Quality of life and rehabilitation in social and professional life after autologous stem cell transplantation

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Background: In this study, we report on quality of life (QOL) in long-term survivors after high-dose chemotherapy and autologous stem cell transplantation (ASCT) with special emphasis on rehabilitation in social and professional life.

Patients and methods: The European Organization of Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ)-C30 questionnaire was sent by mail to 391 patients 1 to 12 years (median 31 months) after ASCT. The procedure was performed at our institution alone. Of the questionnaires 78% were returned and evaluated.

Results: Of the 238 patients who had an occupation and were employed, 132 (55%) have returned full time (68%) or part time (32%) to their previous occupation. A total of 139 patients (46%) received a 3- to 4-week inpatient rehabilitation treatment in specialised institutions following ASCT. Employment status post-transplantation and QOL were similar in these patients as compared with those who did not participate in rehabilitation programmes. Of the 304 evaluable patients, 39% reported physical problems that reduced their satisfaction with sex and intimacy. The general QOL was significantly reduced in the first year, improved with interval to transplant, and reached the level of the general population after 4 years.

Conclusions: Our retrospective data showed that ASCT has a significant, unfavourable impact on QOL, including reintegration into social and professional life. Most symptoms and scores returned to normal after 3 to 6 years. Employment status and QOL were similar in patients who participated in a rehabilitation programme and those who did not.

Key words: blood stem cell transplantation, high-dose chemotherapy, quality of life, rehabilitation

Introduction

High-dose chemotherapy (HDCT) followed by autologous stem cell transplantation (ASCT) has been shown to be beneficial for a variety of malignant and autoimmune diseases [1–4]. For patients who have suffered relapse of high-grade non-Hodgkin’s lymphoma and Hodgkin’s disease [1, 2, 5, 6], the role of ASCT has been established. For breast cancer and some other solid tumours, however, the impact of this treatment strategy remains controversial [7–9]. As experience with ASCT has become more widespread and the number of patients who have survived for longer periods after the procedure has increased, data concerning health-related quality of life of bone marrow or stem cell transplanted patients have accumulated [10–14]. Interest is now focused on the frequency and severity of early and late psychosocial sequelae.

All these data might provide valuable information for the assessment of the overall impact of HDCT and ASCT on the long-term benefits for cancer patients.

Data from studies published thus far have been limited by short follow-up periods and by the small number of survivors. A few studies have analysed QOL in long-term survivors of autologous and allogeneic bone marrow transplantation (BMT) [15–20], but data on QOL in long-term survivors of stem cell transplantation are scarce.

The long-term goal of any treatment strategy for a life-threatening disease should include reintegration into previous social and professional life upon completion of the healing process, in addition to the ‘cure’ of the underlying disease. For cancer patients who have undergone autologous transplantation, this issue has been addressed in terms of returning to work and some authors have reported rates of 60–90% [16, 18, 21–25]. A higher educational status and younger age have been found to be major factors associated with the likelihood of resuming previous employment [16, 23, 26]. Another issue
that remains controversial is whether in- or outpatient rehabilitation after transplantation might improve long-term QOL, and psychosocial and occupational reintegration [23, 26–30].

In this report, we have analysed the results of a cross-sectional study of QOL, post-transplant inpatient rehabilitation, and employment status in 304 survivors of ASCT. The objectives of this study were: (i) to determine long-term QOL in patients following ASCT in relation to interval from transplant; (ii) to determine if long-term QOL and re-employment following ASCT are related to sociodemographic factors (age, gender, educational level); (iii) to define the relationship of inpatient rehabilitation programmes in specialised institutions with the healing process; and (iv) to determine the proportion of patients that are reintegrated into professional life.

Materials and methods

The patient population included all adult survivors of stem cell transplantation at the Department of Medicine V, University of Heidelberg, as of June 1, 1987. Records with the clinical data of all patients who underwent ASCT were reviewed retrospectively and all surviving patients as of March 31, 1999 were contacted. A letter describing the study along with three questionnaires, as detailed below, were sent to all eligible patients. The Joint Ethics Committee of the University of Heidelberg approved the questionnaire and survey procedures. Those who returned the questionnaire gave their informed consent.

