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Rehabilitation during intensive treatment of acute leukemia including allogeneic stem cell transplantation – a qualitative study of patient experiences

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-029470
Article Type:	Research
Date Submitted by the Author:	28-Jan-2019
Complete List of Authors:	Jepsen, Lene Østergaard; Odense Universitetshospital, Friis, Lone Smidstrup; Rigshospitalet, Hematology Hoybye, Mette Terp; Regionshospitalet Silkeborg, 3. Interdisciplinary Research Unit, Elective Surgery Center Marcher, Claus Werenberg; Odense Universitetshospital, Hematology Hansen, Dorte; University of Southern Denmark, National Research Centre for Cancer Rehabilitation, National Research Centre for Cancer Rehabilitation, Research Unit of General Practice
Keywords:	Leukaemia < HAEMATOLOGY, REHABILITATION MEDICINE, Everyday life, QUALITATIVE RESEARCH

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4 Rehabilitation during intensive treatment of acute leukemia including allogenic stem cell
5 transplantation – a qualitative study of patient experiences
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Abstract

Objectives

The diagnosis and treatment of acute leukemia affect physical, psychosocial and existential functioning. Long-lasting treatment periods with impaired immune system, hygienic and social restrictions challenge patient well-being and rehabilitation as compared to other cancer patients. This study elucidates how acute leukemia patients, treated with curative intent in an outpatient setting assess their physical, psychosocial and existential capability during and following treatment, and furthermore reports on the health initiatives offered to support their rehabilitation.

Design, setting, participants and interventions

We conducted qualitative, semi-structured individual interviews with 16 acute leukemia patients, six months after end of treatment in the patients' home. This was the final interview, in a line of three carried out as part of a larger qualitative study.

Results

None of the patients were satisfied with their physical capability at the time of interview and experienced substantial impairment of functional capabilities. For the majority of the patients, their sole exercise during treatment was the performance of daily chores. Later on exercise levels and physical abilities differed from patient to patient. All patients struggled with anxiety and expressed a need for continuous progress in treatment and well-being to be feeling safe. It took an unexpected effort to regain a meaningful social life and patients still had to prioritize activities.

Conclusions

Acute leukemia patients suffered physically, psychologically and existentially throughout their illness trajectory. Rehabilitation initiatives deriving from the health care system and municipalities held room for improvement. The physical activity in daily chores was manageable and should be encouraged in future rehabilitation programs.

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Summary**Strength and limitations of the study**

- A relatively small number of participants impede generalization to the wider population of hematological cancer patients
- The patients showed a high degree of self-preservation instinct during the illness trajectory, which may indicate a selection bias
- The theoretical framework of rehabilitation may strengthen the possibility of analytical generalization

Funding

This work was supported by the University of Southern Denmark 400.000 Kr., the Region of Southern Denmark 500.000 Kr., The Danish Cancer Society 465.000 Kr., the Anders Hasselbalch Foundation 20.000 Kr., the Family Hede Nielsen Foundation 25.000 Kr. and the joint research pool between National University Hospital and Odense University Hospital supporting the highly-specialized functions 40.000 Kr.. The National Research Center of Cancer Rehabilitation, University of Southern Denmark is partly funded by the Danish Cancer Society.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Author contribution

LJ participated in the design of the study, carried out the interviews, analysed data and drafted the manuscript. LF participated in the design of the study and in the discussion of the analysis and the results. She also critically revised the manuscript important intellectual content. CM participated in the discussion of the analysis and the results. He also critically revised the manuscript important intellectual content. MH participated in the design of the study and in the discussion of the analysis and the results. She also critically revised the manuscript important intellectual content. DH participated in the design of the study and in the

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4 discussion of the analysis and the results. She also critically revised the manuscript important intellectual
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6 content. All authors read and approved the final manuscript.
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Patient consent form

10
11 Written informed consent for publication of their transcribed interviews was obtained from the patients and
12
13 their spouses. A copy of the consent form is available for review by the Editor of this journal.
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Data sharing

17
18 The dataset generated and analyzed during the current study are not publicly available because it is
19
20 containing information that could compromise research participant privacy but are available from the
21
22 corresponding author on reasonable request.
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Keywords

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28 Rehabilitation, acute leukemia, everyday life, qualitative study
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Word count

33
34 3.505
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Introduction

Patients with acute leukemia (AL) undergo extraordinary long periods of intensive treatment with high susceptibility to sudden and dramatic changes in their health condition and prognosis [1]. Impairment of the immune system necessitates substantial hygienic and social restrictions. However, during the last decade outpatient management has been introduced and has increased. Rehabilitation needs and offers are challenged by these changes. Little clinical or research attention has been paid to rehabilitation and survivorship care for this specific group of cancer patients.

In this paper the concept of rehabilitation refers to specific initiatives and efforts by health professionals but is also an analytical concept to describe the process in which the patients reframe a sense of self [2].

The existing knowledge underlines beneficial effects of rehabilitation to cancer patients. From few studies, we know that physical exercise is feasible and safe for AL inpatients, even those with critical cytopenia. Beneficial effects on physical performance, fatigue and quality of life have been shown [3-9]. As an example a six week supervised exercise and health counseling intervention to AL patients during outpatient management showed physical, functional, psychosocial, and symptom benefits [8]. Patients undergoing allogenic hematopoietic stem cell transplantation (HSCT) due to hematological malignancies have also shown significant benefit from exercise interventions without reports of negative effects [9].

Health-related quality of life of hematological cancer patients is lowered mainly due to reduced role functioning, insomnia and fatigue [10,11]. Unmet needs of rehabilitation are strongly associated with impaired quality of life for cancer patients in general [12]. Psychological counseling, physical rehabilitation, sexual and financial support and practical help have been found to be important but needs vary with age, gender and cancer diagnosis [13,14].

The existing knowledge underlines the beneficial effects of rehabilitation. However, the rapid changes of treatment setting, patient population and lack of knowledge of existing evidence may leave patients with unmet needs and functional impairment. Bridging the knowledge gap between existing rehabilitation and the

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4 expectations of patients intensively treated for AL may inspire future rehabilitation initiatives, and through
5
6 these improve wellbeing of an increasing and still older group of patients.
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9 Based on patient interviews this paper elucidates how AL patients treated with curative aim assess their
10
11 physical, psychosocial and existential capability during and following treatment and health initiatives
12
13 supporting their rehabilitation.
14

15 16 **Material and methods**

17 18 **Design**

19
20 The material derives from individual interviews with 16 patients, six months after end of treatment. These
21
22 interviews were the third and final interview, conducted as part of a larger qualitative study, which combined
23
24 participant observation in the outpatient setting (OPS), individual patient interviews, and group or individual
25
26 interviews with their relatives [15,16].
27

28
29 Semi-structured interviews were conducted based on a thematic interview guide [15]. The first topic was
30
31 ‘impact on everyday life practices’ where rehabilitation issues were addressed by questions such as ‘Try to
32
33 describe your present physical capability and how you reached that level’. The question was repeated for
34
35 psychosocial and existential well-being. The second topic ‘the home’ explored daily life at home and the
36
37 roles of the family whereas the third topic ‘hygiene’ addressed the impact of intense hygiene requirements.
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40
41 Patients were not involved in the research design.
42

43 44 **Participants and interviews**

45
46 Participants were Danish speaking AL patients intensively treated with a curative aim. All were managed in
47
48 the OPS, ‘the Home Unit’ at the Department of Hematology, Odense University Hospital (OUH) and
49
50 subsequently followed in the outpatient clinic at OUH or at the National University Hospital, Copenhagen or
51
52 at Aarhus University Hospital if allogenic transplanted [15].
53

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55 Twenty-six patients were included consecutively from May 2013 to August 2014, and out of this group 16
56
57 took part in this third interview six months after end of treatment (Figure 1). Table 1 shows the demographic
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4 characteristics. The interviews were conducted in the patients' home and lasted from 40 to 115 minutes
5
6 (mean 68 minutes). All interviews were digitally recorded.
7

8 9 **Context for rehabilitation**

10
11 Rehabilitation has previously been understood as a practice related to the post-treatment life of patients, but
12
13 expectations have changed. The facilities and practices of the hospital during in- and outpatient management
14
15 may be considered a context of rehabilitation of AL patients.
16

17
18 Each year the Department of Hematology, OUH receives about 45 newly diagnosed AL patients who are
19
20 candidates for curative intended chemotherapy. The course of treatment contains periods as inpatient as well
21
22 as periods as outpatient where the patients during periods with severe hematological cytopenia, stay at home
23
24 and appear at follow-up visits every second day [15].
25

26
27 The OPS was situated next to the hematological department, OUH. Both in- and outpatients could use the
28
29 fitness facilities located within the department. A physiotherapist was present twice a week to instruct the
30
31 patients. During treatment patients could request a referral to a physiotherapist, a psychologist, a chaplain or
32
33 a medical social worker at the department.
34

35
36 Before receiving the transplant, patients were instructed in some simple exercises by a physiotherapist.
37
38 Furthermore, all patients had an exercise-bike in their bed-room during periods of isolation.
39

40
41 Psychologists from The Danish Cancer Society were available to patients and relatives in facilities close to
42
43 the hospital.
44

45
46 In Denmark, the overall responsibility of rehabilitation is located at the local municipality levels (98
47
48 municipalities/5.6 million inhabitants) with different rehabilitation offers and knowledge about cancer and
49
50 AL due to different populations, staff and geographic size [17].
51

52 53 **Theoretical framework and analysis**

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55 The study took outset in the World Health Organization definition of rehabilitation [18], but simultaneously
56
57 acknowledged that rehabilitation formed an analytical approach to the physical, psychosocial and existential
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4 challenges facing the AL patients, and was not a structural or organizational intervention as such. This paper
5 aims to study the configuration of rehabilitation needs as experienced by AL patients and to draw attention to
6 possible contextual factors that should be taken into account in future programs. To further support our
7 analytical exploration, the theoretical framework included International Classification of Functioning,
8 Disability and Health (ICF) pointing out the interaction of health condition, body function and structure,
9 activity, participation, and personal as well as environmental factors [19].

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18 The data was analyzed thematically through an inductive ongoing process of four steps inspired by Miles and
19 Huberman [20]. First, the interviews were transcribed by a secretary and read several times by LØJ to gain
20 an overall understanding of the material. Secondly, specific text pieces were identified as the content and
21 context related to each other and the study aim. Thirdly, descriptive codes were produced and assigned.
22
23
24
25
26 Finally, the text was condensed into categories. The group of authors discussed the meanings and
27 understandings during the whole process.

28 29 30 31 **Ethics**

32
33 Informed consent was obtained from all individual study participants. The study was approved by The
34 Regional Scientific Ethical Committees for Southern Denmark (S-20122000 86), the Danish Data Protection
35 Agency (J. no. 2008-58-0035) and the Department of Hematology, OUH. The first author had no
36 professional medical interaction with the participants during the study period. We carefully recognize that
37 participation in research while undergoing treatment for a serious illness puts strain on patients.
38
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44 45 **Results**

46
47 Patients did not use the word 'rehabilitation' about the process of regaining physical, mental and social
48 functioning. Rehabilitation was therefore an analytical condensation of the AL patients' assessments of their
49 capability and experiences of supportive initiatives. Subcategories of physical activity, mental well-being
50 and social activity were constructed. Existential reflections and challenges emerged during interviews.
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56 Reorganization of the everyday life practices was a first step for many of the patients. This process began
57 when being discharged from hospital the first time and continued after end of treatment. They described how
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4 they had lacked the energy to participate in a full day's program, and for example had escalated activities
5
6 from twice a week to every second day and from one to five hours. Their pace was still slow through all
7
8 activities, and a nap in the afternoon was often needed. They preferred projects without a deadline (Table 2,
9
10 quote 1).

