

EDUHEM 2018
VIII International conference on intercultural education and
International conference on transcultural health: THE
VALUE OF EDUCATION AND HEALTH FOR A GLOBAL,
TRANSCULTURAL WORLD

WELL-BEING IN STUDENTS AFFECTED BY RARE DISEASES: A
DIDACTIC PROPOSAL OF INCLUSION

Maidier Pérez de Villarreal (a)*

*Corresponding Author

(a) Public University of Navarre, Pamplona, Spain, maider.perezdevillarreal@unavarra.es

Abstract

Rare diseases (RD) or less frequent diseases affect at least 5 of 10.000 inhabitants. Due to the many disabling conditions, such as long lasting diagnostic procedures or the need of several medical treatments affecting some RD affected children in school age, they usually miss classes and need curricular adaptations. According to data from the INE, there might be 38.000 people RD affected in Navarre and 1300 disabled children, from which at least 372 children in school age could be RD affected. Schools should have the mechanisms to identify these students, as a great part would have special educational needs, derived in some cases of cognitive deficiencies, but in others, of absences forced by treatments and medical operations. Some of them also suffer from the ignorance and bullying of their peers, who scarcely understand their complicated daily routine accomplishment and the incomprehension of their teachers. The use of Cmap Tools software, together with a planned intervention based in Positive Psychology in each school from Navarre, attended by one or more RD affected child, is proposed in this article, for the creation of a Knowledge Model based on the specific RDs affecting children in Navarre. This way, a RD based Knowledge Model net could be built (regional, national and international), together with affected and non-affected students. The net would provide meaningful knowledge and could be useful for any school attended by other children suffering the same disease in Spain or other European countries, specifying the educational needs a child affected by that RD can have throughout the different educational levels. This could become a powerful international tool for normalizing RD and including affected students in the educational field, creating inclusive schools, and therefore spreading the knowledge to the social field.

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Keywords: Inclusive schools, knowledge model net (KMN), meaningful learning, positive psychology pedagogical actions (PPPA), rare disease affected students (RDAS).



1. Introduction

Education faces some challenges in the first two decades of the XXI century. According to González (2018), in the new society knowledge and information will prevail as well as the ethic of responsibility (opposite to the ethic of obligation) and the use of information and communication technologies (ICT) will widespread. The future school will take into account quality, inclusiveness, and will encourage students, to get long life intrinsic motivation to learn, flow in the tasks entrusted, engagement and discipline for universal literacy.

1.1. Context in the educational field

The current context in the educational field, is facing a paradigm change, in which the teacher's classical role has to evolve (Meichenbaum & Biemiller, 1998), being the teaching dimension subordinated to what it is learnt and how students will learn better and will get what they have set as a target. According to Posner, Strike, Hewson, & Gertzog (1982), society needs a conceptual change, since education is based in learning and focused on the students' accomplishments. 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. Positive and inclusive institutions should include all members of society and provide the tools to perform best practices, by assuming compromises in order to provide society and especially disabled members a better service (Villar and Alegre, 2004). In this paradigm, students can play an active role not only learning about the final product, but through the process itself (metacognition). The teacher's responsibility is primarily to create conditions that facilitate a good school climate and make possible the transformation of information in useful and non-arbitrary knowledge, which is incorporated through inclusive concepts in the students' cognitive structure promoting the storage in the long-term memory. This educational frame should be appropriate for all kind of students, emphasizing attention to diversity and the inclusion of all students, especially Rare Disease Affected Students (RDAS), who face difficult situations not only in order to satisfy their health needs, but to focus in their educational needs, being imperative to initiate a mental change in society, which starts at the base of awareness in the initial steps of education, to give rise to empathy, acceptance and inclusion.

1.2. GERNA association

GERNA, is an association which meets people and families from Navarre affected by some of the rare or infrequent diseases already diagnosed or in the way to be diagnosed. It emerged from the need to gather the entire group of families and people with RD, making their common needs visible and proposing solutions to improve their wellbeing and quality of life. The Educational sector of GERNA met with teachers from the Public University of Navarra, with the aim of standardizing a protocol to carry out educational interventions in schools to make visible RDAS, show their reality to their peers and promote awareness as a previous step to avoid bullying, since it has been reported (Arostegui, Monzón, & Ozerinjauregui, 2017), the vast majority of RDAS suffer or have suffered bullying at school. The social awareness and normalization of children affected by RD is as important as the provision of educational methodologies that facilitate their curricular adaptation and their well-being through positive psychology pedagogical actions (Zufiaurre and Pérez de Villarreal, 2016), which encourage their self-esteem and

fosters their learning experiences through mindfulness, flow, engagement and motivation (Seligman and Csikszentmihalyi, 2000) and balances physical, emotional, cognitive, motivational and social, dimensions, which interact together to give a form to the learning experiences.