Patient characteristics

From 1987 to 1999, 799 patients underwent HDCT followed by ASCT at the Department of Medicine V, University of Heidelberg, Germany. In April 1999, we mailed the questionnaires to all patients who were still alive as of March 31, 1999 (n = 391). The questionnaires were returned by 338 patients: a compliance rate of 86%. Of these, 34 questionnaires were considered non-evaluable due to missing sheets of the questionnaire or a missing name. Thus, the final study sample consisted of 304 respondents (78% of all patients contacted). The demographics are listed in Table 1. At the time of the survey, the median age of the patients was 49 years, with a range from 17 to 67 years. The questionnaire was completed at a median of 36.0 months post-ASCT (SD 26.4 months). In 47 patients, ASCT had been performed more than 5 years previously and in five patients more than 10 years previously.

A variety of pre-ASCT conditioning regimens were used in the present sample. Total body irradiation (TBI) and cyclophosphamide were used in the majority of cases of low-grade non-Hodgkin’s lymphoma and acute leukemia [34–36], cyclophosphamide, Carmustin, etoposide (CBV) in most cases of Hodgkin’s lymphoma [37–40], and Carmustin, etoposide, Ara-C, melphalan (BEAM) in cases of high-grade non-Hodgkin’s lymphoma [41, 42]. Single or double ASCT with high-dose melphalan alone or together with TBI was used in multiple myeloma [43]. Single, double and triple high-dose chemotherapy was administered in patients with breast or ovarian cancer [44, 45].

The remission status was available for 293 patients (96%): 229 patients (78%) were in remission at the time of the study, and 64 had relapsed (22%). As for the level of education, 93 of the respondents (31%) had received a higher educational level as defined by passing the ‘Abitur’, which is equivalent to matriculation examination, or had acquired a university degree.

General population

We compared patients’ scores on the European Organization of Research and Treatment of Cancer Quality of life Questionnaire (EORTC QLQ-C30) (V 3.0) against reference values from a Norwegian general population survey generated by Hjermstad et al. [31]. This sample was based on a random draw of all inhabitants by the Office of the National Register. It was considered to be representative of the adult Norwegian population. In this study, all participants received a thirty-three item questionnaire, EORTC QLQ-C30 (+3), by mail in addition to a questionnaire on sociodemographic data, illness and health. The EORTC QLQ-C30 (+3) was an interim version which was later replaced by version 2.0 and then the current version 3.0. A total of 1965 Norwegian subjects completed the questionnaires: a response rate of 68%. Results from this survey were considered as representative data on the QOL in the general European population, categorised according to gender and age groups.

Rehabilitation programmes

There was no standardized rehabilitation treatment, but the institutions concerned all specialised in oncologic rehabilitation. In the German health care system, patients with malignant diseases are entitled to a place on an inpatient rehabilitation programme provided by specialised facilities. Health or annuity insurance companies pay for these programmes following cancer treatment. Participation is voluntary and health insurance providers encourage their members to participate, with the intention of improving the rate of reintegration into professional life. Most insurance providers have special contracts with specific rehabilitation centres. Most countries outside Germany do not routinely make rehabilitation available.

Description of measures

Three self-administered instruments were used to collect data on QOL, rehabilitation and social reintegration. The EORTC QLQ-C30 (V 3.0) is an internationally validated thirty-item questionnaire specifically designed for multidimensional measurement of QOL in cancer patients [32]. It includes five functioning scales (physical, role, emotional, cognitive and social functioning), three symptom scales (fatigue, nausea and vomiting and pain), and six single items (dyspnea, sleep disturbance, loss of appetite, constipation, diarrhoea and financial difficulties). It also includes two questions on patient overall QOL and overall physical condition, allowing a global QOL score to be obtained. A German translation of this questionnaire has been available since 1993, its psychometric properties have been validated, and comparisons with other studies using the same questionnaire in various languages have been made possible.

The EORTC QLQ-C30 (V 3.0) was scored using the algorithms as reported by Fayers et al. [33]. The total score is calculated from the scales and single items and ranges from 0 to 100. A high total score for functioning scales and global QOL scale indicate a high level of functioning or QOL.

