them and one fifth (20%) as not important at all.

#### 3.3.5. User perspective on AT

In the second part of the survey participants' opinions and ideas in relation to AT were investigated. This part consisted of open-ended questions, so that participants could state their opinion in more detail. The data was transcribed and reviewed independently by two researchers. After analysis, six main categories of ATs were identified and agreed between the researchers. They were mobility, activities of daily living (ADLs), personal activities of daily living (PADLs), information technology (IT) technologies, safety technologies and 'other'. Because of the variety of answers, some of the categories required a more in depth analysis and for a better description of participants' views additional sub-categories were defined. 'Mobility' includes technologies to assist in transfer from one place or position to another and doing exercises. 'ADLs' included home-care skills while 'PADLs' describe self-care skills including taking medication, dressing and using bathroom. 'Safety technologies' include personal alarms and all technologies supporting safety of their users and the IT category include technologies addressing problems with using a computer. AT mentioned in answers to all four questions included in this part of the survey are depicted in Fig. 3 and described in more detail in next part of this section.

The aim of the first question was to obtain opinions about AT that the respondents did not like. Nineteen participants answered this question and identified 24

technologies that they did not like. Half of the technologies ( $n = 12$ ) were designed for assistance in mobility. They included bike for exercises, technologies for transferring in/out of bed ( $n = 2$ ) and from one place to another ( $n = 4$ ), e.g. wheelchairs, as well as aids for walking ( $n = 5$ ), e.g. a walking frame or a cane. Seven technologies to help in PADLs were mentioned. They included technologies installed in bathrooms ( $n = 5$ ), e.g. bath lift or a grab rail for a shower, and aids in dressing ( $n = 2$ ), e.g. putting on trousers or tights. The rest of the technologies reported by participants included those to help in ADLs ( $n = 1$ ), using computer ( $n = 3$ ), e.g. speech recognition software, and other ( $n = 1$ ). There were two reasons why the technologies were disliked. The first was insufficient utility of the technologies ( $n = 6$ ). The second reason was pride and the fact that a person using a particular technology did not want other people to think that they are disabled ( $n = 2$ ).

*'A cane which I don't like using – as it labels me, also it is not very effective (causes embarrassment)'*  
(Participant no. 35).

The next question was about AT and their features that were liked and whether the respondents considered them helpful. Twenty seven participants identified technologies that were, in their opinion, useful. Eighteen of forty technologies mentioned in this question addressed problems with mobility including technologies for transferring in/out of bed ( $n = 3$ ), e.g. hand grabs and from one place to another ( $n = 3$ ), special chairs ( $n = 5$ ), e.g. rise recliner, as well as aids for walking ( $n = 6$ ). The respondents identified 14 technologies that were useful in doing their PADLs. They were used for dressing ( $n = 4$ ), taking medication ( $n = 6$ ), e.g. pill box, or installed in bathroom ( $n = 4$ ), e.g. bath seat. Three people said that they found safety technologies, e.g. personal alarms, useful and five reported aids that helped them using computer very helpful. The respondents identified ATs in general rather than their specific helpful features. One person mentioned that it was useful to have information about 'gadgets' available.

Eleven participants answered the question investigating the improvement of technologies to make them more useful. They suggested ten technologies that could be improved. Most ideas were reported for assistance in mobility ( $n = 6$ ). They included size and weight reduction of wheelchairs as well as their battery performance (prevention of sudden discharge and longer life time). There were only a few improvement

demands for walkers ( $n = 1$ ), chairs ( $n = 1$ ), and getting in/out of bed technologies ( $n = 1$ ). Three improvements for assistance in using a computer were reported. They included perfecting software, large keypads, and voice activated computer programmes.

*'Could speech recognition software be perfected to cope with difficulties of speech in PD?'* (Participant no. 34).

One improvement for bath equipment was proposed. Two participants said that it would be useful to have better information and training on how to use technologies.

