available at www.sciencedirect.com

ScienceDirect

journal homepage: www.ejconline.com

Follow-up care after childhood cancer: Survivors' expectations and preferences for care

G. Michel[a,*], D.M. Greenfield[b], K. Absolom[a], R.J. Ross[c], H. Davies[d], C. Eiser[a]
On behalf of the Late Effects Group Sheffield

[a]*Department of Psychology, University of Sheffield, Western Bank, Sheffield S10 2TP, UK*
[b]*Academic Unit of Clinical Oncology, Weston Park Hospital, Sheffield S10 2SJ, UK*
[c]*Academic Unit of Endocrinology and Reproduction, Royal Hallamshire Hospital, Sheffield S10 2JF, UK*
[d]*Academic Unit of Child Health, Sheffield Children's Hospital, Western Bank, Sheffield S10 2TH, UK*

ARTICLE INFO

Article history:
Received 9 December 2008
Received in revised form 13 February 2009
Accepted 26 February 2009
Available online 26 March 2009

Keywords:
Survivors
Cancer care
Long-term care
Neoplasm
Child

ABSTRACT

Aims: To describe (1) self-rated quality of life, late effects and perceived future vulnerability, (2) expectations before a follow-up appointment, subsequent satisfaction and preferences for different models of care and (3) differences between survivors in quality of life, perceived late effects, vulnerability, expectations regarding follow-up, information needs (topics they want to and did discuss) and preferences for different models of care depending on risk stratification among childhood cancer survivors.

Method: One hundred and twelve of 141 survivors (18–45 years), diagnosed before 16 years and >5 years since diagnosis completed questionnaires before and after a follow-up appointment (or an abridged questionnaire if they did not attend an appointment within the study period). We collected data on physical (physical component score [PCS]) and mental (mental component score [MCS]) quality of life, late effects, future vulnerability and expectations about care (*clinical*: identification of late effects; *supportive*: employment, relationships). Medical information was extracted from case notes.

Results: MCS and PCS were comparable to population norms, but 55.5% of survivors reported $\geqslant 1$ late effect (range 1–9). *Clinical* care was rated more highly than supportive care ($p < 0.001$) especially in those with worse PCS ($p = 0.042$). *Supportive* care was rated highly by survivors who reported more late effects ($p = 0.040$), higher future vulnerability ($p < 0.001$) and lower MCS ($p = 0.005$), and by women ($p = 0.014$). Regardless of risk stratification, consultant-led follow-up was valued higher than other models (nurse-led care, GP-led care or postal/telephone follow-up, $p < 0.001$).

Conclusion: Childhood cancer survivors are in favour of sustaining long-term follow-up care within the existing consultant-led model but this is not feasible given the increasing number of survivors. In the future we therefore need to develop alternative services which will provide the best medical care for each survivor's needs.

1. Introduction

Advances in treatment of childhood cancer have resulted in 5-year survival rates above 75%.[1–3] However, treatment-related late effects (second malignancies, late mortality, and endocrine, pulmonary and psycho-social problems) affect approximately two-third of the survivors.[4–6] Given the relatively high risk and broad spectrum of late effects, evi-

---

* *Corresponding author*: Tel.: +44 114 222 65 83; fax: +44 114 276 6515.
E-mail address: g.michel@sheffield.ac.uk (G. Michel).

0959-8049/$ - see front matter
doi:10.1016/j.ejca.2009.02.026

dence-based guidelines to direct appropriate follow-up care have been developed.[7–10]

The major goals of follow-up include detection and treatment of late effects, health education, and provision of support and advice.[9] As survivor numbers increase, indefinite follow-up in paediatric clinics is both unfeasible and inappropriate. Consequently, a relatively simple three-level model of risk stratification has been proposed.[11] Where initial treatment is limited to surgery or low-risk chemotherapy, postal or telephone follow-up is recommended (level 1). Nurse or GP-led follow-up is considered appropriate following chemotherapy and/or low-dose radiation (level 2), and medically supervised follow-up is indicated following radiotherapy (>24 Gy) or megatherapy (high-dose chemotherapy; level 3). The system should be flexible allowing easy transition between levels according to individual need.[12]

Missing from this risk stratification approach is any recognition of individual views about long-term follow-up.[10,13] Survivors differ in their expectations, with some wanting information about late effects and treatment, while others come simply for reassurance.[14] In addition to the physical late effects associated with treatment, survivors may experience psychological distress for many years.[15–18] Post-traumatic stress disorder and suicidal tendencies occur in approximately 10%.[19,20] Thus, it is important to offer a broad range of services that take account of survivors' views and circumstances.[13,14,21,22] Furthermore, previous work suggests that survivors differ in their expectations regarding *clinical* (identification and treatment of medical problems) or *supportive care* (information about social or health issues) when attending follow-up.[23] Survivors also differ in their understanding of their vulnerability for future late effects,[23] which may influence their view about and preferences for follow-up. Consequently, changes to organisation of care need to take account of the diverse physical and psychological late effects that can occur, and survivors' expectations about the kind of care they want.

