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## Uses of Information and Communication Technologies by hospitalized pupils: what humanization?

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### Abstract

The aim of our contribution is to understand the way pupils who suffer from chronic illness use new Information and Communication Technologies (ICTs). The main question was: does the ICTs in Education contribute to the “rehumanization” of schooling? This research was based on 60 semi-conducted individual interviews. ICTs lead professionals to think about humanization in its practical form. ICTs seem to have positive effects on “well-being” for students in a hospital schooling context. In contrast, humanization of ICTs in the hospital setting does not necessarily seem to go through virtual social links.

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## **1. Introduction**

### *1.1. National Context*

In France, in the field of health, Information and Communication Technologies (ICTs) play an important role at all levels; patient, professional, political and scientific [1]. With the “Hospital Plan 2012” [2] in modernizing hospitals, the diverse calls for projects of “ASIP Health” (an agency for information system shared health care), “CNSA” (a system of government funding for the ageing population and people with disabilities), the deployment of Health ICTs solutions is reinforced in the sanitary and medico-social structures and establishments. The numerical Hospital program launched by “DGOS” (General management of care provision) in July 2011 [3] defined the national strategy of hospital information systems for 2012-2016.

### *1.2. The research problem*

In a political domain according to equal schooling opportunities for people who are handicapped (stated in the law of 11 February 2005) [4], what access do hospitalized children and teenagers have to schooling? What is the role of ICTs in their education? Is the continuity of schooling facilitated by ICTs? What are the potential advantages of ICTs in the humanization of young patients during a long-term hospital stay? Firstly, it can reduce social isolation and schooling exclusion. Secondly, it can limit the stigma of illness, by socialization and therapeutic effects.

Children and teenagers build their career pathways on the basis of their current situation in which continuity and meaningful association play a vital role. Between the succession of painful events and interruptions in schooling and biography of children and teenagers who are hospitalized. Our aim was to know if there were gains in depth and consistency through the ICTs and the benefits to the individuals and their school and biographical pathways. In this case, the main question was: Does the ICTs in Education contribute to the “rehumanization” of schooling? It is often feared that this can contribute to the “dehumanization” of schooling and the creation of “digital students”. In this paper, we define (re)humanization as the shift of the context of care by the students hospitalized, running through ICTs. Therefore, this shift helps them to restore a learning environment at the hospital, and makes them actors. In this sense, ICTs are an enabling factor of (re)humanization of the school at the hospital.

As indicated in the European Charter of rights to education for children and adolescents in hospital and at home [5], new technology should be included to avoid isolation of the student. Moreover, the policy for the new school year of 2011 stated that: “the development of digital use initially depends on the provision of digital workspace which offers a simple and secure framework for internet usage in schools and reinforces links with families”.

## **2. Methodology**

After three trial interviews, this research was based on 60 semi-conducted individual interviews (with teachers, professionals in education, manager of school and pupils aged 8 to 17 years), which were recorded. These interviews were directed by guided questions. In order to facilitate a practical approach to the usage of ICTs, we asked students for a “demonstration” of their computer usage. The goal was to keep this exchange simple and concrete. The interviews were transcribed and data was entered using AtlasTi software. Two types of analysis were conducted: thematic content and interpretative. These methods of analysis were chosen to provide a better understanding of thought processes and actions of students in their daily use of ICTs, highlighting the different forms of usage.

### **3. (De)humanization concept of “ICTs in Education”**

Like all introductions to major innovations in society, ICTs has always provoked as much obsession as reluctance in its usage. Moreover, with the onset of the internet, researchers of social sciences hold two radically opposed arguments. On one hand, technophiles, such as Lévy [6], puts forward the notion that the internet allows a “collectivization” of consciousness, a “noosphere”, using the terminology of Teilhard de Chardin [7], a collective intelligence and improved communication, which is abundant and transparent. On the other hand, authors have criticized the “cult” of the internet, which causes one to neglect their body, such non-involvement. It is related to the deterioration of real social links in favor of the virtual links [8], the omnipresent communication and performance of goals [9]. The emergence of ICTs in education has provoked and continues to feed into a number of debates on the efficacy of the usage of technologies in learning and the role of technology in education.

