ORIGINAL ARTICLE

Hospital attendance patterns in long term survivors of cancer

R Johnson, B Horne, R G Feltbower, G E Butler, A W Glaser

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See end of article for authors' affiliations

Correspondence to: Dr A W Glaser, Children's Day Hospital, St James's University Hospital, Beckett Street, Leeds LS9 7TF, UK; adam.glaser@leedsth.nhs.uk

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Aims: To identify attendance patterns in a childhood cancer long term follow up clinic, in order to inform decision making strategies for efficient, cost effective local and national surveillance of survivors.
Methods: Cross-sectional review of 385 individuals >5 years from completion of cancer therapy in childhood or adolescence, attending a regional paediatric oncology and haematology centre.
Results: Attenders were younger than non-attenders in the <18 age group; no differences were found for ⩾18 year age group. Those attending clinic were more recently off treatment; no significant difference existed for those <7 years from completion of therapy. A greater proportion of attenders were in the most affluent socioeconomic groups with a greater proportion of non-attenders in the lower groups. Those in full time education or training were more likely to attend and those unemployed were less likely. Multiple regression analysis confirmed a significant trend in reduction in attendance with increasing social deprivation, and that attenders were more than twice as likely to be in full time education or training.
Conclusions: Following cancer treatment in childhood and adolescence, attendance at long term follow up programmes is determined by social factors including education, employment, and deprivation.

Stepwise improvement in childhood cancer survival over the past three decades has resulted in five year survival rates in excess of 70%.[1 2] It is estimated that one in 900 young adults (15–44 years of age) in the general population are survivors of malignancy.[3] The ''cost of cure'' in this growing group of long term survivors remains undefined. A standardised systematic approach to the long term evaluation of such patients is therefore needed to determine risk, to enable modification of future therapeutic protocols, and to enable the early detection of morbidity.

Late sequelae include recurrence, second primary tumours, cardiovascular disease, endocrine, metabolic, and reproductive health problems alongside an array of psychosocial difficulties.[1 2] However, evidence detailing the precise risks of sequelae to treatment and benefits of long term follow up for all patients is currently lacking.[1]

The United Kingdom Children's Cancer Study Group (UKCCSG) Late Effects Group has identified these issues and is considering proposals for long term evaluation after cancer. Stratification of survivors by treatment has been proposed with varying intensities of subsequent clinical evaluation.[1] No published data exist for these individuals relating to patterns of compliance with long term surveillance programmes. Evidence from other types of clinic shows that patients who default on appointments do suffer morbidity.[4 5]

This study aims to identify patterns of attendance in a long term follow up (LTFU) clinic in a regional paediatric oncology and haematology unit in order to inform decision making strategies for efficient and cost effective local and national surveillance of childhood cancer survivors.

SUBJECTS AND METHODS

Subjects

Data were collected on patients with appointments for the Yorkshire Regional Centre for Paediatric Oncology and Haematology LTFU clinic in 2001. Five years from completion of therapy individuals are transferred to this clinic for aftercare. The majority of patients continue to be offered annual or biennial follow up appointments for life. Clinics are coordinated by a consultant paediatric oncologist, consultant paediatric endocrinologist, and specialist nurses in oncology late effects and endocrinology. In this hospital, a small number of patients, considered to be at low risk (no radiotherapy or known organ toxicity, over 10 years from completion of treatment and successful progression of growth and development) are followed up with brief postal questionnaires in the intervening years between clinic reviews. Patients reviewed by questionnaire in 2001 were not due to be seen in clinic and have been excluded from the study. Four patients who were less than five years post-treatment, yet attended the LTFU programme, were also excluded.

Patients were classified as attenders or non-attenders. Those who came to or cancelled appointments were classified as attenders. Patients who do not attend their first appointment are offered another appointment. Following three failures to attend an appointment, the patient's general practitioner is contacted in an attempt to contact the patient. Consequently a patient due to be seen in clinic in 2001 could default on several appointments in that year. Those classified as non-attenders fell into two groups: either they did not attend their first appointment only (group A), or they did not attend their first appointment and subsequent appointments (group B).

Methods

Data were obtained from several sources: a clinic database holding patient information; treatment summaries; a previous employment study; and retrospective review of case notes. Variables collected included age (as at the midpoint of 2001), sex, diagnostic group (leukaemia, lymphoma, brain, bone, and other solid tumours), time elapsed since the end of treatment (years), social deprivation (Townsend scores[6] generated from the postcode and divided into five categories based on the distribution of the ranks from Yorkshire. A negative Townsend score indicates more affluent than average. Deprivation increases when moving from a more negative to a more positive score[6]), treatment level (surgery only; chemotherapy with or without cranial irradiation; radiotherapy/bone marrow transplant[1]), recurrence (Y/N),

employment (employed, in education, unemployed, other), English as first language (Y/N), and ethnicity.

