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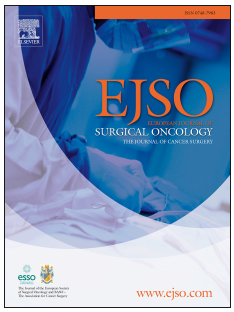

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Patient preferences for clinical follow-up after primary treatment for soft tissue sarcoma: a cross-sectional survey and discrete choice experiment

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ABSTRACT

BACKGROUND: Patients treated for soft tissue sarcoma (STS) require long-term follow-up to detect recurrent or metastatic disease, yet marked differences exist in clinical approaches to the length of follow-up, frequency of consultations and investigations undertaken at follow-up visits. There has been no published work assessing patient expectations or the acceptability of post-treatment follow-up strategies. This study aimed to assess the patient acceptability of different follow-up strategies following curative surgery for soft tissue sarcoma and to investigate the hypothetical levels of recurrence risk at which different follow-up regimes were acceptable.

METHODS: Patients were recruited from the Royal Orthopaedic Hospital in Birmingham. The study used a cross-sectional survey incorporating a best-worst scaling discrete choice experiment to assess patient preferences regarding different aspects of follow-up.

RESULTS: 132 patients participated (47% response). The nature of investigations undertaken during follow-up was the most important aspect of post-surgical care. Patients typically preferred appointments routinely consisting of clinical examination and chest x-ray, and for follow-up to remain in secondary care rather than general practice.

CONCLUSION: Clear protocols for STS patient follow-up can improve consistency and equity of care. In determining the optimum follow-up plan for STS patients from the patient perspective, this study provides valuable information that should be considered alongside the clinical effectiveness of follow-up strategies to maximise patient outcomes and use NHS resources appropriately.

Keywords: soft tissue sarcoma, follow-up, secondary care, discrete choice experiment, best-worst scaling

INTRODUCTION

In England, approximately 2,300 patients are diagnosed with soft tissue sarcoma (STS) each year [1]. STS can occur in any anatomical location [2], and surgical excision with or without adjuvant radiotherapy is the usual treatment for localised disease [3]. However, there is a significant risk of local recurrence and metastasis following primary treatment. Ten-year local recurrence rates are between 10 and 20%, and ten-year survival is 50 to 60% [4,5] Within this, there can be significant variability by tumour type, size and location [6,7]. Prognostic factors for tumour relapse are complex; the risk of metastasis is associated with tumour grade, size and depth, while local recurrence risk is associated with grade and excision margin [5].

Given the risk of recurrence or metastasis following primary treatment, STS patients require long-term follow-up, which may continue for up to ten years. However, there remains controversy as to the optimum patient follow-up regime, and follow-up may produce either reassurance or anxiety for patients [8,9], particularly as 40% or more of patients will never develop recurrent disease [1,10].

Routine follow-up includes clinical examination and regular chest x-rays, but the value of more sophisticated follow-up investigations remains uncertain [1]. US studies demonstrate significant heterogeneity in clinical practice [11,12]. The American National Comprehensive Cancer Network and American College of Radiology have produced consensus-based guidelines for sarcoma follow-up [13], stratified by grade and tumour site. A survey of UK practice showed differences in the length of follow-up, frequency of consultations and the investigations undertaken at follow-up visits [14]. The National Comprehensive Cancer Network in the UK has issued post-treatment guidelines for the clinical management of STS but these are consensus rather than evidence-based [15]. Finally, the European Society for Medical Oncology (ESMO) has issued its own follow-up guidelines, recommending tailored patient follow-up regimes based on risk assessments of tumour grade, size and site [16]. In addition to clinical uncertainty about STS follow-up, there is no published work assessing the acceptability of different potential post-treatment regimes from the patient perspective.

This study aimed to assess the patient acceptability of different follow-up strategies following curative STS surgery and to investigate the hypothetical levels of recurrence risk at which different follow-up regimes were acceptable.

PATIENTS AND METHODS

This study used a cross-sectional survey incorporating a best-worst scaling (BWS) discrete choice experiment (DCE) to elicit information regarding patient preferences for different aspects of the STS follow-up regime. Participants were also asked to choose between low, moderate and intensive follow-up schedules at a range of hypothetical recurrence risks from 0% to 100%.

