CONCERNED ABOUT THEIR LEARNING: WHAT MATTERS TO MATHEMATICS STUDENTS SEEKING TO STUDY DESPITE ABSENCE FROM SCHOOL OWING TO CHRONIC ILLNESS

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Increasing numbers of young people experience disruption to their education owing to chronic illness. Many seek to continue their learning despite absence from school for prolonged or accumulative periods of time. The need to consider ways to support them arose in the context of a project called *Link 'n Learn* funded by the Australian Research Council (2008-2010). This paper reports on one aspect of a collective case study of students absent from school with diverse types of chronic illness and their mathematics teachers. It highlights that students focussed on their desire for interaction to continue study whereas their teachers were concerned about issues of illness.

What do students worry about when they miss mathematics lessons at school owing to a chronic illness? When they want to continue their studies nonetheless, what matters to them? What concerns do their teachers have about these students' learning during absence? This paper explores these issues for senior secondary students with chronic illness, who want to continue their mathematics studies, and their teachers at school. Understanding more about their concerns has implications for the educational support of increasing numbers of young people who experience disruption to their education while managing a chronic illness.

For most young people a big part of normal life is attending school. For those with chronic illness, being absent and losing contact with teachers and peers may create apprehension about disrupted friendships and falling behind academically (Charlton, Pearson, & Morris-Jones, 1986). Research has found that keeping things as normal as possible decreases their anxiety, increases their sense of control and helps them cope better with treatment (Bessell, 2001; Brown & Madan-Swain, 1993). Opportunities to connect to school and continue their learning may provide welcome distraction. Disconnection from school over time may lead to students becoming reluctant to return to full-time attendance (Bessell, 2001; Haas & Fosse, 2008). Addressing students' social and academic needs also improves their quality of life and employment prospects (Charlton, et al., 1986; Lightfoot, Wright, & Sloper, 1999).

Although on-site hospital schools traditionally oversee the educational needs of inpatients, medical advances and de-centralised healthcare have resulted in shorter stays

and therefore reduced access for young people to the available learning support. Those who are not hospitalised, nor well enough to return to school, often spend lengthy periods of time at home: "out of sight" of hospital schools and their own schools. Yet federal and state legislation mandates schools to provide educationally for all of their enrolled students. How might schools avoid their students with chronic illness being "out of mind" during absence? Government-funded home-tutoring programs typically provide one hour of educational support per week for students absent from school for prolonged periods but eligibility and availability vary across educational sectors (Shaw & McCabe, 2008) and these programs are deemed inadequate on their own.

The ARC-funded *Link 'n Learn* project, of which the collective case study is a part, involved a partnership between the Royal Children's Hospital (RCH) Education Institute and the Melbourne Graduate School of Education at the University of Melbourne. It explored the possibilities of school-based educational support utilising communications technologies to connect students with chronic illness to their schools (Wilkie & Jones, 2010). The collective case study focussed on the interaction between senior secondary mathematics students and their teachers to achieve 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*. The following section provides details on the context for the study by discussing why academic continuity in mathematics was the focus.

Context for the research

Chronic illness often goes hand-in-hand with absence from school and young people miss out on learning opportunities at school for lengthy periods or accumulatively over time, which often leads to significant gaps in their education. This is of particular concern in the domains of literacy and numeracy (Chekryn, Deegan, & Reid, 1987; Shiu, 2001). Secondary students absent from school undergoing cancer treatment have expressed particular anxiety about mathematics: they tend to be well aware that many university courses require mathematics study at Years 11 and 12 as a pre-requisite. Yet researchers believe that students' independent attempts to keep up with their studies by trying to accumulate factual knowledge are an ineffective way to learn in this domain (Charlton, et al., 1986; Fottland, 2000). There is overwhelming consensus that interaction between teachers and students is fundamental to effective education. Sociocultural perspectives consider mathematical learning as "an inherently social activity" (Schoenfeld, 1994, p. 62) that involves both "individual and collective learning processes" (Van den Heuvel-Panhuizen, 2003, p. 10). Clarke (2001) suggests that locating "learning solely within social practice or solely within the cognising individual" is a mistake (p. 297).

Independent study of mathematics is problematic for young people absent from school. This is corroborated by education advisors at the RCH Education Institute who commented that students bring their textbooks with them to hospital but struggle to learn from them. They also highlighted that mathematics was the hardest subject for them to support, particularly in the secondary years, because of the specialist knowledge required. Research has found that some students had trouble accessing any support at all for their mathematics learning during absence from school; others received some tuition in hospital but this "bore little or no resemblance to what they would have done in

school" (Charlton et al., 1986, p. 1345). Visiting teachers who tutor students at home state similar concerns about their lack of mathematics expertise (Searle, Askins, & Bleyer, 2003).