11
12
13 Limited house-keeping tasks, such as cutting the grass or vacuuming the house which would have posed no
14
15 problem prior to the onset of illness were now 'physically demanding'. This challenged them substantially
16
17 and greatly impacted their daily lives and psychosocial well-being. They had expected this during treatment
18
19 but six months after end of treatment, the patients had expected to be 'back to normal'.
20
21

22 **Physical activity**

23
24 Nearly all patients reported that they went for walks, but the intensity, the distance and how often varied
25
26 between patients and times during the illness trajectory. Some patients with neuropathy in the feet could only
27
28 walk brief distances, whereas others walked for 1½ hour. The simple exercises, including the use of elastic
29
30 exercise bands, as instructed at OUH were used by many patients (Table 3, quote 1).
31
32

33
34 Referral from the hospital to the municipality for rehabilitation services was not systematic. The service
35
36 offered by the municipalities comprised group training with other types of patients, one hour twice a week
37
38 for six to twelve weeks. All experienced to be the only patient with AL/HSCT. By the end of the course of
39
40 training many were told that they performed too well to continue in the group. The patients described a lack
41
42 of enthusiasm and competences by the health care professionals in the municipalities (Table 3, quote 3).
43
44

45
46 After concluding chemotherapy, a handful of patients exercised more intensively in a fitness center; did bike
47
48 rides of 50 kilometers, swims of 1000 meters or three to four kilometers of running. They wanted to regain
49
50 their usual physical strength and fitness but also aimed to be prepared if the AL relapsed (Table 3, quote 2).
51

52
53 None of the patients were satisfied with their physical status six months after the end of treatment or with
54
55 being less capable than expected. In hindsight they reflected that it had been too easy to 'escape' the
56
57 physiotherapist during hospitalization. They did not remember having been encouraged to be physically
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59 active when referred to the OPS. In the first interviews [15] the patients described how they prioritized
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4 socializing with fellow patients in the OPS to the detriment of physical training. Still, they did not participate
5
6 in organized training but were more active through all the unnoticed activities at home, such as doing the
7
8 laundry, the dishes or walking the stairs [15]. However, activities that were part of their everyday life were
9
10 not perceived by patients as exercise.
11

12
13 The outcome of training programs offered by the municipality was experienced by the patients as low, and
14
15 they often performed too well to continue the program. Being evaluated in this way seemed
16
17 counterproductive to their motivation to continue training and produced dissatisfaction with their own
18
19 physical capability at the time of the last interview. The lack of physical capability still prevented the
20
21 patients from engaging in everyday life activities as they used to and wanted to.
22
23

24 **Mental well-being**

25
26 The treatment and the physical capability strongly influenced the mental well-being of the patients. When
27
28 not feeling better or when physical symptoms caused uncertainty the patients felt challenged (Table 4, quote
29
30 1).
31

32
33 Anxiety was always present but seldom shown, patients reported. Small things like a spot on the skin
34
35 initiated a flow of thoughts: graft versus host disease – AL relapse – death. One way to avoid these thoughts
36
37 was to be occupied with practical tasks and another way was to talk to family members or friends. All
38
39 patients used these coping strategies to a varying extent, and furthermore they talked to fellow-patients, when
40
41 meeting in the OPS.
42
43

44
45 AL had challenged their invulnerability and sense of self which was usually shaped by work or social
46
47 activities. Therefore, many patients raised the existential question: ‘Who am I – besides being a leukemia
48
49 patient?’ (Table 4, quote 2). Patients had perceived that being cured was the end of the illness trajectory. The
50
51 stepwise prolongation experienced by everyone was psychologically draining. Furthermore, it was hard
52
53 never to be given a ‘cured-date’. As an alternative some patients made their own goals for when to view
54
55 themselves as cured (Table 4, quote 3).
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4 Few patients had consulted a psychologist during the illness trajectory. The majority experienced no need to,
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6 especially not in the beginning when survival and physical issues had priority. Later, it was a barrier to seek
7
8 counseling knowing they would have to describe their illness trajectory once again.
9

10
11 Mental well-being was influenced by flow in treatment and physical capability. Most patients addressed the
12
13 mental challenges by talking to family and friends, which was also reflected by the fact that few patients had
14
15 contacted a psychologist.
16

Social activity

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19 As previously described the social life of patients suffered while being inpatients, while outpatient
20
21 management allowed for more time spent together with fellow patients. This type of community became an
22
23 important and highly valued part of their social life [15].
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26
27 The difference between friends and acquaintances became more apparent as time went by. Losing contact
28
29 with persons previously counted as friends was a mental strain (Table 5, quote 1). As the trajectory proceed
30
31 patients wanted the conversation to turn away from illness and treatment on to everyday things and the future
32
33 (Table 5, quote 2).
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36
37 The treatment precautions during periods with severe hematological neutropenia meant that patients only
38
39 saw a few people at a time and that nearly all social activity took place at home or at the hospital. Returning
40
41 to a more regular social life after end of treatment was overwhelming and unexpectedly demanding (Table 5,
42
43 quote 3).
44

45
46 Six months after the end of treatment the energy level of patients was still impaired. Patients thus had to
47
48 choose for themselves what to participate in, and social activities were in competition with practical tasks,
49
50 physical activity and work (Table 5, quote 4).
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52
53 The patients described how it was unexpectedly demanding to regain a meaningful social life. None of the
54
55 patients experienced or expected that social life had the attention of professional intervention.
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Discussion

Six months after the end of treatment AL patients were dissatisfied with their physical, psychological and social capability. The rehabilitation support during all phases of treatment including HSCT and the following phase of recovery were experienced as non-existing, minimal or inadequate.

Patients did not exercise as much as they wanted to. This seemed in line with a long hematological tradition of avoiding physical training during periods of cytopenia even though a recent study has shown that patients may be able to attend physical training and benefit from this during treatment [8,21]. Less contact with healthcare professionals during outpatient management and thereby less focus on the potential benefits of physical activity may also serve as an explanation. In our study six months after the end of treatment, patients did not recall that there might have been attention to physical activity during the course of treatment. At the same time they describe having refused the physiotherapist's training offer and prioritized the social engagement while at the OPS [15]. It was a deliberate choice showing that the patients' attitude towards training changed during the treatment period. They had no motivation for physical training during the first part of the illness trajectory but felt highly motivated after end of treatment. According to the patients the municipalities did not offer training courses matching their needs – at that time. Some patients experienced that they were performing too well to participate which contrasted their own perception of lacking physical capabilities to participate in everyday activities. Individual needs assessment based on the ICF-model could assist future patients as well as the responsible practitioners in the municipalities to evaluate the functional level and performance of individual patients [19].

It is relevant to consider that there is a difference between the patients' attitudes and concrete actions regarding physical training during treatment. In the late modern society, patients are expected to take individual responsibility for their own health and health behavior – such as physical exercise, healthy food and so on [22]. It may be experienced as stigmatizing to the patients not to satisfy such expectations. This could, as a context for blaming the health care system for a lack of attention, moving the responsibility away from the self and to the system [22,23].

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4 In line with the ICF-model the treatment and the physical capability strongly influenced the mental well-
5 being of the patients [19]. Few patients called for easier access to psychologists but the majority found no
6 need since they experienced support from family, friends and other health care professionals. This is in line
7 with a questionnaire study among 132 mixed hematological and oncological patients [24]. Internationally,
8 systematic needs assessment has been recommended as part of routine cancer care to uncover substantial
9 needs for professional support that would otherwise not be addressed [18]. However, none of the patients in
10 our study have had such a consultation. Another explanation to the sparse demand for psychological support
11 may be that the weakest patients declined to participate in the study, had left, or that demanding existential
12 problems surface later.
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24 The patients had to prioritize caring for themselves even though it sometimes caused emotional limbo, as
25 described in a previous focus group interview study of mixed cancer patients [25]. Social reintegration
26 unexpectedly required an effort, and they had to challenge themselves step-by-step. None seemed to expect
27 professional help and no one stated that they should have been warned of the social challenges. This gives
28 the impression that the patients made no connection between their social life and the possibility of
29 professional support, e.g. as part of rehabilitation in line with the definition [18] and ICF-model [19].
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37 **Strength and limitations**

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39
40 The study design with a relatively small number of participants impedes generalization to the wider
41 population of hematological cancer patients. The majority of patients received a HSCT as the final treatment
42 entity, and we were not able to differentiate our analysis in this regard. The patients showed a high degree of
43 self-preservation instinct during the illness trajectory, which may indicate a selection bias. However, the
44 theoretical framework of rehabilitation may strengthen the possibility of analytical generalization. Using the
45 ICF-model as basis of the data analysis, the focus was on physical, psychological and social functioning of
46 the body, activity and participation together with health-related and environmental factors. In a
47 rehabilitation perspective of this specific group of cancer patients six months after intensive treatment seems
48 a short time. Additional data after one year or longer may show other aspects and perspectives on for
49 example, late mental or existential problems that cause other needs for rehabilitation.
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Perspectives

This study has several implications for future patients. The patients wanted the rehabilitation process to begin shortly after the start of treatment. This is in line with all rehabilitation recommendations [19,18] and highlights the need for focus on maintaining instead of catching up lost capabilities.

The need for continuous motivation by health care professionals was underlined. Patients' understanding of and focus on the importance of physical activity for future performance are important, especially on days with exhausting symptoms or bad mood. Even minor everyday activities like the change of linen counter loss of muscle and impaired physical capability [8]. Simple exercises could be introduced shortly after the start of treatment and be supervised through treatment including the OPS. Perhaps it is possible to couple these with social engagement with fellow patients. This may support continuity and activities across different hospitals, home and municipality initiatives improving well-being and quality of life among patients.

Psychological counseling may support some patients, but health care professionals should be aware of patient barriers rising from the need to 'tell their story' once more.

A review of the evidence for the treatment initiated precautions can lead to improve patients' participation in role functioning, family- and social life. Furthermore this study suggests timely preparation of patient and family members for them to understand that regaining a normal social life after end of treatment will be another demanding phase.

Conclusion

In conclusion, the findings of this study contribute to our understanding of how AL outpatients treated with curative intension, including HSCT, experience rehabilitation up to six months after end of treatment.

None of the patients were satisfied with their physical capability six months after end of treatment. They managed to be physically active through daily tasks and had not experienced being offered an exercise program matching their needs at the end of treatment when their motivation for being physically active arose. Psychologically the patients struggled with anxiety with regards to infections or relapse, and their perceived needs for progress in the treatment and in everyday functioning to feel well. Talking to family and friends

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4 was experienced as a good way of addressing psychological challenges. The precautions stipulated by the
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6 hospitals restricted social life and it unexpectedly demanded an effort by the patients to regain a meaningful
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8 social life.
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11 Room for improvement of rehabilitation initiatives, from both the health care system and the municipalities,
12
13 has been identified. Regular needs assessment should be used to understand changes in health and motivation
14
15 during the illness trajectory. Health care professionals should remember that six months after end of
16
17 treatment is too early to expect full recovery of many everyday basic skills. For the benefit of the patients,
18
19 information about the rehabilitation process can be given up front, but must be addressed continuously.
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21

22 23 24 **Acknowledgements**

25
26 The authors wish to thank all the patients who participated in the study for their valuable contributions
27
28 during a difficult period of their lives. This study was funded by the University of Southern Denmark, the
29
30 Region of Southern Denmark, The Danish Cancer Society, the Anders Hasselbalch Foundation, the Family
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32 Hede Nielsen Foundation and the joint research pool between National University Hospital and Odense
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34 University Hospital supporting the highly-specialized functions. The National Research Center of Cancer
35
36 Rehabilitation, University of Southern Denmark is partly funded by the Danish Cancer Society.
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Figure 1: Enrollment of patients

