Towards a Roadmap for implementing a Socio-constructivist learning framework for chronically ill children to learn with their classmates while still in hospital

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In this chapter we aim, primarily, to look at the educational status of children and young people suffering with a chronic illness, whose forced separation from the school environment together with the illness itself, highlight a set of specific needs which, cannot always be covered by the teaching staff in the Hospital Schools and the Home Care services. The problems that these children face is discussed together with how their specific needs can be addressed with the use of different types of information technologies, more commonly known as Web 2.0 tools, which in turn support a social constructivist learning framework. Furthermore, we have employed a Delphi methodology to consult with key stakeholders and then to construct a Roadmap about how to implement the effective use of ICTs to support the education of children who suffer from these chronic illnesses.

Keywords: Hospital Schools, Socio-constructivist Learning, Information Technologies, Roadmap

1. Needs and educational constraints of children and young people suffering from a chronic illness

We know that serious illness can cause serious disruption to child’s life. This is because a prolonged period of illness is not the norm for children and if hospitalization is required, it is particularly stressful for the child. This is due to the fact that the child must accept the new role of becoming a patient and has also to adapt to a series of circumstances which are new and bewildering together with functioning in an environment which is quite different from the one that s/he is used to. There are other stresses too, such as treatment procedures, anxiety amongst family members which the child has to cope with, together with missing out on the regular school routine.

It is not only hospitalized children but also those convalescing in their own homes who share this separation from their school environment and thus from their classmates. The physical, psychological and emotional side effects [1] which separation from school can bring with it for these children can place them at an educational disadvantage with respect to their classmates [2].

In this work our aim is to deal with the particular needs of children with chronic illness, due to their discontinued presence in the classroom. Among those whose work is dedicated to these children are the teachers at the Hospital Schools and those who work in Home Care services. We have consulted both these groups in building our roadmap, which pays particular attention to a variety of needs and constraints which are derived from:

- the emotional upset of the illness which manifests itself through insecurity, low self esteem, sadness or depression, resulting from having left their so called ‘normality’ and are no longer certain about what the future holds for them.
- the separation from their school environment which also includes friends and classmates. This also contributes to sadness and low self-esteem due to the fact that relationships become less and less intense and frequent.
- the need to interpret what is happening to them. Ignorance breeds fear. Letting them know what is happening and how it is going to happen prevents pain and brings serenity. Faced with the uncertainty that the situation causes them, adolescents search the Internet [3], possibly somewhat chaotically and without using rational criteria.
- a need to prevent a delay or failure at school given the decline in the pace of learning, due to the illness. As the Convention on the Rights of the Child stipulates, every child has the right to pursue his schooling during a stay in hospital.

Figure 1 illustrates the needs and constraints mentioned above as a 4-quadrant diagram.
2. Types of needs and educational strategies to meet the different needs

Leaving to one side health and medical concerns, which would be important to integrate with educational needs, in a joint action based around the sick child, we can summarise the educational activities which have been included in the previous four categories, as summarised in Figure 2, which we will explain in more detail below.

2.1 Activities and strategies aimed at reducing emotional effects

Psychologists assure us that when adults are faced with pain or depression in children they seek, by way of cognitive and emotional processes, to create empathy with the children and with their families. The most effective way to foster confidence in children is by becoming close to them, allowing them to share their weaknesses and fears. Sometimes the anxiety felt by the adults who care for the sick children is so great that instead of supporting the children, this worry overwhelms them and promotes insecurity and low self-esteem. This is a natural reaction since sometimes the situation is very upsetting and fear some for the families [4]

More and more effort is being made to cover the psychological and emotional needs of ill pupils: the web pages of hospital classrooms show great progress is being made with respect to this objective. For example by suggesting different types of entertaining activities which help to distract the children, this is because dwelling less on their illness reduces their anxiety, depression or physical discomfort.
Among these types of activities we have observed that quite a few are geared towards enhancing multiple representations of a given reality. We would like to focus particularly on those which are aimed at boosting children’s creativity. We do not consider it useful to propose the repetition of a given model more or less perfectly, but rather to foster divergent thinking, a task which we should all take very seriously[5].

