




Hull and East Yorkshire Hospitals 
NHS Trust

EXECUTIVE SUMMARY OF MAIN FINDINGS

Oncology Health Service Audit June 2006

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1. BACKGROUND

In 1999, a unique Oncology Health Service was established in Kingston upon Hull. A description of the Service, together with the rationale, has been published by the House of Commons Select Committee on Palliative Care¹. Essentially, high levels of psychosocial and psychiatric morbidity have been widely reported in the United Kingdom and elsewhere in patients with cancer, as well as in their families². Work previously carried out in Aberdeen by the Director of the Oncology Health Service showed that much of this morbidity could be prevented by providing a service that was staffed by specially trained personnel and which was fully integrated physically, functionally and financially with other parts of oncology provision³. The model (now widely referred to as “the Hull Model”) has attracted considerable interest nationally and internationally.

A previous audit carried out soon after the Oncology Health Service began showed extremely high levels of satisfaction by patients, relatives and health care professionals in hospital and in the community⁴. In contrast to other services which are accessed predominately by middle class women with breast cancer, this audit showed that the sociodemographic characteristics of the users indicated that the service was used by men and women, with all types of cancers, from all sociodemographic backgrounds. Moreover, almost as many relatives as patients used the service. At the time this audit was carried out, the Centre at Castle Hill had not yet been opened.

The purpose of the present audit, therefore, was to obtain up-to-date information about the characteristics of service users, and to extend the previous audit by obtaining information about the reasons for attendance, levels of distress and quality of life of

¹ House of Commons Select Committee on Palliative Care. 2004. Appendix 17. Memorandum by Hull and East Yorkshire Hospitals NHS Trust (PC 19). (<http://www.publications.parliament.uk/pa/cm200304/cmselect/cmhealth/454/454we19.htm>)

² Zabora, J, Brintzenhofenszoc, K, Curbow, B, Hooker, C and Piantadosi, S (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10, 19-28.

³ Walker L G, Walker M B, Heys S D, Ogston K, Miller I, Hutcheon A W, Sarkar TK and Eremin O (1999). The psychological, clinical and pathological effects of relaxation training and imagery during primary chemotherapy. *British Journal of Cancer*, 80, 262-268.

⁴ Walker L G, Walker M B and Sharp D M (2003). The organisation of psychosocial support within palliative care. In M Lloyd Williams (Ed). *Psychosocial Issues in Palliative Care*. Oxford University Press, Oxford. ISBN 0-19-851540-5.

patients. In addition, the audit aimed to compare patients attending as “drop ins” (that is without being referred) with those who had been referred by a health care professional.

2. METHODOLOGY

(a) Permissions

Approval to carry out the audit was obtained from Hull and East Yorkshire Hospitals NHS Trust.

All participants gave written informed consent.

(b) Study design

This was a cross sectional study of all patients with cancer accessing the service during a consecutive 5-day period in June 2006. Although many relatives access the service and receive support and psychological interventions, they were not included in this audit.

(c) Materials

An audit booklet was constructed. This consisted of a series of questions designed to obtain reliable information about sociodemographics and clinical history. For patients who had been referred, there were questions about the referral process and reasons for referral. This part of the booklet was completed by a member of the Oncology Health Service staff in collaboration with the patient and with reference to case notes where appropriate. The booklet also included the Hospital Anxiety and Depression Scale which is a widely-used screening tool for psychiatric morbidity⁵ and a scale to measure satisfaction and quality of life⁶. These were completed and returned anonymously.

⁵ Zigmond A S and Snaith R P. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 1983, 67, 361-370.

⁶ Walker L G, Walker M B, Heys S D, Ogston K, Miller I, Hutcheon A W, Sarkar TK and Eremin O (1999). The psychological, clinical and pathological effects of relaxation training and imagery during primary chemotherapy. *British Journal of Cancer*, 80, 262-268.

Approval for reproducing these questionnaires was obtained from the relevant authorities.

Percentages throughout have been rounded to the nearest whole number. Between-group comparisons have been made using appropriate parametric and non-parametric statistics. Alpha was set at 0.05 (two-tailed).

3. MAIN FINDINGS

Participants

Excluding relatives, and relatives who were Oncology Health Service patients (i.e. they were receiving a psychological intervention), 145 patients accessed the Centres during this 5-day period and 135 of these gave written consent to participate in the audit. (Two patients were too ill to participate, one had learning difficulties and could not give valid consent, and four were unable to participate because of other commitments. Three patients declined to participate.)

Gender

Unlike previous studies which have reported that 70-80% of patients accessing support services in the UK are female, 56% of patient accessing the service were female and 44% were male.

Socio-demographics

The mean age of the patients was 61 years (median 62, range 31-90).

Seventy-four percent were married or cohabiting, and 14% were widowed.

Sixty-two percent had not had any tertiary education. Twenty-two percent had a university degree. Thirty percent were retired, 33% had a manual occupation, 14% had a clerical/administrative post, and 17 % had a professional occupation.

The Townsend Deprivation index⁷ (a measure of socio-economic deprivation) showed 66% of the patients came from the three most deprived quintiles (22% from the most deprived quintile).

Clinical History.

Twenty-two percent had breast cancer, 21% had colorectal cancer, 16% had lung cancer, and 8% had prostate cancer. Patients with the full range of cancer diagnoses attended.

Seventy-seven percent of patients were suffering from primary cancer. Fifty-one percent had undergone surgery for the current episode; 72% had received, or were receiving, chemotherapy; 38% had received, or were receiving, radiotherapy and 21% were receiving hormone therapy.

Type of Attendance

Sixty percent attended as “drop-ins”, 10% were seen as inpatients in one of the wards, and the remainder attended by appointment. In 13% of cases, this contact was their first contact. The median number of previous visits was 8; the mode was 3 and the range was 1 to over 100 attendances.

