Outpatient management of acute leukemia patients
The experience of patients and their relatives
Jepsen, Lene Østergaard
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PhD thesis
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Faculty of Health Science, University of Southern Denmark
Department of Hematology, Odense University Hospital
2015
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Lene Østergaard Jepsen

Odense, December 2015
2. This thesis at a glance

This thesis concerns intensively treated acute leukemia patients during admission, outpatient management and until six months of follow-up.

2.1 What is already known on this subject?
- Inpatient treatment of acute leukemia patients means long periods in cramped space and social isolation. Patients and relatives are highly distressed
- Engagement in daily activities serves a functional purpose, but is also essential to physical functioning and creating meaning in life for cancer patients
- Outpatient management is to an increasing extend the concept of managing intensively treated acute leukemia patients as well as other severely ill patient groups
- Physical exercise is found to be feasible and safe to acute leukemia patients even with critical cytopenia, and with beneficial effects on physical performance, fatigue and quality of life
- Generally, cancer patients report unmet needs with regard to most aspects of rehabilitation from early to late phases of illness

2.2 What does this study add?
- The inpatient setting of acute leukemia patients may improve by learning from the outpatient setting in relation to organizational perspectives such as securing patient administrated time
- The outpatient setting provided motivation to engage in everyday life and improved the mental and social well-being of the patients. Family relations were strengthened during outpatient management
- The patients’ motivation to physical activity was low during the first part of the illness trajectory. However, after six months, the patients missed adequate training offers
- The patients were physically active through activities of daily living during outpatient management
- Professional rehabilitation interventions of any kind were experienced as few by the patients
- The responsibility of the spouses highly affected everyday life of the whole family
- The social life of the spouses suffered substantially, especially during outpatient management
3. List of original papers

The PhD thesis is based on the following papers, which are referred to by their Roman numerals:

I. Outpatient management of intensively treated patients with acute leukemia – the patients’ perspective

Lene Østergaard Jepsen, Mette Terp Høybye, Dorte Gilså Hansen, Claus Werenberg Marcher, Lone Smidstrup Friis


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

Lene Østergaard Jepsen, Lone Smidstrup Friis, Mette Terp Høybye, Claus Werenberg Marcher, Dorte Gilså Hansen

Manuscript submitted to Supportive Care in Cancer. ID: JSCC-D-15-01139

III. Living with outpatient management as spouse to intensively treated patients with acute leukemia

Lene Østergaard Jepsen, Lone Smidstrup Friis, Dorte Gilså Hansen, Claus Werenberg Marcher, Mette Terp Høybye

Manuscript submitted to Palliative and Supportive Care. ID: PAX-OA-2015-0202
## 4. List of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AL</td>
<td>Acute leukemia</td>
</tr>
<tr>
<td>ALL</td>
<td>Acute lymphoblastic leukemia</td>
</tr>
<tr>
<td>AML</td>
<td>Acute myeloid leukemia</td>
</tr>
<tr>
<td>CVC</td>
<td>Central venous catheter</td>
</tr>
<tr>
<td>GvHd</td>
<td>Graft-versus-host disease</td>
</tr>
<tr>
<td>GvL</td>
<td>Graft-versus-leukemia effect</td>
</tr>
<tr>
<td>HSCT</td>
<td>Allogenic hematopoietic stem cell transplantation</td>
</tr>
<tr>
<td>HU</td>
<td>Home Unit</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>MAC</td>
<td>Myeloablative conditioning regimen</td>
</tr>
<tr>
<td>MDS</td>
<td>Myelodysplastic syndrome</td>
</tr>
<tr>
<td>NMAC</td>
<td>Non-myeloablative conditioning</td>
</tr>
<tr>
<td>OUH</td>
<td>Odense University Hospital</td>
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<tr>
<td>QOL</td>
<td>Quality of life</td>
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5. **Preface**

As a registrar in the Department of Hematology, Odense University Hospital I became interested in the group of patients with acute leukemia because of their very complex treatment trajectory. They suffer a severe life-threatening disease, receives intensive chemotherapy, having side-effects and infections, which were all handled during long admissions in hospital with many precautions. Trying to strengthen the patients’ quality of life during the long treatment periods, the department established outpatient management from 1 February 2010 which at Odense University Hospital was named The Home Unit. Outpatient management is where the patients live at home, but appear every second day for follow-up visits. Being there to experience the transition from inpatient to outpatient management gave rise to thoughts about how the treatment trajectory influenced the life of the patients and their relatives. When consultant Lone S. Friis suggested that I looked deeper into this, I was ready.

At the same time The National Cancer Plan III - Denmark (1) was introduced, focusing on the needs of individual rehabilitation assessments to respond to the physical, psychological and social aspects of the cancer trajectory. Evidence of effects, feasibility, safety and economy were present but evidence from the patient perspective was lacking. How did the patients experience the course of treatment, and what where their own perceptions of their needs in the rehabilitation area? This led to the aim of this thesis where outpatient management and rehabilitation are seen from the perspective of acute leukemia patients and their relatives to create results that can be used to improve outpatient management in the future, to become better at meeting the different needs of patients and their relatives.
6. Introduction

This thesis explores outpatient management of acute leukemia (AL) in the perspective of patients and their relatives. Through this introduction I will give a picture of how previous knowledge of AL and the specific organization of treatment, rehabilitation and the role of the relatives have developed and led to this project.

The incidence of AL has been stable over the last decade in Denmark (2) similar to other countries like Great Britain and The United States of America (3, 4). The incidence continuously shows two peaks in occurrence in early childhood and later adulthood. The age-dependent mortality is high, and with an ever-aging population there is an increasing focus on development of treatment and supportive care at a personalized level. Indications for treatments, including intensive chemotherapy combinations and hematopoietic stem cell transplantation, are widened continuously, and for those reasons, the patients become more dependent on the health care system, individualization of admissions and follow-up visits at the hospitals. This is in line with the general development for cancer patients in the Western countries, where the number of treated patients and survivors is increasing (5). This has raised a debate about follow-up, treatment of late effects, and rehabilitation of cancer patients because of a growing understanding that many of these patients need help to get back an independent and satisfactory life after treatment.

Research and development projects show that working with the principles of rehabilitation may be beneficial to both people and society (6).

In an international perspective rehabilitation contains an understanding, principles and methods to gather the different efforts made in the medical, psychological, social, pedagogic, educational and occupational areas with the aim of reaching the best performance status, an meaningful everyday life, ability to take part in society and a good quality of life (QOL) for the patients in need (7). In Denmark rehabilitation was conceptualized with The Danish White Book on Rehabilitation from 2004 as a basis of common understanding, attempting to prepare rehabilitation to be put into practice (7). Focus is not only on the
patient, but also on the surroundings and society, which requires experts from different areas to work towards the same goal. With The National Cancer Plan III – Denmark in 2010, The Danish Health Authority recommended that all cancer patients and survivors should regularly have assessed their needs of rehabilitation, and afterwards it has been stipulated how to share the responsibility and put it into daily practice (1, 6, 8). In the field of cancer treatment the concept of rehabilitation is still new, and the evidence is still growing in years where the concept of rehabilitation is to become a part of clinical practice. Research from the patient perspective will therefore be power knowledge in the development of clinical daily practice.

Curative chemotherapy treatment regimens for AL have changed little over the last several decades, while the supportive care has significantly improved, providing the possibility of a more flexible management of the patients. In recent years patients with AL nationally have, to a greater extent, been managed in a safe and feasible outpatient setting, where they live at home, but appear often at follow-up visits at the hospital (9-12). Later, the concept of outpatient management of AL patients is seen to develop in other European countries and The United States of America, where it still is in its tentative beginnings (10) but everywhere it seems to be the concept of the future with fewer beds and shorter periods of hospitalization, leading to more treatment outside the hospital at the patients’ homes. Developing a new concept of management, the primary research has been engaged in its safety and feasibility resulting in a lack of knowledge of the patient’s and the relative’s perspectives. This perspective is very important to future initiatives in health care systems, working with the approach of outpatient management and patient centered care. Research into the patient’s and the relative’s perspectives are in general sparse, but will be essential to the further development of outpatient management, especially when aiming to fulfill the individual needs of patients and their relatives.

Still AL patients are often excluded from research studies regarding physical training or psychosocial group interventions during the course of treatment because they are considered to be in too bad health to
participate. Therefore most of the evidence in this field is based on patients with solid tumor cancer forms. However, this evidence cannot be transferred to AL patients, creating a lack of research and evidence in rehabilitation initiatives for hematological cancer patients.

Traditionally, relatives of inpatients were on the sideline, with no active part in treatment. Commonly, they would be merely a passive bystander or be ignored during the course of treatment (13). With outpatient management, the role of the closest relative has become a key issue in treatment (10). Being the close relative of a person with cancer has been described as a multifaceted role, comprising psychological, empathetic and practical challenges and it has been found that relatives find their caregiving role important (14, 15). Evidence is still sparse, especially when it comes to the relatives’ own perspective. Knowledge of relatives to intensively treated AL patients where special precautions influence everyday life is also sparse and therefore a need of specific research into these relatives is present.

AL patients constitute a special group of cancer patients and outpatient management seems to play a growing role in future treatment of these patients. The overall idea of this study is to gain knowledge from the patients’ and relatives’ perspective using qualitative interviews as the main research method. How different treatment initiatives such as outpatient management and all that goes with it influence the everyday life of the patients and their relatives. Furthermore, looking into rehabilitation from the patient and relative perspective, we seek information about their experiences with different initiatives to see if outpatient management contains room for early rehabilitation together with the kinds of challenges it may produce. The choice of the vulnerable, intensively treated patients with AL is an attempt to secure information about demanding procedures like outpatient management and rehabilitation at a level where they are not excluded.
7. Background
In the following section I will go into detail with AL, organization of AL treatment, rehabilitation and the role of the relatives.

7.1 Acute leukemia
AL is a heterogeneous malignant disease in the blood producing stem cells in the bone marrow. As a consequence of the disease, the bone marrow loses the ability to produce the essential cells of the blood (erythrocytes, leukocytes and thrombocytes) (16). The main group of AL patients is constituted by the subgroup with acute myeloid leukemia (AML) which counts for more than 90% of the patients. Other subgroups are acute lymphoblastic leukemia (ALL) and high risk myelodysplastic syndrome (MDS). AL patients were treated with variations of combination chemotherapy and had long lasting cytopenia periods in common, without any function of the bone marrow. The procedures of providing the chemotherapy and the concomitant supportive care are the same, so looking into the practices of care and rehabilitation; it can be assumed that the cytopenia period has the same basis of impact on their everyday life, despite the differences in diagnosis and treatment that caused it. It is beyond the scope of this thesis to describe all the groups of malignant bone marrow diseases in details. AL subgroups can be viewed as one group regarding outpatient management and rehabilitation. Furthermore, AML accounts for the largest number of patients in a hematologic ward which is why this specific diagnosis is described in the following.

The incidence of AML in Denmark is around 250 new patients per year with a five years survival rate at 50% for patients younger than 60 years old, and a poor 15% for patients more than 60 years old (17). The treatment with curative aim contains combinations of intensive chemotherapy in three to four cycles. Each cycle critically reduces the function of the bone marrow for three to four weeks, and the patients have a highly increased risk of infections and bleedings. In this period they need supportive care with blood transfusions and prophylactic antibiotics, among other things.
The health conditions of the patients may quickly change to the worse during the course of treatment, especially in the beginning. Chemotherapy has a wide range of well-known side-effects, such as nausea, fatigue, hair loss and pancytopenia, which often greatly impacts the patients (18). Symptoms caused by the disease itself, such as pain, fever, anemia, infections, bleedings and weight loss also contribute to the overall condition of the patients (18). In general, the patients have a well-known high risk (about 10 %) of dying from secondary acute conditions, such as fungal infections during the treatment trajectory.

The first cycle of chemotherapy and the following cytopenia period are handled during hospital admission (four to five weeks). If eligible the patients are referred to outpatient management which means that in the following cycles of chemotherapy the patients are in hospital when they receive chemotherapy (eight to ten days), but at home in the cytopenia periods (three to four weeks). If not eligible for outpatient management they are inpatient during all cycles of chemotherapy, and the following neutropenia periods equaling five weeks of admission every time and overall four to six months with only few scattered weeks at home.

Allogenic hematopoietic stem cell transplantation (HSCT) was introduced to hematological patients in Denmark in the 1990s. The course of AL treatment is terminated with HSCT in a growing number of the patients in order to reduce the risk of relapse. Risk stratification based on the subgroup of AL and treatment response stipulates the indication. In recent years there has been a growing incidence of HSCT due to increasing indications, including the possibility of transplanting elderly patients (more than 60 years old). In the year 2000 the non-myeloablative conditioning (NMAC) HSCT (the so-called mini-transplantation) was introduced in Denmark. Prior to HSCT, patients receive different types of conditioning regimens according to their age, co-morbidity and/or state of disease. The myeloablative conditioning regimen (MAC) means that the bone marrow cells of the patient are eradicated before donor stem cells are given. NMAC is a less intensive regimen where the function of the bone marrow and the immune system of the patient only are reduced prior to HSCT. The procedure of receiving stem cells is similar to having a blood
transfusion, and it takes three to four weeks before the bone marrow starts producing blood cells. During this period the high risk of infections and bleedings are present again, and some of the patients are isolated during hospital admission. Following MAC HSCT the bone marrow will regenerate from donor stem cells (full donor chimerism) after three to four weeks. Following NMAC HSCT the cell population will be mixed in the first two to three months after HSCT, in that some of the bone marrow stem cells are donor derived and some are patient derived (mixed chimerism). That means following MAC HSCT the new immune system will be functioning after three to four weeks after transplantation, whereas it takes up to three months after NMAC HSCT to reconstitute a fully donor derived immune system being able to fight the AL cells (graft-versus-leukemia effect (GvL)). Differences in stem cells from patient and donor require immune suppressing medication to avoid rejection of the new bone marrow, and later on to avoid or reduce the risk of severe graft-versus-host disease (GvHd). However, the patients may suffer from different grades of GvHd and the medication often causes side-effects to them as well. GvHd is a condition where the new immune system reacts against the patient’s organs e.g. skin, mucosa, gut and liver. The immunosuppressive medication and the risk of GvHd require alertness from the patients and contact to the hospital in case of fever or other symptoms. Six months after transplantation the immune suppressing medication is gradually reduced and discontinued, if possible.

7.2 Organization of acute leukemia treatment
Traditionally, until five years ago, patients with AL have been treated as inpatients and have therefore been bedridden in hospital during most of the four to six months long treatment period. It has been reported that taking patients out of their everyday life for such a long period makes them lose daily functions and roles and thereby their identity (19). It has earlier been pointed out that people living with life-threatening diseases could benefit from engagement in daily activities, and that it not only served a functional purpose, but also was essential to creating meaning in life (20, 21). Many patients experienced problems maintaining everyday life during hospitalization. As inpatient, large amounts of time was spent waiting for services and care from providers, which placed inpatients in a constant waiting position (22). Even though inpatients
received social visits, they have been found to suffer social isolation and to lose their roles in the everyday
routines of the family (22).

The well-established inpatient setting provided a safe environment of treatment and care to the AL
patients but new possibilities of supportive care used for AL patients made it possible for the patients to
stay at home. For example the high risk of infection due to an insufficient bone marrow function was
reduced by broad spectrum antibacterial tablet prophylaxis. Previous it was shown that outpatients
benefited from decreased rates of nosocomial infections reducing use of intravenous antimicrobial therapy
(12) and thereby reducing total treatment costs (11). A growing number of patients challenged the
numbers of beds in the wards which in an organizational perspective created a need to reduce the number
of very long admissions through new ways of management. It had been described how AL patients’ and
their relatives’ mental well-being and social life suffered during admission (19) to meet some of these
challenges the concept of outpatient management was developed with the patients being at home as much
as possible.

The existing knowledge of outpatient management has focused on feasibility and infections because safety
of course had first priority and if showing to fail could have closed the treatment concept overnight.
Evidence of patient and relative perspectives of outpatient management is very sparse. However, this
knowledge is important if we want to find out if the kinds of setting support patients in maintaining
everyday life during the illness trajectory and how to improve the quality of treatment. Can outpatient
management give room for rehabilitation? The relatives and the family were mentally distressed by the
absence of the patients at home during admissions, but how were they affected by outpatient
management with the patients at home most of the time?

Shifting between two settings, inpatient and outpatient, respectively, may affect the patients, but do the
patients experience a difference in the two settings? Is outpatient management just a variation of inpatient
management to save some beds or does the settings differentiate in areas that are experienced as
important to patients and the closest relatives? Without this knowledge the quality of outpatient management cannot be sufficiently improved in a health care system known for patient-centered care.

This curiosity underlines the importance of research-based knowledge of the AL patients’ experience of the transition from inpatient to outpatient, as well as the everyday life perspective of outpatient management. It is also essential to the development of the outpatient management in a direction where needs of physical, psychological and social support are addressed to each individual.

### 7.3 Rehabilitation

Changes in treatment and an increase in survival of AL patients has made cancer rehabilitation a subject of increased focus in the health care system’s approach to these patients (23) and to cancer patients in general as stated in The National Cancer Plan III - Denmark (1). Rehabilitation is different from treatment, which primarily targets the disease, the symptoms and the cure, but ideally rehabilitation takes place parallel with treatment as an integral and coordinated component. Rehabilitation should furthermore continue into long-term cancer survivorship.

Cancer rehabilitation aims to reduce the physical, psychological, and social consequences of the malignant disease and its treatment, for the patients and their families (6, 7). AL covers a handful of very heterogeneous diseases, which makes the rehabilitation process different from patient to patient, and makes it vary over time for the same patient. In spite of this, AL patients also have some conditions in common, e.g. the neutropenia period after receiving intensive chemotherapy with the high risk of infections. In this study we look at the configuration of rehabilitation needs and draw attention to possible contextual dimensions that need to be taken into account together with AL patients’ experiences of rehabilitation initiatives.

The World Health Organization’s definition of rehabilitation is: ‘Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual,
psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination’ (24).

Rehabilitation can be seen as a structural, political and clinical concept but also as an analytical concept. In this study it was an analytical approach to the social, physical and existential challenges facing AL patients. How contextual factors needed to be taken into account when assessing the AL patients’ experiences of potential rehabilitation initiatives. The analytical concept was used to describe the process in which the patient has to reframe a sense of self following intensive cancer treatment (25).

Implicit in the common understanding of cancer rehabilitation is an idea about getting people back to their old selves and lives from before the AL diagnosis. Patients, however, find it difficult to return to a state of normalcy since the yardstick for what is normal no longer exists for them (23). Cancer has changed their view of life and self-perception, and their previously well-known social communities have changed.

The theoretical framework included International Classification of Functioning, Disability and Health (ICF) (26). The ICF-model includes physical, psychological and social functioning with focus on the body, activity and participation together with health-related and environmental factors. It includes personal resources, and not only lowered functioning. The classification is interactive, circular and reason neutral and can be used inter-disciplinarily and across different sectors. This provided an analytical way of understanding the patients’ rehabilitation experiences and functional capability assessment. See figure 1.
Physical, psychological and social functioning is affected by the fundamental change of everyday life caused by AL and its treatment (21, 27, 28). Rehabilitation, such as physical exercise and social engagement may support patients’ QOL and their return to a ‘normal’ life after treatment. Physical exercise may be overwhelming without continuously encouragement, especially for patients with low levels of energy due to pancytopenia and long periods in bed. Precautions stated by the hospital during the course of treatment hinder patients from gathering at places with many people, such as public transport, grocery stores and social events, thus impairing social life.

Literature has shown that physical exercise was feasible and safe to AL patients even with critical cytopenia due to intensive chemotherapy and with beneficial effects on physical performance, fatigue and QOL (29-32). To patients undergoing HSCT supervised exercise interventions have also shown significant benefits without reporting any unexpected or negative effects (33). Health related QOL of hematological patients is lowered by reduced role functioning, insomnia and fatigue as the main reasons (34). Cancer survivors in general have expressed needs of psychosocial rehabilitation after discharge from hospital because of fear
of death, and social stigmatization, which were not taken care of neither by the health care system nor by others (35). Studies with focus on psychosocial rehabilitation to AL patients were not found during the literature search made prior to study start. Searching for knowledge from other cancer patients groups I found that this literature also was sparse. A randomized trial from Denmark found no improvement in distress, QOL or self-related health following psychosocial cancer rehabilitation in form of a one-week residential course among breast, prostate and colorectal cancer patients (27, 36).

The existing knowledge underline that physical activity are beneficial and safe during inpatient management of AL patients, even to the most critically ill. This knowledge needs to be enhanced by studies in the outpatient setting to ensure safety under these different circumstances but also to shed light on if and how these AL patients are capable of being physical active in daily living. How are the possibilities of being physical active compared to the inpatient setting? Psychosocial aspects of outpatient management still have to be investigated to find out if the outpatient setting and time at home facilitate mental well-being and engagement in social life.

How can the outpatient setting make rehabilitation possible as opposed to the inpatient setting? The outpatient setting was implemented aiming to enhance focus on rehabilitation in the early illness trajectory of AL patients but it has not been evaluated how patients experience rehabilitation initiatives in this setting. Experiences of daily practices in the perspective of patients will be power knowledge in all aspects of rehabilitation to find out if there is a potential of development and quality improvement beneficial to patients, relatives and the health care system.

