

# A pilot study exploring the effect of discharging cancer survivors from hospital follow-up on the workload of general practitioners

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## SUMMARY

**Background.** The tradition of routine, long-term follow-up of cancer patients in the outpatient clinic has led to busy clinics and long waiting times. Many cancer patients are anxious and have become dependent on the specialist clinic for reassurance. General practitioners (GPs) have been shown to be willing to assume greater responsibility for the routine follow-up of breast cancer patients, but patients have demonstrated a preference for hospital follow-up. If patients are discharged unwillingly, their rehabilitation may be at the cost of an increased demand on GP practices.

**Aim.** To determine the consequences for GPs of discharging long-term cancer patients from a hospital outpatient follow-up clinic.

**Method.** A consecutive sample of 65 patients under annual review in a hospital oncology clinic were offered a planned discharge in which their return to the clinic, if necessary, was guaranteed. The 41 patients who accepted discharge were monitored. Anxiety and depression rates were assessed using the Hospital Anxiety and Depression Scale (HADS) at the time of discharge and four months later at a home interview. The GPs of all patients who were discharged were sent questionnaires four and twelve months after discharge to evaluate consultation rates and change in psychological morbidity.

**Results.** The results showed no significant increase in the consultation rates during the 12 months after discharge compared with the previous 12 months. There was no significant change in the level of patients' anxiety or depression at four months after discharge. The great majority of GPs (71%) reported no change in their perception of patients' levels of anxiety or depression. GPs thought there was a need for more specialist Macmillan nurses working in the community and highlighted the importance of fast-track specialist referral.

**Conclusion.** Discharging this group of long-term cancer survivors did not increase the workload of GPs. However, GPs' concern over the lack of availability of Macmillan nurses in the community suggests that primary care services may find it difficult to cope adequately with the special requirements involved in cancer patient care. Finally, there is a need to address the further training requirements of GPs in the routine follow-up of cancer patients.

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## Introduction

DOUBTS about the value of routine hospital follow-up for cancer survivors have been expressed for many years.<sup>1,2</sup> A recent survey of United Kingdom (UK) oncologists has shown that only 15% of patients are discharged at five years and 43% at 10 years.<sup>3</sup> Traditionally, the main goal of systematic follow-up has been the early detection of recurrence, but research shows that routine follow-up confers little survival benefit,<sup>4,5</sup> even when intensive methods are used.<sup>6-9</sup>

General practitioners (GPs) have long regarded the re-attendance of many patients as unnecessary<sup>10</sup> and now wish to manage their patients' chronic health problems themselves.<sup>11</sup> A recent survey of the views of GPs showed that the majority were willing to assume greater responsibility for the follow-up of their patients with breast cancer, while acknowledging the need for further training.<sup>12</sup>

However, patients themselves appear to be firmly wedded to the system of regular clinical examination, which was rated the most important component of follow-up by patients,<sup>13</sup> and preferably based in the specialist outpatient clinic.<sup>14,15</sup> An audit of our own clinic found that, despite previous attempts to discharge long-term patients in remission, one fifth of the patients had attended the clinic for more than 10 years.<sup>16</sup> The difficulty of discharging long-term outpatients is well known<sup>17,18</sup> and more pronounced in cancer patients because of their fear of recurrence.<sup>19</sup> In this cancer unit, we have embarked upon a system of planned discharge for long-term cancer survivors, which guarantees their future return to the clinic if necessary.<sup>20</sup> The aim of this study was to evaluate the impact on GPs of patients' discharge from long-term outpatient care and to monitor any changes in patients' level of anxiety or depression during the initial months after discharge.

## Method

### Setting

Some 1500 patients attend the oncology clinic at Barnett general hospital each year, new referrals constituting approximately 10% of the total. Twice-weekly clinics are held, staffed by the consultant, a GP hospital practitioner, a Macmillan sister, and junior doctors.

### Participants

**General practitioners.** A total of 33 GPs participated, seven of whom had more than one patient discharged.

**Patients.** Any patient who had attended the oncology outpatient clinic for more than five years, who was well, free of recurrence, had no treatment morbidity, and had graduated to annual visits, was eligible. A consecutive sample of 65 patients (61 women and four men) was obtained. The unequal gender distribution reflects the fact that the great majority of long-term attenders are female patients with breast cancer. Of the total sample, 18

patients refused the planned discharge, six patients were considered unsuitable for discharge because of persisting treatment-related morbidity (e.g. lymphoedema), and 41 patients accepted the planned discharge. The majority (29 patients, 71%) were breast cancer patients. Five patients had cancer of the uterus/endometrium, three patients had ovarian cancer, and the remaining four patients had lymphoma (1), and cancer of the cervix (1), thyroid (1), and tongue (1). The diagnosis in those refusing discharge was not recorded but was broadly similar.

