'Absence Makes the Heart Grow Fonder': Students With Chronic Illness Seeking Academic Continuity Through Interaction With Their Teachers at School

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> Increasing numbers of young people experience disruption to their schooling owing to chronic illness. Absence from the day-to-day life of their school for prolonged or accumulative periods of time can erode their sense of belonging and create anxiety about falling behind academically. Maintaining positive connections to school can meet their desire for normalcy and realisable educational goals. Part of a project called Link 'n' Learn, funded by an Australian Research Council Linkage grant (2008–2010), this in-depth gualitative case study of 22 participants - senior secondary students and their mathematics teachers investigated academic continuity: students' access to and utilisation of opportunities to learn effectively so that academic progress is made despite disruption to full-time schooling. The students experienced diverse types of chronic illness, medical interventions, and patterns of absence from school. They all sought to continue their school studies. Their teachers highlighted surprise, concern and discomfort related to students studying during serious illness, and school workload issues. Ambiguities about educational responsibility for students during absence were widespread. Teachers demonstrated hesitance to initiate contact with students, but students nevertheless expressed their desire for teachers to remain involved with them. Implications for the educational support of young people with chronic illness are presented.

> Keywords: school absence, chronic illness, secondary education, academic continuity, student-teacher interaction

To be sick is not to be sequestered from life. (Frank, 2007, p. 380)

For many children and young people, their health condition, although considered chronic, can be managed without significant interference with the normal trajectory of their schooling. They may require a medical treatment regime, such as inhalation for asthma or insulin injections for diabetes, but are still able to attend school successfully. For others, having a chronic illness such as cancer or anorexia nervosa means that they require intensive treatment and are therefore unable to attend school: they may need

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to be hospitalised and convalesce at home for prolonged periods of time; they may require regular, recurrent cycles of treatment that cannot be administered at school; or they may need intermittent periods of hospitalisation and recuperation. There are varying definitions for chronic illness but O'Halloran, Miller and Britt (2004) suggest the following four qualifying criteria: it lasts for at least six months, has a pattern of recurrence or deterioration, has a poor prognosis, and impacts on an individual's quality of life.

Some children are born with chronic illness; others are diagnosed in infancy, childhood or adolescence. Australian statistics indicate that there are increasing incidence and survival rates for some types of chronic illness over the past few decades (Australian Institute of Health and Welfare, 2007, 2009). For example, more than 700 children in Australia are newly diagnosed with cancer every year (RCH Education Institute, 2008) and cancer in adolescence has increased by approximately 30% in the last three decades (National Cancer Statistics Clearing House, 2010). On average, 75% of children and young people with cancer can now be cured (Chronic Illness Alliance, 2007). There are subsequently increasing numbers of surviving Australians who experience chronic illness in their youth.

Improvements in medical treatment and decentralised approaches to health care have resulted in those with chronic illness being less likely to spend extended periods of time in hospital; they may be inpatients for short periods and recuperate at home. Others receive some types of medical treatment as outpatients or at home (Potas & Jones, 2006; RCH Education Institute, 2008). Less time in hospital means that young people have reduced access to educational support from on-site hospital schools, but they are still too unwell to attend school. Home visits by tutors or visiting teachers may be prescribed in some programs, but eligibility and availability vary across educational sectors (Shaw & McCabe, 2008). In Victoria, the Visiting Teacher Service provides only one hour per week for students in the state education sector after they have already been absent from school for an extended period. Those students whose absence from school is recurrent or intermittent are more likely to have no interim educational provision at all.

Even though schools generally advocate the principle of *access to education* as a fundamental right for all students, in practice it can be difficult to achieve for those with chronic illness (World Health Organization, 2002). While federal and state legislation mandate schools to support all of their enrolled students educationally, Ashton and Bailey (2004) assert that Australia does not have adequate policy guidelines to accommodate students with chronic illness. The policies that do exist do not define the specific nature of support to be provided, and lack an adequate framework to help teachers provide for students absent from school with chronic illness.

The long-term nature of chronic illness and subsequent absence from school mean that these students need academic continuity, defined in this study as students' access to, and utilisation of, opportunities to learn effectively so that academic progress is made despite disruption to full-time schooling. Addressing students' learning needs and interests minimises educational disadvantage and improves future quality of life and employment prospects (Charlton, Pearson, & Morris-Jones, 1986; Lightfoot, Wright, & Sloper, 1999). It also meets students' desire for a sense of normalcy (Yates et al., 2010), broadened choices, and increased hope. For many young people, opportunities to continue their learning provide welcome distraction from the imposition of medical treatment. Research has found that keeping things as normal as possible for young people decreases their anxiety, increases their sense of control and helps them cope better with treatment (Bessell, 2001; Brown & Madan-Swain, 1993; Rynard, Chambers, Klinck, & Gray, 1998; Shute, 1999).

Because incidence and survival rates for chronic illness are on the increase, schools are more likely to have such children and young people enrolled as students in their

school. Teachers are consequently faced with increased challenges (Shiu, 2004). This article highlights a study undertaken as part of a larger project called *Link 'n' Learn* funded by an Australian Research Council Linkage Project grant for 3 years and undertaken by the Royal Children's Hospital (RCH) Education Institute and the Melbourne Graduate School of Education, the University of Melbourne. Findings from the study related to three educational domains: academic support of students with chronic illness, mathematics learning, and the use of communication technologies. This article focuses in particular on findings relevant to students and their teachers at school relating to each other during absence, and to school-based support of students with chronic illness. The following section provides details on the context for the project by describing traditional educational support for children with chronic illness and previous pilot projects that explored the potential for school-based support using technologies for interaction.

