HELPING STUDENTS WITH A CHRONIC ILLNESS CONNECT TO THEIR TEACHERS AND SCHOOL

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Abstract

Many Australian students miss extended periods of schooling as a result of an illness and the subsequent time spent in hospital and convalescing. Such extended absence inevitably disrupts the academic work of these students, as well as presenting them with an array of social challenges. In an ARC funded project researchers are investigating ways of connecting such students with their school and their studies through the use of digital technologies.

Issues relating to the use of these technologies for learning by students absent from school are explored, as are reasons for an apparent lack of commitment to the process by some teachers. Requirements are canvassed for teacher professional learning that might prepare a teacher to confidently video conference with one absent student as part of a normal classroom lesson.

Introduction

Over the three year life of the Link ‘n Learn project the researchers will have worked with more than 25 school age students from years 1 to 12. These students have a chronic illness that is interrupting their education, and have been referred to the research project through the Royal Children’s Hospital in Melbourne (RCH). A team that comprises teachers from the student’s school, hospital educators from the RCH Education Institute (RCH-EI), and researchers have worked together to develop, implement and evaluate communication strategies, support structures and continuing professional development programs with the overall aim of providing effective eLearning for the students. Within the context of maintaining academic engagement with school for a group of students who are unable to attend school for prolonged periods, the project is investigating the effectiveness of a variety of different technologies including notebook computers, netbook computers, video conferencing, chat and online learning. The major questions being addressed are:

1. How do the students themselves experience participation?
2. What demands are made of each of the key participants in this new educational environment — student, teacher, hospital staff, parents?
3. What support and infrastructure are required from (a) the hospital, and (b) the school, to facilitate effective student participation in online learning for continuing study?
4. What support, including professional development, is required for teachers whose students are participating in such a program?
5. Could similar approaches be applied to assist other non-attending (marginalised, rural, remote) student groups?

This paper will focus on some aspects of questions 2, 3, and 4 that relate to teachers who are asked to make changes to their normal modus operandi in order to include an absent student experiencing a chronic illness. For some teachers this can be a confronting encounter, as chronic illness has been defined as

…an illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. It will certainly affect the person's quality of life (CIA, nd).
When this occurs to a student they have been teaching, a first reaction of many teachers is to assume that there will be no interest in schooling until the student regains their health. However this is not what the research is indicating. Almost every student participant has expressed a strong desire to remain connected to teachers, schooling, and peers.

A variety of different uses of digital communications technologies are being investigated in order to build on current practice and extend understanding of roles for technology use in the mitigation of isolation from school. The student participants in the study are associated with the Royal Children’s Hospital in Melbourne, but findings from the project might have applicability to other groups within Australian society, such as students in rural and remote communities, and students disconnected from school for a range of other reasons. Here we focus on a range of issues associated with the involvement and necessary professional learning related to the use of digital communications technologies by the teachers who are participants in this project.

**Background**

Over the past five years the authors have participated in a series of research projects that have used video-recorded lessons as the primary method of data collection. Some projects have included images of students while other projects have recorded whoever has used a classroom interactive whiteboard. However all these projects were based around teaching and learning with digital technology in a classroom or computer room. In all projects the teachers have been willing participants who have shown a high level of interest in seeing and discussing the video record of their lessons.

In this paper we report on data from a series of case studies that collectively constitute an Australian Research Council funded Linkage Project between the University of Melbourne and Royal Children’s Hospital Education Institute. Each case study focuses on a student whose schooling was being interrupted by a chronic illness and consequent hospital treatment and recuperation. Despite prolonged absences from school, all students clearly expressed a desire to continue their schooling making use of digital communications technology to connect to a teacher. Improvements in medical knowledge and treatment are resulting in students with chronic illness spending less time in hospital, and an increased amount of time recuperating at home. In 2005 the RCH-EI provided educational support to 1,248 students, with 72% of them spending under three weeks at the RCH (Potas, 2006).

![Student in hospital or at home with notebook and mobile phone.](image1)

![Teacher working with class and video conferencing to absent student.](image2)

*Figure 1. Schematic representation of planned interaction.*

In most instances the initial request from both students and researcher was for the teacher to agree to video conference those lessons deemed most important. The decision about when video conferencing was appropriate was left to the teacher, but was obviously affected by such variables as the nature of the chronic illness, the current stage in the treatment-recuperation cycle, the level of schooling (from grade 4 to year 12), and the subject being taught. Eleven year 11 or 12 students studying Victorian...
Certificate of Education (VCE) mathematics constituted a specific subset of the overall project (Wilkie and Jones 2009). While a passing reference will be made to one of these VCE mathematics students, all other data used in this paper comes from other students.

