What happens when they go home? An investigation of education support for students following discharge from the RCH

RCH Education Institute
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WHAT HAPPENS WHEN THEY GO HOME?

AN INVESTIGATION OF EDUCATION SUPPORT FOR STUDENTS FOLLOWING DISCHARGE FROM THE RCH

Summary

Chronic illness is estimated to affect approximately 18% of children. Around one third of these (6.5%) have a chronic illness severe enough to interfere with participation in normal activities such as school (Newacheck & Halfon, 1998), and approximately 1.6% of children of school age are regularly unable to attend school due to their chronic illness (Kaffenberger, 2006).

In Australia, children and adolescents who miss school when hospitalised due to their chronic illness generally receive additional education support, most usually from a hospital based school.

Contemporary health care has increasingly moved to a decentralised model as hospital inpatient stays are reducing in both frequency and duration. Children and adolescents with chronic illnesses are spending more time recovering at home prior to most returning to school thereby shifting the burden of care to parents, schools and medical teams.

But, little is known about the need for and provision of education support during periods of recovery at home and the transition back to school.

This research project aimed to fill that gap. We contacted parents of patients who had worked with an Education Institute teacher at The Royal Children’s Hospital during their time in hospital, approximately one month after the patient had been discharged. Forty three parents agreed to participate in a structured telephone interview. We asked parents questions about the type of education support their child or young person both needed and received while recovering at home, the importance of education support at home, who provided the support, and how useful they believed the support was.

We found that one in three children were still at home and had not returned to school one month after discharge.

Of the children who had attended school during the month after discharge, two out of three had a period of time at home prior to returning to school. For these children the average amount of time spent at home prior to returning to school was 13 days. However, the average length of stay recovering at home for all students – regardless of whether they had returned to school or not was 21 days – as at the time of the follow up telephone interview.
When children or adolescents returned to school, one in three returned on a part-time basis.

Nearly half (47%) of the parents reported that their child/adolescent received help with their education while staying at home. However, the likelihood of receiving educational support while at home increased with the length of time spent at home.

Of those who had received help with their education while recovering at home, all but one parent reported that the help was both useful and important. Nonetheless, 1 in 3 reported that the help was not enough. Parents reported that they wanted additional help in the forms of home tutoring, better communication with the child’s home school and more information and more social support from classmates or the teacher.

Two out of three parents reported that their child or adolescent received additional support upon the return to school. Nearly all of these parents thought that the additional education support that their child received was important, useful, was enough and was easy to access. However, when we asked parents if their child needed any additional help with their education and learning upon returning to school 43% said that they did need additional help. The main types of additional help that was needed and not received included: private tutoring, modified school work, help in relation to motivation and learning and better communication with the school.

This research project has identified a need for additional education support in the home and during the transition back to school for approximately half of the children and adolescents following discharge from hospital. Current provision of education support appears fragmented and parents need more and better coordinated support, communication and information exchange. Contemporary models of education support need to take these findings into account to have the best chance of meeting the educational and learning needs of the child or adolescent with a chronic illness in a changing system of health care provision.

The report concludes with a discussion of the implications of these findings for both policy and practice and reviews some of the literature on model education support or hospital to school transition programs.
Introduction

The Royal Children’s Hospital (RCH) Education Institute provides education support to approximately 2000 hospitalised students each year. While at the RCH these children and young people receive personalised learning support from a hospital based teacher who works in collaboration with the child or young person, their parents or caregivers, and their regular school teacher/s. It is well known that prolonged absence from school increases a student’s risk of early disengagement from education and learning, and underachievement at school. Education support in hospital aims to ensure that students remain connected to learning as well to minimise the effect of absence from school due to hospitalisation on educational achievement. But advances in medical science and efficiency pressures aimed at discharging patients as early as possible means that students are increasingly spending more time recovering or continuing to receive treatment and care at home. While the RCH Education Institute provides education support during hospitalisation, after being discharged from hospital the student’s education reverts to being the responsibility of their regular enrolled school. Little is currently known as to what education support is either required by or provided to these students, both when they are recovering at home and when they return to their regular school.

It is not known how many students have a period of recovery at home after discharge from hospital, or how long they spend recovering at home. Many will stay for a shorter or longer period at home before transitioning back into their regular school. Some students will experience multiple cycles of hospitalisation, recovery at home and subsequent return to school. It is not clear how families find out about and make use of support services that are available to students at home or during transition back to school. There is no centralised service that assesses whether particular students require support, what kinds of support they require, which students are eligible and how the support should be organised and provided. In most cases it is up to parents to manage their child’s educational needs as best they can in conjunction with their regular school, both during recovery at home, and when the child enters or returns to school.

Research aims

This research project aims to address the gap in understanding of hospitalised students’ educational journey back to school in two ways. Firstly, this research project has been designed to gather information about students’ education support needs during their recovery time at home and in their transition back to school. This information will give an insight into the variety and extent of students’ needs during this period of time. Such needs may include: need for physical support (ramps, accessible classrooms and toilets, access to specialised or modified equipment); need for academic support (homework help, tutoring, communication with teachers, classroom aides); need for health support (flexible timetabling, administration of medications at school); and need for social support (connection to friends, peers and classmates, open communication between school and family, health education for classmates and teachers). It is envisaged that the education support needed at home may differ quite considerably from the support needed during transition back to school, however it is likely that there will also be some overlap of needs across both time periods.
Secondly, as there is no centralised service that organises education support for students who are recovering at home or are in the transition back into regular school, this research project collected information about the diversity of organisations that provide educational support, accessibility and perceived usefulness of support.