Background and Context

For children who are hospitalised for extended periods of time, the most common form of educational provision is in on-site hospital schools that offer bedside teaching or lessons in a classroom within the hospital. Hospital schools traditionally had little to do with patients' schools of origin (Fels, Shrimpton, & Robertson, 2003), but in recent years, have increasingly liaised with them to develop learning plans consistent with curriculum programs from a student's school. Although educational support is often provided during lengthy hospital stays, concern about those who are in and out of hospital repeatedly, or who spend considerable time recuperating at home, remains. Unpredictable and sporadic patterns of hospitalisation and recuperation decrease the likelihood of ongoing educational support from either a hospital school or a student's own school. In recognition that schools of origin may be better situated to provide academic continuity for students out of the reach of hospital support programs, the RCH Education Institute undertook three pilot projects to investigate the potential for students with chronic illness to remain connected to their own schools and continue with school studies both during hospital stays and recuperation at home.

The *CYCLE* (Children and Youth Connected with Learning Technologies to Education) project involved hospitalised children and young people being supported by education advisors to maintain contact with their schools of origin (Fels et al., 2003). A key feature of this project was that schoolteachers delivered the curriculum and provided all the required learning materials and tasks, rather than hospital education advisors. E-mail, facsimile, and telephone were used most often for interaction with schools, with parents being relied upon to courier materials. In an initial evaluation, students indicated that they liked being able to keep up with their own regular schoolwork. Many positive psychosocial benefits were reported because students could maintain a routine, know what was happening in their studies, keep in touch with peers, and maintain an important non-medical aspect of their lives. Issues highlighted were a lack of equipment and the technological knowledge of teachers. The need to provide teachers with information about the students' health status was also raised. It was found that as there were no school policies about prolonged absence, ad hoc processes for monitoring a student's progress had to be developed.

Another pilot project called *WellCONNECTED* was conducted for 18 months in 2004 and administered online connections between 20 Year 11 and 12 students with chronic illness and their teachers using a virtual classroom package called *Manhattan* (Potas, 2005). Whilst capable of much more, Manhattan was found to be used mainly for e-mail contact with teachers and classmates. In a detailed evaluation of the pilot project, Cook (2005) highlighted teachers' inadequate technology skills. Students, however, were positive, with all of them recommending it for other students in a similar position to themselves. They reported feeling more motivated to succeed. Despite an expensive and intensive training program, it was concluded that Manhattan was too complex for this type of use. The teachers themselves reported that they actually found the training ineffective and that their workloads were too high for them to invest the time needed to master the skills required. They also felt that they could not justify allocating so much time and attention to the support of only one student.

The *Back on Track* project was initiated by the RCH Education Institute in 2005 and sponsored by the Bone Marrow Donor Institute for nearly four years until the global financial crisis resulted in withdrawal of funding (the *onTrac@PeterMac* program, however, which is based on *Back on Track*, continues at the Peter MacCallum Cancer Institute in Melbourne). The project explored educational support by schools for students undergoing treatment for cancer and likely to be in and out of hospital repeatedly and absent from school for several months. Education advisors organised meetings with schools to help them develop modified learning programs, oversaw the provision of laptops and internet access in hospital and at a student's home, and administered student and school login access to the online communication system (initially Manhattan then Adobe® ConnectTM). The teachers interviewed frequently commented on the considerable addition to their workload, and that their schools did not provide time or other resources to help them manage the extra effort involved in supporting their absent students (Campbell & St Leger, 2006).

Several practical and procedural issues were highlighted by the pilot projects, which is unsurprising given the coordination and infrastructure required for the interaction of so many stakeholders: students, families, teachers, schools, medical and health personnel, and hospitals. Previous research has referred to complexities at the intersection of healthrelated and educational contexts (for example, Ashton & Bailey, 2004; Bolton, Closs, & Norris, 2000; Eiser, 2000; Fowler, Johnson, & Atkinson, 1985; Lynch, Lewis, & Murphy, 1992). Yet the positive experiences and feedback of students, the advent of increasingly accessible and flexible technologies, and concern for students not receiving adequate support during absence from school resulted in continuing research efforts. The following section describes the design of an in-depth collective case study, one part of the larger *Link 'n' Learn* project, to examine the potential for achieving academic continuity for senior students in mathematics.

Research Design

4 |

It was considered important to explore the viewpoints and perceptions of both students with chronic illness and their teachers about their experiences: what it meant for them. What did students find hard about absence from school? What mattered to them academically? What was learning mathematics like away from the classroom? What did they hope for, aim for, expect? What was it like to interact with teachers or peers using technologies? And how were teachers personally affected by having a student with chronic illness? What mattered to them as a teacher providing support? What was it like to maintain contact with a student during absence from lessons?

Collective Case Study: Student-and-Teacher Pairs

A qualitative collective case study of students and their teachers was chosen as a suitable methodology that would allow us to explore in depth and over time how students and

teachers experienced and perceived their interactions with each other during absence from school for the purpose of academic continuity — 'a contemporary phenomenon within its real-life context' (Yin, 2003, p. 13). A 'descriptive and interpretive' approach (O'Toole & Beckett, 2010, p. 43), acknowledging the shaping role of the researcher and the need for 'ongoing reflexive attention' (Yates, 2003, p. 224), was taken. Student-and-teacher pairs best defined the constitution of 'a case' (Adelman, Kemmis, & Jenkins, 1980), and involving both students and their teachers in the research and seeking their different perspectives — their 'voice' — were considered crucial for exploring experiences and issues, multiple viewpoints and perceptions (Clough & Nutbrown, 2007; Creswell, 2007; Mertens, 2005). Multiple perspectives may also minimise misinterpretation, and identify apparent inconsistencies (Stake, 2006).