An idealised representation of what the researchers intended is shown in Figure 1. It is idealistic because the student appears fit and well, which is obviously not the case when they are in hospital or recuperating at home. It is also idealistic in as much as it seems that enabling this sort of interaction between home/hospital and school is straightforward. As will be discussed in a later section, the technological aspects were generally straightforward, and any problems were easily overcome. It is the fact that a teacher is represented as working with a class while simultaneously communicating with an absent student that makes this diagram idealistic.

With the development of digital communication networks it has become possible to extend teaching and learning beyond the traditional school environment. For students at school this adds another layer to their education experiences, but for students absent from school for extended periods it offers a hope that they can continue their education and stay connected to teachers and peers. It has been reported that using computers to make links between school and home can help develop autonomy and individualised learning, as well as encouraging increased parental involvement (Becta, 2008). Several studies have shown that online learning through electronic communication links can benefit students who are absent from school for a variety of reasons (Duckworth, 2001; Harris and Kington, 2002).

A Becta (2004) review of research into teacher professional development and ICT noted many problems in the UK despite focussed funding in this area. Of relevance to this paper are the findings that trying to develop ICT skills alone is much more difficult for a teacher than if they are learning in conjunction with a group of peers, either from the same school or online, and that professional learning that is adapted to meet a teacher’s specific needs is more likely to be effective. In general, teachers in the Link ‘n Learn project have had no contact with other teachers facing the same issues, and they have received very limited relevant professional learning.

Among other findings, a recently published research report argues that the main uses of technology by teachers relate to lesson preparation and school administration, and that teachers in technology-rich schools continue to use technology in ways that support their already existing teacher-centered instructional practices (Palak and Walls, 2009, p.417). These findings are relevant to this discussion because all of the teachers contacted to be participants in Link ‘n Learn had a system or school provided notebook computer, and taught in schools that had internal networks that allowed classroom connection to the internet. Information obtained from student interviews suggests that while few of the schools were technology rich, none was technology poor.

The second finding noted above shows that the presence of technology, by itself, will not cause teachers to change their pedagogical strategies or classroom practice. This finding is critical to the project as we were asking participating teachers to change their existing practice and pedagogy in order to accommodate video conferencing, or some other mode of digital communication, with an absent student while at the same time teaching and managing the other students in the class.

Method of data collection and analysis

The main method of data collection used for the Link ‘n learn project has been interviews with students and teachers. A substantial majority of the student interviews have taken place on a hospital ward while the student was undergoing treatment. In general these interviews have been audio-recorded, and the researcher has made field notes to supplement the interview. The interviews are selectively transcribed and a Miles and Huberman (1994) matrix technique applied to determine categories and establish relationships. Where ever possible students were interviewed two or three times over a school year, while teachers were interviewed when they entered the project and later when their student returned to school on a regular basis and so was no longer part of the project.
In addition to the interviews, when they agreed to participate in the project both students and teachers were requested to complete a questionnaire that asked about their use of digital technologies, and their perceived personal proficiency in using the technologies for learning or teaching.

**Discussion**

The participants in this study are students who were referred to the Royal Children’s Hospital in Melbourne (RCH) to undergo treatment for a chronic illness. The nature of the illness is not relevant to this report, but some generalisations about chronic illness in general need to be established.

All students in this study were absent from school for extended periods, although as Figure 2 illustrates, there are several patterns of absence from school and attendance at the RCH. The terms intermittent and regular are used here to describe two characteristics of school attendance. Some students regularly attend school for part of each week, and also spend time at the hospital. In the categorisation being described here, such students have a regular and on-going pause in their school attendance. Wilkie and Jones (2009) illustrate this style of attendance through Faraji\(^1\), a student who is at the hospital for treatment every Monday and Friday and at school for the other three weekdays. At first this pattern of school attendance might not appear to fit into the description of prolonged absence. However for Faraji this means that he is absent from school for 40% of every week, and there are consequences to his connection to learning. As Wilkie and Jones (2009) report, the mathematics teacher and Faraji were so concerned about the lessons being missed each week that they agreed to experiment with a form of video conferencing for the Monday and Friday lessons that Faraji could not attend.