### Procedure

The GPs of all 41 patients discharged were sent an introductory letter describing the study. The GP questionnaire was sent four months after discharge and requested information on the patients' consultation rates in the 12-month period before discharge, evidence of any change in the patients' level of anxiety or depression, and the availability of counselling within the practice. An open-ended question invited comment on community oncology care in general. Twelve months after discharge, a second short questionnaire was sent to all GPs requesting information on the number of consultations in the 12-month period and whether any cancer-related problems had occurred. Copies of both questionnaires are available on request from the authors.

All patients considered suitable for discharge were interviewed in the clinic before their consultation and completed the Hospital Anxiety and Depression Scale (HADS).<sup>21</sup> Patients who accepted the discharge arrangements were interviewed at home four months later, where they completed a second HADS questionnaire.

### Results

An initial response rate of 88% to the four-month GP questionnaire was increased to 95% following the 12-month questionnaire after reminders were sent to the non-responders. Results were obtained for 39 discharged patients. No further information was obtainable about two patients: one patient was not known by the GP and one patient died within the year after discharge.

The change in the number of consultations in the 12-month period before and after discharge ranged from -7 to +15 with a median of +1. This slight increase in consultation rates in the year following patients' discharge was non-significant ( $P = 0.193$ , Wilcoxon signed rank test). The great majority (33/39 patients) had consulted with their GP at least once during the year after discharge. Figure 1 shows the number of consultations made by patients in the 12 months before and after discharge.

Of the five patients who consulted their GP more than 12 times in the 12-month period after discharge, one returned to the

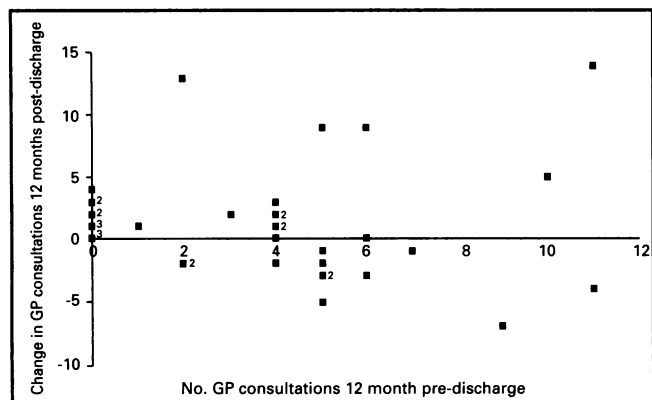


Figure 1. Change in frequency of GP consultations ( $n = 37$ ).

clinic with cancer-related morbidity. The consultation rates of the remaining four patients represented a considerable increase compared with rates in the 12 months before discharge, during which consultations jumped from two, five, six and 11, respectively. None of these consultations was for cancer-related problems, but one patient was perceived by her GP as being more anxious, one was reported by her GP to be in poor health, and the third opted to return to annual hospital follow-up because of anxiety that a recurrence would not be detected. The fourth, who consulted her GP more than 25 times during the year, did later return to hospital follow-up because of fears of recurrence. Interestingly, her initial HADS anxiety score was 15, the highest recorded in our patients and thus she was defined as a 'case' (> 11). Two of these five patients scored more than eight (possible case) on the initial HADS anxiety subscale.

The great majority of patients (71%) were perceived by their GP as having no change in anxiety or depression four months after discharge. A change was observed in two patients (one patient more anxious and one depressed). Of the remaining responses to this question, GPs reported not being aware of any change, either because the patient had not been seen by them since their discharge or because they did not know the patient well enough to assess change.

Analysis of HADS scores of the total sample at the time of possible discharge showed that 22% (9/41) of those accepting discharge had an anxiety score of 8 or more compared with 56% (10/18) of those refusing discharge. This was statistically significant ( $\chi^2 = 6.470$ ,  $df = 1$ ,  $P < 0.02$ ).