The “non-human” characteristic of e-learning is often evoked. In the same way, beyond pedagogical interest, the partnership of distance education with traditional classroom education with the goal of creating links is often generated. In the field of health, the ICTs has equally ignited many debates.

Much research [10]; [11] has focused on the usage of information and communication for specific illnesses within forums. These surveys highlight the role of patients in the management and treatment phase as well as the exchange of medical information. Other research mentions the role of ICTs (in education) for disabled people. In our research, we observed a compensation effect for people with neuro-motor impairments.

### **4. ICTs adaptation for the health and well-being of young patients**

ICTs lead professionals (doctors, occupational therapists (OTs), teachers and managers of institutions) to reflect on humanization in its practical form. OTs work on the adaptation of new technology for people with physical impairments, such as adapting the pupils’ wheel chair, so, they can use their laptops, there also work on fine motor movements and innovations such as computer mouse control with their little finger or via, eye or tongue movements OTs are not alone in their work and innovations in the adaptations of ICTs. Teachers also assist pupils with impairments in the form of micro-innovations. Such work has been described by E. Von Hippel [12] as ascending innovations or innovative use. That is to say that teachers in observing and listening to their pupils are actors of innovation. For instance, a technology teacher created an innovation for pupils with motor impairments allowing them to be more autonomous if a bug attacked their personal computer. The amateur system allows pupils to simultaneously press three keys on their keyboard (“ctrl+alt+del”). The micro-innovations of teachers are multiple and are not restricted to ICTs.

A sports teacher was lead to construct himself a piece of wood adapted to wheel-chairs in order to be able to score goals. In the same manner, an art teacher invented an extendable paintbrush that pupils could hold in their mouth to allow them to paint. Finally, teachers have voluntarily created a lot of micro-innovations in a pragmatic and intuitive way to help the students manage their constraints.

The use of ICTs by teachers also allows adaptations. Again, a sport teacher explained to us that he used recorded auditory and visual videos to help pupils in wheel chairs understand the rules and strategies of sports games. These rules were specific to handicapped members of the group. A lot of teachers also insist on the benefits of instructive learning software for people with cognitive difficulties. In particular, this software provided pupils with a framework for doing exercises. According to one teacher, instructive learning software favors an environment that is entertaining and encourages students to do exercises, rather than discouraging them. Furthermore, this teacher adapts herself to the cognitive difficulties and diverse impairments of students. Each pupil has his own personalized laptop. For example, a student with

a significant visual problem has a special configuration with enlarged characters and a magnification system.

For teachers as well as principals, ICTs isn't an end point. It has above all a pedagogical role. During the interviews with teachers, it was revealed that the ICTs have to allow children and teenagers, to open themselves up to the outside world. The new information and communication technologies are employed based on pedagogical needs and also the pathologies of pupils. Regarding the usage of technology in class, all teachers insist on individualizing their programs. The classes are small, in general, between 6 and 13 children maximum. The ICTs reinforces this individualization and appears to favor it.

In general, teachers recognized the positive role of ICTs. They felt that it not only helped children to overcome their handicaps but that it also made students feel they were following a school curriculum that was similar to their counterparts in regular schools.

We were able to highlight different forms of ICTs usage in relation to types of pathologies. Based on discussion with doctors and teachers, for addiction pathologies such as games and cyber addiction, the use of ICTs is very limited. For such addictions, pediatric hospitals and medical centers (CMP) are in a delicate and ambiguous position. Those, whom we were able to interview, suffered from digital isolation and gradually lost social links with peers and family. They sought refuge in a digital world, especially video games, as reported by one interviewee who would spend his nights playing such games in his old college. In contrast, for disorders such as school phobia, agoraphobia and hyperactivity, the usage of ICTs is clearly recommended. For such disorders, ICTs stimulate concentration and the desire to acquire new knowledge. In this case, ICTs in education provide reassurance and an extension of a familiar context. There are two distinct types of technological adaptations for students who are in hospital, one for physical handicaps and another for psychological problems.

