

10th National conference

Association for the Welfare of Child Health

28th – 29th April 2005

**HEALTHY SOLUTIONS FOR CHILDREN- making the right
choice.**

Enhancing the educational experience for children with chronic
illness- what parents want educators to know.

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ABSTRACT

Parenting a child with a chronic illness is a challenging experience. The number of children with chronic illness is rising with estimates of approximately 30,000 children (3.5%) in metropolitan Sydney with severe chronic illness. This article highlights challenges faced by students with chronic illness and their families, and examines the impact of absenteeism. Factors that impact on the school experience are identified and recommendations given for enhancing the educational experience of students with chronic illness and their families.

Introduction

Succeeding at school is important for all children, academically, socially, and emotionally. Children with a chronic illness are more likely to encounter difficulties at school due to increased absenteeism, disjointed relationships with peers, and disrupted school experience. Success at school for the chronically ill student often requires the combined efforts of educators, parents, students and medical personnel.

This study examines the impact of chronic illness as observed by parents on their children in the educational context.

Incidence of CI

Thompson and Gustafson's (1996) definition of chronic illness as 'a condition which: lasts for a considerable period of time or has a sequelae which persists for a substantial period, and persists for more than 3 months in a year or necessitates a period of continuous hospitalisations for more than a month' (Thompson & Gustafson, 1996:4), was used in this study. Statistics reported by the Australian Bureau of Statistics (2002) indicate that 15% of Australian children have a long term health condition, and approximately 3.5% have a severe chronic illness. In the Sydney area this equates to approximately 28,000 children. Inclusive practices in education in NSW schools ensure that the majority of students with chronic illness attend their local school.

Impact of CI on child

School is the 'normal' place to be for young people. Sexson & Madan-Swain (1993), note that school may represent the only place where children with chronic illness can be viewed as children and students rather than as patients. Returning to school is an

important step for a student with a chronic illness, both in terms of their physical well-being and their social survival (Sullivan, Fulman & Zigmond, 2001) and returning to school in the early stages of their illness makes the process of reintegration easier (Katz, Varni, Rubenstein, Blew, & Hubert, 1992).

The support and encouragement of friends is critical at this stage. Children who have friends have a more positive attitude to school (Perry, Dockett & Howard, 2000; Dockett, 2004), and a positive attitude to school is related to reduced levels of absenteeism, and academic and social success (Shiu, 2001).

Whilst students with chronic illness share most things in common with their healthy peers, they also have specific and individual needs. Students with chronic illness are 'at risk' for a range of associated problems. Research has shown that forty percent of children with chronic illness experience school related problems including poor school performance, difficulties interacting with peers, poor psychosocial adjustment including depression, anxiety, social withdrawal, as well as an increased likelihood of learning disabilities (Pless & Stein, 1996; Stuber, 1996, Shiu, 2005). Graetz and Shute, (1995) reported some students with chronic illness as less preferred as playmates, more isolated and lonely, and Cameron (1998) reported a high incidence of peer rejection and /or bullying of children with chronic illness.

Present study

Despite increases in the numbers of children with chronic illness and the challenges they face, few studies have addressed the Australian experience of parenting and educating a child with chronic illness. This study examines challenges faced by students with chronic illness and their families. The impact of absenteeism, and factors that impact on the

school experience, are identified with recommendations given for enhancing the educational experience of students with chronic illness and their families.

Method

A random sample of 500 (or 25%) of government schools from each of 40 state school districts participated in a survey on parents perceptions of the educational experience for their child with chronic illness. One hundred and twenty one parents completed and returned the surveys with an additional 62 schools returning surveys, indicating they had no students with chronic illness.

The parents' sample was representative of the state by respondent's educational level, chronic illnesses included, school sizes and type (primary, secondary, central and special). Parents of non-English speaking backgrounds were underrepresented in the study, due possibly to the complexity of the language in the survey instrument, or failure of Principals to nominate students from non-English speaking backgrounds, suggesting the need for further research in this area.

Survey Instrument

Based on a review of literature and research in the area of chronic illness, a survey was designed that provided both quantitative and qualitative information on parents perceptions of the issues facing themselves and their child in the educational context.

Forty multiple-choice items were included to provide quantitative information on a range of issues identified in the literature review.

