

## **KNOWLEDGE MODELS AS MEANINGFUL AND LONG LIFE LEARNING ALTERNATIVE FOR RARE DISEASE AFFECTED STUDENTS**

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**Abstract.** Rare diseases (RD) are considered all diseases affecting to the same or less than 5 between 10.000 inhabitants, criteria followed by most European Countries. Since most RD incur disabling conditions, patients seldom reach adult life or attend class regularly. However, there are some less serious conditions which are compatible with a better quality of life during childhood and youth. During this period and in cases in which students may attend classes (in person or virtually), we suggest the possibility of using Cmap tools in order to create knowledge models based on most common RD in Navarra. In the context of a natural science class addressing health and illnesses, RD affected students and their mates may learn some of the symptoms, difficulties of diagnostic, treatment possibilities, foundations and research groups of the most common RD held in Navarra (Spain), so that students get to know the characteristics of some of the diseases their mates suffer and will make them be more empathic with them and their immediate realities, making RD sound less rare. By this process, RD affected students feel more creative and valuable for society, which increases their self-esteem. Also the use of Cmap Tools provides items to measure what students know and helps them appreciate how their cognitive structure has changed and developed regarding their previous knowledge, stimulating a meaningful learning and avoiding conceptual misconceptions.

**Keywords:** Rare Diseases, Knowledge model, Concept maps, Cmap Tools, Meaningful learning.

### **1 Introduction**

Rare diseases (RDs) are considered all diseases affecting to the same or less than 5 between 10.000 inhabitants, criteria followed by most European countries. According to EUCERD (European Union Community of Experts on Rare Diseases) the total number of people affected by RDs in the EU is estimated at between 27 and 36 million. Most RDs are genetic diseases, the others being rare cancers, auto-immune diseases, congenital malformations, toxic and infectious diseases among other categories (González and García, 2008) which produce severe disabling conditions, and some patients seldom reach adult life or attend class regularly.

The RDs Strategy of the Spanish National Health System includes seven strategic lines focusing on education and training in the seventh strategic line, in which our proposal could be implemented.

In spite of the lifelong impact which many RDs entail and the unquestionable complexity involved in many of these diseases, we have the moral duty of improving their education considering their right to be educated and take part of a changing society as human beings and develop themselves according to their possibilities, since there are some less serious conditions which are compatible with a better quality of life during childhood and youth. During this period and in cases in which students may attend classes (in person or virtually), we suggest the possibility of using TICs (Technology of Information and Communication) such as Cmap tools. By using this tool we can facilitate their learning by creating knowledge models, which may help them be more creative and feel more valuable for society, therefore increasing their self-esteem.

### **2 Educational perspective for RD affected students**

The educational change that pushes the current context requires a shift in the predominant positive-behaviorist model that favors mechanical rote learning, ideal breeding ground for the existence and maintenance of conceptual errors (González, Morón and Novak, 2001), to another cognitive-constructivist that stimulates meaningful learning to allow students to build and master knowledge, therefore to be more creative and critical (Meichenbaum and Biemiller, 1998). Furthermore, the education of the XXI century needs to face a number of challenges: some come from the so-called society of knowledge and information, which can be summarized in a change of an ethic of obligation for another of responsibility, widespread use of information and communication technologies, the so called ICT, and the requirement of a school, in generic terms, of quality, accountable to society and which encourages in students, future knowledge workers, universal literacy, motivation to learn and discipline for long life learning.

It is in this new context in which the teacher classical role has to change. It is a new concept which is on the basis of education where the teaching dimension (emphasis on teaching or taught in) is subordinated to what it is learnt and how students will learn better and will get what they have set as a target. That is to say, education is a concept based in learning and student-centered. Primary and Secondary Schools as well as Universities have to use their potential in order to promote teaching/learning quality, define adequate learning results and point the way to get them. They are institutions that have to integrate all members of society and provide the tools to perform best practices, assume compromises in order to provide society and especially handicapped members a better service (Villar and Alegre, 2004).

This work pretends to be a proposal to evaluate the effectiveness of using Knowledge models (KMs) to stimulate meaningful learning in students, especially those affected by RDs.

