Clinic audit for long term survivors of childhood cancer

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Abstract

Follow up for survivors of childhood cancer is considered essential in order to document any continuing impact on growth, fertility and other systems, as well as provide appropriate care and information to individuals themselves. Appropriate follow up needs to take into account the survivors' own views about reasons for attendance and perceived satisfaction with the services provided. Information was sought from 93 survivors (more than five years from diagnosis) and 68 of their parents regarding current attendance, understanding of the purpose of the clinic and satisfaction, and future preferences. Patients' main reasons for attending were to gain reassurance that they were well and information about the disease. There were some discrepancies between the types of information patients would like from clinic attendance and what they remembered being given. Parents were more positive than patients. Our data suggest that (i) knowledge in survivors is poor and (ii) it may be possible to define a subgroup for whom less frequent follow up is appropriate. A key component of care must involve education of patients, both about their past and the implications for future health.

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Follow up of survivors of childhood cancer is considered mandatory. While the likelihood of relapse is small for those who survive five years from completion of treatment,¹ long term problems involving growth and fertility,² respiratory,³ or cardiac damage,⁴ as well as educational and psychological problems,⁵ have been reported. Surveillance is therefore necessary in order to record instances of long term damage. In addition it is important to inform patients and their families of possible long term risks to health. This dual approach is hoped to influence future treatment protocols so as to minimise late effects while maintaining effective cure rates.

The issue of appropriate follow up is, however, complicated. Recent estimates give an overall five year survival after treatment for malignant disease in excess of 60%.⁶ For staff, the number of survivors now places a huge burden on time and resources.⁷ For patients, the reasons for attendance may seem unclear,

especially where treatment took place during early childhood. Knowledge can be poor among survivors of childhood cancer.⁸ At the same time, patients may feel that it is more important to look to the future, rather than dwell on the past. For these reasons, we might anticipate declines in attendance, especially with increasing time from diagnosis, and where patients may see themselves as 'cured'.

In order to encourage attendance for routine follow up appointments, it is therefore essential that clinic staff are responsive to patients' needs and make efforts to ensure that the service offered fulfills patients' expectations. For this reason, we undertook an audit of our current practice, with a view to ensuring a match between patients' expectations and service provision. Our focus is therefore on patients' perceptions of the rationale for follow up and their evaluation of clinic organisation and practice.

Since we were concerned that attendance may deteriorate as young people become more independent of their parents, information was collected separately from patients and their parents. Thus, we hoped to identify the extent to which patients and their parents had similar views about the appropriateness of, and need for, long term follow up.

Patients and methods

Referrals to the clinic include adolescents (>12 years) and young adults who have been off treatment for at least five years. The clinic aims to provide an appropriate setting for young people, to encourage 'handover' of care from parent to young adult, and to provide information regarding long term prognosis. Clinics are held on a monthly basis during normal clinic hours throughout the year and follow up is usually on an annual basis for each patient. The clinic was set up in September 1994 and is manned by two oncologists and a general practitioner interested in adolescent care.

The questionnaires were distributed at six consecutive clinics. Patients and where appropriate, their accompanying parent, were approached and asked to complete a questionnaire concerned with their opinions about the clinic. Rating scales were explained and patients and parents were encouraged to work independently.

A total of 138 patients were offered appointments to attend these clinics. Of these, 21 attended but were not included in the study. (This was for practical reasons; they may have arrived very late in clinic or had appointments

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in other departments.) A further 24 patients did not attend, representing a failed attendance rate over the six month period of 17%. A total of 98 patients were approached and agreed to participate. No family who was approached refused to take part. However, three families failed to complete the questionnaire because of language difficulties and two families did not complete although English speaking. Two patients were unable to complete the questionnaire themselves because of learning difficulties. Questionnaires were therefore completed by 91 patients. In addition, 56 mothers and 16 fathers who attended clinic with their child completed a parallel form of the questionnaire.

For the 93 patients in the total sample, there were 55 males and 38 females. Mean age of the group was 16 years (range = 11–26 years, SD=3.8) and mean number of years since diagnosis was 11 (range = 6–24 years, SD = 3.4). For the purposes of this paper, we distinguished two diagnostic groups: leukaemia or lymphoma ($n=51$) and solid tumours ($n=42$). Two diagnostic groups were used as these patients were previously cared for in separate clinics. The follow up programme from the end of treatment until five years off treatment varied between the two groups.

