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Original Paper

Socio-medical Situation for Long-term Survivors of Hodgkin's Disease: a Survey of 459 Patients Treated at One Institution

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We present the socio-medical situation for 459 adult disease-free long-term survivors of Hodgkin's disease (HD) 3–23 years after first line curative treatment. In 1994, 557 patients were sent a self-report questionnaire relating to their social status and 459 patients (82%) replied. Educational or professional plans were changed due to HD in 142 patients (32%). After 6, 12 and 18 months from start of treatment, 52, 82 and 95% of the patients, respectively, had returned to their job or education. The sum of full-time and part-time employment was in men 78% at diagnosis and 85% at follow-up, and in women 57% at diagnosis and 64% at follow-up. Only 2% of men and 3% of women did not have a job at follow-up in 1994. At diagnosis 2% of the patients were permanently disabled versus 19% at follow-up in 1994. Age >40 years at diagnosis, increased the total score of psychological distress and fatigue and long-term disablement after first line treatment were predictors for permanent disablement. Transient or permanent sexual problems were reported in 16% and 13%, respectively. MVPP (mustine, vinblastine, procarbazine and prednisone) or LVPP (chlorambucil, vinblastine, procarbazine and prednisone) chemotherapy was responsible for most cases of early menopause in women older than 30 years, and of infertility in both men and women. In summary, most long-term HD survivors had adapted well to their socio-medical situation except a high number of permanently disabled patients. By focusing more on factors predisposing for permanent disablement and early treatment for these, more patients may be helped to return to their job.

Key words: Hodgkin's disease, employment problems, family problems, fertility
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INTRODUCTION

HODGKIN'S DISEASE (HD) often affects young people. Long-term disease-free survival has increased considerably during the last 30 years, especially in young patients [1–3]. Nevertheless, follow-up studies of successfully treated patients have shown that this therapeutic success has costs; it is accompanied by a wide range of physical, psychological and social problems [4–18]. These problems have an influence upon functioning and the feeling of well-being. Long-term quality of life in HD patients has been addressed in only a few studies from the U.S.A. [4, 11] and Europe [12–15]. Most work-related problems reported in long-term survivors of HD are health-related limitations in the types of work that they could do, as well as poorer performance [4, 6, 11, 12, 15]. In most studies, the percentage of employed individuals is comparable to that among healthy controls, but more survivors than controls worked part-time due to health problems. Late sexual problems of HD and its treatment include decreased interest in sex, decreased levels of sexual activity, increased incidence of ejaculatory dysfunction [4, 12] and fertility problems [4, 12, 19–24]. More frequent separations and divorces in long-term survivors of HD are reported in some studies [4, 25], and less frequent in another study [12].

Most psychosocial studies in HD are based on selected or small samples. In Norway, the treatment of adult HD patients in the whole of Norway was centralised to The Norwegian Radium Hospital (NRH). Since 1985, patients from the Eastern and Southern parts of Norway have still been treated at NRH. The high number of unselected patients treated according to standardised protocols at one institution with close follow-up for many years yields an excellent sample

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for long-term follow-up studies. We have previously presented medical problems [9], psychological distress [17] and fatigue [18] in long-term survivors after HD. In this study, we present the influence of HD on education, employment, fertility and family life of the same patient population.

PATIENTS AND METHODS

HD survivors

This study comprised 557 consecutive adult patients between the age of 15 and 61 years when admitted to the NRH during 1971–1991 and still alive in complete remission at the age of 74 years or younger by the end of 1993. All clinical data on disease and treatment characteristics are based on the hospital records. The biopsies were classified according to the Rye nomenclature [26]. Staging was performed according to the Ann Arbor nomenclature for clinical staging [27]. In this study a self-administered questionnaire was used. This method offers the opportunity to examine many patients and gives the participants sufficient time to recall problems. We used a self-constructed questionnaire (Appendix) regarding the sociomedical situation because we, at the time, did not find other satisfactory questionnaires covering these problems. The questionnaire was mailed in 1994 to all 557 patients. Non-compliers received one reminder. The present study comprised 459 HD patients who had replied to the questionnaire (compliance rate 82%). 56 patients had relapsed after first line treatment and were relapse-free in 1993 after second line treatment. The observation time is the time from start of first line treatment to the date of follow-up in 1994.

Late medical somatic sequelae [9], psychological distress [17] and fatigue [18] in the population are presented separately.