The research questions for the project were:

1. What education support do students need in the period following discharge from the RCH?
2. What education support do they get when they are at home and when they are transitioning back to school?
3. Who provides the education support, and how is it organised and accessed?
4. How useful is the received support for the students?
5. What gaps exist in the provision of education support?

**Methodology**

The research project took a mixed methods approach. Primary data was gathered through a telephone administered questionnaire with a parent or guardian of school-aged students who had recently been discharged from the RCH and who had worked with an RCH Education Institute teacher during their stay in hospital. Both closed and open ended questions were part of the questionnaire. Parents or guardians were contacted via a letter one month after their child had been discharged from hospital. The letter included a participant information statement that explained the nature and purpose of the project and allowed parents to decline to participate if they wished. If parents had not opted-out of the research up to three attempts were made to contact them by telephone and invite their participation. Participation involved answering a series of questions over the telephone about their child’s education support. If the student had already returned to school, questions were asked about their length of stay at home, the education support that was needed during that time and the support that was received. Questions were then asked regarding the education support which was needed and received during the transition back to school. If the child had not yet returned to school at the time of the telephone questionnaire, a shorter questionnaire was used to collect only information about the education support needed and received during recovery at home. At this point permission was also requested to follow up these families in a further month’s time, to ascertain how many students had still not returned to school two months after their hospital discharge.

Before starting the data collection, a pilot version of the questionnaire was trialled with the parents of two current patients in the hospital, who had previously been admitted and discharged and were now readmitted. Questions were asked about the period after the child’s previous time of hospitalisation. The participants for the pilot study were recruited through Education Institute teachers on wards. The Education Institute teachers gave the parents or guardians the information statement and they were contacted by telephone two to three days later. This pilot allowed us to refine the questionnaire.
The study was conducted during the month of September 2014. Research ethics approval was obtained from the RCH Human Research Ethics Committee prior to the commencement of the study.

**Study sample**

During the study month we contacted parents of all patients who had worked with an Education Institute teacher and who had been discharged from the RCH in the previous month. Initial contact was made by mail, approximately four weeks after their discharge date. If the parent agreed to participate, a telephone interview was undertaken and recorded. The interview followed a standard questionnaire that was created in the web based program RedCap. Responses to closed answer questions were recorded in RedCap by the researcher as the telephone interview progressed. Longer, open ended responses were audio-recorded and later transcribed for qualitative analysis.

In all, 167 students were discharged from hospital during the five weeks preceding the study month, making their family eligible to participate in the research. Letters of invitation were sent to each of these families. Two letters were returned as undeliverable. Up to three attempts were then made to contact the remaining 165 parents by telephone. Sixty nine parents were unable to be contacted by telephone. Telephone contact was therefore made with 96 parents. Of these, a total of 43 parents or guardians agreed to participate in the telephone survey, giving a response rate of 44%, a high rate for cold calling telephone interviews. Ninety-eight percent of parents called were female (mothers).

Thirty of these respondents (70%) reported their child had returned to school at the time of the telephone interview, while thirteen of the respondents (30%) reported that their child had not yet returned to school. Permission was sought to follow up with these parents one month later, to see if their child had since returned to school, however only six of these parents were able to be re-contacted. None of these parents reported that their child had returned to school since the previous interview had been conducted. For the majority of these, the reason for their child not returning to school was because the child had been readmitted to hospital. For this reason the results of the two-month follow up interview are not included in this report.

We asked the gender of their children and in total there were slightly more males (53%) than females (47%). Children ranged from being in Kinder/Prep (3-5 years) through to post-secondary (18 years) but nearly half (44%) were in the lower secondary years 7 to 10 (age 12-16) (Figure 1). Eighty-four percent of students had an Individual Learning Plan during their time working with an Education Institute teacher.
The majority of patients had been inpatients in either the cancer (Kookaburra) or neurological (Cockatoo) wards at the RCH (Figure 2).
Results

Respondents in this research reported that their child fell into one of three categories after their discharge from hospital:

1. Student returned to school immediately after discharge from hospital
2. Student spent a period of time recovering at home before returning to school
3. Student was still recovering at home one month after discharge and had not returned to school.

Research results have therefore been analysed according to the following categories:

- Education support at home, which includes two groups:
  - students who had not returned to school one month after discharge, and
  - students who had returned to school but who had a period of time recovering at home prior to their return to school.

- Education support upon return to school.

The results are presented according to these categories and for each of these categories the following themes are identified and explored: receipt of education support; importance of education support; type of support provided; who provided the support, and the usefulness of the support. Both qualitative and quantitative data are included in this section, along with a selection of direct quotations which illustrate important points in the parents’ own voices.

Education support at home

Students who had not returned to school one month after discharge

One in three children were still at home and had not returned to school approximately one month after discharge. Parents reported several reasons that generally fall into two categories: the readiness of the child or young person to return to school or the readiness of the school to receive the child or young person back at school.

Child not ready to return to school

Nine out of 13 parents reported that their child was not well enough to return to school and needed the time to recover.