There were no differences in chronological age between patients who did not attend (mean=15.8 years) compared with those who did (mean=16.0 years) nor in terms of diagnostic group. Although there were more males ($n=19$) than females ($n=5$) who did not attend, this did not differ from the total group ($\chi^2=3.2$, not significant)

QUESTIONNAIRE

As no standardised instrument was available, we developed a structured questionnaire based on pilot interviews with patients and discussions with medical staff. Following a recognised approach to questionnaire design and attitude measurement⁹ we constructed a series of statements which were rated on 5 point Likert scales. The endpoints of the scales were labelled appropriately (for example 'not helpful-very helpful' or 'not at all important-very important'). The questionnaires for patients and parents covered the same topics, with changes made where necessary to the wording.

The questionnaire was divided into four sections.

(1) Current attendance

Patients were asked to report: (i) how frequently they attended clinic (three, six, nine, 12, or >12 months); (ii) practical difficulties that might constitute barriers to attendance (taking time off school or work, length or cost of journey, catching up with work afterwards, explaining to friends).

(2) Perception of clinic visit

Patients were asked about (i) their understanding of the purpose of annual follow up (to gain information about the illness, and the future,

make parents happy, take part in research, help other children, check for side effects, check blood, ease mind, meet other people in the same situation, make sure they were well in future, keep in touch with hospital staff); (ii) their satisfaction with interaction with staff (opportunity to speak to doctor alone, confidentiality, preference for male or female doctor); (iii) the kind of information they wanted and perceptions of what was generally given at clinic.

(3) Current health and knowledge

Patients were asked to report (i) any ongoing difficulties (physical, educational, or social) that were attributed to the illness; (ii) the name of the illness and satisfaction with knowledge.

(4) Future preferences

Patients were asked (i) what they would do if they were worried in the future (talk to someone in the family, read a leaflet, phone the hospital, see their general practitioner (GP), try to forget, deal with it alone, talk to friends); (ii) how they would like to be looked after in the future (keep coming, come less often, come only when worried, complete a postal questionnaire instead of coming, transfer to an adult clinic, see their GP only, be seen in a group).

In addition, we collected demographic information including age, gender, diagnosis, and years since diagnosis. Diagnoses were confirmed through medical records.

OVERALL TREATMENT OF RESULTS

Data analysis was carried out using SPSS-X. First, results are reported for the total sample of patients. Student's t tests are used to calculate mean differences between groups (for example between male and female patients, diagnostic groups, between those reporting that they have problems as a result of the illness and those who have none, and between those who report more benefits in attending than those who report few). Second, a subsample was defined that included a matched group of parents and their child and t tests were used to determine any differences within families ($n=68$ parent-child pairs).

All the results reported are significant at the $p<0.05$ level or beyond.

Results

PATIENT DATA

Current attendance

The majority of patients attended clinic on an annual basis (66%). In addition, 23% attended at six month intervals, 3% at three month intervals, and 3% at nine month intervals. One patient reported attendance every two years.

Females reported more problems explaining where they were going to their friends compared with males ($t = 2.3$, $p<0.05$). There were no differences between males and females in terms of difficulties experienced taking time off from work, or catching up with school or work after clinic visits. Females felt it was more important to keep contact with hospital staff compared with males ($t = 2.9$, $p<0.05$).

Table 1 Information wanted and perceived to be offered in the clinic (ratings made on 1-5 scales with higher scores indicating more information wanted and offered)

	Information		<i>t</i> *
	Mean (SD) wanted	Mean (SD) offered	
Side effects of treatment			
Fertility	3.82 (1.46)	2.53 (1.51)	7.25
Growth	4.02 (1.34)	3.42 (1.41)	3.49
Test results			
Radiography results	3.26 (1.54)	2.27 (1.41)	5.77
Blood counts	3.44 (1.52)	2.53 (1.54)	5.21
General information			
Diet/what you should eat	3.14 (1.44)	2.02 (1.29)	5.97
What to do about smoking	2.63 (1.62)	1.60 (0.97)	5.10
What to do about alcohol	2.54 (1.56)	1.55 (0.97)	5.67
Sexuality and contraception	2.76 (1.54)	1.76 (1.18)	5.54
Drugs	2.74 (1.67)	1.53 (0.95)	6.47
Exercise	3.22 (1.50)	2.41 (1.36)	4.27
Other			
How you get on with mum or dad	2.75 (1.57)	2.04 (1.45)	3.49
School or work	2.96 (1.59)	3.30 (1.52)	1.67 (NS)
Information about other children I know	2.45 (1.44)	1.74 (1.17)	4.36

* Except for 'information about school or work', all significant at $p < 0.001$ level.

