

APTIC: A SOCIAL NETWORK TO IMPROVE THE QUALITY OF LIFE OF PATIENTS ASSOCIATIONS' MEMBERS.

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Summary

This work presents the APTIC social network as a tool to improve the quality of life of members of patients' associations. This network (built in open source code) is based on the health psychology premises, as it considers some key variables such as self-efficacy, empowerment or social support. Our social network aims to enable the individual members of patients' associations (mostly parents of children with chronic and rare diseases) and professionals to share experiences, information, advice and, ultimately, to offer them on-line tools to improve the quality of life of the entire family.

Introduction

ICT are beginning to be an integral part of the daily activities of many individuals, and this implies the need of making substantial changes in the policies, the professional interventions and in the care of their own health (Jadad, 2006; Pousada, Valiente and Boixadós, 2007). Online communities of patients associations help increase the perception of social support and self-efficacy in taking care of their own health, at the same time that increase the empowerment of patients and their relatives. As a consequence, they improve the quality of life of members and their families. We study the effect of the activity of associations on their wellbeing, emphasizing individual responsibility to control their health. Our communities develop a peer to peer structure, as opposed to the traditional professional-user structure, and cover the needs of information, self-help and mutual support (Eysenbach, 2005). In this context of peer to peer communication, taking place both in these physical and online spaces, our project sees ICT as a tool to improve services, to promote autonomy and a more efficient health management. We also study the effect of creating physical spaces (such as the 'Espai d'Associacions' of Hospital de Sant Joan de Déu in Barcelona) and online spaces (such as the social network APTIC) that complement the associations services to patients and relatives.

Members of patients' associations needs

Conducted a needs analysis on new technologies uses and their effects on the wellbeing of individuals: 35 patients associations participated in the study, 74 members surveyed, 12 of them participated in 3 focus groups.

Relevant results:

- A 2.0 web should provide: relevant, screened, and accredited information; support and help to individuals; and also provide identity referents.
- Members value mainly the information gathering easiness, but its possibilities as a collaborative space are not particularly esteemed.
- Individuals perceive ICT as tools for improving their knowledge of the disease, patient autonomy and the relationship with health professionals. In other words, a 2.0 web must allow for the improvement of their daily lives.

Communities are the base of our social network

The strenght is on the community cultivation

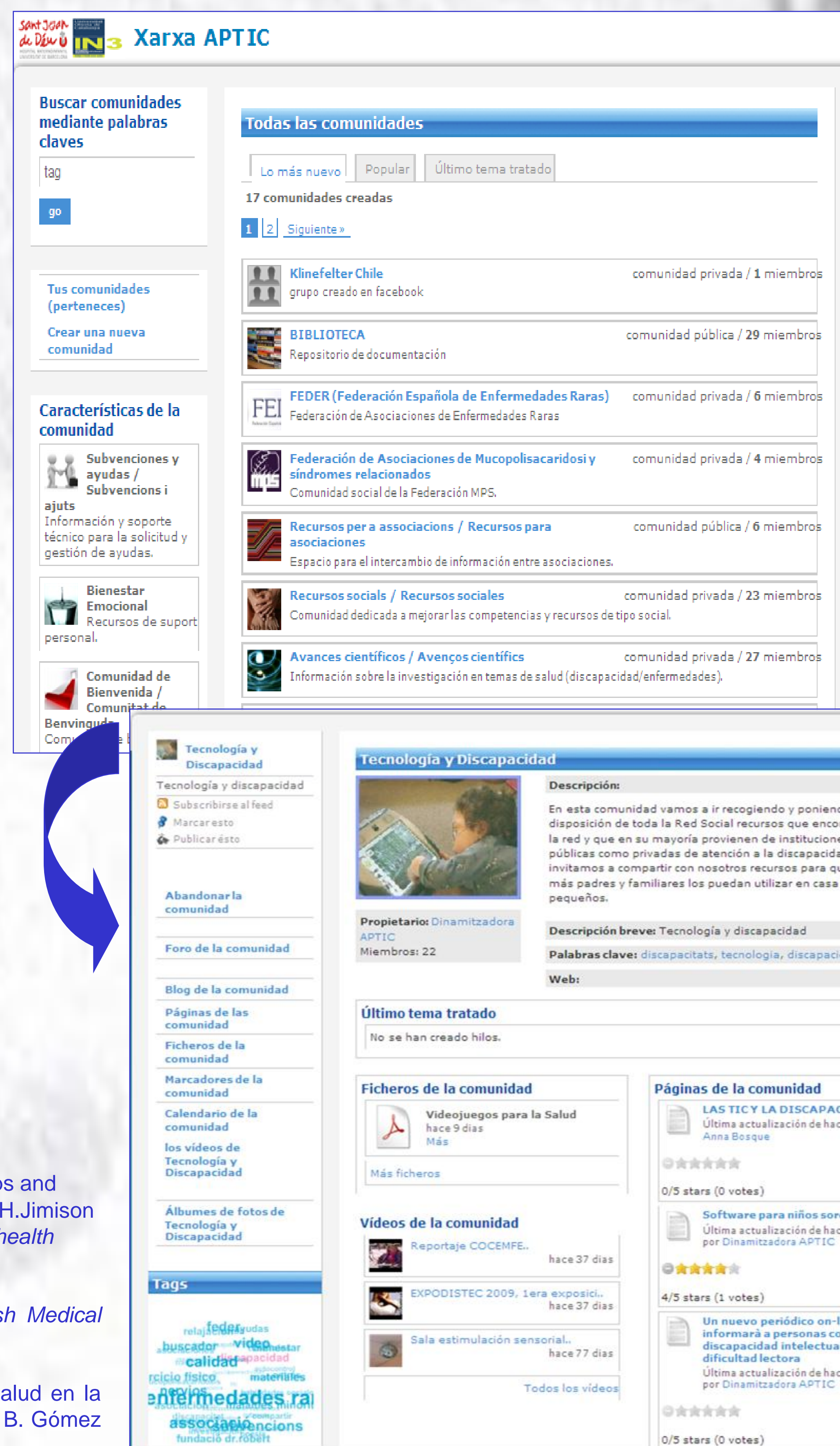
Running the network May 2010

Community coordination

- ✓The role of the community coordinator: a 24h reference for users.
- ✓Sending customized messages.
- ✓Identifying key users and encouraging them to post useful information.
- ✓Creating general communities with useful, accredited and updated information.
- ✓Creating private communities managed by key users.

Restricted access

- ✓Access questionnaire.
- ✓Login and password once the community coordinator has confirmed the user identity.
- ✓Compliance with the *User Guide* and the *Terms of Use*.
- ✓General communities and private communities.



Users: 41 families, 90 professionals

Communities:

- ✓General communities: 'Welcome', 'Diary', 'Social and Economic benefits and grants', 'Library', 'Educative resources', 'Technology and disability', 'Emotional wellbeing', 'Health resources', 'Scientific advances', 'Among us'.

- ✓Associations communities: Espai d'Associacions of Hospital Sant Joan de Déu, FEDER, MPS Spain, ADIAM, Lowe Spain, Klinefelter Chili.

Information:

1456 messages; 97 uploaded files; 44 uploaded videos; 17 debate topics.

Broadcasting actions:

- Mailing (federated associations);
- Facebook group (428 members);personal invitations; press notes, brochure.

Next steps...

- Improve functionalities, specially mobile functionalities.
- Identify and support community coordinators.
- Work for users' loyalty.
- Send the users formative bits.

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