

Patient Opinion of The North of England Bone and Soft Tissue Tumour Service

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1. Introduction

Sarcomas are a rare and diverse group of cancers thought to have a common embryological origin¹. Due to the rarity of these cancers patients are managed in specialist centres by experienced multidisciplinary teams. Service evaluation is playing an increasing role within the NHS and user involvement is seen as key to the planning, delivery and evaluation of cancer services. NICE has recommended that mechanisms should be in place to ensure that views of patients and carers should be considered in the evaluation of cancer services.² Patient satisfaction is a significant performance indicator and an important tool in assessing whether cancer services meet the needs of service users.

The Bone and Soft Tissue Tumour service gained recognition as a Specialist Sarcoma Centre in 2004. Subsequently, a service evaluation audit was carried out in 2005. Based on recommendations from this audit and the NICE guidelines for specialist cancer services, The Bone and Soft Tissue Tumour service have formed standards with auditable outcomes. This re-audit aims to evaluate the current service and compares the findings to the standards set. Where applicable the results are also compared to the previous audit.

2. Methods

Trust registration and ethical approval obtained.

Design – retrospective audit using a questionnaire (piloted on 5 patients) The questionnaire was based on four major themes identified from the current standards: face-to-face contact with healthcare professionals, knowledge of support services, access to the specialist nurse and hospital stay.

Setting – Bone and Soft Tissue Tumour Clinics, Musculoskeletal outpatients, Freeman Hospital

Subjects – all follow-up patients with a diagnosis of sarcoma. 45 patients were approached and all responded.

Time for data collection – 4 weeks

Outcome measures:

- Knowledge of support services
- Access to a specialist nurse
- Satisfaction with consultations and hospital stay rated on a five point Likert Scale
- Free text section to indicate comments and suggestions.

3. Results

- Of the 45 patients sampled, 28 were male and 17 were female. There was no noticeable difference in satisfaction reported by males or females.
- 100% of patients sampled reported receiving sufficient information about their diagnosis and service provided by the Bone and Soft Tissue Tumour Service.
- 100% of patients were 'satisfied' or 'very satisfied' with the explanations regarding investigations and results.

Fig. 1 Percentage of patients who had knowledge of support services



Fig. 2 Percentage patient satisfaction with hospital stay

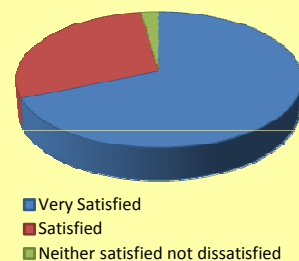
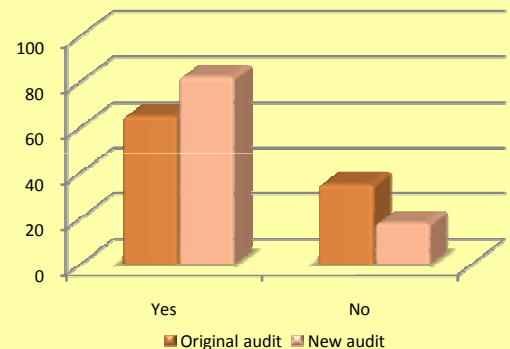


Fig. 3 Percentage of patients who had access to a specialist nurse.



4. Discussion

The results of this survey suggest that not all the standards set by the Bone and Soft Tissue Tumour Service are being met.

- Access to a specialist nurse improved with a 47% reduction in those not accessing a specialist nurse.[Fig. 3] But, 18% of patients did not see a specialist nurse. An increased demand on the specialist nurse service is a possibility. This is important as, of the people who accessed the specialist nurse (37/45) 100% felt the encounter to be 'useful' or 'very useful'. Additionally, access to a specialist nurse or key worker is one of the important outcomes for sarcoma centres as outlined by NICE.²
- Compared with the original audit, patient knowledge of support services seems to have decreased.[Fig.1] In particular, patient awareness about the helpline fell by 13%. The reasons for this are unclear, but it could be that patients are more reliant on the internet or alternative sources for additional information and reassurance about their condition.³
- In the other key themes of face-to-face contact with healthcare professionals and hospital stay, the Bone and Soft Tissue Tumour Service performs well.

5. Conclusion

- Patients report a high rate of satisfaction with the Bone and Soft Tissue Tumour Service. In particular, delivery of information (diagnosis, investigations and results) and hospital stay scored highly.
- It is necessary to explore the reasons for the differences in knowledge of support services and access to a specialist nurse in order to meet set standards and further improve the service.

6. Limitations

- Sample size – 45 patients is a small number and may not be fully representative.
- Patient recall – the questionnaire relied on patient recall. Due to the nature of follow up, the original diagnosis may have been ≥ 5 years ago. Patients may view things more positively in retrospect.
- Questionnaire bias – Often patients have attended multiple hospitals and seen different doctors as part of their treatment. This can lead to confusion with questions regarding consultations and referral.
- Patient loyalty – patients may feel 'disloyal' to their consultant if they rate any of the sections poorly
- The results apply to the service at the Freeman Hospital only and are therefore not generalisable.

7. Recommendations

If the following recommendations were implemented, it would be necessary to re-audit in one year to ascertain the benefit of these changes.

1. Variation in knowledge of support services among patients may be improved through the introduction of information packs. Empirical evidence has shown the benefit of information packs in cancer patients.⁴
2. Consider introducing another specialist nurse to the current service which may enable every patient to be allocated a key worker.
3. Consider recommending appropriate alternative materials (e.g. websites and books) to ensure patients remain well supported.

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References

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