THE IMPACT OF A MANAGED TRANSITION OF CARE UPON PSYCHOSOCIAL CHARACTERISTICS AND PATIENT SATISFACTION IN A COHORT OF ADULT SURVIVORS OF CHILDHOOD CANCER

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ABSTRACT

OBJECTIVE: Many adult survivors of childhood cancer receive care in paediatric departments, despite national policy to transition their care to adult services. When long-term follow-up care for survivors of childhood cancer in our region moved from a paediatric to an adult environment in 2009, we prospectively assessed the impact of this change on patient satisfaction.

METHODS: Questionnaire data were collected in paediatric and adult clinical environments regarding the level of satisfaction with care, and potential mediators; quality of life, psychological health and social difficulties. Predictors of satisfaction and optimum longitudinal risk based care were described using path analysis and compared to previously described models.

RESULTS: There was no significant difference in satisfaction between the paediatric and adult settings. Short waiting times and increased understanding of the purpose of follow-up were significantly associated with increased satisfaction. Those with a higher perception of health problems and those that were older were more likely to not attend all of their clinic appointments.

CONCLUSIONS: Within our service, transition to adult care did not impact significantly upon patient satisfaction. Shorter waits and knowing why participants were attending the clinic increased satisfaction. Joint working between adult and paediatric cancer professionals enabled adult survivors of childhood cancer to receive highly satisfactory care in adult services.

OBJECTIVE

Over 75% of children who presented with cancer in the UK in the 1990s survived at least five years; this proportion grew rapidly before then, and continues to improve [1]. In the UK in 2000 more than 26,000 people were alive following successful treatment for childhood cancer. Half of those are now over 19 years of age [2].

These childhood cancer survivors are at substantial risk of chronic toxic effects of the cancer, and the treatment that achieved a cure. Approximately 60% of adult survivors of childhood cancer have at least one chronic medical problem, including endocrine, cardiac or pulmonary toxic effects, poor mobility, neuro-psychological difficulties and sub-fertility [3-4]. Many of these effects are symptomatic, and show no evidence of declining beyond 25 years of diagnosis [5].

These young adults require risk-adapted assessment, care planning and long term management of their illnesses [6]. The issue of transition of care is common to many specialities [7], and many researchers have evaluated how best to undertake this process [8-10]. National policy in the UK and overseas has recognised the importance of effective transition for young people with chronic illness from paediatric to adult places of care, as well as the problems ineffective transition may create [11-13]. Success of cancer treatment for young people should not only be judged by cure from the malignancy but additionally by the ability of the survivor to do what they could reasonably have expected to be able to do if they had not had cancer. There are concerns that the continuing care needs of this young adult population may not be best met by paediatric oncologists within in a children's cancer environment, and may require transition to an adult place of care [14-15]. However, professionals, groups of young people and their carers worry about this transition; including loss of confidence, decrease in quality of disease control, and increased failure to attend appointments [16]. The range of transition models for survivors of cancer is wide [7,9,10,17], ranging from ongoing care within a unified hospital based team, through shared clinics leading to handover from child to adult services, to devolution of care to primary care physicians, and there remains uncertainty about the most effective and preferred system [7].

Until 2009, long term adult survivors of a malignancy diagnosed under the age of 18 and treated within two cancer networks (Yorkshire Cancer Network and Humber and Yorkshire Coast Cancer Network) were followed up within a paediatric outpatient clinic irrespective of age or needs. The service for patients aged over 18 is now provided within an adult cancer centre in Leeds. We achieved this as a managed transition of patients from the clinic in the children's setting to that in the adult setting, including developing joint multi-professional working. The consultations in the children's environment were with doctors and nurses from a paediatric training and experience, whereas in the adult environment they were with doctors and nurses either from a paediatric or an adult training and experience. The consultations during either clinic were driven by patient concerns and covered the range of issues of morbidity, risk, screening and self management, as described by Skinner et al [15]. Moreover a shared ethos of patient-centred risk-based cancer survivorship care, including supported self management was developed between the two disciplines.