General population controls

3,297 Norwegian citizens aged 19–74 years were randomly drawn from The National Register of Citizens by the Norwegian Government Computer Centre, representative for the entire Norwegian population [28]. 2,214 subjects (compliance rate 67%) responded on a self-report questionnaire including items of family life. The responders did not differ in age from the non-responders. Mean age was 43 years. Non-responders had received one written reminder.

Treatment

Before 1980, stage I and II patients with supradiaphragmatic disease received mantle field irradiation only, or combined with irradiation of infradiaphragmatic lymph nodes [29]. Patients with infradiaphragmatic stage I and II received inverted Y-field. Stage III patients received total nodal irradiation and stage IV patients received six to eight cycles of combination chemotherapy.

Since 1980, stage I and II patients with risk factors for relapse: B-symptoms, subdiaphragmatic disease, bulky tumour, histological lymphocyte depleted type or four or more sites involved, received four cycles of combination chemotherapy before irradiation to mantle or inverted Y-field. Stage I and II patients without risk factors received mantle field irradiation only. After 1980, stage III and IV patients received eight cycles of combination chemotherapy and involved field irradiation to bulky mass or residual disease. Combination chemotherapy was administered as MVPP [30] (mustine, vinblastine, procarbazine and prednisone), LVPP [31] (chlorambucil, vinblastine, procarbazine and prednisone), ABOD [32] (doxorubicin, bleomycin, vincristine and dacarbazine), alternating LVPP/ABOD [33], and EBVP [34] (epirubicin, bleomycin, vinblastine and prednisone). Mantle field and inverted Y-field irradiation was given in 20 fractions of 2 Gy 5 days a week to a total dose of 40 Gy before 1985, and after 1985 as 23 fractions of 1.8 Gy 5 days a week to a total dose of 41.4 Gy.

Statistics

The data were analysed using the SPSS for Windows version 6.1 software (SPSS Inc., Illinois, U.S.A.). Statistical procedures included chi-square statistics and two-sided *t* tests (independent samples). The level of significance was set at $P \leqslant 0.05$.

RESULTS

Patient characteristics

The characteristics of the 459 respondents are shown in Table 1. The mean age at time of diagnosis was 32 years and at follow-up was 44 years. There were no statistically significant differences between compliers and non-compliers in relation to age, sex, disease stage, type of treatment or time since diagnosis.

Professional plans and career

446 patients (97%) answered the questions covering whether their education or professional plans or career had changed because of HD. 142 (32%) answered yes, 239 (54%) answered no, and 65 (15%) were in doubt. Of the 142 patients who had changed educational or professional plans and career, 13 (9%) had lost their job and had problems getting a new job, 41 (29%) were permanently disabled, 63 (44%) reported less ambition for education or job and 24 (17%) had more ambition for education after HD, preferring high school or university studies.

Prolonged disability after first line treatment predicted a change to professional plans ($P = 0.002$). Forty-six per cent of patients who were disabled for more than 12 months had their career changed versus 18% of patients disabled for less

Table 1. *Patient characteristics* (n = 459)

	No.	%
Mean age		
At time of diagnosis:	32 years (range 15–60 years)	
At time of follow-up:	44 years (range 19–74 years)	
Sex		
Female	204	44
Male	255	56
Stage		
I and II	278	61
III and IV	181	39
Primary treatment		
Irradiation only	174	38
Chemotherapy only	65	14
Chemotherapy and irradiation	218	48
Surgery only	2	< 1
Observation time (years)		
3–6	89	19
7–10	101	22
11–14	108	24
15–23	161	35

than 6 months. Age at diagnosis, educational level or employment status were not predictors of changed educational or professional plans.

Length of disability after first line treatment

After the start of first line treatment, 239 patients (52%) had returned to their education or job after 6 months, 376 patients (82%) after 12 months and 436 (95%) after 18 months. Factors predisposing for being disabled over a period longer than 12 months were age more than 40 years at diagnosis ($P = 0.04$), full-time employment at diagnosis ($P < 0.001$), stage III and IV disease ($P = 0.007$), combined chemotherapy and radiotherapy ($P < 0.001$) and high total scores of depression ($P < 0.001$), of anxiety ($P = 0.05$) and of fatigue ($P = 0.05$).