"The thing is because he is not well enough now... That's why... And I am afraid that if he goes back to school then you know one of the kids was sick so he might get sick as well.” (Parent 10)

"Also emotionally she is still recovering too, still a bit tired and still, yeah, still gets upset; she never used to before. So I think she is just, you know, we only need to get in the car and she is wondering where we are going and are we going back and so I still don't think she is feeling like it is over yet.” (Parent 20)
“She had surgery a month ago and the doctors wanted her to be at home for one month before returning to school so that she had time to recover from her surgery.” (Parent 18)

“He’s not allowed to go to school because he’s on immune-suppressing drugs for the next few weeks, still. [He will] get seriously ill if he does.” (Parent 26)

Four parents reported that their child couldn’t attend school because of their recovery regime. The parents explained that these medical activities prohibited the students to attend school.

“At the start he was doing a lot of physio and things as well, so just, appointments prevented him as well.” (Parent 26)

The physical appearance of the child also played a role in the decision to not return to school.

“Also physically her appearance and the big scars and everything on her head, I, I just don’t want her to be stared at or to feel different.” (Parent 20)

One parent of a 3.5 year old child was waiting for a place in day care and recognised the value of child care in preparing the child for kindergarten the following year, while another parent of a child of kindergarten age thought it wasn’t that important to attend.

“So she was at 3 year old Kinder and so we have decided not to put her back into Kinder just yet... I think because she doesn't need to go, as in you know, it is an option whether or not she goes to 3 year old Kinder. That is different to I guess than if she had been in prep then we wouldn’t really have had a choice.” (Parent 20)

School not ready to receive child or young person

Two parents reported that the support necessary for the child to attend school had not been organised or that teacher aid funding had not been received.

“My daughter had a tracheotomy at the beginning of June. Even though I had kept the school informed of all the things that have been happening to her, they have not, they still have not put the support in place that she will need to attend school, and so I have not been able to take her to school.” (Parent 37)
“She missed the whole first term of this year, which I think is appalling because she was well enough to go to school. But she couldn’t because of money, basically... there wasn’t a medical reason for that. That was because the education department. Because she needs a teacher aide at school, the school can’t afford to be paying someone if they’re not getting paid from the education department. But it took the education department a whole term to approve the funding. And I was ropable. I just could not believe... the child can’t attend school until the funding comes in. I just think that’s ludicrous, I think it’s wrong. Especially when a child has an illness and obviously they’re not at school as much as everyone else.” (Parent 2)

Students who had returned to school but who had a period of time recovering at home
Thirty of the 43 respondents reported that their child had returned to school since being discharged from hospital approximately a month earlier. Of these 30 students, 20 (67%) had some time at home before returning to school (Figure 3).

Figure 3  Was your child at home before returning to school?

The median length of stay at home prior to returning to school \((n = 20)\) was 7 days. However, 9 (45%) parents reported their child had a stay at home of 2 or more weeks (Figure 4) making an average length of stay at home for this group of 13 days.\(^1\)

\(^1\) The average length of stay at home for all students who had a period of time recovering at home \((n = 43)\) was 21 days, regardless of whether they had returned to school or not one month after discharge.
Of these 30 students, 2 out of 3 returned on a part-time basis. The reasons given for part-time attendance mostly included the student being unwell, tired or having to attend medical appointments or treatment. Three participants mentioned that their child had been readmitted to the hospital after their initial return to school.

“If she’s unwell because sometimes her condition plays up a little bit, which gives her real bad headaches she’ll have a day in bed and the next day it’s fine.” (Parent 2)

“So at times she goes to school and then she calls me from school. She is too sick to stay at school, she can’t breathe and I’ve had to go and get her from school.” (Parent 25)

“There will be days that he has to come home because he is totally exhausted but that is the deal with the viral infections … He goes to school as long as he can and then when he is tired, he just comes home. He rings up and I will just pick him up.” (Parent 15)
Nine parents (approximately one in three) reported that their child did not attend school as they had planned. One parent reported that their child returned to school quicker than expected, while another reported that they could not plan the school attendance of their child at all.

“It was quicker than what we had planned because ... the surgeon had thought he’d need a bit extra time but he recovered quickly. We’d planned for him having more time off but he didn’t really need it.” (Parent 32)

“We cannot plan anything because you never know how unwell he is going to be.” (Parent 22)

Receipt of education support at home
We asked parents questions about the type of education support their child or young person both needed and received while recovering at home, the importance of education support at home, who provided the support, and how useful they believed the support was.

While nearly all parents (97%) reported that it was important that their child received education support during their recovery at home, the majority (53%) reported that they received no education support (Figure 5).

Figure 5  Did your child get any help with his/her education while he/she was staying at home?

When we asked parents why they did not receive education support during the period the child was recovering at home, the most common reasons were that help had never been offered, or that they did not know education support at home was available.
“I didn’t know that you could get help at home. If I had known that, I would have got the help at home when he was recovering from surgery. That would have been fantastic. Because then he wouldn’t have been missing out on so much time in the period being at home and recovering, we could have been more working on some areas where he needed to be worked on to get up to scratch for school. That would have been fantastic if I had known that.” (Parent 11)

“I wouldn’t have a clue because we haven’t been told anything if there was anybody able to come out [to our home].” (Parent 19)

“Well, we only just find out that he could have qualified for help at home. Nobody told us about the visiting school teacher program until about a week ago… So the school didn’t tell me about it and neither did the teacher from the hospital tell me that there was such a thing.” (Parent 17)

Other reasons parents gave for why they did not receive education support at home during the period of the child’s recovery were that the child or young person was not well enough, was tired or that they were not interested.

