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Predictors of clinic satisfaction among adult survivors of childhood cancer

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ABSTRACT

Childhood cancer survivors experience a wide range of late-effects. As survival rates improve, follow-up in paediatric clinics becomes less feasible, and alternative models of care have been proposed. In this study, satisfaction among those attending a traditional paediatric late-effects clinic was compared with a multi-disciplinary clinic in an adult setting. Survivors (adult clinic n = 93, paediatric clinic n = 105, age 16–39 years) completed measures of symptoms, understanding of vulnerability to late-effects, purpose of follow-up, satisfaction and number of topics discussed. Predictors of satisfaction were: number of topics discussed, greater understanding of the purpose of follow-up and sex. Females, and those reporting longer waiting time were less satisfied. Aspects of clinic organisation, including shorter waiting times and opportunities to discuss health concerns, are more important in determining patient satisfaction than clinic type. Survivors' understanding of the purpose of follow-up is also integral in determining satisfaction.

1. Introduction

Survival rates for childhood cancer vary across Europe, but are around 75% in the UK.[1] It is estimated that 1 in 715 adults are survivors of childhood cancer[2] and approximately two-thirds experience late-effects.[3,4] Specific late-effects are dependent on previous treatment[5] and potentially compromise quality of life (QOL).[6] Long-term follow-up is recommended to: i) determine links between treatment and late-effects, and ii) screen and inform individuals so as to provide timely intervention. Guidelines for age appropriate follow-up have been described.[7]

Although follow-up has traditionally been provided in paediatrics, alternative models, including multidisciplinary care from both paediatric and adult services, nurse-led clinics and permanent discharge to primary care, must be considered to manage the increasing number of survivors and provide the range of care required.[8–11]

Transferring patients from paediatric to adult services can be logistically complicated and expensive.[12,13] Paediatricians can be reluctant to transfer care to adult oncologists, given their less specialised knowledge of treatments sequelae. Young people and their families often find it difficult to leave the care of paediatricians who treated their initial disease,

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and parents fear they will be less welcome in adult clinics.[14,15] Against this, transition to adult care can convey an optimistic sense of the future.[9] Adult care may also provide a more suitable forum in which to discuss and treat health issues pertinent to older survivors (e.g. fertility and sexual functioning).

Ultimately, attendance at follow-up depends on patient preferences and understanding. Major barriers to attendance cited by survivors in the US include lack of relevant knowledge, and financial implications.[16] Differences in service organisation between the US and UK mean it is important to approach survivors in the UK directly to determine their views about follow-up care.

We first describe survivors' understanding of their late-effects, symptoms, vulnerability and understanding of purpose of follow-up. Second, we compare their views about paediatric and adult-based care, predicting that satisfaction would be greater among those attending paediatric rather than adult led follow-up. Third, we attempt to identify key variables associated with clinic satisfaction.

2. Patients and methods

Survivors were recruited from a paediatric clinic housed in an outpatients department in a children's day hospital in West Yorkshire and staffed by a paediatric oncologist with an interest in late-effects, staff grade clinician and late-effects nurse. Survivors were able to to discuss lifestyle behaviours with nursing staff prior to appointments with the doctor. Thirty minute consultations were scheduled.

The second clinic is multi-disciplinary and held in an outpatient department of a teaching hospital in South Yorkshire, UK. The service was established to provide care by specialists with expertise in paediatric oncology and adult medicine (endocrinology, haematology, reproductive medicine and psychiatry). Where specific health problems occur, survivors are referred to the appropriate specialist. Survivors over the age of 16 years are routinely transferred from the local paediatric services. Consultations are scheduled every 10 minutes.

2.1. Sample

All eligible survivors attending clinic over a 12 month period were asked to take part. Eligibility criteria included treatment for cancer before the age of 16 years and currently aged 16–40 years. We excluded survivors with learning or sensory problems who were unable to complete questionnaires alone.

2.2. Procedure

Ethics approval was obtained from appropriate local committees. On arrival at clinic, reception staff gave survivors an information pack which included information about the study, consent form and questionnaire. Survivors completed one questionnaire before seeing clinic staff (Time 1). A second questionnaire was posted to survivors after their appointment with a freepost envelope for return (Time 2). Survivors who failed to return their second questionnaires within two weeks were sent up to two reminder letters.