The aims of this study were therefore to inform provision of care by determining the follow-up needs of a cohort of survivors. Specifically, we aimed to describe:

1. Self-rated quality of life (QOL) [physical (physical component score [PCS]) and mental (mental component score [MCS])[24]], self-reported late effects and perceived future vulnerability to late effects among a cohort of survivors.
2. Expectations before a follow-up appointment, subsequent satisfaction with the appointment and preferences for different models of care.
3. Differences between survivors in QOL, perceived late effects, perceived vulnerability for late effects, expectations regarding follow-up, information needs (topics they want to discuss before the appointment and those discussed) and preferences for different models of care depending on risk stratification.[11]

2. Patients and methods

2.1. Participants

A cohort of young adults treated for childhood cancer was recruited from the Late Effects Clinic in Sheffield, UK. This is a consultant-led clinic with input from a paediatric oncologist, endocrinologist and late effects specialist nurse.[25] A reproductive specialist and psychiatric support are available if needed. Prior establishment of this clinic facilitated identification of eligible survivors. Eligibility criteria were age (18–45 years at the time of survey), diagnosis of any childhood cancer (<16 years of age), >5 years since diagnosis and currently registered in the Late Effects Clinic. Exclusion criteria were palliative care (prognosis <6 months), and insufficient fluency in English to provide written consent.

2.2. Procedure

Eligible patients were identified from hospital databases and clinic lists between December 2006 and January 2008 (Fig. 1). Those attending hospital follow-up during this period were contacted by post approximately one week before appointments (Time 1) and sent information about the study, consent form and questionnaire (T1 questionnaire) and asked to complete these prior to follow-up. On leaving the clinic (Time 2), survivors were given a second questionnaire to be completed at home (T2 questionnaire). Eligible survivors not attending routine follow-up during the study period were sent an information sheet, consent form and abridged questionnaire which did not include questions about the follow-up appointment by post. Questionnaires completed at home were returned in freepost envelopes. The study was approved by the South Sheffield Ethics Committee and all survivors gave written consent.

2.3. Measures

2.3.1. T1 (questionnaire before appointment)

- *Demographic information*: Chronological age and gender.
- *Health-related quality of life*: The SF-12v2 assesses eight domains of QOL which can be combined to two summary scores: PCS and MCS. Excellent reliability and validity have been established.[24]
- *Late effects and vulnerability*[23]: Eighteen cancer-related health problems were listed (Fig. 2). Ratings of perceived vulnerability were made on five-point scales (1 'very unlikely' to 5 'very likely') or 'I already have this problem'. Two scores were calculated: total number of late effects (0–18) and vulnerability (range 1–5) where higher scores indicate greater perceived vulnerability.
- *Expectations regarding follow-up*: Survivors rated the importance[1–5] of different reasons for attending follow-up (nine items). Previous factor analysis[23] revealed two scales: *supportive* care (receive psychological support, get advice about everyday things, talk to staff who understand what I have been through, get advice about how to keep healthy) and *clinical* care (get reassurance about my health, get advice about late effects, get the best medical care, check cancer has not come back). One additional item (help clinic staff learn more about late effects of cancer and treatment) did not load on any of the two scales.[23]
- *Topics for discussion*: Survivors were asked to indicate what they wanted to discuss at their next appointment from a list of 10 topics (1 strongly disagree–5 strongly agree; Fig. 3).

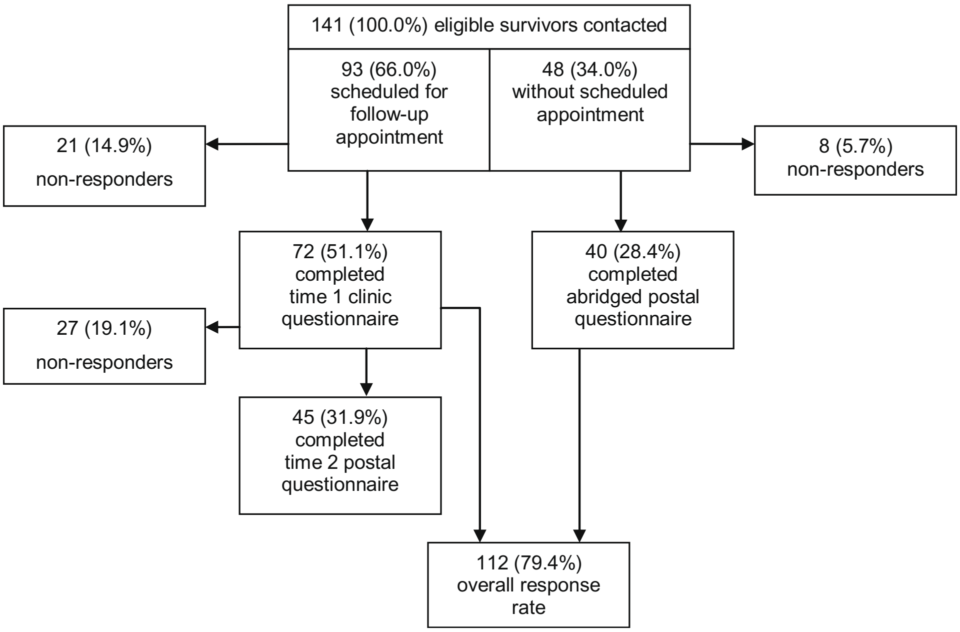

Fig. 1 – Participation in study.