Employment

Employment status at diagnosis and at follow-up in 1994 is shown in Figure 1. At diagnosis 193 men (76%) and 75 women (37%) were employed full-time, and at follow-up in 1994, 176 men (69%) and 70 women (34%) were in full-time employment. 7 men (3%) and 42 women (21%) were employed part-time at diagnosis and this number increased to 42 men (16%) and 61 women (30%) at follow-up in 1994. The number of women who were housewives decreased from 45 (22%) at diagnosis to 34 (17%) at follow-up. 231 patients (50%) had the same job at diagnosis and at follow-up.

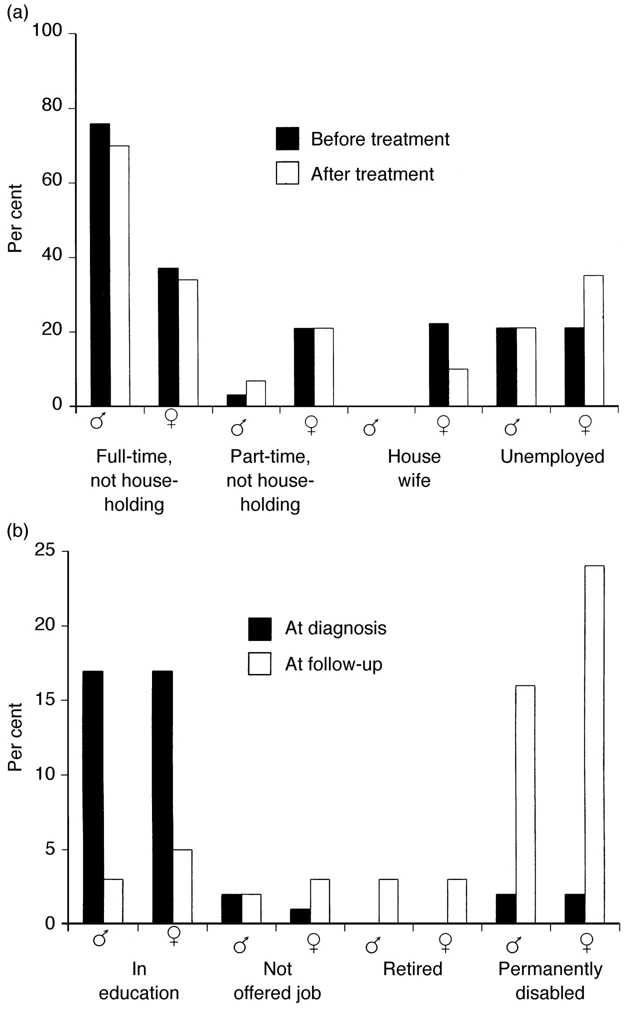

Figure 1. (a) Employment status of 459 Hodgkin's disease (HD) patients at diagnosis and at follow-up in 1994. (b) Reasons for not being employed for 459 HD patients at diagnosis and at follow-up in 1994.

54 men (21%) and 42 women (21%) were unemployed at diagnosis versus 61 men (24%) and 71 women (35%) at follow-up in 1994. The main reasons for not being employed are shown in Figure 1(b). A high percentage of the patients (17% of men and women) were students at diagnosis, versus 3 and 5%, respectively, at follow-up. The high percentage of patients who were students at diagnosis is due to the high proportion of young patients; 47% of the patients were between 15 and 29 years at diagnosis versus 11% in the same age group at follow-up in 1994. Two per cent of men and 1% of women had no job at diagnosis versus 2% of men and 3% of women at follow-up in 1994.

4 men (2%) and 5 women (2%) were permanently disabled at diagnosis versus 40 men (16%) and 48 women (24%) at follow-up. A total of 88 men and women (19%) were permanently disabled at follow-up in 1994 versus 10% in the general population in Norway aged 20–80 years [35]. 48 patients (10%) received 100% disability pension, 21 patients (5%) received 50% disability pension and 19 patients (4%) received temporary disability pension, most of them waiting for a permanent disability pension. In addition, 13 patients (3%) were retired at follow-up in 1994. Age more than 40 years at diagnosis was a strong predictor for permanent disability ($P < 0.001$). Thus, 39% of the patients aged more than 40 years at diagnosis were permanently disabled in 1994 versus only 4% of patients aged 15–29 years and 16% aged 30–39 years at diagnosis. Other factors predisposing for being permanently disabled were low educational status ($P < 0.001$), full-time employment at diagnosis ($P = 0.002$), combined treatment with chemotherapy/radiotherapy ($P = 0.005$), high total scores on depression ($P < 0.001$), anxiety ($P < 0.001$) and fatigue ($P < 0.001$). Patients who had exertional dyspnoea and pains and stiffness in the neck and shoulders after mantle field irradiation, had increased frequency of permanent disability ($P = 0.002$). In a study presented separately [36–38] of lung function and echocardiography in 116 patients age 15–49 years 5–13 years after mantle field irradiation, more than half the patients had cardiac or pulmonary sequelae, and in one third of them both organs were affected. Patients with both cardiac and pulmonary sequelae demonstrated a larger degree of physical dysfunction than the other patients, and nearly 30% of them received disability pension. When we asked all the patients who received disability pension for the reason why they were permanently disabled, 9% answered that they were suffering from chronic sequelae after HD and treatment, and 9% answered that they were suffering from other diseases not related to HD.

