

User Profiling of People with Disabilities

A Proposal to Pervasively Assess Quality of Life

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Abstract: This paper presents and discusses an ongoing work aimed at defining the profile of people with disabilities, i.e., automatically assessing their quality of life, through a sensor-based telemonitoring system. To illustrate how the approach works, a case study is presented and discussed.

1 INTRODUCTION

Profiling users comes from the need to acquire information about habits, preferences, tastes as well as demographic data of the users of a service or a system (Godoy and Amandi, 2005) (Armano et al., 2010). In healthcare domain, profiling users helps healthcare providers, medical doctors, and carers to improve their knowledge about the patients and personalize treatments and tasks, accordingly. In our view, a relevant part of the profile of people with health diseases is their Quality of Life (QoL); i.e., the subjective experiences or preferences expressed by an individual in relation to specified aspects of her/his QoL, with a particular reference to the health status (Sutherland and Till, 1993). Therefore, we propose to use the assessment of QoL of patients as a proxy of the definition of their profile.

Currently, to assess QoL, several questionnaires have been proposed and adopted; users are asked to answer to a predefined set of questions about their mental and psychological status and feeling. Although they are largely adopted, answering them could become tedious and annoying for users. Answering them could also be impossible in cases of severe impairment of the user. Hence, other solutions need to be investigated. Telemonitoring is a way to assess QoL at distance (Clark et al., 2007). Telemonitoring can be useful to collect information on patients' health-status parameters that provide a measure of their QoL and their level of functional diversity, taking into account not only functional and cognitive factors, but also psychological, social, and participation ones.

In this paper, we present a proposal to pervasively assess QoL *automatically gathering* standardized information by a sensor-based telemonitoring system. This proposal is part of the research carried out within *BackHome*¹, an EU project about physical and social autonomy of people with functional diversity, in which Brain-Neural Computer Interfaces (BNCIs) and other assistive technologies are used. *BackHome* supports the transitions from hospital care to post rehabilitation at home to discharge (Daly et al., 2012).

The rest of the paper is organized as follows. Section 2 gives a view of the background. In section 3, we describe a scenario aimed at highlighting how the approach illustrated in Section 4 can be put in practice. Section 5 presents the proposed case study. Section 6 ends the paper with conclusions and future work.

2 QUALITY OF LIFE ASSESSMENT

2.1 Definitions

QoL (sometimes referred to as *Health-Related QoL* or HRQoL) is defined by the subjective experiences or preferences expressed by an individual, or members of a particular group of persons, in relation to specified aspects of health status that are meaningful, in definable ways, for that individual or group (Sutherland and Till, 1993). According to (Gotay and Moore, 1992), QoL is a state of well-being defined

¹<http://www.backhome-fp7.eu/backhome/index.php>

by two components: (i) the ability to perform everyday activities, which reflects physical, psychological and social well-being, and patient satisfaction with levels of functioning, and (ii) the control of disease and treatment symptoms. Also, as Lerer (2000) suggests, e-health consumers are now empowered by an increased ability to obtain health information via the Internet, with the main objective to maintain the highest possible level of QoL.

The World Health Organization (WHO) defines QoL as the individuals' perception on their position in life within the cultural context and the value system in which the individuals live and with respect to their goals, expectations, norms and worries (WHO, 2007). It is a multidimensional and complex concept that includes personal aspects, like health, autonomy, independence, satisfaction with life and environmental aspects such as support networks and social services, among others.

QoL could also be considered as a dynamic and changing concept that includes continuous interactions between the person and the environment. Accordingly, QoL in ill people is related to the interaction among the disease, the patients' character, the change in their life, the received social support, as well as the period of life in which the disease appears.

Healthcare organizations use several tools to acquire QoL-related information. These tools make use of specific terms, which are sometimes ambiguous: descriptor, grade, index, indicator, parameter, questionnaire, scale, score, and test. The terminology used in this paper is defined as follows and is part of an ontology, which we defined (and encoded in OWL 2 (Hitzler et al., 2009)) based on standard nomenclatures and ontologies (Ceccaroni and Subirats, 2012):

- *Indicator*: a (subjective or objective) parameter, category, or descriptor used to measure or compare *activities and participation, body functions, body structures, environment factors, processes, and results* (e.g., *dressings*).
- *Index*: a combination of indicators, questionnaires and possibly other indexes. The function representing this combination gives as summarizing result a *score* (e.g., *Barthel index*).
- *Item*: a single *question* or *concept* (e.g., *Mobility*).
- *Questionnaire* (or *instrument* or *test*): a set of questions (or *items*) answered using a scale (e.g., *EQ-5D*).
- *Scale*: a mapping between some ordered (qualitative or quantitative) values (or *grades*) and their description. These values are used to answer questionnaires (e.g., *I have no problems in walking about, I have some problems in walking about,*

I am confined to bed).