Providing effective mathematics education support for students whether they are in hospital or at home has proved a difficult challenge. Previous research conducted at the RCH Education Institute explored online communication between students with chronic illness and their schools, and recommended the exploration of strategies specifically to support learning in mathematics (Campbell & St Leger, 2006). The positive feedback from student participants about using communication technologies to keep in touch with school, the advent of increasingly flexible and affordable options, and concern for the inadequacy of current educational support, led to ongoing research efforts including the *Link 'n Learn* project. The following section describes the design of a collective case study to address the need for further research into support approaches and to also consider the perspectives of young people who are looking ahead to university and want to continue mathematics study despite chronic illness.

Research design

There are multi-faceted issues and concerns when a student is unwell and absent from school: a complex context at the intersection of medical and educational domains. Students are in and out of hospital, often stuck at home, too unwell to attend school but seeking to continue their studies nevertheless; teachers at school are busy with their classes and teaching, and have a student they no longer see every lesson. The student's goal is academic continuity in mathematics, their hope is for support from school, and the possibility is for interaction mediated by technologies. In designing a collective case study, I sought to focus on this interaction between a student and their mathematics teacher—between student–and–teacher pairs—keenly interested in their viewpoints and perceptions, their experiences and issues. A pair best represented my understanding of what constituted "a case" (Adelman, Kemmis, & Jenkins, 1980).

An important aspect of the study was gathering data over time rather than just at one moment as a snapshot. Young people by definition experience chronic illness over extended periods of time. I chose to construct a collective case study around a small number of students and their teachers (22 participants), methodologically so that I could develop in-depth understanding of their activities, experiences and perceptions over time and explore multiple viewpoints (Stake, 2006). An interpretive reflexive approach focusing on detail also required a manageable number of subjects.

I sought to utilise as many sources of data as possible (Creswell, 2007) while remaining sensitive to the dignity of students during a potentially traumatic period. Initial data were gathered about each student's and teacher's concerns, interaction preferences and perceived support needs. Informal conversations, observations (hospital and school visits), emails and text messages provided ongoing data about the nature and frequency of communication between a student and teacher. Once students returned to school full-time or the end of the academic year was reached, interviews were conducted individually with the student and their teacher. These provided opportunity for the students and teachers to reflect on their interactions with each other: on what was important to them; their teaching/learning experiences; particular issues they faced;

outcomes of their experiences; and advice they would give to others in a similar situation.

The students in this study had different levels of self-perceived ability in mathematics, various types of chronic illness, and diverse patterns of absence from school (see Table 1).

Table 1. Students' mathematical ability, type of illness, treatment, and absence from school.

CASES	Self-perceived mathematics ability (1-10)	Type of chronic illness	Medical treatment	Absence from school
Adam & Mr Alston	7	nasopharyngeal carcinoma (solid cancerous tumour)	surgery, then cycles of hospitalisation (a week or more), recuperation at home (a few weeks), and outpatient appointments	prolonged (9 - 10 months)
Belinda & Mr Bluett	8	osteosarcoma (solid cancerous tumour)	surgery, then cycles of hospitalisation, recuperation at home, and outpatient appointments	prolonged (7 - 8 months)
Cate & Ms Curtin	5	anorexia nervosa	repeated hospitalisation (up to 6 weeks at a time) and outpatient appointments	prolonged and recurrent (6 weeks at a time repeatedly over 3 years)
Debbi & Mr Davis	8	conversion disorder, chronic fatigue syndrome	hospitalisation for testing (6 weeks), then recuperation at home with outpatient appointments	prolonged (2 months), intermittent (absent weeks at a time; missed approx. half year)
Elijah & Mr Everest	5	osteosarcoma (became terminal at end of year)	cycles of hospitalisation and recuperation at unit near hospital or at home, then palliative care at home	prolonged (whole year)
Faraji & Mr Fabiano	5	reflux nephropathy (causes renal failure)	haemodialysis for several hours in hospital ambulatory ward Mondays & Fridays every week	recurrent (Mondays & Fridays every week)
Gareth & Mr Grady	6	acute lymphoblastic leukaemia (became terminal part-way through year)	cycles of hospitalisation and recuperation at home, then extended hospitalisation	prolonged (previous year then 7 months as participant)
Harry & Ms Heath	8	osteosarcoma	surgery, then cycles of hospitalisation, recuperation at unit near hospital or at home, and outpatient appointments	prolonged (9 months) then intermittent
Irene & Ms Ingleton	7	multiple sclerosis	hospitalisation for testing, then outpatient appointments	intermittent
Joelle & Ms Joskin	8	cochlear implant complications	intermittent hospitalisation for surgery or treatment (up to two weeks each time), recuperation at home	intermittent (previous year), prolonged (3 months), intermittent (1 month)
Kody & Ms Kiselow	7	acute myeloid leukaemia	cycles of hospitalisation, recuperation at home, and outpatient appointments	prolonged (6 months)