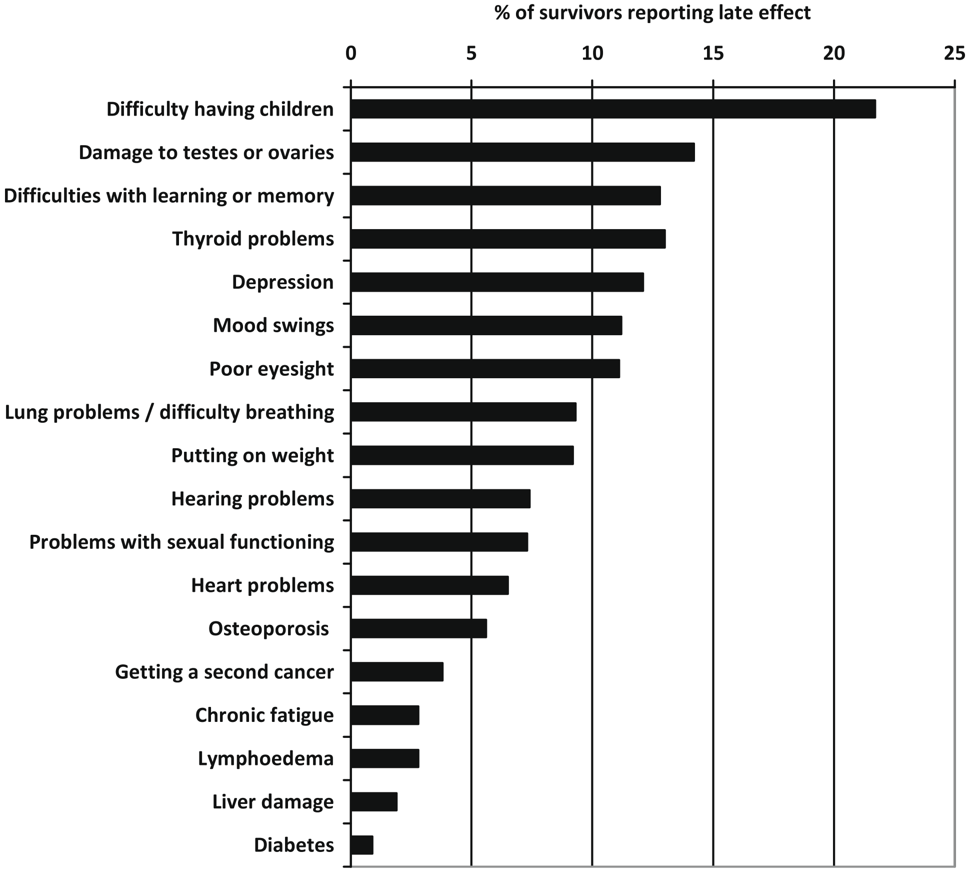

Fig. 2 – Proportion of survivors reporting different late effects.

- *Helpfulness of additional follow-up services*: Survivors were asked to rate the helpfulness (1 'not at all helpful' to 5 'very helpful') of additional services (support groups, professional counselling, nutritional information, employment/career support). An alternative response was provided: I already use this service.

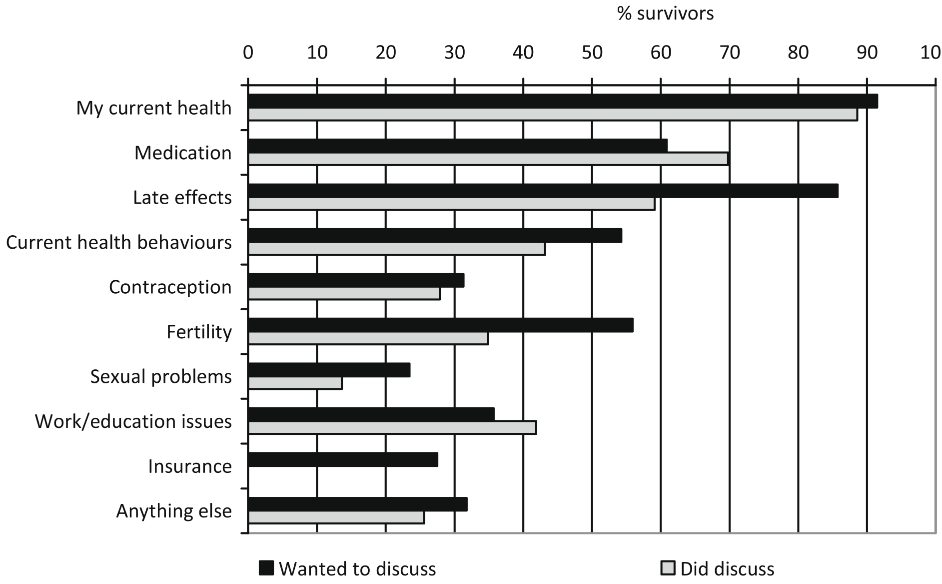

Fig. 3 – Frequency of topics survivors wanted to and did discuss at the clinic appointment.