2.2 Questionnaires for Assessment of Quality of Life

Several questionnaires have been proposed and adopted to assess QoL. Let us summarize here the most widely adopted:

- The *WHOQOL-BREF* questionnaire (Murphy et al., 2000) comprises 26 items, which measure the following broad domains: physical health, psychological health, social relationships, and environment.
- The *EQ-5D-5L* questionnaire (The EuroQol Group, 1990) was developed by the EuroQol Group in order to provide a generic measure of health status. Applicable to a wide range of health conditions and treatments, it provides a simple descriptive profile and a single value for health status that can be used in the clinical and economic evaluation of healthcare as well as in population health surveys.
- The *RAND-36* questionnaire (Hays et al., 2001) is comprised of 36 items that assess eight health concepts: physical functioning, role limitations caused by physical health problems, role limitations caused by emotional problems, social functioning, emotional well-being, energy/fatigue, pain, and general health perceptions.
- The *Short Form (36) Health Survey* (SF-36v2) (Ware et al., 2001) is a questionnaire about patient health status and is commonly used in health economics in the quality-adjusted life year calculation to determine the cost-effectiveness of a health treatment. The SF-36 and RAND-36 include the same set of items, however the scoring of general health and pain is different (RAND et al., 1992).
- The *Barthel* questionnaire (O'Sullivan and Schmitz, 2007) is used to measure performance in Activities of Daily Living (ADLs). It uses ten variables describing ADLs and mobility. The higher the score derived from this questionnaire, the greater the likelihood of being able to live at home with independence following discharge from hospital.

2.3 Existing Standardization Efforts

Several standard terminologies and classifications exist, which can be used for an interoperable representation of QoL. Some examples are: the Systematized Nomenclature of Medicine Clinical Terms

(SNOMED CT); the Unified Medical Language System (UMLS); the International Classification of Diseases version 10 (ICD-10); and the International Classification of Functioning, disability and health (ICF) defined by the WHO. In addition to terminologies and classifications, information models such as the virtual Medical Record (vMR) contribute to solve interoperability problems in the electronic exchange of QoL information.

Several questionnaires are used to evaluate functioning, disability and health. The ICF classifies these concepts, specifies their range of values, and can be used to solve interoperability problems among health institutions that employ different measuring questionnaires. To this aim, questionnaire items can be encoded to ICF concepts following the standardization methodology proposed by Cieza et al. (2005). Difficulties in mapping clinical questionnaires to standard terminologies and ontologies in the rehabilitation domain (e.g., data from questionnaires having a finer granularity than ICF categories) have been addressed in (Ceccaroni and Subirats, 2012) and (Subirats et al., 2012). ICF core sets are subsets of the ICF that have been created according to specific pathologies or rehabilitation processes. Core sets are useful because, in daily practice, clinicians and other professionals can use only a fraction of the about 1400 categories found in the ICF.

3 A REFERENCE SCENARIO

The next real case may illustrate the urgent need for automatic, interoperable assessment of QoL for people with disabilities caused by neurological disorders².

Chara is a woman in her thirties who used to be a painter. She was so gifted that she could earn a living from painting. About eight years ago she started to have difficulties holding her paint brush. She was diagnosed with Amyotrophic Lateral Sclerosis (ALS). She was devastated because it meant that in the near future she would no longer be able to paint. She became tetraplegic and artificially ventilated, and she was so depressed that she refused treatment when diagnosed with pneumonia. Luckily, she survived and just recently had her first session with BNCI-based Brain Painting (Münssinger et al., 2010). We let her speak: “Here is my feedback to my first brain painting image. I am deeply moved to tears. I have not been able to paint for more than five years. Today I again had butterflies in my stomach, a feeling that I have

missed so much. I was so sad; I was plagued by fears of loss. For me the picture I have created is so very typical me, no one else paints in my style, and despite five years of absence, I’m simply an artist again. I’m back to life!”

To achieve an automatic and interoperable QoL assessment for people like Chara, several actions need to be taken, as part of our proposal.