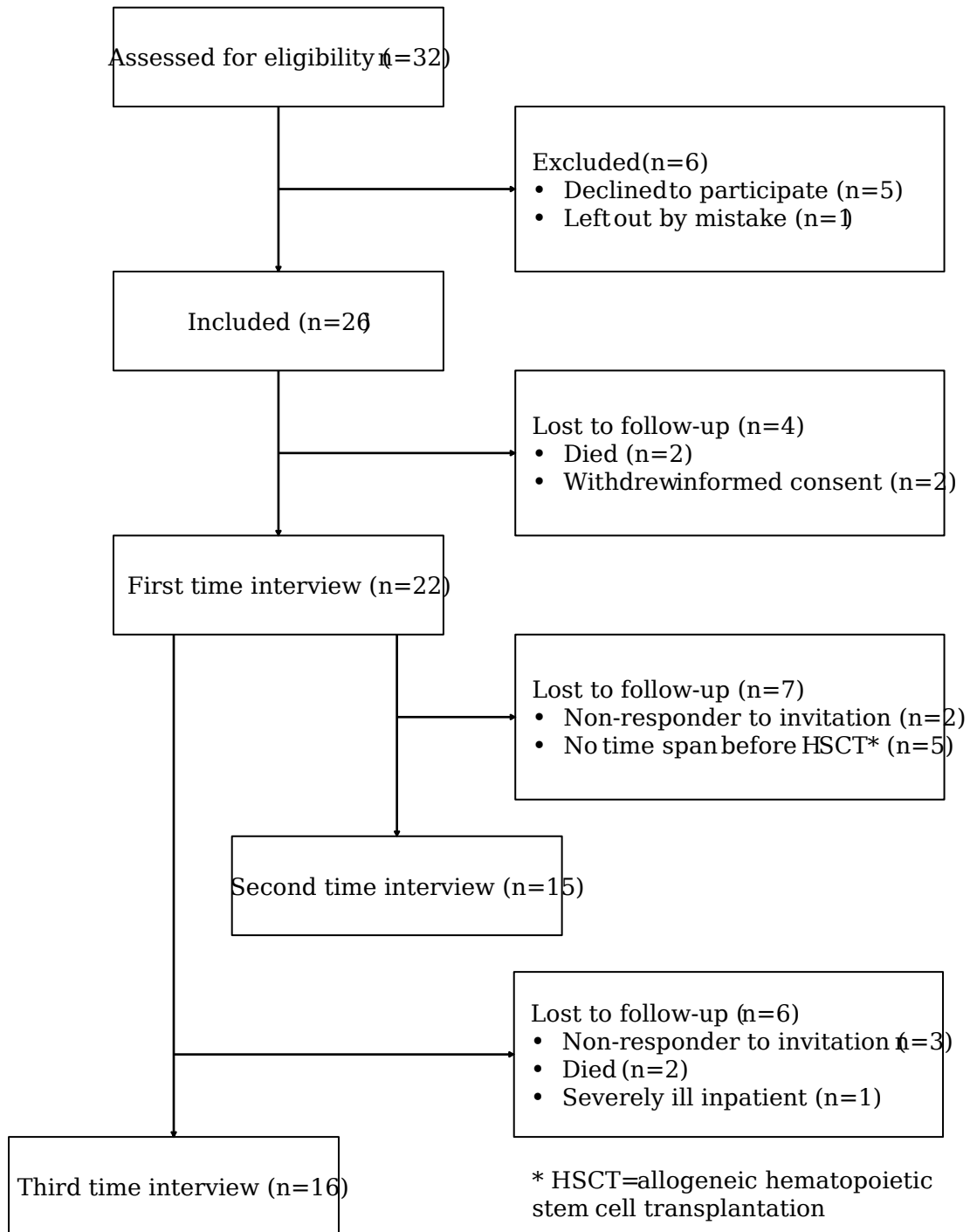


Table 1 Demographic characteristics of study participants (n=16)	
Sample characteristics	Description
Gender	
Male	9 (56 %)
Female	7 (44 %)
Age (years)	
< 60	8 (50 %)
≥ 60	8 (50 %)
Marital status	
Married or common-law relationship	13 (81 %)
Single/divorced	3 (19 %)
Education	
Unskilled workers	2 (12 %)
Skilled workers	10 (63 %)
Further education	4 (25 %)
Diagnosis	
Acute myeloid leukemia (AML)	11 (69 %) (3 relapse)
Chronic myeloid leukemia in myeloid blast crisis (CML)	1 (6 %)
Chronic myelomonocytic leukemia (CMML)	1 (6 %)
Refractory anemia with excess blasts (RAEB)	1 (6 %)
Acute lymphoblastic leukemia (ALL)	2 (13 %)
Time from diagnosis to third interview (weeks)	Mean 51.9 ; range 40-72
Treatment status	
Outpatient Clinic follow-up	3 (19 %)
Allogenic hematopoietic stem cell transplantation, <i>National University Hospital, Copenhagen</i>	8 (50 %)
Allogenic hematopoietic stem cell transplantation, <i>Aarhus University Hospital</i>	2 (12 %)

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Second line therapy, Odense University Hospital	3 (19 %)
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For peer review only

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Table 2 Sample statements from participants		
Quote	Patient	Statement
1	25	'If I have to do something that is physically demanding, it will have to be something that I can go on and off. Otherwise I will not begin because I know that I will not be able to finish it.'

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Quote	Patient	Statement
1	10	'I've only made those exercises and I feel a little – guilty about it because they said: You should just [walk] half an hour round the neighborhood. [] I'm a little afraid to fall. The energy level is also crucial. But now for example to day I would be able to do it. I would be able to walk half an hour. But then tomorrow maybe I'm just as limp as a dishrag.'
2	23	'For me, who comes with muscles, which are nor destroyed or cut in but just slack after lying in a bed – the training [arranged by the municipality] is worth nothing.'
3	18	'So I was active. [] But I also think I had constantly in my mind – if the – my leukemia comes back, I'll fucking be in good shape, right.'

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Quote	Patient	Statement
1	19	'But I think psychologically or mentally we are pretty strong. That's not a problem, right. That I can recognize clearly. The only time I got a knock, right, was when the one kidney stopped working. There I thought damn, what is brewing now. Because it was like, it is after all a serious matter, right and it is obviously clear that it had to do with everything else – in some wired way.'
2	23	'Principally you are a lot because of you training and the background you have and what you do.'
3	25	'Your status gets chronic. I have actually not lurked exactly what you get, but I have certainly been told that I do not get a fitness-for-duty certificate. So I just had, in a different way, to define to myself when I'm recovered. And I am when I run my next half marathon. Then I will have to start somewhere. And the sooner I get started after all, the sooner I run a half marathon, the sooner I'm recovered.'

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Table 5 Sample statements from participants: Social activity		
Quote	Patient	Statement
1	21	'It's actually been more intense, I think, if one can say so. So you are together, that is, you think more about it when you are together. That's because we want to see them. It is not just that, eej, now we have to invite them, now is such and such. That's not how it is. You see these people because you want to have anything to do with them.'
2	25	'When we get together with friends, then there is a lot of talk about my illness. And that's fair enough, so now let's talk about it and then move on. I also need some input, from the outside.'
3	18	'Yes, I have also begun to go and watch a football match and stuff even that it's not my interest at all. But it is- to learn to get along in those large gatherings. That was enormously difficult I think. All that noise I should get used to. It is difficult when you have been just inside the house without anything. So it's something that you have to get used to, puuhh, you are just tired, right. It's crazy when you suddenly have to be social in that way, right. That was tough, I think. So I challenged myself that way.'
4	2	'And then I was at work yesterday morning and in the afternoon I should have been to a co-worker's 60 th birthday reception. But then I just went home to take a nap and when I woke up to go out there... But then I just had to admit I needed to protect myself. So I wrote a nice little note. I have said that I would help and that meant a lot to them. But that's something I have learned. Even when something is important to others I have to prioritize because I myself have some goals and I have to feel and realize that I cannot jump to everything.'

BMJ Open

Rehabilitation during intensive treatment of acute leukemia including allogeneic stem cell transplantation – a qualitative study of patient experiences

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-029470.R1
Article Type:	Original research
Date Submitted by the Author:	03-Oct-2019
Complete List of Authors:	Jepsen, Lene Østergaard; Odense Universitetshospital, Friis, Lone Smidstrup; Rigshospitalet, Hematology Hoybye, Mette Terp; Regionshospitalet Silkeborg, 3. Interdisciplinary Research Unit, Elective Surgery Center Marcher, Claus Werenberg; Odense Universitetshospital, Hematology Hansen, Dorte; University of Southern Denmark, National Research Centre for Cancer Rehabilitation, National Research Centre for Cancer Rehabilitation, Research Unit of General Practice
Primary Subject Heading:	Haematology (incl blood transfusion)
Secondary Subject Heading:	Qualitative research
Keywords:	Leukaemia < HAEMATOLOGY, REHABILITATION MEDICINE, Everyday life, QUALITATIVE RESEARCH

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4 Rehabilitation during intensive treatment of acute leukemia including allogenic stem cell
5 transplantation – a qualitative study of patient experiences
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4 **Abstract**
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6 **Objectives**
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8 The diagnosis and treatment of acute leukemia affect physical, psychosocial and existential functioning.

9 Long-lasting treatment periods with impaired immune system, hygienic and social restrictions challenge
10 patient well-being and rehabilitation as compared to other individuals with cancer. This study elucidates how
11 acute leukemia patients, treated with curative intent in an outpatient setting, assess their physical,
12 psychosocial and existential capability during and following treatment, and furthermore reports on the health
13 initiatives offered to support their rehabilitation.
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22 **Design, setting, participants and interventions**
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24 We conducted qualitative, semi-structured individual interviews with 16 acute leukemia patients, six months
25 after end of treatment in the patients' homes. This was the final interview, in a line of three, carried out as
26 part of a larger qualitative study.
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31 **Results**
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33 The data was analyzed thematically through an inductive ongoing process consisting of four steps, resulting
34 in the following three categories: physical activity, mental well-being and social activity. None of the
35 patients were satisfied with their physical capability at the time of interview and experienced substantial
36 impairment of functional capabilities. All patients struggled with anxiety and expressed a need for
37 continuous progress in treatment and well-being to be feeling safe. It took an unexpected large effort to
38 regain a meaningful social life, and patients still had to prioritize activities.
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47 **Conclusions**
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49 Acute leukemia patients suffered physically, psychologically and existentially throughout their illness
50 trajectory. Rehabilitation initiatives deriving from the health care system and municipalities held room for
51 improvement. Future programs should pay attention to the contextual changes of treatment of this patient
52 group and individuals' changing needs and motivation of physical exercise.
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Summary

Strength and limitations of the study

- A relatively small number of participants may challenge generalization to the wider population of individuals with hematological cancer
- The patients showed a high degree of self-preservation instinct during the illness trajectory, which may indicate a selection bias
- The theoretical framework of rehabilitation may strengthen the possibility of analytical generalization

Funding

This work was supported by the University of Southern Denmark, DKK 400.000, the Region of Southern Denmark, DKK 500.000, The Danish Cancer Society, DKK 465.000, the Anders Hasselbalch Foundation, DKK 20.000, the Family Hede Nielsen Foundation, DKK 25.000 and the joint research pool between National University Hospital and Odense University Hospital supporting the highly-specialized functions, DKK 40.000. The National Research Center of Cancer Rehabilitation, University of Southern Denmark is partly funded by the Danish Cancer Society.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Author contribution

LØJ participated in the design of the study, carried out the interviews, analyzed data and drafted the manuscript. LF participated in the design of the study and in the discussion of the analysis and the results. She also critically revised the manuscript. CM participated in the discussion of the analysis and the results. He also critically revised the manuscript. MH participated in the design of the study and in the discussion of the analysis and the results. She also critically revised the manuscript. DH participated in the design of the study and in the discussion of the analysis and the results. She also critically revised the manuscript. All authors read and approved the final manuscript.

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4 **Patient consent form**

5 Written informed consent for publication of their transcribed interviews was obtained from the patients and
6
7 their spouses. A copy of the consent form is available for review by the Editor of this journal.
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11 **Data sharing**

12 The dataset generated and analyzed during the current study is not publicly available because it contains
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14 information that could compromise research participant privacy, but is available from the corresponding
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16 author on reasonable request.
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20 **Keywords**

21 Rehabilitation, acute leukemia, everyday life, qualitative study
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Introduction

Patients with acute leukemia (AL) undergo extraordinary long periods of intensive treatment with high susceptibility to sudden and dramatic changes in their health condition and prognosis [1]. Impairment of the immune system necessitates substantial hygienic and social restrictions. However, during the last decade, a paradigm shift in the treatment of these severely immune insufficient patients has occurred. The patients who were formerly isolated at the hospital during their highly intensive treatment are now managed in the outpatient setting while concurrently living at home. Rehabilitation needs of the patients and rehabilitation offers by the health care system are challenged by these organizational changes. However, little clinical or research attention has been paid to rehabilitation and survivorship care for this specific group of immune insufficient individuals with hematological cancer managed in an outpatient setting.

In this paper, the concept of rehabilitation refers to specific initiatives and efforts by health professionals but is also an analytical concept for describing the process in which the patients reframe a sense of self [2].

