Designers and stroke research

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RESEARCH

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Abstract

Introduction
Stroke is a major cause of prolonged impairment in industrialized countries. Although healthcare studies suggest that relying on Assistive Products (AP), instead of personal help diminishes dysfunction and promotes independence, several authors alert to the problems of discontinuance in use or abandonment of AP.

Methods
A list of 42 Activities of Daily Living (ADL) was developed and applied, along with the Barthel Index, in personal interviews to 67 stroke patients so as to assess: patients' degree of capability in performing each task; types of help used; and how these aids were being used. Methods deriving from healthcare research were deployed alongside design research methods. This combination allowed for quantitative and qualitative data analysis.

Results
Data analysis shows that stroke patients do not use AP as intended in order to achieve independence, that there is a great lack of awareness about APs and that there are APs on the market that are not suited for stroke patients' use.

Conclusion
Our findings are consistent with healthcare literature on frequently used AP, but they add important data on *how* these are being used. Furthermore, we have identified feelings shared by the majority of patients concerning ADL performance, with *fear* as the overriding concern.

Statistics show that stroke is the most important cause for morbidity and prolonged impairment in Europe [1]. Official Portuguese numbers state that about 54% of stroke victims become dependent of others, even after the period of rehabilitation treatment is over [2]. Authors argue the benefits of using equipment help instead of personal help [3, 4]. Verbrugge, Rennert and Madans [5] state that using equipment alone, i.e. Assistive Products (AP) to perform Activities of Daily Living (ADL), enhances efficiency and reduces task demand, thus promoting independence, compared to people who mostly rely on personal help [6]. On the other hand, authors alert to the undesired phenomena of AP abandonment and discontinuance in use [7-9].

Even with the help of therapists and clinicians in choosing appropriate AP, some users remain reluctant to adopt AP. This reluctance may be related to psychosocial reasons instead of physical, usability and functionality reasons alone [10]. There has been a growing interest amongst the designers' community in creating AP which fulfil users' needs, expectations and emotions (for a description of these concerns in a wheelchair design see Desmet and Dijkhuis (2003) [10]); to achieve this, the design's methodologies for data gathering have proved their benefits, such as in the research conducted by Hirsch, Forlizzi et al. [11]. In the past few decades, researchers on design have proved the importance of emotions in the interaction with products [10-15]. Verbrugge, Rennert and Madans [5] have also discussed the fact that one of the challenges related to AP were to improve them at an aesthetic level.

Considering stroke patients, the lack of AP adoption and use might also be related to a high rate of post-stroke depression [16-21], since it affects patients' will and motivation to recovery [22, 23].

The inclusive design approach aims at responding to these problems, namely through fading away the encompassment of stigma [24]. There are many AP which are only needed for specific impairments, but there are also several daily living aids (e.g. aids for dressing or cooking) which, as noted by Pullin, could be designed so as to enable their way into general consumer goods [25]; ideally this would lead to this type of products starting to be seen as common and not being labelled as AP, which are often associated with disability [25].

Methodology

A cross-sectional research was conducted so as to assess stroke patients' degree of capability in ADL performance,

types of AP used and emotions related to AP use. In order to assess patients' degree of capability in performing ADL, a list of 42 ADL was developed, based and adapted from the work of authors in healthcare research [5, 26-28]. After intense research on existing AP, some ADL were added, for which the use of AP could be foreseen. Patients were to answer to their degree of capability in the last week considering each task, by means of one in five possible options: "Totally capable", "Capable with difficulty", "Capable with help", "Incapable" or "Does not know/Never tried". This would give a depiction of the ADL patients found easier and more difficult to perform. Also, the research aimed at addressing in which ADL patients made use of more assistance and what types of help were being used. Thus, whenever the response would fall into "Capable with help", patients were asked to refer to the type of help, i.e. personal, equipment or both, and to specify it (e.g. spouse + crutch).

So as to allow results' comparisons to those from healthcare research, the Barthel Index (BI) [29] - which is an index used to measure a person's daily functioning and degree of dependence - was applied to all patients. Personal and stroke data from each patient were also gathered. This was done with the help of healthcare professionals who agreed to take part in the study. Patients' recruitment was conducted through a local stroke association, a local social support centre, a centre for professional rehabilitation and 7 physical rehabilitation clinics. Patients were contacted by each of the entities involved, and after their agreement on taking part in the study they were approached by the researchers. All patients were given and read aloud an informed consent, which explained the aim of the study, guaranteed patients' privacy and allowed for interrupting the participation at any time.