This study sought to answer the following central research questions:

- 1. What concerns did students and their teachers have about continuing mathematics study during absence from school owing to chronic illness?
- 2. What were the perceptions of students and teachers about their interactions during absence from full-time school attendance?
- 3. What were the facilitators of and impediments to students' access to and utilisation of opportunities to learn effectively?
- 4. How was the degree of academic continuity experienced by students related to outcomes for students and teachers?

The referral of students to the RCH Education Institute or the *onTrac@PeterMac* program, for the duration of their absence from full-time school attendance, and the decision to include only Years 10, 11 and 12 students wanting to continue studying mathematics provided clear boundaries for selecting cases. Cases were chosen on a conceptual rather than representative basis to consider the experiences of students with different types of chronic illness and varying patterns of absence from school, providing opportunity to examine the issues from several angles (Miles & Huberman, 1994).

Students who sought to continue their mathematics study were selected for this particular project because previous research has indicated that this is one of the most difficult domains in which to learn independently during absence from lessons. Students miss instructional learning opportunities at school and are likely to suffer from gaps in their understanding, which impedes further learning (Chekryn, Deegan, & Reid, 1987; Shiu, 2001). Research has identified that studying mathematics in isolation is not usually effective; collaborative learning and frequent interaction between teachers and students are required (Gadanidis, Graham, McDougall, & Roulet, 2002; Kennedy, Ellis, Oien, & Benoit, 2007; Reeves, Vangalis, Vevera, Jensen, & Gillan, 2007). Table 1 provides demographic data for each student-and-teacher pair, previous subject results and grade aims (for the year during which students were absent), and students' selfreported ability and attitude towards mathematics on a scale (1–10 or 1–5: low to high). Pseudonyms (with matching first letters) have been used to identify student-and-teacher pairs.

The types of chronic illness experienced by students in the study included cancer, anorexia nervosa, conversion disorder, renal failure, multiple sclerosis and cochlear implant complications. Most students experienced prolonged absence from school ranging from 6 months to a year, often followed by months of intermittent absence. A few students

TABLE 1Demographic Data About the 22 Participants

ATTRIBUTES CASES	STUDENT						TEACHER		SCHOOL	
	Year	Sex	Perceived maths ability (1–10)	Maths attitude (1–5)	Previous maths grade	Grade aim (year of absence)	Years teaching	Allotment	Sector	Туре
Adam & Mr Alston	10	М	7	4	А	В	26+	Full-time, maths only	State	Coeducational
Belinda & Mr Bluett	11	F	8	5	Satisfactory	Satisfactory	21–25	Full-time, 2+ domains	State	Coeducational
Cate & Ms Curtin	12	F	5	3	Satisfactory	Satisfactory	6–10	Full-time, extra responsibilities	State	Coeducational
Debbi & Mr Davis	10	F	8	4	С	А	3–5	Full-time, 2+ domains	Independent	Coeducational
Elijah & Mr Everest	10	М	5	3	Satisfactory	Satisfactory	0–2	Full-time, maths only	State	Coeducational
Faraji & Mr Fabiano	12	М	5	3	Satisfactory	Satisfactory	21–25	Full-time, extra responsibilities	State	Coeducational
Gareth & Mr Grady	11	М	6	4	Unassigned	Unassigned	11–15	Full-time, extra responsibilities	Independent	Coeducational
Harry & Ms Heath	10	М	8	4	В	В	3–5	Full-time, maths only	State	Coeducational
Irene & Ms Ingleton	11	F	7	5	Unassigned	B+	16–20	Full-time, extra responsibilities	Catholic	Girls school
Joelle & Ms Joskin	10	F	8	4	A+	А	21–25	Full-time, maths only	Independent	Girls school
Kody & Ms Kiselow	11	М	7	3	А	А	26 +	Full-time, maths only	Independent	Coeducational

experienced accumulative intermittent absence and one student recurrently missed 2 days of school every week (for haemodialysis in hospital).

Data Collection

Whilst aiming to utilise opportunities to collect data from as many sources as possible, it was essential to remain sensitive to the dignity of students and aware of their need for privacy and emotional space at times. Remaining attuned to their current state of health and the appropriateness of involvement during a potentially distressing and vulnerable period of time was necessary. To gather initial data from students and teachers in the least intrusive and time-consuming way whilst finding out sufficient information to arrange technology-mediated interactions promptly, a questionnaire was designed, containing a variety of open- and close-ended questions with opportunities for additional comments. Initial data collected included demographic data, mathematics-related information about learning/teaching preferences, concerns about study and support, and technology-related information about confidence and preferences for interaction.

Throughout their participation, students and teachers were communicated with regularly (telephone, e-mail, face-to-face) to document their activities, experiences, and comments over time. Whenever possible and appropriate, their technology-mediated interactions with each other were observed firsthand, such as in the hospital with a student or at school with a teacher and class. Detailed observation notes and reflections were recorded in a researcher's journal.