In the last question potential technologies that would be useful for participants were investigated. Twenty nine respondents answered this question and reported 43 ATs. Most technologies ( $n = 18$ ) were to help in mobility. They included technologies for changing body position ( $n = 9$ ), transferring from one place to another ( $n = 8$ ), and doing exercises ( $n = 1$ ). Participants also thought that it would be helpful to use ATs for PADLs ( $n = 8$ ). PADLs included dressing ( $n = 2$ ), e.g. putting on socks, bath equipment ( $n = 2$ ), and medication intake ( $n = 4$ ). Support in ADLs was reported useful by six respondents and included, e.g. aids for writing, *'any to aid/improve my writing'* (Participant no. 15) or opening jars. Personal alarms were considered to be useful for two participants and six of them would be pleased to use electronic technologies like laptop or PDA and computer improvements, e.g. *'something to steady the mouse'* (Participant no. 17). Three other technologies including vibrating massager, glasses for double vision, and technology to reduce tremor, *'some mechanical technology to reduce tremor in hands and arms'* (Participant no. 44), were mentioned. There was also need for information about technologies ( $n = 2$ ).

## 4. Discussion

### 4.1. Sample representation

The physical limitations reported by respondents in this survey are consistent with commonly reported problems for people with PD [17] and not unexpected given the age range and duration of disease reported by participants. Mobility issues, gait disturbance, falls and fatigue are all reported as a common problems among people with PD affecting many areas of daily living [2, 6,9,24]. The results of the study show that fatigue was

the most frequent problem for the survey respondents. Over half of the participants (54%) suffered from it frequently or all the time and 70% reported that they get tired fast often or all the time. This is consistent with the findings of Herlofsen and Larsen [10] that reported that 50% of people with PD participating their study had fatigue.

#### 4.2. Assistive technologies

The purpose of the study was to investigate the use of AT among people with Parkinson's disease and their opinions about them. This has been not reported to date. In general, the survey respondents did not use many ATs. Only a few participants ( $n = 5$ ) reported the use of ATs to help themselves in tasks of self-care and household tasks. In both kinds of task the assistance of other people was more commonly used than ATs and depending on the task, up to 20% and 33% of the survey respondents used the assistance of others in self-care and household tasks, respectively. The reason why ATs were not commonly used may be explained by the level of independence reported by the participants. As reported in previous sections over 60% of them could perform self-care and household tasks on their own independently. However, it is interesting to note that many more respondents used the assistance of other people to undertake such activities rather than using ATs. Low utilisation of ATs could be caused by several factors. These include lack of knowledge of existing technologies and the fact that some activities are not performed very often and there is no need for the participants to do them on their own. Another factor could be inappropriate design of ATs, which was reported by some participants in the open-ended part of the questionnaire. While it is not possible to draw a 'cause and effect' relationship, it is notable that those who reported not using assistance for certain tasks of daily living a higher incidence of ongoing fatigue.

In the case of mobility a higher proportion of participants made use of ATs compared to the assistance of other people. Of note is that most of the technologies used by the survey participants were rather simple mechanical technologies and did not involve advanced computer technology. Over half of the participants (56%) used technologies such as canes or walkers and only five percent used automated technologies such as powered wheelchairs. The reason for the common use of technologies to improve mobility could be, as reported before, that most of the participants had mobility constraints and the technologies mentioned above

could greatly improve their independence and quality of life. Changing location or body position are activities that humans tend to perform very often and it is desirable for them to be performed independently. The reported use of simple mechanical technologies may be because they are widely available, commonly prescribed by Healthcare Professionals, and relatively inexpensive.

Despite the possibility that people affected by PD might suffer from cognitive impairment [14], to date there have been no 'definitive studies' of memory aids for them [3]. These survey results show that 60% of the respondents, who did not use memory aids, reported lack of sufficient information about ATs for memory support as well as difficulties in their use. This indicates that they may not realise what useful technology is available or the utility of existing technologies may not meet the needs of people with PD. In addition, 41%–43% of participants said that even though they did not use currently any technologies to help their memory they noted that such technologies could be useful for them to support tasks such as scheduling appointments (41%), taking medication (42%), and 'things to do' (43%). In comparison, only 27% of the respondents, who did not use personal alarms, reported lack of sufficient information about them as well as difficulties in their use as a factor. A small proportion (up to 15%) used ATs to help themselves in activities such as medication management or gait monitoring, however, 51%–53% of the respondents who did not use any of those technologies declared that they could be useful for them. Few of the survey participants used ATs to support other daily activities such as writing.