2.3.2. T2 (questionnaire after appointment)

- *Information about appointment*: Survivors were asked how long they waited before the appointment, length of time with the doctor and if they had a physical examination (yes/no).
- *Topics discussed*: Survivors were asked which of the topics listed in the T1 questionnaire were discussed.
- *Satisfaction*: This questionnaire was developed to assess outpatient satisfaction in an oncology population.[26] Survivors rated 29 statements (1 'strongly agree' to 4 'strongly disagree'; e.g. the doctor seemed to brush off my questions; I feel the doctor was being honest with me). After reverse coding certain items higher values indicated more satisfaction.
- *Preferences for follow-up*: Four models of care were described (postal/telephone follow-up, GP-led follow-up, nurse-led follow-up and consultant-led follow-up).[11] Four statements were presented with each description (e.g. 'I think this type of care would be suitable for me', 'I would not be happy with this type of care'). Survivors were asked to rate their agreement with each statement on five-point scales (1'strongly disagree' to 5 'strongly agree').

Those who did not attend during the study period completed: Demographic information, health-related quality of life, late effects and vulnerability, expectations regarding follow-up and preferences for follow-up.

Medical information: The following information was extracted from medical records: diagnosis based on the International Classification of Childhood Cancer (ICCC-3[27]), age at diagnosis, date of diagnosis and time since diagnosis. Based on anonymised treatment summaries, risk stratification[11] was coded by two independent coders. Agreement between the two coders was excellent (96.5%; $\kappa = 0.93$; $p < 0.001$).

2.4. Statistical analyses

Analyses were performed with SPSS 11 for Macintosh. Scales were scored according to manuals or published papers. Factor analysis of the *expectations* scale confirmed the original two-factor solution (Cronbach's alpha in our study: supportive care $\alpha = 0.84$, clinical care $\alpha = 0.71$). Factor analysis of the *satisfaction* scale[26] produced a one-factor solution with excellent internal reliability ($\alpha = 0.95$). Internal reliability for the *preferences for follow-up* was good: postal/telephone follow-up $\alpha = 0.85$, GP-led $\alpha = 0.89$, nurse-led follow-up $\alpha = 0.88$, consultant-led follow-up $\alpha = 0.81$. *Topics for discussion* were recoded into 'want to discuss': 4 agree and 5 strongly agree, and 'not want to discuss': 1 strongly disagree–3 neither disagree nor agree.

For the *SF-12*, we determined differences between our sample and population norms using paired sample *t*-tests to compare each survivor with his/her age- and gender-matched norm score. *t*-Tests and correlations were used to determine associations with *expectations regarding follow-up*. Statistically significant variables were included in a multivariable regression analysis to predict *expectations regarding follow-up*. *t*-Tests and χ^2-tests were used to determine differences between survivors with different risk stratification. Power to detect a small effect of $r = 0.4$ with $p = 0.001$ was 0.87.

3. Results

3.1. Sample

There were 141 survivors (67 (47.5%) men) who fulfilled the eligibility criteria during the study period (Fig. 1). Ninety-three of these (66.0%) had a follow-up appointment within the study duration, 72 (51.1%) completed a T1 questionnaire and 45 (31.9%) completed the T2 questionnaire. Of 48 survivors who had no scheduled appointment during the study period, 40 (28.4%) returned questionnaires by post. Thus 112 questionnaires (49 men, 43.8%) were completed (overall response rate was 79.4%). Details of the sample are summarised in Table 1. There were no differences between responders and non-responders in gender, chronological age or age at diagnosis.

3.2. *Aim 1: Self-rated QOL (PCS and MCS), late effects and perceived future vulnerability to late effects*

Survivors' PCS (mean = 53.0; 95% confidence interval (CI): 51.5–54.5; $p = 0.827$) and MCS (mean = 47.3, 95% CI: 45.1–49.5; $p = 0.664$) were comparable with United States (US) population norms.[24] There was no association with age, but women had lower MCSs (mean = 44.6; 95% CI: 41.5–47.8) than men (mean = 50.7; 95% CI: 48.2–53.3; $p = 0.006$). 55.5% of survivors reported at least one late effect (95% CI: 46.2–64.8) and 30.0% (95% CI: 21.4–38.6) reported two or more late effects. Women (mean = 1.86; 95% CI: 1.39–2.33) reported more late effects than men (mean = 1.02; 95% CI: 0.42–1.61; $p = 0.039$). Older survivors also reported more late effects ($r = 0.20$; $p = 0.035$). The most common late effects were difficulty having children, and damage to testes/ovaries (Fig. 2). Perceived vulnerability to future late effects (mean = 2.61; 95% CI: 1.28–3.94) was not associated with gender ($p = 0.562$) or age ($p = 0.957$).