Although conversations and observations throughout the interactive phase of the data collection provided significant data, a semistructured interview was also conducted with each student and teacher individually, either at the end of the academic year or when a student returned to school full-time. It provided opportunity to ask students and teachers to reflect on their interactions with each other, their learning/teaching experiences, and the outcomes of their involvement, such as the student's mathematics results, sentiments about future study, and the teacher's perceived changes to their beliefs or practice. The interview schedule was designed to allow students and teachers to articulate their views on specific issues, to raise their own issues, and for the interviewer to explore emergent themes and triangulate observations and interpretations (Stake, 1995).

Data Analysis

Analysis of data from the collective case study is based on in-depth examination of each student-and-teacher case as well as comparison across cases. Emergent themes from the case study are based on data analysed through line-by-line coding, pattern searching and on direct interpretation of observations (Stake, 1995). The computer analysis software program NVivo Version 8 was utilised for interpretive coding, pattern searching, grouping of codes into conceptual sets, memo writing and graphical modelling using transcribed text from students' and teachers' questionnaires and interview transcripts, and the researcher's journal of observations and reflections (Bazeley, 2007). Coding was undertaken throughout the project to enable emergent analytical themes to reshape perspective, improve instrumentation, and allow for additional data collection to fill in gaps (Miles & Huberman, 1994). Data collection for four student-and-teacher pairs was conducted over one year, and for seven pairs the following year. Peer review of data analysis and cross-checking of themes were systematically undertaken by the chief investigators from the *Link* 'n' Learn project to increase the robustness of findings (Lincoln & Guba, 1985).

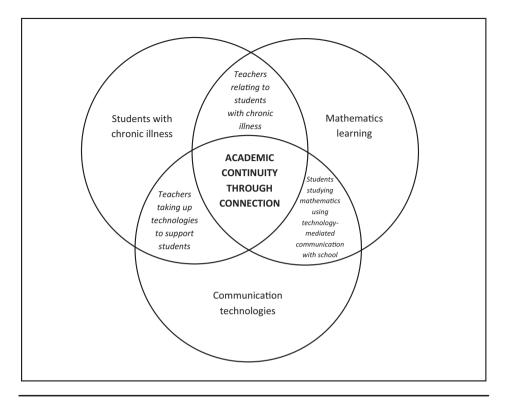


FIGURE 1

The Central Theme of Academic Continuity Through Connection.

Discussion

There are multifaceted issues and concerns when a student is unwell and absent from school — a complex context at intersection of medical and educational domains, made even more so because students' medical interventions are now more likely to cycle between hospital stays and recuperation at home, rather than involve extended hospitalisation. A number of key themes were highlighted by the study — depicted in Figure 1 — and the central theme uniting them was conceptualised as *academic continuity through connection*. This was what students sought, and they wanted to achieve it by receiving support from their own teachers at school, by continuing to participate somehow in life at school, and by continuing with their usual schoolwork.

The following discussion focuses specifically on seven findings relevant to students seeking academic continuity, teachers and students relating during absence, and responsibility for education support that impact on the academic continuity experienced by students. Other themes relating to students' ability to study mathematics independently, and the learning/teaching of mathematics through online interaction, are discussed elsewhere (Wilkie, 2011a, 2011b). Issues surrounding the feasible use of technologies for connection between students with chronic illness and teachers at school have been previously explored (Wilkie & Jones, 2010).

Teachers Finding Out Their Student is Absent with Chronic Illness

A teacher's professional role at school — teaching students in a class — is generally well defined. They relate to groups of students in a classroom setting, and focus on their teaching, the students' learning, and the structure of a timetabled lesson. They also communicate with students outside of lessons; for example, providing extra help or as a tutor or form teacher. They discuss a student's progress with parents during interviews or telephone conversations. The mainstay of a teacher's normal role is seeking to get the best educational outcomes for cohorts of students — individuals but in classes together.

Finding out one of their students is absent from school with chronic illness, shifts the teacher's focus from the class to an individual, from an educational domain to a serious medical one — likely to be unfamiliar for them in their professional role. They express the intent to be supportive and demonstrate care, but could also feel concerned about how best to benefit their student. They may highlight uncertainty about their responsibilities now that their student is no longer at school full-time, and whether it is appropriate or practical for them to maintain contact. They may worry about being privy to medical information and the risk of blurring the line between professional and personal involvement. They wonder if they even have enough information to know what to do, how to respond. A teacher reflected:

I think, again this probably relates to that idea of, of getting information to people as early as possible, clear, thorough information \ldots that helps the teacher understand, why, you know, why they should be trying to keep in touch. (Mr Davis, Q7, 7.2, 16/10/2009)

Having a student with chronic illness may affect teachers' delineation of their professional role.

Students Seeking to Study and Teachers Responding With Concern

All of the students who participated in this study were keen to continue their school studies. They hoped to maintain contact with their teachers and continue with their learning in at least a few subjects while they were absent. Students gave a variety of reasons for wanting to continue with mathematics schoolwork:

To get a better understanding and to prepare myself for VCE [Victorian Certificate of Education: Years 11 and 12]. (Adam, 9/5/2008)

To keep future opportunities open for me. (Debbi, 15/08/2008)

I don't — I'm not good getting 'A+'s but I just want it to be a pass. That's all I want it to be. (Elijah, Q6, 5/11/2009)

I have nothing to do. (Gareth, 17/02/2009)

So I am up to date with maths when I sit my school certificate exam. (Harry, 19/03/2009)

I love maths. (Joelle, 23/04/2009)

As a possible pre-requisite for uni studies. (Kody, 17/03/2009)

Yet this desire seemed to surprise their teachers at school, many of whom expected that students would want to ignore their schooling and focus solely on medical issues for the time being. Some teachers felt that students, in their best interest, *should* do so. As one student explained so poignantly, 'All the teachers said, "Don't worry about your schoolwork", but I *want* to continue with maths' (Gareth, 17/2/2009). Even the two students

in the study who eventually died wanted to continue with their schoolwork whenever they were able, despite the reservations of their teachers.