“Probably because she’s still in active treatment at the minute and I think those couple of days she was just really tired – she probably didn’t even think about any schoolwork in those couple of days.” (Parent 29)

“She has an allowance for a tutor, perhaps once a week but that can’t be at home. It is going to be when she is either in the library or the school. So that can make it very difficult because if she is not well and not well enough to leave the house sometimes that can’t happen.” (Parent 7)

“He is just not interested in doing that and I am not going to force him when he is sick so no, we had no support.” (Parent 17)

Another parent reported that their child didn’t get education support at home because the specialised support was not available due to a lack of training for staff and related policy restrictions.

“We can’t get that support because the people don’t have training in tracheotomy care… My home care service, they have cancelled my support for [student’s name]’s personal care because their policy and procedure states that their staff are not allowed to look after any clients with a tracheotomy….” (Parent 44)
Some parents had had contact with the student’s regular school but commented that the school thought the student was fine with school or that the school work was not a priority.

“I called the school but they said that they thought it was not necessary to give him homework because he was quite up to date with school work... We did make contact with the school but they said everything was okay... we have called the school on three occasions, we’ve actually got parent teacher tonight so we’ll find out more details, but they seem to think [student’s name] is travelling okay.”  (Parent 38)

“Oh we’ve had contact with the school. I kind of have the feeling that because [student’s name] is at a special school, because she’s intellectually disabled, there’s been no, like, supporting her with school work has not been a priority.”  (Parent 44)

We also observed a relationship between the number of days the child was at home recovering and the receipt of education support. As Figure 6 shows, the longer the child stayed at home the more likely they were to receive support. One in three children or young people (33%) who were at home for less than a week received education support. Half of those who were at home for between one and two weeks received education support, while nearly three out of four (72%) of those who were at home for three or more weeks (regardless of whether they had returned to school or not) received education support. However, when we looked at the subset of only those who had not returned to school after approximately one month, only 43% of parents reported that their child or young person had received education support.

Figure 6  Percentage of those who received education support at home by length of stay at home

![Figure 6](image-url)
**Importance**

As previously mentioned, nearly all parents reported that education support was important. Education support was seen as important in preventing the child from falling behind – particularly around ‘core’ subjects such as maths, and increasing the child’s motivation.

“*Yes, absolutely, because he’s been so sick for so long he’s got behind in his schoolwork.*“ (Parent 26)

“*Oh definitely, because if they’re away for an extended period of time then they can really fall behind ... you definitely need all of that extra support, for sure.*“ (Parent 43)

“*Particularly around maths, where if you miss a few weeks it can be very difficult to catch up. So something like maths, and maybe science, you know, you need some of these foundational topics before you move on to the next one. I think it is probably fairly important for the most part. With things like humanities, history, and geography – that’s usually fairly easy to pick up in your own time. So something like maths and science, we’ll probably look at that.*“ (Parent 39)

“*Yeah, the help has been really good... it’s motivated her, it’s kept her going. Because a lot of the time she’s been so tired that she just sleeps half the day and it gives her a reason to get out of bed.*“ (Parent 34)

But, some parents had reservations about the importance of education support due to the young age of the child.

“*I don’t think so purely based on her age. I think definitely if she was a year or two older then ... I would sort of be looking at it more and trying to see what is available... I think it would be a nice to have more than a need to have.*“ (Parent 20)

Two parents preferred to make their own arrangements for the provision of education support rather than accept that which was on offer as they felt more empowered and in control of the provision of the support.

“*We do it anyway so it doesn’t matter if it is available. We probably wouldn’t take it anyway. We just pay for our own tutors, only because we want to pick our own tutor...We don’t need specifically, you know, Ronald McDonald say that you can have this person at this time when we might not be able. It is just easy for us to have our own times... [student’s name] is not well a lot so we would like the*
flexibility that we can bring a tutor and say ‘can we come Monday, Wednesday, Friday?’ and we can do that while Ronald McDonald has fixed days so we tend to miss out on so much on these set days because he is away.” (Parent 15)

**Type of support provided**

We asked parents to indicate the types of support that they received while their child was at home. The four most common types of support were information about what was happening at school, the teacher showing an understanding of the nature of the child’s illness and the implications on his/her learning, support from classmates and/or teachers, and ongoing communication with the school (Figure 7).

**Figure 7  Type of support provided at home**

The parents explained that the students received information about what was happening at school via an e-mail from the teacher or the teacher visiting the student at home.

"They send his work through the Ipad and he just has to do the work and then he just sends it back.” (Parent 15)

This parent also described that the student only got information about the core subjects because the other subjects were less important.

"It was mainly English and Maths but not the other subjects. English, Maths, Science I should say. And that is really the subjects that we would like him to concentrate on, we don’t think it would work, you know cooking is something that
he is ... We just think that Maths, English, Science is more important than any of those trivial subjects.” (Parent 15)

The participants reported that the students got social support from the teacher and/or the classmates via different media: e-mail, messages, recordings, visits and Skype.

"They all kept in touch with her. They sent her emails, her friends message her, they've sent cards home and little gifts and her teachers have come to see her with recordings from the class saying they hope she feels better and everything. So that’s been fantastic.” (Parent 37)

"We Skype into the class room and his mates come over when he is well enough ... [student’s name] will Skype into the class or the class will Skype him, usually just before lunch so while the kids are getting ready for lunch, they will have a catch up and see what he has been up to and they will tell him what they have been up to ... just social.” (Parent 17)

Parents reported that while a main teacher understood the nature of the child’s illness and the implications on their learning needs, they were not sure how widely this was known among other teachers.

