Absence from school related to cancer and other chronic conditions


Abstract
Absence from school during the first year after starting major treatment for cancer or chronic or orthopaedic conditions was examined. Retrospective data were collected on 72 children and obtained from hospital records, school registers, and interviews with parents and teachers. Median initial absences caused by treatment were 91, 29-5, and 15 days for cancer, chronic, and orthopaedic patients respectively. The mean proportions of the remaining school time in the year occupied by absences caused by treatment and those not caused by treatment were respectively 17% and 17% for oncology patients, 8% and 12% for chronic patients, and 2% and 11% for orthopaedic patients. The only significant factor associated with the amount of absence caused by treatment was the type of illness. Increased absence not caused by treatment was associated with the amount of treatment time and the patient being a girl. The proportion of absence not caused by treatment decreased if the mother was educated beyond the age of 18. The possible reasons for and effects of excess absence are discussed.

Research has shown, for at least 30 years, that children with chronic conditions are likely to have up to 50% more absence from school than other children do.1–9 It is quite possible that some of these studies are underestimates of the real situation because parental reporting was used. Parents have been shown to under report their child’s absence.7 Studies of children with specific, as well as general, chronic conditions such as bronchial asthma,10–12 cardiac problems,13 and kidney diseases14 have also shown that these children miss considerably more school time than their classmates or siblings.

Child cancer patients have only comparatively recently been studied with regard to school, as a greatly improved prognosis has allowed most to return to their education. Many of these children appear to have very high absence rates after their return to school,15–17 which decrease but are still considerable two18 or three years19 after diagnosis.

It is inevitable that children who are chronically ill or who are receiving treatment will miss time from school, but the question arises as to whether or not the quantity of absence is directly related to their condition.

The study described in this paper, which is part of a larger research project on children’s return to school after treatment for cancers,20 funded by the Cancer Research Campaign, attempts to shed light on the reasons which lie behind these excess absences.

Methods
SAMPLE
The sample was drawn from hospitals in the south east and south west of England. The sampling procedure was as follows: all cancer patients aged 4 to 16 years, except those with brain tumours, and those who were not resident in the UK, or who were not fit to return to school, were identified from the hospital and ward lists and entered consecutively into the sample as they reached one year from diagnosis. For each cancer patient, so far as was possible, a matched patient of the same age and sex who had reached one year from the start of major treatment for a chronic or orthopaedic condition was also selected.

Seventy two children for whom complete sets of absence data were available were included in the study. Forty three for whom absence data could not be obtained from the schools were excluded. However, as table 1 shows this loss did not appear to be selective and no bias is assumed.

Their diagnoses included, acute lymphoblastic leukaemia, acute myeloblastic leukaemia, chronic myelocytic leukaemia, Wilms’ tumour, non-Hodgkin’s and Hodgkin’s lymphomas, rhabdomyosarcoma, osteogenic and Ewing’s sarcomas, and germ cell tumours.

Table 1 Distribution of sample. Results are number (% of total)

