School (re)entry after childhood cancer treatment

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Returning to school post cancer

- Major milestone
  - Symbolises return to ‘normal life’
  - Promotes peer socialisation
  - Encourages development of independence
  - Provides opportunity for self-mastery/self esteem building
  - End of ‘patient’ identity?

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Prevatt, 2000
Young cancer survivors’ educational pathways are complex

- More likely to need special education
- More likely to repeat a grade
- Less likely to have close friends/confidants
- Less likely to graduate from high school
- Less likely earn advanced degrees

Rapid school re-entry is encouraged by multiple authorities (e.g. American Cancer Society) however, it can be fraught with challenges

Hudson, 2003
Langeveld, 2003
Returning to school post cancer

Factors that can facilitate successful school re-entry

✓ Environmental factors (e.g. inclusive school culture, positive staff attitudes)

✓ Practical factors (e.g. tailored educational plans, effective consultation between professionals and families)

✓ Parental factors (e.g. knowledge of school system, support of education)

✓ Hospital school support

✓ Medical team input

Edwards, Henry, Green, & Meade (2010), Baumeister (2004), Bessel, (2001)
Re-entry can be hampered by

- Ongoing absenteeism (above normal 3 years post tx)
- Poor communication between professionals
- Treatment side-effects, particularly CNS tumours/cranial radiation
- Reluctance to return to school with physical changes
- Parental concerns about infection risk or stress

However,
Limited research regarding impact of survivor’s return to school on siblings

- Evidence suggests a detrimental effect on academic achievement (Lahteenmaki et al, 2002)
- School support identified as central theme of concern by parents and nurses (Von Essen, 2003)
- Possible that siblings bear a hidden burden of stress
Current study  

Research questions

1. Which physical, psychological and social factors impact school re-entry?

2. How do families perceive their child’s academic performance after returning to school?

3. Do families perceive that schools provide adequate support during re-entry?

4. What effect (if any) does the survivor’s return to school have on their healthy sibling?
Methods

- Recruitment via Sydney Children's Hospital medical records, invited by letter
- Interested families opt-in (with one follow-up phone call)
- Semi-structured individual telephone interviews
- Miles and Huberman 1994
- Response rate: 34%
Eligibility criteria

1. Cancer treatment during childhood (<12 years) or adolescence (12-18 years)
2. Treatment protocol completed
3. < 5 years post treatment
4. Returned to (or started) school after treatment
112 interviews with individuals from 45 families

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Family size 1-5 (mean cluster 2.8)
Average distance between SCH and home: 239 km
25% separated/divorced parents
Family concordance generally high
Spontaneous reporting- likely conservative estimates
Cancer diagnoses

- Leukaemias
- Bone tumours (sarcoma)
- Lymphoma
- Germ cell tumour
- Brain
Results

Fatigue was a key issue (35% child, 89% adol)

“It was pretty tough, he was unlikely to do a full day and then … he was unlikely to do 3 full or 3 part days on a week…. he was just exhausted … maybe even up to twelve months later.” (father)

One-third needed to ‘ease back in’ part-time

Relatively long lasting: nearly half (adol) reported it lasted 12 month+
Results

Physical symptoms

- Concentration difficulties (67% child, 47% adol): often related to fatigue
- Concentration difficulties likely to be attributed to age/gender in young survivors
- Issues of mobility and/or disability
  “I changed [school] after the first month because my legs were really sore from the chemo and there was lots of stairs” (student)
- Nausea and vomiting less common
Results

Psychological symptoms

- Considerable anxiety (child: 34%, adol: 74%)
  “…because I hadn’t really done much schooling for six months I had issues with stress and stress management and freaking out” (survivor)

- Exams especially daunting; students unsure of their current ability and content of exams
  “he was just so anxious and in fact he had a test … and English he’s fantastic in, and he just couldn’t write and he ran out of the room in the end in tears.” (mother)

- Lower personal confidence
Results

Social aspects

- Many returned to school bald, however not all concerned about this
- Resuming old friendships generally positive, with many feeling supported by their classmates
- Social difficulties (child: 34%, adol: 26%)
  - changed friendship groups, less ‘fit’ with old friends
  - difficulties initiating new friendships (child)
  - difficulty separating from parents (child)
  - group rules: turn taking (child)
  - perception of friends as immature (adol)
Results

Social aspects: Child

‘he couldn’t relate to his peers at all…he would get on better with the high school kids and the teachers rather than his peers.’ (mother)