The survey was designed to elicit information from parents in the following areas:

1. Impact of chronic illness on the child
2. Academic achievement

3. Student absenteeism
4. Educational support services accessed by students
5. Friends and friendships
6. Communication -home and school
7. Family coping
8. School's management of student medical needs
9. What makes happy children

Findings

1. Impact of chronic illness

Of the 121 students reported in the study, 52 (43%) were female and 69 (57%) were male. More than 45 different illnesses were identified. These were categorized by a Pediatrician into Oncology (14, 12%), Respiratory (28, 23%), Connective Tissue (12, 10%), Neurological (28, 23%), Diabetes (25, 21%), Cystic Fibrosis (17, 14%), and Other (61, 50%) including renal, injury, chronic fatigue, immune, cardiac and other rare illnesses. The majority of children had one illness (79, 65%), in addition, a further 28 (23%) had two illnesses, 8 (7%) had three illnesses, and six (5%) had four or more illnesses.

Illnesses were categorised as mild (11, 9%), moderate (38, 31%), or severe (72, 60%) according to parent perception of the impact of illness on their child. The majority of illnesses had existed for more than two years (111, 92%). Parents of 89 (74%) children reported that their child's participation in everyday activities at school was restricted by their illness. All years at school were represented in the study.

2. Academic Achievement

The clear majority of parents (88%) identified attending school as important for their child. Academic achievement and success at school were also reported as important by the majority of parents (70% and 75% respectively). Nearly half of all parents surveyed (47%) indicated they were concerned about their child’s academic progress at school- indicating that succeeding at school was not measured only by academic achievement. Only 60% of students with chronic illness were performing at the same level academically as their peers, and nearly half (44%) were having difficulty keeping up with the school workload.

Whilst 76% of parents and 42% of students reported requesting additional work during extended absences, just over one third (38%) of parents reported that their child was provided with catch up work following a long absence, and 40% indicated that no catch up work was provided.

One third (33%) of students were reported to receive support with school-work from their peers, and this increased with their year at school. Only 8% of year 10-12 students were not receiving support academically from their peers, emphasizing the increasingly important role peers play in the lives of older students.

3. Absenteeism

Absenteeism figures are represented in Table 1.

Table 1. Absenteeism from school due to illness

Degree of Illness	Average Days absent per year
Mild Illness	10.81
Moderate Illness	13.9
Severe Illness	41.7

Children with severe illness are clearly accounting for the majority of sick days and missing significantly more school than their peers. Parents of students with absenteeism greater than 40 days per year (n=49 or 40%), are 'at risk' for a number of factors. A significant correlation (Pearson's correlation significant at the 0.01 level- 2 tailed) was found between absenteeism and each of the following: difficulty keeping up with school work (r=.350), concerns for their academic performance (r=.244), lack of provision of catch up work (r=.244), being treated differently to their peers (r=.277), and reduced social contact with friends(r=.244). Parents are clearly indicating that particularly for students with high absenteeism, school is a very challenging environment, academically, socially and emotionally.

4. Educational Support Services

Parents were asked to identify the forms of support made available to their child by checking against a list of identified forms of support, as well as self-report of any additional supports students were receiving. Supports included teacher aide time, nurse or paramedic support, support teacher for reading, numeracy or learning difficulties, additional class teacher time, hospital school, peer or buddy tutoring or social skills programs, distance education, tutoring, school counselor, and contact with home school during absences. Support was rated as none or minimal for no supports, some where one or two forms of support were identified, and lots of support where three or more supports were reported. Figure 1. indicates a marked fall off in reported support to students as the amount of absenteeism increased. Over half of students with absenteeism in excess of 40 days were receiving minimal or no support, in contrast to a quarter of students with

absenteeism 20 days or less. Only a quarter of parents of students with absenteeism over 40 days reported that their child received lots of support.

