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Problems at Social Re-integration of Long-term Cancer Survivors

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To assess the long-term consequences of cancer for everyday life, a postal survey in the Netherlands was done among 849 ex-cancer patients. Almost all responders were self-supporting to a large extent. Compared with the period before diagnosis, the socioeconomic position had not changed in 62%. 28% of the responders who were employed at the time of diagnosis (10% of all responders), were now housekeepers (99% female). Absence from work at survey did not differ significantly from absence in the year before diagnosis. A history of cancer tended to have a negative impact on promotional prospects and income. Ex-cancer patients were often confronted with problems when they tried to take out insurance or to modify an existing policy. The psychological well-being of the responders was low, compared to the average Dutch population.

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INTRODUCTION

IN PAST decades, the major emphasis in care of the cancer patient was directed at earlier diagnosis and refinement of treatment. The goal was to increase the quantity of life [1]. The number of cancer and ex-cancer patients is expected to increase in the future, in part because of the increased longevity of our population and the higher rates of cancer in the older population and in part because of advances made in diagnosis and treatment [2]. Cancer, primarily a chronic disease state, affects a person as a whole and restricts his or her somatic and psychosocial performance [3]. Most cancer patients are in their middle years, the period of greatest productivity and greatest family, social and community responsibility [4]. Work, leisure activities and social relationships are several of the many dimensions that determine a person's quality of life [5]. Increasing numbers of patients who have been treated for cancer are, given their medical state, able to return to society and to their duties [6, 7]. In many cases, "cured" cancer patients cannot easily re-adapt to

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society, although from a medical point of view their disease is under control. To help these patients to re-adapt, exploration of the psychosocial problems that the well motivated "cured" cancer patient may encounter—for instance when he or she tries to secure a good position in society—is required [7–17].

The first step in understanding the problems of long-term survivors is listing the nature and extent of the problems that arise [5]. We are especially interested in the following: (1) to what degree do impediments occur in everyday activities; (2) what, if any, problems exist when a patient returns to a previous job or tries to obtain a new job; and (3) what insurance problems are there?

Many studies on psychosocial problems of cancer survivors have focused on specific tumour groups [14–16, 18] or have been restricted to the first years after treatment [13, 18]. The subject has been reviewed by Tross and Holland [17].

PATIENTS AND METHODS

In 1987 a postal survey was done among 849 ex-cancer patients of the regional cancer centre for the south-west Netherlands (over two million inhabitants), as part of the tenth anniversary of the Comprehensive Cancer Centre Rotterdam. The characteristics of this population and their psychosocial problems, which are possibly related to their cancer or its treatment, were surveyed. The ex-cancer patients had to meet the following four conditions: (1) the cancer was diagnosed in 1978–1980; (2) the treatment and post-treatment check-ups all took place in the cancer centre; (3) the patient was alive and no relapse had been demonstrated for at least 5 years; and (4) at the time of diagnosis, the patient was under 60. The first and third condition together form the concept "cured of cancer". The fourth condition is added to avoid distortion of the results by the effects of ageing (retirement). Data on histological diagnosis and localisation of the primary tumour were obtained from the archives of the cancer centre. Data on social status and performance state of the patients were collected by postal survey.

The survey consisted of 149 questions (190 items) on the following: background information (family status, education); medical data (check-ups, complaints, aids); everyday activities (degree of independence); social characteristics before and after treatment (employment, income); perceived consequences of the disease or treatment; relationships with family and friends; leisure activities; and some psychological aspects. Several questions were extracted from existing questionnaires on, for instance, health in general and problems of the disabled used by the Dutch Bureau of Statistics. These questions have been adequately tested and used in many situations. The reliability and validity of the instruments from the Dutch health survey are discussed by Van Sonsbeek [19]. Psychological well-being was assessed by the Dutch version of the Affect Balance Scale (ABS) [20], which has been validated among various groups [21]. The face validity of the questionnaire was further assured by discussing it with experts (in oncology, insurance, rehabilitation). The questionnaire was subsequently pretested among several ex-cancer patients. The size of the questionnaire resulted from the aim obtaining as much relevant information as possible about the social status of the patients at the time of diagnosis as well as at the time of survey. Since the responders only had to answer those questions that were relevant, the actual number of questions to be answered was less (on average 67).

Table 1. Primary tumour sites

Site	ICD codes	No. (%)
Head and neck	140–149, 160, 161	66 (10)
Skin	172, 173	50 (8)
Breast	174	214 (33)
Female reproductive system	180–184	156 (24)
Male reproductive system	185–188	47 (7)
Lymphatic system	200–205	61 (9)
Other		38 (6)
Unknown		17 (3)
Total		649 (100)

RESULTS

In the archives of the clinic, 849 cases met the study criteria and received questionnaires. 722 (85%) responded and 649 questionnaires (76%) were completed satisfactorily. Differences between responders and non-responders could only be assessed for the primary tumour site. The response by primary tumour site varied from 67% ("other") to 79% (tumours of skin and female reproductive system), so there was no major difference in response for this variable. In the results, differences by tumour site, age or sex are only mentioned if significant.