The existing knowledge underlines beneficial effects of rehabilitation to individuals with cancer. From a few studies, we know that physical exercise is feasible and safe for AL inpatients, even those with critical cytopenia. Beneficial effects on physical performance, fatigue and quality of life have been shown [3-9]. As an example, supervised exercise and health counseling intervention for patients with AL during outpatient management showed physical, functional, psychosocial, and symptom benefits [8]. Patients undergoing allogenic hematopoietic stem cell transplantation (HSCT) due to hematological malignancies have also shown significant benefit from exercise interventions without reports of negative effects [9].

Health-related quality of life of individuals with hematological cancer is lowered mainly due to reduced role functioning, insomnia and fatigue [10,11]. Unmet needs of rehabilitation are strongly associated with impaired quality of life for individuals with cancer in general [12]. Psychological counseling, physical rehabilitation, sexual and financial support and practical help have been found to be important, but needs vary with age, sex and cancer diagnosis [13,14].

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4 Summing up, the existing knowledge underlines the beneficial effects of rehabilitation to patients with AL.
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6 However, the rapid changes of treatment setting, patient population and lack of knowledge of existing
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8 evidence may leave patients with unmet needs and functional impairment. Knowledge about patients'
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10 experiences and expectations from the very special context of outpatient management may have the potential
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12 to improve well-being of an increasing and still older group of intensively treated patients.
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15 Based on patient interviews this paper elucidates how patients with AL treated with curative aim assess their
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17 physical, psychosocial and existential capability during and following treatment and health initiatives
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19 supporting their rehabilitation.
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21

Material and methods**Design**

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27 The material derives from individual, semi-structured interviews with 16 patients, six months after end of
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29 treatment. This type of interview was deemed suitable to access and explore patient experience in an open
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31 manner to allow for patients to add their own perspectives to the interviewer's agenda. These interviews
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33 were the third and final interview, conducted as part of a larger qualitative study with the overall aim of
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35 exploring the outpatient setting as a context of intensive cancer treatment [15,16]. We combined participant
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37 observation in the outpatient setting (OPS), individual patient interviews, and group or individual interviews
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39 with their relatives. Patients were consecutively invited by and gave consent to the first author, LØJ, who
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41 conducted the interviews. LØJ presented herself as a PhD student and young medical doctor with previous
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43 experience in the department.
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47 Semi-structured interviews were conducted based on a thematic interview guide [15]. The first topic was
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49 'impact on everyday life practices' where rehabilitation issues were addressed by questions such as 'Try to
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51 describe your present physical capability and how you reached that level'. The question was repeated for
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53 psychosocial and existential well-being. There was one main question to each topic, and depending on the
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55 patient's answers, three to eighteen additional questions to facilitate a talk covering the topic sufficiently.
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The second topic, ‘the home’, explored daily life at home and the roles of the family, whereas the third topic ‘hygiene’ addressed the impact of intense hygiene requirements.

Patient and Public involvement

Patients were not involved in the research design.

Participants and interviews

Participants were Danish speaking patients with AL intensively treated with a curative aim. All were managed in the OPS, ‘the Home Unit’ at the Department of Hematology, Odense University Hospital (OUH) and subsequently followed in the outpatient clinic at OUH or at the National University Hospital, Copenhagen or at Aarhus University Hospital if allogeneically transplanted [15].

Twenty-six patients were included from May 2013 to August 2014, and out of this group, 16 took part in this third interview, six months after end of treatment (Figure 1). Table 1 shows the demographic and clinical characteristics.

Table 1 Demographic and clinical characteristics of study participants (n=16)	
Sample characteristics, third interview	Description
Gender	
• Male	9 (56 %)
• Female	7 (44 %)
Age (years)	Mean 55.1; range up to 75)
• < 60	8 (50 %)
• ≥ 60	8 (50 %)
Marital status	
• Married or common-law relationship	13 (81 %)
• Single/divorced	3 (19 %)
Education	
• Unskilled workers	2 (12 %)
• Skilled workers	10 (63 %)

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<ul style="list-style-type: none"> • Further education 	4 (25 %)
Diagnosis*	
<ul style="list-style-type: none"> • Acute myeloid leukemia (AML) 	11 (69 %) (3 relapse)
<ul style="list-style-type: none"> • Chronic myeloid leukemia in myeloid blast crisis (CML) 	1 (6 %)
<ul style="list-style-type: none"> • Chronic myelomonocytic leukemia (CMML) 	1 (6 %)
<ul style="list-style-type: none"> • Refractory anemia with excess blasts (RAEB) 	1 (6 %)
<ul style="list-style-type: none"> • Acute lymphoblastic leukemia (ALL) 	2 (13 %)
Time from diagnosis to third interview (weeks)	Mean 51.9; range 40-72
Treatment status	
<ul style="list-style-type: none"> • Outpatient Clinic follow-up, Odense University Hospital 	3 (19 %)
<ul style="list-style-type: none"> • Allogenic hematopoietic stem cell transplantation, National University Hospital, Copenhagen or Aarhus University Hospital 	10 (62 %)
<ul style="list-style-type: none"> • Second line therapy, Odense University Hospital 	3 (19 %)
<p>The CML, CMML and RAEB special leukemia diagnoses, which are chronic diseases, but often turn into acute leukemia after a short time. Therefore, they received treatment equivalent to acute leukemia patients' regimens and were handled identically to them.</p>	

The interviews were conducted in the patients' home and lasted from 40 to 115 minutes (mean 68 minutes).

All interviews were digitally recorded.

Context for rehabilitation

Rehabilitation has previously been understood as a practice related to the post-treatment life of patients, but the facilities and practices of the hospital during in and outpatient management may be considered a context of rehabilitation of patients with AL. In addition, non-hospital settings may be part of the rehabilitation.

The course of treatment for newly diagnosed patients with AL who are candidates for curative intended chemotherapy contains both in and outpatient periods. The latter where the patients, during periods with severe hematological cytopenia, stay at home and appear at follow-up visits every second day [15].

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4 The OPS was situated next to the hematological department, OUH, where all the patients could use the
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6 fitness facilities located there. A physiotherapist was present twice a week to instruct the patients.
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9 Before receiving the transplant, patients were instructed in some simple exercises by a physiotherapist.
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11 Furthermore, all patients had an exercise-bike in their bed-room during periods of isolation at the hospital.
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14 In addition to physical exercise, patients could, at any time, ask for a referral for individual advice by a
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16 physiotherapist, a psychologist, a chaplain or a medical social worker at the department. Furthermore,
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18 psychologists from The Danish Cancer Society were available to patients and relatives in facilities at the
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20 hospital.
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23 In Denmark, the overall responsibility of rehabilitation is located at the local municipality level (98
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25 municipalities/5.6 million inhabitants). Due to different demographics, staff and geography of the
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27 municipalities, patients meet different offers and knowledge about their disease [17].
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30 **Theoretical framework and analysis**

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32 The study was based on the World Health Organization (WHO) definition of rehabilitation [18], but
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34 simultaneously acknowledged that rehabilitation formed an analytical approach to the physical, psychosocial
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36 and existential challenges facing the patients with AL, and was not a structural or organizational intervention
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38 as such. This paper aims to study the configuration of rehabilitation needs as experienced by patients with
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40 AL and to draw attention to possible contextual factors that should be taken into account in future programs.
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42 To further support our analytical exploration, the theoretical framework included International Classification
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44 of Functioning, Disability and Health (ICF) pointing out the dynamic interaction of health condition, body
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46 function and structure, activity, participation, and personal as well as environmental factors [19].
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50 The data were analyzed thematically through an inductive ongoing process of four steps inspired by Miles
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52 and Huberman [20]. First, the interviews were transcribed by a secretary and read several times by LØJ to
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54 gain an overall understanding of the material. Secondly, specific paragraphs were identified as the content
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56 and context related to each other and the study aim. Thirdly, descriptive codes were produced and assigned.
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4 Finally, the text was condensed into categories. The group of authors discussed the contents and
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6 interpretation of data throughout the process.
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Ethics

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11 Informed consent was obtained from all individual study participants. The study was approved by The
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13 Regional Scientific Ethical Committees for Southern Denmark (S-20122000 86), the Danish Data Protection
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15 Agency (J. no. 2008-58-0035) and the Department of Hematology, OUH. The first author had no
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17 professional medical interaction with the participants during the study period. We carefully recognize that
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19 participation in research while undergoing treatment for a serious illness puts strain on patients.
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Results

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24 Patients did not use the word ‘rehabilitation’ about the process of regaining physical, mental and social
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26 functioning. Rehabilitation was therefore an analytical condensation of the AL patients’ assessments of their
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28 capability and experiences of supportive initiatives. Subcategories of physical activity, mental well-being
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30 and social activity were constructed and will be described separately in the following, although strongly
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32 interrelated as conceptualized by WHO and in the ICF-model [19]. Existential reflections and challenges
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34 emerged during interviews.
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38 Reorganization of the everyday life practices was a first step for many of the patients. This process began
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40 when being discharged from hospital the first time and continued after end of treatment. They described how
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42 they had lacked the energy to participate in a full day’s program, and for example had escalated activities
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44 from twice a week to every second day and from one to five hours. Their pace was still slow through all
45
46 activities, and a nap in the afternoon was often needed. They preferred projects without a deadline (Table 2,
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48 quote 1).
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Table 2 Sample statements from participants		
Quote	Patient	Statement
1	25	‘If I have to do something that is physically demanding, it will have to be something that I can go to and from. Otherwise I will not begin because I know that I will not be able to finish it.’

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Limited house-keeping tasks, such as cutting the grass or vacuuming the house which would have posed no problem prior to the onset of illness were now ‘physically demanding’. This challenged them substantially and greatly impacted their daily lives and psychosocial well-being. They had expected this during treatment, but six months after end of treatment, the patients had expected to be ‘back to normal’.

Physical activity

Nearly all patients reported that they went for walks, but the intensity, the distance and how often varied between patients and times during the illness trajectory. Some patients with neuropathy in the feet could only walk brief distances, whereas others walked for 1½ hour. The simple exercises, including the use of elastic exercise bands, as instructed at OUH were used by many patients (Table 3, quote 1).

Table 3 Sample statements from participants: Physical activity

Quote	Patient	Statement
1	10	‘I’ve only made those exercises and I feel a little – guilty about it because they said, You should just [walk] half an hour round the neighborhood. [] I’m a little afraid to fall. The energy level is also crucial. But now for example to day I would be able to do it. I would be able to walk half an hour. But then tomorrow maybe I’m just as limp as a dishrag.’
2	23	‘For me, who comes with muscles, which are nor destroyed or cut in but just slack after lying in a bed – the training [arranged by the municipality] is worth nothing.’
3	18	‘So I was active. [] But I also think I had constantly in my mind – if it – my leukemia comes back, I’ll fucking be in good shape, right.’

Referral from the hospital to the municipality for rehabilitation services was not systematic. The service offered by the municipalities comprised group training with other types of patients, one hour twice a week for six to twelve weeks. All the participants of this study experienced being the only patient with AL/HSCT. By the end of the course of training many were told that they performed too well to continue in the group. The patients described a lack of enthusiasm and competences by the health care professionals in the municipalities (Table 3, quote 2).

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After concluding chemotherapy, a handful of patients exercised more intensively in a fitness center; did bike rides of 50 kilometers, swims of 1000 meters or three to four kilometers of running. They wanted to regain their usual physical strength and fitness but also aimed to be prepared if the AL relapsed (Table 3, quote 3).

None of the patients were satisfied with their physical status six months after the end of treatment or with being less capable than expected. In hindsight they reflected that it had been too easy to ‘escape’ the physiotherapist during hospitalization. They did not remember having been encouraged to be physically active when referred to the OPS. In the first interviews [15] the patients described how they prioritized socializing with fellow patients in the OPS to the detriment of physical training. Still, they did not participate in organized training but were more active through all the unnoticed activities at home, such as doing the laundry, the dishes or walking the stairs [15]. However, activities that were part of their everyday life were not perceived by patients as exercise.

The outcome of training programs offered by the municipality was experienced by the patients as low, and they often performed too well to continue the program. Being evaluated in this way seemed counterproductive to their motivation to continue training and produced dissatisfaction with their own physical capability at the time of the last interview. The lack of physical capability still prevented the patients from engaging in everyday life activities as they used to and wanted to.

