

PARKSERVICE: Home support and walking aid for people with Parkinson's disease

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Abstract-PARKSERVICE is a telemedical application currently being validated in the EU. The objectives are to provide a combination of home clinical and social support for people with Parkinson's disease with a revolutionary walking aid that uses "visual cues" to enable improved mobility. Early results are presented and the outlook of home telemedicine and visual cueing for people with PD is discussed.

I. INTRODUCTION

PARKSERVICE is a new telemedical application combining home-based support for people with Parkinson's disease (PD) and a PD-specific walking aid which uses a strategy known as visual cueing. PD is estimated to affect 100-180 per 100,000 of the population (with most surveys favoring the higher estimate) and has an annual incidence of 4-20 per 100,000[1]. Taking a population of approximately 450M citizens this implies 450,000-900,000 people with PD (PWP) in the EU.

PD is a progressive, incurable neurological disease resulting in depletion of the neurotransmitter dopamine in the brain. Currently all therapy is symptomatic and primarily based on pharmacological enhancement of dopamine levels via the drug *levodopa*.

The three cardinal signs of PD are *bradykinesia* (decrease in movement), *resting tremor* (shaking, usually of the extremities of the limbs) and *rigidity* (muscular stiffness, cramps). As the disease progresses PWP typically suffer from gait abnormalities, falling and periods of complete immobility (*akinesia* or "*freezing*"). Additionally there are complications associated with long-term use of *levodopa*, including daily *fluctuations* between "on" periods of good symptom control (normal mobility) with "off" periods of poor symptom control (poor mobility) and even *dyskinetic* periods of exaggerated poorly controlled mobility. Transitions between these phases are primarily associated with the concentration of *levodopa* in the blood, but can be triggered precipitately by tiredness or stress. Episodes of "freezing" can occur in either "on" or "off" phases, although on-phase freezing is rare and difficult to treat[2]. Freezing is associated with falling and heightened levels of anxiety. Falls are common in PD: two thirds of people with PD fall each year with most eventually becoming fallers [3].

It is well known that some subjects who experience freezing can suddenly and dramatically "break out" of their frozen posture in the presence of particular cues, the nature of which vary with the individual. For example, some PWP who are unable to walk normally can dance to music, walk over obstacles, stripes or up stairs or when emotionally stimulated. (PD literature includes episodes of paralyzed PWP running out of burning buildings). Enhanced mobility under these conditions is known as *paradoxical kinesia*. (This is described in more detail below.)

Good management of PD requires clinical specialists both for accurate diagnosis and regular follow up. Periodic adjustments of drug regime are normal. Management is complicated because of the difficulty PWP experience getting to clinics, and in *fluctuating* PD, because the PWP may present few disabling symptoms during an appointment. Additionally there is a European shortage of neurologists [4].

PD is an expensive disease. In the UK the total annual direct cost of care including NHS (National Health Service), social services and private expenditure per patient have been estimated at ~€9,000 (£5,993, 2003) per patient per year [5]. With a total UK population of 60M this implies a total direct cost of PD in the UK of ~€1,000M (2003).

The same study estimated total annual direct costs of €6,300 for patients living at home, €23,260 for patients whose time was divided between home and an institution and €29,300 for patients in full-time institutional care.

Thus, every year someone with PD can stay at home, rather than take up part-time institutional care, saves (UK, 2003) €14,000/year.

The relevant aspects of PD can therefore be summarized as follows: PWP suffer varying and complex symptoms associated both with the disease itself and with the long-term use of *levodopa*, the primary pharmacological therapy. The effects of PD are particularly profound on mobility (with associated loss of confidence and social exclusion). Some

PWP display a startling recovery of mobility in the presence of “cues” such as stripes on the floor. The management of PD is complex and expensive, both in per-patient terms and in total (since PD is a widespread disease). PWP may experience difficulties finding suitable neurologists, traveling to clinics, and describing symptoms whilst there.

In many ways, therefore, PWP present an excellent group for telemedicine: the disease is widespread, affects mobility, there is a shortage of neurologists and treatment is expensive. The presence of *paradoxical kinesia* also presents intriguing possibilities for enhancing mobility (which are described below).

II. PARKSERVICE

PARKSERVICE is an application of telemedicine targeted specifically at PWP. The service consists of three parts: PARKLINE, a TV-based communication system for the PWP at home, PARKCLINIC, a complementary system for clinicians and INDIGO, a mobility aid for PWP mediated through PARKLINE.

Firstly, through PARKLINE, a PWP is connected through the Internet to their clinician and to other PWP. The primary medium of interaction is exchange of off-line video which can take place via broadband or dial-up connection. PWP can make short videos of themselves using a web-cam controlled by television remote control (via a multimedia PC). The objective is to provide a simple user experience with push-button interface. After taking a video the user can review it, reject it or distribute it to a list of other PARKSERVICE users including their own clinicians.

PARKLINE also supports other ways of data exchange: particularly a symptom diary (which is useful for understanding a patient with fluctuating PD) and text messaging (which obviously requires a keyboard).

Secondly, since PARKLINE requires special hardware to enable user access PARKCLINIC has been provided for secure clinical access through web browsers. With PARKCLINIC a clinician can view videos uploaded by PWP at home, send text messages to them or upload videos of their own.