In the setting of this transition, we aimed to examine

1. whether this transition of services was associated with a change in the impact of care upon patient reported outcomes, especially patient satisfaction. A model describing predictors of patient satisfaction with long term follow-up services in these two settings has been described [18]; we also aimed to validate this model (Fig. 1).
2. the relation between attendance and the barriers and enablers to longitudinal risk-based health care for adult survivors of childhood cancer as described by Oeffinger [19]. Oeffinger et al described barriers and enablers to providing optimal longitudinal risk-based survivorship health care, based upon behavioural models of health beliefs, locus of control and health care utilisation [19]. We chose to examine Oeffinger's framework of barriers and enablers in our service because it may improve our understanding of areas to improve with survivors and healthcare providers, controlled within the relatively uniform local NHS healthcare system.[19]. We chose not to examine the health care provider and health care system described by Oeffinger as within one acute NHS trust these are likely to be uniform.

PATIENTS AND METHODS

In order to determine whether transition from a paediatric to an adult based long term follow-up clinic altered the impact of the service on adult survivors of childhood cancer, consecutive eligible attendees at the clinic in children's services (prior to the change of clinic environment) and a separate cohort of consecutive eligible attendees in the adult environment (after the change of clinic environment) were asked to complete questionnaires. This was not a longitudinal study; questionnaire data in each environment was collected on separate cohorts with no participant being included in both settings.

Eligibility criteria and recruitment

Survivors over the age of 18 were eligible to participate if they were diagnosed with cancer before their 18th birthday and were at least 5-years post completion of treatment. This time frame was chosen to align with the timing of transferral from acute "on treatment" clinical service to the long term follow-up program. Eligible attendees at the clinic placed in children's services were asked to complete a questionnaire at the time of their clinic appointment in addition to a postal follow-up questionnaire. After the transition of the clinic to adult services, a further group of eligible attendees were recruited and asked to complete the same two questionnaires. No participant was included within both cohorts. Fluency in English and the ability to complete the questionnaire was also required [20]. The study was granted ethical approval by the Leeds East PCT Ethics Review committee (REC application 07/H1306/116).

Measures

Information extracted from medical notes included diagnosis group and age at diagnosis. Socioeconomic status was defined using the 2007 Index of Multiple Deprivation (IMD) based upon the individual's residential address and postcode at the time of participation [21].

The questionnaires in this study were built upon measures used in a previous study of the same issues [18]. The following measures used within this study are described in detail by Absolom *et al* [18]; parental attendance, understanding of the purpose of follow-up, the number of topics discussed, the perception of waiting time and the perception of time with clinic staff (consultation time). Patient satisfaction was determined using the total score of the patient satisfaction with communication questionnaire (PSCQ) as in [18]. The following additional measures were included in this study;

1. Quality of life (QOL)
   Participant's quality of life was measured using the 41-item QOL-CS, a specific cancer survivor quality of life measure [22]. An overall score was calculated by summing up all scores after reversal of scales where appropriate. The QOL score ranges from 0-400, where high scores indicate greater quality of life.

2. Psychological Health
   The psychological health of participants was quantified by totalling the score to each of the 12 items on the General Health Questionnaire (GHQ-12) [23]. The score ranges from 0-32, where a higher score indicates better health.

3. Social Distress
   The social difficulties index (SDI) was used to calculate a social distress measure [24]. The score ranges from 0-44, with higher scores indicating a greater degree of social difficulties.

4. Illness perception and locus of control
   The illness perception questionnaire (Brief IPQ-R) was used to assess how severely the participant feels they are affected by their illness [25]. Scores of the 11 items were summed, total score ranged from 0-110 with higher scores indicating an increased degree of perceived severity.

5. Perceived Health Problems
   The Perceived Health Problems (PHP) questionnaire assessed how likely the participant perceived themselves to develop the following health problems; inability to have children, heart problems, getting a second cancer, putting on weight, liver damage, hearing problems, difficulties with learning and memory, lung problems/difficulty breathing, poor eyesight, problems with sexual functioning, early menopause. Scores of these 11 items were summed, total score ranged from 0 to 55, with higher scores indicating that the participant believes they had a greater likelihood of developing any of these health problems.

