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Circles of Health: Towards an advanced social network about disabilities of neurological origin

Laia Subirats [a,b,*], Luigi Ceccaroni [a], Raquel Lopez-Blazquez [b,c,d], Felip Miralles [a], Alejandro García-Rudolph [b,c,d], Jose M. Tormos [b,c,d]

[a] *Barcelona Digital Technology Centre, Roc Boronat, 117, 5th Floor, MediaTIC Building, 22@ District, 08018 Barcelona, Spain*
[b] *Universitat Autònoma de Barcelona, Campus UAB, 08193 Bellaterra, Spain*
[c] *Institut Guttmann, Institut Universitari de Neurorehabilitació adscrit a la UAB, Camí de Can Ruti sn, 08916 Badalona, Spain*
[d] *Fundació Institut d'Investigació en Ciències de la Salut Germans Trias i Pujol, Camí de Can Ruti sn, 08916 Badalona, Spain*

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ABSTRACT

Objectives: This research is concerned with the study of a new social-network platform, which (1) provides people with disabilities of neurological origin, their relatives, health professionals, therapists, carers and institutions with an interoperable platform that supports standard indicators, (2) promotes knowledge democratization and user empowerment, and (3) allows making decisions with a more informed opinion.
Methods: A new social network, Circles of Health, has been designed, developed and tested by end-users. To allow monitoring the evolution of people's health status and comparing it with other users and with their cohort, anonymized data of 2675 people from comprehensive and multidimensional medical evaluations, carried out yearly from 2006 to 2010, have been standardized to the International Classification of Functioning, Disability and Health, integrated into the corresponding medical health records and then used to automatically generate and graphically represent multidimensional indicators. These indicators have been integrated into Circles of Health's social environment, which has been then evaluated via expert and user-experience analyses.
Results: Patients used Circles of Health to exchange bio-psycho-social information (medical and otherwise) about their everyday lives. Health professionals remarked that the use of color-coding in graphical representations is useful to quickly diagnose deficiencies, difficulties or barriers in rehabilitation. Most people with disabilities complained about the excessive amount of information and the difficulty in interpreting graphical representations.
Conclusions: Health professionals found Circles of Health useful to generate a more integrative understanding of health based on a comprehensive profile of individuals instead of being focused on patient's diseases and injuries. People with disabilities found enriching personal knowledge with the experiences of other users helpful. The number of descriptors used at the same time in the graphical interface should be reduced in future versions of the social-network platform.

1. Introduction

A disease or injury may have multiple disabling effects of various levels of severity, and cause varying degrees of health problems. The *global burden of disease* (GBD) links average loss of health to disease and injury's causes through *disability-adjusted life years* (DALYs) [1] and disability weight factors. The DALY extends the concept of potential years of life lost due to premature death to include equivalent years of healthy life lost by virtue of being in states of poor health or disability. The weight factor reflects the severity of the disease on a scale from 0 (perfect health) to 1 (death). The term *disability* has a number of different meanings and, in particular, is not seen by some as a synonym or proxy for loss of health. However, the *World Health Organization* (WHO) uses the term *disability* to refer to loss of health, where health is conceptualized in terms of functioning capacity in a set of health domains such as mobility, cognition, hearing and vision, and we adopt this use for the term. According to the WHO, of the world's population of 6.5 billion in 2004, 19 million (3%) were severely disabled and another 80 million (12%) had moderate longterm disability, which is a barrier for personal development as well as social integration. People with disabilities of neurological origin are mainly people

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* Corresponding author at: Barcelona Digital Technology Centre, Roc Boronat, 117, 5th Floor, MediaTIC Building, 22@ District, 08018 Barcelona, Spain. Fax: +34 93 553 45 41.

E-mail addresses: lsubirats@bdigital.org (L. Subirats), lceccaroni@bdigital.org (L. Ceccaroni), rlopez@guttmann.com (R. Lopez-Blazquez), fmiralles@bdigital.org (F. Miralles), agarciar@guttmann.com (A. García-Rudolph), jmtormos@guttmann.com (J.M. Tormos).

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Table 1
Comparison of existing tools which integrate bio-psycho-social information in the healthcare domain.