2. Problem Statement

2.1. Vee diagram and Knowledge Models for helping the curricular adaption of RDAS

The social awareness and normalization of children affected by rare diseases is as important as the provision of educational methodologies that facilitate their curricular adaptation. Constructivism, supported by authors such as Ausubel, Novak and Gowin is the selected learning pathway for this proposal, using the methodology of concept maps (CCMM) and the design of Gowin's Vee diagram, to undertake educational changes. Novak and Gowin (1984), already developed the technique of concept mapping, being CCMM diagrams which indicate relationships between words or key concepts. They are useful tools for describing structures of disciplinary knowledge through hierarchies of concepts or of meanings and go from general concepts to more specific ones and depend on the interpretation and explanation of who makes them sense. Information gets displayed by clicking on graphic icons, which represent documents or other CCMM, and which are linked to concepts. The root map contains resources and is available when downloading the software Cmap Tools, v. 6.03 from the Institute for Human and Machine Cognition (Cañas et al., 2004).

Knowledge modelling is proposed (Novak and Cañas, 2006), as a methodology to be used in primary and secondary school for getting children awareness towards the difficult daily reality their RD affected mates must face, and at the same time it can be useful for promoting meaningful learning and facilitate curricular adaptations. Several research studies (Ausubel, 2002; González, 2008; Novak and Gowin, 2006; Ballester, 2002) have showed the power of CCMM for improving teaching, because it allows the creation of substantive and transparent didactic material; for the diagnosis of students' prior knowledge (Ausubel, 2002), and for getting long life learning through the design of instruction following the current curriculum and its implementation.

3. Research Questions

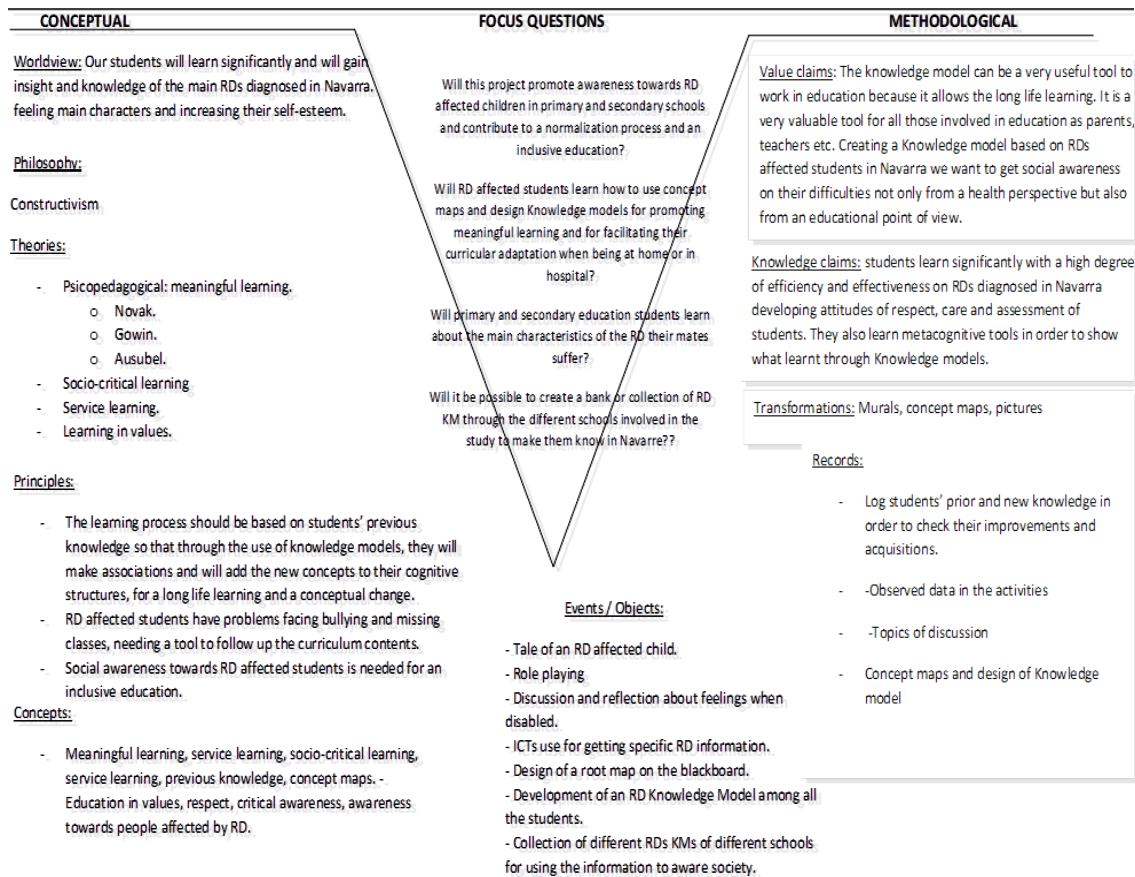


Figure 01. Vee diagram showing both sides, conceptual and methodological, and highlighting the focus questions which will guide the project.