One way to do this is to make use of computer applications which allow children to express themselves in different languages: drawing, inserting images in documents, making up little stories (storytellers), etc. Moreover they allow them to project their fears or fantasies and thus reduce their anxiety [6].

2.2 Activities and strategies designed to maintain the relationship with the school and friends

Different authors insist that it is very important that a total disconnection of the child from his/her school should never occur, and thus maintaining contact with friends is always healthy. It is also of benefit if sick children maintain a connection with children in other hospitals, since children with problems which are the same as or similar to their own, also tends to be advantageous.

Platforms are being set up to facilitate the exchange of messages between children and their classmates as well as to encourage the use of blogs, forums, Instant Messenger, Facebook, Twitter, etc. Nowadays we benefit from artefacts and computer applications to make this constant communication with peers possible and from an early age, children are capable of using them comfortably. We can make use of new technologies to mitigate the loneliness and isolation suffered by the child who is absent from school and from the home environment. Internet connection is becoming more and more ubiquitous and communication is becoming more visual (Skype, videoconferences, etc.) and not only verbal. This will especially benefit the youngest children, who are not yet skilled in writing, even if it in an abbreviated language.

2.3 Activities and strategies aimed at maintaining their academic performance

One of the aims of the Hospital School is to offer children a place where they can continue with the normal course of their school activities, without experiencing important delays in their academic progress. Particular emphasis is placed upon preventing the marginalization of the educational process for those children of school age who are in hospital or who are convalescing for long periods of time. We know that some children do not begin to display learning difficulties until several years after their treatment has finished [7], [8]. For this reason the Hospital Schools have started to tackle this problem from a proactive rather than a reactive standpoint. That is, not waiting to intervene just when the child has failed at school but rather trying to alleviate matters before they happen. Preventative interventions can be incorporated into the child’s education before the total impact of the delayed effect is established.

We would like to point out that the more sensible option during periods of absence from school is not so much trying to follow the specific curricular content of the different subjects at the pupil’s educational level, but rather to focus on the promotion of certain skills and cognitive competences.

The generic skills which should be acquired or refined first should be those associated with the use of computer tools in order to write, draw and communicate in a general way hence acquiring a set of generic skills which will be beneficial throughout their school lives and beyond. More and more children already master many of these types of computer applications but their stay in hospital or at home could present an ideal period in which to become more proficient in the use of any one of them.

Furthermore, promoting mechanisms for relating, recalling, solving problems, and paying attention to a particular activity over a prolonged period of time could prove very useful given that the lack of stimuli from their school, social and emotional life is especially detrimental to these types of cognitive skills. Furthermore, the families are rarely aware of the possible connection of promoting these skills while the medical treatment is being followed.

2.4 Activities and strategies aimed at getting to know to know one’s own body works

Different studies have shown that when a patient possesses more information about his illness and about the treatment he is receiving, his health improves. By health, we mean the complete state of physical, mental and social wellbeing, and not only the absence of conditions or illnesses [9]. Arnau et al [10] said: with the implantation of the health education programme we wish to reduce the anxiety the patient suffers due to the lack of information and knowledge, as well as the readmissions arising from a lack of self care. As is pointed out by the Group of Educators for Asthma, quoting Ronchetti et al. [11], using an educational intervention for children with asthma, the number of emergency treatments of children who suffer from this condition is significantly reduced [12]. We also know that health education reduces anxiety in young patients who are going to undergo a cardiac catheterization. The patient is clearly able to cope with the procedure when they understand the test. We know that health education leads to a statistically significant reduction inpatient anxiety [13].

It is more and more common for nursing staff to incorporate health education or education for health in their work protocols. The aim is that patients start to comply with the medication and medical regime that has been designed to alleviate their symptoms. Therefore, educational interventions which are designed to improve the patient’s nutritional
guidelines and to improve his self-care [10] are carried out, to increase the probability of the treatment being followed through [14] or to reduce the anxiety associated with some more or less invasive diagnostic tests [13]. Studies carried out have shown that patients’ health improves.