2.3. Measures

2.3.1. Time 1 questionnaire

1) Parental attendance – Survivors indicated whether they attended clinic with a parent or alone.
2) Symptoms – Survivors were asked to indicate any symptoms [generic (e.g. pain, nausea, breathlessness and fatigue) and those common to survivors (e.g. weight gain and mood swings] experienced in the previous six months that they attributed to cancer treatment.
3) Late-effects and vulnerability – We listed 12 common late-effects: i) early occurring (e.g. poor eyesight and hearing problems); ii) gonadal dysfunction (e.g. early menopause, infertility); and iii) late occurring (e.g. cardiac dysfunction, second cancer). Survivors were asked to rate how likely they were to develop each problem (1 'very unlikely' to 5 'very likely'). An alternative response 'I already have this problem' was provided. Two scores were calculated: i) mean vulnerability to future late-effects, and ii) total number of late-effects currently experienced.
4) Purpose of follow-up – We assessed *psychological support: (For me coming to clinic is important to: receive psychological support; get advice about everyday things like insurance; talk to staff who understand what I have been through; get advice about how to stay healthy);* and *clinical support*: advice about late-effects; reassurance about my health; the best medical care; to help the staff learn more about cancer. Ratings were made on 5 point scales ranging from 1 'strongly disagree' to 5 'strongly agree'.

2.3.2. Time 2 questionnaire

1) Topics discussed – Survivors were asked to indicate any of 11 topics discussed during consultations (current health, medication, future health worries, concerns about past treatments, health behaviours, contraception, fertility, sexual problems, difficulties with work/education, insurance and other).
2) Satisfaction with Consultation – [17] Survivors rated 16 items (The clinic staff...seemed to lack experience with my medical problems; seemed sympathetic; answered all my questions; seemed to know what they were doing) on a scale from 1 'strongly agree' to 5 'strongly disagree'. After reversal of appropriate items, a total satisfaction score was calculated (range 16–80) so that higher scores indicate greater satisfaction.
3) Perception of time waiting in clinic – Survivors rated 'I waited too long at the clinic before seeing staff' on a scale from 1 'strongly agree' to 5 'strongly disagree'.
4) Perception of time with clinic staff – Survivors were asked to rate how satisfied they were with the amount of time with clinic staff (1 'much too short' to 5 'much too long').
5) Preferences for future follow-up – Seven models of care were listed (GP; specialist nurse clinics; annual telephone follow-up; specialist nurse when necessary; continued

care at current clinic; postal questionnaire; none). Survivors were asked to indicate their future preferences for follow-up care.

2.4. Patient information

Medical information (diagnosis, treatment history, current age, and age at diagnosis) was taken from individual treatment summaries. Treatment severity was based on UKCCSG guidelines[8]: Level 1 (surgery or low dose chemotherapy alone), Level 2 (chemotherapy and/or low dose cranial irradiation) and Level 3 (radiotherapy or megatherapy).

Socio-economic status (SES) was based on a postcode based consumer classification system from 1 (high SES) to 5 (low SES).[18]

2.5. Treatment of the data

Analyses were conducted using SPSS version 10. Descriptive statistics were calculated for all variables and reported as means (M) and standard deviations (sd). Internal reliabilities (Cronbach's alpha) were calculated for all scales. Preliminary analyses were conducted to determine demographic and medical differences between groups using t-tests, one-way anovas and chi-squared analyses. Pearson correlations were used to measure associations between age, time since diagnosis, understanding the purpose of follow-up, clinic satisfaction and number of topics discussed during consultations. A model was formulated of the possible predictive relationships between clinic type and sex (independent variables), number of topics discussed, perceived length of consultation, time waiting in clinic, understanding purpose of follow-up (intervening variables) and satisfaction with consultation (dependent variable). Path analysis was conducted to assess the direct and indirect effects of the predictor variables on satisfaction. Strength and significance of the paths was assessed using multiple regression techniques.[19] Pathways showing significant beta weights were retained in the final model.