![Figure 2. Categories of school attendance.](image)

A second form of extended absence from school occurs when students have discontinuities in their schooling that cannot be planned for ahead of time. This is categorised as being intermittent and irregular. Myra was a Grade 5 student whose school attendance fitted this category. Treatment for the chronic illness necessitated Myra being transported more than 100 kilometres from her home to the RCH when she began to feel unwell or when results of frequent blood tests indicated the need for chemotherapy. Both before and after treatment Myra was too ill to attend school, and she could spend four or five days at a time receiving treatment. She attended school when she could, but was absent for considerable periods whose occurrence and duration could not be predicted and planned for.

Olive is a Year 10 student involved in a transplant. Following any form of transparent operation, bone marrow or organ, the patient has to undergo a period of isolation from all but a limited number of family members and medical staff. After a few weeks the participants in this project who had received

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\(^1\) Faraji, Myra, Olive and Ifran are pseudonyms for student participants of Link ‘n Learn.
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a transplant were well enough to want to make contact with classmates, and Olive was no exception. Because she was still in isolation, digital communications was the most suitable approach. In the months prior to her transplant operation Olive’s school attendance pattern had been first intermittent and regular and then, as her condition worsened, intermittent and irregular. When not in hospital she was usually well enough to attend school. However this changed again following Olive’s transplant operation when she was unable to attend school for a period of several months. There was no indication during this prolonged absence that Olive wanted to abandon her ongoing connection to learning through her school.

A fourth category of school attendance was for students whose chronic illness created physical or psychological issues that prevented them attending school. Ifan is a Grade 5 boy whose physical appearance has been changed to such an extent that he did not want his peers to see him. He was also quite ill and was not physically able to go to school. Social communication with a small group of peers was carried out using web-based video conferencing, with Ifan having control of the camera on his computer so he could determine how much of him his peers could see.

From the perspective of a teacher

So far the four categories of student attendance at school have been described from the point of view of students. This has to be the starting point as the physical, emotional and psychological well-being of the student is paramount. Becoming aware of what a student wants and might be able to accomplish is an initial step for a teacher. Each of the categories of school attendance has its problems and implications for both teacher and student.

Teachers working with a student whose attendance is intermittent and regular can develop a routine of connection as long as the school timetable is based on weekly or fortnightly cycles. Timetables that make allowance for public holidays and events such as sporting carnivals prevent an ongoing routine being established. Some teachers found the approach that worked best for them and their students was to try and introduce new concepts or material only when the student was expected to be at school. Other teachers, such as Faraji’s mathematics teacher, allowed the needs of the student to overcome a perception of a personal lack of technical skills and limited understanding of how to teach in a video conference environment. With some support from colleagues and a project researcher, this teacher went ahead and through trial and error developed skills and techniques that enabled him to successfully teach most of the class in a classroom and Faraji through video conferencing.

Unfortunately not all teachers and schools reacted in such a positive manner for the student. When Olive first joined the project her school attendance was categorised as intermittent and regular. She missed every third Monday and Tuesday, and attended school on the other days. Although this pattern was known to her teachers, there was no response on either an individual or a school level to repeated requests from RCH-EI staff to investigate the use of video conferencing when Olive was in hospital.

At one meeting between some of Olive’s school co-ordinators and teachers and RCH-EI staff, it was argued that because she was intelligent and a fast learner she could quickly catch up the work she missed while at hospital two days every three weeks. While this might have true at that time, it was not going to be true following Olive’s transplant. Even though the school co-ordinators and teachers knew Olive was going to have a transplant and would subsequently be absent for some months, offers to set up video conferencing and provide professional learning were not taken up. In fact the school staff did nothing, so that when Olive had her transplant operation the teachers had no idea how they could record crucial lessons for her to watch later, or how they could use digital technology to establish a connection to schooling between Olive in medical isolation and her teachers.

It was not uncommon for RCH-EI staff and researchers to be told that a school’s computer hardware and software were out of date and unreliable, and therefore it would be a waste of time to experiment with video conferencing or any other form of digital communication. This happened several times with different schools, even though all that was required at the school was a computer with an internet connection, browser software, and a webcam or other camera. This excuse was particularly galling.
when it was known that teachers in these schools had access to a personal notebook computer with built-in camera and microphone, browser software, and internet capability.

**Teacher professional learning**

Over the two years this project has been running, researchers and teachers have investigated a range of different approaches to using digital communications technology to keep students connected to the learning. The most used hardware and software is displayed in Table 1.