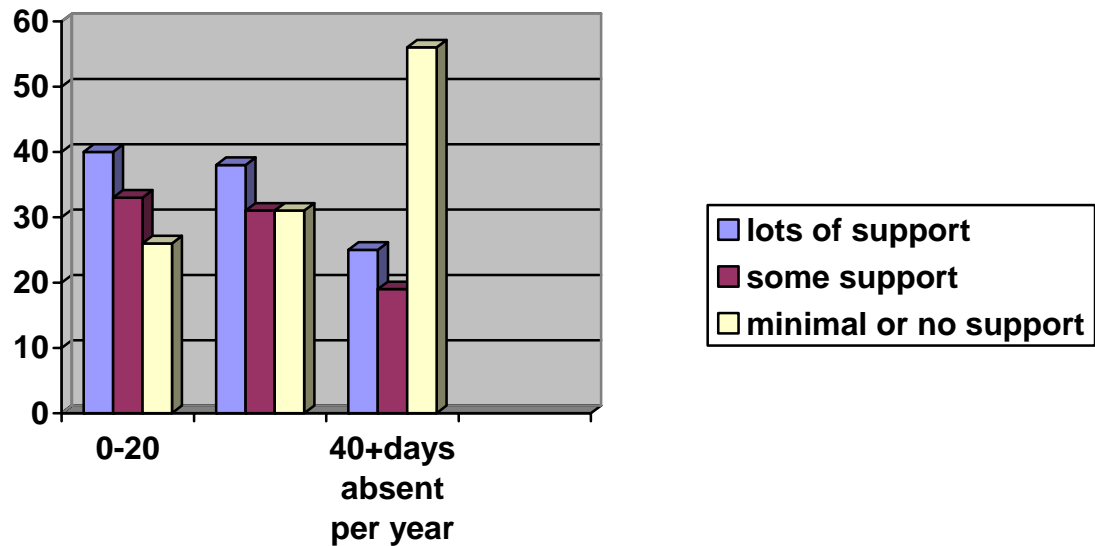


Figure 1. Student absenteeism and level of support

Supporting students with high levels of absenteeism is obviously a very complex issue.

This pattern of declining support with increased absenteeism, however, suggests that many schools are 'losing contact' with students who have high absenteeism. Whatever the reasons, the outcome remains that many of these students are slipping through gaps in educational services at a critical stage in their development, increasing the impact of illness in their life.

There is also a significant correlation (Pearson's correlation significant at the 0.01 level- 2 tailed) between student absenteeism and difficulty with family coping ($r=.244$). The greater the level of absenteeism, the more likely parents are to have difficulty coping with their child's illness. This may be due to many factors, including financial pressures and loss of income or work, time constraints impacting on relationships with siblings and partners and work commitments as well as the burden of illness. Whatever the reasons,

they only highlight the need for 'increased' support to students with extensive absenteeism to in turn support families. This is a very significant issue that schools and families need to face and address together.

5. Friends and friendships.

Parents generally (80%) recognize school as an important source of social support for their child. Whilst 57% of parents report their child is happy at school, this leaves a further 43% of parents either unsure or clearly concerned about their child's enjoyment of school. Two fifths of parents (40%) reported their child has little contact with their peers out of the school setting- with only 42% of children contacted by friends from school when in hospital for long stays. Given the importance of friends and friendships in healthy adjustment to school, and the role of friends in the healing process, supporting and facilitating friendships must be a major consideration for these students.

Children for whom there were few indications of social support, found it more difficult to return to school, and there was a significant correlation (Pearson's correlation significant at the 0.01 level- 2 tailed) between level of social support and having difficulty making friends ($r=.620$) a lack of contact from peers whilst in hospital ($r=.359$), the child being the victim of bullying, ($r=.383$), and being generally unhappy at school ($r=.480$). These figures strongly support the need for families and schools to facilitate and nurture the development of friendships between students with chronic illness and their peers.

6. Communication home and school

Nearly two thirds of parents (62%) indicated they wanted to be more involved in their child's education and in determining educational goals for their child. Whilst parents report they communicate regularly with the school, only 43% of parents reported talking

to teachers about their educational concerns for their child, and only slightly higher than half (55%) of parents report being informed when their child was having problems with academic work at school. Just over one third (37%) of parents indicated that teachers do not have enough time to talk about their child's individual educational needs.

This data would suggest that whilst parents are keen to be involved in educational decision making for their child, and they are frequently communicating with the school, this dialogue isn't necessarily directed toward the educational needs of their child, and they are frequently not being given sufficient information about their child's academic progress.

7. Correlates of families having difficulty coping

Families having difficulty coping with their child's illness, demonstrated a significant correlation (Pearson's correlation significant at the 0.01 level- 2 tailed) with having a child who hates school ($r=.193$), has poor peer relationships ($.277$), has difficulties keeping up with academic work ($r=.328$) and is reluctant to request additional work to do during absences ($r=.264$); their parents have limited communication with the school ($r=.204$), and they don't participate fully in school activities ($r=.211$), and their academic performance is compromised ($r=.252$). The focus for supporting families and in turn assisting them to cope better with their child's illness needs to address supporting peer relationships and academic progress through provision of catch up work and additional support for learning, and building home/school communication. The benefits include improved social support, reduced absenteeism, a happier child and less stress on the family.