3. Results

3.1. Sample

Time 1 questionnaires were completed by 198 survivors (adult clinic n = 93, paediatric clinic n = 105). There were no significant differences between survivors attending the two clinics in chronological age, age at diagnosis, sex or treatment severity (see Table 1), but more central nervous system (CNS) survivors attended the adult than the paediatric clinic.

The return rate for the Time 2 questionnaire was 79.6% for the adult and 70.5% for the paediatric clinic ($\chi^2 = 2.2$, $P = 0.14$). Women were more likely to return questionnaires than men (84.2% vs 66.0%, $\chi^2 = 8.7$, $P < 0.05$) but there were no other differences between the groups in terms of diagnosis, treatment severity or SES.

3.2. Scale reliability

Cronbach's alphas for all scales were considered adequate (vulnerability $\alpha = 0.76$, psychological support $\alpha = 0.87$, clinical support $\alpha = 0.81$, satisfaction with consultation $\alpha = 0.91$).

3.2.1. Survivors' perceptions of current health status and the purpose of follow-up

40.2% of survivors reported one or more symptom (M = 1.16, sd = 1.95) in the last 6 months that they attributed to cancer: pain (19.8%); stiff joints (12.5%); fatigue (12.4%); mood swings (12.2%); headaches (9.2%) and breathlessness (8.8%). There were no differences between men (M = 1.05 sd = 1.89) and

Table 1 – Demographic and clinical variables

	Adult clinic (n = 93)	Paediatric clinic (n = 105)	χ^2 or T value
Time 1			
Age (sd)	23.29 (5.53)	23.89 (5.60)	0.37
Age at diagnosis (sd)	7.35 (4.64)	7.96 (4.38)	0.93
Time since diagnosis (sd)	16.60 (7.30)	15.93 (5.62)	0.70
Males %	52.7	51.4	0.03
Socioeconomic status (sd)	3.37 (1.54)	3.21 (1.43)	0.50
Diagnosis n (%)			
Leukaemia/lymphoma	46 (49.5)	62 (59.0)	1.83
Solid tumours	35 (37.6)	39 (37.1)	0.01
CNS tumours	12 (12.9)	4 (3.8)	5.49*
Treatment severity n (%)			
Level 1 (low risk)	3 (3.2)	5 (4.8)	0.58
Level 2	42 (45.2)	55 (52.4)	0.31
Level 3 (high risk)	48 (51.6)	45 (42.9)	0.22
Time 2			
Return rate (%)	74 (79.6)	74 (70.5)	2.16
Age (sd)	23.92 (5.84)	24.18 (5.79)	0.27
Males %	48.6	43.2	0.44

* $P < 0.05$.

women (M = 1.29, sd = 2.01). Level 3 survivors reported more symptoms (M = 1.56, sd = 2.21) than level 2 survivors, (M = 0.89, sd = 1.67, p < 0.05). Level 1 survivors reported no symptoms.

35.5% of survivors reported at least one late-effect (M = 0.65, sd = 1.04). The most common were infertility, heart problems and, for women, early menopause (Fig. 1). Women tended to report more late-effects (M = 0.80, sd = 1.17) than men (M = 0.52, sd = 0.89, p = 0.06). Level 3 survivors reported more late-effects (M = 0.87, sd = 1.22) than level 2, (M = 0.48, sd = 0.85, P < 0.05) or Level 1 survivors (M = 0.38, sd = 0.52).

Mean vulnerability scores were similar for men (M = 2.35, sd = 0.66) and women (M = 2.49, sd = 0.73, p = 0.17). Survivors reported most vulnerability to infertility, heart problems, second cancers and weight gain (Fig. 1). There were no differences between the levels of treatment severity for vulnerability.

Survivors reporting more symptoms also reported more late-effects (r = 0.39, P < 0.001). Older survivors reported greater vulnerability (r = 0.20, P < 0.01), as did those longer since completion of treatment (r = 0.21, P < 0.01). Women were more likely to report the purpose of clinic in terms of psychological support than men (women = 3.92, sd = 0.82, men = 3.59, sd = 0.79, P < 0.05). There were no significant correlations between current age, age at diagnosis, time since diagnosis, number of symptoms or vulnerability and perceived purpose of clinic (psychological or clinical support). However, those who reported more late-effects considered psychological support more important (r = 0.16, P < 0.05).