3.3. *Aim 2: Expectations prior to a follow-up appointment and satisfaction afterwards*

Survivors rated *clinical* care ($N = 112$; mean = 4.55; 95% CI: 4.46–4.64) more highly than *supportive* care ($N = 112$; mean = 3.63; 95% CI: 3.47–3.78; $p < 0.001$) for attending follow-up. Women rated *supportive* care as more important (mean = 3.80; 95% CI: 3.59–4.01) than men (mean = 3.40; 95% CI: 3.17–3.63; $p = 0.014$). Survivors who reported more late effects ($r = 0.20$; $p = 0.040$), higher future vulnerability ($r = 0.49$; $p < 0.001$) and lower MCS ($r = -0.27$; $p = 0.005$) rated *supportive* care as more important than survivors with fewer late effects, lower vulnerability and higher MCS. *Clinical* care was only associated with lower PCS ($r = -0.20$; $p = 0.042$). There was no association between risk stratification, age at diagnosis or time since diagnosis and *clinical* or *supportive* care. In the multivariable regression for *supportive* care only self-reported vulnerability remained statistically significant ($p < 0.001$, Table 2).

At the clinic, most survivors wanted to discuss their current health (65/71; 91.5%), and late effects (60/70; 85.7%). Current health (39/44; 88.6%) was also the topic most frequently discussed during appointments. For other topics there was less agreement between what survivors' intended to discuss and what they did discuss (Fig. 3). The mean number of topics survivors wanted to discuss was 4.66 (95% CI: 4.09–5.23), but fewer were discussed ($M = 3.98$ (95% CI: 3.39–4.57; $t = 1.83$; $p = 0.074$)).

Mean *satisfaction* with the last appointment was 3.26 (95% CI: 3.12–3.40; $N = 45$). There was no difference between men and women ($p = 0.183$) and no association with age ($r = 0.05$; $p = 0.766$), but survivors were more satisfied if they discussed topics that they wanted to discuss ($r = 0.46$; $p = 0.002$). Satisfaction was not associated with the time spent waiting before the appointment ($r = -0.02$; $p = 0.911$), duration of appointment ($r = -0.27$; $p = 0.067$) whether or not there was a physical examination ($p = 0.252$) or with either *clinical* ($p = 0.983$) or *supportive* care ($p = 0.059$).

Survivors rated consultant-led follow-up higher (mean = 4.06; 95% CI: 3.91–4.22; $N = 85$; $p < 0.001$) than nurse-led (mean = 3.30; 95% CI: 3.11–3.49), GP-led (mean = 2.68; 95%

Table 1 – Sample description.

	N	%		
Total	112	100.0		
Questionnaire completed				
Follow-up attender	72	35.7		
No scheduled appointment	40	64.3		
Gender				
Male	49	43.8		
Female	63	56.3		
Diagnosis				
Leukaemias	44	39.3		
Lymphomas	21	18.8		
CNS tumours	14	12.5		
Other solid tumours	33	29.5		
Risk stratification[a]				
Level 1	1	0.9		
Level 2	60	53.6		
Level 3	51	45.5		
	Mean	SD	Min	Max
Age at time of the study	28.2	7.0	18.1	45.1
Age at diagnosis	7.0	4.5	0.1	16.0
Time since diagnosis	21.3	7.9	5.9	36.1

CNS: central nervous system, SD: standard deviation, min: minimum value, and max: maximum value.

[a] Risk stratification according to Ref. [11].

Table 2 – Multivariable regression analyses showing characteristics associated with supportive reasons for care.

	Standardised β	*p*
Gender	0.16	0.082
Mean vulnerability for late effects	0.35	<0.001
Total number of reported late effects	0.10	0.252
MCS	–0.12	0.205

Adjusted $r^2 = 0.201$, $F = 7.62$; $p < 0.001$.

CI: 2.45–2.91) and postal/telephone care (mean = 2.69; 95% CI: 2.47–2.91). Forty-four (51.8%) rated consultant-led care highest and 25 (29.4%) rated all four models as equally preferable. Survivors were positive about the helpfulness of additional services [nutritional information (mean = 3.4, 95% CI: 3.0–3.7; *N* = 68), professional counselling (mean = 3.1, 95% CI 2.8–3.4), advice on employment or careers (mean = 3.1, 95% CI 2.7–3.4) and support groups (mean = 3.0, 95% CI 2.7–3.3)]. One survivor had received professional counselling previously and another received vocational guidance.