Sexual problems

Of 439 patients who answered the question on whether the disease and treatment had changed their sexual interest and activity, 72 patients (16%) had transient and 57 patients (12%) long-term sexual problems. Of the 42 patients who reported on the kind of sexual problems, 20 patients (48%) felt less interest in sexual activity, 13 women (31%) had symptoms of menopause, and 7 male patients (17%) had erection problems.

Table 2. Marital status at follow-up in 1994 of 459 Hodgkin's disease (HD) patients (mean age 44 years) and of 2,214 control persons (mean age 44 years)

	HD patients		Controls	
	n	%	*n*	%
Unmarried	73	16	466	21
Married or living as married	330	72	1,551	70
Divorced or separated	43	9	113	6
Widowed	13	3	77	3

Fertility

Women. Of 187 women who were menstruating at diagnosis, 164 (88%) had regular menstruation. After treatment, 145 were menstruating, and 90 women (62%) had regular menstruation. All women whose age was less than 30 years at diagnosis were menstruating after treatment. After age 30 years, the percentage of amenorrhoic women increased with increasing age. Of 69 women who had lost their menstruation cycle after treatment, 56 (81%) had received combination chemotherapy containing an alkylating agent and procarbazine and 8 patients (12%) had received inverted Y-field irradiation. Thus, 93% of women who had permanently lost their menstruation after treatment, had received treatment known to induce ovarian failure. Of 18 women (9%) less than 40 years of age who wished but did not succeed in being pregnant, 12 (67%) had received chemotherapy containing an alkylating agent and procarbazine, and 1 woman had received inverted Y-field irradiation. Thus, 72% of the infertile women had received treatment known to reduce fertility.

Men. 52 men (20%) had tried but not succeeded in fathering children. Of these, 36 (69%) had received chemotherapy containing an alkylating agent and procarbazine and 8 men (15%) had received inverted Y-field irradiation. Thus, 84% of men who did not succeed in fathering children had received treatment known to reduce fertility. 37 men had cryopreserved their semen before the start of chemotherapy, and in 7 cases a child was fathered.

Family life

Family status at follow-up of the patients in 1994 and of the controls selected in 1996 is shown in Table 2. HD patients differed from controls with a lower incidence of unmarried persons and a higher incidence of divorce and separation. The differences were significant for men aged 30–39 years ($P=0.001$) and for women aged 40–49 years ($P=0.02$).

DISCUSSION

We have previously published studies of medical problems [9], psychological distress [17] and fatigue [18] in long-term survivors after HD. In this study we studied the medicosocial situation for the same population. The main findings in this study were that one third of the patients had changed their professional plans due to HD, that most patients had returned to former jobs or studies after 12 months from the start of treatment, and that the number of patients who were permanently disabled at follow-up in 1994 was twice the number in a control population. The family status was in most patients not influenced by the disease.

In one third of patients the disease had influenced their choices with regard to education and/or professional career. Limitations of physical and role functioning were the main reasons for reducing professional ambition, whereas in a minority of patients the disease had inspired them to more ambitious plans. In general, many patients reported that the disease had taught them to give priority to family and friends and to enjoy life. In a study from Stanford [4], 81% of the employed cases had work ambition unchanged or greater than before treatment for HD, and 19% were less ambitious. A French population-based case–control study of 93 patients reported results in agreement with our findings [15].