3.2.2. *Comparison of paediatric and adult clinics*

Survivors at the two clinics did not differ in number of symptoms or late-effects, vulnerability or perceived purpose of

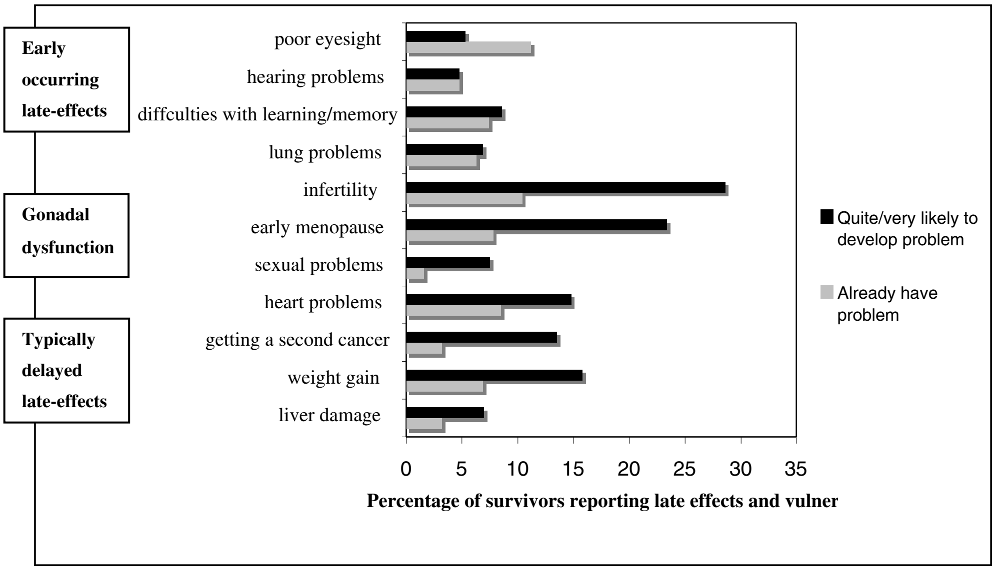

Fig. 1 – Percentage of survivors reporting late-effects and future vulnerability.

Table 2 – Differences between survivors attending the paediatric and adult clinic

	Adult	Paediatric	χ^2 or T value
	Mean (sd)		
Health status			
Number of symptoms in last 6 months	1.31 (2.0)	1.04 (1.91)	0.96
Number of late-effects	0.72 (1.16)	0.60 (0.93)	0.84
Total vulnerability score	2.40 (0.68)	2.44 (0.72)	0.68
Purpose of follow-up			
Psychological support	3.71 (0.81)	3.78 (0.83)	0.55
Clinical support	4.41 (0.57)	4.47 (0.50)	0.91
Clinic factors			
Accompanied by parent	52.3%	47.6%	0.42
Percentage of survivors wanting to continue care at current clinic	95.9%	87.8%	3.18
Number of topics survivors reported discussing	3.72 (1.70)	5.36 (1.70)	5.90**
Perception of time waiting in clinic	2.51 (1.19)	2.69 (1.19)	0.91
Perception of time spent with staff	2.85 (0.52)	2.97 (0.30)	1.71
Satisfaction with consultation	63.93 (8.65)	67.26 (7.47)	2.50*

* P < 0.05.
** P < 0.001.

follow-up and were equally likely to be accompanied by a parent. The majority wanted to continue follow-up at their current clinic (Table 2). Survivors attending the paediatric clinic discussed a greater number of topics than those at the adult clinic (Table 2). Concerns about past treatment (29.7% vs 50.7%, $\chi^2 = 6.16$, $P < 0.01$), health behaviours (37.3% vs 95.9%, $\chi^2 = 55.63$, $P < 0.001$) and insurance (7.4% vs 49.3%, $\chi^2 = 29.56$, $P < 0.001$) were discussed more frequently in the paediatric clinic. Perceptions of time waiting in clinic or time with staff did not differ between the two clinics. Survivors attending the paediatric clinic reported greater satisfaction than those attending the adult clinic (paediatric = 67.26, adult = 63.93; $P < 0.05$).