"He’s got quite a few teachers because he’s got quite a few subjects. The aide’s coordinator does [know the illness and the implications of it on his education] and she has provided information for the other teachers. But, to be honest, I haven’t even met some of the other teachers so I don’t know what their understanding of it is.” (Parent 32)

Parents also reported on the ways in which their child was able to maintain social connections with school and friends.

"And she [the school teacher] came and visited her a couple of times.”

"She received pictures of the children in her class and stories from her classmates.”

Who provided the support
The three most common sources of support were: the child’s regular school (teacher or other support staff), family or friends and community organisations (Red Kite, Ronald McDonald House, Community Asthma Project and Challenge) (Figure 8).
Further, all parents reported that it was relatively easy to get the support, although some explained that they had to wait until it was organised or approved, or they had to ask for it.

"Yes, very easy. Once it got approved from [name of organisation] I found a tutor myself in our area." (Parent 37)

"I did have to ask for some homework or just that someone could be sent out because none was given to him when he left school. But once I asked for it he did get it. I had to chase it, but it came.“ (Parent 32)

**Usefulness of support**

All but one parent reported that the help they received at home was useful. It helped the child or young person 'stay in touch' with school and 'keep up', and it reduced the child’s anxiety about school.

"Yeah definitely it means you can keep up with some of the things they’re doing while he’s away. Keeps you in touch a bit.” (Parent 1)

"Definitely, definitely. She was always a bit concerned with maths even beforehand and to not be at school it caused her a bit of anxiety, not being in class and maths being the weaker subject. But since having the tutor when we were home, she was very flexible; it just made her more calm and being able to
have the one on one has allowed her to be more confident with her maths work. It’s been fantastic.” (Parent 37)

One parent explained that the support was less useful if the child was not able to focus and lacked motivation, while another who said the support was not useful explained that the information that was sent from the school was not complete which made it impossible for the child to do the task.

“I got the homework for him but there was a fair chunk he couldn’t follow without being at school to access some of the information that was needed...The homework could have been a little bit better. Sort of information-wise, like this one assignment he needed a book that he didn’t have access to, to do it, and he couldn’t go on without it, so he couldn’t do any of that particular assignment... They were trying to be helpful but I think they just overlooked a bit of it. It would have been helpful if he had the complete picture of what he needed.... I felt there was a bit of wasted time that he could have spent at home doing more stuff.” (Parent 32)

Most parents (two out of three) reported that the support they received at home was enough. However, one in three reported that while the help received at home was useful, it was not enough.

“Well, one of the teachers at the hospital had contacted the school because [student’s name] was sick and lost some school time last year but the school never acted on anything while he was home sick. It’s like when he’s home sick he’s forgotten about... It’s like, when he’s home sick they don’t care – he’s my problem, not their problem, even though he’s missing school.” (Parent 31)

Most parents wanted either more of what they got or some additional support that they had not received. Most parents wanted a teacher to come to the home (e.g. home tutoring).

“I don’t know, the main thing that he wants that I want him to get is a teacher. You know, you come here home and teach him.” (Parent 10)

“She was a bit unwell but she was well enough to do work just not well enough to be at school. Even for a couple of hours, if someone could come in with her schoolwork and let her know what’s going on in the classroom so that she’s able to do it. Obviously she needs someone to tell her what’s going on.” (Parent 2)
But parents also wanted the school to have a better understanding of the situation and more communication with the school.

“When I talked, last time, to the coordinator, they said ‘oh I thought she was too sick for us to send homework’. But the nature of this sickness is she can be very sick in the morning and get a little bit better and when she gets a little bit better she opens a book, that’s what she does... in a way they just say ‘alright she won’t do it’ and when she gets back it makes it harder. That’s why I’ve explained so many times to send it [homework] over and then if she gets a little better, she can manage it in the afternoon, if she feels a little bit better she can start reading something.” (Parent 25)

“Maybe just a little bit more communication, I suppose, from the school. It’s Year 7 so it’s very different to primary schools. So I think that alone, trying to work out the difference between primary and secondary ... Maybe a little bit more communication, like, just to speak to a teacher. Rather than everything over, it’s called Compass now that the school has, everything can be on Compass sometimes. Just a good old-fashioned phone call is nice.” (Parent 38)

Some parents had difficulties expressing what kind of education support their child needed. Very often the word ‘everything’ was mentioned.

“I would like to get him everything that he, you know, needs to have ... if I could get someone to come out and help with... Anything that can sort of help him and guide him in the right direction that would have been fantastic.” (Parent 11)

Clearly this parent is aspirational and wanting the best for his/her child. But it also possibly suggests that this parent needed assistance in identifying more specifically and articulating the kinds of education support that were needed.
**Education support upon return to school**

In this section we report on education support that students received while returning to school. Again, we asked parents questions about the type of education support their child or young person both needed and received while returning to school, the importance of the education support during this time, who provided the support, and how useful they believed the support was.

**Receipt of education support upon return to school**

Again, while nearly all parents (97%) reported that additional support upon the child’s return to school was important only two out of every three students received additional support.

Of those who did not receive additional support with the child’s return to school, two parents said that additional support was not needed, one parent said they didn’t ask for additional support, while two parents provided comments about the unpredictable nature of the child’s illness and the difficulty teachers have in finding time to provide additional support.