The majority of patients, 54%, were accompanied to the Centre. In almost all cases (97%) the person accompanying the patient was a relative.

Of those who had been referred, Hospital Clinical Nurse Specialists referred 26%, General Practitioners referred 13%, Surgical Oncologists referred 13%, Clinical and Medical Oncologists referred 11%, Ward nurses referred 8% and Community Clinical Nurse Specialists referred 5%.

Of those referred, 58% had been referred to a clinical psychologist and the remainder to a Clinical and Research Nurse Specialist (Behavioural Oncology).

⁷ The Townsend Index is based on postcode and takes into account home ownership, overcrowding, car ownership and employment status.

A clinical psychologist was involved in the management of 36% of all those attending, and a Clinical and Research Nurse Specialist (Behavioural Oncology) was involved with 70% .

Reasons for Attendance

The main reasons for referral stated in the referral documentation were anxiety (51%), depression (28%), existential concerns (28%) and to improve quality of life (26%).

For all patients (“drop-ins” plus referred patients), the main reasons for attendance identified by Oncology Health Service staff were anxiety (27%), adjustment reaction (23%), quality of life concerns (19%), depression (13%), concerns about the family (13%), social circumstances/welfare rights (12%), existential concerns (10%), procedural distress (2%) and suicide risk (2%) (percentages sum > 100 due to multiple concerns).

Thirty eight percent had been formally assessed using DSM IV criteria. Of these, 41% met the criteria for an anxiety disorder, 15% depression and 7% adjustment disorder and 2% acute confusional state (the remainder did not meet diagnostic criteria for any disorder).

Distress and Quality of Life

The mean score on the anxiety scale of the Hospital Anxiety and Depression Scale (HADS) was 7.95 (median 7, range 0-20). Using recognised criteria, 31% scored in the clinically significant range with a further 19% scoring in the “borderline” range.

The mean score for the HADS depression scale was 5.43 (median 5, range 0-18). Nine per cent scored in the clinically significant range with a further 20% scoring in the borderline range.

Current quality of life was assessed using a five point scale. Ratings were as follows: very poor – 2%, poor – 13%, neither good nor poor – 19%, good – 45%, and very good – 21%.

Comparison of referred patients and patients attending as “Drop ins”

Forty-eight percent of patients attending for an appointment compared to 22 % of those attending as “Drop ins” had clinically significant anxiety ($p < 0.001$). There was a similar, but insignificant trend for depression (14% and 9% respectively, $p = 0.08$).

Ninety-eight per cent of patients attending by appointment, compared to 93% of “Drop ins” were “very satisfied” with the service received from the Oncology Health Service.

Management

Many patients were managed in several different ways (hence the figures add up to more than 100%).

Forty-two per cent were advised to access the drop in, 59% were given supportive psychotherapy, 34% received relaxation therapy (with or without guided imagery), 25% were given cognitive-behavioural psychotherapy, 11% received psychotropic medication, 10% were given existential psychotherapy and 23% were “monitored”. In 2%, no further action was planned.

In 25% of cases, in addition a referral to another agency was arranged (including welfare rights officer (in-house), general practitioner, hospice, dietician, physiotherapist, district nurse, Macmillan nurse, palliative care team, social worker, lymphoedema nurse, medical or clinical oncologist).

Patient satisfaction with the Oncology Health Service.

One-hundred percent of the patients were satisfied with the service they had received from the Oncology Health Service (95% were “very satisfied” and 5% were “satisfied”) (To minimise dissimulation, these questionnaires were completed anonymously and put by the respondent in a sealed box).

4. CONCLUSIONS

Equity of use

The National Cancer Plan has emphasised the need for cancer services to be equitable. This audit has demonstrated a uniquely high level of equity of use in terms of sociodemographics and clinical characteristics. Previous reviews⁸ have found that only 23-29% of patients accessing support services are male whereas in this audit 44% were male. More generally, this audit has shown that the service is used by men and women, young and old, from all socioeconomic backgrounds, and with all types of cancer. The findings, therefore, provide further vindication for “the Hull Model”.

Psychological and psychiatric morbidity

Given that the Service aims to prevent psychological and morbidity, the ratio of clinically distressed to non-clinically distressed patients is appropriate. It is also appropriate that patients attending by appointment are significantly more distressed than those attending as “Drop-ins”.

Interventions

Patients are accessing the full range of services from welfare rights advice and self-help methods to improve quality of life on the one hand, to pharmacological interventions and highly specialised psychosocial interventions for clinically significant morbidity on the other hand.

Patient Satisfaction

All 135 respondents were “satisfied” or “very satisfied” with their treatment in the Oncology Health Centres.

5. FINAL COMMENT






⁸ Williams E R L, Ramirez A J, Richards M A, Young T, Maher E J, Boudioni M and Maguire P (2000). Are men missing from cancer information and support services? *Psycho-Oncology*, 9, 364.

In conclusion, this audit has confirmed the value of “the Hull Model” in meeting the psychosocial needs of patients with cancer receiving treatment within the National Health Service and within the framework set out in the National Cancer Plan.

6. APPROVALS

This report was discussed and approved by the Oncology Health Service Partnership Group (OHSPG)⁹ at a meeting on the 24th January, 2007.

⁹ The OHSPG is constituted as follows:

-  4 patients who use the service,
-  3 partners of patients,
-  3 clinicians who use the service (medical oncology, surgical oncology, nursing),
-  2 managers representing Hull and East Yorkshire Hospitals NHS Trust (Divisional Manager and Nurse Manager, Cancer and Diagnostic Services), and
-  3 members of the Oncology Health Service.