<table>
<thead>
<tr>
<th>Illness type</th>
<th>Main sample</th>
<th>Subsample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Boys</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>18 (16)</td>
<td>10 (14)</td>
</tr>
<tr>
<td>Chronic</td>
<td>11 (10)</td>
<td>5 (7)</td>
</tr>
<tr>
<td>Orthopaedic</td>
<td>10 (9)</td>
<td>7 (10)</td>
</tr>
<tr>
<td>Secondary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>18 (16)</td>
<td>7 (10)</td>
</tr>
<tr>
<td>Chronic</td>
<td>7 (6)</td>
<td>4 (6)</td>
</tr>
<tr>
<td>Orthopaedic</td>
<td>10 (9)</td>
<td>7 (10)</td>
</tr>
<tr>
<td>Subtotal</td>
<td>74 (64)</td>
<td>40 (56)</td>
</tr>
<tr>
<td><strong>Girls</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>9 (8)</td>
<td>8 (11)</td>
</tr>
<tr>
<td>Chronic</td>
<td>8 (7)</td>
<td>7 (10)</td>
</tr>
<tr>
<td>Orthopaedic</td>
<td>6 (5)</td>
<td>5 (7)</td>
</tr>
<tr>
<td>Secondary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>6 (5)</td>
<td>4 (6)</td>
</tr>
<tr>
<td>Chronic</td>
<td>6 (5)</td>
<td>4 (6)</td>
</tr>
<tr>
<td>Orthopaedic</td>
<td>6 (5)</td>
<td>4 (6)</td>
</tr>
<tr>
<td>Subtotal</td>
<td>41 (36)</td>
<td>32 (44)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>115</td>
<td>72</td>
</tr>
</tbody>
</table>
The chronic diseases included renal failure, cardiac conditions, asthma, and others. The orthopaedic conditions included thoracic scoliosis, club foot, trauma, and others. The decision to include thoracic scoliosis and club foot in this group was taken because the treatment pattern more closely resembled that for orthopaedic conditions than for chronic ones.

DATA COLLECTION

The data was collected in the following ways:

(1) Data on the dates, duration, and nature of treatment were obtained from hospital records, and were recorded in a diary format which enabled inpatient and outpatient treatment and check ups to be distinguished from each other.

(2) Details for school absences were obtained from the attendance registers in the children’s schools.

(3) Background information was collected by structured questionnaire interviews with the parents and teachers of the children.

Only the 72 children for whom all three sets of data were available were included in the analysis.

All data collection was carried out with the full permission of the relevant ethical committees, consultants, directors of education, headteachers, and parents.

ANALYSIS OF DATA

The analysis of the data was carried out using the Statistical Package for the Social Sciences (SPSSX).

(1) Amount of absence caused by initial treatment

The length of initial treatment was recorded in days absent from school, excluding weekends and school holidays. All absences therefore include only the days on which it would have been possible for the child to attend school but did not. Medians and interquartile ranges were calculated as well as means and SD (table 2).

(2) Amount of absence caused by further treatment after return to school

The mean and SD and the medians and interquartile ranges were also calculated for the following treatments: (a) further hospital inpatient treatment in days, (b) follow up outpatient treatment in days, and (c) follow up outpatient clinic visits for check ups in days.

Table 2 Amount of absence caused by initial treatment: school days absent (number between date of diagnosis and return to school)

<table>
<thead>
<tr>
<th>Descriptive Statistics</th>
<th>Patient Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cancer (n=29)</td>
</tr>
<tr>
<td>Mean</td>
<td>85.21</td>
</tr>
<tr>
<td>SD</td>
<td>59.22</td>
</tr>
<tr>
<td>Median</td>
<td>91</td>
</tr>
<tr>
<td>Minimum, maximum</td>
<td>6, 184</td>
</tr>
<tr>
<td>Interquartile range</td>
<td>25, 142</td>
</tr>
</tbody>
</table>

(3) Proportion of absence caused by treatment after return to school after initial treatment

Because the length of initial treatment absence varied greatly, the amount of time available for attendance at school during the remainder of the year after diagnosis also varied considerably. It was therefore more meaningful to consider the proportion of absence by relating the amount of absence to the school time available for attendance.

Dates of school holidays were obtained from local education authorities in the areas studied. The actual possible attendance time for each child was accurately calculated, taking holidays into account, from the date of return to school to the end of the year after diagnosis; this gave the proportion of overall treatment absence (inpatient, outpatient, and clinic check ups).

(4) Patterns of absence caused by treatment

The patterns were examined visually by transferring the diary data to graph paper.

(5) Proportion of absence not caused by treatment after return to school after initial treatment

The same conditions applied to these calculations as to those for absence caused by treatment in (3) above. Absences not caused by treatment were taken to be all those absences recorded in the school attendance registers that were not accounted for by hospital inpatient or outpatient treatments or check ups specifically recorded in hospital records in relation to the disease under consideration.

