PAPERS AND SHORT REPORTS

Psychological problems associated with diagnosis and treatment of lymphomas

I: Retrospective study

JENNIFER DEVLEN, PETER MAGUIRE, PATRICIA PHILLIPS, DEREK CROWTHER, HANNAH CHAMBERS

Abstract

Patients treated for Hodgkin's disease and non-Hodgkin's lymphoma have a better prognosis than other patients with cancer so may have a lower prevalence of psychological and social morbidity. Trained interviewers used standardised methods to assess 90 patients at a mean of 32 months after the diagnosis of Hodgkin's disease or non-Hodgkin's lymphoma. Chemotherapy and radiotherapy had commonly caused adverse effects including hair loss, vomiting, nausea, and loss of appetite. Although most patients were free of disease and not receiving treatment at follow up, some still suffered from a lack of energy (31 patients), loss of libido (19), irritability (22), and tiredness (19); 30 patients complained of continued impairment of thinking or disturbance of short term memory. After diagnosis 21 patients had suffered from an anxiety state or depressive illness, or both, while 27 had experienced borderline anxiety or depression, or both. Mood disturbance was positively correlated with adverse effects of treatment, particularly those affecting the gastrointestinal tract. Social adjustment was less affected, but failure to return to work, or a long delay in returning to work, and a persistent lack of interest in leisure activities gave cause for concern.

These findings of substantial psychiatric and social morbidity in patients with Hodgkin's disease and non-Hodgkin's lymphoma prompted a prospective study of these patients to determine their nature and duration.

University Department of Psychiatry, Withington Hospital, West Didsbury, Manchester M20 8LR

JENNIFER DEVLEN, PHD, research fellow
PETER MAGUIRE, FRCPSYCH, senior lecturer
PATRICIA PHILLIPS, SRN, RSCN, research nurse
HANNAH CHAMBERS, BSC, SRN, research nurse

University Department of Medical Oncology, Christie Hospital, West Didsbury, Manchester M20 9BX

DEREK CROWTHER, PHD, FRCP, professor

Correspondence to: Dr J Devlen, Department of Psychiatry, University of Manchester, Rawnsley Building, Manchester Royal Infirmary, Manchester M13 9WL.

Introduction

Most patients treated with radiotherapy and chemotherapy for Hodgkin's disease and many patients with non-Hodgkin's lymphoma can expect to survive for at least 10 years after diagnosis and may be cured.[1] Thus psychological and social morbidity ought to be lower than in patients with cancer with a poorer prognosis[2] or those whose treatment entails the loss of a crucial part or function of the body.[2-4] We conducted a retrospective study to determine if this was so.

Patients and methods

We studied 98 patients with Hodgkin's disease or non-Hodgkin's lymphoma who had consecutively attended a medical oncology clinic at the Christie Hospital during a period of six months for treatment and follow up. Patients were interviewed at home by a trained interviewer (JD or HC) using a semistructured approach. Each interview was recorded on audiotape to permit rating of data and checks of reliability. The toxicity of treatment and social and psychiatric morbidity were assessed.

Treatment toxicity—Patients were questioned in depth about their treatments and any side effects they had experienced. Scales were developed to rate 13 key side effects—for example, for vomiting 0=no vomiting experienced; 1=mild vomiting (one to five episodes a day for one or two days); 2=moderate (six to 10 episodes a day for one or two days or one to five episodes a day for three or more days); 3=severe (more than 10 episodes a day or six to 10 episodes a day for at least three days). A total adverse effect score for each patient was calculated by summing these 13 separate scores (maximum score=38).

Social morbidity—A shortened version of the standardised social interview schedule was used to assess patients' occupational or housework role, leisure activities, social contacts, domestic interactions, marriage, and family life.[5] Ratings were made for three time periods: before diagnosis, between diagnosis and the month before interview, and the month before interview.

Psychiatric morbidity—An abbreviated version of the present state

examination was used to assess if symptoms of anxiety and depression had occurred within the month before interview.[6] Then the patient was requestioned about each symptom to determine whether it had been present between diagnosis and the month before interview and, if so, its severity and duration. A depressive illness was diagnosed if depressed mood was present and accompanied by four or more of the following symptoms: hopelessness, social withdrawal, self depreciation, lack of self confidence, loss of appetite, early waking or delayed sleep, anergia, loss of libido, and irritability. Borderline depression was diagnosed if depressed mood was accompanied by fewer than four of these symptoms. An anxiety state was diagnosed if nervous tension was present and accompanied by four or more of the following symptoms: muscular tension, irritability, restlessness or fidgeting, tiredness, lack of concentration, early waking or delayed sleep, anxiety, loss of interest, inefficient thinking, tension pains, neglect due to brooding, and anxious foreboding. Nervous tension accompanied by fewer than four other symptoms of anxiety was rated as borderline. All data from the present state examination were rated by one interviewer (JD), and 10 audiotapes were randomly selected for independent rating by a second trained rater. Kappa coefficients were calculated for each item.[7] The mean value of kappa was 0·81 (SD=0·19), indicating high reliability.[8]