“I think ... it’s probably due to the stage she’s up to with her treatment. Because she’s still actively getting treated for her leukaemia it’s a bit unpredictable how much school she’s going to be doing. Due to the irregularity of her being at school there’s just nothing in place there.” (Parent 29)

“You know you feel like sometimes the teachers they have their own schedule. And also because they are so busy also you have to find some time for you and a lot of the time they don’t find it. By the time they find it, a lot of the time my daughter says ‘I’ve already covered this thing now mum’. It’s very complicated really.” (Parent 25)

**Importance**

Of the 30 parents who reported that the child had returned to school, 28 said that it was important that help was available during the transition back to school. One parent who believed that the additional help at school was important had reservations, however, based around a perceived inflexibility of support services to fit in with the changeable wellness of the child.

“I feel it is important. I’m just not sure how, it depends on [student’s name]’s frame of mind at the time as to how well that help will be received by her. So whilst I’m saying it’s important, there are days she just can’t face her work. Whether it’s a matter of just trying to get back in that pattern, I’m not sure.” (Parent 30)

One parent who reported that support upon return to school was not important thought that it wasn’t important because of the young age of the child. One parent didn’t answer the question about the importance of additional support upon the child’s return to school.
"If she was older, absolutely. But I think at this stage we didn’t really need it.” (Parent 9)

**Type of support provided**

As Figure 9 shows, the main types of additional support upon return to school included social support from friends or teachers, additional communication and information from the school, and the teacher understanding the nature of the illness and implications on the child’s learning.

"Yes they made a card, the class made a card and all the kids wrote in it and gave it to him when he got back.” (Parent 32)

"The principal rings every week just to make sure [student’s name] is okay, if he needs anything.” (Parent 15)

"I just have a close liaison with her classroom teacher on the days that I think she’s going to be able to come to school and try and coordinate what might be the most appropriate time for that to happen.” (Parent 36)

Figure 9  **Type of support upon return to school**

Parents also described other types of support which included sending work home, flexibility with hours of attendance at school, additional ‘people’ support and environmental adjustments to meet the needs of the child (Table 1).
### Table 1  Other types of support upon return to school

<table>
<thead>
<tr>
<th>Theme</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sending work home</td>
<td>“Offering, you know, make things easier for her, sending work home, sending tests home, just making themselves available.”</td>
</tr>
<tr>
<td></td>
<td>“We asked the teachers for work to be sent home just in terms of, yes that’s the only, just so that he can stay up to date with what is happening in class.”</td>
</tr>
<tr>
<td>Flexible hours</td>
<td>“The teachers were flexible with the time for an exam. [Child’s name] could make the exam that she missed at another time that worked for her.”</td>
</tr>
<tr>
<td></td>
<td>“There was flexibility for [child’s name] to leave school earlier if necessary.”</td>
</tr>
<tr>
<td>Additional people support</td>
<td>“The carer took [child’s name] to the school and would stay the whole day together with [child] at school.”</td>
</tr>
<tr>
<td></td>
<td>“The school gives a lot of pastoral care to [child’s name].”</td>
</tr>
<tr>
<td>Environmental adjustment</td>
<td>“[Child’s name] has limited vision so the teacher would print out the documents for her in a bigger print.”</td>
</tr>
<tr>
<td></td>
<td>“The school organised in collaboration with three other schools and DSR (Disabilities Sport and Recreation) a wheelchair basketball competition.”</td>
</tr>
</tbody>
</table>

### Who provided the support
Support was provided overwhelmingly by school teachers or other staff. But other sources of support to a much lesser extent included (in order of frequency of responses): community organisations, family/friends and RCH Education Institute teachers.
Usefulness of education support upon return to school

Nearly all (85%) of those who received support when the child returned to school indicated that the support was useful and 80% thought that the amount of additional support received was enough.

"Of course, because it helped her catch up on what she was missing out on.” (Parent 33)

Further, of the 21 students that received additional education support while returning to school, 19 said that it was easy to get the help.

“We have known about it since year 7. We knew there was a learning centre there and they said straight away since we said [student’s name] isn’t well. They said 'if he ever gets behind, just tell him to mention that he is behind and they automatically send kids that need the one on one care to go there’... He could just arrange a time when he was supposed to be doing like PE where [student's name] doesn't do much PE because he is not well enough, he has only got one lung. So he could say ‘okay, can I go to the learning centre?’, and they would say ‘fine’ because there is always someone there so you just go there and get the help to catch up, which was good.” (Parent 15)

"Yeah, it’s easy. She just has to ask and the teachers will help her.” (Parent 33)

The two parents that reported that it wasn’t easy to get support while returning to school stated that the tutor was not very consistent in turning up and the school teachers didn’t fully understand the student’s health situation.

“I think he [tutor] came but he is a bit, he has got a lot of other things going on too so it is a little bit hard to come. He is not that reliable in turning up.” (Parent 13)

“They [the school teachers] just think when you’re back at school, you’re back at school, and everything is back to normal. It doesn’t matter about having been sick.” (Parent 31)

Even though nearly all parents thought additional education support upon the child’s return to school was important, useful, enough and easy to access, when we asked parents if their child needed any additional help with their education and learning upon returning to school 43% said that they did need additional help (Figure 10).
Did your child need any other help with his/her education when he/she returned to school?

The main types of additional support that was needed and not received included: private tutoring, modified school work, help in relation to motivation and learning, more communication with the school and an integration aide (Figure 11).

Types of support needed but were not received upon the child’s return to school
Other kinds of support that were needed related to classmates being informed about the student’s illness, information about what support was available, coordination of education support, and help with transport between the child’s home and school.

One parent mentioned that her son was bullied when he returned to school. Another participant explained that the situation with classmates could be less difficult if they are knowledgeable about the health situation of the student.

