



# Only minor impairment of health related quality of life (HRQL) in adult long-term survivors of acute lymphoblastic leukemia (ALL)

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## Background

Compared to survivors of childhood leukemia, only little is known about late effects and Health Related Quality of Life (HRQL) of adult patients with ALL. With the improvement of survival-rates up to 40% in the last 10 years, the status of long-term survivors of adult ALL is of increasing interest. The German Multicenter Study Group for Adult ALL (GMALL) has conducted 7 consecutive prospective studies for de-novo ALL since 1981. All patients received intensive chemotherapy with or without stem cell transplantation. This is the first interim-analysis of HRQL in long-term survivors of GMALL studies 02/84–06/99

## Methods

A questionnaire with 191 questions was sent out to patients of 5 consecutive GMALL studies, who were alive at least 5 years after diagnosis. HRQL was evaluated with the EORTC-QLQ-C30 questionnaire, and the correspondent Q-Leu Module. In addition, questions concerning health-status, fertility-issues, social-family-life and working-conditions were enclosed. Results were described and if possible compared to the German normal population.

## Health-status and late effects:

For this interim analysis, questionnaires from 152 patients were eligible. Median age at time of interview was 40 years (21-70). 64% patients who completed the questionnaire were male, 36% were female. The median-time from diagnosis was 10 years and median age at diagnosis was 29 years (15 – 62)

More than 80% of the patients estimated their own chance to stay healthy as „very good“ or „good“ 85% of the patients estimated their own activity just as well as prior to their disease (ECOG 0 or 1). 11% were capable of only limited self-care (ECOG 2) 4% were not capable of only limited self-care or completely disabled (ECOG 3 or 4).

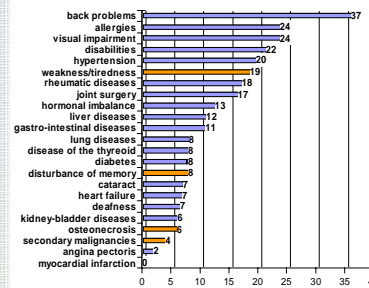
The most frequently reported health-problems were back problems (37%), allergies/visual impairment (24%), disabilities (22%) and hypertension (20%).

Women underwent more often joint-surgery than men (25% vs 11%).

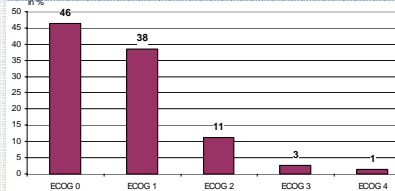
Men more often reported hypertension (28% vs 9%), gastrointestinal- (15% vs 6%), liver- (15% vs 6%) and kidney or bladder-diseases (9% vs 2%). Cardiac problems were very seldom.

Reduced mental-capacity, loss of concentration and limited physical-function were major self-reported complaints in the comment-fields of the questionnaire

## Self-reported health-problems



## Patients self-estimated ECOG



## Fertility

Fertility after therapy is a major concern of patients, but preservation opportunities were offered only in 23% of men and in none of the women.

- 42% of the patients had a median number of 2 children before their disease (between 1 and 5)
- Amazingly, only 30% of all patients wished to have children after therapy. More than half of these patients fathered children. Medical interventions were only used in a limited number of men.
- 67% of fertile women report normal menstruation after the disease. Premature menopause was mentioned in 21% and 14% had other abnormalities in their menstruation cycles. Thus, menstruation-abnormalities occurred in 35%

## Working-Life

- The employment-rate of patients after therapy was slightly higher than prior to the disease (65% vs 59%)
- More patients worked part-time afterwards (14% vs 6%)
- 35% report worse, 41% unchanged and 25% better working life
- Permanent severe disability (> 50 degree of disability) was the main reason for restrictions in working life

## Rehabilitation

Changes since or through the disease:

- 73% have a better attitude/outlook on life
- 70% have closer relationship to friends and family
- 54% have unchanged and 28% worse sexual relationships
- 43% have unchanged and 38% worse recreation-opportunities (mostly due to limited physical function)

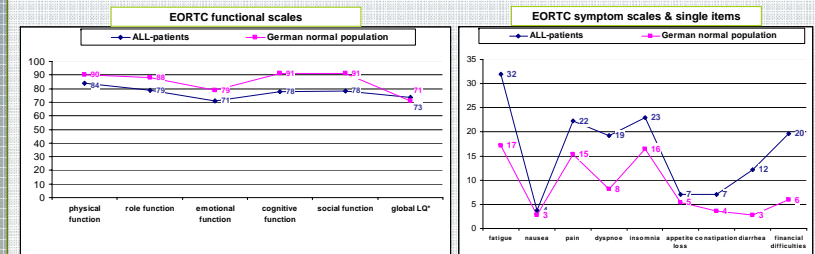
## Social & Family Life

## Results

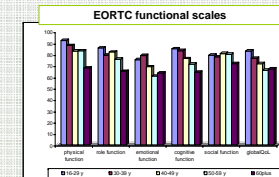
## EORTC QLQ-C30:

### ALL patients vs. German normal population

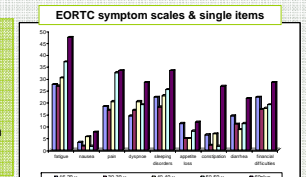
EORTC functional scales – especially cognitive and social function - were slightly reduced, compared to the German normal population (Schwarz et al, Eur J Cancer, 2001), but overall QoL was even better. Fatigue was the main impairment in symptom scales.



## Age & Gender



High scores in the functional scales show high functionality (=positive). High scores in the symptom scales and single items show a high grade of impairment (=negative)



EORTC-symptom scales showed that fatigue and low physical-functioning increased particularly in elderly patients. Gender-differences concerned pain and insomnia, whereas women were less impaired than men.

## Conclusions

- Overall HRQL of patients 10-years after diagnosis of ALL is only slightly impaired compared to the normal population. Major differences concerned cognitive-, and social-functioning.
- Amazingly, self-reported QoL did not strictly correlate negative with obvious health-problems.
- The evaluation of fertility is particularly difficult; if no objective measures e.g. sperm quality were taken, it depends on the wish of patients to have children. In patients with the wish to have children, fertility appeared to be preserved in over half of them.
- High QoL-scores, also in patients with health problems, suggest that coping-strategies play an important role. Therefore evaluation of QoL at several time-points (before, during and after therapy) is preferable to optimize supportive-care and to improve psycho-social support

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