### 7.4 Relatives

The closest relative has a key position in the treatment of patients with AL and indeed those managed in an outpatient setting. They have to collaborate with the patient and health care professionals, keeping track of treatments and procedures and at the same time they are the never failing support of the patient besides taking care of the rest of the family and full time work. Does outpatient management induce special
challenges to the relatives that are unknown but important to relatives’ health and wellbeing and should be considered by the health care professionals during development of the concept of outpatient management?

Focusing on relatives to AL patients and their experiences, especially in the outpatient setting, is a relatively new research area which may explain why the literature is sparse. A previous post treatment questionnaire study with spouses of AL and highly malignant lymphoma patients found that spouses experienced existential, emotional, practical and physical distress and restrictions due to changes in the couples’ mutual relationship (37). They also had to give up on several of their usual everyday life practices.

Studies including relatives to other cancer patients or to patients with kidney diseases have shown that being an involved participant in the care of the patient, assuming responsibility and being taken into account and treated with respect by the professionals, made close relatives feel empowered (38). Does the outpatient setting perhaps facilitate empowerment of the relatives to AL patients as well? Relatives reported a higher average number of concerns than patients themselves; concerns which were focused on family issues and unmet needs regarding information on medical treatment and supportive care for the patient (39-41). Is this even more distinct during outpatient management with practical tasks and expectations from the health care system? In the context of the individualization in the late modern society?

The existing knowledge of relatives’ experiences of cancer patient treatment suggests that unmet needs of their own have a great, often negatively, impact on their everyday life. Thus, the feeling of empowerment due to close involvement in treatment, decisions and support may develop.

Research-based knowledge on the relatives’ experiences as intensively involved care takers at home during outpatient management is insufficient to further qualify the programs and to ensure an endurable trajectory of the relatives. Many questions were still to be answered at the time of starting this project. Based on the three papers this study explores a number of the questions highlighted above.
8. **Objective**

The overall objective of this thesis is to explore how outpatient management may offer an opportunity to meet well-known physical and psychosocial challenges in AL treatment and what new challenges it may produce for patients as well as their relatives.

In line with the three papers the specific aims were:

8.1 **Aim 1**

How is treatment in the Home Unit (HU) experienced by AL patients at different times during treatment?

How is everyday life of the family affected by the special requirements of the HU?

How do AL patients experience keeping up their social relations during treatment in the HU?

How do AL patients experience participating in family related activities both in and out of the home?

8.2 **Aim 2**

How do AL patients experience everyday life six months after end of treatment?

8.3 **Aim 3**

What special challenges does the HU present to the relatives?
9. Methods and material

This study uses qualitative methods and combines participant observation, individual interviews and group interviews (42), which are described in the following sections of design, setting, participants, data collection and analysis along with the ethical considerations.

9.1 Design

The study uses qualitative methods with an interest to understand, describe and construct the qualities of human experiences in AL treatment. How the phenomenon of interest is perceived, experienced and engaged (42-44). Qualitative methods were considered to be the best choice to address the aim of this study and elucidate the experience of AL from the perspective of the patients and their relatives. The study combined three different methodological strategies to strengthen the complexity of the material and the knowledge gained by researching the phenomenon from different perspectives. See figure 2.

Figure 2 Overview of study design

<table>
<thead>
<tr>
<th>Method</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant observation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First individual patient interview</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Second individual patient interview</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Third individual patient interview</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual relative interview</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group interview of relatives</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9.1.1 Participant observation

Participant observation was used in this study to gain knowledge of everyday life and activities performed among AL patients, staff and environment (42). It is a central method in ethnographic work, as a unique way to gain insight into the social lives of people, their relations and their contemporary interactions with the surroundings, be it material or organizational (42, 45, 46). The participant observation carried out in this study was inspired by the methodological approached of ‘focused ethnography’ (47), as a way to intensively and briefly, over a short period of time collect ethnographic data. In this study the data
produced by participant observation contributed to the further development of the study, as an inspiration for the interview guides made prior to the interviews. The focused participant observation further provided a contextual insight for the following interview study, as it provided me with an enhanced understanding of the social life among patients, relatives and staff in the HU. Participant observation took place over three days during to different months and is documented as field notes and a drawing (see figure 3)(48).

9.1.2 Individual interviews
Semi-structured individual interviews were conducted three times with each patient to get insight into their perspective on outpatient management and rehabilitation needs. Further individual interviews were conducted with a few relatives to AL patients (n=5). The interview method is good to produce knowledge of the life situation of people, their experiences, attitudes and point of views (42, 43). It is not a neutral technique but an interaction between two people where the positioning plays a role in both production and interpretation of the material. My approach was intended to be receptive, empathic and listening. The chosen semi-structure left space for dialog, reflection and adjustments along the way.

9.1.3 Group interviews
To obtain knowledge from the relatives of AL patients, a group interview technique was chosen (49). The method allows several participants in a social context to be interviewed simultaneously. Broad and in-depth knowledge of certain questions and subjects can be gained from the discussion among participants and their answers to questions (49). During the interview my role as the interviewer was nondirective, with the participants being responsible for setting an agenda from the five questions asked. The questions formulated for the group interview were based on knowledge gained through the participant observation and the individual interviews that had been conducted up till that time.

9.2 Setting
The study took place at The Department of Hematology, OUH which consisted of two wards (X1 and X2), a reception (X3) and an outpatient clinic (X4) together with a fitness room. In conjunction with the ward X2 is the outpatient setting called the Home Unit where outpatient management takes place. In this section the
ward X2, the fitness room and the HU are described together with the course of treatment and its prerequisites.

The ward X2 consists of nine bedrooms which each are shared by two patients. The rooms are equipped with a cupboard, a bed, a bedside table and a soft-chair for each patient and then a shared washbasin. There is also a common room providing soft-chairs and small tables along the walls and a 12 person dining table with chairs in the middle of the room. A television, a computer workstation and a children’s corner is present.

A fitness room is placed between the two wards. The room is about 20 square meters and is equipped with two exercise bikes, a step machine, wall bars, step benches, elastic bands, exertubes, floor mats and a big exercise ball. Furthermore, two chairs, a little table and a television are present. On the walls there are two framed pictures and two posters with exercise suggestions.

The HU consists of two separate rooms. The main room is about 50 square meters and designed with a small table and soft-chairs where the patients and their relatives sit. A bed in the middle of the room functions as a couch for interactions between the nurse and the patients. At the front of the room there are two computer workstations for the nurses. The room is furthermore equipped with a television, some magazines, a refrigerator with cold beverages and a small table with coffee and snacks for the patients. There is no wall decoration, and the overall design is sterile and hospital-like. The smaller adjacent room is used for consultations with the doctor and for patients who need to rest. The HU typically hosts six to eight patients and relatives for three to eight hours between 8.00 am and 4.00 pm. During visits, all patients are seen by a doctor. See figure 3.
An important prerequisite for being managed in the HU is that an adult relative is present at night (see appendix 1). Due to safety precautions patients also have to measure temperature, blood pressure, take prophylactic antibiotics and record their overall wellbeing in diaries. All patients have a tunneled central venous catheter (CVC) from which they or their close relatives draw blood samples, change the dressing of and flush. Patients are instructed to avoid any contact with persons carrying an infection (including close family members) and avoid places with crowds gathered, such as grocery stores, public transport and social gatherings. At home, the whole family should intensify the hygienic precautions and eschew mold. All directly and indirectly precautions are apply 24/7. Upon enrollment in the outpatient program the patient and the spouse have a formal meeting with a nurse who clarifies the precautions, the need for collaboration on tasks and procedures and the principles of the HU.
Each year the Department receives approximately 60 newly diagnosed AL patients from the Region of Southern Denmark including 45 receiving curative intended chemotherapy. Following the first treatment cycle and pancytopenia period, around 33 of these patients will be managed in the HU.

The course of treatment contains periods as inpatient and periods as outpatient where they live at home and appear at follow-up visits every day or every second day in the HU. After finishing management in the HU the patients either have follow-up in the outpatient clinic at OUH or an HSCT at the National University Hospital, Copenhagen. If the patients wished to they could have the HSCT at Aarhus University Hospital. The indication for HSCT was stipulated according to their specific AL. See figure 4. The first six months of follow-up after HSCT is at the hospital of transplantation.

**Figure 4 Course of AL treatment**

![Course of AL treatment diagram](image)

C= chemotherapy as inpatient; HU= Home Unit; Out.= outpatient follow-up; A-HSCT= allogenic hematopoietic stem cell transplantation

Rehabilitation initiatives may include a wide multidisciplinary range of professionals (medical doctors, nurses, physiotherapists, occupational therapists, psychologists, chaplains and social workers) who contribute with their expert knowledge to the rehabilitation process. During the course of treatment, patients are referred to relevant professionals within the Department by indication of a medical doctor. Their own general practitioner is available by appointment and The Danish Cancer Society had several counsellors for patients and relatives. The offers are free of charge for the patients.
9.3 Participants

9.3.1 Patients
Participants were Danish speaking AL patients receiving intensive treatment with a curative intent and who are accepted to be managed in the HU. The number of enrolled patients was chosen with the aim of including 20-25 patients to secure that at least ten patients should be available for the third interview expecting that some patients would be lost during the study period.

I invited 32 patients to participate in the study, six of which were excluded (see figure 5). One of them saw her as introverted and found the interview method unacceptable, which is why she declined to participate; four could not cope with research participation in addition to the treatment obligations; and one was left out by mistake. Twenty-six patients were therefore included consecutively from May 2013 to August 2014.

After inclusion but before the first interview two patients died unexpectedly and two withdrew their informed consent because they could not cope with research participation in addition to being managed in the HU. These four episodes made me change the inclusion process from inclusion during the last part of admission to inclusion at one of the first visits in the HU. Afterwards I saw no similar losses of patients before the first interview resulting in 22 patients interviewed the first time.

Two patients did not respond to the invitation for the second interview and five patients had no time span between outpatient management in the HU and HSCT for medical reasons, which is why I ended up with 15 interviews at the second time point. The five patients left out because of time issues all expressed willingness to participate in the third interview if possible.

Of the 22 patients interviewed the first time, three did not respond to the invitation to the third interview, two died and one patient was inpatient after transplantation for more than six months, making an interview impossible. 16 patients were therefore interviewed the third time. That was more than expected when the study was designed. Demographic characteristics of patients are found in table 1.
**Figure 5** Enrollment of patients

- Assessed for eligibility (n=32)
  - Excluded (n=8)
    - Declined to participate (n=5)
    - Left out by mistake (n=1)
  - Included (n=26)
    - Lost to follow-up (n=4)
      - Died (n=2)
      - Withdrew informed consent (n=2)
  - First time interview (n=22)
    - Lost to follow-up (n=7)
      - Non-responder to invitation (n=2)
      - No time span before HSCT* (n=5)
  - Second time interview (n=15)
    - Lost to follow-up (n=6)
      - Non-responder to invitation (n=3)
      - Died (n=2)
      - Severely ill inpatient (n=1)
  - Third time interview (n=16)

* HSCT = allogeneic hematopoietic stem cell transplantation
<table>
<thead>
<tr>
<th>Sample characteristics (n=26)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13 (50 %)</td>
</tr>
<tr>
<td>Female</td>
<td>13 (50 %)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td>(mean 56.7; range 26-74)</td>
</tr>
<tr>
<td>&lt; 60</td>
<td>13 (50 %)</td>
</tr>
<tr>
<td>≥ 60</td>
<td>13 (50 %)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married or common-law relation</td>
<td>19 (74 %)</td>
</tr>
<tr>
<td>Single/divorced</td>
<td>3 (11 %)</td>
</tr>
<tr>
<td>Unknown</td>
<td>4 (15 %)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Unskilled worker</td>
<td>4 (15 %)</td>
</tr>
<tr>
<td>Skilled worker</td>
<td>14 (55 %)</td>
</tr>
<tr>
<td>Higher education</td>
<td>4 (15 %)</td>
</tr>
<tr>
<td>Unknown</td>
<td>4 (15 %)</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Acute myeloid leukemia (AML)</td>
<td>18 (69 %) (3 relapse)</td>
</tr>
<tr>
<td>Chronic myeloid leukemia in myeloid blast crises (CML)</td>
<td>1 (4 %)</td>
</tr>
<tr>
<td>Chronic myelomonocytic leukemia (CMML)</td>
<td>1 (4 %)</td>
</tr>
<tr>
<td>Refractory anemia with excess blasts (RAEB)</td>
<td>2 (8 %)</td>
</tr>
<tr>
<td>Other myeloid leukemia</td>
<td>1 (4 %)</td>
</tr>
<tr>
<td>Acute lymphoblastic leukemia (ALL)</td>
<td>3 (11 %)</td>
</tr>
<tr>
<td><strong>Time from diagnosis to first interview (weeks)</strong></td>
<td>Mean 8.6; range 3-15 (n=22)</td>
</tr>
<tr>
<td><strong>Time from diagnosis to second interview (weeks)</strong></td>
<td>Mean 19.7; range 13-28 (n=15)</td>
</tr>
<tr>
<td><strong>Time from diagnosis to third interview (weeks)</strong></td>
<td>Mean 51.9; range 40-72 (n=16)</td>
</tr>
<tr>
<td><strong>Treatment status at time of first interview</strong></td>
<td>(n=22)</td>
</tr>
<tr>
<td>1 course of chemotherapy</td>
<td>5 (23 %)</td>
</tr>
<tr>
<td>2 courses of chemotherapy</td>
<td>13 (59 %)</td>
</tr>
<tr>
<td>3 or more courses of chemotherapy</td>
<td>4 (18 %)</td>
</tr>
<tr>
<td><strong>Treatment status at time of second interview</strong></td>
<td>(n=15)</td>
</tr>
<tr>
<td>2 courses of chemotherapy</td>
<td>3 (20 %)</td>
</tr>
<tr>
<td>3 courses of chemotherapy</td>
<td>5 (34 %)</td>
</tr>
<tr>
<td>4 courses of chemotherapy</td>
<td>5 (34 %)</td>
</tr>
<tr>
<td>5 or more courses of chemotherapy</td>
<td>2 (12 %)</td>
</tr>
<tr>
<td><strong>Treatment status at time of third interview</strong></td>
<td>(n=16)</td>
</tr>
<tr>
<td>Outpatient clinic follow-up</td>
<td>3 (19 %)</td>
</tr>
<tr>
<td>Allogenic hematopoietic stem cell transplantation, <em>National University Hospital, Copenhagen</em></td>
<td>8 (50 %)</td>
</tr>
<tr>
<td>Allogenic hematopoietic stem cell transplantation, <em>Aarhus University Hospital</em></td>
<td>2 (12 %)</td>
</tr>
<tr>
<td>Second line therapy, Odense University Hospital</td>
<td>3 (19 %)</td>
</tr>
<tr>
<td><strong>Awaiting allogeneic hematopoietic stem cell transplantation at time of first interview</strong></td>
<td>16 (73 %)</td>
</tr>
</tbody>
</table>
9.3.2 Relatives
A relative was defined as the person living with the patient during outpatient treatment and, together with the patient, was responsible for meeting the obligations of the HU. Relatives were invited to participate in the study only after agreement with the patient.

All 22 patients interviewed the first time gave permission to invite their relatives to participate in the study, which I did. Six did not respond to the invitation. Four declined to participate with an explanation of no interest of participating in a group interview or when five friends constituted ‘the relative’ for example. One relative was interviewed together with the patient in a third interview because of a wish from both of them due to a difficult treatment trajectory. Eleven relatives were therefore included from March to November 2014. See figure 6. Demographic characteristics of spouses are found in table 2.

All included relatives turned out to be spouses. This in a way ‘changed’ the study because it then became a study of patients and their spouses and not a study of patients and relatives in more general terms.
Figure 6 Enrollment of relatives

Included patients (n=26)

Lost to follow-up (n=4)
- Died (n=2)
- Withdrew informed consent (n=2)

Relatives assessed for eligibility (n=22)

Lost to follow-up (n=11)
- Declined to participate (n=4)
- Non-responder to invitation (n=6)
- Interviewed together with patient (n=1)

Included relatives (n=11)

Group interview (n=8)

Individual interview (n=5)
Table 2 Demographic characteristics of relatives

<table>
<thead>
<tr>
<th>Sample characteristics (n=11)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (27 %)</td>
</tr>
<tr>
<td>Female</td>
<td>8 (73 %)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>&lt; 60</td>
<td>7 (64 %)</td>
</tr>
<tr>
<td>≥ 60</td>
<td>4 (36 %)</td>
</tr>
<tr>
<td>Relationship to the patient</td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>3 (27 %)</td>
</tr>
<tr>
<td>Wife</td>
<td>8 (73 %)</td>
</tr>
<tr>
<td>Families with children (years)</td>
<td></td>
</tr>
<tr>
<td>&lt; 18</td>
<td>2 (18 %)</td>
</tr>
<tr>
<td>≥ 18</td>
<td>8 (73 %)</td>
</tr>
<tr>
<td>No children</td>
<td>1 (9 %)</td>
</tr>
<tr>
<td>Time from patient diagnosis to relative interview (weeks)</td>
<td>Mean 27.4; range 7-50</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Skilled worker</td>
<td>6 (55 %)</td>
</tr>
<tr>
<td>Unknown</td>
<td>5 (45 %)</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>4 (36 %)</td>
</tr>
<tr>
<td>Retired</td>
<td>3 (27 %)</td>
</tr>
<tr>
<td>On leave because of partner’s illness</td>
<td>1 (9 %)</td>
</tr>
<tr>
<td>On leave because of own illness</td>
<td>3 (27 %)</td>
</tr>
</tbody>
</table>

9.4 Data collection
In the following the data collection is described for each of the three methods including the preparation of the interview guides.

9.4.1 Participant observation
The participant observation (45) took place in the HU at three different days after agreement with the nurse on duty each time. I was present in the main room before any patients and relatives arrived and stayed all day. I sat by the small table together with patients and relatives with a little pad of paper used for notes. The permission to be present was negotiated with each individual as they arrived in the HU and permission was granted in all cases.

Given the methodological framework of focused ethnography (47) the participant observation paid particular attention to:

- The design of the HU
- People and their activities
- Interactions between people and between people and objects

Field notes (46) were written straight after the conclusion of each observation session in the HU. See an example of field notes in appendix 2.

Participant observation (45) in the HU was limited to three days as it purely served the purpose of providing contextual insight for me to use onwards in the study and in planning of the interviews to address the central aims of the study. The observations provided me with a good impression of the everyday life of the HU and of the key social importance that this environment came to play in the AL trajectory.

9.4.2 Individual interviews
Three individual interviews were planned with each patient (42). A longitudinal design was chosen to explore how time as a context could be important to the patient experience of outpatient management. The specific time points for the consecutive interviews were chosen to gain information from the patients just after they had experienced a transition in management and setting to understand how they handled the different conditions together with impact from their AL and treatment in relation to everyday life. See figure 7. The exact interview time varied in accordance with the individual trajectories of each patient.

- The first scheduled interview was conducted right after the transition from inpatient to outpatient management and took place during one of the patients’ first visits in the HU while waiting on blood count results. It was conducted in a separate room.
- The second scheduled interview was conducted right after finishing outpatient management and mainly in the home of the patients.
- The third scheduled interview was conducted six months after end of treatment. That could either be after six months of follow-up or six months after HSCT. These interviews were also conducted in the home of the patients.
The first interviews lasted from 30 to 90 minutes (mean of 60 minutes).

The second interviews lasted from 40 to 115 minutes (mean of 80 minutes).

The third interviews lasted from 40 to 115 minutes (mean of 68 minutes).

9.4.2.1 Interview guide
An interview differs from an everyday conversation by having an aim and using an interview guide focusing on specific topics and questions (43). The type of questions helps to direct the structure of the interviews ranging from being very loosely to very tightly structured with a semi-structure as an average. A semi-structure was chosen for this study, creating space for dialog, reflection and adjustments along the way, which was important in the attempt to get the patients to describe their experiences of being an AL patient, managed in an outpatient setting. The questions were formed inspired by the knowledge obtained by participant observation and the approach of James P. Spradley (44). Types of questions could be descriptive to explore usual practices, but also specific situations like asking the patients to describe their last visit to the HU. The answers to these questions often offer unlimited opportunities for investigating smaller aspects of their experience, which then can be specifically asked together with asking the patients to give an example. All questions were open-ended to facilitate a descriptive answer from the patients. Small adjustment were made along the way when I recognized that I never asked a specific question from the

Figure 7 Individual interview time points

C= chemotherapy as inpatient; HU= Home Unit; Out.= outpatient follow-up; A-HSCT= allogenic hematopoietic stem cell transplantation
1, 2, 3 = first, second and third interview time point respectively
guide or if it was observed that a question did not make sense to the patients, but in general I found the interview guide to work very well. See the interview guides of the individual patient interviews in appendix 3 (first interview), 4 (second interview) and 5 (third interview).

All interviews were digitally recorded. I transcribed the first three interviews to learn from the process, whereas the remaining interviews were transcribed verbatim by a secretary. See an example of a transcribed individual patient interview in appendix 6.