Most teachers are familiar with short-term illness affecting a student's attendance at school, but it is of minimal duration and schoolwork can be caught up with relative ease. A Year 11 coordinator described her conversation with a student absent for a few weeks with glandular fever: 'don't worry about work; just get better'. Chronic illness is *different*: its long-term duration impacts a student's schooling with far greater force and catching up is much more difficult after prolonged or accumulative absence.

Parsons (1978) describes his theory of the 'sick role' and proposes three social-structural features that relate to how those with illness are perceived by others: first, that 'being in a state of illness is not the sick person's own fault'; second, that they ought to be exempt from 'ordinary daily obligations and expectations'; and, third, that they are expected to seek help and take measures to 'maximise the chances to facilitate recovery' (p. 21). Is it possible that teachers consider schoolwork for students with chronic illness as belonging to the daily obligations from which students ought to be exempt while they are unwell? Yet Frank (1995) argues that these social meanings have little relevance for those who experience illness as a 'permanent background and intermittent foreground of their lives' (p. 82): those people who are ill yet 'spend more of their time not being patients' (p. 156). Given today's medical advances, more children and young people are surviving chronic illness and more people live day to day having to manage a chronic health condition; for them, the issue may not be about *getting better* but rather about 'how to live a good life while being ill' (p. 156).

Two teachers in particular questioned the benefit to students of continuing with study during treatment for cancer. One teacher (Mr Alston) was not present at a school meeting organised for his student (Adam) to discuss the possibilities for ongoing study. He therefore did not hear his student express his aim to continue schoolwork in at least English and mathematics during his absence for cancer treatment. After a noticeable lack of contact from the teacher with his student over several months, a hospital education advisor wrote an e-mail to the teacher reiterating that his student did indeed want to continue learning: 'he enjoys your maths class and teaching style and wants to remain connected' (6/6/2008). The teacher's reluctance persisted:

I just felt for the kid, to be honest. I thought, 'Why are you doing this stupid maths when you're so ill?' to be quite honest. And I thought, 'Well maybe the research might say it's best to try to be as normal as possible. But is that really avoiding the issue? You're undergoing this serious medical intervention and you're worrying about your vectors.' So I found it a bit difficult to understand ... (Q6, 30/10/08)

Another teacher (Mr Grady) described his initial response to being asked to support his student's mathematics study during treatment for cancer:

I suppose at the start of our contact, my thinking of, well, I suppose, probably my first thoughts were, well, why, why would Gareth or his family or like, why would they want to be doing this? Like, who cares about maths — in that situation [chuckle]? Or who cares about, your, your schooling in that situation? What, what does it matter? You know, put it off for a year or two. (Q4.2, 16/10/2009)

He spoke with the student's head of house at school who then contacted the hospital education advisor to ensure the school was right in supporting Gareth academically. Once he knew it was his student's own wish to continue study, the teacher was happy to become involved.

Research into teachers' beliefs found that if a teacher sees the effectiveness of a teaching practice in action, they might change their beliefs about it. Or if they change their beliefs, they might subsequently change their teaching practice (Philipp, 2007). One teacher maintained his belief that mathematics study was inappropriate for a student with cancer, whereas another teacher did seem to change his initial response. It is possible that actually seeing his student's positive response during a videoconference session made a difference to him. He said, 'I could see he *liked* it' (Mr Grady, Q8.7, 26/10/2009).

Students seem comfortable with, and may even prefer, their education advisor mediating with their teachers at school and letting them know of the student's interest in ongoing study. Yet some teachers seemed to question if this was really an accurate message from the student or if it was what the education advisor wanted them to hear. One teacher (Mr Fabiano) was asked directly by his student to videoconference during lessons with him while he underwent twice-weekly haemodialysis treatment, and the teacher did so consistently and with enthusiasm throughout the year. Another teacher (Mr Bluett) willingly posted work home for his student and video-recorded lessons once he confirmed that it was what his student wanted. Students who seek to continue study and teachers being uncomfortable about their doing so is one issue. Teachers needing to be convinced that the *student* wants to study is another issue. Mediation by education advisors does not appear to ameliorate either of these concerns. How this information can be communicated effectively to teachers to assuage their concerns about students with chronic illness continuing study and the appropriateness of their involvement remains a challenge.

Ambiguity for Schools and Teachers About Responsibilities

An Australian study highlighted that the longer a student is absent from school, the more likely they are to receive declining support from their school (Shiu, 2005). Another Australian study of adolescents with chronic illness found that schools were perceived by parents as not supporting students during lengthier absences (Shute & Walsh, 2005). One teacher in this study said of her student, 'He was in my class, up until he was actually diagnosed' (Ms Heath, Q1.2, 18/11/2009). No one at school contacted him at all for several months; the hospital education advisor intervened at the request of the student the following year, and even then the support provided was minimal. The student's year-level coordinator, having been requested to send schoolwork, expressed his assumption that the *hospital* was responsible for that, not his school (even though the student was from interstate and in a different education system). Do some schools believe that students absent from school are no longer their responsibility?

