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# Design of Technology and Technology of Design. Activity Analysis as a Resource for a Personalised Approach for Patients with Parkinson Disease

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## Abstract

Using a personalised medicine perspective, ECOTECH aims at developing new tools and methodologies to characterise and overcome at-risk situations for patients with Parkinson's disease in their daily life activity. With the cooperation of a multidisciplinary research group, patient situations have been studied in real life context in both hospital environment and home and community settings. Gait, in particular, has been assessed by combining data from an onboard sensor system, ethnographic observations and self-confrontation interviews. We discuss the results of this study with respect to the so-called activity analysis framework which is considered both as a resource for the design of new technologies and as a technology of design in the healthcare domain. In particular, we consider the potential for innovations regarding here, with the integration of onboard sensors, 1) the design of training 2) the design of artefact and work formats 3) the design of new mechanisms for health knowledge generation and validation.

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## 1. Introduction

Technological innovations have progressed considerably in response to the needs of people in vulnerable or at-risk situations, such as elderly populations. Such technology has served to i) maintain independence through progress in rehabilitation tools, intelligent housing, alarms, adaptive aids and communication technology; ii) contribute to health through the develop-

ment of biomedical devices, surgical implants (e.g. neurostimulation), computerised medical imaging techniques, biomedical engineering applied to bodily tissue (regeneration), or onboard systems for monitoring vital signs (see [1] for a review of such projects based in France). The development, integration and application of onboard sensor technology is central to the ECOTECH project which focuses on personalised medicine.

Specifically, it aims to characterise gait disturbances in ecological settings and to detect and overcome risk situations for patients with Parkinson's disease (PD) by 1) designing new clinical evaluation methods and tools to identify patient difficulties when walking and provide accurate measures of patient response to treatment and 2) informing the planning of other interventions from therapeutic education, with the use of compensatory strategies, to environmental adaptation. This project benefits from a French–Taiwan partnership with a SME special-

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ising in ergonomic sensor equipment. It incorporates research groups specialising in neurology/neuroscience and movement disorders, technology and physiology as well as ergonomics.

The conditions for successful innovation and implementation (defined as the “process of integrating a new technology into established workflows”) are not bounded to technological progress or societal processes (see for instance [2]). In the present article, we consider the so-called approach of activity analysis [3,4] as a vital resource in the design of new health and well-being technologies. The results of this study have been obtained through the analysis of the activity of PD patients in daily life situations. As such, the social, cultural, material and technical circumstances for any given activity are patently unique [3,4]. It provides for particularly rich and complex data which, by its very nature, enables a contextualised account of that activity:

- daily life events for PD patients occur in social settings which strongly determine the individual’s course of action. Age, health personal circumstances (single, married, separated, widowed, living with family) and competing commitments of people within a patient’s support network are defining elements of a patient’s situation;
- the cultural and historical dimensions are manifest in the activity of a patient through the person’s relationship to their health and disease as well as their rapport with health-care services;
- material and technical constraints equally structure the person’s activity in terms of financial resources, technical aides, modified or adapted living environments and physical access to places which the person frequents;

Activity, such as it is conceived in this study is a global dynamic integrating:

- modalities of actions implicating motor abilities and whole corporality. Gait and mobility are considered in the wider scope of daily activities (locomotion is rarely an objective in itself);
- a cognitive and perceptive dimension implicating decision making, preoccupations, capacity for anticipation, focus upon attentional modalities (e.g. symptoms, fatigue), anticipation of difficulties in locomotion, fixation upon certain symptoms;
- the way in which people generating understanding (i.e. learning through one’s own experience) through metacognitive processes and practical knowhow;
- affective states or affective dynamics through the course of the activity. This may imply concerns, fear, satisfaction, surprise, relief, frustration, shame, disappointment, anger, pleasure or hope. Emotional states may be of varying spectra, complexity or stability (not every patient studied presented with the same combination of emotions). Emotional dynamics are experienced with varying levels of intensity. Emotional valence may be hardly perceptible, a background to the experience—or at the other extreme, particularly intense, dominating the way in which an event is experienced.

The duration of such dynamics are also a subject of interest.

Typically, healthcare research involves the development of experimental protocols using neuroimaging or biomechanical markers or participant observation of hospital activities [5,6]. Going beyond the traditional distinctions of disciplines, we present here a part of the results in order to discuss the potential of these processes based upon activity analysis as a resource for the design of new technology and as technology *per se* in design.

## 2. Material and method

### 2.1. Ecological study

Our objective is to study the “situated action” [7] of patients with Parkinson’s disease in the particular circumstances (social, cultural, material and technical contexts) in which acting invariably occurs. One aspect of this work has involved ethnographic observation of patient and clinical staff activities including:

- thirty clinical consultations for the purposes of examining patient–doctor interactions through the course of Parkinson’s disease management;
- six UPDRS (Unified Parkinson Disease Rating Scale) evaluations to review clinical processes and functional evaluation techniques;
- three medical team meetings pertaining to patient selection for surgical intervention (deep brain stimulation);
- eight hours of observations (over two separate sessions) for each of 8 patients with Parkinson’s disease in their natural setting—within the home and in the wider community. Particular interest was invested in those circumstances likely to provoke gait disturbances.

### 2.2. Integrated approach

Using a holistic approach, ethnographic observations (supported by audiovisual recordings) of patients in their daily life routine (see last point of 2.1) have been coupled with data obtained from onboard sensors. This process was followed by the completion of self-confrontation interviews in order to understand the patient’s subjective experience of the activity in question.

Thanks to a cooperation between French and Taiwanese groups [8], gait and locomotor disturbances were monitored during unconstrained activity using a system of wearable sensors (see Fig. 1). For the purposes of the present paper, only data recorded from one accelerometer, inertial motion units and surface electromyography (sEMG) sensors fixed to the lower limbs are presented.

All data obtained from onboard sensors have been synchronised with video data using CAPTIV software (TEA).

Self-confrontation interviews (approx. 2 hours) were conducted after each recording. This involves obtaining a first person accounts of particular sequences of the patient’s activity [9]

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