The group consisted of 467 women (72%) and 182 men (28%). Age ranged from 16 to 69 (mean: women 55.5, men 51.5). Table 1 shows the primary sites. Cancers of the breast and female reproductive system were encountered most frequently with 370 cases (57%) of all cancers. For 75% of the responders the duration of treatment was less than half a year; for 11% it was more than 1 year (particularly in patients with tumours of head and neck, male reproductive system and lymphatic system). The duration of treatment was more than a year for 30% of responders aged 21–45, whereas only 16% of the responders older than 65 were treated for over a year. 5% received some kind of rehabilitation therapy. 91% of the responders were still under the supervision of a medical specialist. 67% felt comfortable with these regular checkups, but 5% saw them as a burden.

Over 50% of the responders still had physical symptoms attributed to their disease or its treatment, especially impairment of energy, palpitations or shortness of breath (20%), or symptoms of the arms, hands and neck (19%). The last symptom particularly occurred in women treated for breast cancer (77%). 45% of the responders used special aids as a result of their disease or treatment. 75% of these aids were breast prostheses; 2% made use of special facilities at home. 78% of the responders considered themselves healthy and 20% disabled. However, for everyday activities (personal hygiene, cooking), most functioned autonomously. Only 2% were cared for at home.

Socioeconomic data

A large part of the questionnaire concerns the socioeconomic position, both at the time of the diagnosis of cancer (1978–1980) and at the time of survey (1987). Socioeconomic positions were classified as follows (combinations were possible): housekeeping, retired, employed, unemployed and other (e.g. student). Table 2 compares the socioeconomic positions at the times of diagnosis and survey. In 1987, the social activities of 62% of the responders were identical to those at the time of diagnosis. The responders,

*Table 2. Socioeconomic position at time of cancer diagnosis and at time of survey**

	1987					
1978–1980	House-keeping	Retired	Employed	Unemp-loyed	Other	Total
Housekeeping	396 (45%)	71 (8%)	45 (5%)	3 (0%)	3 (0%)	518 (58%)
Employed	86 (10%)	57 (6%)	137 (16%)	9 (1%)	20 (2%)	309 (35%)
Unemployed	3 (0%)	1 (0%)	3 (0%)	1 (0%)	1 (0%)	9 (1%)
Other	11 (1%)	11 (1%)	14 (2%)	0 (0%)	14 (2%)	50 (6%)
Total	496 (56%)	140 (16%)	199 (22%)	13 (1%)	38 (4%)	886† (100%)

*Data for both times had to be available.
†This number exceeds number of responders because of possibility of marking several categories.

who were employed at the time of the diagnosis and were now housekeepers, accounted for the largest group that had changed (10%). This group is predominantly female (99%). Furthermore, of the people who were employed at the time of diagnosis, 18% were now retired and 3% now unemployed.

Difficulties per category of activities

Housekeepers. This group had to answer questions on their capacity to keep house. 380 answered. 19% considered themselves disabled and 28% felt hampered as a result of the physical consequences of their disease or its treatment. For instance, 24% could not do strenuous housekeeping such as making beds or cleaning windows. Most of the complaints expressed by housekeepers concerned impairment of arms, hands and neck (17%). On being asked, just 11% of these responders said they would be employed now, if they had not had cancer.

Pensioners. The questions for this group were answered by 83 subjects. The mean age of retirement was 61. 25% retired under 60. 17% retired because of the physical consequences of the disease and 12% felt hampered in everyday activities. 56% of these responders thought they would have been retired anyhow, even if they had not had cancer. Only 5 responders in this group claimed they would have been employed now if they had not had cancer.

Employed. 146 employed people answered. Most worked full-time and received full payment. Only 7 received a reduced salary, of whom 3 claimed this to be a result of a reduced performance state or a physical disability as a result of the disease. 17% of the employed people considered themselves disabled, of whom one third had adapted work or special working conditions. Absence from work now (1986–1987), expressed in days per year, did not differ significantly from absence in the year before diagnosis. Of the 92 responders who expressed their opinion about possible promotional prospects or better income, 53% had a positive judgement. On the other hand 17% experienced impediments at work that were attributed to the disease or treatment.

Unemployed. Only 10 subjects answered the questions for this group. 5 felt obstructed in everyday activities or in finding a job as a result of their disease. Only 2 said they would have been employed now if they had not had cancer.

Income

Table 3 shows the main sources of income at diagnosis and survey. Differences from the results in Table 2 can partly be explained by the fact that responders could fit into several categories in Table 2.

In the past five years 6% of the responders made use of some kind of financial facility as a result of their disease. 18% (men 26%, women 15%) thought they were in a worse financial position than they would have been if they had not had cancer. More than half (62%) were very definite in answering this question.

Insurance

Since diagnosis, 22% of the responders have tried to take out insurance or to modify an existing insurance policy (37% of the employed responders). Generally this took place in the first 5 years after treatment. Only 13% of them who are employed now tried to take out insurance earlier, that is at diagnosis or during treatment. Almost half were under 45.