Comparison of the HADS scores of the 41 patients accepting discharge showed no significant differences in anxiety (Wilcoxon signed rank test,  $P = 0.47$ ; see Figure 2) or depression (Wilcoxon signed rank test,  $P = 0.25$ ; see Figure 3) between the time of discharge in the outpatient clinic and four months later at

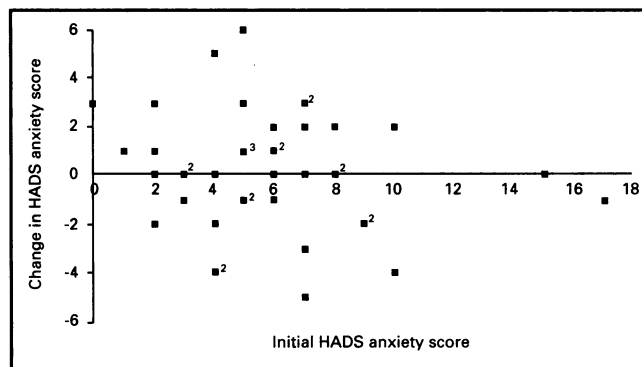


Figure 2. Change in anxiety four months after discharge ( $n = 40$ ).

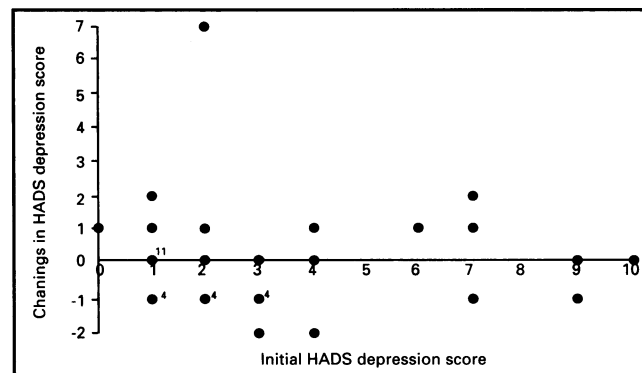


Figure 3. Change in depression four months after discharge ( $n = 40$ ).

the home visit.

The 18 responses to the invitation to comment on oncology care in the community showed two main concerns: the need for more Macmillan nurses in the community and the need for fast and easy access to specialist opinion.

Twelve months after the discharge of the last patient, a total of six patients had returned to the clinic. Two were referred by their GP, one with a new primary bronchogenic carcinoma and one with suspected recurrent breast cancer. Four were self-referred: two with (unfounded) fears of recurrence, one patient requesting a return to routine annual follow-up, and one wanting only a single consultation regarding hormone replacement therapy.

### Discussion

The results of this small study have shown that discharging a group of long-term cancer survivors did not increase the workload of GPs or lead to a significant increase in psychological morbidity at the end of 12 months of observation. It has been noted that a subgroup of patients have high anxiety scores and seem less likely to accept discharge. Of those who accepted discharge, there were some with high anxiety who did not do well. Further research is needed to find the best way to identify this group early in their treatment and to evaluate methods of helping them proactively, equipping them with survivorship skills to be less dependent on hospital follow-up.

The traditional system of routine follow-up in the outpatient clinic will change as a result of the new structure of the NHS driven by market forces.<sup>22</sup> This can be seen in a new NHS research and development programme focusing on the primary and secondary care interface, including the appropriateness of outpatient follow-up.<sup>23</sup> The NHS Executive has recently published guidelines to purchasers on the follow-up of breast cancer patients.<sup>24</sup> This highlights evidence of no benefit to patients in intensive follow-up and advocates a system of routine minimalist follow-up to be undertaken by GPs.

Cancer patients have special requirements, clinical and psychosocial; it may be possible to establish a system of shared care, the benefits of which have been demonstrated in some other specialties.<sup>18,25,26</sup> This might deal with GPs' concerns with the importance of easy access to specialist opinion and whether the psychosocial needs specific to cancer patients can be met currently in primary care.

This study only investigated the consequences for GPs of discharging cancer patients from outpatient follow-up; more research of primary care services is needed to evaluate the likelihood of their being able to withstand the impact of larger numbers of cancer patients requiring routine follow-up care in the community. Finally, we would agree with the recent document *Improving outcomes in breast cancer*.<sup>24</sup> There is a need to identify the further education and training needs of GPs in the special skills required for the routine care of these patients.

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