Patients were classified into groups of those of school age (11–16 years), further education age (16–18 years), and those above these ages for analysis of age. These age groups were based on academic years running from 1 September to 31 August.

Statistics

Statistical tests for the univariate analysis consisted of the χ^2 or Fisher's exact test, χ^2 test for trend, and the Student's *t* test or Mann-Whitney U test (dependent on numbers of patients and normality assumptions). Factors found to be significantly associated with attendance were then included in a multivariate logistic regression model. The employment categories ''unemployed'' and ''other'' were combined to a single category in order to comply with Cochran's rule.[7]

RESULTS

Data were collected for 100% of patients in the study for all variables except social deprivation score and employment. Social deprivation scores were matched to 92.2% of patients' postcodes (92.4% of attenders and 91.3% of non-attenders). Employment data were available for 86.8% of patients (89.2% of attenders and 75.4% of non-attenders).

In total data were collected on 385 patients (age range 5.74–38.83 years, mean 18.94 years; 184 females, 201 males). Of these 316 (82%) were classified as attenders and 69 (18%) were classified as non-attenders. Of the non-attenders 50 were classed as group A and 19 were classed as group B.

The analysis revealed significant differences between attenders and non-attenders in the following variables: age; time since end of treatment; social deprivation score; and employment. For each of these variables there were no significant differences between the subsets of non-attenders, group A and group B.

Age (table 1)

Attenders were younger than non-attenders. Attenders had a mean (SE) age of 18.5 (0.368) years, whereas non-attenders had a mean (SE) age of 21.0 (0.68) years ($t = -3.31$, $p = 0.0013$).

There was a difference in the proportions of those aged under 18 years and those aged 18 years or over in the attenders and non-attenders (table 1; $p = 0.0145$). Attenders were younger than non-attenders in the under 18 years age group (difference in medians −1.9, 95% CI −3.1 to −0.7). There were no significant differences in age of attenders and non-attenders in the 18 year plus age group.

No significant differences in proportion were observed when comparing the 11–16 and 16–18 year old age groups.

Time since end of treatment

Attenders were more recently off treatment than non-attenders (Mann-Whitney U test, $p = 0.0003$). The difference between the medians for time since end of treatment of attenders and non-attenders was −2.5 years (95% CI −3.9 to −1.2). More detailed analysis revealed that this was true of patients seven years or more off treatment (Mann-Whitney U test, $p = 0.0001$). For those seven years or more off treatment, the difference in median time since end of treatment of attenders and non-attenders was −2.4 years (95% CI −3.6 to −1.2). There was no significant difference in time since end of treatment between attenders and non-attenders less than seven years off treatment (Mann-Whitney U test, $p = 0.282$).

Table 1 Number (%) of attenders and non-attenders by age group

Age group	Attenders	Non-attenders
<18 years	159 (87%)	23 (13%)
⩾18 years	157 (77%)	46 (23%)

$p = 0.0145$.

Social deprivation scores (fig 1, table 2)

Attenders tended to be from less deprived areas than non-attenders (Mann-Whitney U test, $p = 0.0062$). The difference in median scores between attenders and non-attenders was −1.3 points (95% CI −2.4 to −0.4 points). There was no significant difference in the distribution of scores of attenders compared to the quintiles of the background population of Yorkshire. However, the distribution of scores of non-attenders differed significantly from the background population of Yorkshire ($\chi^2_{trend} = 9.07$, $p = 0.0026$).

There was a greater proportion of attenders in the most affluent socioeconomic groups, whereas there was a greater proportion of non-attenders in the lower groups (fig 1; $\chi^2_{trend} = 10.46$, $p = 0.0012$).

Those of lower socioeconomic status were less likely to attend, but the reduced odds of attendance did not reach significance (table 2). This may be a function of the sample size as there is a trend towards non-attendance as deprivation increases (test for trend, $p = 0.003$).

Employment (tables 3 and 4)

There was a significant difference in proportions of the groups ''employed'', ''education'', and ''other'' between attenders and non-attenders (table 3; $\chi^2 = 14.37$, $p = 0.0008$). There were no significant differences in proportions between attenders and non-attenders in those above compulsory school age or those aged 19 years and over.

On average, those in full time education or training were more likely to attend, and those unemployed or other were less likely to attend than those in employment (table 4).