In the field of paediatrics, the explanations offered by the medical and healthcare staff about the children’s medical state should complement the educational work carried out by the hospital schoolteachers. Medical terminology is a far cry from being easily understandable to a child. Skill and experience in communicating with children, in knowing the concerns of each one, comes from the teachers who are in contact with them; thus we must call for the involvement of the teaching staff in helping to make the explanations received from healthcare personnel understandable.

Health education has two fundamental objectives:

*To prepare people to take informed decisions which favour health and, to achieve their participation in the educational process through a critical attitude and an implication in decisions which favour health [15].*

With health education we aim to teach knowledge, lifestyle habits and healthy attitudes to improve individuals’ health and wellbeing.

If we propose to impart health education in ordinary schools it should be for all pupils. There is no reason why it should be relegated to the care of healthcare personnel in the case of sick children.

One of the teachers’ tasks is to achieve, via the different curricular areas, the primary goal of children evaluating and correctly situating the real dimensions of their illness [16].

Children, like adults, spontaneously construct a mental model of their illness for themselves, about how their body works and what part of their organism has stopped it working correctly. In order to learn to live with their chronic illness (be it diabetes, kidney failure, asthma or other chronic conditions) it is essential that the children have built a mental model of the illness and of its evolution which is as close as possible to reality. In order to reduce levels of stress, anxiety and depression [17] educational interventions should be adopted which are not aimed at distracting patients or making them forget, but rather towards the acceptance of what they know to be true. Protecting the patient from imaginary situations or suppositions by offering him truthful information about his illness is beneficial, as the research quoted above has shown.

2.5 Returning to school as an expert

We know that being back at school is good for a child with a chronic illness. School tends to be the place where the chronically ill child demonstrates his/her skills and abilities. The hospital or family home can provide an adequate context in which to become an expert in a variety of skills. We believe that Grau [18] was right when she says that: It is important that the child experiences his/her return to school rather likes/he was returning from a long trip, from which s/he has lots of stories to tell, and the teacher should take advantage of this excellent opportunity.

For this purpose, it is interesting to hear Ann G. Bessell’s account [19], of trying to preserve her son’s education, after he had been diagnosed with leukaemia and her fight to foreground his regular schoolwork and knowledge acquisition so that he could maintain a semblance of a normal life. Bessell says: “Jonathan was very excited and determined to return to school, but soon began to experience the isolation of someone who was “different. His optimism never wavered, but he became upset and frustrated when no one seemed to care about his schoolwork. Teachers would not collect his homework or would avoid giving him class assignments. It appeared that the pervasive attitude was to minimize the importance of his education”

Unfortunately, when children are excluded from school or they are not provided with educational opportunities, they are being told that there is no hope for them. Bessell’s account continued:

“My son was fighting for his life and he perceived his problems as opportunities to allay fears and educate others. He would explain his illness in great technical detail and he would quote optimistic statistics concerning his positive prognosis”

3. Didactic proposal

From this perspective we launch a proposal which will encourage pupils to become “experts” in the knowledge of their own or some part of their body. This raises a number of diverse challenges but nowadays we have the technological media to realise this goal. It can become possible for the children to go back to school and explain in detail many of the things which they have learned while absent from the school environment. They may have become familiar with topics from the Natural Sciences such as the three vital functions of living beings (nutrition, interaction with the environment and reproduction) and, depending on the children age, with the cellular structure.

They might have learned how a particular organ of their body works and in the course of acquiring this specific knowledge different needs might also being attended to such as:

- Improving in self-esteem: placing him/her in good stead with respect to his/her classmates
- Improving self-efficacy: realising that they can learn something and teach it.
Understanding and learning something they care about knowing, thus making sense of their condition. Their main interest is to know about their own body. Their biology, anatomy and physiology are the most important in this respect and moreover this knowledge can be shared.

- Reducing their insecurity by introducing certain rationality into their health behaviour, as they have a certain idea of the reasons for their treatment.
- Acquiring skill in the use of ICTs for educational purposes.

Various studies [20], [21] bear witness to the fact that, using ICTs oriented towards teaching, we can involve those children who are demotivated from learning whilst improving their self-esteem.