3.4. *Aim 3: Differences related to risk stratification*

Survivors were coded to the following risk levels: level 1 (*N* = 1), level 2 (*N* = 60; 53.6%) and level 3 (*N* = 51; 45.5%). Subsequent analyses are based on the 111 survivors coded to levels 2 and 3 only. There were no differences between these groups in terms of gender ($\chi^2 = 0.82$; $p = 0.664$), but level 3 survivors were older, longer since diagnosis, reported more late effects and a higher vulnerability for future late effects (Table 3). There was no association between risk stratification and MCS, PCS, *expectations about follow-up* or *topics discussed*. Regardless of level, survivors did not differ in *preference for different models of follow-up care*. Both groups rated the familiar model of consultant-led care higher than other models. Level 2 survivors valued support groups higher (mean = 3.3, 95% CI: 2.9–3.8) than level 3 survivors (mean = 2.7, 95% CI: 2.3–3.1; $p = 0.038$), but there was no difference regarding other *additional services*.

4. Discussion

We aimed to provide an overview of the physical and mental health of childhood cancer survivors and their views about follow-up care in order to inform discussions about provision of appropriate care for this group. Our cohort reported good PCS and MCS, comparable with a general population, though women had lower MCS than men. The number of self-reported late effects was similar to numbers reported in the Childhood Cancer Survivor Study.[5] The cohort was relatively young (mean age = 28.2 years) and consequently the incidence of late effects (such as infertility) may increase in the future. As in other studies, women reported more late effects than men.[5] The diverse nature of late effects suggests that multi-disciplinary care should be an integral part of any model of follow-up care.

Survivors rated *clinical* reasons for attending the clinic more highly than *supportive* reasons, suggesting they expect to be informed about the disease and its consequences rather than discuss social or family issues. Those with worse PCS tended to value *clinical* care as especially important. *Supportive* care was rated as more important to those individuals with worse MCS and those more concerned about future late effects. Thus, survivors' perceptions of their current and future problems may contribute to their preferences for different kinds of information. Routine assessment of these variables may be useful to guide the kind of care offered to survivors. At the same time, these results suggest that there is a need for a range of support services to be available at late effects clinics.

Survivors wanted to discuss a broad range of topics but reported that only some of these were discussed during the appointment. While most wanted to discuss 'current health', 'medication' and 'late effects' were also of general concern, but less frequently discussed. Satisfaction with the appointment was higher if preferred topics were discussed. In contrast with other studies[23] satisfaction was not associated with *clinical* reasons, length of waiting time, duration of appointment or gender. Our data suggest that discussion of important topics during the appointment may contribute significantly to survivor satisfaction. Survivors valued the famil-

Table 3 – t-Tests showing differences between survivors of different risk stratification (level 2 versus level 3).

	N	Level 2		*N*	Level 3		*t*	*p*
		Mean	95% CI		Mean	95% CI		
Pearson characteristics								
Age at study (years)	60	26.4	24.8–28.0	51	30.5	28.5–32.5	–3.25	0.002
Time since diagnosis (years)	60	19.4	17.4–21.4	51	23.8	21.6–26.0	–3.02	0.003
Age at diagnosis (years)	60	6.9	5.7–8.1	51	6.9	5.7–8.1	0.03	0.979
Late effects								
Vulnerability for late effects (range 1–5)	58	2.5	2.3–2.7	50	2.8	2.6–2.9	–2.00	0.048
Number of self-reported late effects (range 0–18)	59	1.1	0.6–1.5	50	2.1	1.4–2.7	–2.54	0.012
Acceptability of follow-up care models (range 1–5)								
Telephone follow-up	46	2.8	2.5–3.1	38	2.6	2.3–2.9	0.80	0.425
GP follow-up	46	2.8	2.5–3.2	39	2.5	2.2–2.8	1.50	0.137
Nurse follow-up	46	3.3	3.1–3.6	39	3.3	3.0–3.6	0.17	0.864
Clinic follow-up	46	4.0	3.7–4.2	39	4.2	4.0–4.4	–1.54	0.128

iar consultant-led model highly, though they were open to alternative models of care.

No major differences between survivors depending on risk stratification were identified. This may largely reflect current practice whereby the majority of survivors (levels 2 and 3) are assigned to consultant-led care. They are not offered, or likely to be aware that alternative models of care are possible. Satisfaction with consultant-led care is high, and influences expectations about future care. However, consultant-led care may not be routinely necessary for all survivors (especially levels 1 and 2 survivors). The consultant-led model is expensive and lacks the structure to offer the supportive care anticipated by some survivors. Integrative multi-disciplinary collaboration may help to offer comprehensive care to survivors of all risk levels.