9.4.3 Group interviews
In the original protocol it had been planned to conduct focus groups interviews with relatives (49-51).

However, it turned out to be more difficult to include them in the study than I had expected. Spouses were highly engaged as caregivers in the patient trajectory, which made it difficult to plan focus group interviews where more of them could be present simultaneously. This resulted in the intended focus group interviews to be converted into group interviews as a limited number of patients showed up. With this limited number of participants it was not deemed possible to create the social interaction and dynamic between participants, which is crucial in focus group research.

The group interviews were conducted in a room at OUH. All patients were aware of and had agreed to the invitation of their relative. The first group interview lasted 60 minutes and the second one 90 minutes.

Five spouses expressed a wish to participate with an individual interview since they were not able to attend the group interview, which then became the plan in order to maximize the material. Spouses independently chose the interview location, resulting in two interviews that were conducted at the hospital and three in their homes. The interviews lasted from 60 to 90 minutes (mean of 75 minutes).

The time from patient diagnosis to spouse interview varied from seven to fifty weeks. That was done in order to get as many participants as possible among the relatives. It widened the material to shed light on the whole course of patient treatment.
9.4.3.1 Interview guide
Topics covered in both types of interviews were inspired by the participant observation and the individual interviews conducted up till the time of spouse interviews. Guidelines were framed by the focus group approach by John Knodel (49). The questions were open-ended and general in nature. The aim was to find out how it was experienced to be a relative to an AL patient without asking directly about the situation of the individual relative. Five questions were used:

1. Try to give examples of how everyday life is like as a relative to a patient in the HU?
2. Which things/tasks came with being a relative to a patient in the HU?
3. What has it meant to your home that your spouse has been a patient in the HU?
4. If I say the word ‘hygiene’, what do you think?
5. How do you, as a relative, experience the HU concept?

All interviews were digitally recorded and transcribed verbatim by a secretary. See an example of a transcribed spouse group interview in appendix 7.

9.5 Data analysis
An inductive approach was taken in the analysis of all data (52). Organizing of data started with an interpretive and flexible reading to construct a version of what I saw in data and what I thought to be able to infer from them (53). The emphasis was placed on the patients and their relatives’ interpretations and understandings of things and social phenomena connected to the patients’ trajectory of illness. To continue the process, a cross-sectional indexing was made because of the predominantly text-based data where I wanted an overview of their coverage and scope (53). I saw the indexed data as retrievals of ‘unfinished resources’ rather than end products which made me able to conducted further analysis of the data.

In the following, I describe how the data analysis took form according to the method, and how everyday life, time and rehabilitation constitute the conceptual framework of the study.
9.5.1 Participant observation
After expanding the notes, from the pad of paper used during participant observation, into descriptive observations, reflections were written down (48). The material was read several times and then themes emerged which were used as inspiration for development of the interview guides.

Furthermore, I gained knowledge of the everyday life in the HU, about patients and relatives together with procedures and activities necessary to the treatment of the patients. That comprised a basis of knowledge used during all following aspects of the study and served as a context for the analysis of data.

9.5.2 Individual and group interviews
The analysis of the transcribed text was inspired by the approach described by Miles and Hubermann (54).

The analysis was an ongoing process and was performed in four steps, switching back and forth between the steps throughout the process.

1. The interviews were read several times to gain an overall understanding and sense of the material.
2. Specific text pieces were identified as the content and context related to each other and to the aim of the study.
3. Descriptive codes were produced and attached to the text.
4. The text was condensed into categories based on the codes.

To support this analytical exploration I brought the material into a dialogue with the theoretical framework of everyday life, which is described below.

9.5.3 Conceptual framework of the analysis
In this study I tried to gain knowledge about outpatient management of AL patients and the concept of rehabilitation in an everyday life perspective to be able to clarify how mutual changes of the phenomenon takes place. The intension was not to predict but to pay interest to able to distinguish between factor and phenomenon. This meant that this study had a ‘changeable’ ontology to maintain focus on the changes and meanings of a phenomenon (52).
Taking a social constructivist approach in this study, the central analytical approach was that social phenomena, such as the everyday life and experiences of patients and spouses, are intersubjective, shaped by interactions in the context of specific social realities (55). This is consistent with the overall theoretical approach of the everyday life world (56) where knowledge (of everyday life) is constructed through interpretation and description of behavior, rather than predetermined and collected.

The study is situated in the overall context of late modern society, which is characterized by an awareness of global risks, individualization and reflexivity (57). The individualization in late modern society also carries over to the health care sector, making individuals, exceedingly, responsible for their own health. Patients are expected to take responsibility for their own lives, including their illness and thereby expected to take an active part in the treatment hereof (57, 58). They have to make decisions in respect to their autonomy but not all patients want to do that. Some wants to be patients consulting experts for help in the situation (59). To participate in decisions has been articulated as a god way of involving patients in their own illness and management of it to improve care outcome, reduce costs of the health care system, making the patients cope with illness in everyday life and to optimize management of treatment and lifestyle (59). The outpatient management of AL patients is an example of that and reflects that organization of the health care system has changed to follow that line (5, 59).

Given the objective and setting of this study theories of everyday life was a productive approach to inspire analysis. Theories of everyday life as described by Birte Bech-Jørgensen (60-62), Alfred Schutz (56, 63), Peter Berger (55) and Thomas Luckmann (55) were chosen as the theoretical framework of this study. Bech-Jørgensen has, in her inductive research, mainly used observations and interviews, and finds this essential to describe the everyday life of the ‘user’ by their experiences (60). She points out that the researcher of everyday life needs to be open-minded and on the distance to be able to understand and interpret, which is in accordance with the approach in this study. The analysis of everyday life must build on studies of social relations, as this partly constitutes the conditions stated in the theory of Schultz (63) and
experienced through methods by Bech-Jørgensen (64). Relations of many kinds such as patient-spouse, patient-staff, patient-patient and patient-room are analyzed in this study as they were of significance to the everyday life of the patients and their relatives.

9.5.3.1 Time
Basically ‘time’ is experienced courses of events and occurrences which are organized at two levels (62). Both Schutz and Bech-Jørgensen have, with their work explained different aspects which are useful to my understanding and analysis of the material of this study. Schutz describes an inner and an outer time (56). The inner time is awareness where experience relates to the past through memories. The spatial homogenous outer time can be quantified and combined to the inner time through bodily movement shaping ‘the living presence’ (56). Bech-Jørgensen talks about an intervening period used by unusual people (for example artists, addicts or homeless people) as a flexible transfer from inner to outer time, trying to handle this condition (62). A strategy of time is often used to create meaning in life.

9.5.3.2 Everyday life
Several anthropologists and sociologists have described and conceptualized ‘everyday life’ including Schutz (63) and Bech-Jørgensen (60). Everyday life is in its simplicity ‘the life we live every day’ (p 29) according to Bech-Jørgensen (60). Everyday life as an object cannot be defined sociologically but can be described through processes, activities and relations. The interaction between structural and organizational conditions and the ways people handle it can then be said to form their everyday life. A distinction may be drawn between conditions formed by society, interpersonal relations and individual factors. See figure 8.
How people handle different objects will all ways be interpreted as intentional, even though handlings may not be it (55). In this study it is assumed that patients and relatives conduct intentional handlings which bring forward a need to differentiate between intentions such as receiving chemotherapy to get cured for AL or to live in accordance with the precautions stated by the HU to avoid infections among other things.

People define different situations they experience in everyday life from their biographic situation by use of their experience. This shapes the ‘common sense’ constructions or the ‘common sense world’ as described by Berger and Luckmann (55). People need a common knowledge, language and outer time to shape the ‘common sense world’ where interactions can take place with no problems. During a social change the individual needs to adjust the knowledge, language and outer time to make sure that the objective reality stays similar to the subjective reality (55). This process of socialization becomes relevant to all participants of this study as they or their spouses are diagnosed with AL. The meeting with the health care system with fellow patients, staff, the medical nomenclature and appointments all day long requires changes through the process of socialization to enable the ‘coping’ of the patients in the ‘system’. Actually, it is a resocialization process which takes place due to an alternation influenced by external conditions (55).
Basically people take their everyday life and the surrounding world for granted and create routines to be reproduced and repeated, the ‘matters of course’ by Bech-Jørgensen (60). She argues that the more exiting activities actually are those that we do not recognize because they are maintaining the order of the ‘matters of course’. For AL patients in outpatient treatment it may be many small daily activities they have to do and through analysis these activities may be important to certain aspects such as physical activity.

9.5.3.3 Rehabilitation
Please see the description in section 7.3.

9.6 Ethical considerations
To participate in a research project while having a life-threatening disease puts an extra strain on the patients and their relatives. It has, however, been shown that patients found strength by participating in qualitative projects like this where focus was on their experience of the illness trajectory (19). The patients and relatives in this study were happy that they had the opportunity to express their experiences of getting ill and going through the intensive course of treatment to a ‘neutral’ person with a basis of knowledge of the disease and treatment. Some patients acknowledged the third interview as a good way of ‘summing up’ their illness trajectory.

The first interviews were scheduled according to a patient’s follow-up visit in the HU and were conducted while the patient was waiting on blood count results or got a blood transfusion, meaning no prolongation of the visits. There were no extra visits, but they had to invest time for the second and third interviews in their homes. The participants got no direct benefits from participating.

The patients were informed, written and verbally, that participation was voluntary and of the possibility to withdraw their written consent. They gave informed consent to participate in the research project and to usage of information from their hospital health records. See Participant information leaflet in appendix 8 and the informed consent form in appendix 9. The inclusion process was solely handled by me to avoid the pressure on the patients that can be experienced if they are asked by the health care professionals involved in their treatment.
The patients were also informed that I was a PhD student, a doctor of medicine and formerly employed at the Department, but also that I was on leave so they would not meet me in a professional relation regarding their medical treatment. The relation between the patient and me was uneven due to my status of being a medical doctor, and I was aware of that. The participants were told that they were the experts and that it was their experiences that were the aim of the study. A reflexive approach to my medical knowledge on the subject was used, trying to meet the patients on their home ground. I was not a representative of the hospital or department and was aware of the possibility of an evaluation of the staff and procedures.

Permission to conduct the study was obtained from the Department of Hematology, OUH where the study took place. The study was approved by The Regional Scientific Ethical Committees for Southern Denmark (S-20122000 86) (See appendix 10) and the Danish Data Protection Agency (J. no. 2008-58-0035) (See appendix 11). It was conducted in accordance with the Declaration of Helsinki II (65).
10. Literature search

With the aim of getting a basis of knowledge on relevant areas for the overall project I conducted a literature search. Databases were searched several times during the period from writing the protocol to writing this thesis. The main search was run in February and March, 2015, and afterwards a regular alert service was used from all databases. In the following my strategy is described.

Initially, the World Wide Web (www) was used for sporadic, unstructured searches as inspiration to the subjects and keywords. Later six databases were selected because they each represented a different segment of the literature.

- **Scopus**: offers a very broad array of literature, covering natural science, medicine and technology
- **PubMed**: usually used for medical literature by medical doctors
- **Embase**: covers the fields of social science and medicine through journals, which are not included in PubMed
- **Cinahl**: mostly nursing and care science including physiotherapy and occupational therapy
- **Web of Science**: known for the Citation Index and the conference abstracts
- **Bibliotek.dk**: Danish literature

In the first ‘quick and dirty’ search it became clear that the amount of literature in the field of AL and outpatient management was sparse, so a broad search strategy for the systematic search was chosen and similar areas and illnesses were included. Three searches were conducted with the keywords shown in the following table 3:

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Search keywords</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search 1</td>
<td>Acute leukemia, outpatient, rehabilitation, everyday life</td>
</tr>
<tr>
<td>Search 2</td>
<td>Cancer, outpatient, rehabilitation, everyday life</td>
</tr>
<tr>
<td>Search 3</td>
<td>acute leukemia /cancer, outpatient, relative, rehabilitation, everyday life</td>
</tr>
</tbody>
</table>
In every facet synonyms to the keywords were found and searched as well. The words were searched with an asterisk (*) so that the ending of the word meant nothing, if the database required that. Also subject headings were used in relevant databases, such as Mesh terms in PubMed. Afterwards the Boolean operator OR was used to tie the different synonyms together in the facets and the Boolean operator AND to connect the facets. Thus a strategy to primarily include as much as possible and then finally reduce the number of hits. Delimitation was not used in the searches, and neither was the Boolean operator NOT. Every search has been evaluated to see if relevant hits were found according to the aim of the study. The first screening was based on title and abstract. Afterwards, the full text of those articles was red and the relevant ones saved as a search result. See an example of a search in table 4 and figure 9. This process was repeated in each of the six databases.

In the writing process of the manuscripts and the thesis the need of further exploring of some issues arose which is why different small searches were made to find additional literature (the snowball method).

Relevant articles were handled in EndNote. The search method was evaluated with a librarian at the Library of University of Southern Denmark.
Table 4 Example of search 1 in Scopus, All fields. Search ran 16 February, 2015

<table>
<thead>
<tr>
<th>Facet 1</th>
<th>Facet 2</th>
<th>Facet 3</th>
<th>Facet 4</th>
<th>Facet 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acut*</td>
<td>AND</td>
<td>Outpatient*</td>
<td>AND</td>
<td>Everyday*</td>
</tr>
<tr>
<td>(2,987,144)</td>
<td>Leukemia*</td>
<td>(409,605)</td>
<td>Rehabilitati*</td>
<td>(230,364)</td>
</tr>
<tr>
<td></td>
<td>OR</td>
<td>OR</td>
<td>(800,122)</td>
<td>AND</td>
</tr>
<tr>
<td></td>
<td>Leukaemia*</td>
<td>Ambulat*</td>
<td>Surviv*</td>
<td>Life*</td>
</tr>
<tr>
<td>(786,816)</td>
<td>OR</td>
<td>(345,039)</td>
<td>(2,852,222)</td>
<td>(5,546,167)</td>
</tr>
<tr>
<td></td>
<td>Semi-ambulat*</td>
<td>“Life-style”</td>
<td>“everyday”</td>
<td>OR</td>
</tr>
<tr>
<td>(35)</td>
<td>OR</td>
<td>change”</td>
<td>life”</td>
<td>“daily”</td>
</tr>
<tr>
<td></td>
<td>“Partial”</td>
<td>“Life change”</td>
<td>activities”</td>
<td>OR</td>
</tr>
<tr>
<td></td>
<td>hospitalization*</td>
<td>event”</td>
<td>“activities of”</td>
<td>“activities of”</td>
</tr>
<tr>
<td>(1,921)</td>
<td></td>
<td>(19,560)</td>
<td>daily living”</td>
<td>daily living”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physical*</td>
<td>(84,121)</td>
<td>(84,121)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(7,627,767)</td>
<td>OR</td>
<td>OR</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exercise*</td>
<td>Participat*</td>
<td>Work*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(930,309)</td>
<td>(1,211,881)</td>
<td>(7,474,067)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Psycho*</td>
<td>OR</td>
<td>“Family”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(3,708,438)</td>
<td>Social*</td>
<td>related”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>OR</td>
<td>(3,431,370)</td>
<td>(6,449)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Therap*</td>
<td>OR</td>
<td>Support*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(7,188,146)</td>
<td>Social*</td>
<td>(5,993,371)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>OR</td>
<td>(670,771)</td>
<td>“Social”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>network”</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(152,487)</td>
</tr>
<tr>
<td>987,144</td>
<td>786,816</td>
<td>678,304</td>
<td>19,492,562</td>
<td>203,019</td>
</tr>
</tbody>
</table>
Figure 9 Search matrix, search 1 in Scopus, All fields. Search ran 16 February, 2015

- Acute leukemia 354,694
- Outpatient 678,304

- Acute leukemia AND Outpatient 7,228
- Rehabilitation 19,492,562

- Acute leukemia AND Outpatient AND Rehabilitation 6,731
- Everyday life 203,019

- Acute leukemia AND Outpatient AND Rehabilitation AND Everyday life 71

- Relevant title or abstract 12
- Relevant after reading full text 6
11. Results

The results presented in the three papers (I, II, III) correspond with the three aims presented in this thesis. In this section the results from the papers are reproduced in facsimile. The results of the first two papers can be seen as a continuum from start of treatment till six months after end of treatment describing experiences of treatment in the different settings, the everyday life and social activities in the patient perspective. The third paper explores experiences and challenges in the same areas but in the perspective of the spouses. Three main results areas can be described:

- The transition between inpatient and outpatient management and its influence on everyday life
- Patients’ experiences of everyday life six months after end of treatment
- Outpatient management and its influence on the everyday life of the spouses to AL patients

11.1 Paper 1

The patients highly valued being able to maintain everyday life and routines throughout the treatment trajectory, and that life, as closely as possible, resembled life before the diagnosis of AL (I) (66).

‘Having been able to maintain my everyday life as much as was actually possible, I think, mentally meant everything to the course of my illness in the end. It may still go in the wrong direction and end badly, once I’m all done with my treatment here, but it’s what we talked about, the quality of life.’ (Patient 23)

Similar psychosocial concerns and challenges were predominant in the inpatient and outpatient conditions, but studying the transition between conditions elucidated how similar concerns may have different expressions in the everyday life of the patients depending on the setting. Four main categories emerged, through our analysis that reflected the predominant issues that were put in perspective by the transition between inpatient and outpatient treatment: 1) Everyday activities 2) Privacy 3) Social relations 4) Patient involvement in care.
11.1.1 Everyday activities

Alternative to being at the hospital 24/7, everyday life as an outpatient consisted of both days at home and days of follow-up visit at the HU. Patients and relatives could more freely plan their own time and make schedules that enabled them to maintain everyday life routines.

‘I actually do the same things as I used to, but I do them slower, and I may only manage half.’ (Patient 15)

Most patients described it as satisfactory to contribute to the everyday life of the family, engaging in everyday tasks.

‘It is a satisfaction [to take part in everyday life] because it is not agreeable to me to just sit in the couch and watch all those series [on television] all day long. [...] being part of everyday life.’ (Patient 24)

Patients considered their visits to the HU as a tiresome activity, which should claim as little time as possible. They experienced the time at the hospital as time they could have spent at home. The staff recognized this, which was reflected by their practice of calling the doctor as soon as a patient was ready for consultation to minimize waiting.

‘I just want to go home, right, because when your counts are low, wow, you are tired the next day [after visits in the HU], right. You are completely done.’ (Patient 18)

Inpatient days, in contrast, consisted of different necessary tasks and activities that often required interaction with other people, and largely occurred on the terms of the department. This left the patients no possibility for individual planning of their time. Patients pointed out differences between days with or without chemotherapy, but independent of that, inpatients used a huge amount of time every day waiting to have blood drawn, a variety of examinations, treatments to be given, food, ward rounds etc. Being constantly available to the professionals prevented the patients from doing things independently, like for example being physically active.
‘I don’t think you have time for it [Physical activity]. You have to be present when the doctor is here, ‘cause I don’t think he’ll come searching for you three or four times.’ (Patient 1)

So while time was important in both treatment conditions and patients spent a lot of time waiting on procedures to be performed, time in the outpatient setting seemed to have another dimension, as it was experienced by the patients as their own time, in contrast to inpatient time, which was purely hospital time.

11.1.2 Privacy
Patient privacy as outpatients was guarded by the domestic sphere of the home. During visits to the HU, privacy was not explicitly requested by the patients. Consultations with the doctor at the HU took place in a separate room but afterwards, patients often freely shared their news with fellow patients.

This contrasted the situation as inpatient, where consultations during ward rounds often took place with a roommate present behind a curtain.

‘It is not insignificant when you have 5 x 2 meters right? Who is behind the curtain.’ (Patient 15)

The absence of privacy as an inpatient impacted the patients. The shared bedroom made patients seek out spaces in the hospital outside the department.

‘Completely depending on my wellbeing – If I was feeling good I got a requisition and we took our meals at the patient hotel. My husband and I did that a few times when we got visit here [at the hospital]. And then privacy was ensured because over there you just found a corner where you could sit and hang for hours if you wanted. We did that some times. It was a way to get some privacy. But it was only possible in the periods when I felt good; otherwise I simply didn’t have the strength for it.’ (Patient 15)
It was remarkable that the high, everyday privacy of outpatients was freely negotiated in the HU, where they chose to share private details about their treatment and illness. For inpatients to obtain brief moments of privacy, they sought it in other (public) places in the hospital.

11.1.3 Social relations
The key issue in everyday social life as outpatients was the presence at home, which strengthened the sense of being a part of the family and kept up normal family relations.

‘I’m there when they come home from school, right. I’m there for dinner. I’m there to say good night, when they need a bath and when they are doing homework and all those everyday stuff that you do as a family. That I’ll say means a whole lot.’ (Patient 24)

Being at home made it possible to participate in the social life of the family, and not feeling estranged, which was often a consequence of inpatient treatment.

As mentioned above, patients found visits to the HU a time-consuming and tiresome activity. However, they tried to make the best of it, and with time, it became an important and highly valued part of their social life during outpatient treatment. They described the atmosphere as relaxed, informal and confident. This also included their relatives.