Results

Of the 98 patients recruited, one died; five were not able to be interviewed, and two patients were excluded because the tape recorder failed. The final sample therefore comprised 90 patients, and none refused. The sample was representative of all patients entered into clinical trials for treatment of these diseases over the previous five years. There were 47 men and 43 women (mean age 44·4 (SD 17·6) years, range 17-73 years). The mean time from diagnosis to interview was 2·7 years (range 6 months to 6 years, median 2·2 years).

Treatment toxicity—Table I shows the severity of each side effect experienced by the patients, who were treated with radiotherapy or chemotherapy, or both. Symptoms persisting at follow up were a lack of energy (31 patients), loss of libido (19 of the 77 patients who had had an active sex life before their illness), irritability (22 patients), and tiredness (19 patients). Thirty patients also complained that their thinking or short term memory was impaired.

Psychiatric morbidity—Table II shows the results obtained with the present state examination. Over the whole assessment period 21 patients suffered from an anxiety state or depressive illness, or both, and a further 27 experienced borderline anxiety or depression, or both. Depression and anxiety correlated positively with total toxicity scores (for depression Kendall's $\tau=0{\cdot}324$, $p<0{\cdot}001$; for anxiety Kendall's $\tau=0{\cdot}204$, $p<0{\cdot}01$) and with adverse effects affecting the gastrointestinal tract, particularly nausea, vomiting, diarrhoea, loss of appetite, and sore mouth.

Social morbidity—The extent to which patients participated in their usual leisure activities declined substantially from the period before they became ill to follow up, and patients expressed considerable dissatisfaction about this (table III). Eight of the 66 patients in regular employment before they became ill stayed off work for longer than a year despite a good physical recovery, and 17 patients gave up their jobs.

TABLE I—*Ratings of adverse effects of treatment experienced by 90 patients*

	None	Mild	Moderate	Severe
Hair loss	15	24	14	37
Nausea	28	26	17	19
Vomiting	34	11	10	35
Sore mouth	51	13	21	5
Change in perception of taste	57	21	12	
Sore skin	68	19	3	
Loss of appetite	39	19	13	19
Pain	68		22	
Constipation	59	22	8	1
Peripheral neuropathy	48	28	14	
Increased appetite	60	19	11	
Conditioned response	82	4	4	
Diarrhoea	74	5	10	1

TABLE II—*Psychiatric morbidity in 90 patients after diagnosis of Hodgkin's disease or non-Hodgkin's lymphoma and one month before interview. Values are numbers of patients*

Psychiatric morbidity*	After diagnosis†	One month before interview‡
Depressive illness	17	1
Borderline depression	24	5
Anxiety state	11	2
Borderline anxiety	9	7

*Patients with combined depressive illness and anxiety state are included twice—that is, under depression and under anxiety; the same applies for patients with both borderline illnesses.
†Eight patients had both depressive illness and anxiety state and five both borderline depression and anxiety; two patients had depressive illness with borderline anxiety.
‡One patient had both depressive illness and anxiety state and one both borderline depression and anxiety.

TABLE III—*Extent of and satisfaction with leisure activities of 90 patients before and after diagnosis of Hodgkin's disease or non-Hodgkin's lymphoma and at interview. Values are numbers of patients*

	Before diagnosis	After diagnosis	At interview
	Extent of leisure activities		
Adequate	79	59	64
Less than adequate	8	21	18
Moderately inadequate	3	7	7
Very inadequate		3	1
	Satisfaction with leisure activities		
Reasonably satisfied	86	63	69
Minor dissatisfaction	3	22	17
Marked dissatisfaction	1	2	2
Severe dissatisfaction		3	2

Discussion

Our study was retrospective and possibly subject to errors of recall. The low incidence of conditioned response compared with the findings of Morrow *et al*[9] suggests that patients may have forgotten these effects with time. Thus our findings are probably an underestimate of the true impact of treatment for Hodgkin's disease and non-Hodgkin's lymphoma; even so, adverse effects of treatment were common and similar to those reported previously.[10]

Psychiatric morbidity was three to five times higher than that found in subjects in the community.[11,12] Although social morbidity was low, we were concerned that a substantial proportion of patients delayed returning to work or failed to do so even though they were free of disease, had stopped receiving treatment, and were free of anxiety or depression. We were also concerned about the substantial proportion who had persistent symptoms and complained of memory impairment. We therefore conducted a prospective study to determine the exact nature, timing, and duration of these adverse psychological and social sequelae.

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