(6) Background factors related to absences not caused by treatment

These factors, including those identified in the interviews with parents and teachers, were related to the outcome variable. This outcome variable was determined as follows:

\[
\text{Outcome} = \frac{A - B}{\text{Total number of school days}}
\]

B consists of two parts, namely, all school days between the date of diagnosis and return to school, plus all school days after the return to school and the end of the observation period. This therefore provides a measure of treatment severity by means of its amount.

One point to consider when modelling this proportion is that the number of days not caused by treatment after the return to school is bounded by the number of school days from the return to school to the end of the observation period. If this latter period of time is only five days long then the maximum number of days absence not caused by treatment possible after the return to school is also five days. In terms of our outcome/dependent variable this particular situation would produce a very low proportion. Hence, only patients who have recorded a reasonable length of time from their return to school to the end of the observation period can be seen as possible frequent absentee.
The background factors included in the regression modelling are shown in Table 3. The findings are, of course, based on a small sample and must therefore be interpreted with caution. Nevertheless much of the research on this topic which has been mentioned earlier in this paper is also on small samples due to the relative rarity of childhood cancers.

Results

(1) Amount of absence caused by further treatment

As Table 4 shows, orthopaedic patients had no outpatient follow up and few admissions to hospital subsequent to the initial treatment. Cancer patients, and to some extent chronic disease patients, can follow a rigorous course of treatment and monitoring. Outpatient treatment for chronic diseases was rare, but admissions as inpatients and check up visits were relatively frequent as they were for cancer patients.

(2) Patterns of absence caused by treatment

When observed graphically three main types of treatment pattern emerged.

(a) One long, or relatively long, treatment followed by regular short absences each usually of one, or a few, days' duration for follow up treatment or monitoring of progress. This pattern was the most frequent one for the cancer patients. Visually the regularity of the single day absences was strikingly clear and was due to the outpatients' clinics attended being held on the same day of the week throughout the year.

(b) Repeated admissions to hospital for relatively short periods from a few days to one or two weeks in length. This pattern was relatively infrequent in this sample of children and was seen for only a few of the cancer patients and some of the chronic cases, such as asthmatics. Most of the patients with other chronic diseases which required surgery, including transplants, followed more closely the pattern described in (a) above.

(c) One long absence with very few subsequent visits to outpatients' clinics. This pattern was most frequent in the orthopaedic cases where, once the condition had been corrected, further treatment and monitoring were largely unnecessary.

(3) Proportion of absence caused by treatment and that not caused by treatment after return to school after initial treatment

Table 5 shows that the cancer patients were likely to lose a greater proportion of their school time in absence caused by follow up treatment than either the chronic or orthopaedic patients. Many of the children had absences from school not directly accounted for by actual sessions of treatment or monitoring.

As Table 5 shows, the cancer patients had the highest median proportion of absence not caused by treatment. Chronic and orthopaedic
patients after the return to school had more absence not caused by treatment than that caused by treatment.

(4) Factors related to the proportion of absences
The size of sample was not large enough to permit separate analysis of the factors related to each of the three disease groups, therefore the results expressed here related to the absences overall.

(a) Factors related to absence caused by treatment—The only significant factor related to increased proportions of absence caused by treatment was the type of condition being treated. Absences caused by follow up treatment for the cancer patients were significantly longer than those of the chronic disease patients \( (p=0.001) \) and those of the orthopaedic patients \( (p<0.0005) \). The difference between absences caused by follow up treatment between chronic and orthopaedic patients was less significant \( (p=0.02) \).

(b) Factors related to absence not caused by treatment—As table 6 shows, when the individual background factors were entered into a regression analysis the following associations with the outcome/dependent variable were found:

(i) An increase in the proportion of absence caused by treatment after return to school was associated with an increase in the outcome variable, that is, proportion of absence not caused by treatment.