To assess transplant-specific long-term sequelae related to sexuality, we included a further questionnaire with another 26 questions. This so-called BMT module questionnaire, developed by the Fred Hutchinson Cancer Research Center [19], is a descriptive inventory of late complications of BMT. Because it is not extensively validated, descriptive statistics were used to summarise the results. In this report, we focused on the items associated with sex/warmth/intimacy. The items are scaled identically to those of EORTC QLQ-C30 (V 3.0), with 4-point Likert scales linearly transformed to 0–100 scales. An additional questionnaire, designed for this study, included nine questions related to educational level, employment status before and after transplantation, and the utilisa-
tion of inpatient rehabilitation facilities. Respondents could indicate their educational level and employment status in a comprehensive list, with an open-ended question at the end. Patients were categorically asked whether they had participated in rehabilitation programmes, but there was no question concerning the reasons for referral to these programmes or the motivation to participate. We requested information about the interval between ASCT and rehabilitation and the interval between ASCT and the resumption of their previous profession. Patients were asked to estimate the effect of rehabilitation facilities and programmes on their ability to reintegrate into their previous professional life.

Statistical analysis

Descriptive statistics (frequencies, medians, means) were applied to analyse the correlation between clinical, sociodemographic and QOL data. Differences between groups were tested with Fisher’s exact test (nominal categorical variables), t-test for independent and paired samples (scale and item scores), and Kruskal–Wallis analyses of variance where appropriate. Multiple regression with stepwise analysis and the Chi-square test were used to analyse the interrelation between sociodemographic variables and QOL/reintegration data. A conservative $P$ value of 0.01 was taken to indicate statistical significance in all tests, because of the multiple comparisons. Partially incomplete data were also included in the analyses and missing values were entered by use of techniques as recommended in the EORTC manual [33].

Results

Quality of life

Of the 304 respondents, 67% rated their ‘global QOL’ as good to excellent, and 64% considered their ‘global physical health status’ as good to excellent (mean score 66.7, SD 21.3). Only 5% rated their global QOL or health status as poor (Table 2).

Relationship to interval since transplant. Most of the symptom and function scores were superior in patients with a longer
interval to transplant but lower than reference values even after several years. Scores for diarrhoea, constipation, appetite loss, nausea and vomiting were significantly better in patients analysed in the first year after ASCT compared with patients with a longer interval to transplant. Global health was rated better with greater interval to transplantation and reached the level of the general population after 4 years (Figure 1). Cognitive function was slightly reduced in patients in the first year after transplantation and did not differ significantly in patients with longer post-transplant period. Only in the very long-term

Table 2. Mean scale and item scores from The European Organization of Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ)-C30

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Age (years)</th>
<th>Employed</th>
<th>Unemployed</th>
<th>Rehabilitation</th>
<th>No rehabilitation</th>
<th>General population^a</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>304</td>
<td>76 86 118 24</td>
<td>132 172 139 165</td>
<td>1965</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functioning scales^b</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive</td>
<td>76</td>
<td>77 75 75 76</td>
<td>80 72 73 78</td>
<td>87</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Emotional</td>
<td>64</td>
<td>73 62 61 59</td>
<td>71 58 63 65</td>
<td>83</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>73</td>
<td>80 76 72 60</td>
<td>83 66 74 72</td>
<td>90</td>
<td></td>
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<tr>
<td>Role</td>
<td>58</td>
<td>69 60 56 36</td>
<td>70 49 57 59</td>
<td>93</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>64</td>
<td>70 63 63 51</td>
<td>75 56 64 64</td>
<td>86</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global QOL^b</td>
<td>67</td>
<td>75 69 65 58</td>
<td>74 61 68 65</td>
<td>75</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom scales^c</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Dyspnoea</td>
<td>33</td>
<td>25 32 34 42</td>
<td>25 38 32 33</td>
<td>14</td>
<td></td>
<td></td>
<td></td>
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<td>Pain</td>
<td>28</td>
<td>17 23 30 45</td>
<td>16 38 29 28</td>
<td>21</td>
<td></td>
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<td></td>
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<tr>
<td>Fatigue</td>
<td>41</td>
<td>30 40 44 55</td>
<td>31 49 42 41</td>
<td>29</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Insomnia</td>
<td>33</td>
<td>25 33 36 35</td>
<td>26 38 36 30</td>
<td>20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appetite loss</td>
<td>12</td>
<td>7 10 13 26</td>
<td>5 18 13 12</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea/vomiting</td>
<td>6</td>
<td>4 4 6 20</td>
<td>2 10 6 7</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td>11</td>
<td>7 7 11 21</td>
<td>8 13 13 10</td>
<td>11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>12</td>
<td>8 9 12 18</td>
<td>8 15 11 12</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial hardship</td>
<td>31</td>
<td>32 31 33 15</td>
<td>24 37 31 31</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