Thirdly, INDIGO is a new mobility aid which uses video delivered through a pair of glasses to trigger *paradoxical kinesia* in suitable PWP.

Therefore, using PARKSERVICE a PWP at home can video their evolving symptoms of PD and their response to different drug regimes. They can experiment with visual cueing, exchanging video records with their clinicians and other PWP. For those PWP who exhibit *paradoxical kinesia* a secondary component of PARKSERVICE, INDIGO, can be used to enhance mobility throughout and beyond the home.

III. TELEMEDICINE AND PD

As long ago as 1993 a pilot study of telemedicine for patients with Parkinson's disease demonstrated the possibility of dependable and valid remote-assessment of these patients. Patients also viewed this technology as enabling access to

better health care [6]. This result was confirmed in 2002 in a study which included the adjustment of PD medication via videophone [7]. However, few research initiatives have made an impact on the market. This is unfortunate because PWP represent a particularly appropriate population for telemedicine for the following reasons:

- The disease is widespread
- Clinical treatment is expensive
- There is a shortage of neurologists
- Travel is difficult
- Assessment by video has been validated
- Some PWP react strongly to appropriate video stimulation (*paradoxical kinesia*).

Therefore the opportunity exists to make a cost-effective case for telemedicine beneficial to people with PD.

IV. INDIGO AND PARADOXICAL KINESIS

An important component of PARKSERVICE is a mobility aid called INDIGO. INDIGO consists of a pair of glasses with integrated visual display and wearable electronics which feed visual cues to the wearer, triggering *paradoxical kinesia* in suitable PWP.

Many people with PD have difficulty initiating and sustaining walking in conditions which would normally present no problems (such as an unobstructed corridor). The degree of these mobility difficulties can vary with the subject, the time of day and the stage of disease but are always accompanied by severe loss in quality of life. Typically when people with PD can only move very slowly or completely freeze (phases called “*bradykinesia*” and “*akinesia*” respectively) they feel vulnerable and isolated. Accompanying symptoms include an expressionless “masked” face, a weak voice and bent posture. Social interaction becomes extremely difficult and each year many deaths and injuries occur as people with PD attempt to move whilst in this state.

Paradoxically, when visual “obstructions” are placed in their way, a small proportion of people with PD undergo a dramatic release from these symptoms and can suddenly stand up straight, speak strongly and walk normally: an effect called *paradoxical kinesia*. These “obstructions” can be as simple as pieces of paper set down on the floor and are usually referred to as visual “cues”.

The physiological mechanisms of *paradoxical kinesia* are not understood and until recently there was little opportunity to analyse it or exploit it. However, technology has now evolved to the point where a user, wearing adapted glasses, can see visual cues, such as virtual “pieces of paper” wherever they looked whilst continuing to negotiate the real world, interacting normally with other people. This allows certain people with PD to walk, to talk and to socialise where before they were effectively paralysed.

Visual cues do not trigger *paradoxical kinesia* in all PWP but the number of suitable PWP and the nature of the visual cueing that is most effective is not known. It is believed that PWP in the intermediate stages (II-IV on the Hoehn-Yahr scale of I-V) respond. In earlier work we estimated 15% of

this population would benefit from visual cueing but this was not statistically significant. [8]

It is therefore expected that PWP will need to experiment with different visual cueing, by downloading selections of video on to their home television. If they find they respond positively the PARKSERVICE consortium will provide an appropriately configured INDIGO.



Figure 1. INDIGO in use with darkened glasses.

To date, the most popular choice for visual cues has been simply black and white stripes scrolling upwards. [8]

V. MARKET VALIDATION

Validation trials of PARKSERVICE will take place in summer 2006 involving several associations of PWP and clinical investigators. Additionally independent clinical trials of INDIGO will take place led by the Institute of Neurology, London. The major areas of investigation are listed below:

Drug management by video: the clinical assessment of PWP by video. This has been investigated before – if these results can be confirmed this would be of enormous importance to the market validation of telemedicine for PWP.

Social inclusion of PWP: do PWP report a greater feeling of connectedness to their clinicians and other PWP given the ability to make and exchange messages from home, principally by video.

Walking aids based on visual cueing: INDIGO, and devices using cueing, have become increasingly available in the last few years. However, none has become a mature product. This may be due to a lack of clinical validation of this new device which should be addressed by clinical trials.

In addition to these issues, to be addressed this summer, a market analysis has been performed. Recalling that PARKSERVICE is aimed at users who have Parkinson's disease with targeted symptoms living at home who have or could get Internet access and taking prevalence figures of 100-200 per 100,000 of the general population, adjusting for disease stage, Internet availability, and possible co-morbid conditions such as dementia, we estimate 180,000 to 360,000 potential PARKSERVICE users in EU-25. Interestingly, 60% of the PD telemedicine market lives in UK, France, Germany and Italy.

We also examined the trends in the PD market for telemedicine. The patient population will steadily grow, due to the combined effect of the growth in the general population in Europe and of the longer life expectancy of ageing people and PWP in particular, but these demographic effects will be dwarfed over the next few years by the effect of Internet penetration into European households. Considering an unchanged prevalence of PD, we estimate an increase of the population of PWP by 6,000 between 2006 and 2008.

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