The following discussion focuses on one particular aspect of the collective case study: the concerns of the students—what mattered to them when trying to learn mathematics during absence from school—and the concerns of their teachers. Other themes relating to the learning and teaching of mathematics through online interaction and to academic continuity are discussed elsewhere (Wilkie, 2010).

Discussion of findings

Previous research has highlighted the anxiety young people with chronic illness may experience about falling behind academically (Hedström, Ljungman, & von Essen, 2005). I sought to explore this issue further specifically in the domain of mathematics and as it related to students' attempts at independent study and their being absent from lessons at school. I also examined teachers' perspectives on their concerns for their student's ongoing study. These themes are discussed in turn in the following three subsections.

Students' concerns: Continuing mathematics study away from school

All students indicated that *not being able to ask questions while studying* concerned them. A majority considered that *having to figure things out for themselves* was "most hard". Yet overall there was no correlation between the level of concern about these two issues and students' perceived ability in mathematics, for example:

> The textbook work looks really complicated when no-one's there to explain. (A, 9/5/2008, *high ability*)
> On my own, like if I needed help, I couldn't just ask the teacher. (B, Q6.4, 27/11/2008, *high ability*)
> It was hard doing stuff and not having a teacher there to show me how to do it. (C, Q3.3, 24/11/2008, *lower ability*)

One student's indication that this was *not* a concern for him was surprising since he had given up trying to study on his own quite quickly: "a month into being sick" (H, Q2.2, 13/11/2009). Perhaps he indicated this to signal to me his high ability; later in the year he admitted that he had struggled with independent study: "I used to try, I did a bit of commerce work and a bit of maths work myself but I found it too hard so I just stopped" (Q2.1, 13/11/2009). Davis, Hersh, and Marchisotto (1995) found that in mathematics "better students tend to demand instant understanding" but when learning becomes difficult, this may be "debilitating" and cause resistance to further study (p. 315).

A majority of students expressed concern about the *motivation to keep going with study*. One said that "you get behind with it and you just can't be bothered doing it" (C, Q9, 24/11/2008). Another student indicated no concern about his motivation, and indeed his determination to continue study was apparent until terminal cancer intervened. One student's indicating no concern was initially surprising because he expressed a low level of self-perceived ability, yet demonstrated self-motivation throughout the year and completed all the work his teacher gave him. He said "I'm not good getting 'A pluses' but I just want it to be a Pass. That's all I want it to be" (E, Q6, 5/11/2009).

Concern about *not having enough energy to keep up with the work* elicited surprising responses: I had expected more students to consider ill health an issue. One student with chronic fatigue syndrome indicated she only found it "somewhat hard" to manage. Another underwent haemodialysis twice a week (fatigue is a major side-effect), yet he indicated that he did *not* find lack of energy an issue. Of the six students with cancer, only one reported lack of energy as being "most hard". I had observed first-hand the intense treatment each of these students underwent; and two students with aggressive osteosarcomas maintained positive attitudes even when they were noticeably unwell. Do some students genuinely not experience ill health as affecting their learning or do they intend to show their determination that they are getting on with life anyway, despite their illness? Does ongoing study during illness symbolise this resolve? Whether or not feeling unwell is an issue, students seemed to want to portray that their study and motivation struggles are about the lack of assistance, not "sickness".

Students' concerns: Absence from mathematics lessons

The two major concerns of students regarding their absence from mathematics lessons were missing out *on hearing the teacher's explanations* and *on being able to copy down notes in class*. Unsurprisingly, all teachers reported high use of these activities in their lessons. *Not being able to ask questions or to seek individual help from the teacher* were

also of concern to a majority of students (and their teachers). One student said, "I like to get everything done in person with [teacher name]" (E, Q7.1, 5/11/2009). Four students indicated more concern than their teachers about individual help; four pairs expressed a similar high level of concern. In comparing students' with teachers' concern about taking notes in class, students generally expressed more anxiety than teachers (Figure 1).