6. Attribution of Health Problems
   The attribution of health problems (AHP) questionnaire assessed whether the participant attributed any of the following symptoms to their cancer; pain, sore throat, nausea, breathlessness, weight loss, fatigue, stiff joints, sore eyes, wheeziness, headaches, upset stomach, sleep difficulties, dizziness, loss of strength, weight gain, problems with sexual function, and mood swings. Scores indicate the number of symptoms attributed to cancer, ranging from 0 to 17.

The survivor related factors described in Oeffinger's model were measured using the following questionnaire items:

Cancer Experience – GHQ-12 total score, QOL-CS Psychological Well-Being subscale, Brief IPQ-R questions 7 and 8 ("How well do you feel you understand your illness?" and "How much does your illness affect you emotionally?");

Core Health Beliefs – Brief IPQ-R question 6 ("How concerned are you about your illness?"), PHP Score, QOL-CS Physical Well-Being subscale;

Internal Modifiers – age at time of survey, gender, deprivation, ethnicity, SDI self and others subscale;

External Modifiers – attendance demographics ("have you come here today with…?" and "will the person accompanying you be coming into the consultations with the clinic staff?"), AHP score;

Health Locus of Control – Brief IPQ-R questions 3 and 4 ("How much control do you have over your illness?" and "How much do you think your treatment can help your illness"?).

Statistical Analysis

Questionnaire outcomes between the paediatric and adult follow-up clinics were summarised and differences assessed using the appropriate statistical test (Chi-squared, Fisher's exact, T-test, Mann-Whitney or Mantel Haenzsel). The internal consistency of all scales was tested using Cronbach's alpha [26].

Predictors of satisfaction were analysed initially by determining whether any of the demographic variables and questionnaire measures correlated with satisfaction using Spearman's rank correlation coefficient. An a priori hypothesis of possible predictive relationships between those variables that were significantly correlated with satisfaction was devised from previous literature and authors' consensus. The strength and significance of each relationship within the a priori model was determined using standardised regression coefficients (beta weights) derived from linear regression models [27]. This replicates the procedure used previously [18].

The theoretical model of longitudinal risk-based care by Oeffinger was used as an a priori model which we tested using the same methods described above.

The outcome of optimum longitudinal risk-based care was examined as a binary variable to indicate whether the participant either attended all their appointments or not. Non-attendance was defined as someone who did not attend without prior cancellation or rescheduling of their clinic appointment (i.e. those who cancelled or rescheduled the appointment were classed as having attended all their appointments). The size of the dataset did not allow us to measure attendance status according to the proportion of attended appointments out of all appointments.

RESULTS

Complete data were available for a total of 143 participants, of whom 69 attended routine appointments in the paediatric setting, and 74 attended adult outpatient appointments. Patient

demographics and medical information comparing the two clinic environments are given in Table 1. The internal consistency of all scales was satisfactory (understanding clinical purpose α=0.67; quality of life α=0.92; general health α=0.86; social distress α=0.71; satisfaction α=0.89; perceived health problems α=0.71; Brief IPQ-R α=0.64).

No significant difference was found between the clinics according to any of the demographic or medical variables. More patients in the adult clinic attended independently from their parents. Table 2 provides a summary of answers to each questionnaire measure by clinic environment; - again, no significant differences between the paediatric and adult clinics were found.

Patient Satisfaction

Initial univariate analysis showed significant correlation between satisfaction and the following variables; gender, age at diagnosis, age at time of questionnaire, participants' understanding of the purpose of follow-up and their perceived waiting time (supplementary material - Table A). The predictive relationships between these variables were tested in a multivariate path analysis (Fig. 2). Clinic environment (paediatric outpatients vs. adult outpatients) was not significantly correlated with satisfaction; however, it was retained in the analysis as it was of primary interest in this study. The path analysis resulted in a final path diagram containing only significant paths – this is represented in Fig. 2. The result showed that waiting time had a significant and direct effect upon satisfaction, such that a participant who agreed with the statement "I waited too long before seeing clinic staff" had a lower satisfaction score compared to a participant who neither agreed nor disagreed. Similarly, participants' understanding of the purpose of follow-up had a direct and significant effect upon their overall satisfaction score; more understanding created a higher degree of satisfaction. Gender had an indirect effect upon satisfaction such that females understood the purpose of follow-up better and perceived their waiting time to be less compared to males, and therefore had a greater degree of satisfaction.