Mental well-being

The treatment and the physical capability strongly influenced the mental well-being of the patients. When not feeling better or when physical symptoms caused uncertainty the patients felt challenged (Table 4, quote 1).

Table 4 Sample statements from participants: Mental well-being

Quote	Patient	Statement
1	19	‘But I think psychologically or mentally we are pretty strong. That’s not a problem, right. That I can recognize clearly. The only time I got a knock, right, was when the one kidney stopped working. There I thought damn, what is brewing now. Because it was like, it is after all a serious matter, right and it is obviously clear that it had to do with everything else – in some weird

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		way.'
2	23	'Principally you are a lot because of you training and the background you have and what you do.'
3	25	'Your status gets chronic. I have actually not spotted exactly what you get, but I have certainly been told that I do not get a fit-for-duty certificate. So I just had, in a different way, to define to myself when I'm recovered. And I am when I run my next half marathon. Then I will have to start somewhere. And the sooner I get started after all, the sooner I run a half marathon, the sooner I'm recovered.'

Anxiety was always present but seldom shown, patients reported. Small things like a spot on the skin initiated a flow of thoughts: graft versus host disease – AL relapse – death. One way to avoid these thoughts was to be occupied with practical tasks and another way was to talk to family members or friends. All patients used these coping strategies to a varying extent, and furthermore they talked to fellow-patients, when meeting in the OPS.

AL had challenged their invulnerability and sense of self, which was usually shaped by work or social activities. Therefore, many patients raised the existential question: 'Who am I – besides being a leukemia patient?' (Table 4, quote 2). Patients had perceived that being cured was the end of the illness trajectory. The stepwise prolongation experienced by everyone was psychologically draining. Furthermore, it was hard never to be given a 'cured-date'. As an alternative some patients made their own goals for when to view themselves as cured (Table 4, quote 3).

Few patients had consulted a psychologist during the illness trajectory. The majority experienced no need to, especially not in the beginning when survival and physical issues had priority. Later, it was a barrier to seek counseling knowing they would have to describe their illness trajectory once again.

Mental well-being was influenced by flow in treatment and physical capability. Most patients addressed the mental challenges by talking to family and friends, which was also reflected by the fact that few patients had contacted a psychologist.

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Social activity

As previously described the social life of patients suffered while being inpatients, while outpatient management allowed for more time spent together with fellow patients. This type of community became an important and highly valued part of their social life [15].

The difference between friends and acquaintances became more apparent as time went by. Losing contact with persons previously counted as friends was a mental strain (Table 5, quote 1).

Table 5 Sample statements from participants: Social activity

Quote	Patient	Statement
1	21	'It's actually been more intense, I think, if one can say so. So you are together, that is, you think more about it when you are together. That's because we want to see them. It is not just that, argh, now we have to invite them, now is such and such. That's not how it is. You see these people because you want to have something to do with them.'
2	25	'When we get together with friends, then there is a lot of talk about my illness. And that's fair enough, so now let's talk about it and then move on. I also need some input, from the outside.'
3	18	'Yes, I have also begun to go and watch a football match and stuff even though that it's not my interest at all. But it is- to learn to get along in those large gatherings. That was enormously difficult I think. All that noise I had to get used to. It is difficult when you have been just inside the house without anything. So it's something that you have to get used to, yikes, you are just tired, right. It's crazy when you suddenly have to be social in that way, right. That was tough, I think. So I challenged myself that way.'
4	2	'And then I was at work yesterday morning and in the afternoon I should have been at a co-worker's 60 th birthday reception. But then I just went home to take a nap and when I woke up to go out there... But then I just had to admit I needed to protect myself. So I wrote a nice little note. I have said that I would help and that meant a lot to them. But that's something I have learned. Even when something is important to others I have to prioritize because I myself have some goals and I have to feel and realize that I cannot jump to everything.'

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4 As the trajectory proceeded patients wanted the conversation to turn away from illness and treatment on to
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6 everyday things and the future (Table 5, quote 2).
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9 The treatment precautions during periods with severe hematological neutropenia meant that patients only
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11 saw a few people at a time and that nearly all social activity took place at home or at the hospital. Returning
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13 to a more regular social life after end of treatment was overwhelming and unexpectedly demanding (Table 5,
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15 quote 3).
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18 Six months after end of treatment the energy level of patients was still impaired. Patients thus had to choose
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20 for themselves what to participate in, and social activities were in competition with practical tasks, physical
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22 activity and work (Table 5, quote 4).
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25 The patients described how it was unexpectedly demanding to regain a meaningful social life. None of the
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27 patients experienced or expected that social life had the attention of professional intervention.
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Discussion

32 Six months after the end of treatment patients with AL were dissatisfied with their physical, psychological
33
34 and social capability. The rehabilitation support during all phases of treatment including HSCT and the
35
36 following phase of recovery were experienced as non-existing, minimal or inadequate.
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40 Our results from the interviews conducted during earlier treatment phases showed that maintaining everyday
41
42 life was highly prioritized by patients as well as spouses [15,16]. In line with that, patients reported that they
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44 did not exercise as much as they wanted to. In contrast with the evidence, a long hematological tradition of
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46 avoiding physical training during periods of cytopenia may still be in practice [8,21]. Patients did not recall
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48 professionals' attention to physical activity during the course of treatment. At the same time they describe
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50 having refused the physiotherapist's training offer and prioritized the social engagement while at the OPS
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52 [15]. Less contact with healthcare professionals during outpatient management may be another important
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54 barrier. Our third interview thereby adds that the patients' attitude towards training changed substantially
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56 from having no motivation to feeling highly motivated after end of treatment. According to the patients the
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4 municipalities did not offer training courses matching these needs – at that time. Some patients were
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6 informed that they were performing too well to participate. Perhaps because they did not suffer from any
7
8 specific disability but were very generally weakened. The termination of the training course contrasted their
9
10 own perception of lacking physical capabilities to participate in everyday activities. Individual needs
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12 assessment based on the ICF-model including ‘activity’ and ‘participation’ could assist future patients and
13
14 responsible practitioners to better understand patients’ functional level and motivation [19].
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18 It is relevant to consider that there is a difference between the patients’ attitudes and concrete actions
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20 regarding physical training during treatment. In the late modern society, patients are expected to take
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22 individual responsibility for their own health and health behavior – such as physical exercise, healthy food
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24 and so on [22]. It may be experienced as stigmatizing to the patients not to satisfy such expectations. This
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26 could, as a context for blaming the health care system for a lack of attention, be moving the responsibility
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28 away from the self and to the system [22,23].
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32 In line with the dynamic of the ICF-model the treatment and the physical capability strongly influenced the
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34 mental well-being of the patients and vice versa [19]. Few patients called for easier access to psychologists
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36 but the majority found no need since they experienced support from family, friends and other health care
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38 professionals. This is in line with a questionnaire study among 132 mixed hematological and oncological
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40 patients [24]. Internationally, systematic needs assessment has been recommended as part of routine cancer
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42 care to uncover substantial needs for professional support that would otherwise not be addressed [18].
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45 However, none of the patients in our study have had such a consultation. Another explanation to the sparse
46
47 demand for psychological support may be that the weakest patients declined to participate in the study, had
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49 left, or that demanding existential problems surface later.

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51 The patients had to prioritize caring for themselves even though it sometimes caused emotional limbo, as
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53 described in a previous focus group interview study of mixed individuals with cancer [25]. Social
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55 reintegration unexpectedly required an effort, and they had to challenge themselves step-by-step. None
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57 seemed to expect professional help and no one stated that they should have been warned of the social
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4 challenges. This gives the impression that the patients made no connection between their social life and the
5 possibility of professional support, e.g. as part of rehabilitation in line with the definition [18] and ICF-model
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7 [19].
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Strength and limitations

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13 The study design with a relatively small number of participants hampers generalization to the wider
14 population of individuals with hematological cancer. The majority of patients received a HSCT as the final
15 treatment entity, and we were not able to differentiate our analysis in this regard. The patients showed a high
16 degree of self-preservation instinct during the illness trajectory, which may indicate a selection bias.
17
18 However, the theoretical framework of rehabilitation may strengthen the possibility of analytical
19 generalization. Using the dynamic ICF-model as basis of the data analysis, the focus was on physical,
20 psychological and social functioning of the body, activity and participation together with health-related and
21 environmental factors. In a rehabilitation perspective of this specific group of individuals with cancer, six
22 months after intensive treatment seems a short time. Additional data after one year or longer may show other
23 aspects and perspectives on for example, late mental or existential problems that cause other needs for
24 rehabilitation.
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Perspectives

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40 This study has several implications for future patients. The patients wanted the rehabilitation process to
41 begin shortly after the start of treatment. This is in line with all rehabilitation recommendations [19,18] and
42 highlights the need for focus on maintaining instead of catching up lost capabilities.
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47 The need for continuous motivation by health care professionals was underlined. Patients' understanding of
48 and focus on the importance of physical activity for future performance are important, especially on days
49 with exhausting symptoms or bad mood. Even minor everyday activities like the change of linen counter loss
50 of muscle and impaired physical capability [8]. Simple exercises could be introduced shortly after the start of
51 treatment and be supervised through treatment including the OPS. Perhaps it is possible to couple these with
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4 social engagement with fellow patients. This may support continuity and activities across different hospitals,
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6 home and municipality initiatives improving well-being and quality of life among patients.
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9 Psychological counseling may support some patients, but health care professionals should be aware of
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11 patient barriers rising from the need to ‘tell their story’ once more.
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14 A review of the evidence for the treatment-initiated precautions can lead to improved patients’ participation
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16 in role functioning, family- and social life. Furthermore this study suggests timely preparation of patient and
17
18 family members for them to understand that regaining a normal social life after end of treatment will be
19
20 another demanding phase.
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Conclusion

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26 In conclusion, the findings of this study contribute to our understanding of how outpatients with AL treated
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28 with curative intension, including HSCT, experience rehabilitation up to six months after end of treatment.
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31 None of the patients were satisfied with their physical capability six months after end of treatment. They
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33 managed to be physically active through daily tasks and had not experienced being offered an exercise
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35 program matching their needs at the end of treatment when their motivation for being physically active arose.
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38 Psychologically the patients struggled with anxiety with regards to infections or relapse, and their perceived
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40 needs for progress in the treatment and in everyday functioning to feel well. Talking to family and friends
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42 was experienced as a good way of addressing psychological challenges. The precautions stipulated by the
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44 hospitals restricted social life and it unexpectedly demanded an effort by the patients to regain a meaningful
45
46 social life.
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49 Room for improvement of rehabilitation initiatives, from both the health care system and the municipalities,
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51 has been identified. Regular needs assessment should be used to understand changes in health and motivation
52
53 during the illness trajectory. Health care professionals should remember that six months after end of
54
55 treatment is too early to expect full recovery of many everyday basic skills. For the benefit of the patients,
56
57 information about the rehabilitation process can be given up front, but must be addressed continuously.
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Figure 1: Enrollment of patients

Acknowledgements

The authors wish to thank all the patients who participated in the study for their valuable contributions during a difficult period of their lives. This study was funded by the University of Southern Denmark, the Region of Southern Denmark, The Danish Cancer Society, the Anders Hasselbalch Foundation, the Family Hede Nielsen Foundation and the joint research pool between National University Hospital and Odense University Hospital supporting the highly-specialized functions. The National Research Center of Cancer Rehabilitation, University of Southern Denmark is partly funded by the Danish Cancer Society.