(ii) Patients whose mothers were educated above the age of 18 were associated with a decrease in proportion of absence not caused by treatment.

(iii) Girl patients were associated with an increase in absence not caused by treatment.

(5) Absence before diagnosis
It seemed reasonable to examine absence during the year before diagnosis, but unfortunately data were available for only 49 children out of the 72. Table 7 shows their prediagnosis absences. They were significantly different \( (p=0.01) \); this was due to the children with chronic diseases having a mean absence of more than twice as many days in the year than the other two groups had.

With such a reduced sample it was not possible to make a meaningful comparison between absence before and after diagnosis with regard to associated factors.

Table 7 Absence in days during the school year before diagnosis (reduced sample for whom data were available)

<table>
<thead>
<tr>
<th>Descriptive statistics</th>
<th>Patient group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cancer ( n=17 )</td>
</tr>
<tr>
<td>Mean</td>
<td>15-12</td>
</tr>
<tr>
<td>SD</td>
<td>12-68</td>
</tr>
<tr>
<td>Median</td>
<td>14</td>
</tr>
<tr>
<td>Minimum, maximum</td>
<td>1, 50</td>
</tr>
<tr>
<td>Interquartile range</td>
<td>6, 20</td>
</tr>
</tbody>
</table>

Discussion
On average the cancer patients in this study lost 35%, chronic disease patients 19%, and orthopaedic patients 13% of their available school time in the remainder of the year after their initial treatment. This loss of school time was a combination of absence caused by treatment and that not caused by treatment.

(a) Absences caused by treatment
The tendency now appears to be towards shorter hospital admissions for children. This present trend permits many children to return to school at the earliest possible opportunity, but makes the need for outpatient treatment or further short admissions to hospital more frequent.

The graphic representation of these absences, especially for the cancer patients, showed that they often fell regularly on a particular day of the week when the paediatric outpatient clinic is held. A previous study showed that this presents problems for some children because they miss the same lessons each time they visit the clinic and thus fall behind in the specific school subjects taught on that day. This presented special problems in mathematics and, for the younger children, in reading. Both these subjects require actual teaching and cannot be caught up by the individual child working alone. It has been suggested that holding paediatric clinics out of school hours would help, or calling children to outpatients’ clinics on different days of the week if this were feasible for the treatment regimen.

(b) Absences not caused by treatment
Some of the absence not caused by treatment is certainly related to the illness. The proportion of absence not caused by treatment was significantly related to the amount of absence that was caused by treatment. Many child cancer patients on chemotherapy suffer nausea and vomiting after treatment, causing them to miss school. Some also have anticipatory sickness before their treatment. However, the social factors found to be related to the amount of absence not caused by treatment suggest that more than the disease and treatment are responsible for these absences.

(i) Girls are more likely than boys to have increased absence—Other studies have shown that girls with cancer and chronic illness are likely to have more school absence than boys are. This also applies generally. It has been suggested that a cultural expectation that
boys should give in to illness less easily than girls might have something to do with this difference. There is evidence that girls' attitudes to health do differ from those of boys. For example, girls were significantly more likely to pay attention to pain, to express fear of getting hurt, and to tell others when they were not feeling well. It has also been suggested that there might be a higher incidence of illness such as dysmenorrhoea in adolescent girls.

(c) Mother's education—Previous research has shown that the predicted number of days that a child with a chronic disease was away from school was found to decrease as the education of the primary caregiver increased. Our study also showed the level of mother's education to be an important factor. The reasons for this association are not clear but several might be suggested. Mothers who left school at the earliest opportunity and perhaps disliked school themselves might have a negative attitude to school and be unwilling to 'force' their child into it. It is also suggested that mothers with less education might have less skill and knowledge to overcome some of the problems associated with the disease. There is also the likelihood that these mothers are less affluent. Hardship and poverty have been shown to be linked with high absence rates in children with chronic illness, and in general. These families are less likely to own a car, and transport to school of a child with physical problems could then present difficult problems, especially if the mother was unfamiliar with the procedures needed to get transport provided.

