

A special tool for special children: creating an ICT tool to fulfil the educational and social needs of long-term or chronic sick children.

E. Lombaert^{*1,2}, **P. Veevaete**^{1,3}, **D. Schuurman**^{1,3}, **L. Hauttekeete**^{1,3} and **M. Valcke**^{1,2}

¹ IBBT Interdisciplinary Institute for BroadBand Technology, 9000 Ghent, Belgium

² GHENT UNIVERSITY, Department of Education, H. Dunantlaan 2, 9000 Ghent, Belgium

³ GHENT UNIVERSITY, Department of Communication, Korte Meer 7/9/11, 9000 Ghent, Belgium

Keywords special educational needs; computer assisted learning

1. Introduction

The present paper focuses on a systematic investigation of the needs of long-term or chronic sick children aged 8 to 12 with regard to their *social contacts* and *education*. Earlier research suggests that childhood illness affects both learning and psychosocial development (e.g. Bessel, 2001). Information and Communication Technologies (ICTs) have already been used to support these children (e.g. Fels, et.al., 2001). Therefore, the second aim of the present study is to explore the needs in view of supportive ICT-tools. Starting from the needs analysis results, technical specifications and functionalities are formulated to result in the actual development of an ICT-tool in Flanders.

2. Theoretical framework: the importance of involvement

In a regular classroom setting all pupils engage in activities similar to the activities of their peers: they take the same classes, they have lunch together, etc. The school setting offers children a focused arena of activity and interaction which long-term sick children seem to lack (Bessell, 2001). These children do not any longer share this reference framework with healthy peers. Hence, they occupy an exceptional position in their 'normal' world. Furthermore, social after-school activities and school trips are often impossible for them. This increases their feelings of social isolation and loneliness. In the present study feelings such as belonging and shared experiences are embedded in the term 'involvement'. Continued involvement with school is believed to be important in a long-term or chronic sick child's life.

In this study the term *involvement* indicates the feelings of belonging towards all school related events in childhood. A literature review suggests the existence of two major types of involvement: *instructional involvement* and *social involvement*.

Firstly, *instructional involvement* is defined as the involvement of long-term or chronic sick children with all instruction related activities at the school to which the child went before school absence. This type of involvement seems crucial as quality instruction is important for long-term or chronic sick children to assure later academic achievement and a smooth school re-entry after absence. In line with these findings, Bessell (2001) and Searle and colleagues (2003) have claimed that neither hospital education nor home instruction is the most favourable option for the instruction of long-term or chronic ill children. Secondly, school involvement is not only academically favourable as the maintenance of friendships and the feelings of belonging are probably even more important aspects of what is called 'involvement'. Long-term or chronic sick children often have hard times maintaining social contacts with classmates

* Corresponding author: Evelien Lombaert, e-mail: Evelien.Lombaert@Ugent.be, Phone: +32 92 64 86 74

(Lightfoot et al., 1999; Mukherjee, Lightfoot, & Sloper, 2000; Shiu, 2001). This is a harrowing finding as social support is positively related to treatment management, disease adjustment and health-promoting behaviour (La Greca, Bearman, & Moore, 2002). In line with these literature findings, in the present study *social involvement* is defined as the involvement of long-term or chronic sick children with all informal and social activities at the school where the child went before school absence.

In this paper, we focus on the needs of long-term and chronic ill elementary school children with regard to both types of involvement. Technological specifications are subsequently derived from the research findings in order to develop an ICT-based tool fulfilling these needs.

To identify needs with regard to *instructional involvement* a theoretical framework developed by Valcke (2005) is proceeded from. Instructional activities are defined as activities consisting of five instructional components: (1) learning objectives, (2) subject matter, (3) instructional media, (4) didactical strategies, and (5) assessment. All these components are assumed to be integrated within the instruction activities in regular classroom settings. The limited research available on the topic of instruction for long-term and chronic sick children indicates that most of these children are not exposed to each instructional component in the same way (Bessell, 2001; Searle, et al., 2003). Hence, the present study focuses on the needs of these children to be involved more with the instruction in their original classroom setting regarding these five components.

The identification of the needs of these children concerning *social involvement* is based on the eco-triadic model of Shields & Heron (1995). This systemic approach towards long-term and chronic sick children proceeds from three 'systems', which play an important role and are interrelated in a sick child's life: the school system, the family system and the medical system. In the present study the relationships between the family system and the school system are explored.