‘You form a family-like relationship with those you meet. Oftentimes you’ve met as inpatients and then you meet in the HU, and well… it’s like it is a little family out here [in the HU] because we follow each other.’ (Patient 21)

In this context, the patients did not view waiting time as an issue, as they experienced time as simultaneously used for treatment and socialization.

‘Well we talk about… a lot of it concerns our illness. How were your counts [blood counts] the last time? Well, they were like... How were your counts, and like that and how were... yeah, gosh Jens are you here now, we hadn’t seen you, we thought so and so, you know –
and where were you... So 75% of conversation concerns illness. Leukemia in general, right, which I find quite natural. And then there are uhmmm wives and children and grandchildren and traveling and vacation. And what was on TV yesterday? And ohhh are you reading that book at the moment, right? And this was in the newspaper yesterday, and so on, right. Like common conversation.’ (Patient 10)

This contrasted the modest patient relationships established during inpatient periods, where privacy seemed to have a higher priority than social engagement with fellow patients. Although some inpatients described good interpersonal dynamics with their roommates, it never reached the familiar level of social interactions in the HU.

Many outpatients established close relationships and met at private events, even after finishing the treatment.

Visits during treatment from family and friends were welcomed both as inpatient and outpatients, but the patients; in general, felt more relaxed receiving visits in their home environment. Coordinating visits at home was easier, and the patients could control the conditions of visits, such as their duration.

Social interactions with fellow patients showed an impact from the transition between inpatient and outpatient management with a suffering social relationship as inpatient.

11.1.4 Patient involvement in care
The patients were generally surprised to realize that the staff expected them to take an active part in their medical treatment. Particularly as outpatients, they had to manage the special precautions and take responsibility for their own care. To many patients, this seemed like an overwhelming responsibility until they returned home to realize that they were fully capable of handling it. The patients took pride in following the precautions as closely as possible, but did however recognize that the precautions limited everyday life.
'Well, you don’t go home and start eating honey or blue cheese as you usually do. You don’t go out gardening and you don’t start helping out with the reconstruction of the bathroom your brother is doing upstairs. [...] So in a way they [the special precautions] have influenced my behavior – but it’s been – interfering with manageable areas.’ (Patient 23)

Involvement of patients in their own care seemed to influence their interpretation of personal responsibility for the treatment outcome. They might blame themselves for getting common complications such as neutropenic fever.

‘I try to maintain as much of an everyday life as is possible - ummm, necessarily within the limits the HU has outlined for it to be so clean and don’t do this and that. But when I believe in it and find it to be sensible and fair then I would also defend doing it because I also know who is to blame if it goes wrong – that’s me.’ (Patient 23)

As outpatients, they sensed this responsibility 24/7, which meant that the management concept was constantly of concern, and the special precautions were always valid. Although it required an effort from the patients, this was not viewed as a burden, as the alternative would be hospitalization, which was considered worse.

‘It is a great deal that has to be managed and planned I think. It surprised me. It also surprised me that I find it hard or challenging at times. When I was working I could have had a hectic day from 8 am to 3-4 pm but then I would come home and there was just something new on the agenda – a change. That doesn’t happen now [as a patient in the HU]. It all runs 24/7.’ (Patient 15)

Inpatients, however, did not feel the same responsibility. They had only few tasks to perform, and it was easy to get help, if needed.
‘You have to do your bed as inpatient if you are able to because it is good to your arms. In the beginning I thought: now just stop. That’s your [the nurse] job. But I had second thoughts since.’ (Patient 1)

Both inpatients and outpatients had to take precautions and perform certain everyday tasks. However, the sense of responsibility for the management of own care was experienced to a much higher degree by outpatients, in the context of their own home, without health care professionals around.

11.2 Paper 2

Patients did not use the word ‘rehabilitation’ about the process of regaining physical, mental and social functioning. Rehabilitation was therefore an analytical condensation of the AL patients’ assessments of their capability and experiences of supportive initiatives. Subcategories of physical activity, mental well-being and social activity were constructed (II) (67).

To many of the patients the organization of the everyday life practices was a first step. This process began when coming home after hospitalization the first time and continued through the illness trajectory. They described how they had lacked the energy to go through a full day’s program, and at time of interview had escalated activities from twice a week to every second day and from one to five hours. The pace was still slow in all activities and a nap in the afternoon was often needed. Projects without a deadline were preferred.

‘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.’

(Patient 25)

Housekeeping tasks, such as cutting the grass or vacuuming the house which would have been no problem prior to the illness were ‘physically demanding’ now, challenged them substantially and greatly impacted their daily life. This was expected during the course of treatment but six months after the patients had expected to be ‘back to normal’.
11.2.1 Physical activity

Nearly all patients 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. Elastic bands were handed out by the physiotherapist at OUH, and the simple exercises instructed in at the hospital 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)

Ending chemotherapy, a handful of patients exercised more intensively in a fitness center, doing bike rides of 50 kilometers, swims of 1000 meters or three to four kilometers running. They wanted to get back 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 the – my leukemia comes back, I’ll fucking be in good shape, right.’ (Patient 18)

Referral from hospital to municipality for rehabilitation happened if and when they or their doctor came to think about it. Waiting time from referral to start was usual. The exercise offered in the municipalities was training in a class with other patients, one hour twice a week for six to twelve weeks. Everyone experienced to be the only patient with AL/HSCT and at the end of the period many were told to be ‘too good’ to continue in the class. Disappointment regarding the enthusiasm and competences of the health care professionals in the municipality was apparent.

‘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.’ (Patient 23)
None were satisfied with their physical status six months after end of treatment being less capable than expected. Thinking back it had been too easy to ‘escape’ the physiotherapist during hospitalization. Shifting to the outpatient setting they did not remember having been encouraged to be physically active. In the first interviews (66) the patients described how they prioritized to socialize with fellow patients in the outpatient setting to the detriment of physical training. In line with the first interviews they still not participated 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 as described previously (68). Activities that were part of their everyday life were not considered as training.

Regardless of treatment status the patients experienced little focus on physical activity from the health care professionals. The outcome of training programs in the municipality was low, and surprisingly the patients often were ‘too good’ to continue the course, which mismatched their motivation to continue and dissatisfaction of own physical capability at time of last interview. The lack of physical capability still prevented the patients from engaging in everyday life activities as they used and wanted to but none of them challenged the municipality to optimize their training offer.

11.2.2 Mental well-being
The treatment and the physical capability strongly influenced the mental well-being of the patients. It was mentally challenging in periods when not feeling better or when physical symptoms caused uncertainty.

‘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.’ (Patient 19)

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, patients found. Another way was to talk to family members or friends, which all used to varying extent. They also used talking to fellow-patients as a coping strategy, especially while in the HU, but also when they happened to meet each other later on at the hospital.

AL had challenged their identity and security that were shaped by work or social activities, which raised the existential question to many patients: Who am I – besides being a leukemia patient?

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

Patients believed that the illness trajectory ended up with survival. The stepwise prolongation experienced by everyone due to unexpected occurrences was mentally draining. Furthermore it was hard never to be provided a ‘cured-date’. As an alternative some patients marked their own goals for when to view themselves as cured.

‘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.’ (Patient 25)

Few patients had consulted a psychologist during the illness trajectory. The majority experienced no need to, especially not in the beginning where survival and physical issues had first priority. Later on, it was a barrier to describe their illness trajectory once again.

Mental well-being was influenced by the flow in treatment and their 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.
11.2.3 Social activity
As previously described the social life of patients suffered while they were inpatients, while outpatient management allowed for more time spent together with fellow patients, which became an important and highly valued part of their social life (66).

The difference between friends and familiar people became more apparent as time went by. Losing contact to persons counted as friends was a mental strain.

‘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.’ (Patient 21)

As the trajectory proceeded patients wanted the conversation to turn from illness and treatment into everyday things and the future. They could no longer cope with too much talk of illness.

‘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.’ (Patient 25)

The treatment precautions meant that patients only saw few people at a time and that nearly all social activity should take place at home or in hospital. Returning to a more normal social life after end of treatment was overwhelming and unexpectedly demanding (Table 5, quote 3).

‘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. Al 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.’ (Patient 18)

Six months after the end of treatment the energy level of patients was still impaired. Patients thus had to choose for themselves what to participate in and social activities were in competition with practical tasks, physical activity and work.

‘And then I was at work yesterday morning and in the afternoon I should have been to a co-worker’s 60th 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.’
(Patient 2)

The patients described how it was unexpectedly demanding to regain a meaningful social life. They wanted to focus on the future with input from the outside. No one experienced or expected that social life had the attention of professional intervention.

11.3 Paper 3
The profound challenge to the everyday life of the family was a predominant issue (III) (69). Accounts from the spouses of AL patients, focused on the category of everyday life, were organized into four descriptive categories: responsibility, challenging partnership, the family, and social network. No gendered variations were noticed. The spouses noted that the changes were out of their control, which may have caused a different approach to the whole situation than if they had decided to change thing themselves. Here, it was imposed on them.
11.3.1 Responsibility
Spouses were keen to act and assume responsibility when necessary. They experienced feelings of additional responsibility when the patient-status shifted from inpatient to outpatient, accompanied by the particular precautions specified by the HU for the patient’s time at home. It was described as a huge job to keep up with the precautions. A key issue was that the house had to be prepared before the patient came home from the hospital with meticulous cleaning and all potted plants removed.

‘I feel that I have a sense of responsibility – dammit I have to keep myself at bay not to develop OCD [Obsessive Compulsive Disorder] to bacteria... well, because I think, well if he [the patient] gets sick is it because my cleaning wasn’t meticulous enough.’ (PP10, individual interview. Spouse to a man with relapse of acute myeloid leukemia)

It was a demanding responsibility for the spouses to observe and react adequately to sudden symptoms of the patients, like fever or bleedings. Spouses and patients did not always agree on when to discuss symptoms with the hospital staff. At all hours they could call the Department to discuss a situation and ask for advice, but still they had to make independent decisions at home.

‘So they [the nurses] gave the advice that we should measure the temperature again before we went to bed, but by then it was late, almost 11.00 pm and I had imagined that I would go to bed. So I ended up saying that in light of the circumstances he was fairly well, and then, well, we went to bed. I considered waking up at 3.00 am to repeat the measure [of the temperature] – but well, it went alright...’ (PP6, group interview. Spouse to a man with acute lymphoblastic leukemia)

The spouses stressed how important it was that the nurses on call were positive and confident and gave instructions in accordance with previous information received, because otherwise it caused uncertainty and insecurity. They experienced that the health care professionals were serious about their concerns and
discussed issues in a productive manner. However, the weight of the responsibility and the impact on everyday life surprised them.

‘I think that’s just how it is. But it just really surprised me, how much responsibility you get. Tina [the nurse] had really told us a million times. It wasn’t because she hadn’t done what she could to warn me. [...] I think they do what is possible to ensure you are equipped for the challenge – well equipped - really... You just have to chirp any kind of small concern, and they were ready for talking and helping. I think there’s also good support to be found in making it work. And she [the nurse] asked me several times – can you cope with it because otherwise he [the patient] is staying here [in hospital]. And that’s really where I think you answer yes without any idea of what you are really up to.’ (PP10, individual interview. Spouse to a man with relapse of acute myeloid leukemia)

It was remarkable that the weight of responsibility surprised the spouses even though they felt well informed. This speaks to the pervasive impact of outpatient management on the psychosocial well-being of the spouses, where the structural demands of caregiving add additional burden to their everyday life.

11.3.2 Challenging partnership
All spouses described how the patient had been emotionally affected during treatment. Patients were more short-tempered and experienced sudden uncontrollable episodes of crying. The spouses described how they tried to cope with these powerful emotional changes.

‘I think, going through the procedures they [the patients] do, then you [the patients] can get a little – well – it takes less to – for you to get annoyed and such. You get more edgy and I think you can sense that. And that’s probably just how it is and then you just have to – well, hold your tongue’ (PP8, group interview. Spouse to a man with acute myeloid leukemia)

The extra precautions and the medical tasks that characterized everyday life of the partnership (e.g. caring for the CVC) placed the spouses in a nurse-like role. This was accepted by spouses as the natural order in
the situation, though it often challenged their relationship when the patient did not behave as advised by
the health care professionals.

‘They [the health care professionals] can’t be blamed that they have a self-willed patient
who once in a while does things he is not allowed to because now his patience can’t be
stretched any further. That is where we had the largest conflicts. It is when he has done
something that he is not allowed to do, then I get all hysterical because... I’ll be damned if he
gets ill again, gets some bacterial infection.’ (PP10, individual interview. Spouse to a man
with relapse of acute myeloid leukemia)

The prescribed medication was administrated by the spouse in all but one case and it was considered an
important and complex task. The other procedures were often more equally shared between patient and
spouse, but the spouse expressed a strong desire that the patient would be more responsible and take on
more of the effort to get things done.

‘That’s what Thomas always says, “she will take care of it” – and I gladly do that, but I just
don’t always want to – it’s just once in a while – then you become so full of it because then
there are injections and then there is changing of this and that and then there are pills and it
is a 100 times during that day – well, yeah, it’s not worse than that, but there is just so much,
and then there is also just a bit with the blood sugar when steroids are given. It is just
constantly every two or three hours something has to happen. And then just now and then
you sigh deeply and say: Could you at least just once in a while try to take over a bit? ‘But are
you tired of me?’ yes – no, that’s not what it’s about, right... But I’m also knocked over a bit...
but then I take another round and try to steel myself again, right.’ (PP6, group interview.
Spouse to a man with acute lymphoblastic leukemia)
Spouses experienced that patients were mostly not able to think about anything other than themselves and getting through their illness. This left the responsibility, the caretaking and the communication with their children in the hands of the spouses.

‘Because the first time she was picked up [by the ambulance] I remember, when she was lying on the stretcher and was about to enter the ambulance. Then you stand there beside her, and then she says - looking me deeply in the eyes, then she says: ‘Now you are the one to take care of our children’. It really trickled down my spine. And I think I have a fairly good and strong mind.’ (PP7, group interview. Spouse to a woman with relapse of acute myeloid leukemia)

The natural order of the partnership was challenged by the psychosocial changes of the patients. Furthermore, the caregiver role of the spouses created an unequal distribution of the responsibility and the medical tasks, which caused conflicts between them.

11.3.3 The family
In families with young children the spouse felt torn between the patient and the children, whereas grown-up children were experienced as partners in managing the fear, thoughts and practical things like keeping the house and garden.

‘She [daughter] has also spent much time at home with me, whenever it was possible. And she wants to – also on weekends with her boyfriend, and they have all been like that. [...] It was good to be together when dad was over there [at the hospital], right. [...] That has been really good, because we’ve talked much about it with each other, all the time and every time something happened.’ (PP11, individual interview. Spouse to a man with acute myeloid leukemia)

With the patient at home, young children had to organize their play-dates according to the blood test results of the parent, as not to attract unnecessary infections to the house. Children were very alert to the
movements and well-being of the ill parent, noticing and measuring the severity by little things, such as if they were present to read a bed time story.

‘Just when he [the patient] got home he was standing there looking at the stairs and I could hear how he sighed and fought to ascend the stairs. To him it was climbing of the highest caliber. [] Fourteen days later or something like that, then suddenly the oldest [boy] said: ‘Dad, have you recovered?’ [] And Johan said no and asked why. ‘Well, you could follow me up the stairs this time’. So he registered this – and he notices a lot.’ (PP10, individual interview. Spouse to a man with relapse of acute myeloid leukemia)

Relations in the family between the patient and their spouse, their children, their grandchildren and their siblings were strengthened during the trajectory of AL. The spouses were delighted and emphasized this as one of the few good things that followed from the cancer.

‘Well, a trajectory like this also does some marvelous things, as Jacob and his two siblings have developed the closest, most loving relationship that you can imagine. And now that he has also opened up to his grandchildren, really he has never been caring much for the kids. The boys, the kids, our children, it’s always been mommy. [...] Really, it’s a new world that’s opened up to him, I must say. A good world. A world where he really feels that he means a lot to the family if just he allows himself to.’ (PP2, individual interview. Spouse to a man with chronic myelomonocytic leukemia)

Despite all the hurdles that appeared during the course of treatment the spouses experienced that relations of the family network were strengthened. The age of the children, however, seemed to be crucial to how the children were perceived. The spouses either saw them as resources, helping out with structural needs in everyday family life, or as vulnerable beings that needed extra attention and care because of the situation, adding to the strain on the spouses.
11.3.4 Social network
The patient was at the center of attention from all sides and their needs had first priority. All spouses found that self-evident, but as the course of treatment prolonged they could not keep neglecting their own needs. They expressed that family and friends were very important relations as a means of creating a personal space away from the patient and as an outlet to express their feelings and fears, which they did not want to share with the patient.

‘The ill gets constant care, the ill all the time gets: ‘Oh you are so good at this, and well, and are told how marvelous it is and so on and so forth’ but the one standing at the sideline... [...] What I want to say is that it’s not particularly easy to be a relative. And then it is really good that you have a network, and you have... In my case not friends but my family.’ (PP2, individual interview. Spouse to a man with chronic myelomonocytic leukemia)

Having the patient live at home with the intensified hygiene standards and other precautions, affected the normal social life of the whole family. All members learned to live and act in accordance with the patients’ blood counts and be very alert when numbers were low. This often prevented having guests in the home.

Actually we don’t think that we have had many visits because, well first it was winter. And now with grandchildren, right, they catch all kinds of infections in school and kindergarten. [...] And our daughter, she understood that very well and she didn’t think that they should come here if there was the least to worry about. And Christmas we celebrated by ourselves at home because, well his numbers were very low and then we wouldn’t risk anything. We had a nice Christmas on our own.’ (PP5, group interview. Spouse to a man with acute myeloid leukemia)

Furthermore, the spouses felt uncomfortable leaving the patient home alone and felt that it was unfair to the patient if they participated in a gathering with family or friends. As a result, they rarely did.

The spouses expressed a need of their social network for supportive reasons, but at the same time they were so conscientious to respect the precautions stated by the HU that it hampered their social life.
12. Discussion

The discussion section is separated in a discussion of the findings and methodological considerations.

12.1 Discussion of findings

In the three papers the findings of the study are discussed separately in accordance with each of the three aims. The intention of this section is a general discussion across the findings of the three papers and is divided into the following dilemmas between patients and their spouses:

- Everyday life
- Time
- Responsibility
- Rehabilitation

12.1.1 Everyday life

Outpatient management reduced the periods as inpatient away from family, home and daily life and increased periods at home which created much better opportunities for the patients to engage in everyday activities and social life (I). It has previous been argued that the everyday life world was the most meaningful facing an unfamiliar circumstance (56) which was according to findings in this study where patients enjoyed the possibility of being at home, to be a part of the family and to contribute with small practical tasks. The engagement in everyday activities has previously been shown to be beneficial to patients suffering a life-threatening disease (20, 21, 70). Everyday life was described through processes, activities and relations (60) and experiences in this study supported that outpatient management was beneficial to the everyday life of the patients.

This was in contrast to the experiences of the spouses (III). They described how their everyday life also changed significantly with the diagnosis of AL to the patient but in a different way. An example was the often rapidly changing health status of the patients, due to the high risk of infections and bleedings, which was challenging for the close relatives and came into conflict with planning and maintaining everyday life,
in particular in families with younger children (14, 71). They experienced that everyday rhythm was dictated by the health status of the patient and all the necessary medical observations and interventions and described a challenging balance between able to manage their own needs and the needs of the patient, which has been pointed out previously in a single study (72). The changed situation of both patient and spouse required a ‘new’ common knowledge, language and outer time to reshape the ‘common sense world’ where interactions took place (55). The new agenda was shaped on the terms of the patient which negatively impacted the everyday life of the spouses, especially for spouses where small kids were part of the family or those who were still a part of the workforce.

12.1.2 Time
This study found that inpatients’ days were governed by time, scheduled by the practice and availability of the staff and thereby mainly controlled by outer time (I) (56). Outpatient time was split by the intervening period in the HU/outpatient clinic with a gradual shift to predominant use of time at home, which is mainly controlled by inner time (56, 62). The patients described how waiting all day long as inpatients added to their feeling of being at disposals of others and hindered them in activities such as using the fitness room. This was an example of how outer controlled time prevented them from engagement in everyday life in the inpatient setting (73). The follow-up visits in the HU also included waiting on blood count results and different procedures but in this setting waiting time was used to socialize with fellow patients and on treatment such as blood transfusions. Patients experienced that an effort was made from the health care professionals to minimize waiting time which they appreciated because the time spent at home was the most important to them. Even though outer time also controlled time in the HU it was experienced more positively by the patients. The follow-up visits in the HU were only part of the outpatient management concept and patients described how time at home freely could be used by them to small daily activities in the context of the family. This was an example of that inner controlled time added to the possibilities of performing meaningful daily tasks as part of everyday life during outpatient management. The experience
of time seemed to be one of the major differences between the inpatient and the outpatient setting according to the patients who preferred the later one.

During inpatient periods the spouses experienced that, conversations with health care professionals, different patient examinations and visits at the hospital were time consuming because of waiting time and a need to fit into the rhythm of the ward. This outer time controlled agenda was added to the spouses’ own obligations and tasks in everyday life and took inner time from them. The spouses lost time which they could manage on their own which may be one of the explanations of the burden feeling of spouses during outpatient management which compromised their opportunities for expression. The awareness of experiences and the past constituted inner time (56) and shaped room for reflection which might be missing by the relative to a cancer patient during outpatient management.