**Table 1. Technology used in Link ‘n Learn project.**

<table>
<thead>
<tr>
<th>Technology</th>
<th>Details</th>
<th>Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notebook computer</td>
<td>Toshiba donated by charity</td>
<td>Provided to students by RCH-EI</td>
</tr>
<tr>
<td>Netbook computer</td>
<td>Lenovo S10 from Victorian Government contract</td>
<td>Provided to students by RCH-EI</td>
</tr>
<tr>
<td>Webcam</td>
<td>ARC funded</td>
<td>Provided to selected students by researcher team</td>
</tr>
<tr>
<td>Headset with microphone</td>
<td>ARC funded</td>
<td>Provided to selected students by researcher team</td>
</tr>
<tr>
<td>Graphics tablet</td>
<td>ARC funded</td>
<td>Provided to selected students by researcher team</td>
</tr>
<tr>
<td>Wireless lapel microphone</td>
<td>ARC funded</td>
<td>Provided to some teachers by the research team</td>
</tr>
<tr>
<td>Interactive whiteboard</td>
<td>Shhlink – Adobe Connect</td>
<td>Trialled for recording mathematics lessons</td>
</tr>
<tr>
<td>Video conferencing software</td>
<td>Dimdim</td>
<td>2 video channels, 20 audio channels</td>
</tr>
<tr>
<td></td>
<td>Skype</td>
<td>Two video channels</td>
</tr>
</tbody>
</table>

When Link ‘n Learn commenced the RCH-EI has a collection of notebook computers donated by charitable organisations, in particular the Bone Marrow Donor Institute. These computers were distributed to selected students who agreed to participate in one of several research projects. Because of the source of the donation, most of the selected students were being treated for a cancer related illness. In 2009 the Department of Education and Early Childhood Development began providing more than fifty netbook computers for use across all wards of the RCH. In some cases students have been provided with headsets because they have been video conferencing from a public area of a ward.

At one stage the researchers experimented with the use of interactive whiteboards (IWB) for recording the presentation of important lessons and for enabling another form of interaction between the absent student and their peers. It was found to be quite feasible with Shhlink for a teacher to pass control of an IWB to the student in hospital. The graphics tablet was a simple version of this form of sharing, without the need for the IWB. The tablets have been very good for mathematics lessons, as the student can easily hand-write mathematical symbols and equations that are difficult to generate on a keyboard.

Already the Link ‘n Learn project has shown that there is an urgent need for ongoing teacher professional learning that could assist teachers to make more student centred and effective in their uses of digital technologies for teaching. Interim findings from Link ‘n Learn appear to be showing that some common beliefs about teachers and technology are in fact unsubstantiated myths. For example, much professional learning about educational technology has been based on a cascade model – train one teacher from a school and that person will lead by example and train other, who in turn will train yet others. There have been occurrences where one teacher who has been supported to begin using video conferencing to connect with an absent student has offered to help colleagues who also teach the absent student, but no other teachers have taken up the offer. In every case where this has occurred in the project, both the student and a researcher have also asked other teachers to become involved.

Another myth is that it will be easier to involve teachers in supporting absent students if the school involved promotes itself as having a caring and student centred ethos. From the schools involved in the project it appears that there is no difference between Government, Catholic and Independent
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schools in the degree of support offered to students absent due to a chronic illness. Among the four student participants whose school attendance pattern was described earlier, Faraji is enrolled at a Government school and Olive at a catholic school. Faraji’s mathematics teacher has overcome some personally significant technology obstacles in learning how to video conference with Faraji while at the same time managing and teaching the rest of the class. However this effort has not yet been sufficient to inspire any of Faraji’s other teachers to also try video conferencing. As was noted earlier, teachers at Olive’s school have offered a series of excuses and reasons for not either offering video conferencing support before Olive’s operation, or readying themselves to support and connect with her following the operation.

As part of the Link ‘n Learn project some guidelines have been developed to assist teachers in connecting to students with either Shhlink or Dimdim. When considered necessary a researcher has visited the school to provide practical assistance to a group of teachers.

Conclusion

As a consequence of improvements in the diagnosis and treatment of chronic illness, it is probable that in the near future more teachers will be expected to support the learning of students absent from school for extended periods. At the same time digital communication technologies are becoming both easier for the non-technical person to use and ubiquitous in Australian society. In conjunction with these developments it is critical that professionals, both medical and educational, and parents listen to what young people with a chronic illness are saying they want to about their education. Two things that quickly became clear about the students in this project are the strength of character they display in a time of personal trauma and uncertainty, and their clearly articulated desire to stay connected to their learning through contact with teachers and classmates.

The Link ‘n Learn project has shown that using digital communications to connect to absent students is feasible with the equipment already available in schools. What has not yet been established is an effective way of engaging some teachers in this process.

References