3.1 The incorporation of ICTs with chronically ill children and the socio-constructivist approach to learning

Although contact between classmates may not have been lost thanks to mobile phones, on-line forums, Facebook, email, etc. we know that deep learning is achieved by constructing Knowledge together as a community of learners. At this moment in time it is no longer necessary to wait to go back to school to share knowledge with one’s classmates, nor is normal e-learning enough. In order to share knowledge and build it together we can avail of computer tools which allow for the teaching of content which situates the young patient in an environment where socio-constructivist learning can take place.

Pupils all over the world are being provided with digital content via a VLE a webpage and there is currently enough data to evaluate this type of implementations. Given the high level of development observed in different hospitals in Australia and the level of analysis and research on its effectiveness it is worth present the findings from two projects set up by the Royal Children’s Hospital (RCH) Education Institute [22] of Melbourne in order to meet the educational needs of children suffering from chronic illnesses. These are known as the WellCONNECTED[23] and ‘Back on Track’[23] projects. Moodle platforms, or equivalent VLEs, have been used to deliver digital teaching materials, to pupils with chronic illnesses and chat sessions were also organized. Some pupils however complained that in spite of regularly receiving the work they needed to complete, they missed the teacher’s explanations in the classroom as well as the discussions with their classmates, about this work. They considered that references to textbooks were not an adequate method of obtaining information and these types of activities could not substitute the learning opportunities which take place ordinarily in the context of a classroom [23], where interaction with classmates can help building knowledge.

Communication technologies including videoconferencing by webcam, interactive digital whiteboard, with classroom management programs and shared use of applications were finally considered the ways to offer opportunities for a real socio-constructivist learning during the treatment and recuperation of pupils with chronic illnesses. And these were successful ways to alleviate these children’s particular learning difficulties which were due to their absence from the physical classroom.

4. Can we transfer these practices in reality?

The educational proposal outlined above is no mere chimera. Technically it is already possible to build knowledge in conjunction with the teacher’s explanations and sharing and debating with classmates. We can see to it that children with chronic illnesses, remaining in hospital or at home, participate in class sessions and that they can contribute their skills and be allowed to shine in certain areas.

While all this is possible, one must not only be willing to use these tools but also be proficient in their use. To this end, from our centre, CRECIM, Ms.M. Saez from our centre CRECIM, and Dr. D. Whitelock from the Open University are working on a Roadmap describing the steps which must be taken to achieve this goal, and to document the obstacles which will have to be overcome in this process.

4.1 Collaborative construction of a Roadmap

In order to build this Roadmap we have followed a Delphi methodology, asking, via a series of questionnaires, and then using the findings to ask the experts to reach a consensus about their vision for ICT usage in supporting the education of chronically ill children. Particularly in the field of science education [24]

The educational Experts who were consulted in this field included both kinds of teaching staff (hospital and/or home care), hospital health care personnel (doctors, nurses, psychologists) or policy makers and other educational authorities, such as researchers in hospital pedagogy, in the teaching of sciences, in the design of educational materials as well as the responsible technicians in the different Autonomous Communities, members of NGOs or Associations of patients.

According to the data collected, we can state that, practically (98%), all the professional groups consulted (teachers, healthcare personnel, educational administration personnel, researchers and others) coincide in saying that young ill people should be able to use ICTs to continue their education process, whether in hospital or at home and avail of an Internet connection in order to communicate with their family, classmates and friends.
However when the possible uses of ICTs are made explicit, it can easily be deduced that ICTs are fundamentally seen as a means of communication (with the reference school to send/receive class work, with family, with peers, etc.) more than as a medium of information, as support in the face of emotional upsets (e.g. improvement in self-efficacy) or as a stimulus to acquire some cognitive abilities (relating, classifying, organizing information, etc.) or of some skills (except skills in the use of ICTs). This does not mean that few activities are being carried out for this purpose, but that ICTs are not being used for them.

In relation to content, consensus also exists about what should constitute the basic foundation in Natural Sciences, which may be the object of the educational materials, in relation to the knowledge of the human body. Such content will be adapted to the pupils’ ages. The essential thing is to situate the knowledge within a generic outline to which new content can be added:

- Nutrition function (Ingestion, Metabolism, Excretion) aimed especially at children suffering from kidney, heart, metabolic, or respiratory conditions, or with eating disorders, etc.
- Interaction with the environment especially for those suffering from neurological, ophthalmological, or auditory conditions, and of all the organs necessary to capture signals from the environment (external and internal) and for responding to them.
- Reproduction function especially designed for young people with genetic conditions.