“The classmates being informed and more aware of the child's illness... Sometimes he finds it hard to carry his books and things because he has arthritis and he gets quite sore when he has to carry stuff around. I don’t think the other kids, I don’t think they’re even aware at this stage, of what he’s got at this stage. So it can be a bit tricky.” (Parent 38)

More information about what help with students’ education is provided by different parties, was needed by a parent.

“Just more information, you know, to know what is around and what could help her.” (Parent 7)

Another respondent commented that there was a need for someone coordinating the education support for the student.

“Probably a bit more coordination in that from the hospital perspective, that would have been good... Yes, like I felt I was having to do it all the time and I wasn’t there. Like I had to work and I just felt that there was a large gap. And it would have been good if there was somebody that took the role of arranging and organising... I just feel like there is a missing link and she does seem to need... someone that can take charge and give her little chunks of steps to take to finally achieve that goal of finishing year 12 and I know I can't do that.” (Parent 21)

Transport between the student’s home and school should be in place, one participant noted.

“The only thing that I think is missing, but I don’t think it’s the responsibility of the school anyway, is around transport to and from school, which we’re hopefully getting some help through Centrelink for that anyway. So, that’s been challenging with my work and my wife doesn’t drive because she has chronic back pain. So getting that support from Centrelink is very important but that’s obviously not something that comes through the school.” (Parent 39)
Discussion

This is the first study that has systematically collected information about the need for and provision of education support for children and adolescents with a chronic illness following discharge from hospital.

There is a need for the provision of additional education support for children and adolescents with a chronic illness following discharge from hospital. When we contacted the parent of a child or adolescent with a chronic illness approximately four weeks after the child’s or adolescent’s discharge from hospital we found that only one in four reported that their child or adolescent had returned to school without a period of time recovering at home. Of the three in four who, at the time of the telephone call interview, were either still at home or who had had a period of time at home before returning to school, the average length of stay at home was 21 days. While nearly all those who had a period of time at home said that the provision of education support was important, approximately only half reported that they had received some form of education support for their child or adolescent. A little more encouragingly, of those who had received education support at home, two thirds reported that the education support was enough – leaving one in three who reported that the education support they received was not enough. Thus these data might suggest that the level of need for the provision of additional education support for chronically ill children and adolescents following discharge from hospital may be quite large.

But not all children and adolescents needed additional education support and we found a correlation between the amount of time spent at home and the provision of education support. Nearly half of the children and adolescents either returned to school straight after discharge or were at home for less than a week. Half of those who were at home for between one and three weeks received education support and this increased to three out of four for those who were at home for three or more weeks. Nonetheless, for the subset who were still at home and had not returned to school approximately four weeks after discharge (roughly one in three of the sample) only 43% reported that they had received education support.

Besides being at home for only a short period (less than a week), a common reason parents reported for not receiving education support was the severity of the child’s illness or treatment regime. Parents frequently reported that their child’s state of wellness was not constant – either well or not well – but frequently varied not only between days but also within a day. Flexibility in the provision of education support or attendance at school was often requested. This is consistent with the work of Shaw and McCabe (2008) who suggest that “Although challenging administratively, schools may need to be prepared to provide, for example, homebound services on one day, one-half day of school the next, and a full day of school on the third day” (page 82).

Parents were very aware of the need for education support that covered three main areas: medical, academic and social. The four main types of support that parents reported receiving while the child was at home were: information about what was happening at school, the teacher showing an understanding of the nature of the child’s illness and the implications on his/her learning, support from classmates and or teachers, and ongoing communication with the school. The main types of additional support upon return to school included social support from friends or teachers, additional
communication and information from the school, and the teacher understanding the nature of the illness and implications on the child’s learning.

The main areas of support that parents reported they wanted more of included: a teacher coming to the home, the school having a better understanding of the situation (the child’s illness and impact on the child’s learning and motivation), and more ‘communication’ with the school. This focus on communication and more information sharing is consistent with the literature on hospital to school transitions. Kaffenberger (2006), goes as far as to say that lack of communication between the family, medical team and school personnel is the greatest barrier to school re-entry.

"Making the transition back to school is a complex, many-phased process that requires individualized services for each student. The barriers and challenges to school re-entry facing the three groups of stakeholders (families, medical teams, and school personnel) include a lack of communication, a lack of information and training, and unsupportive school system policies. A lack of communication among the three groups is the greatest barrier to smooth school re-entry”. (Page 4)

Finally, our study showed that education support during absence from school after discharge from hospital and during the period of a child’s or adolescent’s return to school comes from many and a diverse range of sources. Most often, though, parents reported that support was provided from the school by both teachers and the student’s peers. This finding together with the expressed need for more communication and information provides a strong argument for improvements in the management and coordination of the provision of education support, which in many cases falls disproportionately to the parent, with their knowledge and readiness to be an advocate for their child (Madan-Swain et al., 2004). In the next section we review some of the literature on model hospital to school transition programs and their principles.

Implications for policy and practice

Chronic illness is estimated to affect approximately 18% of children. One third of these (6.5%) have a chronic illness severe enough to interfere with participation in normal activities such as school (Newacheck & Halfon, 1998), and approximately 1.6% of children of school age are unable to regularly attend school due to their chronic illness (Kaffenberger, 2006). If these estimates from research undertaken in the United States of America can be translated to Australia then the figures would indicate a prevalence of 761,212 school age children who have a chronic illness, 274,882 with a chronic illness severe enough to interfere with participation in school, and 67,663 who are unable to attend school for significant amounts of time due to their chronic illness.