Patient recruitment and data collection

The Royal Orthopaedic Hospital (ROH) maintains a database of patients treated for soft tissue sarcoma, which was searched by a research nurse to identify eligible participants aged 18 and over, with a diagnosis of any soft tissue tumour (excluding retroperitoneal or periabdominal sarcomas as these patients are not followed up at ROH) who had undergone curative treatment. Patients were not eligible for the study if they were aged under 18 at the time of primary treatment, were diagnosed fewer than 6 months or more than 10 years previously, or had a serious or unstable medical or psychological condition that would compromise study participation.

All eligible patients were posted a study information pack seven days before their next follow-up clinic visit. On arrival at the clinic, the research nurse took informed consent from those who wished to participate in the study, and administered the survey and DCE. Sociodemographic information (age, gender, employment status, education level, distance between patients' home and ROH) was collected, and anonymised clinical information was extracted from the hospital database for each participant. This included data relating to primary treatment (age, date of diagnosis and treatment, STS histology, tumour size, grade, site), and any information relating to disease recurrence.

Discrete choice experiment and best-worst scaling

Discrete choice experiments (DCE) elicit preferences for goods or services based on individual intentions in hypothetical situations [17]. The DCE method has several variants; this study used the best-worst scaling method [18,19], which identifies patient preferences for healthcare

service provision by examining trade-offs that individuals are prepared to make between different aspects of healthcare. BWS involves identification of key characteristics (attributes), each of which has two or more levels, in order to develop a series of scenarios incorporating various combinations of attribute levels to describe different aspects of healthcare service provision [20]. Attributes were derived from published literature [11,12,14], and clinical guidelines [15, 21-23].

Four attributes were chosen: length of follow-up, frequency of follow-up visits, clinical investigations and choice of healthcare provider. These were perceived to best combine the important characteristics of follow-up appointments in the simplest manner. Each attribute was assigned three levels, derived from the literature and clinical relevance. As the inclusion of all possible combinations of attributes and levels would result in 81 (3^4) scenarios, a subset of nine orthogonal scenarios (fractional factorial design) was obtained via a statistical design website (http://www.research.att.com/~njas/oadir/) [24]. For each scenario, participants were asked to choose the aspect that they perceived as the best and worst option (Figure 1).

Acceptability of follow-up at different risks of recurrence

Participants were also asked to choose their preferred follow-up schedule (low, moderate and intensive) at a range of hypothetical recurrence risks ranging from 0% to 100%. Low-level follow-up comprised one follow-up visit per year in general practice, incorporating only a clinical examination. Moderate follow-up comprised two visits annually, conducted by a specialist hospital nurse, including clinical examination and chest x-ray. Intensive follow-up consisted of quarterly visits to a specialist hospital doctor, incorporating a clinical examination and MRI/CT/ultrasound scan.

Data analysis

BWS analysis focused on the number of times a participant chose a particular attribute/level as best or worst. Each best-worst combination was analysed as paired data, plotted as one data point at the individual level, and assessed using conditional multinomial logistic regression. The

regression co-efficients indicate the additional utility value for each attribute-level in comparison to the baseline provided by the lowest rated attribute-level. Utility values can be interpreted in a cardinal way e.g. if the difference in level values for one attribute is twice that of another attribute, this corresponds to twice the value of improving the level on the former attribute. The method also allows an assessment of the scenario that contains the highest number of desirable components, has the highest utility value, and is acceptable to most participants. Patient preferences for low, moderate or intensive follow-up schedules were analysed descriptively and the results presented graphically. Data were analysed using Stata version 12 (StataCorp, 2011).

Justification of sample size

The sample size was based on pragmatic rather than statistical criteria and was maximised within the resources available. It was anticipated that 300 patients would be eligible to participate during the data collection period (May to December 2012). Achieving a 60% response rate would thus give a sample size of 180 patients.

RESULTS

Response rates

286 patients were eligible to participate over the data collection period. 133 patients consented to participate, representing a 47% response rate. One participant withdrew after consenting, thus data were collected for 132 patients in total.