Outpatient management often allowed for the patient and the relatives to spent more time together which previous has been described to strengthen their mutual relationship and to create meaning in life for the relatives (14). The spouses in this study described in line with that how relations across the family were strengthened as one of the positive things following the diagnosis of AL to the patient. But at the same time they described how the emotional character of the patient changed during the course of illness challenging their partnership. The caregiver role of the spouses due to practical medical tasks, administration of the prescribed medication and the stipulated precautions also contributed to the ‘new’ constellation of their relationship. The patient and the spouse gained more time together during the course of illness but it was time where their mutual roles were changed and time where the illness tied them together so the quality of the time spent together could be questioned.

12.1.3 Responsibility
The transition from inpatient to outpatient management was a very important shift for the patients and relatives (I). It has been described how AML patients had to readjust their expectations, experienced a shift in responsibility and simultaneously had a growing desire to understand the long-term plan when they
shifted from inpatient to outpatient management (74). Throughout the whole course of AL treatment the patients struggle with the responsibility brought on by the situation. They were responsible for practical procedures, for following the stipulated precautions, progression through the different health sectors and their own life together with that of the family in general. The patients’ desire to take on the necessary responsibility varied according to their physical status (75), but when feeling well during outpatient periods they seemed to accept the responsibility that came with outpatient management. To take on the responsibility meant that the patients could stay at home for a longer time which all had a strong wish about after having been inpatient for three to five weeks during the first course of chemotherapy. This created motivation and the patients expressed to feel okay about the responsibility. They did not see the responsibility as a ‘big issue’. This was in line with the individualization in late modern society where individuals in general were seen as responsible for their own life including their health (5, 57-59).

Experiences of the spouses were in conflict with those of the patients according to responsibility (III). The spouses indeed had the feeling of responsibility and described how they took over management for the complex course of treatment, especially during outpatient management. They felt that the patients did not participate in the responsibility leaving how to handle the different conditions to the spouses having a great impact on everyday life (60). Being a relative to a cancer patient always impact the life of the relative(37), but because of the lacking immune system of AL patients, the relatives were put in a very special situation. Precautions stipulated by the hospital did not only affect the patient but the whole family and created a constant hyper-awareness of the spouse. Being alert and constantly monitoring patients became a persistent state of the spouses as also shown for partners of chronic heart failure patients in an outpatient clinic (76). This may account for a large part of the burden described by the spouses.

None of the spouses ever questioned or refused the caregiver tasks even though they found it overwhelming and stressful (III). It seems that the spouses themselves expected to be responsible, active caregivers trying to live up to an unspoken late-modern ideal of relatives of cancer patients (77). The
possibility of saying no to outpatient management is probably not present but to refuse the caregiver role should be a possibility. As elderly patients are intensively treated and managed at home the caregivers also are growing old which may be a challenge to the health care system placing many practical tasks and responsibility by relatives.

In some cases a ‘we’ developed between the patient and the spouse describing a joint approach to the responsibility and practical tasks of the course of treatment (III). Dyadic coping has previously been described in couples of other cancer diseases and pre-dialysis chronic kidney disease (38, 78-80) where a feeling of empowerment came to both the patient and the relative. A sense of empowerment may provide a feeling of being able to maintain everyday life practices despite all the illness-related concerns and tasks (81). Even though some couples created a common front in this study empowerment was sparsely represented. In cases where a ‘we’ did not develop it could be casual or be due to a deliberate choice. Some patients might simply be to week with no resources because of the illness to be able to take actions on the necessary tasks and in these cases the spouses were forced to take over the responsibility without the possibility of developing a ‘we’. One patient in my study was fairly well despite illness and treatment and was married to a health care professional who had attention to keep being a partner instead of becoming a kind of health care professional to the sick partner. This patient became an example of one who was able to be responsible, to keep track of the prescribed medicine and learn practical tasks as drawing blood samples from the CVC. In this case a deliberate choice caused the missing ‘we’.

12.1.4 Rehabilitation
The patients must not only survive the AL disease but also return to a meaningful life afterwards. Cancer patients have previously reported unmet needs with regard to many aspects of rehabilitation (82) and evidence between impaired QOL and unmet needs are strong for cancer patients in general (83). Six months after end of treatment AL patients were not satisfied with their physical, psychological and social capabilities (III). In the following sections each of the three key points in rehabilitation, physical activity, mental well-being and social activity, will be discussed.
12.1.4.1 Physical activity

The physical state of the AL patients seemed to influence many areas, among other things their mental state, their social life and everyday activities which made physical activity to a central focus point during the illness trajectory. This was supported by the interactive ICF-model (26). I see two complimentary ways of physical activity for the patients: through daily activities or by exercises or training.

Physical activity was in the department supported by a physiotherapist and a fitness room (III). Despite that the patients experienced little focus on physical activity from the health care professionals as inpatients. This raises the question of who is responsible for the physical activity of the patients. In line with the late modern society’s way of thinking, it is the patients themselves who are responsible (57), but according to the rehabilitation concept, the patients may need professional help to maintain or regain physical strength (24). Thinking back, they said it was too easy to escape the physiotherapist during admission. Through informal conversation with the physiotherapist in the department he has told me that he was frustrated because the patients often had an excuse for not being able to exercise that day e.g. being too tired or waiting for the ward round. At the same time they claim that the professional initiatives were few. Perhaps the patients did not recognize that they declined the rehabilitation offer themselves which might be due to avoiding being stigmatized as not being responsible as an individual and thereby they did not fulfill the ideal of the patient role in the late modern society (57). Perhaps the patient simply was not ready when the physiotherapist turned up without notice, together with having the impression that physical activity is not the first priority in the department? Or did they have too many symptoms to convince themselves about that it was a good idea to get out of bed? Whatever the reason the patients were not able to prioritize training as an important thing during hospital admission making physical activity modest. At that time the patients could not predict or did not think of how much their physical inability would influence their everyday life later on but after finishing treatment they felt that physical training earlier on could have improved their physical capability six months after end of treatment.
The fitness room was rarely used by the patients. As inpatients they described how they felt not to have time to go there and that crossing the stairway from the ward to the fitness room was mentally not possible for many patients in the beginning of the course of treatment (III). During outpatient management they did not even think about bringing clothes for training. As outpatients, the patients described how they prioritized the social life in the HU to the detriment of being physically active. At home they were much more active because they participated in domestic activities without recognizing it as physical training.

These unnoticed activities, as described by Bech-Jørgensen (61) are seen widely across the material of this study. So when the aim was to contribute with small practical tasks the patients could find the will-power even though it sometimes was physical hard. This is a strong argument that physical activity seems to need a practical aim during the course of treatment to get attention from the patient supported by a desire to get back to the most meaning full world of everyday life (56).

Overall, there is a discrepancy between the patients’ approaches to participate in physical training early on in the course of treatment and their concreate actions. Their attitudes towards physical training reflects the late-modern ideal, however they were not able to live up to this in the early phase. After end of treatment, they seem to be able to be physically active just for the sake of being active, having surplus energy to take on more responsibility again (57-59). And then the next dilemma arises because at that time they often are ‘too good’ to participate in the formalized training in the municipality even though that they did not have the strength to go through a full days program (II). None of the patients described that they were ‘referred’ to or integrated to a local fitness center or a local society of any kinds of sports ending treatment in the municipality. It seemed like that the rehabilitation process ended finishing one course of physical training in the municipality with is not in line with the intentions defined for the rehabilitation process (7). Through regular needs assessment I presume that some of these intensively treated severely ill patients will need another course of training thinking of the ICF-model (6, 26).
During development of the outpatient setting it was seen as a potential to enhance focus on physical activity in early illness trajectory (See appendix 1). A six week supervised exercise and health counselling intervention in patients with AL undergoing chemotherapy during outpatient management found physical, functional, psychosocial and symptom benefits in the patients (84). However, this study underlines that physical formalized training was further reduced compared to experiences as inpatients (II). This may be due to lacking convincement of physical training by patients and staff, biased selection of patients, unclear roles and responsibility among the health care professionals because the physiotherapists are not part of the outpatient team. It may also reflect that the patients during pancytopenia may have difficulties by participating in formalized physical training but are capable of improving their general activity level by engagement in everyday life and daily tasks as seen in this study.

The patients expressed an expectation of being back to the level of physical, psychological and social activities as they had before they got the AL diagnosis which they were not six months after end of treatment. From my point of view it is very high expectations to have and perhaps the patients should be better informed according what and when to expect in the different areas. This may prevent unrealistic expectations and thereby strengthen the mental well-being of the patients but also improve the partnership between patient and spouse.

Overall I think these findings support that physical activity during the early course of treatment should be through engagement in daily activities whereas it later on may consists of more regular training.

12.1.4.2 Mental well-being

The identity from being a part of the family and their everyday life was maintained to a certain degree by the outpatient management being mentally very important to the patients (I, II). Prior research found that long admissions made AL patients lose their identity partly due to lost functions and roles in daily life (19).

Anxiety was present and expressed by both patients and their spouses. Fear was expressed as fear of getting an infection but not fear of death, even though both patients and spouses knew of the possibility of
dying from complications during the course of treatment. The death might still be taboo among patients, spouses and health care professionals but the patients in this study were all treated with curative aim and reached complete remission so they saw death from complications as more threatening than death from the illness itself. After end of treatment the patients expressed fear of relapse which then was a fear of the illness coming back. This was another area where changes during the illness trajectory were found through the longitudinal dataset. It might also be the ‘same fear all the time’ just expressed differently. Patients and spouses might also not want to hurt anybody by expressing fear of death which could turn out to be a misunderstood consideration to the counterpart. Protective buffering such as this has previously been found to have adverse psychosocial outcomes to both patients and relatives (85). This is calling for more awareness in clinical practice creating room for patients and relatives to express their anxiety. Information about good communication, reaction patterns and coping strategies may be helpful.

Perhaps fear was not expressed in term of death because the patients and their spouses could not cope with such existential questions in the situation? Many patients and spouses told to me during the interviews that they had to believe in treatment and keep up hope for the future. At the beginning of the illness trajectory, the patients’ physical status and treatment was prioritized (II). Later on, they did not want to ‘go back’ through their medical history, and perhaps six months after end of treatment was not enough time to be ready for digging into existential issues. A gradual shift from physical concerns to psychological challenges has previous been described for AML patients during their course of treatment (86). This shift in concerns should possibly be reflected in the clinical approach to the patient.

A previous randomized controlled trial showed no improvement of emotional wellbeing among caregivers to cancer patients after a complex intervention but found significantly better understanding of symptoms and side effects and that the caregiver information needs were more frequently met (87). Interventions directed relatives are interesting and perhaps development of such should be included in the future development of outpatient management.
Previous it has been found that independence from help or care, well-regulated living conditions and financial security contributed positively to life satisfaction whereas a negative association was found with being off work due to health-reasons and dissatisfaction with physical aspects in long-term survivors of AL following HSCT (88). Assessment of patients’ needs and interventions through different rehabilitation processes may contribute to improve life satisfaction of the patients with is shown to be beneficial.

12.1.4.3 Social activities
Privacy was often compromised in the inpatient setting by limited space and shared bedrooms (I) (75). However, studies have found that this might also facilitate valuable social exchange between patients, if the interpersonal dynamics were good (22, 75). In this study privacy was described as missing during admission which seemed to create a suffering social life of the patients and their close relatives. They did only socialize with fellow inpatients to a low extent describing a need of privacy as the most important missing the single bedrooms at some hospitals. Having single bedrooms at other hospitals the patients missed a common room to socialize with other people but only at time when they felt good.

Being together with fellow patients in the HU became a valued and important part of their social life during outpatient management (II). This is in line with that outpatient management has been described as an advantage for the social life of patients during and following treatment for AL with an improved of QOL in general (10, 89). The patients described how the prioritized the company of fellow patients in order to shape the resocialization necessary due to the alternation of everyday life caused by the diagnosis of AL (55). Periods at home secured the privacy and enhanced the possibility of receiving visits from family and friends despite the stipulated precautions and most important in a way where the patient could direct the visits to fit their mental and physical condition (I).

The spouses described how responsibility and awareness of the patient’s condition caused a guilty conscience when they left the home to participate in social gatherings, so they rarely did (III). They experienced few visits at home due to the stipulated precautions and felt kind of isolated. For the spouses,
their ‘old’ network of family and friends was the most important, becoming a breathing space. Inpatient periods allowed for a ‘normal’ social life of the spouses but due to the changes of their everyday life they rarely used the option and those periods were few because of the outpatient management concept. Overall the social life of the spouses suffered during outpatient management in contract to the in some ways improved social life of the patients.

When diagnosed with AL and in the need of intensive treatment it is not bad to be an inpatient, it is just better to be an outpatient. I think this approach describes the overall findings according to the contexts’ influence on the everyday life practices of the patients very well. Outpatient management is in this study found to improve the patients’ engagement in everyday activities and their psychosocial life. However, the spouses were challenged by the outpatient management concept.

12.2 Methodological considerations
This section will go through some general methodological considerations in terms of reliability, validity and transferability, specifically (53).

In research you strive to find the objective truth. That is also the approach of qualitative research even that the ontology can be floating. Steiner Kvale arguments that knowledge gained in qualitative interviews can be objective and not only subjective as is the common view (43). Reliability in qualitative research can then be viewed as a way to evaluate if a fine piece of craftsmanship through transparent and explicit descriptions of procedures has been made (51). Validity is to control, ask and theorize to find out if the study investigate what it intended to do which also contribute to the transparency and evident findings (43). Transferability is evaluation of the findings of this study in regard to the possibility that they can direct what is going to happen in another situation (43). Analytical generalization includes contextual descriptions and arguments of how the researcher sees transferability possible (43). With that approach it is rational to work with the terms of reliability, validity and transferability in qualitative research and I will go through them one by one but first some general thoughts.
Qualitative studies are based on an understanding of research as a systematic and reflective process. Trustworthiness must be considered at all stages in a scientific research process (43, 90), but especially important is the trustworthiness of the interviewer in relation to the participants in general and in the specific interview situation. I experienced that patients wanted to participate in two and three interviews and opened up their homes for me, making it possible to conduct the interview there. Many of the participants offered me the opportunity of contacting them later on, if I needed additional information from them, even though it was not scheduled as part of the study. I see this as examples of that trustworthiness was obtained.

A prospective design was applied, and I collected data by using participant observation, individual interviews and group interviews in order to follow AL patients’ and their spouses’ experiences with outpatient management through the illness trajectory. The longitudinal data is a strength because of the possibility of exploring development and changes in the patients’ and their spouses’ perspectives and needs throughout the study period (53). The perspective and needs are expected to change over time together with changes in the disease, the treatment and rehabilitation initiatives, and causing changes in the health conditions of the patient.

Another strength is the reflection of clinical practice as it is experienced in outpatient management by the broad sample of patients and their spouses, providing a platform for the future development of this relatively new concept.

12.2.1 Reliability
In qualitative research, combining different methods to shape data from many angles to increase the complexity, is commonly used maximizing the reliability (53). Detailed and varied data from different settings and contexts were obtained by combining participant observation, individual interviews and group interviews in this study, and I had different roles according to the settings, reducing the impact of one specific researcher role in generation of data (91). During participant observation, areas inspired from
focused ethnography (47) were used to ensure systematic observation, documented in field notes. Participant observation involved me as a part of the social world I studied (45) and demanded reflexivity.

I was aware of my background, position and preconceptions continuously during the process of data generation (90). My professional competences as a medical doctor and my background knowledge within the field of hematology and rehabilitation enabled me to remain compassionate and focused during the data collection through participant observations and interviews. In this way, my clinical experience was a benefit to the data quality.

The interview material was obtained using an interview guide and afterwards listened to, read and re-read several times. Different interviews were selected and read by a supervisor, in order to qualify the interpretation. Maintaining transparency through the analysis and credibility through the discussion meant that confirmability of the findings was achieved.

12.2.2 Validity
Participant observation was carried out on different days with a, to me, unknown program of the HU ensuring that the participants were not selected, but being a representative of the patient population. The observations enabled me to gain insight into the contextual factors surrounding the topics of interest and to understand the process by which the verbal accounts obtained through the interviews were expressed. This insight qualified the decisions made during the research process and provided a valuable contribution to answering the aim of this study. Participant observation as an engagement in the context of the study increased the credibility of the findings and the validity of the study in general (91).

The inclusion of participants followed a predefined set of inclusion and exclusion criteria. All patients managed in the HU were eligible for inclusion, and the inclusion period of 16 months provided demographic variations, securing the intended maximum variation of participants. This proved sufficient to develop an adequate amount of rich and saturated interview data which could be thoroughly dealt with, attempting to answer the different aims of this study.
During the whole research process, I was aware that compatibility between the research purpose, research questions, methodology and methods was crucial for the validity of the findings (91).

12.2.3 Transferability
A relative small number of participants in this study may impair the possibility to generalize. Our engagement of a theoretical framework in the analytical work with data allows for an analytical generalization, which is common for qualitative research (92). By adding a theoretical frame, such as the theories of everyday life or the rehabilitation concept the interpretation, will extend the self-understanding of the researcher and go beyond the commonsense-understanding (43).

The intensive treatment of AL with a curative aim, including HSCT, is influenced by health-related, cultural and political conditions. Outpatient management of these patients is still a relatively new concept, and while it has been implemented in Denmark, it is not the preferred method of treating these patients in other Western countries and other parts of the world. The concept is still developing and seems to be the concept of the future in most countries (10). National and local practices contribute to many different specific outpatient programs of AL patients worldwide, but the foundation is built on many years of tradition, treating these patients with an international sharing of experiences and research-based knowledge resulting in identical ways of thinking and building up clinical practice, e.g. having precautions for neutropenic patients.

This study has looked into the experiences of outpatient management from the perspective of patients and spouses, and with the above argumentation in mind I think that the findings can be transferred to other AL patients managed around the world in public health care systems.

Intensively treated AL patients are often rated as very fragile patients due to their lacking immune system and their bad general health conditions. Experiences from this group of patients with outpatient management may inspire to outpatient management of other categories of hematological patients and
patients in general, often with a better health status and no need for the precautions due to a lacking immune system.

12.3 Limitations
All studies have their limitations. In the following I will go through translation of data, selection bias, length of study period and the interview method.

The translation from Danish to English of citations included in the papers may have caused minor linguistic or cultural nuances to be twisted although an effort was made to avoid this. The primary translations I made were discussed with all supervisors to secure the meaning of the quotes and afterwards proofreading was done by a secretary with professional English skills.

All participating patients received curative intended treatment and were evaluated as suitable candidates for outpatient management. The weakest patients were thereby missing, including those living alone without a social network to support them. The patients showed a high degree of self-preservation instinct during the illness trajectory which may indicate a selection of patients who wanted to participate in the study. The advantages of outpatient management of AL described in this study may not be applicable for patients with limited resources.

The majority of patients received a HSCT as the final treatment step, and we were not able to differentiate the rehabilitation process between those with and without. In a rehabilitation perspective, six months after intensively treatment for a life-threatening disease like AL seems a short time. New data after one year or longer may show additional aspects for the longer perspective for example late mental or existential problems.

The interview method used in the study may have favored women in the part concerning the spouses (8 out of 11 participants) but no gendered variation was seen in the statements in our relatively small material. No such favor was seen among the patients. The relatives were initially offered group interview
and maybe women is more likely to participate in groups or more willing to talk. Women may also find it
easier to participate in research as relatives in the spirit of multitasking.

It turned out to be difficult to gather relatives for group interviews. Another design or having the possibility
of individual interviews with the relatives from the beginning might have recruited more relative
participants.
13. Conclusions
This thesis provides valuable insight into the experience of AL patients during outpatient management and how this affects and shapes the everyday life of themselves and their spouses. The conclusions are in the following paragraphs drawn according to the specific aims related to each of the three papers.

13.1 Answering aim 1
Outpatient management facilitates time administrated by the patients and thereby the possibility of maintaining everyday life practices to a higher extent, which was very important to all patients. Time spent together with fellow-patients became an important and highly valued part of social life during outpatient management. Privacy ensured at home was important to patients, and they accepted the necessary responsibility, precautions and procedures that came with it. With few exceptions, outpatient management provided motivation for patients to engage in the everyday life despite severe illness and intensive treatment (I).

13.2 Answering aim 2
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 experienced no matching training offer when motivation for being active came after end of treatment. Mentally the patients struggled with anxiety and the need of progress in the treatment and rehabilitation process to feel well. Talking to family and friends was experienced as a good way of addressing mental problems. The precautions stipulated by the hospitals restricted social life and unexpectedly demanded an effort of the patients to get back a meaningful social life (II).