Females also felt more reassured after a clinic visit compared with males $t = 2.08$, $p < 0.05$)

Perception of clinic visit

Eleven patients (12.2 %) reported they did not feel they had enough opportunity to speak to the doctor by themselves; 16 (17.6%) had no opinion and 63 (70.2%) were satisfied. The majority (78.9%) were satisfied that their concerns were treated confidentially in clinic. Seven patients (7.8%) were not confident about this and 12 had no opinion (13.3%). Sixty two patients (68.1%) had no preference as to whether they were seen by a male or female doctor; six (6.6%) preferred to be seen by a male doctor and 21 (23.1%) preferred a female doctor. Females were more likely to prefer a female doctor ($\chi^2 = 16.9$, $p < 0.001$) but males were less likely to express a preference.

Patients reported differences between the information they would like to be given at the clinic and the information they remembered being offered (see table 1). (This refers only to the information patients felt they wanted and remembered being given; it is not necessarily an accurate account of what actually happens in the clinic.) There was no difference between male and female patients in the kind of information they wanted. However, males were more likely than females to report that doctors talked to them about the dangers of smoking ($t = 2.4$, $p < 0.05$) and alcohol ($t = 2.8$, $p < 0.05$).

Future preferences

There were differences between males and females in terms of what they would do if worried about their health in the future. Females were more likely to report that they would read about the problem compared with males ($t = 2.4$, $p < 0.05$). They were also more likely to talk about the problem with their friends ($t = 2.4$, $p < 0.05$).

Overall, patients expressed positive attitudes to continuing care as it was provided. (Mean ratings given to the different options were keep coming to this clinic (3.9), come to this clinic less often (2.8), come only when I am worried

(2.2), receive a questionnaire once a year (1.8), transfer to an adult clinic (2.3), see my GP only (1.9), or be seen in a group with other people (1.7).)

Knowledge

We did not include a formal assessment of knowledge, but patients were asked to give the name of their illness. Fifteen patients gave no response to this question and five knew only they had had cancer. The rest reported the type of cancer (leukaemia, lymphoma, Wilms' tumour, etc).

DIFFERENCES WITHIN THE PATIENT GROUP

Problems resulting from the illness

Thirty (33.0%) reported that they continued to experience problems as the result of the illness, 16 patients (17.6%) were not sure, and 38 (41.8%) reported they definitely did not. When the patients who reported no problems ($n=38$) were compared with a combined group including those who were not sure and those who reported problems ($n=46$), we found that those with continuing problems felt more worried after clinic visits than those with no problems ($t = 3.01$, $p < 0.05$). They also were less confident about the confidentiality of their interactions with medical staff ($t = 3.6$, $p < 0.05$) and felt that the illness had resulted in many difficulties for their family ($t = 3.1$, $p < 0.05$). Those who thought they had no problems would prefer to be seen only by their GP in the future ($t = 2.2$, $p < 0.05$).

Perceived benefits of attendance

The sample was almost equally divided between those who perceived no benefits or advantages in attending clinic ($n=45$) and those who reported positive attitudes ($n=44$). There were no differences between these groups in terms of any clinical or demographic variables measured, practical barriers (time off work, telling others where they were going), perceived confidentiality in the clinic, preference for a male or female doctor, frequency with which they would like to be seen in the future and type of care they would like in the future (follow up at hospital, by a GP etc), how much they worried beforehand, and whether or not they had problems related to the illness. However, those who reported more benefits gave stronger endorsements to all the reasons for attendance at follow up ($t = 3.2$, $p < 0.05$).

Diagnosis

Attendance was less frequent for the leukaemia/lymphoma group compared with the solid tumours ($t = 4.15$, $p < 0.01$). The leukaemia/lymphoma group reported less difficulties having time off school or work to attend clinic ($t = 2.04$, $p < 0.05$). They also found it less difficult to catch up with their work on return ($t = 2.1$, $p < 0.05$). In terms of their reasons for attendance, the solid tumour group wanted more information compared with the leukaemia group ($t = 2.1$, $p < 0.05$). There were no other differences between the groups.

Table 2 Perceived benefits of clinic attendance (higher scores indicate greater perceived benefit)

	Mean (SD) patient	Mean (SD) parent	<i>t</i> *
To get more information about the illness	3.47 (1.40)	4.01 (1.25)	2.33*
To get more information about the future	4.01 (1.13)	4.63 (0.79)	3.63**
To take part in research	3.36 (1.46)	4.18 (1.13)	4.04***
To help other children in the future	4.22 (1.05)	4.74 (0.73)	3.63**
To check for side effects	4.26 (1.02)	4.65 (0.82)	2.31*
To check my blood	3.31 (1.42)	3.59 (1.46)	1.15
To ease my mind	3.15 (1.54)	4.20 (1.06)	4.69***
To meet other people in the same situation	2.98 (1.36)	3.21 (1.40)	0.88
To make sure I stay well in the future	4.38 (1.10)	4.82 (0.65)	2.71**
To keep in touch with hospital staff	2.50 (1.43)	3.52 (1.32)	4.25***

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

COMPARISON OF PATIENTS' AND PARENTS' DATA

There were 68 families where both the patient and parent attended clinic and completed questionnaires. A series of *t* tests were conducted to establish any differences between parents and their children in preference for different types of care, reasons for attending clinic, perceived difficulties in attending, and the kind of information wanted.