^aHjermstadt et al. 1998 [31].
^bA higher score indicates better functioning.
^cA higher score indicates more symptoms.

Figure 1. Global quality of life and functioning scales and their relationship to interval to transplantation (*P ≤0.01; †Hjermstadt 1998 [31]).
survivors (>8 years) did cognitive function recover to the level of the general population. Role and social functions (daily activities, hobbies, family life, social contacts) as well as physical functions were compromised in both early and long-term survivors of ASCT (Figure 3).

**Relationship to gender.** Male and female survivors did not differ, according to the independent \( t \)-test, in any QLQ-C30 item (Table 2).

**Relationship to age.** Patients were categorized into the following age groups at the time of transplantation: 18–39, 40–49, 50–59 and 60–69 years. The long-term side effects and the reduction in functional scores correlated with age. Significant differences in pain (\( P = 0.0002 \)), fatigue (\( P = 0.0002 \)) and nausea/vomiting (\( P = 0.004 \)) were reported in older patients even a long time after transplantation. Functional scores (except cognitive and social functioning) and Global QOL were also significantly higher among patients in the younger age groups (Figure 2).

**Relationship to employment status and educational level.** Unemployed patients reported poorer scores than their employed counterparts in physical (\( P = 0.002 \)), cognitive (\( P = 0.04 \)), social (\( P = 0.008 \)) functions, and most of the symptom scales (Table 2). Educational level had no significant influence on symptom and function scores or global QOL, except constipation (\( P = 0.001 \)) and nausea (\( P < 0.0001 \)).

**Relationship to post-transplant rehabilitation treatment.** Symptom and function scores or global QOL did not differ among participants and non-participants of inpatient rehabilitation treatment programmes (Table 2).

**Sexuality.** In response to four questions concerning their sex life (BMT module), 17% of survivors reported that they were dissatisfied with their appearance compared with before ASCT, 32% of respondents were dissatisfied with their sexual appeal, 26% with their ability to share warmth and intimacy, and 35% with their interest in sexual thoughts or feelings. In 39% of survivors, physical problems were reported which reduced their satisfaction with sex and intimacy. The latter was reported significantly more often in men than in women (46% versus 34%; \( P = 0.01 \)), in contrast to better scores for men in the aforementioned emotional aspects of sexual function (mean 66% versus 61%; \( P = 0.008 \)).

**Rehabilitation treatment and reintegration**

Most respondents had an occupation and were employed before diagnosis of their malignant disease (\( n = 238; 74\% \)). Three patients were unemployed, 44 were homemakers, and 10 patients were retired. In nine patients there was no information available (Table 1).

After ASCT, 132 patients (55% of those formerly employed) had returned full time (68%) or part time (32%) to their previous occupation. Of these 132 patients, 54% returned to their job within 6 months, 26% within the next 6 months and 20% after 1 year.

Reintegration into professional life was more likely in individuals with a higher educational level (\( P = 0.007 \)). Rate of re-employment was not related to gender. Table 3 shows the relationship between re-employment rate, sociodemographic variables (age, gender, educational level) and the use of rehabilitation treatment. Correlation analysis was performed in order to understand better the interrelationships between these sociodemographic variables. There was a strong correlation between gender and educational level (\( P = 0.009 \)), with a higher proportion of male recipients (39%) with a higher educational level compared with women (25%). There was no correlation between age and gender or educational level. Multiple regression analysis revealed that younger age groups (\( P = 0.00002 \)) and higher educational levels (\( P = 0.03 \)) were associated with a higher probability of re-employment.