### 3 Creation of Knowledge models (KMs)

KMs are useful tools to create meaningful learning and avoid conceptual misconceptions by means of the elaboration of concept maps applying the program Cmap Tools, software by the IHMC (Institute for Human Machine Cognition) in Florida (Cañas, 2004; Novak and Cañas, 2006). This software allows teachers to generate the conditions facilitating students to transform the information in useful, substantive knowledge, to be integrated in their knowledge structure and in their long-term memory. Students play an active role, not only learning about the product and selecting the information, but through the process itself (metacognition), leaving behind the previous behaviorist-positivist model which favoured mechanical-rote learning and advocating a new model, cognitive-constructivist allowing a meaningful learning and critical thinking.

In order to show respect and deference towards several of these rare conditions affecting some students, who are also chronic patients, we suggest the elaboration of a knowledge model working with concept maps, in the context of a natural science class addressing health and illnesses. It could explain some of the symptoms, difficulties of diagnostic, treatment possibilities, foundations and research groups of the most common rare diseases held in Navarra, so that students get to know what some of their mates suffer and will make them be more empathic with them and their immediate realities, making RDs sound less rare. Also the use of Cmap Tools provides items to measure what students know and helps them appreciate how their cognitive structure has changed and developed regarding their previous knowledge.

#### 3.1 V diagram

The V diagram (Figure 1) has been designed in order to answer the following focus questions:

- Could RD affected students learn significantly by using the software Cmap tools?
- Will they get to know some of the characteristics of the main RDs in Navarra?
- Will society get aware of the need and requirement that all children must have access to a decent education?

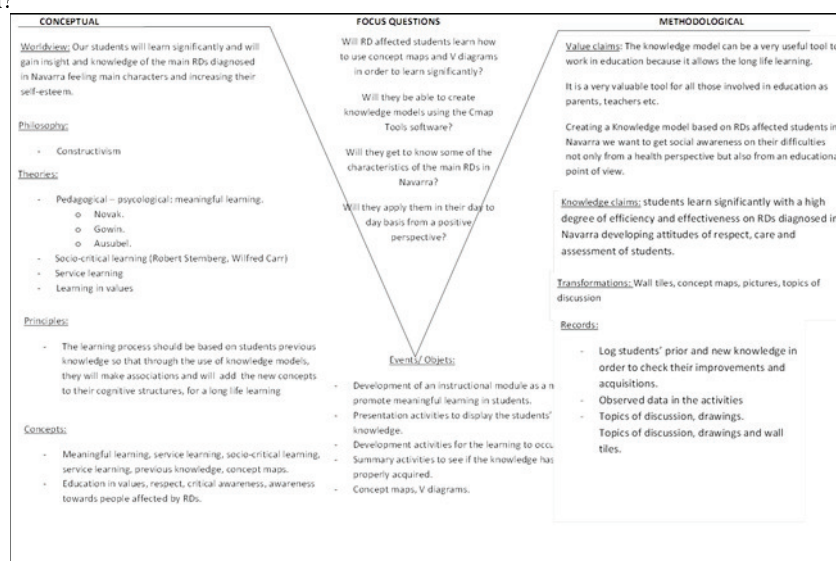
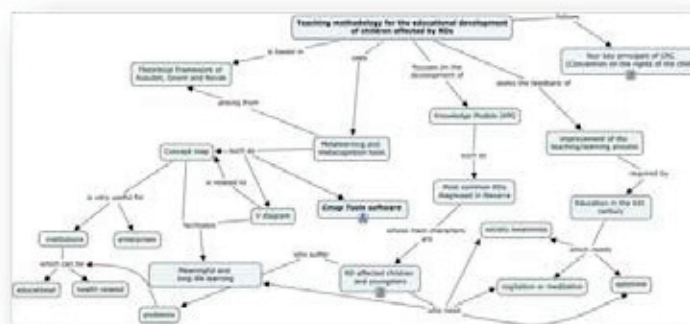


Figure 1: V diagram with the focus questions that highlight the objectives of the work.

By means of this proposal we pretend to give voice to students affected by RDs and try to make them have the same opportunities as any other children to be educated and to live their lives from a wider perspective. In order to fulfill the four key principles of the Convention of the Rights of the Child (CRC), the construction of KMs is provided as a tool available to all children; therefore KMs are built by students and they are examples of meaningful learning and knowledge creative construction (González, 2008; Ballester, 2002).