3. Methodology

Sample

To be included in our research, children had to be between 8 and 12 years old and suffered from a long-term or chronic illness (at least 21 days absence from school or missing 50% of all lessons due to medical reasons) at the moment of the investigation.

Privacy was an important issue to be dealt with during the sample construction process. Since it was not possible to get a list with names of long-term sick children, potential participants were contacted indirectly, e.g. by e-mailing patient organisations, postings on message boards and placing an announcement in 'Klasse', Flanders' leading magazine regarding education practice. Eventually, we found seven children willing to participate in our research. We conducted a face to face structured interview with six of them, whereas one child filled out a simplified interview schedule manually because she was too ill to be interviewed.

Methods: interviewing children

To date, the opinion and needs of sick children themselves are hardly taken into account (Mukherjee, et.al., 2000). In the past, information was mainly obtained from proxies such as parents, teachers, etc. The child itself was not directly involved. Researchers currently criticize this approach: "... [S]urvey researchers are realizing that information on children's opinions, attitudes, and behaviour should be collected directly from the children; proxy-reporting is no longer considered good enough." (Borgers et al., 2000, p. 60-61). In line with this criticism Mauthner (1997) argues that children should be considered as research subjects rather than research objects. Of course, the approach of surveying and interviewing children differs from the approach used in case of adult research subjects. The age of the child should be considered when choosing the appropriate research method. Based on Piaget's theory of cognitive development, Borgers, de Leeuw and Hox (2000) state: "*From 8 years onwards, children can be surveyed*" (2000, p. 63). However, the older the children, the more satisfactory the results will be. Surveying children under the age of six seems problematic (Mauthner, 1997).

As a result, the structured interview is assumed to be the most appropriate method for the purpose of the present study. The following methodological issues, put forward by the literature review, are taken into account. Firstly, the goal of the study has to be clear to the participating child. If the introduction contains too many details, the child may get upset or overwhelmed. To avoid this, we briefly introduced ourselves as researchers interested in the child's learning experiences and social contacts during absence, as suggested by Mauthner (1997). Secondly, Borgers et al. (2000) state that the cognitive development has a considerable influence on the question-response process. In line with this finding, the formulation of the questions has to be adapted to the cognitive phase in which the participating children are situated. First of all it is necessary that the child understands the question. Subsequently, the child has to retrieve relevant information from the brain to formulate a coherent answer or to indicate the best matching answer categories, dependent on the question type. In the present study, two types of questions were used: open questions and questions using structured answer categories. In the first place children were given the opportunity to answer a question in their own words. Subsequently, we posed the same question with a limited number of answering categories, e.g. sorting tasks. These tasks reduce the risk of 'satisficing', which is defined as giving affirmative answers, regardless the question. This action is the result of being scared to say something stupid and the wish to perform well in front of the interviewer (Borgers et al., 2000). This 'satisficing'-effect is amplified by misunderstanding of the question, a low attention level and fatigue (Borgers, et al., 2000). Hence, the choice of sorting and ranking tasks provides the necessary (positive) distraction to avoid this.

Finally, given that the participated children are situated in Piaget's developmental phase of concrete operations, the questions cannot require too many abstract thinking skills. Therefore, visual stimuli (pictures and classroom drawings) were used to concretize the questions. Furthermore, children seem more interested and remember answering categories better when visual stimuli are used (Borgers et al., 2000; Mauthner, 1997). Pictures were selected carefully, keeping in mind the threats listed by Dockrell, Lewis and Lindsay (2000) In particular the threat of a 'grown-up stereotype' of things not always matching with the stereotypes of children. Hence, in the present study only photographs of actual classroom actions and objects were used.

An exemplary question was: *How do you keep in touch with your classmates during the absence period?* The children had to classify following pictures into a "yes" or "no" category. Subsequently they were asked to arrange the pictures according to their preference. Figure 1 and 2 depict exemplary answers to these questions.



Figure 1: classifying answers into a "yes" or "no" category Figure 2: arranging the pictures according to preference

4. Results

In the following paragraphs the main findings of our research will be addressed. First the needs with regard to social involvement are summarized, subsequently needs concerning instructional involvement are discussed.

Social involvement versus instructional involvement

We asked the participating children which aspect of school they missed most: instructional aspects (depicted by a photograph of children and their teacher in a classroom), social aspects (depicted by children playing in the playground) or extracurricular activities such as school trips (depicted by a photograph of children and their teacher getting them on the bus). Each child ranked the social aspects first: contact with peers outside the classroom, spending time in the playground, etc. However, most of them also stressed instructional aspects. Consequently, an electronic tool will have to provide possibilities to stay in touch with the peers, not only when their classmates are in the classroom, but also during breaks and playtime.