‘she asks all her friends if they like her and of course they all, most of them, say ‘no’, which she takes to heart…I don’t know whether that’s because she was raised in hospital where everybody came into that room with a big smile and she was the centre of attention.’ (mother)
“He struggled because he wasn’t used to having to do group activities, he wasn’t used to having to follow the group norms of the classroom... He wasn’t used to playing with all the other kids, I think they intimidated him.” (mother)

“I think at first you are just happy that they’re running around and being a goose or being really naughty, you don’t care. You see them hitting another child, and you think I’m just happy you’re ok.” (mother)
“I think boys at that age must not have any idea about this type of sickness … they think that he is contagious… he used to play with boys who are so active, but now he’s playing with boys who are not active. So he has to develop a whole social network again.” (mother)

“The ovarian cancer needle [HPV vaccine]… Well a big bunch of them went ‘Oh wa, wa, wa, needles, I don’t want to do it.’ So it was a bit difficult for me to have compassion and not crack my nut.” (survivor)
Results

Academic performance

- Adol survivor perceptions on academic impact divided
  - 9/19 believed they had been adversely affected
  - 8/19 believed they were performing as expected

- Parents more concerned: majority reported significant declines relative to pre-cancer performance, esp adol

  `he played catch up in Year 10, but ... he’s now in Year 11, and you know it intensifies even more. I’m not sure he’s ever caught up.” (mother)

- Difficult to judge in child survivors
Results

Academic performance

- Maths most difficult (13/22)
  - Builds on past work
  - Also hard to learn/remember new information

‘we put it down to chemo…I couldn’t retain maths information very brilliantly…mum and I would spend two hours on a method or rule or whatever, and by the end of it I’d be sweet. The next day I’d come to it, sit down, and have no idea what I was doing.’ (survivor)

- Also biology and English
Results

Value of education

- Importance placed on education reduced: both survivor and parents
  
  “she got that far behind and they just gave her that much work to cope with – I just said... well she can leave school. We just didn’t want her getting sick again, worrying about it.” (father)

- Other families (5/22) believed that their child should focus more on studies

- Some families choose more supportive/alternative schools
Results

Parental involvement

- Parents facilitated survivor’s return to school by
  - Driving
  - Employment changes
  - Advocating for child

- 5 parents did not contact teachers: either no need, not wanting extra attention

  “I guess if I was to go round every single teacher and explain his situation, well I could do that I guess, but I don't want him to be singled out either.” (mother)

- Preference for medical team to communicate with school
School support

Teachers positively appraised for emotional and practical support

“the teachers were lovely; they did their extra best to help him through it.” (mother)

Teacher/school support included:

- extra attention in class
- after-class tutoring
- communication during absences
- extra time for assignments, exams
- marks based on prior performance
Results

School support

- Broader communication and support negatively appraised

  “what I did realise was that there was no communication, it was a very big school and there was no communication.” (mother)

- Negative experiences with non-core teachers
  - Detention, sport, chicken pox exposure

- 3 families described a supportive relationship with school counsellor/psychologist
Results

Other support

- Outreach nurse to visit school
  - Unanimously positive appraisals: classmates informed and less fearful

- Many received tutoring; most through charitable organisations, others at school and privately
  - Funding often perceived as insufficient/discontinued prematurely

- School fundraising appreciated
Results

Transitions

- Changing schools or grades significant time of need (45%)
  - Teachers in new school (grade) misled by healthy appearance
  - Perception that support shouldn’t continue forever

“The high school teachers don't know him and he's in a school of, you know, 1400 kids, so they don't know his past, his very recent past - so for them, his difficulties in the classroom are like ‘Oh God, another kid that can't do this stuff’” (mother)
>1/3 negatively affected by cancer (11/28), although mothers more concerned

“he’s an A student and he’s always in the ninety’s and ninety five percentage points but now he’s down in the fifties and so obviously it was affecting him pretty badly.” (mother)

- Disruption during tx, sibling absenteeism
- Social issues (focus on sick sibling, repeating into same year, feeling overshadowed)
Conclusions

- Overall, positive attitude about returning to school, despite physical and/or emotional symptoms
  - Fatigue significant and long lasting
- Parents (esp. mothers) reported greater concerns
  - Concern about academic impact yet reluctant to push/pressure
- Transitions are a critical time of need
  - preparation? warning? support?
Conclusions

- Role of school counsellor?
- Extra support for parents to navigate the system and advocate for their child’s academic needs
- Impact on sibling education under-studied
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