Sixty-seven patients, all living in Northern Portugal, agreed to take part in the study and four patients refused to participate. From October 2008 to June 2009, 28 patients were interviewed at their private homes and 39 were interviewed at the clinics where they had been recruited. Interviews with the patients lasted from 15 minutes to 2 hours (interviews in patients' houses tended to last longer than those carried out in the clinics).

All patients' statements regarding feelings, emotions and expectations towards AP or task performance were transcribed for future text analysis.

Results
Demographics
Mean age of the participants was 68.55 (SD 11.374) and ranged from 39 to 91 years. The majority were women (n=41), retired (n=57) and married (n=47). Fifty-eight participants (86.6%) fell into the education cluster of 0 to 4 years of school attendance. For most patients, 36 or more months had passed since last stroke (56.7%). Sixty-three patients (94%) had gone under physical rehabilitation programs and 38 had left paresis (56.7%).

Degrees of capability

The degrees of evaluation included in the 42 ADL list presented significant correlation values with the BI, specially the "Incapable" and "Totally capable" items, as shown in Table 1. The "Incapable" degree registers the larger number of entries, followed by "Totally capable", and "Capable with help" appearing at third place. When filtering the results through Basic Activities of Daily Living (BADL) mentioned in the list – which consist in self-care activities such as bathing, dressing, toileting, transferring, continence and feeding [28] – , the results are slightly different, with "Totally capable" and "Capable with help" changing positions (Table 2). From the 42 ADL list, the activities most patients were incapable of performing were "Cutting own fingernails", "Cutting meat in the plate" and "Tying laces". On the opposite side of performance are the tasks "Lifting a glass of water and drinking from it", "Opening/closing water taps" and "Watching TV (using remote control)" (Table 3). Patients made more use of equipment help alone than personal help or both (Table 4). There was also a significant relationship between side of paresis (labelled 1= "left paresis"; 2= "right paresis") with results on the BI, r_s=.24, p (one-tailed) < .05.

Assistive products
It was observed that the most commonly used AP were walking aids, followed by bathing aids. These types of AP seem to be the better known amongst patients. In fact, when considering the ADL which scored higher levels of "Capable with help" responses, it was observed that 44.4% of these tasks were under the "mobility" domain, 33.3% under "personal hygiene" and 22.2% under "transfer". The other domains (communication, medication, feeding, dressing and household) presented zero values within this split of results.

Analyzing all AP used by patients (numbers on most used AP in Table 5), the "uncommon" AP represent 45% of all mentioned aids. The word "uncommon" in this context is used to refer to all aids mentioned by patients, which are not included in the annual list of financed AP provided by the Portuguese national health system. The numbers on possession of these "uncommon" AP show a relationship with patients' age, r=-.21, p (one-tailed) < 0.5; and to patient's working status, r_s=.23, p (one-tailed) < .05. Some of the mentioned "uncommon" AP are polytetrafluoroethylene coated pans (easier to wash); back scratcher (picking up clothes from the floor); shopping carts (walking assistance); long handle dust pan (picking up hard objects from the floor – Figure 1).

In addition to collecting data on the types and number of AP used and number of ADL performed with equipment help, information on how these aids were being used was also collected. For instance, if a patient stated she or he was using a cloth to help in peeling vegetables, the patient would be asked to explain the method; or if a patient stated she or he had created a method for rising up from a fall, the interviewer would try to search further into the subject (Figure 2 represents one of these methods, in which the patient needs the help of a person

to hold a chair while the patient climbs it). Another patient was able to show how he moved around in his bedroom with the help of an artisanal custom-made handrail, which helped in guiding him to his bed and getting out of it (Figures 3a and 3b).This routine for data gathering allowed for demonstrations, sometimes *in situ*, of: which objects were being used (1); how they were being used (2); and new methods created by patients for task performance (3).

Fear

Gathering transcribed statements made during the interviews, there were a total of 40 statements about feelings regarding task performance or AP. These statements were divided into "positive feelings expressed" and "negative feelings expressed". The results are 12 statements for "positive" and 28 for "negative". Qualitative text analysis might be controversial due to its hermeneutic principles, but a quantifiable item was detected – the word "fear". Fear was mentioned literally 24 times (60%) in all 40 patients' statements, most often acting as an inhibitor of task performance. Graphic 2 shows the distribution amongst four types of fear mentioned by the patients.