The survey analysis showed a perceived benefit in the use of ATs to support a variety of activities. Jutai et al. [13] noted a 'positive and strikingly similar' relationship between perceived and actual psychosocial impact of ATs to daily living in people with degenerative neuromuscular disease. This suggests that participants in our survey may be missing out on ATs that could possibly be very valuable to their independence and quality of life.

#### 4.3. Personal alarms and falls

Gait disturbances as well as muscle weakness with postural instability [2,24], which are common symptoms of Parkinson's disease, may lead to problems with balance and changing body position and potentially causing an increased risk of falls. The NICE guidelines [18] propose that older people who have sustained

an injurious fall should be informed of ways to cope should another fall occur. One way of minimising the impact of a fall is to prevent 'long-lie' [22]. 'Best practice', as outlined by NICE, is to summon help if unable to get up in order to avoid a long lie which itself can create further health problems, e.g. hypothermia. To minimise a long-lie personal alarms that provide a communication link between the person who has fallen and their caregiver can be useful. The survey results show that for the majority (81%) of the participants it is very important to contact someone in a case of a fall for which the participant is unable to get up. However, the majority of the survey respondents (89%) did not use any personal alarms. The main reason given for that was absence of need (65%), which is an interesting fact considering that 81% of the participants were afraid that they would not be able to contact someone in case of emergency. More than one fifth (22%) of the subjects declared that they did not have sufficient information about existing technologies, a possible reason for their underutilisation.

## 5. Limitations

The response rate for this survey of 59% is consistent with mean response rates reported in medical journals [4] but the results should be interpreted in the context of a possible non-responder bias. While the sample size is small, the physical limitations described by participants suggest that the results may be generalised to people with PD in Ireland. In addition, the description of the sample of participants included people with a very recent diagnosis of PD and long-standing disease suggesting that it is a fair representation of people with PD. The survey instrument did not contain explicit cultural references which would preclude its use in other countries and cultures however one must consider that knowledge and availability of AT is informed by accessibility to AT which, in turn, may have socio-economic and political influences.

## 6. Conclusion

The limitations above notwithstanding, this survey is the first that explores the views and opinions of people with PD about AT. In light of current and future developments in the area of AT for people with disabilities, it provides an indicative set of opinions that can inform design and developments for people with PD. Engage-

ment by designers and researchers with the community of people with PD will ensure that user-centred assistive technologies become available. However, as the results suggest, there is a lack of knowledge about the availability of more advanced assistive technologies that may support people with PD even though many respondents considered that such supportive technologies would be of use to them. For that reason, information dissemination about existing technologies appears to be essential. Methods of informing people with PD about assistive technologies available should be improved which will lead to their broader use and improve independence and quality of life for people with PD in the future.

## Acknowledgement

This work is partially supported by a Trinity College Dublin/Science Foundation Ireland AOIP Ph.D. studentship for which the authors are grateful.

## References

- [1] The technology related assistance for individuals with disabilities act of 1988 (Public Law 100-407), 19 August 1988. 29 U.S.C. Sec. 3002(a)(2).
- [2] A.L. Adkin, J.S. Frank and M.S. Jog, Fear of falling and postural control in parkinson's disease, *Movement Disorders* **18**(5) (2003), 496–502.
- [3] K.E. Anderson, Dementia in parkinson's disease, *Current Treatment Options in Neurology* **6**(3) (May 2003), 201–207.
- [4] D.A. Asch, M.K. Jedrzejewski and N.A. Christakis, Response rates to mail surveys published in medical journals, *Journal of Clinical Epidemiology* **50**(10) (1997), 1129–1136.
- [5] Y. Ben-Shomo, F. finnan, S. Allwright and G.D. Smith, The epidemiology of parkinson's disease in the republic of ireland: observations from routine data sources, *Irish Medical Journal* **86**(6) (Nov. 1996), 190–194.
- [6] A. Chaudhuri and P.O. Behan, Fatigue and basal ganglia, *Journal of the Neurological Science* **179** (Oct. 2000), 34–42.
- [7] S. Coote, B. Murphy and E.K. Stokes, The effect of the GEN-TLE/s robot mediated therapy system on upper extremity dysfunction post stroke, *Clinical Rehabilitation* **22**(5) (2008), 395–405.
- [8] K.H.O. Deane, D. Jones, E.D. Playford, Y. Ben-Shlomo and C.E. Clarke, Physiotherapy versus placebo or no intervention in parkinson's disease, *Cochrane Database of Systematic Reviews* **3** (CD002817), 2001.
- [9] D.J. Gelb, E. Oliver and S. Gilman, Diagnostic criteria for parkinson disease, *Archives of Neurology* **56**(1) (Jan. 1999), 33–39.
- [10] K. Herlofson and J. Larsen, The influence of fatigue on health-related quality of life in patients with parkinson's disease, *Acta Neurol Scand* **107** (2003), 1–6.
- [11] M.K. Holden, Virtual environments for motor rehabilitation: Review, *Cyberpsy-Chology & Behavior* **8**(3) (2005), 187–211.