Before her discharge from the hospital, therapists ask her to answer some questions in order to have an initial assessment of her QoL according to selected standards³. At home, Chara, with the help of a caregiver or of her relatives (but no BNCI experts), is able to put/remove a BNCI system as well as other wearable sensors. In so doing, she can: control a sensor-based smart home, participate in social networks, carry out cognitive rehabilitation, and interact with a telemonitoring system. The telemonitoring system acquires all relevant data about Chara and transmits them to a remote therapist for future analysis. In particular, the system monitors the following daily activities: interaction with home automation devices, communication with relatives and friends, movement around home, and the rehabilitation tasks assigned by the therapist. The telemonitoring system continuously analyses the data gathered by the sensors in order to send alarms in case of detection of abnormal events, if any, and to keep informed the therapist about the performed activities. Furthermore, the system analyses all the data to assess the QoL. In case of QoL worsening, the system sends an alarm to the therapist, who might see it necessary to take action or to change the therapy.

4 PERVASIVE ASSESSMENT OF QUALITY OF LIFE

As already mentioned, currently, approaches to assess QoL rely on questionnaires, which the user is periodically required to answer. The more the user fills the questionnaire, the more the QoL trend is updated. Moreover, the more the questions, the more the QoL trend is accurate. Unfortunately, this process could become tedious and annoying for the users, especially if they are asked to do that frequently; with the potential consequence of users who stop answering questionnaires or give less accurate answers. To take into account these issues we propose, after a *basic profile* has been defined, to adopt a sensor-based telemonitoring system to *automatically fill* it.

²Names have been changed for privacy reasons.

³This is a one-time questionnaire.

4.1 The Approach

The proposed approach falls in the domain of Ambient Assisted Living, which fosters the provision of equipment and services for the independent or more autonomous living of people with disabilities, via the seamless integration of info-communication technologies within homes and residences, thus increasing their physical and social autonomy and reducing the need for hospital readmission. In particular, the proposed approach is aimed at acquiring personalized information through data coming from: (i) a BNCI system that allows monitoring ElectroEncephaloGram (EEG), ElectroOculoGram (EOG), and ElectroMyoGram (EMG); (ii) wearable, physiological, and biometric sensors, such as ElectroCardioGram (ECG), heart-rate sensor, respiration-rate sensor, Galvanic Skin Response (GSR) sensor, EMG switches, Wii remote, and inertial sensors (e.g., accelerometer, gyrocompass, and magnetometer); (iii) environmental sensors (e.g., temperature and humidity sensors); (iv) smart home devices (e.g., wheelchairs, lights, TVs, doors, windows and shutters); (v) devices that allow interaction activities (e.g., a desktop PC); and (vi) devices to perform rehabilitation tasks (e.g., a robot).

In this way, the system is able to monitor the evolution of the user's daily life activity at home, once discharged from the hospital Vargiu et al. (2012). Specifically, the wearable sensors allow to monitor fatigue, spasticity, stress, and further user's conditions. Environmental sensors are used to monitor temperature and humidity, as well as the movements (motion sensors) and the physical position of the user (location sensors). Smart home devices enable physical autonomy of the user and help her/him carry out daily life activities. An Internet-connected device allows the user to communicate with remote therapists, careers, relatives, and friends through Skype, email, or social networks (i.e., Facebook and Twitter). Other devices that allow some kind of interaction and stimulation activities are also taken into account, such as devices to play games, listen to music, paint, or perform other activities.

4.2 Kinds of Data

If the user explicitly agrees, the logs of communication, social, and all other activities are used to study the behaviour and the mood of the user. In this way, the system is able to pervasively assess the QoL of the user *automatically filling* a selected standard questionnaire. Two kinds of data are considered: *monitorable* and *inferable*. On the one hand, all data that can be gathered from the wearable, home automa-

tion, and environmental sensors, as well as the BNCI system (i.e., without relying on direct input from the user) belong to the former category. This kind of data allows, for instance, to answer the question "*How well are you able to get around?*"⁴. On the other hand, all data inferred by analysing data retrieved by the system (e.g., by considering activities performed by the user while interacting with a social network) belong to the latter category. This kind of data allows, for instance, to answer the question "*How satisfied are you with yourself?*"⁵.

Let us note that this does not imply that monitorable and inferable data are necessarily monitored or inferred. In fact, in *BackHome* we decided to not monitor nor infer some data (such as, those related to self-care and sleeping activities), due to privacy issues. Moreover, users can decide to switch off the monitoring of any descriptor.