Participant clinical and sociodemographic characteristics

73 participants were male (55%) and 59 were female (45%), (Table 1). Median age at time of survey completion was 63 years (inter-quartile range (IQR): 47 to 71), with median age at primary diagnosis 57 years (IQR 43 to 67). Median travel time between a participant's home and ROH was 60 minutes (IQR 45 to 90). The most common tumour type was a high grade primary tumour (n=62; 47%), and most tumours occurred in the lower extremity (n=82; 62%). Mean tumour size (diameter) at diagnosis was 9.2cm.

Participant views about follow-up

Participants were asked for their general views about STS follow-up and its perceived importance. All participants felt that attending follow-up visits was important, and the vast majority (n=130; 99%) understood why follow-up visits were necessary. Most respondents felt it important to be included in decision-making about their follow-up regime (n=114; 86%). The most important broad aspect of follow-up visits for most participants was the nature of clinical investigations undertaken (n=96; 73%). The type of healthcare provider conducting follow-up was deemed the least important factor (n=7; 5%).

Discrete choice experiment best-worst scaling

Table 2 shows the frequency with which specific attributes and levels were selected as best or worst choices, and outlines the overall rank for each level derived from the number of times it was chosen as the best or worst aspect of a scenario. The three highest ranked levels were all aspects of the attribute relating to preferred clinical investigations, with clinical examination and x-ray rated highest. The lowest ranked level was follow-up undertaken by a general practitioner,

which was ranked as the best aspect of a scenario 19 times, and ranked worst on 251 occasions. Participants ranked follow-up visits undertaken by a specialist hospital doctor fourth out of the 12 levels assessed overall. Within the frequency of follow-up attribute, 6-monthly clinic visits were seen as most acceptable, and most participants' preferred length of follow-up was five years after primary treatment.

Table 3 shows the conditional logistic regression model of best-worst pairs. As follow-up carried out by general practitioners ranked as the least preferred of all options, this level was assigned a value of zero and the utility for all other coefficients estimated relative to this baseline. Model coefficients indicated that clinical examination with x-ray was the most highly valued attribute level, followed by clinical examination plus intensive investigations and follow-up visits conducted by a specialist hospital doctor. In terms of individual attributes, the one that made the most difference to patients was the healthcare provider. The additional value of seeing a hospital specialist as compared to a GP (1.89) was equal to almost three times the additional value of having an x-ray at clinical examination compared to clinical examination without x-ray (0.68 i.e. 2.503 minus 1.823). Coefficients with the lowest utility (thus representing the least valued attribute levels) were those relating to lifelong follow-up duration and the most frequent follow-up option of a quarterly clinic visit. Taking the highest valued level within each attribute together, the preferred scenario across the patient cohort would be 6-monthly follow-up for five years, in which a hospital doctor carries out a clinical examination and x-ray.

Acceptability of follow-up schedule by hypothetical risk of disease recurrence

Figure 2 shows the number of survey respondents who chose each of the three types of follow-up schedule at different hypothetical levels of disease recurrence risk. 17 participants (12.9%) would choose an intensive follow-up schedule even if they had no risk of disease recurrence, and 4 participants (3.0%) would opt for a moderate level of follow-up even with a 100% risk of recurrence. As might be expected, as the hypothetical risk of recurrence increased, the number of patients who would prefer a more intensive follow-up regime also increased. Once the risk of recurrence became greater than 5%, the intensive follow-up schedule increasingly became the

preferred choice, whilst between 1% and 5%, the moderate follow-up schedule was dominant, and below 1%, the low level schedule was preferred.

DISCUSSION

The main aim of patient follow-up after primary treatment for soft tissue sarcoma is to detect recurrent disease at a time when further treatment can positively influence patient outcomes. STS recurrence rates are high, and regular follow-up can reassure patients about their risk of relapse or developing metastasis as well as providing important opportunities for patients to raise issues regarding physical or psychological consequences of primary treatment. Present guidelines recommend that active follow-up should continue for at least five years, thus at any one time, approximately 15,000 patients in the UK will be involved at some stage in the follow-up process.