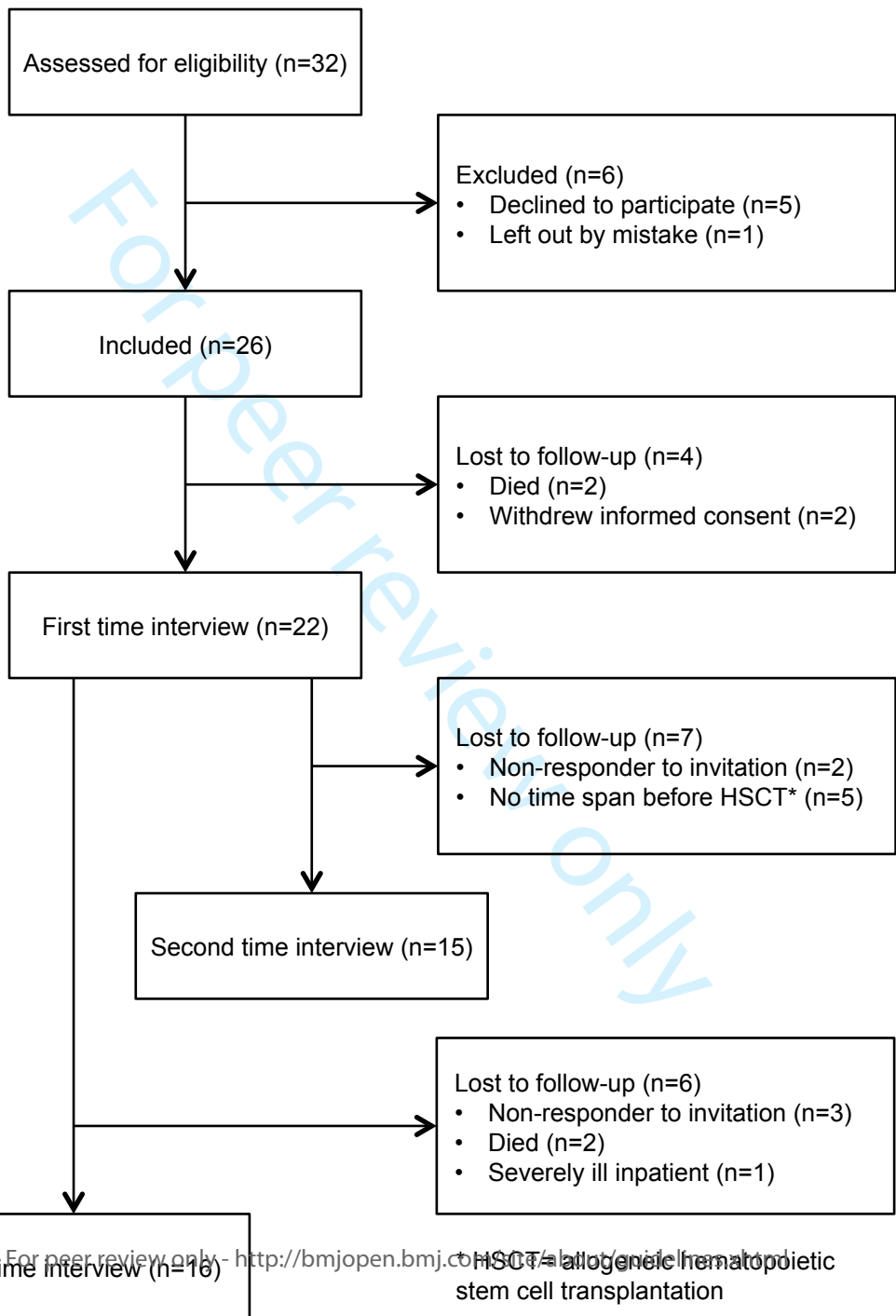
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Figure 1: Enrollment of patients



Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	2

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	5
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	6

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	6
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	6
<p>Context - Setting/site and salient contextual factors; rationale**</p>	8-9
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	7
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	10
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	6

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3	Data collection instruments and technologies - Description of instruments (e.g.,	
4	interview guides, questionnaires) and devices (e.g., audio recorders) used for data	
5	collection; if/how the instrument(s) changed over the course of the study	6
6		
7	Units of study - Number and relevant characteristics of participants, documents,	
8	or events included in the study; level of participation (could be reported in results)	7-8
9		
10	Data processing - Methods for processing data prior to and during analysis,	
11	including transcription, data entry, data management and security, verification of	
12	data integrity, data coding, and anonymization/de-identification of excerpts	9-10
13		
14	Data analysis - Process by which inferences, themes, etc., were identified and	
15	developed, including the researchers involved in data analysis; usually references a	
16	specific paradigm or approach; rationale**	9-10
17		
18	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness	
19	and credibility of data analysis (e.g., member checking, audit trail, triangulation);	
20	rationale**	10

Results/findings

23	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and	
24	themes); might include development of a theory or model, or integration with	
25	prior research or theory	10-15
26		
27	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts,	
28	photographs) to substantiate analytic findings	10-14
29		

Discussion

32	Integration with prior work, implications, transferability, and contribution(s) to	
33	the field - Short summary of main findings; explanation of how findings and	
34	conclusions connect to, support, elaborate on, or challenge conclusions of earlier	
35	scholarship; discussion of scope of application/generalizability; identification of	
36	unique contribution(s) to scholarship in a discipline or field	15-17
37		
38	Limitations - Trustworthiness and limitations of findings	17
39		

Other

42	Conflicts of interest - Potential sources of influence or perceived influence on	
43	study conduct and conclusions; how these were managed	3
44		
45	Funding - Sources of funding and other support; role of funders in data collection,	
46	interpretation, and reporting	3
47		

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

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BMJ Open

Rehabilitation during intensive treatment of acute leukemia including allogenic stem cell transplantation – a qualitative study of patient experiences

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-029470.R2
Article Type:	Original research
Date Submitted by the Author:	22-Oct-2019
Complete List of Authors:	Jepsen, Lene Østergaard; Odense Universitetshospital, Friis, Lone Smidstrup; Rigshospitalet, Hematology Hoybye, Mette Terp; Regionshospitalet Silkeborg, 3. Interdisciplinary Research Unit, Elective Surgery Center Marcher, Claus Werenberg; Odense Universitetshospital, Hematology Hansen, Dorte; University of Southern Denmark, National Research Centre for Cancer Rehabilitation, National Research Centre for Cancer Rehabilitation, Research Unit of General Practice
Primary Subject Heading:	Haematology (incl blood transfusion)
Secondary Subject Heading:	Qualitative research
Keywords:	Leukaemia < HAEMATOLOGY, REHABILITATION MEDICINE, Everyday life, QUALITATIVE RESEARCH

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4 Rehabilitation during intensive treatment of acute leukemia including allogenic stem cell
5 transplantation – a qualitative study of patient experiences
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4 **Abstract**

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6 **Objectives**

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8 The diagnosis and treatment of acute leukemia affect physical, psychosocial and existential functioning.

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10 Long-lasting treatment periods with impaired immune system, hygienic and social restrictions challenge
11 patient well-being and rehabilitation as compared to other individuals with cancer. This study elucidates how
12 acute leukemia patients, treated with curative intent in an outpatient setting, assess their physical,
13 psychosocial and existential capability during and following treatment, and furthermore reports on the health
14 initiatives offered to support their rehabilitation.
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22 **Design, setting, participants and interventions**

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24 We conducted qualitative, semi-structured individual interviews with 16 acute leukemia patients, six months
25 after end of treatment in the patients' homes. This was the final interview, in a line of three, carried out as
26 part of a larger qualitative study.
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31 **Results**

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33 The data were analyzed thematically through an inductive ongoing process consisting of four steps. The final
34 step, selective coding, resulted in the three categories: physical activity, mental well-being and social
35 activity. None of the patients were satisfied with their physical capability at the time of interview and
36 experienced substantial impairment of functional capabilities. All patients struggled with anxiety and
37 expressed a need for continuous progress in treatment and well-being to feel safe. It took an unexpected large
38 effort to regain a meaningful social life, and patients still had to prioritize activities.
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47 **Conclusions**

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49 Acute leukemia patients suffered physically, psychologically and existentially throughout their illness
50 trajectory. Rehabilitation initiatives deriving from the health care system and municipalities held room for
51 improvement. Future programs should pay attention to the contextual changes of treatment of this patient
52 group and individuals' changing needs and motivation of physical exercise.
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Summary

Strength and limitations of the study

- A relatively small number of participants may challenge generalization to the wider population of individuals with hematological cancer
- The patients showed a high degree of self-preservation instinct during the illness trajectory, which may indicate a selection bias
- The theoretical framework of rehabilitation may strengthen the possibility of analytical generalization

Funding

This work was supported by the University of Southern Denmark, DKK 400.000, the Region of Southern Denmark, DKK 500.000, The Danish Cancer Society, DKK 465.000, the Anders Hasselbalch Foundation, DKK 20.000, the Family Hede Nielsen Foundation, DKK 25.000 and the joint research pool between National University Hospital and Odense University Hospital supporting the highly-specialized functions, DKK 40.000. The National Research Center of Cancer Rehabilitation, University of Southern Denmark is partly funded by the Danish Cancer Society.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Author contribution

LØJ participated in the design of the study, carried out the interviews, analyzed data and drafted the manuscript. LF participated in the design of the study and in the discussion of the analysis and the results. She also critically revised the manuscript. CM participated in the discussion of the analysis and the results. He also critically revised the manuscript. MH participated in the design of the study and in the discussion of the analysis and the results. She also critically revised the manuscript. DH participated in the design of the study and in the discussion of the analysis and the results. She also critically revised the manuscript. All authors read and approved the final manuscript.

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4 **Patient consent form**

5 Written informed consent for publication of their transcribed interviews was obtained from the patients and
6
7 their spouses. A copy of the consent form is available for review by the Editor of this journal.
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11 **Data sharing**

12 The dataset generated and analyzed during the current study is not publicly available because it contains
13 information that could compromise research participant privacy, but is available from the corresponding
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15 author on reasonable request.
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21 **Keywords**

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23 Rehabilitation, acute leukemia, everyday life, qualitative study
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Introduction

Patients with acute leukemia (AL) undergo extraordinary long periods of intensive treatment with high susceptibility to sudden and dramatic changes in their health condition and prognosis [1]. Impairment of the immune system necessitates substantial hygienic and social restrictions. However, during the last decade, a paradigm shift in the treatment of these severely immune insufficient patients has occurred. The patients who were formerly isolated at the hospital during their highly intensive treatment are now managed in the outpatient setting while concurrently living at home. Rehabilitation needs of the patients and rehabilitation offers by the health care system are challenged by these organizational changes. However, little clinical or research attention has been paid to rehabilitation and survivorship care for this specific group of immune insufficient individuals with hematological cancer managed in an outpatient setting.

In this paper, the concept of rehabilitation refers to specific initiatives and efforts by health professionals but is also an analytical concept for describing the process in which the patients reframe a sense of self [2].

The existing knowledge underlines beneficial effects of rehabilitation to individuals with cancer. From a few studies, we know that physical exercise is feasible and safe for AL inpatients, even those with critical cytopenia. Beneficial effects on physical performance, fatigue and quality of life have been shown [3-9]. As an example, supervised exercise and health counseling intervention for patients with AL during outpatient management showed physical, functional, psychosocial, and symptom benefits [8]. Patients undergoing allogenic hematopoietic stem cell transplantation (HSCT) due to hematological malignancies have also shown significant benefit from exercise interventions without reports of negative effects [9].

Health-related quality of life of individuals with hematological cancer is lowered mainly due to reduced role functioning, insomnia and fatigue [10,11]. Unmet needs of rehabilitation are strongly associated with impaired quality of life for individuals with cancer in general [12]. Psychological counseling, physical rehabilitation, sexual and financial support and practical help have been found to be important, but needs vary with age, sex and cancer diagnosis [13,14].

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4 Summing up, the existing knowledge underlines the beneficial effects of rehabilitation to patients with AL.
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6 However, the rapid changes of treatment setting, patient population and lack of knowledge of existing
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8 evidence may leave patients with unmet needs and functional impairment. Knowledge about patients'
9
10 experiences and expectations from the very special context of outpatient management may have the potential
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12 to improve well-being of an increasing and still older group of intensively treated patients.
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15 Based on patient interviews this paper elucidates how patients with AL treated with curative aim assess their
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17 physical, psychosocial and existential capability during and following treatment and health initiatives
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19 supporting their rehabilitation.
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Material and methods**Design**

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27 The material derives from individual, semi-structured interviews with 16 patients, six months after end of
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29 treatment. This type of interview was deemed suitable to access and explore patient experience in an open
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31 manner to allow for patients to add their own perspectives to the interviewer's agenda. These interviews
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33 were the third and final interview, conducted as part of a larger qualitative study with the overall aim of
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35 exploring the outpatient setting as a context of intensive cancer treatment [15,16]. We combined participant
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37 observation in the outpatient setting (OPS), individual patient interviews, and group or individual interviews
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39 with their relatives. Patients were consecutively invited by and gave consent to the first author, LØJ, who
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41 conducted the interviews. LØJ presented herself as a PhD student and young medical doctor with previous
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43 experience in the department.
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47 Semi-structured interviews were conducted based on a thematic interview guide [15]. The first topic was
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49 'impact on everyday life practices' where rehabilitation issues were addressed by questions such as 'Try to
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51 describe your present physical capability and how you reached that level'. The question was repeated for
52
53 psychosocial and existential well-being. There was one main question to each topic, and depending on the
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55 patient's answers, three to eighteen additional questions to cover the topic sufficiently. The second topic, 'the
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home', explored daily life at home and the roles of the family, whereas the third topic 'hygiene' addressed the impact of intense hygiene requirements.