Most of the patients had returned to their former jobs or education 12 months after the start of first line treatment. At the time of follow-up in 1994, 19% were permanently disabled, which is twice the frequency of the general population in Norway. Half the permanently disabled patients claimed that HD and problems after treatment were the major reasons, whereas the other half stated that other diseases not related to HD were the reason. In Norway severely and permanently disabled persons receive a disability pension. The low percentage of patients without a job and the high percentage of patients permanently disabled at follow-up differ from other studies of employment status in long-term survivors of HD [4, 11, 12, 15]. It may partly be due to the possibility in Norway of receiving a disability pension, especially older patients, and partly to the high employment rate in Norway. It has to be emphasised that most of the permanently disabled patients with disability pension were more than 40 years old at diagnosis. Others have also suggested that return to work following a disabling illness is less related to the illness than to having alternative resources for financial support [39].

Employment status was, for most patients, unchanged from diagnosis to follow-up in 1994. Half the patients had the same job at diagnosis and at follow-up. Only 2% of men and 3% of women did not have a job at follow-up in 1994. Studies focusing on employment status after HD [4, 11, 12, 15] have shown that the percentage of employed persons is similar or lower as compared with our data.

Sexual problems after HD were apparent for more than 28% of the patients, although in many cases they were of transient nature. However, long-term sexual problems were not uncommon in a substantial number of patients. The frequency of sexual problems in our study compares well with other studies (19-24).

Infertility after HD is in most cases due to gonadal failure after treatment with combination chemotherapy including an alkylating agent and procarbazine [19–24]. We noticed that 81% of the women and 69% of the men who were infertile had received this type of chemotherapy. A high percentage of women older than 30 years lost menstruation after chemotherapy. Children and young adults are more resistant to gonadal damage after combination chemotherapy than adults above 30 years of age [19, 22].

Medical, psychological and social problems coupled with infertility, may have a negative influence on family life and marital relationships. As stated by Fobair and colleagues [4], marital distress is common, especially during the treatment period and immediately after treatment. At follow-up in 1994 we observed only a small increase in the number of separated or divorced persons compared with the general population. Other studies [4, 25] have reported more frequent separations and divorces in long-term survivors of HD. In contrast, Joly and associates [15] observed no difference in marital status among HD survivors as compared with controls in a case–control study.

An important finding in this study was the high incidence of permanently disabled patients, and the close correlation with older age, anxiety, depression and fatigue. The implications of these observations may be to increase staff sensibility for these problems. At the start of first treatment the patients should be informed of the most common problems which long-term HD survivors may have to face, and how to cope with them.

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APPENDIX
THE SELF-REPORT QUESTIONNAIRE REGARDING THE SOCIO-MEDICAL SITUATION

1. Have your education or professional plans or career been changed because of Hodgkin's disease?
   Yes: No: In doubt:
   If yes, in what way?
2. Have priorities in your life been influenced by Hodgkin's disease?
   In what way?
3. Disability during first line treatment
   Full-time disabled, months:
   Part-time disabled, months:
4. Have you been disabled for diseases related to Hodgkin's disease or its treatment after first line treatment?
5. If you are permanently disabled, which disease was the reason for receiving disability pension?
6. Education. At diagnosis At follow-up
   7 years or less
   8–10 years
   11–12 years
   13 years or more
   University studies
7. Employment status At diagnosis At follow-up
   Full-time employed (not housewife)
   Part-time employed (not housewife)
   Full-time housewife
   Part-time housewife
   Unemployed

8. Reasons for not being employed At diagnosis At follow-up
   Not offered a job
   In education
   Retired
   Short-time disabled
   Transitory disability pension
   Permanent disability pension
   Other reasons specified
9. Describe your profession
   At diagnosis: At follow-up:
10. Have your sexual interest and activity been reduced after Hodgkin's disease?
    Transient: Permanent: Not changed:
    In what way has Hodgkin's disease influenced your sex life?
11. For women;
    Menstruation before Hodgkin's disease: Regular: Irregular:
    Menstruation after treatment: Regular: Irregular:
    Were you permanently amenorrhoic before treatment?
    After treatment?
    In which year started menopausal symptoms?
    Have you tried to be pregnant and not succeeded?
    Has a physician been consulted?
    Was the reason for not being pregnant related to the treatment for Hodgkin's disease?
    Other reasons?
12. For men:
    Did you have semen cryopreserved before treatment?
    Is the cryopreserved semen used for insemination?
    If used, was a child fathered?
13. For men and women;
    Your marital status: At diagnosis At follow-up
    Unmarried
    Married
    Living as married
    Separated
    Divorced
    Widowed

In the original questionnaire each question had a short explanation and comment to help the patient to answer.