3.2.3. *Predictors of satisfaction with consultation*

Age, time since diagnosis, diagnosis, treatment severity, number of late-effects and perceived vulnerability were not significantly associated with satisfaction. Positive correlations were found between satisfaction and number of topics ($r = 0.31$, $P < 0.01$), length of consultation ($r = 0.26$, $P < 0.01$) and clinical support ($r = 0.32$, $P < 0.01$). Length of time waiting was negatively associated with satisfaction ($r = -0.32$ $P < 0.01$). Women reported lower satisfaction than men (women = 64.13, men = 67.38, $P < 0.05$).

In order to assess predictors of satisfaction, the following variables were entered into a path analysis: clinic type, reasons for follow-up (clinical support), sex, number of topics discussed, perception of time waiting and length of consultation (see Fig. 2). There were direct effects of number of topics ($\beta = 0.31$, $P < 0.001$), length of consultation ($\beta = 0.21$, $P < 0.01$), time waiting ($\beta = -0.23$, $P < 0.01$), clinical support ($\beta = 0.31$, $P < 0.001$), and sex ($\beta = -0.20$, $P < 0.01$); women gave lower scores on satisfaction. Clinic type was not associated with perceptions of time waiting, length of consultation, or reasons for follow-up. Longer perceived waiting time was associated with a shorter perception of consultation length ($\beta = -0.22$, $P < 0.01$). There was no significant direct effect of clinic type on satisfaction, but clinic type had an effect on number of topics ($\beta = 0.44$, $P < 0.01$; survivors reported discussing more topics at the paediatric clinic), which in turn had an effect on satisfaction ($\beta = 0.31$, $P < 0.01$).

4. Discussion

There are significant challenges to providing a satisfactory follow-up service for survivors of childhood cancer. Increasing numbers and age of survivors prohibit indefinite follow-up in paediatrics, but survivors are apprehensive about moving to adult care.[14] Late-effects are common[3,4] and variable, necessitating a range of expertise. Questions have therefore been raised about the most appropriate model of follow-up. In the current study, survivors in paediatric and adult follow-up were satisfied with the care currently experienced, and few expressed a preference for a different type of service, even though those in the adult clinic might be expected to make unfavourable comparisons with the paediatric service experienced previously.

Problems with adult rather than paediatric care are assumed to relate to increased exposure to information about possible adverse consequences of disease and vulnerability in the future.[20] However, we found no evidence that survivors attending the adult clinic were more informed about late-effects or felt more vulnerable to future problems than those in the paediatric clinic.

In attempting to identify the key determinants of satisfaction, we conclude that, in accordance with previous research, longer waiting times are associated with less satisfaction.[17,21] Other critical variables include aspects of the interaction (number of topics discussed and amount of time with the clinician). Those who viewed the purpose of follow-up in terms of clinical support were more satisfied than those who valued psychological support (advice about insurance or staying healthy). This supports previous findings that understanding of the purpose of follow-up care is associated with satisfaction.[22]