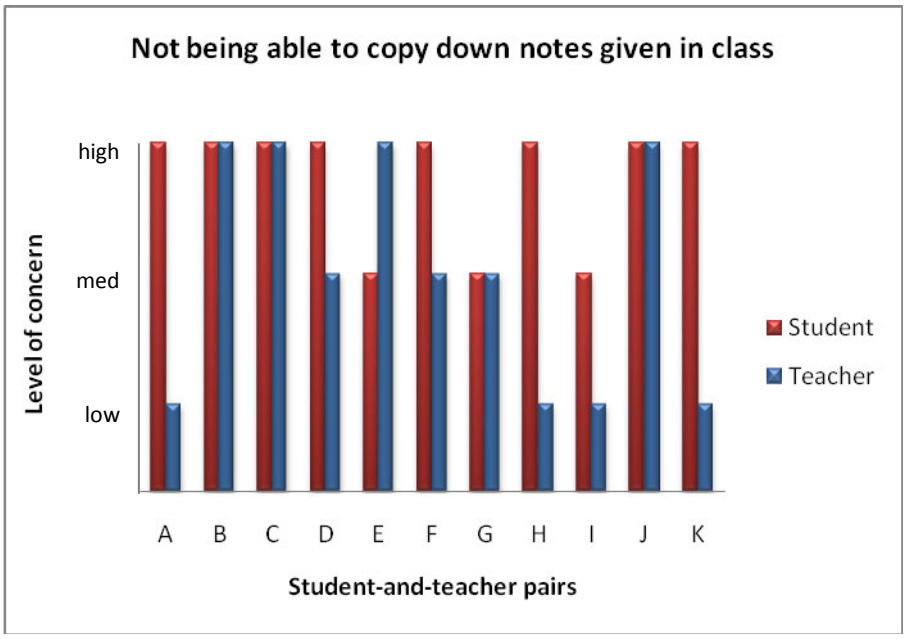

Figure 1. Comparing concerns: not being able to copy down notes.

When initially asked what she needed for mathematics study, one student replied promptly "notes from the board" (B, 11/9/2008). Another student preferred the possibility of having lessons videoed, saying "I learn better in class" and when "I copy down notes" (C, 4/9/2008). One student photocopied notes from her friends but said that "because they didn't write everything out, it was like a different language" (D, Q4.1, 19/11/2008). It seemed that having another student's notes at least provided some information but being able to write one's own notes (via videoconferencing or a videorecorded lesson) was preferable.

Being able to work with friends on problems elicited a wide range of initial responses but none of the students with self-perceived high ability in mathematics categorised working with friends as an activity they thought they would miss most. Do students with high ability rely less on the involvement of peers in their learning or would they like to be perceived as not needing the help of peers? Yet one student with high ability later reflected, "I was studying on my own and not with the class – and it was different because I wasn't learning it in school – but on my own" (J, Q2, 28/7/2009).

There was a range of responses to *missing out on finding out about class work being set* with five students indicating it as a high concern. One student said that if teachers "give out what exercises [are] to be done" to a student who is unwell, it "gives them a fair idea of what needs to be expected, so when it comes to exams or when you go back to school, again it's not a big shock and you don't feel out of it" (D, Q10.1, 10.3, 19/11/2008). Those students whose teachers had already been keeping their students up-to-date with what was happening in class expressed no concern. It seems that knowing

what is happening in lessons is sought by students, even those who have given up on independent study. It seems to provide at least some sense of connection to school even if it might exacerbate their anxiety about falling behind.

In considering students' concerns overall, there was no correlation between a student's perceived level of ability in mathematics and the nature of their concerns about being absent from lessons. Rather, students' favourite learning activities generally correlated with their issues of highest concern about being absent from lessons. There is the sense that the key concern for students is *missing interaction with their teacher*.

Teachers' concerns: Their student studying during absence

Teachers all indicated that they made high use of *explaining* and *stepping through solutions on the board* in lessons, so it is perhaps unsurprising that a majority expressed high concern about students missing out on those activities. Only one teacher was the exception, indicating little concern, yet his student indicated a high level of concern and had even tried to attend some lessons when he was quite unwell. When I met the teacher he initially said that his student "can teach himself" and that "[he] only needs to be told the chapters being covered in class" (Mr A, 15/5/2008). Later in the year he explained that he had wanted to do more for his student but suggested that he could not have, rather than that it would have been unnecessary.

In comparing students' and teachers' levels of concern about student motivation, there was a noticeable mismatch between several pairs (see Figure 2).