Patient and Public involvement

Patients were not involved in the research design.

Participants and interviews

Participants were Danish speaking patients with AL intensively treated with a curative aim. All were managed in the OPS, 'the Home Unit' at the Department of Hematology, Odense University Hospital (OUH) and subsequently followed in the outpatient clinic at OUH or at the National University Hospital, Copenhagen or at Aarhus University Hospital if allogeneically transplanted [15].

Twenty-six patients were included from May 2013 to August 2014, and out of this group, 16 took part in this third interview, six months after end of treatment (Figure 1). Table 1 shows the demographic and clinical characteristics.

Table 1 Demographic and clinical characteristics of study participants (n=16)	
Sample characteristics, third interview	Description
Gender	
• Male	9 (56 %)
• Female	7 (44 %)
Age (years)	Mean 55.1; range up to 75)
• < 60	8 (50 %)
• ≥ 60	8 (50 %)
Marital status	
• Married or common-law relationship	13 (81 %)
• Single/divorced	3 (19 %)
Education	
• Unskilled workers	2 (12 %)
• Skilled workers	10 (63 %)

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<ul style="list-style-type: none"> • Further education 	4 (25 %)
Diagnosis*	
<ul style="list-style-type: none"> • Acute myeloid leukemia (AML) 	11 (69 %) (3 relapse)
<ul style="list-style-type: none"> • Chronic myeloid leukemia in myeloid blast crisis (CML) 	1 (6 %)
<ul style="list-style-type: none"> • Chronic myelomonocytic leukemia (CMML) 	1 (6 %)
<ul style="list-style-type: none"> • Refractory anemia with excess blasts (RAEB) 	1 (6 %)
<ul style="list-style-type: none"> • Acute lymphoblastic leukemia (ALL) 	2 (13 %)
Time from diagnosis to third interview (weeks)	Mean 51.9; range 40-72
Treatment status	
<ul style="list-style-type: none"> • Outpatient Clinic follow-up, Odense University Hospital 	3 (19 %)
<ul style="list-style-type: none"> • Allogenic hematopoietic stem cell transplantation, National University Hospital, Copenhagen or Aarhus University Hospital 	10 (62 %)
<ul style="list-style-type: none"> • Second line therapy, Odense University Hospital 	3 (19 %)
<p>The CML, CMML and RAEB special leukemia diagnoses, which are chronic diseases, but often turn into acute leukemia after a short time. Therefore, they received treatment equivalent to acute leukemia patients' regimens and were handled identically to them.</p>	

The interviews were conducted in the patients' home and lasted from 40 to 115 minutes (mean 68 minutes).

With permission, all interviews were digitally recorded.

Context for rehabilitation

Rehabilitation has previously been understood as a practice related to the post-treatment life of patients, but the facilities and practices of the hospital during in and outpatient management may be considered a context of rehabilitation of patients with AL. In addition, non-hospital settings may be part of the rehabilitation.

The course of treatment for newly diagnosed patients with AL who are candidates for curative intended chemotherapy contains both in and outpatient periods. The latter where the patients, during periods with severe hematological cytopenia, stay at home and appear at follow-up visits every second day [15].

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4 The OPS was situated next to the hematological department, OUH, where all the patients could use the
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6 fitness facilities located there. A physiotherapist was present twice a week to instruct the patients.
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9 Before receiving the transplant, patients were instructed in some simple exercises by a physiotherapist.
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11 Furthermore, all patients had an exercise-bike in their bed-room during periods of isolation at the hospital.
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14 In addition to physical exercise, patients could, at any time, ask for a referral for individual advice by a
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16 physiotherapist, a psychologist, a chaplain or a medical social worker at the department. Furthermore,
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18 psychologists from The Danish Cancer Society were available to patients and relatives in facilities at the
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20 hospital.
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23 In Denmark, the overall responsibility of rehabilitation is located at the local municipality level (98
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25 municipalities/5.6 million inhabitants). Due to different demographics, staff and geography of the
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27 municipalities, patients meet different offers and knowledge about their disease [17].
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30 **Theoretical framework and analysis**

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32 The study was based on the World Health Organization (WHO) definition of rehabilitation [18], but
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34 simultaneously acknowledged that rehabilitation formed an analytical approach to the physical, psychosocial
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36 and existential challenges facing the patients with AL, and was not a structural or organizational intervention
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38 as such. This paper aims to study the configuration of rehabilitation needs as experienced by patients with
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40 AL and to draw attention to possible contextual factors that should be taken into account in future programs.
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42 To further support our analytical exploration, the theoretical framework included International Classification
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44 of Functioning, Disability and Health (ICF) pointing out the dynamic interaction of health condition, body
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46 function and structure, activity, participation, and personal as well as environmental factors [19].
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50 The data were analyzed thematically through an inductive ongoing process of four steps inspired by Miles
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52 and Huberman [20]. Step 1: the interviews were transcribed by a secretary and read several times by LØJ to
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54 gain an overall understanding of the material. Step 2: specific paragraphs were identified as the content and
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56 context related to each other and the study aim. Step 3: descriptive codes were produced and assigned. Step
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4 4: through selective coding the text was condensed into categories. The group of authors discussed the
5 contents and interpretation of data throughout the process.
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8 9 **Ethics**

10 Informed consent was obtained from all individual study participants. The study was approved by The
11 Regional Scientific Ethical Committees for Southern Denmark (S-20122000 86), the Danish Data Protection
12 Agency (J. no. 2008-58-0035) and the Department of Hematology, OUH. The first author had no
13 professional medical interaction with the participants during the study period. We carefully recognize that
14 participation in research while undergoing treatment for a serious illness puts strain on patients.
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23 **Results**

24 Patients did not use the word 'rehabilitation' about the process of regaining physical, mental and social
25 functioning. Rehabilitation was therefore an analytical condensation of the AL patients' assessments of their
26 capability and experiences of supportive initiatives. Subcategories of physical activity, mental well-being
27 and social activity were constructed and will be described separately in the following, although strongly
28 interrelated as conceptualized by WHO and in the ICF-model [19]. Existential reflections and challenges
29 emerged during interviews.
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38 Reorganization of the everyday life practices was a first step for many of the patients. This process began
39 when being discharged from hospital the first time and continued after end of treatment. They described how
40 they had lacked the energy to participate in a full day's program, and for example had escalated activities
41 from twice a week to every second day and from one to five hours. Their pace was still slow through all
42 activities, and a nap in the afternoon was often needed. They preferred projects without a deadline. Limited
43 house-keeping tasks, such as cutting the grass or vacuuming the house which would have posed no problem
44 prior to the onset of illness were now 'physically demanding'. This challenged them substantially and greatly
45 impacted their daily lives and psychosocial well-being. They had expected this during treatment, but six
46 months after end of treatment, the patients had expected to be 'back to normal'.
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Physical activity

Nearly all patients reported that they went for walks, but the intensity, the distance and how often varied between patients and times during the illness trajectory. Some patients with neuropathy in the feet could only walk brief distances, whereas others walked for 1½ hour. The simple exercises, including the use of elastic exercise bands, as instructed at OUH were used by many patients.

‘I’ve only made those exercises and I feel a little – guilty about it because they said, You should just [walk] half an hour round the neighborhood. [] I’m a little afraid to fall. The energy level is also crucial. But now for example to day I would be able to do it. I would be able to walk half an hour. But then tomorrow maybe I’m just as limp as a dishrag.’ (Patient 10)

Referral from the hospital to the municipality for rehabilitation services was not systematic. The service offered by the municipalities comprised group training with other types of patients, one hour twice a week for six to twelve weeks. All the participants of this study experienced being the only patient with AL/HSCT. By the end of the course of training many were told that they performed too well to continue in the group. The patients described a lack of enthusiasm and competences by the health care professionals in the municipalities.

After concluding chemotherapy, a handful of patients exercised more intensively in a fitness center; did bike rides of 50 kilometers, swims of 1000 meters or three to four kilometers of running. They wanted to regain their usual physical strength and fitness but also aimed to be prepared if the AL relapsed.

‘So I was active. [] But I also think I had constantly in my mind – if it – my leukemia comes back, I’ll fucking be in good shape, right.’ (Patient 18)

None of the patients were satisfied with their physical status six months after the end of treatment or with being less capable than expected. In hindsight they reflected that it had been too easy to ‘escape’ the physiotherapist during hospitalization. They did not remember having been encouraged to be physically active when referred to the OPS. In the first interviews [15] the patients described how they prioritized

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4 socializing with fellow patients in the OPS to the detriment of physical training. Still, they did not participate
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6 in organized training but were more active through all the unnoticed activities at home, such as doing the
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8 laundry, the dishes or walking the stairs [15]. However, activities that were part of their everyday life were
9
10 not perceived by patients as exercise.

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13 The outcome of training programs offered by the municipality was experienced by the patients as low, and
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15 they often performed too well to continue the program. Being evaluated in this way seemed
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17 counterproductive to their motivation to continue training and produced dissatisfaction with their own
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19 physical capability at the time of the last interview. The lack of physical capability still prevented the
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21 patients from engaging in everyday life activities as they used to and wanted to.

Mental well-being

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26 The treatment and the physical capability strongly influenced the mental well-being of the patients. When
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28 not feeling better or when physical symptoms caused uncertainty the patients felt challenged.

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31 ‘But I think psychologically or mentally we are pretty strong. That’s not a problem. That I can
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33 recognize clearly. The only time I got a knock, was when the one kidney stopped working.

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35 There I thought damn, what is brewing now.’ (Patient 19)

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38 Anxiety was always present but seldom shown, patients reported. Small things like a spot on the skin
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40 initiated a flow of thoughts: graft versus host disease – AL relapse – death. One way to avoid these thoughts
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42 was to be occupied with practical tasks and another way was to talk to family members or friends. All
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44 patients used these coping strategies to a varying extent, and furthermore they talked to fellow-patients, when
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46 meeting in the OPS.

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49 AL had challenged their invulnerability and sense of self, which was usually shaped by work or social
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51 activities. Therefore, many patients raised the existential question: ‘Who am I – besides being a leukemia
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53 patient?’