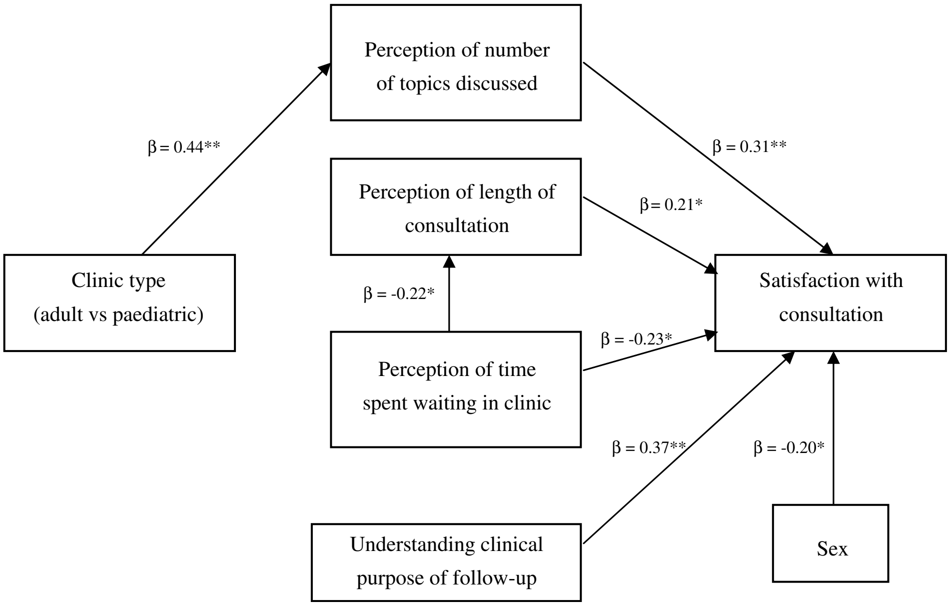

Fig. 2 – Path analysis of the variables associated with satisfaction. *$P < 0.01$, **$P < 0.001$.

Women reported more late-effects and were less satisfied with follow-up than men. They were also more likely to come to clinic for psychological support than men. Their lower satisfaction may be a consequence of more late-effects and desire for psychological support.

When other variables are taken into account, no simple relationship between clinic type and satisfaction was found. This is despite the fact that there were some differences in the organisation of the clinics which might favour the paediatric service. It might be expected that longer scheduled consultation times (30 versus 10 minutes) and input from nursing staff would contribute to satisfaction.

Less than 40% of survivors in our study reported late-effects, which is lower than previous estimates. There are several explanations for this. First, previous work has relied on diagnostic tests that may include asymptomatic conditions that have little immediate impact for individuals. In these situations, survivors may be unaware of their health status.[23] Second, the impact of late-effects on these relatively young survivors may not have peaked. Third, relatively few survivors of CNS tumours, who tend to experience a greater number of late-effects, attended either clinic. Fourth, the relatively low incidence of symptoms and late-effects reported may suggest that previous estimates based on historic cohorts over-estimate the prevalence among more recent survivors. Fifth, the list of late-effects used in the study was not exhaustive, and more information about endocrine[24] and emotional functioning should be included.

Some limitations of the study need to be considered. First, these findings are based on the views of survivors who attend follow-up and are perhaps relatively satisfied with care. Non-attenders are older and more likely to be unemployed than regular attenders.[25] The expectations of non-attenders may pose a greater challenge to the organisation of services.[26]

Second, this was a cross sectional study and does not indicate whether predictors of satisfaction change with time. Our sample was relatively young, reported few symptoms and relatively little vulnerability to future complications. Survivors who are older or experiencing significant late-effects may have different preferences and expectations about follow-up. Third, the return rate for the Time 2 questionnaire was around 70% for both clinics, but included more women than men.

Though a number of models of follow-up care have been described[27–29] there has been little systematic effort to determine survivors' satisfaction. Our findings suggest that survivors themselves may be less affected by differences in location and organisation of clinics than assumed by medical staff. Regardless of the service offered, practical issues about timing and opportunities to discuss more health issues were found to be most critical to satisfaction. Strategies to encourage the empowerment of survivors through better understanding of their health status and the purpose of follow-up (including written information, such as "After Cure"[30]) would also be beneficial.

Conflict of interest statement

We declare no conflicts of interest.