- [12] G.R. Johnson, R. Faragher, P. Gore, R. Orpwood, K. Schep and O. Toussaint, Full reports of the sector panels – Technology. In AGEACTION "Changing Expectations of Life", pages 89–104. Institute for Ageing and Health, Newcastle University, Apr. 2007.
- [13] J. Jutai, P. Rigby, S. Ryan and S. Stickel, Psychosocial impact of electronic aids to daily living, *Assistive Technology* **12**(2) (2000), 123–131.
- [14] Y. Kida, H. Tachibana, M. Takeda, H. Yoshikawa and T. Okita, Recognition memory for unfamiliar faces in parkinson's disease: Behavioral and electrophysiologic measures, *Parkinsonism and Related Disorders* **13**(3) (2007), 157–164.
- [15] C.B. Levine, K.R. Fahrback, A.D. Siderowf, R.P. Estok, V.M. Ludensky and S.D. Ross, Diagnosis and treatment of parkinson's disease: A systematic review of the literature. Evidence Report/Technology Assessment Number 57. (Prepared by Metaworks, Inc., under Contract No. 290-97-0016.) AHRQ Publication No. 03-E040. Rockville, MD: Agency for Healthcare Research and Quality, June 2003.
- [16] W.C. Mann, *Smart Technology for Aging, Disability and Independence: The State of the Science*. Wiley, July 2005.
- [17] National Collaborating Centre for Chronic Conditions. Parkinson's disease: national clinical guideline for diagnosis and management in primary and secondary care. London: Royal College of Physicians, 2006.
- [18] National Institute for Clinical Excellence (NICE). Clinical practice guideline for the assessment and prevention of falls in older people. Royal College of Nursing, Nov. 2004.
- [19] M. Roelands, P.V. Oost, A. Buysse and A. Depoorter, Awareness among community-dwelling elderly of assistive devices for mobility and self-care and attitudes towards their use, *Social Science & Medicine* **54** (2002), 1441–1451.
- [20] A. Schrag, A. Hovris, D. Morley, N. Quinn and M. Jahanshahi, Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability, *Parkinsonism & Related Disorders* **12** (2006), 35–41.
- [21] G.M. Schulz and M.K. Grant, Effects of speech therapy and pharmacologic and surgical treatments on voice and speech in parkinson's disease: A review of the literature, *Journal of Communication Disorders* **33** (2000), 59–88.
- [22] J. Simpson, R. Harrington and N. Marsh, Managing falls among elderly people, *Physiotherapy* **84** (1998), 173–177.
- [23] S. Thobois, F. Delamarre-Damier and P. Derkinderen, Treatment of motor dysfunction in parkinson's disease: an overview, *Clinical Neurology and Neurosurgery* **107** (2005), 269–281.
- [24] D. Wild, U.S. Nayak and B. Isaacs, How dangerous are falls in old people at home? *British Medical Journal* **282**(6260) (Jan. 1981), 266–268.
- [25] World Health Organisation (2001). International Classification of Functioning, Disability and Health: ICF. Geneva, Switzerland: WHO, 2001.