5 A CASE STUDY

Among the several state-of-the-art questionnaires, according to the constraints of *BackHome*, we made a preliminary study by considering the EQ-5D-5L questionnaire (The Euroqol Group, 1990)⁶. The EQ-5D-5L is a brief, self-administered, two-page questionnaire. The first page contains five items describing health status across five dimensions: mobility, self-care, usual activity, pain/discomfort, and depression/anxiety. The second page has a visual analogue rating scale on which the respondent marks an assessment of her/his overall health. Each dimension is divided into five levels which, when taken together, define a total of 3125 (5⁵) unique health states. The responses to the five items in the EQ-5D-5L can be scored using a utility-weighted algorithm (Williams et al., 1995), which has been recommended for use in economic evaluation. The EQ-5D-5L, therefore, provides two single-index measures of health, the rating scale, and the EQ-5D index, ranging from 0 to 100 (Brooks, 1996).

According to Geyh et al. (2007), Table 1 shows the translation of the selected questionnaire into the ICF categories. The visual analogue rating scale, which refers to how good or bad the user feels her/his health is "today", can be also translated on "emotional functions".

The ICF classification allows us to "zoom in" in each EQ-5D-5L dimension and better study its correspondence with the data introduced in Section 4.2:

⁴Item number 15 of the WHOQOL questionnaire

⁵Item number 19 of the WHOQOL questionnaire

⁶An ad-hoc questionnaire is currently under definition.

Table 1: The translation of the EQ-5D dimensions into the ICF categories.

EQ-5D Dimension	ICF Category
Mobility	d4 - mobility d450 - walking d498 - mobility, other specified
Self-care	d5 - self-care d510 - washing oneself d540 - toileting d540 - dressing
Usual Activities	d6409 - doing housework, unspecified d7609 - family relationships, unspecified d839 - education, other specified and unspecified d8509 - remunerative employment, unspecified d9209 - recreation and leisure, unspecified
Pain/Discomfort	b152 - emotional functions b280 - sensation of pain b289 - sensation of pain, other specified and unspecified
Anxiety/Depression	b152 - emotional functions

- *Monitorable Data*

- Mobility. Through the adoption of environmental location sensors, the system is able to know the position of the user, time after time. It is worth pointing out that, in *BackHome*, users are typically on a wheelchair, thus the walking activity is not of interest here. To detect the position of the wheelchair and its movements RFID tags will be embedded into the wheelchair together with following sensors.
- Usual Activities. Being human-computer-interaction made through a BNCI system, it is possible to monitor all the activities performed by the user on the PC and while interacting with smart home control and communication devices. In other words, the system is able, through the BNCI system, to know which action is performed.

- *Inferable Data*

- Usual Activities. The user can interact with her/his family and friends through the support of a communication system (e.g., Skype) or social network (e.g., Facebook and Twitter). Thus, suitable text mining algorithms can be adopted to infer the family and friends relationship status.
- Pain/Discomfort. Text mining algorithms, applied on social networking and communication activities, can also be adopted to assess the degree of pain or discomfort.
- Anxiety/Depression. Changes observed in habits of daily life activities can be studied to assess anxiety or depression. The degree

of anxiety/depression can be also inferred by analysing data on fatigue, spasticity, stress, and further user's conditions retrieved by the BNCI system and the other wearable sensors. Moreover, analogously to pain and discomfort, anxiety and depression can be inferred by the system by adopting suitable text mining algorithms on the performed social activities.

In principle, also self-care activities can be monitored by relying on suitable sensors. Nevertheless, in *BackHome*, for privacy issues, the end-user decided not to monitor such activities. In so doing, to have information about the self-care activities and the corresponding status of the user, direct questions must be performed.

6 CONCLUSIONS

Being interested in profiling people with disabilities by assessing their QoL, in this paper we proposed an approach to automatically assess QoL by relying on a sensor-based telemonitoring system. A case study, which relies on the EQ-5D-5L questionnaire, has been presented. The case study allows us to clarify how a given questionnaire can be automatically filled by relying on a sensor-based telemonitoring system.

This is an ongoing work; we are currently setting up the sensor-based telemonitoring system and we are also selecting, according to the inclusion and exclusion criteria defined in *BackHome*, the end-users who will test the overall system and who will be asked

to test the proposed pervasive QoL assessment approach. Finally, we are planning to assess the validity of the proposed approach with respect to the traditional filling of questionnaire.

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