Of the study sample, 139 patients (46%) received rehabilitation treatment in various specialised institutions in the first year after transplantation. Sociodemographic characteristics of patients who participated in rehabilitation programmes were comparable with those who did not (Table 1). Women
were more likely to participate in a rehabilitation programme than men: 53% of women as compared with 39% of male transplant recipients ($P$ = 0.01). Educational level disease and employment status were the same in participants and non-participants. In the rehabilitation subgroup, there were more lymphoma and breast cancer patients, whereas the percentage of myeloma patients was higher in the non-rehabilitation subgroup ($P$ = 0.001). The functional status and QOL issues before rehabilitation treatment were not determined because of the retrospective design of the study.

For patients who were originally employed before diagnosis of malignancies, there was no difference in reintegration rate into previous professional life between patients who did or did not participate in a rehabilitation programme (42% re-employed after rehabilitation versus 46% with no rehabilitation; $P$ = 0.41; Figure 3). Furthermore, patients were reintegrated earlier if they did not participate in a rehabilitation programme ($P$ = 0.008). These observations were made among the whole patient sample as well as for each disease entity. The results were similar if patients older than 50 years ($P$ = 0.20) or patients who had had a transplant less than 12 months previously ($P$ = 0.12) were excluded from analysis. In formerly employed patients with a higher educational level, professional reintegration was higher in those patients that had participated in a rehabilitation treatment programme ($P$ = 0.02).

The influence of rehabilitation programmes on their physical abilities was generally considered to be good by the patients. On a scale from 1 to 7, with 7 being the highest satisfaction level, the median impact was considered to be 5. When asked about the influence of the rehabilitation programme on their reintegration into professional life, the patients estimated that the impact was only 3 on a scale from 1 to 7.

### Discussion

To determine long-term QOL in patients after ASCT and to define the relationship between rehabilitation programmes and the healing process, which should include reintegration into former social and professional life after ASCT, we studied 304 survivors. The main findings were that: (i) global QOL was superior in patients with a longer interval to transplant but lower than reference values, even after several years; (ii) the long-term side effects and the reduction in functional scores were correlated with age and post-transplant employment status, but not with gender and educational level; (iii) post-transplant employment status and QOL were similar in patients who participated or did not participate in a rehabilitation programme; and (iv) 55% of patients who were employed prior to treatment returned to their previous occupation.

Most of the reports on QOL and rehabilitation after high-dose chemotherapy have focused on patients after BMT. Data on the psychosocial sequelae following peripheral stem cell transplantation emerged in the late 1990s [26, 46–49, 51–55]. Studies on patient samples of more than 120 individuals were, however, scarce and the follow-up period short. The longest follow-up, with a post-transplant interval of 21 years in some cases, was provided by the Seattle and Toronto groups [17, 19].

With the widespread use of peripheral blood stem cells and, hence, a shortened time to recovery, and with the availability of validated and standardised tools since 1993, the long-term psychosocial sequelae of HDCT and ASCT should be viewed in a new light. Our study focuses on the reintegration into social and professional life of patients following ASCT, as well as the possible impact of rehabilitation programmes on these patients. All these factors render this study unique.

After ASCT, 55% of patients employed prior to treatment returned full time or part time to their previous occupation. The most striking observation of our study was the lack of difference in the re-employment rate or QOL scores among those patients who participated in rehabilitation programmes and those who did not. Because of the retrospective study design, we cannot exclude the possibility that patients who underwent rehabilitation programmes were selected because of more severe symptoms after transplantations. However, this is not likely as sociodemographic and disease characteristics were comparable in patients that participated in rehabilitation programmes and those who did not. There was no significant difference in QOL between the two subgroups after rehabilitation programmes. We were not able to collect data on functional status and QOL from the patients after ASCT and before rehabilitation in this trial. Hence, we do not know the baseline level of functioning prior to their referral to rehabilitation. Patients referred to rehabilitation may have