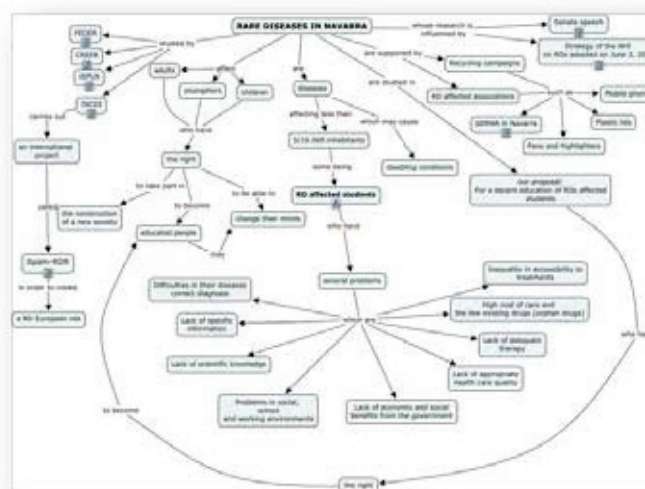
### 3.2 Concept maps (CCMM)

A KM consists of a set of CCMM and digitized resources associated therewith, all in relation to a particular topic. It can also be defined as a collection of CCMM linked to a root map representing increasing levels of specific differentiation. Where appropriate, associated resources (photos, documents, videos, etc.) that are designated generically with graphical icons are linked to the maps' concepts. Subordinated CCMM allow the user to navigate through this model. In this article, we present the KM of "Teaching Methodology for the education of RD affected children". In this root CM (Figure 2) we show all the instructional tools which may help RD affected students get a meaningful and long life learning. Finally in the CM "RDs in Navarra" (Figure 3) the most frequent diagnosed RDs in Navarra are explained, so that any student can learn about their RD affected mates realities.

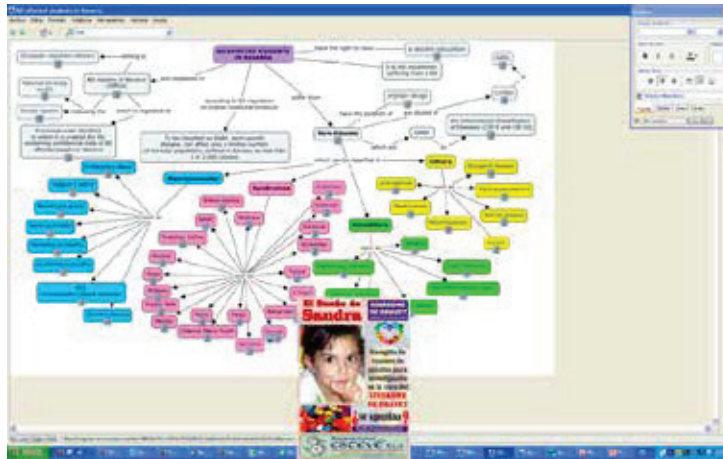


**Figure 2:** Conceptual map of the "Teaching methodology for the educational development of children affected by RDs" based on the construction of KMs.

The process of building a KM on "RDs in Navarra", therefore involves the development of CCMM that represent the knowledge of experts on various aspects of the most common RDs in Navarra. The preparation of these maps can be accomplished through interviews with experts However, the construction of the collection maps is an iterative process in order to ensure thorough coverage of topic maps and faithful representation of expert knowledge (Coffey, Hoffman, Cañas and Ford, 2002; Crandall, Klein and Hoffman, 2006; Ericsson, Charness, Feltovich and Hoffman, 2006; Gonzalez and Zuasti, 2008). Once constructed CCMM, required resources (photos, documents, videos, audio, Web pages, etc.) that best complement and explain the key concepts in concept maps must be selected.



**Figure 3:** Concept map showing the situation of the "Most common Rare Diseases in Navarra".



**Figure 4:** Concept map showing the various RDs diagnosed in Navarra with several deployed resources that correspond to the conceptual map of a specific rare disease (Dravet syndrome) and a photo of an affected child and the campaign of collecting plastic lids in order to use the money for the research of this RD.

#### 4 Summary

This approach forms the basis of the design and implementation of the topic of RDs to achieve meaningful learning of our students, as well as the creative construction of knowledge through modeling of original knowledge. It also pretends to bring the rest of the students, the reality of their colleagues and make the handicapped students capable of constructing their own learning. Evidence to support these value judgments are the results of other investigations (Albisu , San Martín and González , 2006; Ballester, 2008). The KMs built by students facilitate meaningful learning and creative construction of knowledge through a process that is open to facilitate student long life learning. Every student, enabled or disabled has the right to learn for the rest of his/her life (Convention of the rights of the child, 1989).

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