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REFERENCES

1. Kroll ME, Passmore SJ, Stiller CA, Draper GJ, Bayne AM, Brownbill PA, et al. Childhood Cancer-UK. In: Toms JR, editor. *CancerStats Monograph*. London: Cancer Research UK; 2004. p. 63–72 www.sign.ac.uk/pdf/sign76.pdf.
2. SIGN. Long term follow-up of survivors of childhood cancer: A national clinical guideline, 2004.
3. Stevens MCG, Mahler H, Parkes S. The health status of adult survivors of cancer in childhood. *Eur J Cancer* 1998;**34**:694–8.
4. Oeffinger K, Eshelman DA, Tomlinson GE, Buchanan GR, Foster BM. Grading of late-effects in young adult survivors of childhood cancer followed in an ambulatory adult setting. *Cancer* 2000;**88**:1687–95.
5. Wallace H, Green D, editors. *Late-effects of childhood cancer*. London: Arnold; 2004.
6. Eiser C. *Children with Cancer: The Quality of Life*. New Jersey: Lawrence Erlbaum Associates; 2004.
7. National Institute for Health and Clinical Excellence. *Improving outcomes in children and young people with cancer: The manual*. London: National Institute for Health and Clinical Excellence; 2005.
8. Wallace WHB, Blacklay A, Eiser C, Davies HA, Hawkins MM, Levitt G, et al. Developing strategies for the long term follow up of survivors of childhood cancer. *BMJ* 2001;**323**:271–4.
9. Rosen DS. Transition to adult health care for adolescents and young adults with cancer. *Cancer* 1993;**71**:3411–4.
10. Gibson F, Soanes L. Long-term follow-up following childhood cancer: maximising the contribution from nursing. *Eur J Cancer* 2001;**37**:1859–68.
11. Greenfield DG, Absolom K, Davies H, Ross R, Eiser C. Childhood cancer survivors: transition from pediatric to adult care. *Current Medical Literature- GH and Growth Factors* 2003;**18**:83–91.
12. Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child* 1999;**81**:271–5.
13. Scal P, Evans T, Blozis S, Okinow N, Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *J Adolesc Health* 1999;**24**:259–64.
14. Telfair T, Myers J, Drezner S. Transfer as a component of the transition of adolescents with sickle cell disease to adult care: Adolescent, adult and patient perspectives. *J Adolesc Health* 1994;**15**:558–65.
15. Westwood A, D. HL, Willcox P. Transition from paediatric to adult care for persons with cystic fibrosis: Patient and parent perspectives. *J Pediatr Child Health* 1999;**35**:442–445.
16. Zebrack BJ, Eshelman DA, Hudson MM, Mertens AC, Cotter BM, Foster BM, 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.
17. Shilling V, Jenkins V, Fallowfield L. Factors affecting patient and clinician satisfaction with the clinical consultation: Can communication training for clinicians improve satisfaction? *Psycho-Oncology* 2003;**12**:599–611.
18. ACORN. www.caci.co.uk/acorn
19. Kenny DA. 2004. http://davidakenny.net/cm/pathanal.htm

20. Eiser C, Flynn M, Green E, Havermans T, Kirby RM, Sandeman D, et al. Coming of age with diabetes: Patient's views of a clinic for under-25 year olds. *Diabet Med* 1993;**10**:285–9.
21. Probst JC, Greenhouse DL, Selassie AW. Patient and physician satisfaction with an outpatient care visit. *J Fam Pract* 1997;**45**:418–25.
22. 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.
23. Kadan-Lottick NS, Robison LL, Gurney JG, Neglia JP, Yasui Y, Hayashi R, et al. Childhood cancer survivors' knowledge about their past diagnosis and treatment. *JAMA* 2002;**287**:1832–9.
24. Spoudeas HA. Growth and endocrine function after chemotherapy and radiotherapy in childhood. *Eur J Cancer* 2002;**38**:1748–59.
25. Johnson R, Horne B, Feltbower RG, Butler GE, Glaser AW. Hospital attendance patterns in long term survivors of cancer. *Arch Dis Child* 2004;**89**:374–7.
26. Mertens AC, Sposata Walls R, Taylor l, Mitby PA, Witton J, Inskip PD, et al. Characteristic of childhood cancer survivors predicted their successful tracing. *J Clin Epidemiol* 2004;**57**:933–44.
27. Schimmer AD, Dranitsaris G, Ali V, Falconer M, Keating A. The autologous blood and marrow transplant long-term follow-up clinic: A model of care for following and treating survivors of autotransplant. *Support Care Cancer* 2002;**10**:247–52.
28. Hinkle A, Proukou C, French CA, Kozlowski AM, Constine LS, Lipsitz SR, et al. A clinic-based, comprehensive care model for studying late-effects in long-term survivors of pediatric illness. *Pediatrics* 2004;**113**:1141–5.
29. Hudson MM, Hester A, Sweeney T, Kippenbrock S, Majcina S, Vear S, et al. A model of care for childhood cancer survivors that facilitates research. *J Pediatr Oncol Nurs* 2004;**21**:170–4.
30. United Kingdom Children's Cancer Study Group. After Cure. 2005: http://www.aftercure.org/