Current attendance

There were no differences between parents and their children in terms of how frequently they felt it was necessary for the child to attend or in terms of how difficult they said it was to attend.

Perception of clinic visit

There were a number of differences between parents and children in the reasons they felt it was important to attend (see table 2), with parents generally giving more positive ratings than patients. Parents were more confident that whatever was said in clinic was treated confidentially and rated themselves to be better informed than their children ($t = 2.8$, $p < 0.01$).

Future preferences

There were also differences between parents and children in terms of what they would be most likely to do if they were worried in the future. Parents were more likely to report they would ring the hospital ($t = 7.8$, $p < 0.01$) or see the GP ($t = 2.7$, $p < 0.05$). Children more than their parents reported that they would try to forget about it ($t = 3.6$, $p < 0.01$) or deal with it themselves ($t = 2.0$, $p < 0.05$). Parents felt more positive about continuing to come to the clinic compared with their children ($t = 3.6$, $p < 0.01$). In contrast, children were more likely to want to come only when worried ($t = 2.0$, $p < 0.05$).

Discussion

In order to encourage attendance at follow up clinics, we need to ensure that (i) patients understand the reasons why it is important to attend and (ii) clinics attempt to satisfy patients' needs for information. It is important to note that parents were generally more positive about attendance compared with their children. They also rated themselves as more knowledgeable about the illness and were more likely than their children to report that they would contact the hospital if they had concerns related to the illness. Although these findings may not be surprising, they suggest that it is important to ensure that children understand

fully about their disease history and its possible implications as they become increasingly independent and autonomous. These data suggest that information for survivors aimed at increasing awareness of the heightened risks after treatment for childhood cancer are timely, and would be welcomed by the majority of patients.

The non-attendance rate in this sample is relatively high (17%) suggesting that some changes to organisation may need to be considered. Although it had been our intention to establish reasons for non-attendance, this has proved difficult. This age group is clearly relatively mobile. Our difficulties also point to the need to maintain contacts over the years, as once lost, patients can be hard to track down.

The major purpose of an exercise such as this is to identify aspects of the clinic that patients find most beneficial. In this respect, it is important to note that there were no differences between those who reported benefits as a result of clinic attendance and those who did not in terms of demographic and clinic variables, practical barriers involved in attending (time and expense), as well as organisational aspects of the clinic (whether or not they wanted to see a male or female doctor). The critical difference between the two groups was in terms of how important they believed follow up to be. These findings may suggest that attendance is less dependent on organisational aspects of the clinic and more dependent on patients' attitudes toward and understanding of follow up. Ensuring that patients are not lost to follow up may be as dependent on increasing the awareness of personal risks and benefits as making substantial changes in the organisation, timing, or running of the clinic. In the future, more formal assessments of patients' understanding of the rationale for different follow up procedures may be important and essential to the development of appropriate and acceptable information for survivors.

Our data raise other issues that are important for future work. We did not make a comprehensive assessment of knowledge. However, patients themselves reported that they wanted more information and for many attendance at clinic was motivated by a wish to know more about the disease and the implications for the future. Some assessment of the extent of knowledge among survivors would therefore seem to be an important next step. Despite our beliefs that we have adopted an open approach to communication and information giving with our patients, there remains a thirst for information. This is evidenced by the reasons given for follow up. This need may yet be best met by provision of written information, and we plan to develop such materials in the near future.

Given the increasing pressure on staff resulting from the numbers of children now surviving cancer, there needs to be careful discussion about the most appropriate and cost effective way to organise follow up, taking into account the wishes of families as well as the more scientific goals of identifying the incidence of late effects. There was some prefer-

ence among females for seeing a female doctor, but clinics would probably do best to aim for a mixed medical team.

Our data suggest that there is a group of survivors who have no current side effects and personally do not benefit greatly from annual review. For these patients some other form of follow up (or less frequent follow up) may be as appropriate. There is however a second group, who do have continuing problems as a result of treatment, and for these the degree of anxiety and family stress may remain high long after completion of treatment. Such patients and their families may benefit from more frequent surveillance and support. It may be that the most efficient follow up needs to take into account the patient's current health rather than following a standard annual review.

While this work arose because of our concerns in relation to childhood cancer, the increase in number of children surviving other chronic conditions presents similar problems in terms of appropriateness of follow up. Many of the issues discussed here may therefore be of relevance for those involved in the care of survivors of other chronic diseases.^{10 11}

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