Tool	Data	Interope-rability based on:	Social	Graphical representation of:
Circles of Health	MHR	Ontology	Yes	Individuals and population
Patients Like Me [26]	Patient health record (PHR)	No	Yes	Individuals and population
I'm too young for this [29]	Text	No	Yes	Individual
Forumclinic [30]	Text	No	Yes	Individual
Vivu [31]	Text	No	Yes	Individual
HealthVault [32]	PHR	Continuity of care record	Yes	Individual
Aptic [28]	Text	No	Yes	Individual
Mora et al.'s middleware [17]	MHR	Ontology	No	No

Table 2
Questionnaires administered in the PCE, indicating the profile to whom they are administered and if people can self-administer them.

Questionnaire	Profile	Self-administer
Institut Guttmann social scale (ESIG), Personal well being index (PWI), Community integration questionnaire (CIQ)	SCI and ABD	Yes
Craig Hospital inventory of environmental factors (CHIEF), Hospital Anxiety and depression (HAD), Patient health questionnaire (PHQ9), WHO quality of life questionnaire (WHOQOL)	SCI	Yes
Functional independence measure (FIM), Spinal cord injury measure (SCIM), ASIA scale	SCI	No
Patient competency rating scale (PCRS)	ABD	Yes
Behavioral scale, PCRSi (informer), Rancho scale levels of cognitive functioning, Barthel index, Disability rating scale (DRS), Extended Glasgow outcome scale (GOSE)	ABD	No

with *spinal cord injuries* (SCIs) and people with *acquired brain damage* (ABD). SCIs correspond to classes S14.0-S14.1, S24.0-S24.1, S34.0-S34.1 and T09.3 of the *international classification of diseases version 10* (ICD-10) [2], while ABD (which includes non-traumatic ABD or stroke, and traumatic brain injury), corresponds to classes I60-I69 of the ICD-10. In Catalonia (Spain), 50% of people with traumatic SCI are 16–30 years old; and 60% of the ones with *traumatic brain injury* (TBI) (the most common cause of ABD, mostly due to road traffic accidents) are younger than 25 [3]. It is reasonable to assume that similar figures are valid in general for high-income countries.

Because a relevant percentage of people with disabilities of neurological origin is young and, supposedly, used to social networks, in their broadest definition, these networks may be adapted or made accessible to these people, and then used to generate a positive impact on their health [4]. Furthermore, previous research [5] suggests that a significant number of patients with disabilities of neurological origin would benefit from accessible information that is relevant to them, and social networks can be providers of such information.

The objectives of the research described in this paper are:

- *To provide stakeholders (people with disabilities, their family, health professionals and therapists, carers and institutions) with the Circles of Health social-network platform from now on Circles of Health, aimed at supporting multicenter studies using standard indicators.* These multicenter studies use a data set that is collected periodically and forms the basis of rehabilitation processes. Standardized, multidimensional indicators are automatically and dynamically collected, transformed, represented and shared.
- *To promote knowledge democratization, user empowerment and making decisions with a more informed opinion, with Circles of Health that allows people to monitor their evolution and compare with others, and which is not limited to people with disabilities (participation of other stakeholders is encouraged).* This facilitates the e-inclusion of people with disabilities of neurological origin.

The rest of the paper is organized as follows. In this section, some background is provided on Circles of Health, the generation of indicators, knowledge democratization and user empowerment. Section 1.1 presents the people with disabilities' data used for the study and the users of Circles of Health. Section 2 describes technically Circles of Health and the methods for its evaluation. Section 3 describes Circles of Health functionalities and results of its evaluation. Section 4 discusses results obtained and usefulness; and future work is detailed at Section 5. Finally, conclusions are drawn in Section 6.

Table 3
Patient's data from MHR.

Descriptor	Value
Number of people	2675
Frequency	Yearly
Range of years	2006–2010
Number of people with SCI	1815
Number of people with ABD	860

1.1. Circles of Health

In Qvidlab framework [6] carried out at Institut Guttmann, a committee of experts in sociology, psychology, neuropsychology, social work and neurorehabilitation from several institutions identified a set of evaluation questionnaires for describing the bio-psycho-social profile of SCI and brain-injury people, which are the core of *periodic, comprehensive evaluations* (PCEs). This led to an improvement of the information about the problems of people with disabilities, which can have an impact on new laws, decision policies, knowledge democratization, and promotion of research and funding.

In addition, a Ministerial European Conference [7] identified the following needs: (1) achieving the inclusion of each and every individual and community in each and every aspect of the information society; (2) achieving a level of access to information that leads to knowledge democratization and user empowerment; (3) building a global community of support to allow immediate access to