Longitudinal Risk Based Care

A total of 50 participants (35%) attended all their clinic appointments, with the remaining 93 participants (65%) not attending all of their appointments. Attendance status did not differ by clinic environment. Fig. 3 shows the *a priori* path diagram based on Oeffinger's model of optimum longitudinal risk-based care, in which attendance status represents the outcome of interest. The final model (also shown in Fig. 3) consists of all significant paths and shows that the core health beliefs as measured by the perceived health problems questionnaire had a significant and direct effect upon attendance, such that those with a higher perception of health problems were more likely to not attend all of their clinic appointments. Age also had a direct effect upon the outcome variable, such that older participants were less likely to attend all their clinic appointments. Answers to the question: "how well do you feel you understand your illness?" had an indirect effect upon optimum longitudinal risk-based care

such that those who understood their illness less had more perceived health problems and were therefore less likely to attend all their clinic appointments.

CONCLUSIONS

The provision of long term follow-up care to manage and detect late effects for the ever growing cohort of adult survivors of childhood cancer presents significant service provision challenges. As previous patients become older, involvement of adult services are necessary [14-15, 19].

In this study, we found this transition may be achieved without detriment to satisfaction, quality of life, general health or social distress. It appears this is possible if carefully implemented, without detriment to patient retention, care and satisfaction [28-29].

Groups of young people and their carers worry about this transfer, and it is reassuring to note that transition need not necessarily result in any measurable reduction in perceptions of care [30]. However there was not an improvement in satisfaction with care when young adults were no longer looked after alongside small children or by professionals with primary training in children's care. Although patients ascertained in the paediatric setting of care would have been accustomed to that setting over five or more years, and the patients ascertained in the adult setting were new to that setting, this has not introduced a measurable difference in satisfaction.

Our validation of a multivariate model predicting patient satisfaction in this context is simpler than the previous literature. Clinic type (paediatric versus adult) was not significantly associated with satisfaction. The length of consultation and the number of topics discussed at consultation were no longer significant contributors to satisfaction. A prolonged waiting time reduced satisfaction and a greater understanding of the purpose of the service increased satisfaction. These observations are not very different from any other service, whether in health or elsewhere. Females tended to report a greater degree of satisfaction; they understood the purpose of follow-up better. Improving education for males may allow further improvement. In our adult place of care, adult and paediatric trained professionals work together to maintain a unified ethos of care. The greater degree of shared staffing between the adult and children's clinic setting in our study may explain why clinic type was not significant, and our shared multidisciplinary team ethos may also explain why consultation length and the number of topics discussed did not relate to place of care in our current study.

Attendance for care by the chronically ill is important. We were able to demonstrate empirical support for the premise that severity of illness, information about their illness and perception of health problems correlated with attendance for care.

Our measures performed adequately in psychometric terms, although the satisfaction measured is amenable to some simplification [20].

A potential weakness of our study is that there may be subtle biases between the distinct cohorts compared, which we were unable to account for unless a randomised design was implemented. However randomised trials in this situation may not be acceptable to patient

groups. The study sample size (n=143) is adequate for our statistical analyses, yet care needs to be taken when generalising these results. We were only able to collect data from those who attended clinics in either setting, potentially causing under representation of the most dissatisfied patients, who cease attending where transition is problematic.

The issues at stake in transition are complex [31]. Assessing the level of patient satisfaction is only one way to measure the quality of long term follow-up services. We have no data on time to, or rate of, detection of occult late effects, concordance with planned screening schedules in the two settings of care, nor changes in survival which may be a result of the transition of services. We have no qualitative data to elucidate in detail the relevant complex survivor factors, psychosocial and other mechanisms in transition [9,32] that work alongside both physician factors and tailored health service provision [33]. Nonetheless, in many health care settings patient satisfaction is used as a quality measure for evaluation and even remuneration of health care services [34].

Future research in this area may include modelling the impact of patient and staff beliefs, information provision, and the impact of different healthcare models as barriers and facilitators of optimum long term follow-up [4].

Clinically this study demonstrates that transition of care for adult survivors of childhood cancer to adult services is feasible without reducing satisfaction, with care and attention to simple aspects of service delivery such as patient education (in males particularly), manageable waiting times, and a shared ethos of care between children's and adult services.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interests.