Social involvement: needs and consequent ICT-advice

First, we assessed the different contact methods currently used by the participating children. Afterwards, the children were asked to rank eight given contact methods (personal visit, telephone, cell phone, instant messaging, instant messaging with webcam, sending letters, sending drawings and e-mail). We noticed that the children had generally no problem at all with ranking three out of eight possible means of contact. However, once they gave a top five ranking, a further meaningful ranking was difficult.

Most interviewed children keep in touch with classmates using non-technological media such as sending letters and transfer drawings by siblings going to the same school or by parents. Telephone is cited secondly, while cell phones are less used. A cell phone of their own is not a commodity in this specific age group. Personal visits of teachers and peers are generally quite exceptional. Children with specific illnesses sometimes have to stay isolated or cannot have a lot of visitors because they have to rest a lot. It is clear that parents are the door-keepers to the outside world: they pass on notes, pictures, etc. In sum, regular direct contacts with peers and teachers are hardly possible due to time constraints or health issues. Most children do not have direct contact with their teacher on a regular base, and if they do have contact e-mail, telephone and letters are mostly used. The use of technology based contact tools is more or less dependent on computer and internet access in the classroom or at the hospital: in classrooms equipped with an internet connection frequent contacts by e-mail are reported. As to internet access at the hospital, they often have to content themselves with a public computer outside the room, if computers are available at all for patient usage. At home, most participating children report to have a computer connected to the internet. Regardless the access question, instant messaging (e.g. msn messenger, ICQ, ...) and chat with or without webcam are rarely used to keep in touch with classmates. Most of the participating children know these technologies exist, but they are not used.

According to these findings, we assume the need for better organised and structured communication is indisputable, especially for children who are absent for a rather long period (a few months). After all, the longer the absence lasts, the more difficult it seems to maintain regular contacts.

As to the ranking task, children generally prefer conventional means of communication with teachers and peers such as sending letters and drawings to keep in touch with their classmates. However, two twelve year olds state webcam supported chat to be one of their most preferred ways of contact. They perceive drawings as childish. This indicates different requirements a future ICT-tool has to meet to support social involvement dependent on the age of the users. Furthermore, this finding shows a discrepancy between the actual way and the preferred way of communication. No consensus is found with regard to the need for personal visits of peers: some prefer personal visits, others do not. With regard to contacts with teachers, visits are highly appreciated. Unfortunately not every teacher is able to comply with this wish.

With regard to the needs for social contacts we conclude that they depend heavily on the general mental state and health state of the children: no solution is relevant for each case, and flexible solutions should be opted for. In view of these findings an ICT-based tool should offer a wide range of communication modes between which each particular child can choose: live video conferencing, chat rooms, asynchronous forums, audio-links, audio-messaging, video-messaging, etc. A proportion of the children prefer avatar supported solutions, whilst others prefer real-life video images or still pictures.

Instructional involvement: needs and consequent ICT-advice

Most interviewed children are being taught, on average, four hours every week (in line with the Flemish legislation on Home Schooling for long-term sick children). Concerning the curriculum long-term and chronic ill children are being taught, all children state they miss specific curriculum subjects such as art-related subjects, sports and history. Nevertheless, not all children miss actual classroom teaching: some of them consider individual home education to be more time efficient. Others however like the fact they can talk to other children when they attend classroom based courses.

In addition to the curriculum subjects, we investigated the different instructional media that are generally used in the instruction setting of these pupils (e.g. blackboard, pc, radio, TV and books). According to the children, most of these are also used in the learning setting of the hospital, as most hospitals have got some kind of classroom. For children instructed at home the situation seems somewhat different: they have to manage with the media their family possesses. Asking these children about their preferred medium, the computer is cited mostly as their favourite instructional tool. The gaming aspects as well as the understanding that computer skills are essential in their lives are common reasons. This implies that the children will not have many attitude problems towards the ICT tool to be developed. Furthermore, the limited variation in media use in a home instruction setting can be countered by making it possible to follow classroom lessons 'live' through ICT use. For instructional aims, synchronic applications seem crucial. These applications need sufficient audio and video quality to offer the remote child access to a more extensive variety of instructional media: the remote child should understand the classroom radio clearly and should be able to watch the classroom television and blackboard.