Invitation to teachers to participate in the overall *Link 'n' Learn* project resulted in a significant number of refusals (Jones & McDougall, 2010). Of the teachers approached to participate in this study, one declined citing discomfort with the use of technologies and later — perhaps ironically — personal health issues. A few teachers indicated that their involvement was unnecessary since their student could always catch up again once they returned to school. One teacher explained that his student had a strong ability in mathematics and very good memory (she had already been absent a whole term and frequently the previous year). The family and education advisor spoke with the school principal and the student was subsequently placed in another class where her new teacher was pleased to provide support. Another teacher initially declined involvement, indicating that she was 'too busy' (Ms Curtin, 28/8/2008) but changed her mind, albeit reluctantly, after an education advisor appealed to the school principal. There was also a sense of reluctance from some teachers who did participate but maintained minimal involvement

with their student. It is possible that ambiguity about what they ought to do or were even responsible for as a teacher played a part.

Two teachers who did maintain frequent contact with their students and provided significant levels of support indicated that they did so as 'part and parcel' of their usual role:

I didn't actually feel that anything I was doing for Kody was out of the ordinary. I've had other sick children before. I have been teaching for 38 years now and I just did what I considered was normal practice for a teacher supporting a student. (Ms Kiselow, Q4, 21/08/2009)

If it helps the, the students and especially, you know, when, in a situation like that, I'm, I'm really happy to do that, you know. I mean, that's what it's all about, that's why we're teachers you know. (Mr Fabiano, Q6.8, 22/10/2009)

Russell (2006) raises the ethical issue of educational responsibility for students in virtual schools since teachers do not see their students face to face; their ability to monitor academic progress and communicate with students is considered to be less than in a traditional classroom. Black, Ferdig, and DiPietro (2008) assert that too much responsibility can be placed on students to direct their own learning. For students without face-to-face contact at school owing to chronic illness, who is responsible for their academic progress and in what circumstances and to what degree? Are students themselves, or their families? Are hospital schools responsible during inpatient stays? What about outpatients? Or those who are recuperating at home? Are schools aware of their legally mandated responsibility for all of their enrolled students, even during absence? 'The gap between "in hospital" and "at school" is not well covered' (Yates, verbal quote, April 29, 2010).

A recent project funded by the Australian Research Council called *Keeping Connected* studied young people with chronic illness longitudinally. They found that 'levels of support varied widely as did experiences of failure, exclusion and the quality of schools, teacher and school support' and that 'school processes and rules ... do not deal adequately with the experience of a chronic condition as an uneven and continuing process over time' (Yates et al., 2010, p. 10). Education advisors have indicated that some schools are reluctant to provide any educational support for their students during absence from school. This reluctance may, in part, be due to ambiguity surrounding their legal responsibilities and what constitutes mandated reasonable adjustment or provision. It is also likely that they assume hospitals are able to support the educational needs of all the children they treat. Yet in 2009, of the 11,044 individual children and young people who were inpatients at the RCH, only 847 received some form of educational support.

The issue of educational responsibility for a student during absence from school is a complex one and there seem to be no specific guidelines, particularly regarding students with chronic illness. Such issues seem best addressed by clearer governmental policies, greater educational sector involvement and practical school-wide processes rather than on an ad hoc basis by individual teachers.

Teachers III at Ease With Illness

If teachers tend to interpret educational policies regarding special provision and additional needs as referring to students with 'physical or intellectual disabilities' (Ashton & Bailey, 2004, p. 54), would they be more likely or willing to support students who are absent from school owing to injury from an accident, rather than *illness*? Is it the nature of chronic illness that acts as a constraint? Is it possible that discomfort with illness contributes to some teachers' reluctance to remain involved and to provide academic support, even though they know that is what their students seek? As Frank (1995) states, 'one of our

most difficult duties as human beings is to listen to the voices of those who suffer' but also that 'the voices of the ill are easy to ignore' (p. 25).

Research conducted in the United Kingdom identified that students with chronic illness want their teachers to be aware of their condition and how it affects their everyday life (Lightfoot, Mukherjee, & Sloper, 2001). It is important for them to have 'a teacher who understands' (p. 61). Yet teachers have highlighted their struggle to relate appropriately to students with chronic illness. They have reported feelings of shock, worry, uncertainty and frustration (Chekryn et al., 1987; Leaman, 2000; Lightfoot et al., 2001). These feelings were also expressed by the teachers in this study, particularly in relation to their response to their student being unwell and also to their concerns about how to be supportive. Teachers whose students had cancer seemed to respond with significant emotion — sadness, anger, and anxiety — about how to relate to them appropriately. One teacher said that the 'hard bit was knowing that someone so young has to go through so much so early' (Ms Kiselow, Q11, 21/8/2009).

Previous research has highlighted teachers' concerns about their ability to provide emotional support for students with chronic illness and other students at school. They may experience discomfort or struggle personally to come to terms with the illness of their student (Leaman, 2000). One teacher reflected, 'You feel a little bit depressed about it all because you didn't do much because you couldn't do much. And you would have liked to have done more perhaps' (Mr Alston, Q9, 30/10/2008). If the student's illness becomes life-threatening or even terminal, which occurred twice in this study, teachers face additional emotional demands.