70% of those who tried to take out insurance or to modify an existing insurance policy met difficulties (15% of all responders) ascribed to the disease. This percentage was even higher among those at work (80%). Life, medical and funeral insurance were concerned. In 80% the problems were refusal by the insurance company; higher premiums and medical re-examinations both occurred in 36%. These percentages did not differ much between primary tumour sites; only males treated for cancer of the reproductive system met more problems (93%).

Social contacts and leisure activities

There were few changes in this area. Only 5% of the responders claimed to receive less visitors than they used to, and blamed this on the disease or treatment. The questionnaire asked about leisure activities at diagnosis and at survey. The more active

Table 3. Main sources of income at times of diagnosis and survey

	1987				
1978–1980	Employ-ment	Pension	Social welfare	Partner with income	Total
Employment	110 (21%)	50 (10%)	35 (7%)	11 (2%)	206 (40%)
Pension	0 (0%)	33 (6%)	0 (0%)	0 (0%)	33 (6%)
Social welfare	4 (1%)	7 (1%)	18 (3%)	1 (0%)	30 (5%)
Partner with income	13 (2%)	45 (9%)	6 (1%)	186 (36%)	250 (49%)
Other	1 (0%)	1 (0%)	2 (0%)	0 (0%)	4 (0%)
Total	128 (24%)	136 (26%)	61 (12%)	198 (38%)	523 (100%)

forms of leisure activities, (sporting, going out and doing jobs around the house) were done less. More responders spent their leisure time reading, watching television or simply doing nothing (a change of 6%). This did not seem to result from the fact that the individuals were on average 8 years older.

Psychological aspects

The ABS measures positive and negative states of mind. The mean ABS score of the total group of responders was 1.1 (men 1.4, women 1.1). In comparison with the mean ABS score of the Dutch population, 2.0 (men 2.1, women 1.8), the mean score of the study population was lower [22]. There was diminished psychological well-being in the group of long-term survivors of cancer.

DISCUSSION

Care should be taken when generalising from the results of this survey to the general population of ex-cancer patients. The population of patients from the regional cancer centre probably differed from the total population of cancer patients. Also, the age limits, the time between diagnosis and survey and non-response could have led to some selection. Only a limited number of variables could be studied in this survey. The results of the postal survey among 649 ex-cancer patients make an inventory of problems during re-integration in society. Considering the limitations of this survey, the following conclusions can be drawn. Two thirds of the responders thought check-ups, which take place in most cases, to be of great support. However, to what extent would discharge from these check-ups, with the advice to turn to the general practitioner in case of symptoms, have supplied the same support?

On average 8 years after the diagnosis of cancer and at least 5 years after treatment, almost all responders were self-supporting to a large extent. Only 2% were taken care of or nursed at home. Nevertheless, 20% reported themselves as disabled and 45% used aids or prostheses. Over half the responders still experienced physical symptoms or hindrance due to their illness and 28% felt hampered by these physical consequences of cancer.

The socioeconomic position at diagnosis compared with that at survey was unchanged in 62% of cases. The 28% who were employed at diagnosis and who were now housekeepers, were the group that changed most in social activities. Problems due to the disease or treatment existed among small groups doing different social activities. Of the responders who were now housekeepers, 24% could not do strenuous housekeeping anymore. 6% of the retired people thought they would still be employed if they had not had cancer. Of the responders who were employed now, 17% considered themselves disabled, and one third of them had adapted work or special working conditions. Absence from work at survey did not differ significantly from absence in the year before diagnosis. 18% of those employed said they were financially in a worse position than they would have been without cancer. 47% judged their promotional prospects and chances of better income as moderate or pessimistic.

Someone who is cured medically, is still regarded to be a great risk by insurance companies. 70% of the responders who tried to take out insurance or modify an existing policy met difficulties (22% of all responders): refusal, higher premiums or medical re-examinations. This survey confirms the results of other studies [7, 8, 11].

The ABS (psychological well-being) of the responders was lower than the mean score of the Dutch population [22]. At first sight, this was not surprising. Nevertheless, these results contradict many studies among cancer patients that report a better quality of life than the mean [23]. There are two possible explanations. Firstly, our methods for measuring psychological well-being differed. Secondly a rearrangement of positive and negative emotions takes place at the diagnosis of cancer [23]. For example, one may learn to enjoy everyday experiences more. In the same way, when treatment has been completed and the prognosis is good, the emotions may be re-arranged again. The negative aspects and consequences of cancer and its treatment, such as feelings of isolation and mutilation, may predominate [18].

For an increasing number of cancer patients, a time arrives when their doctor declares the cancer cured and treatment ended. It is unfortunate that this does not mean that their struggle with the problems due to disease comes to an end. Adequate psychosocial care should be available. Under ideal conditions the psychosocial care of the long-term cancer survivor should start during treatment, in co-operation with the specialist, and remain available after treatment has ended.

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