### Table 3. Re-employment rate in relation to sociodemographic variables and rehabilitation treatment

<table>
<thead>
<tr>
<th>Variable</th>
<th>Percentage of patients re-employed</th>
<th>$P$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>All patients</td>
<td>55</td>
<td></td>
</tr>
<tr>
<td>Patients who received rehabilitation treatment</td>
<td>42.4</td>
<td>0.54</td>
</tr>
<tr>
<td>Patients who did not receive rehabilitation treatment</td>
<td>45.9</td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;40</td>
<td>59.2</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>40–49</td>
<td>47.6</td>
<td></td>
</tr>
<tr>
<td>50–59</td>
<td>37.2</td>
<td></td>
</tr>
<tr>
<td>60–69</td>
<td>8.3</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>44.5</td>
<td>0.72</td>
</tr>
<tr>
<td>Female</td>
<td>42.5</td>
<td></td>
</tr>
<tr>
<td>Elementary school (10 years) and/or vocational/trade school</td>
<td>39.5</td>
<td>0.007</td>
</tr>
<tr>
<td>High school (&quot;Abitur&quot;) and/or university/college</td>
<td>55.9</td>
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</table>
been more debilitated and distressed and may thus have benefited from the rehabilitation itself with improved QOL and re-employment rate comparable to levels of those patients who did not receive rehabilitation treatment. Unfortunately, we cannot answer this question because of the retrospective study design. In our ongoing prospective trial (not published), data are being collected with respect to the reasons for referral to rehabilitation and the patients’ motivation. It has been designed to clear up this fundamental problem.

A cross-sectional multicentre study in North America comprising 200 patients after BMT showed that 60% had resumed their former occupation after a mean of 43 months [18]; whereas in other centres, proportions of 60–91% have been reported [16, 18, 22–25, 30]. A prospective study at the Fred Hutchinson Cancer Research Center revealed that 36% of survivors returned to work in the first year after transplantation, 78% after 2 years, and up to 91% after 4 years [21].

Increasing age, more advanced disease at transplantation, lower levels of education, and lower status in former job have been reported to be associated with failure to be reintegrated into former professional life [16, 18, 23]. Consistent with these data, our analysis revealed that a higher levels of education and increasing age were associated with a higher likelihood of re-employment. The disease status at time of transplantation and former job status were not examined in the current study.

Several authors describe the short-term influence of rehabilitation on QOL, fatigue, and anxiety during treatment and for a short time thereafter [27–29]. Whereas a positive immediate effect on physical function and psychosocial variables has been reported, a long-lasting impact on QOL scores or reintegration in social and professional life has not been shown. Most countries outside Germany do not routinely make rehabilitation available. This has to be considered when we compare our results to studies of professional reintegration in other countries.

Our results from this cross-sectional study of QOL after ASCT were consistent with several prospective and cross-sectional studies [46–50, 54]. We can confirm that QOL improved with interval to ASCT. Most of our ASCT recipients that completed the questionnaire in the first few years after transplantation reported that their physical health and QOL was compromised. Patients with a longer interval to transplantation reported that their physical health and QOL was compromised. With a longer interval to transplantation reported QOL scores comparable to that of the general population [31]. Similar intervals for recovery have been reported by others [17, 20, 25, 56, 57]. However, deficits in several functional scales (e.g. social, role, physical, cognitive) seemed to persist even after 4 years [21].

As reported by others, a subgroup of patients might need much more time to readjust [15–19, 24, 25, 51, 56–60]. The most frequently reported problems identified were inability to resume social roles, worry about the future, work-related problems, sexual disabilities and infertility, fear of relapse, anxiety and depression.

In contrast to other reports, which found that women have lower function scores after ASCT than men [31], we could not identify any significant difference between genders using the QLQ-C30 (V3.0) questionnaire.

The BMT module, however, indicated that physical problems that diminish satisfaction with sex and intimacy were reported significantly more often in men than in women, in contrast to better scores for men with respect to the emotional aspects of sexual function.

We are aware that the cross-sectional study design can only give an indication of the relationship between inpatient rehabilitation programmes and professional reintegration and QOL. To clarify this relationship, a prospective, controlled trial comparing different concepts of rehabilitation might be necessary to validate their relative roles in the healing process after ASCT. As more and more patients have derived benefits from transplantation, more attention needs to be focused on the long-term psychosocial sequelae of this procedure. We hope that the unexpected findings of this study, together with future research, will lead to a more effective approach in assisting patients in their return to normal social and productive life.

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