13.3 Answering aim 3
The responsibility of the relative in the caregiver role affects everyday life of the whole family. The health care professionals took a considerable effort from the spouses for granted. None of the spouses ever questioned or refused the caregiver tasks although it was overwhelming and stressful. The social life of the spouses suffered substantially due to the precautions stipulated by the HU, and the expectations of time
consuming and close collaboration between spouses and health care professionals. The partnership was challenged, but relations in the family seemed strengthened during the course of treatment as the only positive finding (III).
14. Future perspectives
The knowledge produced in this thesis is of utmost relevance to the future management and rehabilitation of AL patients. The long intensive treatment period, severe and changing symptoms, the lacking immune system and the significant physical and psychosocial needs requires evidence-based knowledge and compassionate health care professionals. The collaboration between patients, their relatives and the different groups of health care professionals have to take departure in the individualization of the late modern society where responsible patients and relatives expect to be seen as important contributors to the course of treatment.

In the following section, the future perspectives are divided into implications for clinical practice, organization of the health care system and research.

14.1 Clinical practice
Some of the implications are already implemented and others will hopefully be in the future. This is reflected in the next two sections.

14.1.1 Implemented implications
The overwhelming responsibility for own care experienced when shifting to outpatient management may be reduced if the patients became familiar with the different self-care procedures (e.g. CVC-care) through supervised training and guidance during admission. Until now this has been a part of the program starting in the HU. Such initiatives would have the additional benefit of securing more inner time (56) for the patients in that they will become more independent of the staff and thereby reducing time used for waiting which then can be used on other things decided by the patients. Patients will need to have a tunneled CVC up front, to be able to learn the caring procedures themselves during admission. This was implemented as standard in the Department of Hematology, OUH some months ago. The surgical process and if the dressing of the CVC is needed is still discussed in the department. Changing the dressing of the CVC takes time and can be troublesome to the patients which are why they look into the future need of that. The measurement of blood pressure, body temperature and oxygen saturation by the patients have been standard during the
last years, but a standard procedure for additional patient and relative education during admission is under development. Forced expiratory volume in one second (FEV1) and positive expiratory pressure (PEP) may be considerable as complementary to prophylactic antibiotics in preventing pneumonia during cytopenia periods (93).

Patients described a feeling of being constantly at the disposal of others, preventing them from everyday activities, especially as inpatients, which can be seen as outer controlled dominated time. A shift in clinical focus providing the inpatients with the possibility of maintaining their own everyday life practices will give more inner controlled time. For example if examinations and ward rounds took place in brief pre-scheduled time-periods, and patients learned the different self-care procedures early on in the course of treatment.

The Department of Hematology at The National University Hospital, Copenhagen has in accordance with the results of this study and interviews with patients from The National University Hospital, Copenhagen changed the traditional ward rounds to consultations in pre-scheduled time-slots (see appendix 13). An effort to minimize waiting time and the feeling of being at constantly disposal of others experienced by the patients can the a good approach when designing the future way of patient management in the whole health care system.

While the physical environment of the HU stimulates conversation, through soft-chairs and tables, the shared bedrooms used by inpatients hold no incitement for conversation. To counter the lacking privacy during admissions the Department of Hematology, OUH has redesigned the common room to facilitate talking in small groups, such as a patient and some relatives or friends. The HU and the room used for consulting the doctor also have been redesigned to secure additional privacy.

The patients are struggling with physical symptoms of the disease and treatment. However, physical training, like simple exercises, should be introduced shortly after start of treatment and be supervised through treatment, whatever the setting. This may support continuity and activities across home, different hospitals and municipal initiatives, improving wellbeing and QOL among patients. The physiotherapist in
the Department of Hematology, OUH is currently working on two pamphlets with simple exercises, one for bed-bound patients and one for the others. To enhance the training effort of the patients numbers have been put on the staircase so they can count the number of stairs walked. Likewise, the corridor of the department is going to have measures of distance on the floor, enabling them to count the distance walked. The patients will have the opportunity of keeping track of their training efforts in the department’s application for cell phones or tablets. Another initiative is pre-mapped walks of different lengths around the hospital area to encouragement of the patients.

14.1.2 Implications to be implemented
Normal everyday tasks, which require physical activity, are not equivalent to hard training, but a natural way of using the body actively. When at home, such activities are not recognized as physical training by patients, but are unnoticed activities as part of everyday life. A better understanding by the patients of the importance of physical activity, through small everyday activities, to secure the performance on days where physical symptoms or bad mood is present, is important. The information pamphlet about being an outpatient contains the precautions stipulated by the department but could perhaps be extended to include a section of encouragements including small exercises, activities and tasks that are allowed during pancytopenia.

Referral to a psychologist may be important for a minor group of patients, but this study supports that preparation to reaction patterns and mental distress might be appreciated by the majority. This could preferably be implemented as part of the education program during admission in the beginning of the course of treatment. The assessment of psychosocial needs of rehabilitation should be regularly done during the illness trajectory due to the change of focus over time described in this study (6).

Not all the precautions taken in outpatient management are evidence based. A clinical reassessment of those would presumably lead to a reduction in precautions. This may optimize the social life of the patients and in turn relieve some burdens from the caregiving spouse, resulting in a better social life for the whole
family. For example if the patients are allowed to go shopping at times with few people in the grocery stores.

Specific focus from the health care professionals on spouses and their particular challenges and needs is essential to ensure a sense of empowerment of the spouses and keep them resourceful and supportive of the patient throughout the illness trajectory. The information initially given about the structure and demands of outpatient management is very important. Ways to proceed with this could be a supportive/educative DVD or application to cell phones, an accompanying pamphlet and group consultations with relatives.

Referring back to the discussion of transferability in the section of methodological considerations (section 12.2.3), I consider the implications of this study to be of concern within the department, nationally and internationally to AL patients and hematological patients in general, but also to other groups of intensively treated patients.

14.2 Organization of the health care system
The findings of this study support outpatient management through more physical activity, social engagement and mental well-being experienced by the patients. In Denmark, the first outpatient management setting for pancytopenia AL patients treated with curative aim came at The National University Hospital, Copenhagen about ten years ago and since then it has become the standard way of managing these patients. The trend about outpatient management is seen worldwide and is still developing to becoming versatile and including the more weak AL patients.

Inspired by hotel-based ambulatory care for complex cancer patients, including HSCT patients, in England (94) the Department of Hematology, National University Hospital, Copenhagen introduced a pilot project with chemotherapy administrated by ambulatory infusion pumps at home 18 months ago (see appendix 14).
Because of positive experiences regarding safety and patient experiences from the project, all departments in Denmark treating AL patients currently are working at delivering chemotherapy by an ambulatory infusion pump where patients live at home and have to appear at follow-up visits at the hospital every other day. Department of Hematology, OUH has just used the ambulatory pump to the first patient.

The expectations are high that this hospital-based home treatment concept soon will include many other hematologic patients together with different oncological patients who receive intensive treatment of long duration. Other groups of patients, e.g. patients who receive intravenous antibiotics for infections over a long time will presumably benefit from hospital-based home care, like this study showed for AL patients. Outpatient management is also used in the management of children with different kinds of cancers and for patients with end-stage kidney disease who receive hemodialysis at home.

Step by step, the majority of treatments given in the health care system can be considered for hospital-based home care, hopefully improving the experience of patients and relatives, avoiding unnecessary hospitalization together with rationalization of inpatient ward beds and improvement in cost-efficiency. The experiences of the tentative beginnings of Hospital-based home care for adult AL patients in Denmark can, with transferability in mind, be used for organization also in other countries.

The patients experienced few professional rehabilitation initiatives during their illness trajectory, which is in line with that rehabilitation is a relatively new concept and not fully implemented yet. In the future rehabilitation implementation it is important to secure collaboration between different health care professionals across different sectors to shape a consistency throughout patients’ illness trajectory as wished by patients in this study, in line with the rehabilitation recommendations (6). This requires extra focus in outpatient management where many procedures will be partly supervised and self-management with a responsibility in line with the late modern culture. The principals of rehabilitation are applicable to all patient groups world-vide. The findings of this study can therefore give valuable information to the organization of rehabilitation in many health care settings.
The spouses in this study are having a hard time through the patients’ course of treatment. The future organizing with expanded outpatient management calls for focus on the relatives and involvement of them through information, collaboration and respect, having in mind that they are the fundamental prerequisite for realizing outpatient management of intensively treated severely ill patients.

**14.3 Future research**
Research based knowledge of outpatient management and rehabilitation is increasing but is still sparse.

This study contributes with important knowledge but also raises ideas to the future research in this field.

Some patients declined to participate in this study because it was too much for them on top of outpatient management. Other patients were not candidates for management in the HU. To get explorative knowledge from those two subgroups of patients, a future qualitative research study should include interviews with them during admission. They can never constitute a kind of control group as they are indeed selected, but knowledge from their perspective may be the key to what it takes to make them candidates for outpatient management, profiting the patients and the health care system. Is it due to unsupportive family conditions, living conditions or culture of the patients or the health care system?

Being able to describe outpatient management and rehabilitation initiatives from the health care professionals’ perspective will contribute with the possibility of discussing different situations or dilemmas from the perspective of both patients and health care professionals. This is important to the future development of daily clinical practice where those groups need to collaborate through the patients’ illness trajectory.

This study found little focus on existential problems from patients and spouses, but as discussed, the follow-up presumably needs to be longer to address this area. Qualitative interview studies or QOL questionnaire studies must continue follow-up as long as possible, at least up to one year after end of treatment.
The findings and experiences of this study could be broadened by a multicenter study, using the same design, taking the methodological considerations into account. This would be a good way to gain information about the uniformity across the different departments, managing the same types and treatments of patients. The gained knowledge could be a way to standardize the procedures in the different departments.

A longitudinal design using qualitative methods could be used for following a patient through the health care system, gaining knowledge about the cross-sectional collaboration. Also about how experiences, needs and relationships change over time.

Knowledge obtained from qualitative studies often inspire to quantitative studies where interventions can be tested and randomized controlled trials can give answers to small areas chosen for further research. For example following this study it could be a good idea to make a physical intervention study to get measures of their physical strength because the patients describe that they are not satisfied with the physical capability six months after end of treatment. It could also be biological markers associated with symptoms, physical training or mental well-being among, other things.

Hospital-based home treatment as described as the future to intensively treated AL patients including HSCT could profit from a qualitative study like the one described in this thesis taking all the suggestions of improvement into account. The obtained knowledge from such a study in this early developing phase will be very powerful to the future development of this concept.
15. Summary

15.1 Background
Outpatient management of intensively treated patients with AL is performed in the HU at the Department of Hematology, Odense University Hospital. The knowledge about how this type of outpatient management is experienced by patients and relatives is sparse.

15.2 Aim
This qualitative study aims to explore how outpatient management may offer an opportunity to meet well-known physical and psychosocial challenges in AL treatment and what new challenges it may produce.

15.3 Methods
This study, based on qualitative methods, combines participant observation in the HU, individual interviews three times with each patient (at the beginning in HU (n=22), ending HU-management (n=15) and six months after the end of treatment (n=16)) as well as group interviews (n=6) or individual interviews (n=5) with their spouses. The first scheduled individual patient interview took place in the HU and was followed by interviews in the homes of the patients at the second and third time. The results are analyzed in an everyday life relational perspective.

15.4 Results
15.4.1 Paper 1
Outpatient management facilitates time administrated by the patients and thereby the possibility of maintaining their everyday life. Time spent together with fellow-patients and their relatives became an important and highly valued part of their social life. Privacy ensured by the home was important to patients, and they accepted the necessary responsibility that came with it.

15.4.2 Paper 2
None of the patients were satisfied with their physical capabilities by the end of treatment, and they struggled with anxiety and the need for progress in the treatment and rehabilitation process. The precautions stated by the hospital restricted social life of the patients, demanding an effort of the patients
to get back a satisfactory social life. Professional interventions only counted for a very small part of the overall rehabilitation process.

15.4.3 Paper 3
Constantly, being in a state of vigilance and attention as a consequence of the undertaken responsibility, made the spouses experience their role as a burden. During outpatient management, the health care professionals took considerable efforts from the spouses for granted. The social life of the spouses suffered substantially due to the precautions stipulated by the HU. However, relations in the family were strengthened during the illness trajectory.

15.5 Conclusion
This study provides valuable insight into the experience of AL patients under outpatient management and how this affects and shapes the everyday life of themselves and their relatives. This helps us understand the need for rehabilitation that arises from patients in the outpatient management setting and how future initiatives and interventions in outpatient management may be implemented in everyday practice.
16. Summary in Danish (Dansk resumé)

16.1 Baggrund
Intensivt behandlede patienter med akut leukæmi håndteres semi-ambulant i Hjemmeenheden, Hæmatologisk Afdeling, Odense Universitetshospital. Der foreligger sparsom viden om, hvordan patienter og deres pårørende oplever denne type af semi-ambulant behandling.

16.2 Formål
Dette kvalitative studie har til formål at belyse, om semi-ambulant behandling kan imødekomme kendte fysiske og psykosociale udfordringer i behandlingsforløbet for akut leukæmi, og hvilke nye udforinger, der opstår.

16.3 Metode
Studie t senkner kvalitative metoder i form af deltagerobservation i Hjemmeenheden, individuelle interviews tre gange med hver patient (ved opstart i Hjemmeenheden (n=22), når behandling i Hjemmeenheden stopper (n=15) og seks måneder efter afsluttet behandling (n=16)) samt gruppeinterviews (n=6) eller individuelle interviews (n=5) med deres pårørende. Første planlagte individuelle patient interview fandt sted i Hjemmeenheden, mens andet og tredje interview fandt sted hjemme hos patienten. Resultaterne er analyseret i et hverdagslivsperspektiv.

16.4 Resultater

16.4.1 Artikel 1

16.4.2 Artikel 2
Ingen af patienterne var tilfredse med deres fysiske kunnen efter endt behandling. De kæmpede med angst og et behov for progression i både behandlingen og rehabiliteringsprocessen. Hospitalets forholdsregler
udgjorde en restriktion for patienternes sociale liv, så det krævede en indsats fra patienternes side at få et normalt socialt liv igen. Professionelle interventioner udgjorde kun en meget lille del af den samlede rehabiliteringsindsats.

16.4.3 Artikel 3
Konstant årvåbenhed og opmærksomhed, som en konsekvens af det ansvar, som ægtefællen havde påtaget sig, gjorde, at ægtefællerne beskrev deres rolle som en byrde. Personalet tog en stor indsats fra ægtefællerne for givet under semi-ambulant behandling, og ægtefællernes sociale liv led under de foreskrevne forholdsregler fra Hjemmeenheden. Som det mest positive blev familierelationerne styrket under sygdomsforløbet.

16.5 Konklusion
Dette studie giver et vigtigt indblik i, hvordan patienter med akut leukæmi og deres pårørende oplever semi-ambulant behandling, og hvordan det påvirker deres og de pårørendes hverdagsliv. Det hjælper os med at forstå, hvilke behov for rehabilitering, der opstår hos patienter i semi-ambulant behandling, og hvordan fremtidige initiativer og interventioner i semi-ambulant behandling kan implementeres i daglig klinisk praksis.
17. Reference list

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18. Appendix 1
Information about the Home Unit to the patients
Patientinformation

Patient i Hjemmeenheden
Hvad er Hjemmeenheden?


Kriterier for at være patient i Hjemmeenheden

- Du har haft en akut leukæmi (AML/ALL) og har fået kemobehandling og er ved at få ”lave tal”.
- Du har haft en forsamtale med en sygeplejerske og din nærmeste pårørende om Hjemmeenheden.
- Du skal have en voksen pårørende ved dig om natten. Bor du alene, så kan du bede en af dine nærmeste flytte ind hos dig i perioden eller du kan flytte hjem til dem.
- Du skal selv kunne administrere din medicin ud fra en medicinliste, som vi giver dig med.
- Du skal kunne klare dig i forhold til at spise og drikke tilstrækkeligt, og du skal sørge for at opretholde en god personlig hygiejne.
- Personalet vurderer, at det er sikkert for dig at være med i Hjemmeenheden.

Forsamtale til Hjemmeenheden


Forsamtalen tager udgangspunkt i dig og dit hverdagsliv, og i de observationer, som du selv skal varetage, imens du er derhjemme. Vi ved det er meget information at få på én gang, og vi gentager derfor forsamtalen med dig og din pårørende under
din anden kemobehandling. Det er efter anden behandling, at du overgår til at blive patient i Hjemmeenheden.

**Dagbog**

Når du er derhjemme, er det kun dig, der kan se og mærke, hvordan du har det. Dagbogen, som du finder bagerst i pjecen, er et redskab, du skal bruge til at notere dine observationer og symptomer i. Du kan her notere, hvordan du har det, og vi vil tage udgangspunkt i dine notater, når du møder i Hjemmeenheden. Du finder nogle spørgsmål, som du kan tage udgangspunkt i ved dagbogssiderne.

Du skal måle din temperatur morgen og aften og notere den i dagbogen. To gange om ugen skal du veje dig, så vi kan følge med i, hvordan det går med at spise.

**Transport**


**Hvordan er en dag i Hjemmeenheden?**

2. Du måler selv dit blodtryk (BT), din puls (P), din temperatur (Tp.) og dit Peak Flow (PF). PF måler du ved at puste i et lille apparat, der viser, hvordan din lungefunktion er. Du skriver dine målte værdier ned, og afleverer det til sygeplejersken.
4. Med udgangspunkt i dine dagbogsnote snakker du med sygeplejersken om, hvordan du har det, og om hvordan det går derhjemme. Hvis der ikke er nogen ændringer i, hvordan du har haft det siden sidst, så er det ikke altid nødvendigt, at en læge tilser dig. Sygeplejersken
vil sikre, at der er kontakt til lægen, hvis der er nogle ændringer i din tilstand.

Du er velkommen til at have en pårørende med i Hjemmeenheden.

**Dit Centrale Vene Kateter (CVK)**


Undersøgelser viser, at der er mindre risiko for infektioner, når du selv varetager plejen omkring dit CVK. En anden fordel ved selv at varetage plejen er, at du er mindre afhængig af plejepersonalet, og at ventetiden ved dine besøg i Hjemmeenheden vil blive kortere. Det kan i begyndelsen virke lidt overvældende at skulle gøre dette selv. Efter kort tid vil det bliver en hverdagsrutine for dig.

Remedierne til CVK-skift udleveres i Hjemmeenheden.

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<tr>
<th><strong>CVK derhjemme – hvad skal du holde øje med?</strong></th>
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<tr>
<td>Du skal være opmærksom på de klassiske infektionstegn ved CVK-indstikstedet:</td>
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<td>- Ømhed</td>
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<tr>
<td>Hvis du oplever dette, skal du kontakte afdelingen med det samme, da det kan være tegn på en begyndende infektion.</td>
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**Feber**


**Ved temperatur på 38.5° C, eller der over, skal du kontakte afdelingen med det samme.**
For at undgå infektioner derhjemme må du ikke omgås mennesker, der er synligt syge med f.eks. forkølelse, nogle der hoster meget eller har influenza. Du må gerne have besøg eller besøge venner og familie, så længe de er raske. Er du i tvivl så er du velkommen til at kontakte sygeplejersken i Hjemmeenheden.

Du skal undgå steder med mange mennesker som biografen, store indkøbssteder, svømmehallen og offentlige transportmidler.

Blødning
Når dine blodplader (trombocytter) er lave, er du i større risiko for at bløde, da dit blod er dårligere til at størkne. I huden vil du få øget tendens til blå mærker end du ellers har, og der kan komme små røde blodudtrækninger, også kaldet petekkier.


Hvad gør jeg ved blødning?
Ved næseblødning kan du lægge lidt knust is i en pose hen over næseryggen. Du kan også spise en is eller sutte på en isterning.

Kulden er med til at trække de små blodkar sammen, og kan hjælpe med til at standse blødningen. Hvis blødningen ikke stopper af sig selv inden for 30 minutter, skal du kontakte afdelingen.

Ved blod i urin eller i afføring skal du kontakte afdelingen.

<table>
<thead>
<tr>
<th>Blod - og blodplade transfusioner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Du skal have blod, når de røde blodlegem er under 5.5 mil./l.</td>
</tr>
<tr>
<td>Du skal have blodplader, når blodpladerne er under 15 mil./l.</td>
</tr>
</tbody>
</table>

Medicin

Du må ikke indtage:
- Panodil, Pinex eller Pamol. Det virkende stof ”paracetamol” virker febernedsættende og kan derfor skjule feber og dermed infektion.
- Ibumetin, Ibuprofen, Kodimagnyl og Magnyl. Disse fire præparater kan være med til at nedsætte dine blodpladers evne til at stærkne blodet.

Vi kan give dig Kodein tabletter med hjem, som du kan tage som et alternativt smertestillende præparat ved f.eks. hovedpine. Spørg sygeplejersken eller lægen inden du tager ny medicin.

**Mad og drikke**

Det er vigtigt, at du holder vægten derhjemme, og du må også gerne tage på. Du skal veje dig to gange om ugen, som der står i afsnittet om dagbogen. Hvis der er store ændringer i din vægt, vil sygeplejersken tale med dig om det ved dine fremmøder i Hjemmeenheden.

Sygeplejersken kan hjælpe dig med gode idéer til mellemmåltider og kalorielige fødevarer. Du har også mulighed for at få en recept med til de proteindrikke, du måske har prøvet i afdelingen.

Du skal sørge for at få godt med væske – vi anbefaler 2L om dagen. Erstat gerne vand med kalorielige drikke som mælk, saft og juice.