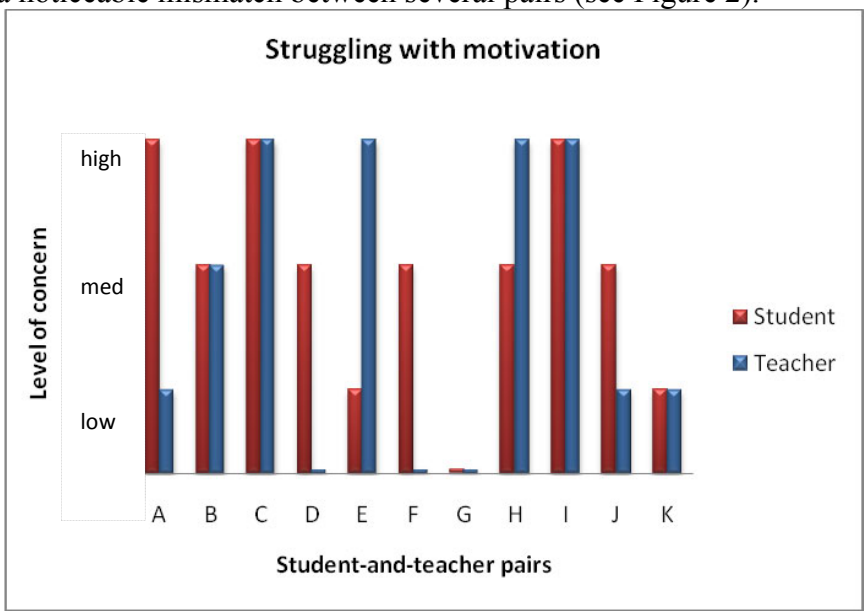

Figure 2. Comparing concerns: struggling with motivation.

In four pairs, the teachers were less concerned than their students; over time the students showed that they were indeed self-motivated but communicated that they struggled. It seemed that staying motivated was an issue that students related more to trying to learn mathematics on their own than to their ill health.

A majority of teachers expressed high concern about their students *struggling to keep up-to-date with work* and seemed to relate this to students' ill health rather than to absence from lessons. Interestingly, three teachers had significant reservations about

supporting their students during absence from school and their students each had cancer. The students expressed little or no concern about ill health affecting study but teachers expressed high concern. In later interviews these teachers reflected on their uncertainty about students with serious illness continuing study:

> I thought, 'Why are you doing this stupid maths when you're so ill?' to be quite honest. (Mr A, Q6, 30/10/08)
> My first thoughts were… 'Why would they want to be doing this? Like, who cares about maths–in that situation? (Mr G, Q4.2, 16/10/2009)

Once one of these teachers understood that his student *wanted* to continue study, he was "happy to go along with what [his student] want[ed]" (Mr G, 10/3/2009). The other two teachers sent a list of topics to their students but remained unconvinced about the appropriateness of study during cancer treatment.

Implications and conclusion

Students in this study seemed to portray that what they need to continue mathematics learning successfully during absence from school are interaction with their teacher and involvement somehow in what is happening in lessons. They seemed less concerned about managing their illness than about their struggles to learn independently–to figure things out for themselves. They seemed to want to convey that being unwell was *not* what they wanted to focus on when talking about their schoolwork; the main issue for them was *involvement* in learning opportunities, not coping with *illness*. One student summed it up poignantly, "I was more worried about school than I was about being sick". Her suggestion was for teachers to provide "just that reassurance of how much you need to do" (D, Q11, 19/11/2008). Teachers, however, focussed more on issues related to ill health and expressed concern about their students' ability to even cope with study.

In considering these differing perspectives, suggestions addressing the educational support of students absent from school with chronic illness include:

- Giving students the opportunity to specify what types of academic support matters to them, for example, photocopied notes, lesson handouts, email updates, telephone calls, videoed lessons, online interaction with their teacher, videoconferencing during lessons, and modified work requirements;
- Encouraging students to tell teachers that they want to interact with them, and teachers to respond with direction and advice about ongoing study; and
- Reassuring teachers that being as normal as possible in their relationship with students and focussing on learning rather than illness are likely to benefit students.

These could be communicated through videos and brochures accessible online from educational authorities and distributed by school support staff to teachers informing them of: 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 emails; 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.

There remain many educational issues to address in supporting young people with chronic illness, unsurprising perhaps given the infrastructure, communication and

coordination required: the involvement of families, schools and hospitals in complex contexts. But the value placed on academic continuity through connection by young people themselves, the importance of minimising their educational disadvantage, and the desire to help them participate fully in life, provides motivation to continue.

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