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57 ‘Principally you are a lot because of you training and the background you have and what you
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59 do.’ (Patient 23)

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4 Patients had perceived that being cured was the end of the illness trajectory. The stepwise prolongation
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6 experienced by everyone was psychologically draining. Furthermore, it was hard never to be given a ‘cured-
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8 date’. As an alternative some patients made their own goals for when to view themselves as cured.
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11 ‘Your status gets chronic. I have actually not spotted exactly what you get, but I have certainly
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13 been told that I do not get a fit-for-duty certificate. So I just had, in a different way, to define
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15 to myself when I’m recovered. And I am when I run my next half marathon.’ (Patient 25)
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19 Few patients had consulted a psychologist during the illness trajectory. The majority experienced no need to,
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21 especially not in the beginning when survival and physical issues had priority. Later, it was a barrier to seek
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23 counseling knowing they would have to describe their illness trajectory once again.
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27 Mental well-being was influenced by flow in treatment and physical capability. Most patients addressed the
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29 mental challenges by talking to family and friends, which was also reflected by the fact that few patients had
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31 contacted a psychologist.
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Social activity

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34 As previously described the social life of patients suffered while being inpatients, while outpatient
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36 management allowed for more time spent together with fellow patients. This type of community became an
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38 important and highly valued part of their social life [15].
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42 The difference between friends and acquaintances became more apparent as time went by. Losing contact
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44 with persons previously counted as friends was a mental strain. As the trajectory proceeded patients wanted
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46 the conversation to turn away from illness and treatment on to everyday things and the future.
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49 ‘When we get together with friends, then there is a lot of talk about my illness. And that’s fair
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51 enough, so now let’s talk about it and then move on. I also need some input, from the outside.’
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53 (Patient 25)
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4 The treatment precautions during periods with severe hematological neutropenia meant that patients only
5 saw a few people at a time and that nearly all social activity took place at home or at the hospital. Returning
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8 to a more regular social life after end of treatment was overwhelming and unexpectedly demanding.
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11 ‘I have also begun to go and watch a football match and stuff even though that it’s not my
12
13 interest at all. But it is to learn to get along in those large gatherings. That was enormously
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15 difficult I think. All that noise I had to get used to. It is difficult when you have been just
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17 inside the house without anything.’ (Patient 18)
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21 Six months after end of treatment the energy level of patients was still impaired. Patients thus had to choose
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23 for themselves what to participate in, and social activities were in competition with practical tasks, physical
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25 activity and work.
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28 The patients described how it was unexpectedly demanding to regain a meaningful social life. None of the
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30 patients experienced or expected that social life had the attention of professional intervention.
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Discussion

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35 Six months after the end of treatment patients with AL were dissatisfied with their physical, psychological
36
37 and social capability. The rehabilitation support during all phases of treatment including HSCT and the
38
39 following phase of recovery were experienced as non-existing, minimal or inadequate.
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42 Our results from the interviews conducted during earlier treatment phases showed that maintaining everyday
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44 life was highly prioritized by patients as well as spouses [15,16]. In line with that, patients reported that they
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46 did not exercise as much as they wanted to. In contrast with the evidence, a long hematological tradition of
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48 avoiding physical training during periods of cytopenia may still be in practice [8,21]. Patients did not recall
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50 professionals’ attention to physical activity during the course of treatment. At the same time they describe
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52 having refused the physiotherapist’s training offer and prioritized the social engagement while at the OPS
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54 [15]. Less contact with healthcare professionals during outpatient management may be another important
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56 barrier. Our third interview thereby adds that the patients’ attitude towards training changed substantially
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4 from having no motivation to feeling highly motivated after end of treatment. According to the patients the
5 municipalities did not offer training courses matching these needs – at that time. Some patients were
6 informed that they were performing too well to participate. Perhaps because they did not suffer from any
7 specific disability but were very generally weakened. The termination of the training course contrasted their
8 own perception of lacking physical capabilities to participate in everyday activities. Individual needs
9 assessment based on the ICF-model including ‘activity’ and ‘participation’ could assist future patients and
10 responsible practitioners to better understand patients’ functional level and motivation [19].
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20 It is relevant to consider that there is a difference between the patients’ attitudes and concrete actions
21 regarding physical training during treatment. In the late modern society, patients are expected to take
22 individual responsibility for their own health and health behavior – such as physical exercise, healthy food
23 and so on [22]. It may be experienced as stigmatizing to the patients not to satisfy such expectations. This
24 could, as a context for blaming the health care system for a lack of attention, be moving the responsibility
25 away from the self and to the system [22,23].
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33 In line with the dynamic of the ICF-model the treatment and the physical capability strongly influenced the
34 mental well-being of the patients and vice versa [19]. Few patients called for easier access to psychologists
35 but the majority found no need since they experienced support from family, friends and other health care
36 professionals. This is in line with a questionnaire study among 132 mixed hematological and oncological
37 patients [24]. Internationally, systematic needs assessment has been recommended as part of routine cancer
38 care to uncover substantial needs for professional support that would otherwise not be addressed [18].
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46 However, none of the patients in our study have had such a consultation. Another explanation to the sparse
47 demand for psychological support may be that the weakest patients declined to participate in the study, had
48 left, or that demanding existential problems surface later.
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53 The patients had to prioritize caring for themselves even though it sometimes caused emotional limbo, as
54 described in a previous focus group interview study of mixed individuals with cancer [25]. Social
55 reintegration unexpectedly required an effort, and they had to challenge themselves step-by-step. None
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4 seemed to expect professional help and no one stated that they should have been warned of the social
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6 challenges. This gives the impression that the patients made no connection between their social life and the
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8 possibility of professional support, e.g. as part of rehabilitation in line with the definition [18] and ICF-model
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10 [19].
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13 **Strength and limitations**

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15 The study design with a relatively small number of participants limits generalization to the wider population
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17 of individuals with hematological cancer. The majority of patients received a HSCT as the final treatment
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19 entity, and we were not able to differentiate our analysis in this regard. The patients showed a high degree of
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21 self-preservation instinct during the illness trajectory, which may indicate a selection bias. However, the
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23 theoretical framework of rehabilitation may strengthen the possibility of analytical generalization. Using the
24
25 dynamic ICF-model as basis of the data analysis, the focus was on physical, psychological and social
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27 functioning of the body, activity and participation together with health-related and environmental factors. In
28
29 a rehabilitation perspective of this specific group of individuals with cancer, six months after intensive
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31 treatment seems a short time. Additional data after one year or longer may show other aspects and
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33 perspectives on for example, late mental or existential problems that cause other needs for rehabilitation.
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39 **Perspectives**

40 This study has several implications for future patients. The patients wanted the rehabilitation process to
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42 begin shortly after the start of treatment. This is in line with all rehabilitation recommendations [19,18] and
43
44 highlights the need for focus on maintaining instead of catching up lost capabilities.
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47 The need for continuous motivation by health care professionals was underlined. Patients' understanding of
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49 and focus on the importance of physical activity for future performance are important, especially on days
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51 with exhausting symptoms or bad mood. Even minor everyday activities like the change of linen counter loss
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53 of muscle and impaired physical capability [8]. Simple exercises could be introduced shortly after the start of
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55 treatment and be supervised through treatment including the OPS. Perhaps it is possible to couple these with
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4 social engagement with fellow patients. This may support continuity and activities across different hospitals,
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6 home and municipality initiatives improving well-being and quality of life among patients.
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9 Psychological counseling may support some patients, but health care professionals should be aware of
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11 patient barriers rising from the need to ‘tell their story’ once more.
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14 A review of the evidence for the treatment-initiated precautions can lead to improved patients’ participation
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16 in role functioning, family- and social life. Furthermore this study suggests timely preparation of patient and
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18 family members for them to understand that regaining a normal social life after end of treatment will be
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20 another demanding phase.
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Conclusion

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26 In conclusion, the findings of this study contribute to our understanding of how outpatients with AL treated
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28 with curative intension, including HSCT, experience rehabilitation up to six months after end of treatment.
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30
31 None of the patients were satisfied with their physical capability six months after end of treatment. They
32
33 managed to be physically active through daily tasks and had not experienced being offered an exercise
34
35 program matching their needs at the end of treatment when their motivation for being physically active arose.
36
37 Psychologically the patients struggled with anxiety with regards to infections or relapse, and their perceived
38
39 needs for progress in the treatment and in everyday functioning to feel well. Talking to family and friends
40
41 was experienced as a good way of addressing psychological challenges. The precautions stipulated by the
42
43 hospitals restricted social life and it unexpectedly demanded an effort by the patients to regain a meaningful
44
45 social life.
46
47

48
49 Room for improvement of rehabilitation initiatives, from both the health care system and the municipalities,
50
51 has been identified. Regular needs assessment should be used to understand changes in health and motivation
52
53 during the illness trajectory. Health care professionals should remember that six months after end of
54
55 treatment is too early to expect full recovery of many everyday basic skills. For the benefit of the patients,
56
57 information about the rehabilitation process can be given up front, but must be addressed continuously.
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Figure 1: Enrollment of patients

Acknowledgements

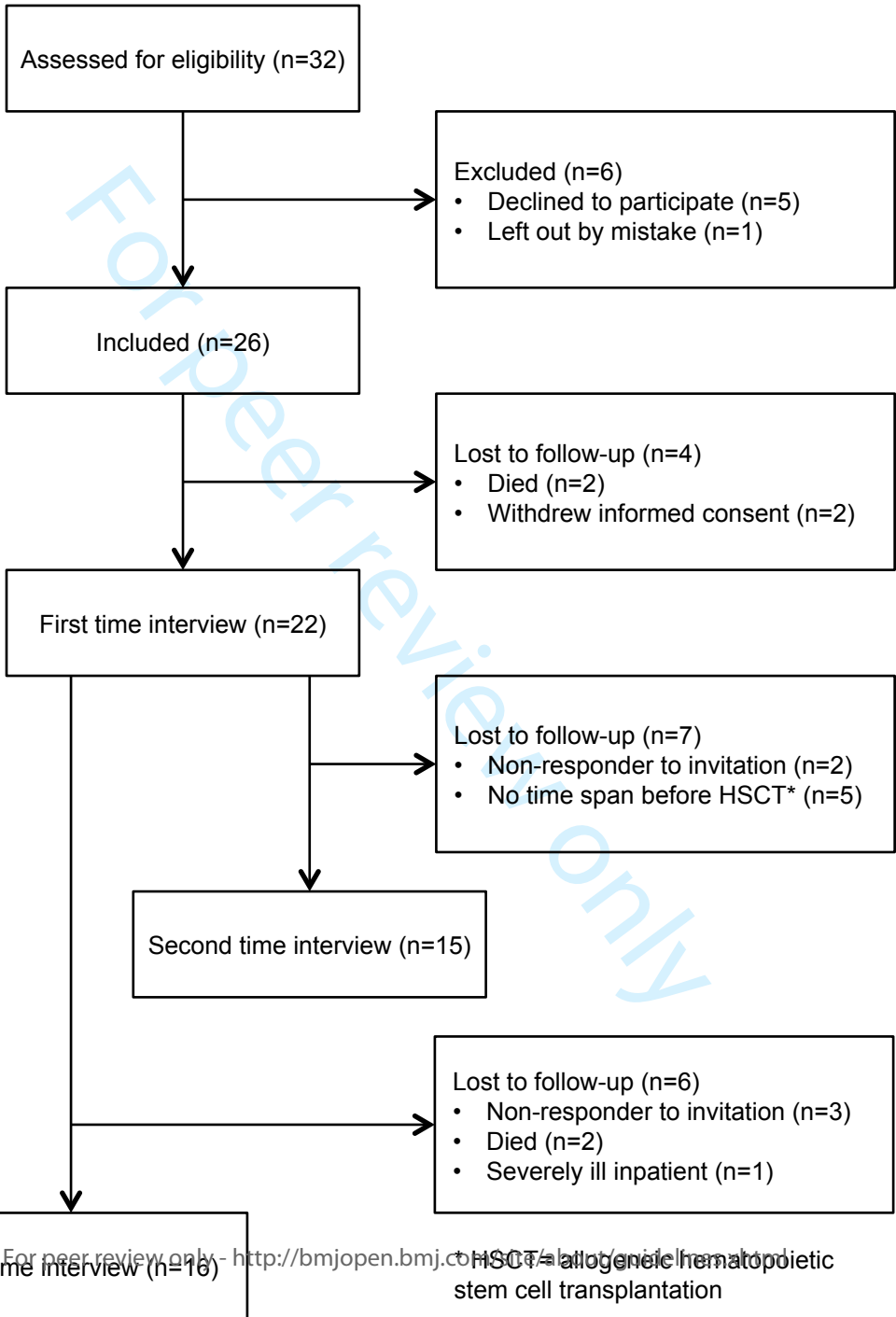
The authors wish to thank all the patients who participated in the study for their valuable contributions during a difficult period of their lives. This study was funded by the University of Southern Denmark, the Region of Southern Denmark, The Danish Cancer Society, the Anders Hasselbalch Foundation, the Family Hede Nielsen Foundation and the joint research pool between National University Hospital and Odense University Hospital supporting the highly-specialized functions. The National Research Center of Cancer Rehabilitation, University of Southern Denmark is partly funded by the Danish Cancer Society.

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Standards for Reporting Qualitative Research (SRQR)*

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Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	2

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	5
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	6

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	6
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	6
<p>Context - Setting/site and salient contextual factors; rationale**</p>	8-9
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	7
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	10
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	6

1 2 3 4 5	Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6
6 7 8	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7-8
9 10 11 12	Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	9-10
13 14 15 16	Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	9-10
17 18 19 20	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	10

Results/findings

23 24 25 26	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	10-15
27 28 29	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	10-14

Discussion

32 33 34 35 36 37	Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	15-17
38 39	Limitations - Trustworthiness and limitations of findings	17

Other

42 43 44	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	3
45 46	Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	3

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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