**Undgå at spise**

Skimmelost og honning da der kan være svampesporer i.

Mad der indeholde råt kød eller æg, da der kan være sygdomsfremkaldende bakterier i.

**Kæledyr**

Du må gerne have kæledyr i hjemmet - du skal dog undgå at have alt for tæt kontakt med dem. De skal ikke sove i samme seng som dig, og skal ikke slikke dig på hænder eller i ansigtet. Vask dine hænder, hvis du har rørt ved dem.

**Blomster**

**Fysisk aktivitet**

Vi anbefaler, at du ikke dyrker anstrengende sport som fodbold, håndbold, løb, fitness, svømning mm. Grunden til dette er, at der kan opstå små blødninger i muskerne ved hård fysiske aktivitet.

Du må til gengæld meget gerne være stille fysisk aktiv f.eks. cykle på en motionscykel, gå på trapper, lave let husarbejde eller gå en lang tur. Din muskelmasse er reduceret efter din første indlæggelse, og du skal stille og roligt begynde at bygge den op igen.

**Træthed**


**Samliv og seksualitet**

Dit samliv med din partner kan fortsætte, som før du blev syg. Der er intet medicinsk til hindring for det, og du kan ikke smitte din partner med kræft. Du udsætter heller ikke din partner for skadelige virkninger efter kemoterapien ved seksuelt eller andet samvær – hverken under eller efter behandlingen.

**Kvinder**

Efter behandling med kemoterapi kan kroppens slimhinder tørre ud. Som kvinde kan det være smertefuldt at have samleje, når slimhinderne er udtørrede. Mange er glade for at bruge en gliderekrem, der kan bruges ved tørhed, svie eller irritation i skeden. Cremen kan hjælpe til at gøre slimhinderne stærkere, tykkere eller mere elastiske. Gliderekmen fås på apoteket eller i forretninger, der forhandler seksuelle hjælpemidler.

**Mænd**

Alt afhængig af hvilken kræftsygdom du er blevet behandlet for, som mand, kan du få nogle fysiske bivirkninger, der kan have indflydelse på dit sexliv, f.eks. erektionsbesvær. Det er forskelligt fra mand til mand, hvilke problemer der opstår, og hvilke behandlingsmuligheder der er bedst for den enkelte. Det bedste råd vil derfor altid være, at du taler med sygeplejersken eller din læge, hvis du oplever en forandring i din krop efter behandlingen.

I ”Patientens bog” findes der et afsnit om seksualitet, som vi vil anbefale dig at læse.

Vi vil meget gerne give individuel vejledning til dig og din partner med udgangspunkt i jeres spørgsmål og behov.
**Hvad er vores forventninger til dig?**

1. Vi forventer, at du eller din pårørende lærer at skifte plasteret ved dit CVK, og selv varetager plejen af det.

2. Vi forventer, at du kort efter din opstart i Hjemmeenheden lærer at tage blodprøver i CVK’et.


Vi tilstræber, at du er hjemme igen ved frokosttid. Hvis du stadig er i Hjemmeenheden, er der mulighed for, at du kan få frokost gratis på patienthotellet eller fra X1. Der er ikke mulighed for, at pårørende kan spise gratis, så de skal have en madpakke med eller spise mod betaling på patienthotellet sammen med dig.

**Vigtig information**

Du skal kontakte afdelingen straks hvis:

- Du måler en temperatur på **38.5°C**
- Hvis du har blødning
- Du har ondt i halsen, føler åndenød eller har andre luftvejssymptomer.
- Der er noget, du er i tvivl om.

Hjemmeenheden kan du kontakte på hverdage mellem 8.00-15.00. Vi kan være optaget hos en patient og ikke have mulighed for at tage telefonen. Så skal du ringe i afdeling X1. I weekenden og på helligdage skal du også kontakte X1.

**Hjemmeenheden: Tlf. 23470567**

**X1: Tlf. 65412961**

Med venlig hilsen
Personalet i Hjemmeenheden, Afdeling X1
**Dagbog**

Vi vil bede dig udfylde dagbogen inden dit næste fremmøde i Hjemmeenheden med udgangspunkt i de nedenstående spørgsmål:

Har du nogen nyopståede problemer?

Har du nogen symptomer på infektion?

Har du nogen symptomer på blødning?

Har du ondt nogen steder?

Får du spist og drukket nok?

Får du lavet let motion derhjemme?

Føler du dig træt?

Har du diaré eller forstoppelse?

Er der noget der gør dig nervøs eller bekymret?

Husker du at tage din medicin?

Hvordan går det derhjemme?

Er der noget du er i tvivl om?

<table>
<thead>
<tr>
<th>Dato</th>
<th>Temperatur Morgen</th>
<th>Temperatur Aften</th>
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<tbody>
<tr>
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Vægt x 2 ugentligt

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<td>Dato</td>
<td>Temperatur Morgen</td>
<td>Temperatur Aften</td>
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</tbody>
</table>
## 19. Appendix 2

### Example of field notes

Deltagerobservation – Feltnoter
Hjemmeenheden dag 1. Fra kl. 07.50 til kl. 15.10

<table>
<thead>
<tr>
<th>Nr.</th>
<th>Deskriptive observationer</th>
<th>Refleksioner</th>
<th>Temaer</th>
</tr>
</thead>
</table>
Ansvar. |
Ansvar. |
| 7   | Tavshed. |  |  |
## 20. Appendix 3

Interview guide, first individual, semi-structured patient interviews

<table>
<thead>
<tr>
<th>Kategori:</th>
<th>Tema:</th>
<th>Spørgsmål:</th>
<th>Uddybende spørgsmål:</th>
</tr>
</thead>
</table>
| Hjemmeenheden (emne nr. 1) | • Indretning  
  • Kommunikation  
  • Samvær  
  • Tilknytningsforhold  
  • Privatliv/følsomme oplysninger  
  • Fysisk aktivitet  
  • Personalet  
  • Ansvar  
  • Tillid  
  • Humor  
  • Pårørende  
  • Hvilke tanker gjorde du dig om HE første gang, du blev præsenteret for den?  
  • Hvordan oplever du det, at der er flere patienter sammen med dig i HE?  
  • Kan du fortælle om nogle af de samtaleemner, der er blandt patienter og pårørende i HE?  
  • Er der emner, som man ikke må snakke om i HE?  
  • Hvem snakker du med i HE?  
  • Hvis du har haft nogle af dine pårørende med i HE, kan du så beskrive din oplevelse af at have pårørende med i HE? Venner?  
  • Hvordan oplever du samværet i HE?  
  • Hvordan påvirker det dit samvær med andre, der ikke er syge, at du kommer i HE?  
  • Hvordan oplever du mulighederne for “privatliv” i HE?  
  • Hvordan oplever du de dage i HE, hvor der er behov for, at der bliver taget individuelle hensyn til dig?  
  • Hvordan oplever du |
<table>
<thead>
<tr>
<th>Kategori:</th>
<th>Tema:</th>
<th>Spørgsmål:</th>
<th>Uddybende spørgsmål:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Påvirkning af hverdagen</td>
<td></td>
<td></td>
<td>mulighederne for fysisk aktivitet i HE?</td>
</tr>
<tr>
<td>(emne nr. 2)</td>
<td></td>
<td></td>
<td>• Har du haft kontakt til medpatienter uden for HE/afdelingen?</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>▷ Hvordan vil du beskrive en typisk HE dag fra du står op til du går i seng?</td>
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<td></td>
<td>▷ Hvordan vil du beskrive en typisk ikke-HE dag fra du står op til du går i seng?</td>
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<tr>
<td></td>
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<td></td>
<td>▷ Hvordan vil du beskrive en typisk dag under indlæggelse på Afd. X fra du står op til du går i seng?</td>
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<td></td>
<td>▷ Hvornår og hvordan planlægger du din hverdag?</td>
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<td>▷ Hvornår og hvordan planlægger du din hverdag?</td>
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<td></td>
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<td></td>
<td>▷ Hvordan har din hverdag ændret sig i forhold til før, du fik akut leukæmi?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>▷ Kan du beskrive, hvordan din medicin og administration af denne påvirker din hverdag?</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>▷ Kan du beskrive, hvordan dit sygdomsforløb påvirker din fysiske aktivitet? (fysisk, psykisk, social omgangskreds, HE/ikke-HE dage)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>▷ Hvordan påvirker dit sygdomsforløb din psykiske tilstand? (Tanker, præst/psykolog)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>▷ Oplever du, at der bliver taget hånd om din psykiske tilstand? I givet fald af hvem?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>▷ Hvilke ting har du selv gjort for at påvirke dit sygdomsforløb?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>▷ Hvad er det, du gerne vil kunne aktuelt, men som du ikke kan pga. din akutte leukæmi?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>▷ Hvilke tanker gør du dig om fremtiden? (Allo-SCT)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>▷ Hvornår og hvordan har du fokus på din sygdom?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>▷ Hvordan påvirker dit sygdomsforløb dit forhold til mad og drikke? (Væskeskema, vægt, sygehusmad, madlyst,</td>
</tr>
<tr>
<td>Kategori:</td>
<td>Tema:</td>
<td>Spørgsmål:</td>
<td>Uddybende spørgsmål:</td>
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<tr>
<td>----------</td>
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<td>----------------------</td>
</tr>
</tbody>
</table>
| **Procedurer** *(emne nr. 3)* | • Oplæring  
• Udførelse  
• Ansvar  
• Bidrage med noget  
• Forskellighed  
• Blod  
• Pt. til pt. | • Hvordan oplever du at deltage aktivt i behandlingen af din sygdom ved at udføre diverse procedurer?  
(Tp., BT, peak-flow, vægt, tage blodprøver fra Hickman kateter, aflevering af blodprøver, forbindingsskift, injektion af GCSF, væskeskema) | • Hvad tænkte du første gang, du blev præsenteret for, at du selv skulle udføre diverse procedurer?  
• Hvilken følelse giver det dig selv at bidrage med noget?  
• Hvordan har du lært de procedurer, du selv skal udføre i forbindelse med din behandling i HE?  
• Hvordan husker du første gang, du skulle udføre en procedure?  
• Kan du beskrive, hvordan du udfører procedurerne, en ad gangen?  
• Hvordan oplever du det ansvar, der følger med, når du selv skal udføre procedurerne?  
• Hvordan oplever du, at I som patienter hjælper hinanden med de praktiske ting?  
• Hvilke tanker får du, når jeg siger ordet “blodprøver”? |
| **Hjemmet** *(emne nr. 4)* | • Ændringer  
• Krav  
• Pårørende  
• Livskontekst  
• Udfordringer  
• Hjem=hjem | • Kan du beskrive de ændringer, der er sket i hjemmet, som følge af din sygdom? | • Hvad er din oplevelse af at være hjemme?  
• Hvordan er det for dig at opholde dig så meget hjemme under sygdomsforløbet?  
• Hvordan oplever du din pårørendes rolle ud fra de krav, der stilles af HE?  
• Har dit sygdomsforløb givet anledning til ændringer af, hvem der gør hvad hjemme |
Indledning:

Velkommen til og tak fordi du ville komme. Det er jeg rigtigt glad for.

Med det her projekt vil jeg gerne finde ud af, hvordan det er at være patient i Hjemmeenheden og derfor vil jeg gerne høre om dine tanker og erfaringer omkring det. Der er altså ikke noget, der er rigtigt eller forkert, og alle svar er lige værdifulde for mig. Resultaterne fra projektet skal være med til at videreudvikle Hjemmeenheden til gavn for fremtidige patienter med akut leukæmi.

Jeg forventer, at interviewet vil tage ca. 1 time.


Afslutning:

Har du en afsluttende kommentar eller noget relevant, du ikke har fået sagt, som vi skal have med, inden vi slutter samtalen?


Oplysninger:

<table>
<thead>
<tr>
<th>Dato / sted:</th>
<th>Diagnose (recidiv?):</th>
<th>Uddannelse:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Navn:</td>
<td>Kur nr.:</td>
<td>Beskæftigelse:</td>
</tr>
<tr>
<td>Alder:</td>
<td>Dato for start i HE:</td>
<td>Sygemeldt aktuelt:</td>
</tr>
<tr>
<td>Køn:</td>
<td>Afventer KMT:</td>
<td>Transport:</td>
</tr>
<tr>
<td>Ægteskabelig status:</td>
<td>Tid siden diagnose:</td>
<td></td>
</tr>
</tbody>
</table>
## 21. Appendix 4

Interview guide, second individual, semi-structured patient interviews

<table>
<thead>
<tr>
<th>Kategori:</th>
<th>Tema:</th>
<th>Spørgsmål:</th>
<th>Uddybende spørgsmål:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hjemmeenheden (emne nr. 1)</td>
<td>Indretning</td>
<td>Hvordan var din oplevelse af at være patient i HE?</td>
<td>Hvis jeg siger “HE”, hvad tænker du så på?</td>
</tr>
<tr>
<td></td>
<td>Kommunikation</td>
<td></td>
<td>Kan du fortælle om nogle af de samtaleemner, der var blandt patienter og pårørende i HE?</td>
</tr>
<tr>
<td></td>
<td>Samvær</td>
<td></td>
<td>Var der emner, som man ikke måtte snakke om/blev taget op i HE?</td>
</tr>
<tr>
<td></td>
<td>Tilknytningsforhold</td>
<td></td>
<td>Hvem snakkede du med i HE?</td>
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<tr>
<td></td>
<td>Privatliv/følsomme oplysninger</td>
<td></td>
<td>Kan du give et eksempel på humor brugt i HE?</td>
</tr>
<tr>
<td></td>
<td>Fysisk aktivitet</td>
<td></td>
<td>Hvis du har haft nogle af dine pårørende med i HE, kan du så beskrive din oplevelse af at have pårørende med i HE? Venner?</td>
</tr>
<tr>
<td></td>
<td>Personalet</td>
<td></td>
<td>Hvordan oplevede du samværet i HE?</td>
</tr>
<tr>
<td></td>
<td>Ansvar</td>
<td></td>
<td>Hvordan oplevede du det, at der var flere patienter sammen med dig i HE?</td>
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<tr>
<td></td>
<td>Tillid</td>
<td></td>
<td>Hvordan oplevede du mulighederne for ”privatliv” i HE?</td>
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<tr>
<td></td>
<td>Humor</td>
<td></td>
<td>Hvordan oplevede du de dage i HE, hvor der var behov for, at der blev taget individuelle hensyn til dig?</td>
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<tr>
<td></td>
<td>Pårørende</td>
<td></td>
<td>Hvordan oplevede du mulighederne for fysisk aktivitet i HE?</td>
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<tr>
<td></td>
<td>Socialt liv</td>
<td></td>
<td>Har du haft kontakt til medpatienter uden for HE/afdelingen?</td>
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<td></td>
<td></td>
<td></td>
<td>Er der nogle af ting, der har ændret sig over tid i HE?</td>
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<tr>
<td>Kategori:</td>
<td>Tema:</td>
<td>Spørgsmål:</td>
<td>Uddybende spørgsmål:</td>
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</tbody>
</table>
| Påvirkning af hverdagen (emne nr. 2) | Hjemme, Tid, Medicin, Mad og drikke, Sociale behov, Fysisk aktivitet | Hvordan vil du beskrive en typisk dag fra du står op til du går i seng? | Hvordan skulle HE være indrettet, hvis du skulle designe den?  
Hvordan var det at sige farvel til HE? |
| |  
| | Hvordan vil du beskrive en typisk dag under indlæggelse på Afd. X fra du står op til du går i seng? |  
| |  
| | Hvordan vil du beskrive en typisk dag fra du står op til du går i seng? | Hvad, fra HE, har du taget med videre i dit liv?  
Hvornår og hvordan planlægger du din hverdag?  
Hvad er ændret i din hverdag i forhold til, da du havde fremmøde i HE hver eller hver anden dag (fysisk og social aktivitet)?  
Kan du beskrive, hvordan din medicin og administration af denne påvirker din hverdag?  
Kan du beskrive, hvordan dit sygdomsforløb påvirker din fysiske aktivitet? (fysisk, psykisk, social omgangskreds)  
Hvordan påvirker dit (netop overståede) sygdomsforløb din psykiske tilstand? (Tanker, præst/psykolog)  
Oplevede du, at der blev taget hånd om din psykiske tilstand? I givet fald af hvem?  
Har du følt behov for selv at gøre noget for at påvirke dit sygdomsforløb? Giv eksempel herpå.  
Olever du begrænsninger i ting, du gerne vil kunne aktuelt, men som du ikke kan pga. det netop overståede behandlingsforløb? Giv eksempel herpå.  
Hvilke tanker gør du dig om fremtiden? (allo-SCT) |
<table>
<thead>
<tr>
<th>Kategori:</th>
<th>Tema:</th>
<th>Spørgsmål:</th>
<th>Uddybende spørgsmål:</th>
</tr>
</thead>
</table>
| Hjemmet (emne nr. 3) | • Ændringer  
• Kontrol  
• Livskontekst  
• Udfordringer  
• Hjem=hjem | • Kan du beskrive de ændringer, der er sket i hjemmet, som følge af din sygdom? | • Nu hvor du ser tilbage på forløbet i HE, hvordan har det så påvirket din hverdag?  
• Har dit sygdomsforløb fået dig til at ændre nogle af de ting, du gør i hverdagen?  
• Kan du sætte ord på forskellene mellem at være indlagt på afd. X2 og så være patient i HE?  
• Hvordan har dit sygdomsforløb påvirket dit forhold til mad og drikke? (Væskeskema, vægt, sygehusmad, madlyst, pårørende ikke får mad på sygehuset, kostændringer, HE-restricctioner) |
| Hygiejne (emne nr. 4) | • Sprit  
• Sygdomssmitte  
• Isolation (HE/X2/hjemme)  
• Familie / socialt liv | • Hvordan er dit forhold til hygiejne, efter dit hidtidige behandlingsforløb, sammenlignet med tidligere? | • Hvad er din oplevelse af at være hjemme?  
• Hvordan har det været for dig at opholde dig så meget hjemme under sygdomsforløbet?  
• Hvordan oplevede du din pårørendes rolle ud fra de krav, der blev stillet af HE?  
• Har dit sygdomsforløb givet anledning til ændringer af, hvem der gør hvad hjemme hos dig? (mad, tøjvask, rengøring) |

111
### Indledning:

Tak fordi jeg må komme og besøge dig i dag og for, at du vil deltage i endnu et interview. Det er jeg rigtigt glad for, og jeg har glædet mig meget til at skulle snakke med dig igen.

Som du måske husker, vil jeg, med det her projekt, gerne finde ud af, hvordan det er at være patient i Hjemmeenheden, og derfor vil jeg gerne høre om dine tanker og erfaringer omkring det. Der er altså ikke noget, der er rigtigt eller forkert, og alle svar er lige værdifulde for mig. Resultaterne fra projektet skal være med til at videreudvikle Hjemmeenheden til gavn for fremtidige patienter med akut leukæmi.

Jeg forventer, at interviewet vil tage ca. 1 time.


### Afslutning:

Har du en afsluttende kommentar eller noget relevant, du ikke har fået sagt, som vi skal have med, inden vi slutter samtalen?