In Australia, children and adolescents who miss school when hospitalised due to their chronic illness generally receive additional education support, most usually from a hospital based school. Hospital based schools have existed for decades. In Victoria and Queensland, for example, hospital based schools were established in the 1930s in part due to the polio epidemic of that time and the large number of children spending lengthy periods of time in hospital (Yule, 1999). But it is questionable whether the traditional
model of teaching and education support in the hospital is keeping pace with changes in the delivery of health care.

Around the world, nations are facing a common target of reducing costs of health care (Shaw & McCabe, 2008). Financial pressures combined with the increased effectiveness of medical treatments have resulted in a reduction of both the frequency and duration of inpatient care to the extent that the provision of outpatient care and home-bound recovery (with or without the provision Hospital in The Home (HiTH)) are on the increase. At the Royal Children’s Hospital admissions to HiTH has more than doubled in the two year period of 2011-2013 (Figure 12).

Figure 12 Admissions to HiTH at the RCH Melbourne 2011-2013

In the USA and Canada outpatient care has become the norm for children and adolescents with a chronic illness. These changes are shifting both the location and burden of care from the hospital to parents in the home, schools and outpatient clinics.

“The evolution of medical care toward increasing outpatient service delivery makes programming for transition from hospital to school more complex. Rather than a 2- to 4- week hospital stay, a child with cancer may have a 1-day admission followed by 6 to 10 outpatient doctors’ visits over that 2- to 4-week period. The illnesses are still severe, yet a share of the burden of care has shifted from hospitals to parents, schools, and outpatient clinics. This decentralized approach to health care often means that children receiving outpatient care have less access to hospital-based teachers, social workers, and psychologists than children experiencing extended hospital stays.” (Shaw & McCabe, 2008:77)

Traditional hospital based schools providing additional education support after discharge from hospital in the home or at the child’s regular school is not the norm in Australia. Traditional models of hospital based education support may need to change given the trend toward a more decentralized model of health care.

This research project has identified an unmet need for additional education support both in the home and during the transition back to school for children and adolescents with a
chronic illness. Current provision of education support is fragmented and parents requested more support, communication and information. This information is useful when considering adaptation of traditional models of hospital based education support that better fit with recent developments in the provision of health care.

But what might a new model education support program look like? And how feasible are they likely to be? Kaffenberger (2006) writes that although model school re-entry model programs have been described in the literature,...

"few programs exist that facilitate school re-entry for students with chronic illness and improve communication between schools and medical teams. While there is agreement that a comprehensive school re-entry program is ideal, staffing issues, funding and a lack of supporting research data about the effectiveness of existing programs limit the number of programs being implemented." (Page 5)

Nonetheless, a review of 16 comprehensive school re-integration programs for students with cancer undertaken by Prevett et al. (2000) revealed six common features of model programs and conclude that central to the success of these programs is the identification of a liaison person who coordinates the process. The six common features are:

1. Identification of a school-based or medical team coordinator of services
2. Provision of direct services to the student
3. Consultation with the family
4. Education of school personnel
5. Provision of information to classmates, and
6. Involvement of the medical team

Shaw and McCabe (2008) suggest that a model education support or ‘transition’ program would be individualised and have four components: homebound instruction, flexible attendance, differentiated instruction and social support.

Madan-Swain et al. (2004) describe a prototypical three-phase model that begins as early as possible after diagnosis and includes follow up after the child has returned to school. As they describe it...

Phase 1 includes hospitalization, initiation of community links, and the development of a school re-entry plan. This phase focuses on assessing the child’s school behaviour and parents’ involvement with the school... arranging participation in interim educational programs like hospital and homebound instruction before school return, and educating peers. Phase 2 includes contact and education of school personnel by the medical and liaison team, focusing on the provision of information regarding the child’s illness and treatment (e.g., scheduling medical treatments and their adverse side effects), planning for absences, anticipating psychosocial adjustment issues (e.g., reaction of school personnel and other children to the child), and developing a plan for educational accommodations or special education services. Emphasis during this phase is placed on preparing the teacher and classmates for the child’s imminent re-entry. Phase 3, the final phase, is for follow-up contact with school personnel and parents. This phase occurs after the child returns to school and continues as needed to provide essential ongoing monitoring to ensure that the child or adolescent is indeed attending school. (Page 646).
Conclusion
There are an estimated 274,882 school aged children and adolescents in Australia with a chronic illness severe enough to interfere with participation in school, and an estimated 67,663 who are unable to attend school for significant amounts of time due to their chronic illness. In Australia, hospital based education support programs or schools have been in existence since the 1930s. But it is questionable as to whether the traditional hospital based school model has kept pace with the changing face of health care. Globally, as well as in Australia, governments are aiming to reduce the burgeoning cost of health care. They target a reduced frequency and duration of inpatient care which advances in medical treatment make possible. Health care provision has moved to a more decentralised model that increasingly involves and shifts the burden of care to the parents during periods of the child’s recovery at home and the child’s regular school personnel. This research project has identified an unmet need for additional education support for some children and adolescents following discharge from hospital during periods of recovery at home and the child’s/adolescent’s return to school. Current provision of education support is fragmented and parents need better coordinated support, communication and information exchange. Contemporary models of education support need to take these findings into account to have the best chance of meeting the educational and learning needs of the child or adolescent with a chronic illness in a changing system of health care provision.
References