For more advanced pupils, knowledge of the cellular structure could be of use to them in order to understand certain illnesses.

4.2 Time line of actions for the implementation of the Roadmap

The suggestions made by the participants in the study to construct a Roadmap for the teaching of the sciences to chronically ill young people using ICTS has been incorporated into to our didactic proposal for the design of materials about understanding the healthy human body. But they could be applied to other areas of the curriculum.

The time line for this implementation falls into three main phases, which are, based around the following activities:

- Provision of infrastructure;
- Formation of multidisciplinary teams to carry out the tasks necessary for the project and to evaluate the same;
- Researching the benefits of such a project, together with the identification of both the challenges and obstacles that need to be overcome.

Parallel with these activities will be the hosting of all the outputs from the project which include the teaching materials on a newly designed web portal, together with other products which are considered suitable for being hosted in virtual repositories.

This first version of the Roadmap which the experts agreed upon includes the following steps:

1. Provision of adequate Infrastructure to ensure secure Internet connections combined with the installation of appropriate hardware and software.
2. Preparation/maintenance of a web portal to host the materials, with a webmaster for updating them.
3. Computer application training: including diversity of Open educational Resources and the pedagogical affordances of these applications.
5. Compilation and selection of existing digital material. That matches chosen subject suitable for a school sciences curriculum.
6. Familiarization and, if necessary, training about the topic chosen from the Natural Sciences curriculum as viewed from the perspective of the three vital Functions of living beings:
7. Customisation by the multidisciplinary teams, of digital sciences materials specifically applicable to young patients. A distribution of topics among different hospitals could be considered. Or also among Autonomous Communities.
8. Refining and Opening the virtual repositories and the web portal for professionals where both new and selected existing materials are hosted.

The roadmap could vary for each Spanish Autonomous Communities, or for each hospital, depending on the possibilities and the personal and political willingness of those responsible for setting it up and running it. Figure 3 presents a time line of the tasks to be carried out.

5. Final Remarks

In this paper we have reviewed the pertinent literature, and have illustrated the benefits which can be obtained from the use of information technologies in hospitals and in the homes of children and young people with chronic illnesses. We have pointed out that it is not enough to use ICTs per se, but rather that attention must be paid to the pedagogical affordances of the range of applications which are available. In this way ICTs can play a role in the optimization of

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It is difficult to influence self-esteem but it is possible to do so with self-efficacy. McConville [25]
pupils’ social relations, the socio-constructivist acquisition of subject matter, and the improvement of pupils’ understanding of their own illnesses, in turn providing an opportunity to improve the young patients’ self-esteem. In this way they will be supported to become “experts” in how their bodies function, with respect to their own illness.

Bearing all this in mind, we have constructed a didactic proposal with the following objectives:

1. To provide computer support to chronically ill children so that their absence from school becomes a period to promote particular cognitive abilities and develop certain skills. If the computer resources can help each pupil to progress at his own pace, we should not restrict them by imposing the teacher’s timetable upon them.

2. To provide information so that the pupils can construct appropriate mental models about the functioning of some parts of their body, to the level of education or maturity that each one reaches.

3. To allow pupils, in certain subjects or in certain designated periods, to learn with their classmates in an environment that supports the social construction of knowledge assisted by adequate communication technologies (which currently include: video conferencing by webcam from the individual laptops and digital whiteboards).

4. To contribute to improving the patients’ or convalescents’ attitude to adapt to their illness and not to be deprived of their previous social and meaningful life activities.

Furthermore, we have employed a Delphi methodology to construct a Roadmap about how to implement the effective use of ICTs to support the education of children who suffer from these chronic illnesses, within a three year time frame.

This work requires an immense effort on the part of the hospital and Homecare teaching staff who should be given the recognition for this important endeavour, which is in turn richly deserved.

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Figure 3. Time line of the tasks to be carried out, according to the designed Roadmap [24]
References


