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PSYCHOLOGICAL DISTRESS AMONG CANCER PATIENTS AND INFORMED CONSENT

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Abstract—This study examines the relationships between satisfaction with information provided, understanding of consent procedures, and levels of anxiety/depression in a sample of patients undergoing radiotherapy for cancer. One hundred patients completed a 13-item self-report questionnaire and the Hospital Anxiety and Depression Scale (HADS). Twenty-two percent of patients could not recall signing a consent form and, for those who did recall, the level of understanding for what they had consented to was patchy. One fourth of patients could not recall being told of the side-effects from radiotherapy and were unable to list even common side-effects, such as tiredness, skin irritation, and sickness. No patient had been told about the low risk of second malignancy. Twenty-eight percent of patients were unhappy with the amount of information offered to them. Thirty percent of patients reached caseness for adjustment disorder +/- anxiety/depression. Thirteen percent of patients reached caseness for major depression. There was a significant correlation between patients who scored highly on the HADS and dissatisfaction with the information provided. Clinical implications and possible mechanisms of these findings are discussed. © 1999 Elsevier Science Inc.

Keywords: Cancer; Consent; Information; Psychological distress.

INTRODUCTION

There are increasing demands for patients with cancer to receive better information about their disease and its treatment as a requirement for obtaining informed consent [1, 2]. Communication about diagnosis, treatment, and consent has important implications for psychological adjustment [3–5]. The faculty of clinical oncology has set a number of quality assurance standards concerned with obtaining informed consent and provision of information adequate for this [6]. Doctors underestimate both the amount and sort of information patients want [7] and often overestimate how effective they have been in imparting accurate information to them [8]. Individual patients vary considerably in their preferences for information [9]. Most patients value honest information sharing and very few decline to have specific information about their diagnosis and treatment when offered [10]. A blanket policy of showering patients with standardized information could be unhelpful and even detrimental to some [11].

Legalistic considerations, essentially seeking release from liability, can become confused with the moral imperative to respect autonomy and facilitate the best deci-

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Table I.—Sociodemographic and clinical characteristics of 100 consecutive attenders to a radiotherapy clinic

	n
Male	30
Female	70
Living alone	21
Breast cancer	47
Other	53
Treatment with radical intent	72
Treatment with palliative intent	28
Prior chemotherapy	25

sion regarding treatment options [12]. The limited effectiveness of methods for helping patients to assimilate information leaves many dissatisfied with the process and at risk of poor psychological adjustment [13, 14]. Psychiatric morbidity among this patient population is high with between 25% and 33% of patients developing a general anxiety disorder, major depressive illness, or adjustment disorder within the first 2 years of diagnosis [15, 16]. Poor psychological adjustment has been shown to be related to the number of unresolved concerns that patients have regarding their illness [18].

METHOD

This study was a cross-sectional survey of consecutive attendees for radiotherapy at the Oncology Centre of the Royal Devon & Exeter NHS Trust.

For each attender, we obtained, from the notes, age, diagnosis, time from diagnosis, treatment intent (radical or palliative), and if prior chemotherapy had been given. Patients were asked if they lived alone or with a partner. All patients who agreed were interviewed by one of us (C.M., G.J., A.L.) and a 13-item questionnaire was completed covering understanding of the consent for treatment procedure and satisfaction with information given. In addition, each subject completed a Hospital Anxiety and Depression Scale (HADS) [17] four-point, 14-item self-assessment questionnaire, which has been found to be a reliable and valid method of measuring the severity of psychiatric morbidity in medical patients [18, 19]. For screening for adjustment disorders and major depression a total cut-off score of 13 was used. For screening for major depression alone a total cut-off score of 19 was used, based on the work of Razavi [29]. Current practice for obtaining informed consent was not evaluated. Each patient was seen by one of six consultant clinical oncologists and written consent was obtained. Each patient was then seen by a radiographer who showed them the planning and treatment area and reiterated common side-effects. As this was a naturalistic study no attempt was made to alter this practice.

RESULTS

Patient characteristics

One hundred and one patients were approached, and one patient declined to be interviewed.

The mean age of our study population was 58 years (SD 13.34 years, range 29–84). Sociodemographic and clinical characteristics of the sample are shown in Table I. Fifty percent of patients were interviewed within 4 months of diagnosis (range 2 weeks to 7 years).

Understanding of treatment and disease

Sixty percent (60 of 100) of patients received information leaflets. Only 29% (29 of 100) of patients felt the likely outcome if they declined treatment was discussed

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