ETHICAL STANDARDS

The study was granted ethical approval by the Leeds East PCT Ethics Review committee (REC application 07/H1306/116).

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TABLES

Table 1 Participant demographic and medical details by clinic environment

Variable	Paediatric outpatients N (Column %)	Adult outpatients N (Column %)	P-value
Gender			
Male	34 (49%)	35 (47%)	0.813[a]
Female	35 (51%)	39 (53%)	
Diagnostic group			
Leukaemia	22 (32%)	19 (26%)	0.236[a]
Lymphoma	13 (19%)	18 (24%)	
Brain tumour	13 (19%)	7 (9.5%)	
Other solid tumour	21 (30%)	30 (40.5%)	
Ethnicity[d]			
Non-south Asian	63 (91%)	68 (92%)	0.876[b]
South Asian	5 (7.5%)	6 (8%)	
Unknown	1 (1.5%)	0 (0%)	
Age at time of questionnaire (years)	**Median Score (IQR)** 24 (21-27)	**Median Score (IQR)** 24 (21.75-32)	0.213[c]
Age at diagnosis (years)	9.05 (5.72-12.90)	10.23 (4.57-13.45)	0.497[c]
Socioeconomic Status[e]	18.78 (10.69-29.95)	15.19 (8.99-23.60)	0.159[c]
Survival time (months)	**Mean Score (sd)** 185.8 (64.4)	**Mean Score (sd)** 211.2 (84.8)	0.105[c]
Total (N)	**69**	**74**	

[a]Chi-Squared test, [b]Fisher's Exact test, [c]Mann-Whitney test, [d]Ethnicity classified as south Asian or other (non-south Asian) based on name analysis, [e]Index of Multiple Deprivation Score, 2007. **Abbreviations** IQR: inter-quartile range; sd: standard deviation

Table 2 Questionnaire summary by clinic environment

Variable	Paediatric outpatients N (Column %)	Adult outpatients N (Column %)	P-value
First visit[a]			
Yes	65 (92%)	65 (88%)	0.186[b]
No	4 (8%)	9 (12%)	
Accompanying person			
Parent	39 (57%)	25 (33.7%)	
Other family member	4 (6%)	7 (9.5%)	
Partner	10 (14%)	21 (28.4%)	0.080[b]
Friend	1 (1%)	1 (1.4%)	
Alone	15 (22%)	20 (27%)	
Number of topics discussed			
None	27 (39%)	25 (34%)	
1-3	7 (10%)	8 (11%)	
4-6	26 (38%)	23 (31%)	0.545[b]
7-9	8 (12%)	16 (22%)	
10-12	1 (2%)	2 (3%)	
Waiting time			
"I waited too long"			
Strongly agree	3 (7%)	1 (2%)	
Agree	10 (24%)	12 (24%)	
Neither agree/nor disagree	12 (29%)	7 (14%)	0.250[b]
Disagree	10 (24%)	19 (38%)	
Strongly disagree	7 (17%)	11 (22%)	
Consultation Time			
"The length of time with the staff, was…"			
Much too short	0 (0%)	1 (2%)	
A bit too short	3 (7%)	6 (12%)	
About right	37 (88%)	38 (76%)	0.501[b]
A bit too long	2 (5%)	5 (10%)	
Much too long	0 (0%)	0 (0%)	
	Median Score (IQR)	**Median Score (IQR)**	
Understood clinical purpose	13 (12-15)	13.5 (12-15)	0.599[c]
Quality of life	257 (200-287)	260 (227-288)	0.382[c]
General health	11 (7-13.5)	10 (7-13)	0.627[c]
Social distress	4 (1-10)	2.5 (1-5.25)	0.066[c]
Satisfaction	66.5 (61-72.25)	68 (60-70)	0.429[c]

[a]First visit to long term follow-up clinic, [b]Chi-Squared test, [c]Mann-Whitney test. **Abbreviation** IQR: inter-quartile range.

Figure 1: Previously described model of clinic satisfaction [18].