Table 1. Forms of ICTs usage in relation to types of pathologies

Types of pathologies	Forms of ICTs usage	Roles of ICTs	Predominant effects of ICTs
Cyber addiction (Games addiction and cyber addiction)	Usage limited	School usage only	Reasonable usage to avoid digital isolation and gradually lost social links with peers and family
Disorders (School phobia, agoraphobia and hyperactivity)	Usage recommended	Concentration and desire to acquire new knowledge	Reassurance and an extension of a familiar context
Physical handicaps (Visual handicaps, disable motor)	Usage recommended	Concentration and desire to acquire new knowledge	Creativity, escape and autonomy

## 5. (Re)humanization of ICTs in Education: ownership, creativity and escape

Sociology of usage demonstrated the complexity of different forms of ownership and acceptance of ICTs. Usage depends on both technological and social frameworks. In the case of the hospitalized students we met, (re)humanization of ICTs is seen at the level of ownership and acceptance, creativity and the sense of escape it provides.

In terms of usage and skills, young hospitalized students seemed to have habits and practices relatively similar to those of young people outside the hospital setting. We find that the basis of a digital youth culture is a sociability based on ICTs and mediated identity construction [13]. The practices of the young people as measured through semi structured interviews and observations in situ are largely focused on communication and playful games and web searches. Despite having better equipment, the skills demonstrated, did not appear better than those of young people in the hospital setting. The only notable

difference, is the context in which young people experienced change: specifically, temporal and spatial (a hospital space excluded from the outside world).

However, for people who present with such complex trajectories and suffering, the skills acquired (while similar to other young people) seem to improve their status. We were able to observe an increase in autonomy through the usage of ICTs, which was for them a “tool for growing” (an independent space away from their parents). The majority of them were proud to be able to learn about computers given their surroundings. In the framework of lessons, students evoked the idea that ICTs in education lead to more concrete work in performing gratifying tasks. It is the sense of escape for students that contribute to the (re)humanization. Many have quoted online travels and possible discoveries in using ICTs. Its usage constitutes a release from daily life in hospital.

Auto-publishing also seems to be a contributing factor in humanization. A male student revealed an entry from his diary recalling his previous experiences to highlight this notion. This piece of writing acted as a mediator between the computer and the internet, and had direct and indirect effects on the student’s self-esteem and his personal and social identity. This personal form of writing is often shared and induces reflection.

For the above reasons, ICTs seem to have positive effects on “well-being” for students in a hospital schooling context. We observed a reduction in the loss of landmarks. In particular, in the suffering and perturbations of daily life and in time intervals dedicated to care and schooling that were not fixed [14].

In contrast, (re)humanization of ICTs in the hospital setting does not necessarily seem to go through virtual social links. In saying this, access is purposely restricted in the hospital context. It is one of the many paradoxes, which we observed. If internet and computer usage was largely encouraged in school time, personal usage was limited. In this context, student gratification from usage was heavily dependent on hospital and school control.

Table 2. Forms of ICTs usage before and during a school setting hospital

Forms of ICTs usage	Before hospitalization	During hospitalization	Effects of ICTs
Personal usage	Predominant usage	Limited usage	Well being
School usage	Limited usage	Dominant usage	Reduction the loss of landmarks
Medical information research	Quasi absent usage	Quasi absent usage	Limited effects

## 6. Conclusion

Based on these initial results, we would like to continue this research at an international level. Our preference would be Canada, in particular Quebec. This is due to the long history and experiences that Quebec, and Canada in general has in using ICTs in Education. For example, in 1999, the network RESCOL-Canada [15] stated that this country was to become the first in the world to be connected to information and communication technologies in all schools and public libraries. We quote many programs such as PROTIC [16], a program which is based on the integration of new communication technology. Since 1997, 64 pupils of lower sixth were trained as the very first cohort of the program characterized by entrepreneurial and technological culture.

Canada has occupied an important place in large-scale experiments in the integration of ICTs in schools or innovative experiments, such as “Writers in Electronic Residence” (WIER) [17]. The idea is based on the creation of network contacts between pupils and expert writers. Canada has also significantly contributed to pilot experiments relating to the integration of ICTs for future teachers. We also observed that scientific reviews written for experts as well as those written for the general public play an important role at international level, for instance Canadian Journal of long distance education, Canadian Review of the study of technology).

For these reasons and for the continuity of this research, we would like to lead an empirical research study with the education center attached to CHU Saint-Justine (University Hospital Center), which is one of the most important in North America. It welcomes between 500 and 600 pupils per year. The aim is to compare the usage of new technology in education for pupils, which have a health pathway between centers in France and Canada, especially Quebec.

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