The following focus questions represented in Figure 1 point to the main objectives of this proposal:

- Will this project promote awareness towards RD affected children in primary and secondary schools and contribute to a normalization process and an inclusive education?
- Will RDAS learn how to use concept maps and design Knowledge models for promoting meaningful learning and for facilitating their curricular adaptation when being at home or in hospital?
- Will primary and secondary education students learn about the main characteristics of the RD their mates suffer?
- Will it be possible to create a bank or collection of RDKM through the different schools involved in the study to make them get known in Navarre?

4. Purpose of the Study

The general objective of this work in the long term will be to standardize a protocol to carry out educational interventions in primary and secondary schools, especially directed to the schools attended by RDAS by using PPPA and to create banks of diagnosed Rare Diseases Knowledge Models (RDKM).

The specific objectives are to offer a methodology in order:

- To promote awareness by showing the complex reality of RDAS to their peers, as a tool for avoiding bullying and for fostering empathy, acceptance and inclusion.
- To facilitate curricular adaptations and meaningful learning through the use of metacognitive tools such as Concept Maps (CCMM).

5. Research Methods

The educational intervention, can be implemented in Primary Education schools, in subjects such as “Natural Sciences”, addressing the second content block of the Natural Sciences Curriculum (BON, September 2005), titled, "The human body and health"; in the subject “Social and civic values”, covering block 1 (The identity and dignity of the person), block 2 (Understanding and respect in international relations) and block 3 (Coexistence and social values); in the subject “Mathematics”, covering the content block 2 (Numbers), block 3 (Measures) and block 5 (Statistic and probability); in the subject “Artistic Education”, encompassing the blocks 5 (Interpretation or acting) and 6 (Listening); in the subject “Physical Education”, including blocks 1 (Perceptive motor skills), 2 (Physical motor skills), 3 (Expressive artistic skills) and 4 (Physical ability and health).

The educational agents involved will be GERNA’s families, teachers from the Primary and Secondary Education schools interested in developing the project, teachers from the Public University of Navarre, and some students already graduated from the Degree in Primary Education, who will be the ones hired by the GERNA association to develop the project in the schools.

5.1. Awareness and Empathy

Being one of the specific objectives of this work the promotion of awareness towards the ones suffering rare diseases among the rest of the students, a program has been designed:

- Visit of GERNA’s teachers (graduated students from the Degree in Primary Education).
 - Activity 1: GERNA’s teachers visit the school where one of the students is affected by a rare disease, and explain what rare diseases are and how many people can suffer them in relation to the total population. This way, the students can study quantities, numbers, proportions and units of measure according to blocks 2, 3 and 5, from the subject Mathematics of the Primary Education Curriculum (BON, September 2005).
 - Activity 2: Then, GERNA’s teachers tell a tale “Charly and the power of the invisible” (in print) about one child suffering a rare disease and pose questions to children about how they would feel if they were in his shoes, how they would act... encouraging a debate or discussion among children, according to blocks 2 and 3 of the subject Social and Civic Values.
 - Activity 3: Role playing. GERNA’s teachers hand out different disability roles to each student so that everyone is limited to any of the activities proposed by the teachers. There will be blind students, deaf, with hip mobility problems, with speaking problems, with problems to breath properly... In each activity, as for example, “you have to drink water from a glass of water”, children will have to think if their new state allows them to do it or not. If they can’t, they will have to tell the rest of the students why they are not able to perform that concrete activity and how they feel. Again, in this activity, the blocks of contents 1, 2

and 3 of the subject Social and Civic Values are used, but also, the blocks of contents 5 and 6 from the subject Artistic Education, and the blocks 1, 2,3 and 4 of the subject Physical Education.

- Activity 4: GERNA's teachers will encourage the children according to the role they have played in activity 3, to reflect on what people they may need in their day to day or who they depend on to function throughout the day, as for instance, parents, friends, teacher, caregiver, nurse, physiotherapist. In this activity, the blocks of contents 1, 2 and 3 of the subject Social and Civic values are the ones used.

5.2. Facilitate curricular adaptations and meaningful learning through the use of metacognitive tools such as Concept Maps (CCMM)

- Development of knowledge models: For this specific goal, it is suggested the creation of Knowledge Models (KM) using Cmap Tools software.