Our study suggests that many survivors receive more intense follow-up than necessary given their risk stratification. However, follow-up seems to be dependent on local resources and expertise. The US childhood cancer survivor study reported that less than 50% of survivors had cancer-related visits to the health care system, with decreasing visits longer since diagnosis and treatment.[28] In the United Kingdom (UK), over 40% of specialists discharge their patients after 5 years of event-free survival and only 35% of patients remain in long-term hospital follow-up.[29] Recommendations of national guidelines[7–9] need to be implemented to avoid any emerging ‘postcode lottery’. Successful transition to adult care or specialised long-term clinics taking into account the views and expectations of survivors is thus essential for all survivors, independent of their risk.

In accordance with other UK studies, survivors in our study reported good MCS.[30] However, these results are based on a relatively blunt measure.[24,31] Evidence from other studies suggests that a significant subgroup reports psychological distress, educational and employment problems, or lower marriage rates.[18,32,33] More information is needed regarding social/psychological consequences and their impact on long-term adjustment. Such information is relatively simple to collect at the clinics and should be a routine part of patient care.[34]

A major strength of the study is the high response rate (>79% contacted survivors). Limitations include the fact that only those receiving consultant-led follow-up care were included. We were unable to trace those who had been discharged from care or had defaulted. As in other work,[12] there were few level 1 survivors, suggesting they had been discharged previously. Generalisation to other survivor populations is limited especially to those not regularly attending follow-up. We could not verify the number or type of self-reported late effects from clinic records since these are not reliably recorded. In the absence of UK data, we used US norms to compare PCS and MCS of our sample against population norms.

Our work contributes to current debates about how to improve outcomes in children and young people with cancer.[35] Given that late effects can occur decades after initial treatment, it is important to involve those who no longer attend clinic follow-up, either because they have been officially discharged or because they choose not to attend. In order to retain those survivors in long-term follow-up, it is necessary to take account of both their medical and psycho-social needs, rather than impose a traditional model of care. Health professionals need to explain the importance of follow-up in order to keep their patient population motivated to attend.

5. Conclusion

Childhood cancer survivors who are still in active follow-up value clinical care and consultant-led follow-up regardless of their risk stratification. The current emphasis in follow-up for clinical care needs to be supplemented by greater awareness of psycho-social problems. Sustaining long-term follow-up care within the existing consultant-led model is highly rated by childhood cancer survivors but is not feasible given the increasing number of survivors. In the future we therefore need to develop alternative services and focus on feasible transition to other services to provide the best medical and psycho-social care for each survivor’s needs.

Conflict of interest statement

None declared.

Acknowledgements

We thank the study participants, Lesley Turner for study coordination and data management, Research Nurse Ann Hetherington for contributing to patient recruitment and collating the medical information, the late effects transition clinic staff at the Royal Hallamshire Hospital, Sheffield, particularly Clinical Nurse Specialist Tanya Urquhart and Clinic Clerk Linda Handley. This study was supported by the Weston Park Hospital Cancer Charity and The Laura Crane Trust. Gisela Michel was funded by the Swiss National Science Foundation (Fellowship Grant PA001-117433/1).

REFERENCES

1. Magnani C, Pastore G, Coebergh JW, Viscomi S, Spix C, Steliarova-Foucher E. Trends in survival after childhood cancer in Europe, 1978–1997: report from the Automated Childhood Cancer Information System project (ACCIS). *Eur J Cancer* 2006;**42**:1981–2005.
2. Ellison LF, Pogany L, Mery LS. Childhood and adolescent cancer survival: a period analysis of data from the Canadian Cancer Registry. *Eur J Cancer* 2007;**43**:1967–75.
3. Stiller CA, editor. *Childhood cancer in Britain: incidence, survival, mortality*. Oxford: Oxford University Press; 2007.
4. Curry HL, Parkes SE, Powell JE, Mann JR. Caring for survivors of childhood cancers: the size of the problem. *Eur J Cancer* 2006;**42**:501–8.
5. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *New Engl J Med* 2006;**355**:1572–82.
6. Geenen MM, Cardous-Ubbink MC, Kremer LC, et al. Medical assessment of adverse health outcomes in long-term survivors of childhood cancer. *Jama* 2007;**297**:2705–15.
7. Children’s Oncology Group. *Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers*; 2004 [accessed 21.09.05]. <http://www.survivorshipguidelines.org>.