Non-significant results (table 5)

The variables for which there was no significant difference between attenders and non-attenders were: sex, diagnostic group, treatment level, and recurrence (table 5). For each of

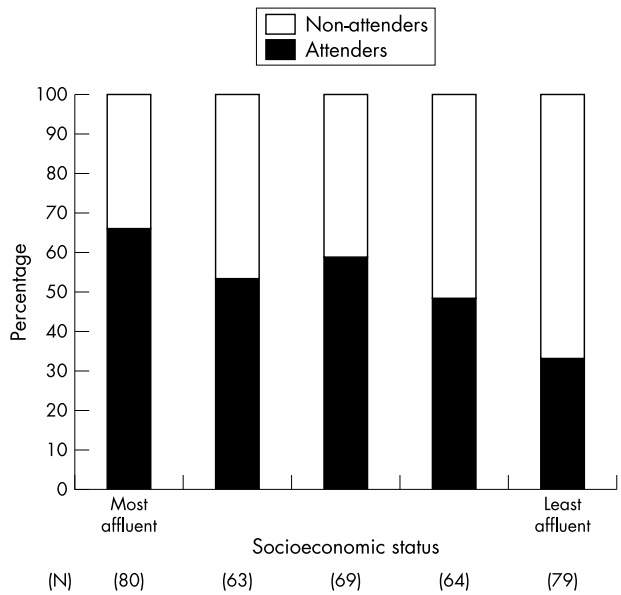

Figure 1 Percentages of attenders and non-attenders in five socioeconomic groups based on the quintiles of the background population of Yorkshire ($\chi^2_{trend} = 10.46$, $p = 0.0012$).

Table 2 Likelihood of attendance according to socioeconomic status

Townsend score	Odds ratio	95% CI
Most affluent	1.0	
↓	0.59	0.28 to 2.07
↓	0.74	0.31 to 2.36
↓	0.48	0.27 to 1.83
Least affluent	0.25	0.23 to 1.3

these variables except diagnostic group (for which there were too few group B cases in each category for meaningful analysis) the attenders were also compared to group B of the non-attenders. There were no significant differences in these variables between attenders and group B.

Yorkshire has a large ethnic community; 9.5% of the total population are non-white, with 7.3% of the total being Asian.[8] English as a first language was a non-significant variable in this study. There were two non-English speakers of 316 attenders and one non-English speaker of 69 non-attenders ($\chi^2 = 0.48$, $p = 0.48$). Asian survivors appeared to be less likely to attend clinic although this did not reach statistical significance ($\chi^2 = 2.937$, $p = 0.09$).

Multiple logistic regression analysis (table 6)

The following variables were included in the multiple logistic regression analysis: age, time since end of treatment, employment status, and social deprivation score. The results for each variable, shown in table 6, are adjusted for all the other factors in the model.

Those in the most deprived socioeconomic group were significantly less likely to attend than the least deprived, when controlling for age, time since end of treatment, and employment status. Evidence of a significant trend with increasing deprivation was still present ($p = 0.011$).

Attenders were still, on average, more than twice as likely to be in full time education or training than non-attenders (OR = 2.17, 95% CI 0.89 to 5.38), and were 50% less likely to be in the unemployed/other category (OR = 0.49, 95% CI 0.15 to 1.61).

The Hosmer-Lemeshow goodness-of-fit test showed that the regression model was a reasonable fit ($p = 0.456$).

DISCUSSION

No previous studies have examined compliance of survivors of childhood cancer with after-care programmes. Benefits of attendance are thought to include surveillance for late recurrence, detection and management of organ toxicities resulting from therapy (surgery, chemotherapy, and radiation therapy), education and empowerment of survivors, and psychosocial support. The aim is to maximise survivors' autonomy, function, and integration within society. Despite the potential benefits of follow up, the overall non-attendance rate in this clinic is currently 18%. This compares to figures in other studies of non-paediatric oncology clinics ranging from 5% to 34%.[9–12] In a previous study at our hospital, non-attendance at paediatric clinics was documented as 25% for general clinics and 27% for specialty clinics.[13]

Table 3 Frequency distribution of those in employment, education, or other for attenders and non-attenders

Employment status	Attenders	Non-attenders	Total
Employed	75 (77%)	22 (23%)	97
Full time education or training	198 (89%) (125 at school)	24 (11%) (12 at school)	222
Other, including unemployed	9 (60%)	6 (40%)	15
Total	282	52	334

$\chi^2 = 14.37$, $p = 0.0008$.

Table 4 Likelihood of attendance according to employment status

Employment status	Odds ratio	95% CI
Employed	1.0	
Full time education or training	2.42	0.70 to 2.52
Other including unemployed	0.44	0.20 to 1.94

Does it matter if survivors do not attend clinic? Those who are well adjusted and satisfied with their lives may not feel the need to continue with long term health surveillance. Appropriate education regarding potential late sequelae would allow them to contact a health professional if any concerns developed. However, some organ toxicities such as cardiac dysfunction require periodic monitoring in a hospital setting. Additionally, the average general practitioner will have one patient diagnosed with childhood cancer every 22 years (unpublished data, Yorkshire Specialist Register of Cancer in Children and Young People). The rarity of these illnesses may mean that the long term surveillance of this cohort of survivors, if performed by primary care organisations, would result in delayed identification of as yet unknown late sequelae. However, regional LTFU programmes would be more likely to detect these, thereby allowing for consideration of modifications to future therapeutic strategies in the treatment of childhood malignancy.