8. School management of student medical needs.

Effective management of a child's medical needs is critical if both schools and families are to feel confident and reassured about the education of a child with chronic illness. Overall, one half of parents surveyed (51%), indicated that teachers at their child's school were familiar with the medical implications of their child's illness, and only half of parents (58%) were confident that the school could meet their child's medical needs. Parents of students with high absenteeism (>40 day) were even less likely to be confident in the school's ability to meet their child's medical needs than parents of students with low absenteeism. The additional stress parents must feel when they are unsure as to how well their sick child will be cared for whilst at school must place a terrible coping burden on families that are clearly already struggling to cope with their child's illness.

9. What makes Happy children

Parents were asked to indicate if their child was happy at school. Nearly 60% of parents indicated that their child was either happy or very happy. Several factors correlated significantly (Pearson's correlation significant at the 0.01 level- 2 tailed) with being happy at school including keeping up with classmates academically ($r=.277$), performing well academically ($r=.425$) and receiving additional support to catch up on missed work ($r=.266$). Students who were happy at school were also missing fewer days of school than students who were unhappy at school ($r=.350$). The ability to do as well as your peers and keep up academically appears to be very important in how well a student copes with school. Notably, receiving additional support to help them catch up and keep up appears to be impacting as well. Students who are able to participate fully at school and join in class activities (sports, excursions, playground games, etc) where they are perceived as the same as other peers, are also likely to be happy at school.

The support of friends and the ability to make friends and be involved in social activities out of school such as parties and other social activities, are strong indicators of whether a student is happy at school. These figures strongly support previous research indicating the importance of friends and friendships in healthy adjustment to school.

Students who are happy at school are also likely to have parents who are actively involved in school life, are informed by teachers about their child's academic progress and communicate regularly with the school.

In contrast, students who are unhappy at school are missing large amounts of schooling, falling behind academically and have poor relationships with their peers. Their families are less likely to communicate regularly with the school about their academic progress, and to be concerned about how well their medical needs are met whilst at school. Their families are also more likely to be having difficulties coping with their illness as.

Recommendations

Schools can make a difference to how well a student and a family cope with chronic illness. The provision of appropriate support, resources and attitudes by school communities can foster an environment that facilitates the academic and social growth the student. The following strategies are focused on enhancing the educational experience for students with chronic illness and reducing the negative impact that illness has in their lives.

Build Communication between home and school

- Talk about a child's academic progress and supports they need
- Share information about their medical progress, concerns about management of medical needs & impact of treatments

- Maintain contact with home and school during absences

Maintain academic achievement

- Monitor academic progress for students with frequent or extended absences
- Co-ordinate support through the school learning support team
- Request and organise provision of work, and copies of notes/ assignments and course work during absences

Build peer relationships

- Encourage friendships and facilitate ongoing involvement of friends/peers during absences and hospitalizations through photos, videos, emails, letters, internet
- Encourage full participation in school life to the extent it is possible for a child.
- Invite friends to be actively involved in the students life during absences
- Encourage involvement in social activities with peers in clubs/sports/interest groups/social outings.

Manage student medical needs

- Ensure schools have a medical management plan that addresses daily needs, identifying a medical emergency, medical emergency strategies, contact numbers, and training of staff in medical procedures.
- Identify staff at the school with responsibility for medical supervision of students, and alternative plans for when staff members are absent.

Support students returning to school

- Academically- assist students to catch up and keep up
- Socially- through welcoming back and fostering of friendships
- Emotionally- listen and give opportunities for talking when ready

- Ensure access all facilities in the school
- Be sensitive to changes in performance due to medications and or treatments
- Monitor impact of medications/treatments on student performance and share information with families

Reduce absenteeism

- Encourage students to return to school as soon as medically viable
- Monitor student attendance and access accurate information on student absences
- Maintain contact with students and families

Support emotional health of student & family

- Build resilience and emotional health through student welfare programs that teach coping skills and strategies for dealing with stress
- Ensure access to school counselor
- Be supportive of students and families & recognize the burden of responsibility in caring for a child with chronic illness
- Address bullying as an important school student welfare issue

Schools that make a difference are inclusive communities that are caring and supportive, that respond to student needs at an educational, social, physical and emotional level. They take responsibility for actively including all students through individualized programs of support, and strategic use of resources within and beyond the school. In this environment, learning for all students is enhanced.

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