This study is the largest investigation of follow-up issues in patients with STS to date, and the DCE best-worst scaling method allowed patients to express preferences for specific aspects of the STS follow-up strategy, thus identifying those with the greatest utility values. Patients perceived the nature of clinical investigations undertaken at follow-up appointments to be the most important aspect of overall post-surgical care and most expressed a preference for follow-up appointments routinely consisting of clinical examination and chest x-ray. As well as being acceptable to most patients, this form of follow-up investigation is clinically sound given that relapses occur most often in the lungs.

Although studies comparing the acceptability of GP vs. hospital clinic follow-up have been undertaken for other tumour types (such as breast cancer) and shown that GP follow-up was perceived favourably by patients [25], participants in this study expressed strong preferences for follow-up to remain in secondary care, as the greatest gain in utility between levels evident within a single attribute was the difference between GP follow-up and follow-up undertaken by a specialist hospital doctor. This may be because patients with STS often experience diagnostic delays within general practice [26] and as a consequence, may have less confidence in their GP facilitating long-term follow-up after completion of treatment. Furthermore, the rarity of soft tissue sarcoma and generally poor prognosis after treatment may be a factor in the observed strong patient preference for specialist follow-up and ongoing monitoring.

Follow-up for soft tissue sarcoma patients is necessary, yet time-consuming and resource-intensive and the lack of consensus about the optimal follow-up strategy has led to significant variation in clinical practice within and between countries. Follow-up is a question of balancing multiple objectives, including maximising patient survival, quality of life, psychological outcomes and physical function [27]. There is clearly some scope for tailored follow-up regimes developed on a case-by-case basis. This study has shown that whilst patient follow-up preferences were generally homogeneous, these preferences changed once the issue of recurrence risk was considered. The thresholds at which patient preferences for follow-up changed between the potential low, moderate and intensive regimes were extremely low: hypothetical local recurrence risks under 1% were associated with a preference for low intensity follow-up regimes, but incremental increases in recurrence risk prompted preferences for higher intensity strategies. Indeed, once the hypothetical risk of recurrence rose above 5%, the majority of patients stated that an intensive follow-up regime would be most acceptable.

Whilst it is encouraging that patient preferences for sarcoma follow-up do not appear to differ significantly from the follow-up regime typically offered by most treatment and surveillance centres, it is likely that the broad agreement between patient preference and the current routine follow-up regime is at least partly due to 'the lure of the familiar'. Thus, many patients prioritise aspects of follow-up scenarios that match their own current treatment most closely. This research was carried out in one centre only, and a larger scale survey may also have shown geographical differences in patient preferences. Nevertheless, our research highlights the need for a randomised study to determine the optimum strategy for follow-up of sarcoma patients with regard to the economic cost, psychological and functional impacts on the patient, the effectiveness of different types of imaging, and to establish whether more intensive follow-up regimes facilitate earlier detection of local recurrence or metastatic disease than less intensive regimes.

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ETHICAL APPROVAL

Ethical approval was obtained from NRES Committee North West – Greater Manchester West in March 2012 (Ref: 12/NW/0200), and R&D approval was given by The Royal Orthopaedic Hospital NHS Foundation Trust R&D department in April 2012 (Ref: ROH09ONCO2). All participating patients gave informed consent for their participation.

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ROLE OF THE FUNDING SOURCE

The study sponsor had no role in the study design, collection, analysis or interpretation of data in the writing of the manuscript, or in the decision to submit the manuscript for publication.

CONFLICT OF INTEREST STATEMENT

All authors state that they have no conflict of interest.

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FIGURE LEGENDS

Figure 1: Best-worst scaling attributes, levels and an example scenario

Figure 2: Participants choosing different follow-up schedules by risk of recurrence