8. Scottish Intercollegiate Guidelines Network (SIGN). *Long term follow-up of survivors of childhood cancer. A national clinical guideline, No. 76*. Edinburgh: Scottish Intercollegiate Guidelines Network; 2004.
9. Skinner R, Wallace WH, Levitt G. Long-term follow-up of children treated for cancer: why is it necessary, by whom, where and how? *Arch Dis Child* 2007;**92**:257–60.
10. Skinner R, Wallace WHB, Levitt GOn behalf of UKCCSG. Long-term follow-up of people who have survived cancer during childhood. *Lancet Oncol* 2006;**7**:489–98.
11. Wallace WHB, Blacklay A, Eiser C, et al. Developing strategies for long term follow up of survivors of childhood cancer. *BMJ* 2001;**323**:271–4.
12. Eiser C, Absolom K, Greenfield D, et al. Follow-up after childhood cancer: evaluation of a three-level model. *Eur J Cancer* 2006;**42**:3186–90.
13. Eiser C, Levitt G, Leiper A, Havermans T, Donovan C. Clinic audit for long-term survivors of childhood cancer. *Arch Dis Child* 1996;**75**:405–9.
14. Earle EA, Davies H, Greenfield D, Ross R, Eiser C. Follow-up care for childhood cancer survivors: a focus group analysis. *Eur J Cancer* 2005;**41**:2882–6.
15. Zebrack BJ, Gurney JG, Oeffinger K, et al. Psychological outcomes in long-term survivors of childhood brain cancer: a report from the childhood cancer survivor study. *J Clin Oncol* 2004;**22**:999–1006.
16. Zebrack BJ, Zeltzer LK, Whitton J, et al. Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma: a report from the Childhood Cancer Survivor Study. *Pediatrics* 2002;**110**:42–52.
17. Zebrack BJ, Zevon MA, Turk N, et al. Psychological distress in long-term survivors of solid tumors diagnosed in childhood: a report from the childhood cancer survivor study. *Pediatr Blood Cancer* 2007;**49**:47–51.
18. Zeltzer LK, Lu Q, Leisenring W, et al. Psychosocial outcomes and health-related quality of life in adult childhood cancer survivors: a report from the childhood cancer survivor study. *Cancer Epidemiol Biomark Prev* 2008;**17**:435–46.
19. Langeveld NE, Grootenhuis MA, Voute PA, de Haan RJ. Posttraumatic stress symptoms in adult survivors of childhood cancer. *Pediatr Blood Cancer* 2004;**42**:604–10.
20. Recklitis CJ, Lockwood RA, Rothwell MA, Diller LR. Suicidal ideation and attempts in adult survivors of childhood cancer. *J Clin Oncol* 2006;**24**:3852–7.
21. Gibson F, Aslett H, Levitt G, Richardson A. Follow up after childhood cancer: a typology of young people's health care need. *Clin Effect Nurs* 2005;**9**:133–46.
22. Zebrack BJ, Eshelman DA, Hudson MM, et al. Health care for childhood cancer survivors: insights and perspectives from a Delphi panel of young adult survivors of childhood cancer. *Cancer* 2004;**100**:843–50.
23. Absolom K, Greenfield D, Ross R, et al. Predictors of clinic satisfaction among adult survivors of childhood cancer. *Eur J Cancer* 2006;**42**:1421–7.
24. Ware Jr J, Kosinski M, Keller SD. A 12-item short-form health survey: construction of scales and preliminary tests of reliability and validity. *Med Care* 1996;**34**:220–33.
25. Greenfield DG, Absolom K, Davies H, Ross R, Eiser C. Childhood cancer survivors: transition from pediatric to adult care. *Curr Med Literat – GH Growth Factors* 2003;**18**:83–91.
26. Loblaw DA, Bezjak A, Bunston T. Development and testing of a visit-specific patient satisfaction questionnaire: the Princess Margaret Hospital Satisfaction with doctor questionnaire. *J Clin Oncol* 1999;**17**:1931–8.
27. Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International classification of childhood cancer, 3rd ed.. *Cancer* 2005;**103**:1457–67.
28. Oeffinger KC, Mertens AC, Hudson MM, et al. Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Ann Fam Med* 2004;**2**:61–70.
29. Taylor A, Hawkins M, Griffiths A, et al. Long-term follow-up of survivors of childhood cancer in the UK. *Pediatr Blood Cancer* 2004;**42**:161–8.
30. Reulen RC, Winter DL, Lancashire ER, et al. Health-status of adult survivors of childhood cancer: a large-scale population-based study from the British Childhood Cancer Survivor Study. *Int J Cancer* 2007;**121**:633–40.
31. Ware EJ. *SF-36 health survey: manual and interpretation guide*. Boston, Massachusetts: The Health Institute, New England Medical Center; 1993.
32. Frobisher C, Lancashire ER, Winter DL, Jenkinson HC, Hawkins MM. Long-term population-based marriage rates among adult survivors of childhood cancer in Britain. *Int J Cancer* 2007;**121**:846–55.
33. Langeveld NE, Ubbink MC, Last BF, Grootenhuis MA, Voute PA, De Haan RJ. Educational achievement, employment and living situation in long-term young adult survivors of childhood cancer in the Netherlands. *Psychooncology* 2003;**12**:213–25.
34. Recklitis C, O'Leary T, Diller L. Utility of routine psychological screening in the childhood cancer survivor clinic. *J Clin Oncol* 2003;**21**:787–92.
35. National Institute for Health and Clinical Excellence. *Improving outcomes in children and young people with cancer. Guidance on Cancer Services*; 2005 [accessed 14.12.07]. <http://www.nice.org.uk/guidance/index.jsp?action=byID&r=true&o=10899>.