Discussion

A deeper qualitative analysis could be needed to add to the results presented regarding fear. This was a quantifiable item within text analysis, which provided some clues as to how to look for further information and answers for questions which have remained unanswered. Nevertheless, the results are noteworthy when thinking about AP design and may well be used in the future as project guidelines. The results suggest AP must convey a feeling of safety in use to stroke patients. Among other examples, this could be done through an appropriate choice of materials so that a better grip could be provided, thus reducing the risks of falling and breaking; appropriate structure to control the objects' weight and strengthen its resistance; and through the design of features to prevent falling such as wrist wraps.

Findings on unmet need and methods created by stroke patients to achieve independence possibly show the importance of including designers in research and development of AP. The typical use of user-centred methods in design research allows the gathering of qualitative data which could be of use when communicating AP design requirements to designers. Regarding the above mentioned example of peeling vegetables, we find, as designers, that existing solutions in the market may pose some dangers when used by stroke patients. Stroke patients often complain about letting objects slip from their hands and not being able to perform meticulous tasks. The commonly found solutions, working by means of pins to hold vegetables, could be potential sources of injury.

Designers could help in the development of new AP namely through creating AP which provide confidence in use and do not encompass stigma. Future collaborations between design and healthcare could be in the area of daily living aids, where the application of inclusive design principles could lead to AP being designed to be sold in other than AP specialized stores, thus bringing the AP to a mainstream level. This could

probably contribute to increasing the numbers on AP use, thus helping to promote stroke patients' autonomy.

Conclusions

Stroke patients presented a high rate of incapability in ADL. Considering the BADL, which are used to measure one's degree of dependence, this rate is even higher. The correlation between obtained scores in capability degrees and the BI scores shows that patients who are incapable or performing BADL are also incapable of performing several ADL. The results have shown patients do not use as much AP as they could to achieve independence, even though most of the times "capable with help" was mentioned, the patients accomplished the task by means of equipment help alone.

The high scores on "equipment help alone", contrast with the range of AP patients actually use. The most common AP used were mobility and bathing aids, whereas aids to other BADL such as "eating" or "dressing" were not commonly used. This finding on lack of AP use was accompanied by the observation of "uncommon" AP used by the patients, whether they were new products, new uses or new methods to accomplish everyday tasks. These results suggest that, while patients lack information on existing AP, they nevertheless need them.

For the design and healthcare collaboration, these findings present a new source of creativity to AP development and are complemented with an alert, based on the finding related to fear, to design AP which promote self-confidence.

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Authors contributed equally to all aspects of the study.

PEER REVIEW
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CONFLICTS OF INTEREST
The authors declare that they have no competing interests

		BI
Totally capable	Pearson Correlation	.797[**]
	Sig. (1-tailed)	.000
Capable with difficulty	Pearson Correlation	.430[**]
	Sig. (1-tailed)	.000
Capable with help	Pearson Correlation	.303[**]
	Sig. (1-tailed)	.006
	N	67
Incapable	Pearson Correlation	-.878[**]
	Sig. (1-tailed)	.000
Does not know / Never tried	Pearson Correlation	-.418[**]
	Sig. (1-tailed)	.000

**. Correlation is significant at the 0.01 level (1-tailed).

Table 1 – Pearson's correlations between evaluated degrees of capability and BI scores

Capability	42 ADL		27 BADL	
	n	%	n	%
totally capable	849	30.3	302	25.0
capable with difficulty	316	11.3	149	12.4
capable with help	443	15.8	342	28.4
incapable	935	33.4	396	32.8
Does not know / never tried	260	9.3	17	1.4
Total	2803	100.0	1206	100.0

Table 2 – Comparison between values for 42 ADL and 27 BADL answers in each degree of capability

Activities of Daily Living	Percentage values				
	TC	CD	CH	Inc	DK
Nail cutting	7,5	6,0	7,5	**79,1**	0,0
Cutting meat in the plate	17,9	9,0	4,5	**67,2**	1,5
Tying laces	14,9	16,4	4,5	**62,7**	1,5
Lifting a glass full of water and drinking from it	**73,1**	10,4	9,0	7,5	0,0
Opening/closing water taps	**70,1**	7,5	0,0	19,4	3,0
Watching TV (using remote control)	**64,2**	4,5	0,0	25,4	4,5

Legend: TC – "Totally capable"; CD – "Capable with difficulty; CH – "Capable with help" – Inc – "Inacapable"; DK – "Does not know/Never tried".