- Activity 5: It is imperative students learn the basis of concept maps (CCMM), since this tool will allow especially RD affected children to continue with their school education when they are at home or in hospital due to the consequences of their illnesses. For that, we can start with the family tree (grandfather, grandmother, father, mother, brother, sister...) so that they become familiar with concepts, hierarchies and associations. In these simple CCMM, children can tell if their families have or not a disease, if it is rare or not, if it is possible its healing or there is a treatment.

- Activity 6: To generate a debate about health and disease. At this point, children will be working block 2 (The human body and health) of the subject Natural Sciences, and children can look for information on the specific RD of their mate in their tablets; then, they put it all together and organize the information in a huge map on the blackboard, which will become the root map of the RD Knowledge Model.

5.3. Creation of Knowledge Models Net (KMN)

-Activity 7: Students use the free software Cmap Tools (Cañas, 2004) to create a Knowledge Model (KM). Concept maps are dynamic creatures, susceptible of changes, as long as the students' cognitive structure changes, making new associations or incorporating new and more inclusive concepts. Working together designing a KM, is a way of cooperative learning, compatible with a constructivist philosophy and the psicopedagogical theories of Novak (1998), Ausubel (2002) and Gowin (1981).

6. Findings

For the proposal of the educational intervention to be carried out in different primary and secondary education schools in Navarre, UPNA's teachers designed a general RD based KM to show the project's final goals and the educational process to follow.

The root map of the KM titled "Educational intervention for RDAS" designed for sensitizing and getting to know some characteristics of Rare Diseases in Navarre and the difficulties RDAS must confront throughout their whole life for favoring social awareness, is the basis of the project.

However, the design of KM through different concept maps some of which can be subordinated to the root map, is a reiterative process which thoroughly covers topic maps and represents faithfully the expert knowledge (Coffey, Hoffman, Cañas, & Ford, 2006; Crandall, Klein, & Hoffman, 2006; Ericsson,

Charness, Feltovich, & Hoffman, 2006). Once the CCMM are designed, resources, such as videos, images, audios, web pages, PDF, PPT, Word documents...can be selected for explaining the key concepts.

7. Conclusion

The main objective of this work in the long term, is to standardize a protocol to carry out educational interventions in primary and secondary schools, especially in some of the schools where RDAS study. The second objective is to create banks of diagnosed Rare Diseases Knowledge Models (RDKM) in the different schools attended by affected children, that can be useful for other schools and other students in the same area, or in another county or country. This work proposes the creation of KMs which contain information based on the educational needs at the different levels of RDAS. Each CCMM inside the root map, derives from the foregoing, and powers its meaning. As a metaphor, the KM is a skyscraper, built with concrete (which is the meaningful learning). It is unique, original, and it is open to any improvements and any addition of new concepts enriching the meaning. CCMM are useful for identifying, understanding and organizing the main concepts we want to transmit and also for itemizing the associations among concepts conforming propositions, which are the basic understanding units of CCMM (González, 2008). Also, when students create CCMM we can get to know what he/she already knows about the topic or related topics, if they have added new concepts to the root map, and if they have made some research on a specific concept, since exploring and investigating are very important tasks for getting the domain of knowledge (Meichenbaum and Biemiller, 1998). The use of CmapTools and the building of their own knowledge, provides students with resources to acquire significant learning, change their cognitive structure at the time it energizes their learning, and enable them to adapt to the rest of the class, despite the abstention of school associated with their disease. The experience of cooperating for building a huge KM, causes positive feelings on students (Pérez de Villarreal, Cano, & González, 2015), and after overcoming cognitive conflicts they tend to realize a change in their own cognitive structure, lasting in the time. Also, the Positive Psychology Pedagogical Actions (PPPA), such as the application of the Four Saps Model (Seligman and Csikszentmihalyi, 2000), promote mindfulness, flow, engagement and motivation, which all together create a class climate, incompatible with bullying.

Finally, being Cmap tools a free software, it can become a powerful tool for allowing children and adults socially and economically marginalized, to be able to learn meaningfully at the same level as in private and subsidized centers, which helps inclusion and education for all. According to the Convention of the rights of the child, every student, enabled or disabled has the right to learn in a meaningful way for the rest of his/her life. This first step of creating RDKM, can be useful for fostering an egalitarian, inclusive and just society, as education is the centre of a network that opens up to the world and breaks the differences of classes and status.

Acknowledgments

We thank people from GERNA who provided insight and experience for the work and the UPNA research group "Holistic and Integral Education" for their support and expertise that greatly assisted the research.

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