Teachers Worried About Workload

Previous research has highlighted time pressure as another possible reason for teachers' lack of contact with students who are absent from school with chronic illness (Chekryn et al., 1987; Mukherjee, Lightfoot, & Sloper, 2000). Teachers who participated in the previously mentioned *WellCONNECTED* and *Back on Track* pilot projects commented on the additional workload in maintaining contact with their student, preparing personalised learning plans, administering schoolwork exchanges, and writing extra contextual information about classroom activities and set work. Teachers from this study also referred to workload pressures and concern about not having enough time on top of their teaching workload to provide support for their student during absence from lessons:

The hardest thing was availability of time. I am busy all the time. Out of five days, about three days I am full-on. I am teaching all day. And I've got yard duty and sometimes some extra duties as well. So I couldn't find much time to help her. (Mr Bluett, Q2.14, 11/11/2008)

It was just quite hard considering I don't have that face-to-face contact all the time, and remembering to supply him with stuff and managing to get it to him is another hard part. (Mr Everest, Q2, 4/11/2009)

It's extra work. In an ideal situation, if I had 22 kids in my class each day of the week, each day of the year, I think things would be perfect. But it's not going to be that way. (Mr Davis, Q6, 23/10/2008)

Teachers all indicated that they did not receive support for themselves such as extra time release or less yard duty from their schools to help them manage their additional workload, but some highlighted that had they asked for support, they would have received it. One teacher (Mr Everest), in his first year of teaching, indicated that he struggled to prepare work to send his student because the school was 'quite badly resourced' (Q9.1, 4/11/2009).

Some other teachers had digital resources that they could easily attach to an e-mail. A few teachers received assistance from their school ICT departments with video-recording lessons and videoconferencing, which was helpful.

As with ambiguity surrounding responsibilities for educational provision, workload and time pressures that constrain teachers' ability to support students with chronic illness are issues that do not seem to be easily managed by individual teachers. Rather, they require sector and school involvement and infrastructure that acknowledge and sustain the commitment required of those teachers. They agree to provide support in principle, but in practice, their involvement is a struggle amidst the demands of a busy school environment.

Teachers Hesitating to Initiate Contact

Although all of the teachers who participated in the study agreed to support their students after having been informed of their students' desire to continue learning mathematics, more than half seemed noticeably hesitant to *initiate* contact. They appeared cautious and uncertain about what to do or say, which seemed out of character when compared to a teacher's usual interaction with students at school. If asked to provide a particular type of support by the hospital education advisor, such as telephone the student, e-mail a scheme of work, or post revision and exam papers home, then they usually would do so, although not always. Specific requests for contact by hospital education advisors (and even a parent) were not responded to by some teachers, even after a long period of time. It appeared that there was more to some teachers' lack of involvement than simply being too busy.

Some teachers demonstrated a lack of confidence in relating to their student, and concern about what to say or do, given the student's circumstances. They seemed uncertain about whether they should 'be the teacher' — helping the student to continue with their academic studies — or focus on health issues and emotional support. One student indicated that his teacher did not want to discuss his schoolwork during telephone conversations; rather 'he was telling [him] to get well soon and not to worry ... yes, and to relax' (Adam, Q3.7, 13/11/2009). It is possible that showing initiative, such as e-mailing schoolwork to the student or posting tests or setting exercises to complete, might be construed as *uncaring*— teachers are compelling the student to do work when they are unwell. A television news reporter visiting students in hospital suggested that making them do schoolwork is 'mean', and an education advisor also said she believed that teachers 'feel mean' sending work for students to complete during treatment (2/4/2009).

A lack of updates on the student's current level of health and progress with schoolwork was also raised by teachers as contributing to their hesitancy and unease. They don't know where a student 'is at' physically or emotionally. One teacher explained:

I wasn't fully aware of whether Debbie was feeling well for a particular week ... I wasn't sure of where she was sitting in regards to her work and whether she was still progressing well. (Mr Davis, Q2.1, 2.3, 23/10/2009)

Previous research findings and concerns expressed by teachers from this study emphasise the disempowerment of teachers educationally when they are ignorant medically (Campbell & St Leger, 2006; Mukherjee, et al., 2000). One teacher summed it up by saying that he 'really felt a bit in the dark' and 'personally felt out of the loop' (Mr Alston, Q2.8, 9, 30/10/2008). Teachers wanted to know what specific support their student sought at a particular time and what work they could handle given their current medical status — and this status could fluctuate unexpectedly with the need to adjust expectations accordingly. Managing the ongoing communication of medical information to teachers and schools so that they can make timely academic decisions continues to be problematic.

Of the teachers who demonstrated noticeable reluctance to maintain contact with their students, most had students undergoing treatment for cancer and one had a student whose mental health condition (conversion disorder) took several weeks to diagnose. He remained cautious throughout his interactions, preferring to wait for the student to contact him. Is it the serious and life-threatening nature of a serious illness or unfamiliarity with a health condition that makes it difficult for teachers to relate confidently to their student? One teacher was the exception: she *did* initiate and maintain frequent contact with her student during his treatment for cancer. She said that she 'felt quite comfortable' interacting with him (Ms Kiselow, Q4, 21/8/2009). When asked about the possible reasons for this, she mentioned experiencing cancer treatment herself and additional chronic illness:

I've been very very ill, umm, for a number of years but I work full-time. Umm, I don't know if it's because I know, how important it is to try and get back to normal, as soon as possible. (Ms Kiselow, Q4.4, 21/8/2009)

Did this teacher's firsthand experience of cancer treatment and chronic illness contribute to her confidence in relating to her student? Findings of the *Keeping Connected* project suggest that 'teachers' knowledge of how best to support young people' needs to be *built* (Yates et al., 2010, p. 12). Assuming teachers already have the confidence and ability to provide such support, particularly for young people who are seriously unwell, is perhaps unreasonable.