The mother's attitude can be important. For example, mean absentee rates in a sample of children with asthma were related to the mothers' view of the severity of the asthma: mild (6.9% absence), moderate (7.9%), and severe (13.9%). There is a real, understandable risk of overprotectiveness by parents and of family patterns of keeping children off school for minor ailments, both of which can lead to more absence than is necessary. The latter was also shown in respect to young cardiac patients. School phobia, based on unconscious conflicts and fantasies, can take many guises and can fool mothers. It can be prevented, but keeping the child off school is not the answer.

Effects

Chronic illness as related to school has been shown to include an increased risk of social isolation, trouble at school, poor attitude to school work, truancy, and school absence. Further negative effects have been shown in a study of asthma patients and other chronic disease patients. 17% and 30% of whom respectively had to repeat a school year. Falling behind and repeating a year was one of the greatest fears and worries expressed by children who had been treated for cancers.

Evidence is totally conflicting as to whether or not excessive absence leads to poorer achievement scores. Some studies showed a link between poor attendance and poor scores, others have failed to do so. There is, however, no doubt that many young cancer patients do experience problems with progress in school subjects.

On the positive side, even as long ago as 1975, a study in the USA of a group of people who had been treated for childhood cancers at least 10 years earlier reported that they had achieved much academically. If this could be done by patients treated over 25 years ago, how much more should be expected of present day cancer patients?

School is important. It is all too easy for parents and teachers to think in the short term, seeing only the immediacy of the disease. Teachers tend to assume that when a child with a known serious illness is absent from school, the absence will be associated with that illness and they also tend to be more lenient to child cancer patients. They therefore accept the absence without question. In fact, the absences not caused by treatment are by no means always related to the illness. A study of asthmatic children in a general practice showed that their absences were rarely related to the asthma, but they were absent for the same reasons as those of children in general, as were some in our study.

Children who suffer serious disease have a future, whether it be short or long. Their careers are important to them, and many have already made their career choice. As one 10 year old girl said, 'if I can't have children, my career is more important to me than to most people. I must leave something good for the world'.

A great deal is already being done, but changing prognosis bring changing needs.

The authors sincerely thank the Cancer Research Campaign for funding the study of which these findings form a part. Grateful thanks also go to the ethical committees, consultants, and directors of education for their permission to carry out the work, and to all the headteachers and staff of the schools and hospitals who helped so much. We also thank David White and Jayne Thompson for their hard work on the analysis. Especial thanks go to the teachers and parents who took part in the interviews.

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Treatment of cardiac arrhythmias using radiofrequency current
As we all know, the cardiologists are getting cleverer and cleverer
with their catheter techniques. Two articles, from workers
in Oklahoma and Michigan, published side by side in the 6 June
issue of the New England Journal of Medicine report high success
rates using radiofrequency current to ablate accessory conduction
pathways in the treatment of the Wolff-Parkinson-White syn-
drome and of recurrent paroxysmal supraventricular tachycardias
(Warren M Jackman and colleagues and Hugh Calkins
Initial attempts at percutaneous catheter ablation used high
energy direct current shocks with a high success rate but serious
morbidity in a few patients. The use of radiofrequency currents
(550-750 kHz) is associated with much less risk. In the first of
these two studies the youngest patient was 6 and five were under
9 years. The youngest in the second study was 15. Elimination
of accessory pathway conduction was achieved in 99% (164/166)
of patients in Oklahoma and 92% (94/102) of patients in Michigan.
In the two studies combined, five of 268 suffered complications—
atrioventricular block in two and coronary occlusion, pericarditis,
and cardiac tamponade each in a single case.
The technique does not supercede drug treatment but it is
recommended for patients with severe symptoms who have not
responded to the drugs.

ARCHIVIST

FS. Everybody’s doing it. See Karl-Heinz Kuck and colleagues (Lancet 1991;337:
1557-61).