Finally, didactical strategies were examined as a component of instruction. The one-to-one teacher-pupil interaction obviously poses no problem as the participating children are mostly taught by a personal teacher for four hours each week. As opposed to the satisfaction of the children with the use of one-to-one didactical strategies, most children explicitly report a lack of group-based didactical strategies. Furthermore sick children want to re-establish their formal contacts with other pupils for instance during group work or peer tutoring activities. In this context, ICT might present a solution to complement and upgrade the current restricted education setting for example by involving them in group-based tasks with their classmates by live video conferencing.

5. Discussion

According to the answers given by the participating children to the question "What do you miss most about school?", we conclude *involvement* is a central issue in a sick child's life. Furthermore, the distinction between instructional and social involvement seems reasonable according to the ways this question was answered.

As to social involvement both synchronous and asynchronous applications of ICT seem important to support long-term and chronic ill children. While all children appreciate the possibility of 'live' chat during the play time, the younger children also need asynchronous features to make and save drawings, text messages, etc. for their classmates. However, the needs analysis indicates that personal contacts are very much appreciated by most of the children. Therefore ICT-use can never replace these real social contacts. ICT can only expand the available ways to keep in touch.

With regard to instructional involvement, ICT is especially appreciated to supplement the existing facilities for long-term and chronic sick children as some children are aware of the advantages of individual instruction. In accordance to the findings with regard to social involvement, for instruction ICT-use can not replace the existing instruction opportunities. All the needs with regard to instruction are situated around one theme: the limited variation on different instructional components as defined by Valcke (2005). Hence, the ICT-application of synchronously being taught via the internet is assumed to fulfil most of the instructional needs. In this context, video and audio quality will influence the degree of success.

Acknowledgement

This study was conducted in view of the ASCIT-project financed by the IBBT – Interdisciplinary Institution for BroadBand Technology – and following partners: Androme, Alcatel, Artec-Electronics, Televic, Vlaams Patiëntenplatform, Hospital School Gasthuisberg (Leuven), Bednet vzw, and Vlaamse Liga tegen Kanker.

References

- [1] Bessell, A.G. (2001). Children Surviving Cancer: Psychosocial Adjustment, Quality of Life, and School Experiences. *Exceptional Children*, 67, 345-359.
- [2] Borgers, N.; de Leeuw, E. & Hox, J. (2000). *Children as Respondents in Survey Research: Cognitive Development and Response Quality*. *Bulletin de Méthodologie Sociologique*, 66 (April), p. 60-75.
- [3] Dockrell, J.; Lewis, A. & Lindsay, G. (2000). *Researching children's perspectives: a psychological dimension*. in Lewis, A. & Lindsay, G. *Researching children's perspectives*. p. 46-58.
- [4] Fels, D.I., & Weiss, P.L. (2001). Video-mediated communication in the classroom to support sick children: a case study. *International Journal of Industrial Ergonomics*, 28, 251-263.
- [5] La Greca, A.M., Bearman, K.J., & Moore, H. (2002). Peer Relations of Youth with Pediatric Conditions and Health Risks: Promoting Social Support and Healthy Lifestyles. *Developmental and Behavioral Pediatrics*, 23, 271-280.
- [6] Lightfoot, J., Wright, S., & Sloper, P. (1999). Supporting pupils in mainstream school with an illness or disability: young people's views. *Child: Care, Health and Development*, 25, 267-283.
- [7] Mauthner, M. (1997). *Methodological Aspects of Collecting Data from Children: Lessons from Three Research Projects*. *Children & Society*, (11), p. 16-28.
- [8] Mukherjee, S, Lightfoot, J., & Sloper, P. (2000). The inclusion of pupils with a chronic health condition in mainstream school: what does it mean for teachers? *Educational Research*, 42, 59-72.
- [9] Searle, N.S., Askins, M., & Bleyer, W.A. (2003). Homebound schooling is the least favorable option for continued education of adolescent cancer patients: A preliminary report. *Medical and Pediatric Oncology*, 40, 380-384.
- [10] Shields, J.D., & Heron, T.E. (1995). The eco-triadic model of educational consultation for students with cancer. *Education & Treatment of Children*, 18, 184-200.
- [11] Shiu, S. (2001). Issues in the Education of Students with Chronic Illness. *International Journal of Disability, Development and Education*, 48, 269-281.
- [12] Valcke, M. (2005). *Onderwijskunde als ontwerpwetenschap* [Instructional Sciences as a Design Science]. Ghent: Academia Press.