In addition to the possible increase in morbidity and even mortality of non-attendance, there may be associated fiscal implications. Non-attendance at outpatient appointments is a common problem, estimated to cost the NHS £360 million per annum.[10] It is therefore important to address the issue of non-attendance in the interests of both patient care and resource allocation.

Studies on non-attendance have looked for patterns in demographic and other data collated from case notes. Reasons most commonly stated for non-attendance are: forgetting, administration failures (failure of notification and cancellation), illness, problems getting time off work, and transport difficulties.[10–12 14–16] Administrative failure is relatively straightforward to address and there is evidence that simple telephone and postal reminders can reduce non-attendance rates,[15 17 18] as can more complex strategies such as self-referral booking systems.[10]

The results show that attendance at the LTFU clinic is affected by both socioeconomic status and employment status independently. Patients become more likely to miss appointments as their deprivation score increases and as their employment level decreases. This is in keeping with the evidence that those of a lower social class have both poorer health and poorer access to healthcare.[19–21] Attendance is not affected by sex or factors relating to the disease process itself

Table 5 Variables for which there were non-significant differences between attenders and non-attenders

Variable	χ^2	p value
Sex	1.42	0.2337
Diagnostic group	1.29	0.8624
Treatment level	0.30	0.8613
Recurrence	0.20	0.6522

Table 6 Odds ratios generated by multiple logistic regression analysis for attenders compared with non-attenders

Variable	Odds ratio	95% CI	p value
Age (y)	1.01	0.94 to 1.09	0.74
Time since end of treatment (y)	0.95	0.88 to 1.03	0.20
Employment status			
Employed	1.0	–	–
Full time education or training	2.17	0.89 to 5.38	0.09
Other including unemployed	0.49	0.15 to 1.61	0.24
Socioeconomic status			
Most affluent	1.0		
↓	0.52	0.19 to 1.44	0.21
↓	0.73	0.26 to 2.06	0.55
↓	0.60	0.22 to 1.66	0.33
Least affluent	0.31	0.13 to 0.75	0.009

(diagnostic group, treatment level, and recurrence). This study also found that this held true not only for those who miss their first appointment, but also for those who miss multiple appointments.

Attenders were younger than non-attenders and were more recently off treatment. However, the logistic regression model shows that these variables do not have an effect when controlling for the other variables. We can have a degree of confidence in the results of the multivariate analysis due to the goodness of fit of the model.

The UKCCSG Late-effects Group suggest that long term follow up strategies could be modified so that those receiving surgery only (treatment level 1) could be followed up by post or telephone, chemotherapy with or without cranial irradiation (treatment level 2) by a nurse or primary care doctor, and only those receiving megatherapy, radiotherapy (other than low dose cranial), or bone marrow transplant (treatment level 3) require medical supervision in an LTFU clinic.[1] Our results show no statistically significant difference in treatment levels between attenders and non-attenders, yet there were still 24 patients (34.8%) missing follow up appointments who were categorised as treatment level 3. Therefore it is important to ensure that these patients are not lost to follow up because of social and logistic factors.

The first step is to make sure that patients are not missing appointments because of administrative failure. Systems already in place in this department that help to avoid administrative errors include issue of the next appointment before leaving the clinic, and sending of postal reminders when the appointment is near. Personalising postal reminder letters may further encourage attendance.

How to solve the difficulties of the socially disadvantaged is more complex. Action must be taken to ensure that even the least affluent can access services. Some suggest that the organisational culture of the NHS needs to change so that it becomes more customer focused.[16 22] Steps might include the provision of evening clinics, or outreach clinics in local primary care premises in deprived areas. Alternatively, assistance with transport could be offered to those who need it.[16] These strategies have obvious financial implications. However, cost savings made in other areas such as by adoption of the outlined strategy suggested by the UKCCSG,[1] and from any resultant reduction in non-attendance may offset this burden.

In summary, this study shows that non-attendance is determined by social factors, including deprivation and employment status. In order to ensure equal and appropriate access to surveillance for all survivors of childhood cancer this must be addressed by LTFU programmes as risk based surveillance strategies are developed.

Authors' affiliations

R Johnson, B Horne, G E Butler, A W Glaser, Yorkshire Regional Centre for Paediatric Oncology and Haematology, Leeds, UK
R G Feltbower, Paediatric Epidemiology Group, University of Leeds, UK

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