Table 3 – Higher values for "Totally capable" and "Incapable" on Activities of Daily Living

Use of assistance	42 ADL		27 BADL	
	n	%	n	%
personal only	146	(34.43%)	116	(35.47%)
equipment only	228	(53.77%)	165	(50.46%)
both	50	(11.79%)	46	(14.07%)

Table 4 – Comparison between sums of types of assistance used in 42 ADL and 27 BADL

Twelve most used ADs*	Mentioned (number of times)	Percentage
1. handrail	34	10.69
2. crutch	33	10.38
3. tripod	25	7.86
4. cane	23	7.23
5. glasses	19	5.97
6. scissors	18	5.66
7. walking frame	16	5.03
8. grab bar	16	5.03
9. bathtub bench	16	5.03
10. knife	16	5.03
11. wheelchair	14	4.40
12. head of bed	10	3.14
Total	240	75.47
others	78	24.53
Total	318	100.0

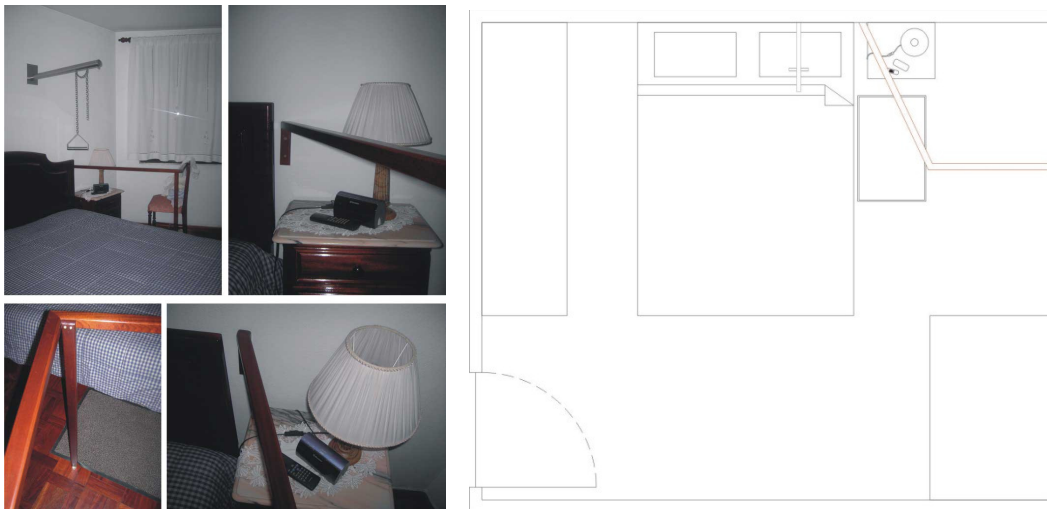* Amongst 53 ADs mentioned in a total of 318 times)
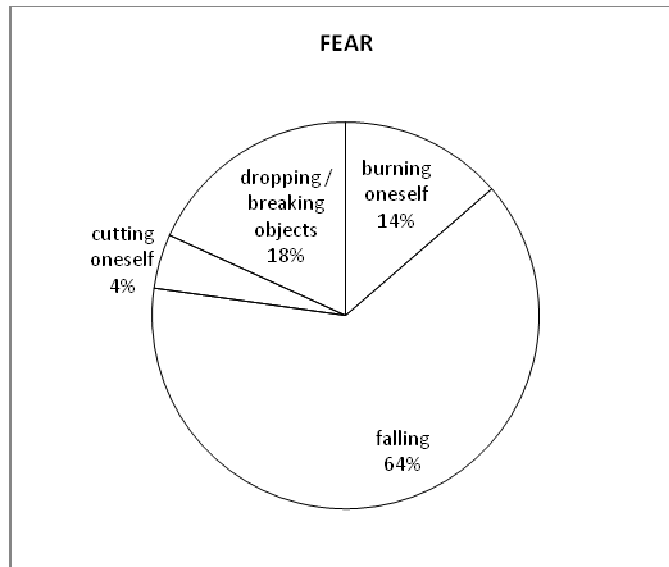
Table 5 – Most frequently mentioned ADs.

Figure 1 – Long handle dust pan used by a patient to pick up objects from the floor

Figure 2 – Representation of the several stages in the method created by a patient to rise up from a fall

Figures 3a (on the left) and 3b (on the right) – Photographs (3a) and CAD drawing (3b) of a patients' bedroom

Graphic 2 – Distribution of types of fear mentioned by patients.