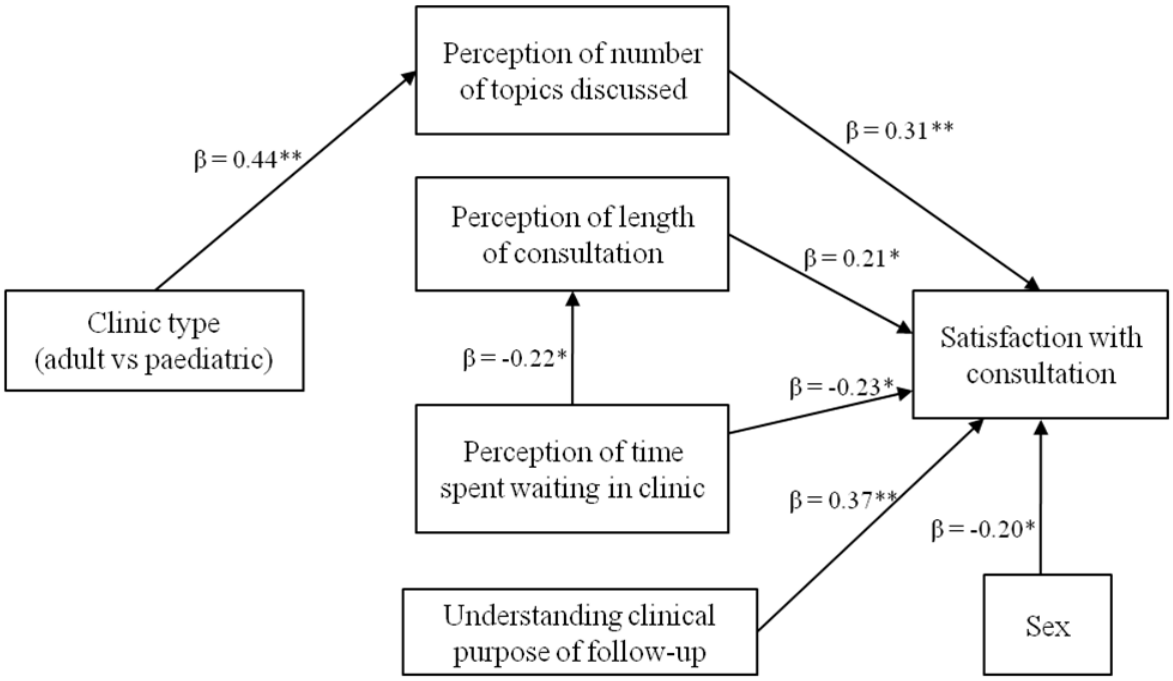

Figure 2: A priori (left) and final (right) model of patient satisfaction

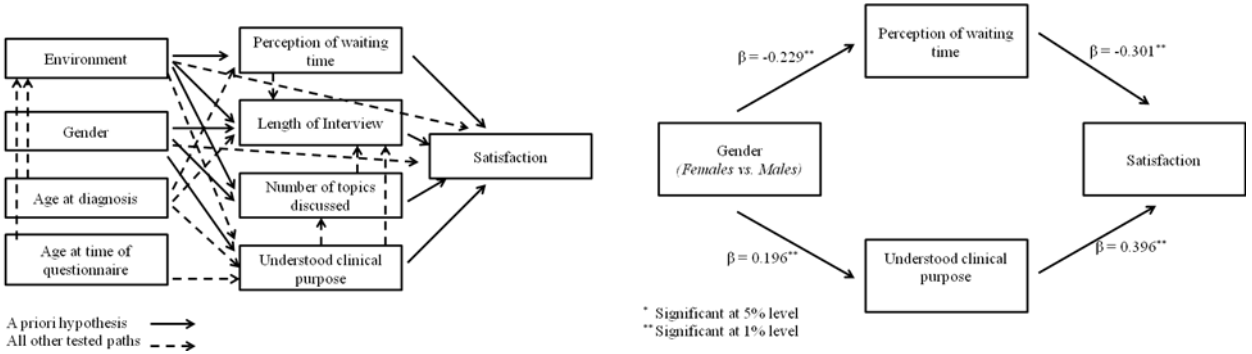

Figure 3: A priori (left) and final (right) model of optimum longitudinal risk-based care