Students Maintain Their Interest in Interaction

At the end of the school year or after they returned to school, students reflected on their experiences of academic continuity. They overwhelmingly expressed their belief that teachers could help students with chronic illness by staying in touch with them:

Just to try and stay in contact with them as much as you can, because they need to have their teacher there. (Cate, Q9.1, 24/11/2008)

Well I think if they have better interaction with the student and the teacher, like, what's expected of them to pass, that's another thing, because, at that time when someone's sick, they don't know what to worry about, whether them being sick, or school. In my case, I was more worried about school than I was about being sick. (Debbi, Q11, 19/11/08)

Just give them all the support they need. (Elijah, Q9.1, 5/11/2009)

Keep in touch regularly. (Harry, Q9.4, 13/11/2009)

They should always help the student, ask them if they need help. Reassure them they will do whatever they can to help them catch up. (Joelle, Q8.2, 28/7/2009)

I think just to, like don't pressure them but just stay in contact and, like I've found with all my teachers, they never, they just gave me the work and said if you're up to it, do it. There was never any pressure and that sort of helped. (Kody, Q10.4, 25/8/2009)

Perhaps knowing that students *want* their teachers to interact with them, to be there for them, even during prolonged absence from school and treatment for serious illness, may increase teachers' confidence in remaining involved so that students can stay connected to their school communities, continue with their studies, and achieve academic continuity as they intend.

Implications

The possibility for academic continuity for young people with chronic illness involves many complex issues, interactions and individuals in personal, educational and medical domains. Yet there may be adjustments to people's perspectives, alternatives or enhancements to current programs and practices, or even broad policy changes that may increase that possibility for the many young people who seek it. The following suggestions relate to the themes and issues about academic continuity that emerged from the research. They are not intended to prescribe what *ought* to be, but rather to suggest what *could* be: to encourage — perhaps provoke further exploration of — ways to improve the educational outcomes for young people, to help them with 'how to live a good life while being ill' (Frank, 1995, p. 156).

- The development and distribution of videos and brochures for teachers of students with chronic illness (also accessible online from educational authorities) could provide them with useful resources and encourage their ongoing involvement with their student during absence from school. Content might include why students might benefit from contact with them during chronic illness, advice from students and teachers who have experienced similar situations, ways to develop modified learning programs, suggested wording for e-mails, and interaction strategies.
- Similar resources could be developed for students (and their families) to inform them of why teachers may worry about study during chronic illness, how to communicate with teachers, and strategies for managing study during absence. Students could be encouraged to be specific about what they would like from their teachers, including types and frequency of communication, types of information sought about schoolwork, teaching/learning opportunities they would find beneficial, and any other details they want their teachers to know.
- Education sectors could provide funding for schools to appoint a staff member as a temporary liaison who regularly contacts students/families and passes on information to the student's teachers.
- Education sectors could provide funding for schools so that teachers can be given temporary extra release time while they support a student with chronic illness; for example, removing them from the yard duty roster, excusing them from taking extra lessons, and minimising their co-curricular commitments.
- It would be worthwhile for teachers to seek the direction and support of their head of faculty, school medical staff and the student's liaison so that they do not feel that they are left making difficult decisions on their own and without adequate knowledge of the student's situation.
- If the student is in the final years of schooling, their coordinator could arrange support measures such as a 3-year completion plan, interrupted studies, or special consideration. The school careers counsellor or personnel from the relevant education sector could follow up university entrance possibilities, as some universities make special provision for young people in exceptional circumstances.
- Education sectors and schools could provide teachers with ongoing emotional support, such as ensuring that the teacher is comfortable with being involved, funding regular debriefing with a counsellor, and providing opportunities to receive professional development about health and education issues or use of digital technologies for interaction.

- School pastoral care providers (year-level coordinators, heads of house, special education staff) could arrange regular meetings as appropriate with the student, family, and subject teachers.
- School executive could remain alert to the teachers who are supporting particular students with chronic illness and find ways to acknowledge and encourage their efforts.

Conclusion

Those who rest satisfied with provisional answers to problems that in reality remain unsolved, warp the answer given them, not knowing that it is partial. (Sertillanges, 1946, p. 104)

The findings and implications shared in this article have highlighted the value that many young people with chronic illness place on maintaining their connections to school and on academic continuity - absence makes their heart grow fonder. For several teachers, finding out that their student wanted to continue their studies despite chronic illness surprised and concerned them; they expected them to focus solely on their medical issues. Some teachers worried about the appropriateness of their involvement and others expressed uncertainty about how they could benefit their student. Ambiguity about responsibility for the academic support of students absent from school was highlighted as an issue best addressed by educational sectors and schools. Finding time to manage the addition to their workload was a struggle for some teachers. Several teachers' hesitance in initiating contact with their student was related to a sense of discomfort about the seriousness of and unfamiliarity with some types of chronic illness, feeling in the dark about their student's prognosis, and a lack of confidence in knowing how and what to communicate. Yet the desire of students for their teachers to remain involved with them during absence from school, and the legal mandate for schools to be educationally responsible for them, suggest that it is important to find ways to build schools' and teachers' knowledge, confidence and ability to support the increasing numbers of young people with chronic illness.

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