Table 1: Participant clinical and sociodemographic characteristics

Variables	Categories	Number (%)
All participants		132 (100.0)
Clinical information		
Median size of tumour (Inter-quartile range)	8.0cm (5.0 to 12.0cm)	
Grade of primary tumour	High	62 (47.0)
	Intermediate	38 (28.8)
	Low	28 (21.2)
	Missing	4 (3.0)
Site of primary tumour	Head and neck	2 (1.5)
	Upper extremity	25 (18.9)
	Trunk	17 (12.9)
	Lower extremity	82 (62.1)
	Missing	6 (4.5)
Histological type	Fibromyxosarcoma	16 (12.1)
	Leiomyosarcoma	16 (12.1)
	Liposarcoma	24 (18.2)
	Malignant Peripheral Nerve Sheath Tumour (MPNST)	4 (3.0)
	Synovial sarcoma	12 (9.1)
	Others	60 (45.5)
Sociodemographic information		
Sex	Female	59 (44.7)
	Male	73 (55.3)
Median age at survey completion (inter-quartile range)	63 years (47 to 71)	
Median age at diagnosis (inter-quartile range)	57 years (43 to 67)	
Employment status	Permanently employed	33 (25.0)
	Part time employed	11 (8.3)
	Self employed	6 (4.5)
	Retired	69 (52.3)
	Unemployed	13 (9.8)
Education	No formal qualification	36 (27.3)
	GCSE/O-Levels	49 (37.1)
	A-Level	10 (7.6)
	University	22 (16.7)
	Postgraduate qualification	15 (11.4)
Median time from home to ROH (inter-quartile range)	60 minutes (45 to 90)	

Table 2: Frequency of level selection as the best or worst aspect of a follow-up scenario

Attributes and levels	Times selected as best	Times selected as worst	Best minus worst	Rank based on best	Rank based on worst	Rank based on best minus worst
Length of follow-up						
5 years	84	98	-14	6	7	5
10 years	86	113	-27	5	8	6
Life long	82	165	-83	7	11	9
Frequency of follow-up						
Once every 12 months	41	94	-53	9	6	8
Once every 6 months	44	90	-46	8	5	7
Once every 3 months	35	122	-87	10	10	11
Preferred clinical investigations						
Clinical examination only	175	49	126	3	4	3
Clinical examination and x-ray	237	11	226	**1=**	**1**	**1**
Clinical examination and intensive investigations	237	21	216	**1**	2	2
Healthcare provider						
General practitioner	19	251	-232	**12**	**12**	**12**
Specialist hospital nurse	33	119	-86	11	9	10
Specialist hospital doctor	97	37	60	4	3	4

Table 3: Conditional logistic regression of best-worst pairs for all respondents

Attributes and levels	Co-efficient	St. Error	P value	95% Confidence interval
Length of follow-up				
5 years	1.377	0.173	<0.0001	1.04 - 1.72
10 years	1.296	0.198	<0.0001	0.91 - 1.68
Life long	0.945	0.212	<0.0001	0.53 - 1.36
Frequency of follow-up				
Once every 12 months	1.142	0.130	<0.0001	0.89 - 1.40
Once every 6 months	1.206	0.152	<0.0001	0.91 - 1.50
Once every 3 months	0.969	0.159	<0.0001	0.66 - 1.28
Preferred clinical investigations				
Clinical examination only	1.823	0.167	<0.0001	1.49 - 2.15
Clinical examination and x-ray	2.503	0.171	<0.0001	2.17 - 2.84
Clinical examination + intensive investigations	2.443	0.197	<0.0001	2.06 - 2.83
Healthcare provider				
General practitioner	-	-	-	
Specialist hospital nurse	1.016	0.136	<0.0001	0.75 - 1.28
Specialist hospital doctor	1.890	0.175	<0.0001	1.55 - 2.23

Figure 1

Attributes	**Levels**	
Length of follow-up visits	• 5 years • 10 years • Lifelong	
Frequency of follow-up visits	• Every 12 months • Every 6 months • Every 3 months	
Preferred investigations to detect recurrence	• Clinical examination • Clinical examination and x-ray • Clinical examination and intensive investigation (ultrasound/MRI/CT scan)	
Choice of healthcare provider	• General practitioner • Specialist hospital nurse • Specialist hospital doctor	
EXAMPLE SCENARIO		
BEST THING		**WORST THING**
	Follow-up visits will continue for 5 years	
	Follow-up visits will take place every 3 months	
	Your follow-up visit will be carried out by a specialist hospital nurse	
	A clinical examination and intensive investigations (such as ultrasound, MRI, CT scan) will be undertaken during your follow-up visit	

Figure 2