### Oplysninger:

| Dato / sted: | Navn: | Antal kure: | Afventer KMT: | Tid siden diagnose: | Sygemeldt aktuelt: | Afsluttet HÆ hvornår: |

Det?
- Oplevede du isolation i dit behandlingsforløb og i givet fald hvordan?
22. Appendix 5

Interview guide, third individual, semi-structured patient interview

<table>
<thead>
<tr>
<th>Kategori: Påvirkning af hverdagen (emne nr. 1)</th>
<th>Tema:</th>
<th>Spørgsmål:</th>
<th>Uddybende spørgsmål:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hjemme • Tid • Tomrum • Klædt på... • Arbejde • Fysisk aktivitet • Sociale behov • Psykisk tilstand • Fremtiden • Medpatienter</td>
<td>• Hvordan vil du beskrive en typisk dag fra du står op til du går i seng?</td>
<td>• Hvornår og hvordan planlægger du din hverdag? • Hvad er ændret i din hverdag efter, at du er overgået til transplantationsforløb på RH? • Har du oplevet et tomrum efter at have afsluttet behandlingsforløbet? • Hvordan havde HE klædt dig på til det videre forløb? • Nu hvor du ser tilbage på sygdomsforløbet, hvordan har det så påvirket din hverdag? • Er du tilbage på arbejde igen? Fuld tid? • Har du kræfter til de samme ting nu, som du havde inden du fik akut leukæmi? • Prøv at beskrive hvad du kan rent fysisk her 6 måneder efter? • Hvordan du er kommet dertil med din fysiske kunnen? • Hvor tilfreds er du med, hvad du kan præstere fysisk? • Hvem ser du i hverdagen? • Hvordan er din omgangskreds efter du har været syg? • Hvilke muligheder har der været for at holde kontakt med familie og venner under sygdomsforløbet? • Hvordan har du taget hånd om, hvordan du har haft det mentalt? Evt. fået hjælp af præst, psykolog, andre? • Oplever du begrænsninger i ting, du gerne vil kunne aktuelt, men som du ikke kan pga. det netop overståede behandlingsforløb? Giv eksempel herpå.</td>
<td></td>
</tr>
<tr>
<td>Kategori:</td>
<td>Tema:</td>
<td>Spørgsmål:</td>
<td>Uddybende spørgsmål:</td>
</tr>
<tr>
<td>-----------</td>
<td>-------</td>
<td>------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Hjemmet</td>
<td>Hjem=heim</td>
<td>Hvilke tanker får du, når jeg siger ordet “hjem”?</td>
<td>Hvor er det at være hjemme uden at skulle møde op på sygehuset så ofte?</td>
</tr>
<tr>
<td></td>
<td>Pårørenderolle</td>
<td></td>
<td>Hvilken betydning har ”heim” for dig efter dit sygdomsforløb?</td>
</tr>
<tr>
<td></td>
<td>Ændringer</td>
<td></td>
<td>Hvordan vil du beskrive din pårørendes rolle nu, hvor behandlingsforløbet er afsluttet?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Kan du beskrive de ændringer, der er sket i hjemmet, i løbet af dit sygdomsforløb? Gælder de stadigvæk?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Har dit sygdomsforløb givet anledning til ændringer af, hvem der gør hvad hjemme hos dig og gælder det stadigvæk? (mad, tøjvask, rengøring)</td>
</tr>
<tr>
<td>Hygiejne</td>
<td>Sprit</td>
<td>Kan du beskrive de forbehold i forhold til hygiejne, der stadigvæk gør sig gældende hos dig?</td>
<td>Kan du beskrive, hvilket forhold du har fået til sprit efter, du har været syg?</td>
</tr>
<tr>
<td></td>
<td>Sygdomssmitte</td>
<td></td>
<td>Hvad tænker du om risikoen for at blive smittet med en infektionssygdom nu? Oplevede du det under sygdomsforløbet?</td>
</tr>
<tr>
<td></td>
<td>Isolation</td>
<td></td>
<td>Oplever du isolation på grund af din hygiejniske standard? I givet fald hvordan?</td>
</tr>
<tr>
<td></td>
<td>Familie / socialt liv</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Indledning:

Tak fordi jeg må komme og besøge dig i dag og for, at du vil deltage i endnu et interview. Det er jeg rigtigt glad for, og jeg har glædet mig meget til at skulle snakke med dig igen.

Som du måske husker, vil jeg, med det her projekt, gerne finde ud af, hvordan det er at være patient i Hjemmeenheden, og derfor vil jeg gerne høre om dine tanker og erfaringer omkring det. Der er altså ikke noget, der er rigtigt eller forkert, og alle svar er lige værdifulde for mig. Resultaterne fra projektet skal være med til at videreudvikle Hjemmeenheden til gavn for fremtidige patienter med akut leukæmi.

Jeg forventer, at interviewet vil tage ca. 1 time.


Afslutning:

Har du en afsluttende kommentar eller noget relevant, du ikke har fået sagt, som vi skal have med, inden vi slutter samtalen?

Tak for dit bidrag både i dag og i det hele taget. Det har været en fornøjelse, og du har bidraget med nogle rigtigt spændende kommentarer, som jeg er sikker på, at jeg får stor glæde af. Farvel og tak for i dag.

Oplysninger:

Dato / sted:
Navn:
KMT eller X4:
Afsluttet HE/KMT hvornår:
Sygemeldt aktuelt:
23. Appendix 6

Excerpt from an individual patient interview

Tredje individuelle patient interview hos patienten.
F=forsker; IP=interview person=patient

F: Men har du oplevet sådan et TOMRUM så efter, ligesom afsluttet behandlingsforløb, transplantation og sådan noget? Kommer der sådan et eller andet, hvor man tænker?


F: Og tænker du energien så er til det?

24. Appendix 7
Excerpt from a spouse group interview

Andet gruppeinterview i Hjemmeenheden.
F=forsker; IP1, IP2, IP3, IP4=interview person=pårørende

F: Han har ikke haft nogen besøg?


IP4: Vi synes bare faktisk ikke, vi har haft så meget besøg også, fordi – for det første så var det vintertid. Ja nu med børnebørn, ikke også. Så – jeg synes, de render ind i både det ene og det andet i skole og i børnehave og sådan noget.

IP2: Ja det - det er lidt svært, når det er børn. Det er smitsomt.


IP3. Jamen det er da rigtigt


IP1: Hvis man ikke slapper af, så - så duer det jo heller ikke, hvis man sidder på nåle.

IP2: Så – så kan man lige så godt ligesom indrømme og så sige, så vil man alligevel hellere sidde alene.
Particip
ant information

Patientinformation om forskningsprojekt

Patienter og pårørendes erfaringer med Hjemmeenheden

POPERH-studiet

Semi-ambulant behandling af patienter med akut leukæmi. Patienter og pårørendes erfaringer – belyst i et rehabiliteringsperspektiv
Undersøgelse af patienter og pårørendes oplevelser og erfaringer med behandling i Hjemmeenheden


Du kan hjælpe os!

Baggrund for undersøgelsen
Vi tror, at patienter kan have gavn af at opholde sig hjemme så meget som muligt under behandlingsforløbet. Derfor oprettede Hæmatologisk afdeling X, Odense Universitets Hospital ”Hjemmeenheden”. Her gives der såkaldt semi-ambulant behandling for patienter med akut leukæmi. Behandling i Hjemmeenheden er i stedet for lange indlæggelser. Man behandles hver anden dag, men bor og sover hjemme.

Når man har fået en alvorlig sygdom som kæft, kan man have brug for støtte af forskellig slags til at komme videre og i gang med hverdagen igen. Man ved dog ikke så meget om, hvilke typer af tilbud og initiativer, der kan være særligt gode til at hjælpe patienter og pårørende videre.

Hvem kan deltage i undersøgelsen?
Patienter med akut leukæmi, som er i gang med et behandlingsforløb i Hjemmeenheden.

Hvordan pårørende oplever forløbet i Hjemmeenheden, vil vi også gerne vide mere om. Derfor inviteres pårørende til at medvirke i undersøgelsen, hvis det er i orden.
med patienten. Den pårørende er den person der, sammen med patienten, skal tage hånd om de forpligtelser, der følger med behandlingen. Det kan være en ægtefælle eller fast bofælle, men også et voksent barn eller en ven. Ønsker den pårørende ikke at deltage, kan patienten godt være med i projektet alligevel.

**Hvordan gennemføres undersøgelsen?**
De pårørende bliver interviewet i grupper med 5-6 deltagere. Interviewene vil foregå i Hjemmeenheden. De varer 1-2 timer.

**Frivilligt og fortroligt**

**Hvem er jeg?**

**Finansiering af projektet**
Undersøgelsen er finansieret af Region Syddanmark, Kræftens Bekæmpelse og Syddansk Universitet. Vi har desværre ikke mulighed for at betale transport i forbindelse med interview eller tabt arbejdsfortjeneste.

**Har du spørgsmål?**
Vi håber, at du med denne information har fået tilstrækkeligt indblik i, hvad det vil
sige at deltage i undersøgelsen, og at du føler dig rustet til at tage beslutningen om din eventuelle deltagelse. Hvis du vil vide mere eller har spørgsmål, er du meget velkommen til at kontakte:

**Lene Østergaard Jepsen**

E-mail: lene.jepsen@rsyd.dk
Mobil: 28921581

**Projektgruppen:**

**Projektleder:** ph.d.-studerende, læge Lene Østergaard Jepsen

**Projektadresse:** Hjemmeenheden, Hæmatologisk afdeling X, Odense Universitetshospital, Sdr. Boulevard 29, 5000 Odense C. Hjemmeenheden
tlf.: 23470567

**Øvrige deltagere:**
Overlæge, ph.d., klinisk lektor Lone Smidstrup Friis, Hæmatologisk afdeling X, Odense Universitetshospital, Syddansk Universitet

Forsker, cant. scient. anth., ph.d. Mette Terp Høybye, Center for Interventionsforskning,
Statens Institut for Folkesundhed, Syddansk Universitet

Centerleder, læge, ph.d., seniorforsker Dorte Gilså Hansen, Nationalt Forskningscenter for Kræftrehabilitering, Forskningsenheden for Almen Praksis, Syddansk Universitet
26. Appendix 9
Informed consent form

Semi-ambulant behandling af patienter med akut leukæmi. Patienter og pårørendes erfaringer – belyst i et rehabiliteringsperspektiv

Erklæring fra deltager:

Jeg har fået skriftlig og mundtlig information om undersøgelsen.

Jeg ved, at det er frivilligt at deltage. Jeg altid kan trække mit samtykke tilbage uden at miste mine nuværende eller fremtidige rettigheder til behandling.

Jeg er oplyst om, at alle oplysninger behandles fortroligt og at offentliggørelse af undersøgelsens resultater sker i anonymiseret form.

Jeg giver samtykke til at deltage i forskningsprojektet.

Jeg giver tilladelse til, at der indhentes oplysninger om mig i hospitalets journaler.

Navn (blokbogstaver):

__________________________

Mobil nr.: E-mail:

__________________________

Jeg er: Patient [ ] Pårørende [ ]

Dato: Underskrift:

__________________________
**Erklæring fra projektleder:**

Jeg erklærer, at deltageren har modtaget mundtlig og skriftlig information om undersøgelsen og har haft mulighed for mundtligt at få besvaret eventuelle spørgsmål af mig.

Efter min overbevisning er der givet tilstrækkeligt information til, at der kan træffes beslutning om deltagelse i undersøgelsen.

**Projektleders navn:**

Lene Østergaard Jepsen

---

**Dato:**

**Underskrift:**

---
27. Appendix 10

Approval from the Regional Scientific Ethical Committees for Southern Denmark
Research: HERP Hjemmeenhedsrehabiliteringsprojekt - Forsøgsprotokol 07-04-2012 final version

The Regional Scientific Ethical Committee for South Denmark has received a request for notifiable.

Based on the information available, the Committee decided that the project is not notifiable, see Committee Act § 14, 2 and can be implemented without the permission of The Regional Scientific Ethical Committee for South Denmark.

In Denmark, it is the responsibility of the research ethics committee system to evaluate biomedical research projects. A biomedical research project means an activity planned according to research methods and which aims at producing new, valuable knowledge about human biological and psychological processes, either in relation to healthy persons or for the purpose of prevention, recognition, relief, treatment or cure of diseases, symptoms and pain, including affecting bodily functions.

Biomedical research primarily comprises research within medical subjects, clinical and socio-medical-epidemiological research. In addition to research of somatic diseases, the concept also covers psychiatric and clinical-psychological diseases and states as well as odontological and pharmaceutical research.

Register research projects and questionnaire projects are to be notified only if human biological material is included in the project. In case of interview based studies similar regulations apply.

Trials on cell lines or the like that originate from a trial with collection of cells or tissue that has obtained the necessary permission need not be notified either.

Trials that have the sole objective to determine the toxicological limit in humans of a chemical are not subject to notification. A chemical in this connection shall mean any substance that is not administered therapeutically.

As mentioned, your project is assessed to fall outside the demarcation of projects that have to be notified to a regional research ethics committee.
As a matter of form, our rejection to evaluate your project does not constitute any ethical consideration or negative evaluation of the content of the project.

**Complaints procedure:**
The Committee's decision may be referred to Committee Act § 26 paragraph. 1, submitted to The National Committee on Health Research Ethics within 30 days after the decision is received.

The National Committee on Health Research Ethics may, for the sake of securing the rights, deal with elements of the project not covered by the complaint itself.

The appeal must be submitted electronically using digital signatures and encryption, if the protocol contains confidential information.

This can be done at: dnvk@dnvk.dk

The complaint must be justified and be accompanied by a copy of The Regional Scientific Ethical Committee's decision and the file which The Regional Scientific Ethical Committee has decided on the basis of.

The case is 17th of August 2012 settled by the Committee Chairman, Dr. med. Birger Møller.

At the Committee's behalf,
sincerely,

Birger Møller
Chairman

/  

Claus Kvist Hansen
Head of Secretariat
28. Appendix 11

Approval from the Danish Data Protection Agency
Vedrørende anmeldelse af:
Semi-ambulant behandling af patienter med akut leukæmi. Patienter og pårørende erfaringer – belyst i et rehabiliteringsperspektiv


Oplysningerne vil blive behandlet på følgende adresse: Sdr. Boulevard 29, 2. sal, 5000 Odense C.

TILLADELSE

Direktionssekretariatet på OUH Odense Universitetshospital meddeler hermed, på vegne af Region Syddanmark, tilladelse til projektets gennemførelse.

Region Syddanmark fastsætter i forbindelse med tilladelser nedenstående vilkår:

Generelle vilkår

Tilladelsen gælder indtil: 31. december 2015

Ved tilladelsens udløb skal du særligt være opmærksom på følgende:

Hvis du ikke inden denne dato har fået tilladelsen forlænget, går Region Syddanmark ud fra, at projektet er afsluttet, og at personoplysningerne er slettet, anonymiseret, tilintetgjort eller overført til arkiv, jf. nedenstående vilkår vedrørende projektets afslutning.

Region Syddanmark
Region Syddanmark gør samtidig opmærksom på, at al behandling (herunder også opbevaring) af personoplysninger efter tilladelsens udløb er en overtrædelse af persondataloven, jf. § 70.

1. Lene Østergaard Jepsen, Ph.D. Studerende, Læge, Hæmatologisk Afdeling X, er, som projektansvarlig på vegne af Region Syddanmark som dataansvarlig, ansvarlig for overholdelsen af de fastsatte vilkår.

2. Oplysningerne må kun anvendes til brug for projektets gennemførelse.


4. Enhver (herunder ansatte i Region Syddanmark), der foretager behandling af projektets oplysninger, skal være bekendt med de fastsatte vilkår.

5. De fastsatte vilkår skal tilfugne iagttagtes ved behandling, der foretages af databehandler.


7. Lokaler, der benyttes til opbevaring og behandling af projektets oplysninger, skal være indrettet med henblik på at forhindre uvedkommende adgang.


9. Oplysninger må ikke opbevares på en måde, der giver mulighed for at identificere de registrerede i et længere tidsrum end det, der er nødvendigt af hensyn til projektets gennemførelse.

10. En eventuel offentliggørelse af undersøgelsens resultater må ikke ske på en sådan måde, at det er muligt at identificere enkeltpersoner.

11. Eventuelle vilkår, der fastsættes efter anden lovgivning, forudsættes overholdt.

Elektroniske oplysninger

12. Adgangen til projektdata må kun finde sted ved benyttelse af et personligt fortroligt password. Kun personer, der er beskæftiget med eller har et andet sagligt formål til projektet må tildeles et pass-
word til projektets data. Passworet skal afgrænses således, at den enkelte projektdeltager alene
har rettigheder til de funktioner, der er relevante for denne, fx forespørg, inddatere eller slettepersionopløsninger. Udførmning og udskiftning af password bør følge Region Syddanmarks ’instrukser
for brug af it’ (NB: OUH har egne instrukser på området).

13. Hvert halve år skal det kontrolleres, at projektdeltagerne har de korrekte rettigheder.

14. Der skal foretages registrering af alle afviste adgangsforsøg. Hvis der inden for en fastsat periode er
registreret et nærmere fastsat antal på hinanden følgende afviste adgangsforsøg fra samme arb-
bejdsstation eller med samme brugeridentifikation skal der blokeres for yderligere forsøg. Der skal
følges op på afviste adgangsforsøg.

15. Der skal foretages logning af alle anvendelser af personopløsninger i forbindelse med projektet.
Loggen skal mindst indeholde oplysning om tidspunkt, bruger, type af anvendelse og angivelse af
den person, de anvendte oplysninger vedrørte eller det anvendte søgekriterium.

16. Såfremt identifikationsoplysninger enten er krypterede, eller erstattet med et id-nummer, skal loggen
alene indeholde oplysninger om bruger og tidspunktet for behandlingen (se. gemme, søge, opdatere
m.v.)

17. Loggen skal opbevares i 6 måneder, hvorefter den skal slettes. Ved særligt behov kan loggen opbe-
vares i op til 5 år.

18. Nøglefiler – krypteringsnøgle, kodensøgle m.v. – skal opbevares forsvarligt og adskilt fra personop-
løsningerne.

19. Ved behov for adgang til projektets data uden for Region Syddanmarks lokalit/ntnetværk, skal dette
ske via enten en VPN-forbindelse eller en Citrix-forbindelse.

20. Ved overførsel af personenforbarel oplysninger via Internet eller andet eksternt netværk uden for
Region Syddanmark skal der tæffles de fornødne sikkerhedsforanstaltninger mod, at oplysningerne
kommer til uvedkommendes kendskab. Oplysningerne skal som minimum være forsvarligt krypteret
under hele transmissionen. Overføres data inden for Region Syddanmarks netværk sker overførslen
krypteret/sikkert.

21. Data må ikke opbevares lokalt på fx C-drevet på pc’er eller USB-nøgler. Dog kan der ske sikker-
hedskopiering af data til udtagelige lagringsmedier. Disse skal opbevares forsvarligt aflåst og såle-
des, at uvedkommende ikke kan få adgang til oplysningerne.

Manuelle oplysninger
22. Manuelt projektmateriale, udskrifter, fejl- og kontrollister, m.v., der direkte eller indirekte kan henføres til bestemte personer, skal opbevares forsvarligt aflåst og på en sådan måde, at uvedkommende ikke kan gøre sig bekendt med indholdet.

23. Manuelt projektmateriale skal slettes, når det ikke længere er relevant for projektet, dog senest ved projektets afslutning 31. december 2015

Oplysningspligt over for den registrerede

24. Hvis der skal indsamles oplysninger hos den registrerede (ved interview, spørgeskema, klinisk eller paraklinisk undersøgelse, behandling, observation m.v.) skal der uddøles/fremsendes nærmere information om projektet. Den registrerede skal heri olyses om den dataansvarligheds navn, formålet med projektet, at det er frivilligt at deltage, og at et samtykke til deltagelse vil enhver tid kan trækkes tilbage.

25. Den registrerede skal endvidere olyses om, at projektet er anmeldt til Datatilsynet via Region Syddanmark efter Persondatalovens bestemmelser, samt at der for projektet er fastsat nærmere vilkår til beskyttelse af den registreredes privatliv.

Indsigtsret


Videregivelse

27. Videregivelse af personhenførbare oplysninger til tredjepart må kun ske til brug i andet statistisk eller videnskabeligt øjemed, der ikke er uforeneligt med det formål, hvortil dataene oprindeligt er indsamlet.


Ændringer i projektet

29. Væsentlige ændringer i projektet skal anmeldes/meddeles til Direktionssekretariatet (som ændring af eksisterende anmeldelse).
30. Ændring af tidspunktet for projektets afslutning skal altid anmeldes/meddeles Direktionssekretariatet.

Ved projektets afslutning

31. Senest ved projektets afslutning (medmindre særlige forhold gør sig gældende for projektet, som skal oplyses til Direktionssekretariatet) skal oplysningerne slettes, anonymiseres eller tilintetgøres, således at det efterfølgende ikke er muligt at identificere enkeltpersoner, der indgår i undersøgelsen.

32. Alternativt kan oplysningerne overføres til videre opbevaring i Statens Arkiver (herunder Dansk Dataarkiv) efter arkivlovens regler.

33. Sletning af oplysninger fra elektroniske medier skal ske på en sådan måde, at oplysningerne ikke kan genetableres. Der bør i denne forbindelse tages kontakt til din lokale it-afdeling (DoIT), jf. instruks for brug af it i Region Syddanmark (OUH har egen lokal instruks, som skal følges)

Ovenstående vilkår er gældende indtil videre. Region Syddanmark forbeholder sig senere at tage vilkårene op til revision, hvis der skulle vise sig behov for det.

Region Syddanmark gør opmærksom på, at denne tilladelse alene er en tilladelse til at behandle personoplysninger i forbindelse med projektets gennemførelse. Tilladelsen indebærer således ikke en forpligtelse for myndigheder, virksomheder m.v. til at udeleve eventuelle oplysninger til dig til brug for projektet.

Region Syddanmarks paraplyanmeldelser for ”Sundhedsvidenskabelig forskning i Region Syddanmark” nr. 2008-58-0035 findes i fortegnelsen over anmeldte behandlinger på Datatilsynets hjemmeside: www.datatilsynet.dk.

Persondataloven kan læses/hentes på Datatilsynets hjemmeside under punktet ”Lovgivning”.

Advarsel – ved brug af Excel, PowerPoint m.v.

Den dataansvarlige skal til enhver tid sikre sig, at dokumenter og andre præsentationer, som publiceres eller på anden måde gøres tilgængelig for andre på internettet, usb-nøgle eller på andet elektronisk medie, ikke indeholder personoplysninger.

Der skal vises særlig agtpågivenhed i forbindelse med brug af grafiske præsentationer i Excel og PowerPoint, da de uforvarende kan indeholde indlejrede persondata i form af regneark, tabeller mv. Præsentationer, der gøres tilgængelig på internettet, skal derfor omformateres til Portable Digital Format (PDF), da dette fjerner eventuelle indlejrede Excel-tabeller.
Venlig hilsen

Troels Hjortebjerg
Jurastudentemedhjælper
29. Appendix 12
Instruction for the Home Unit at Odense University Hospital
Patienter med akut leukæmi behandlet i Hjemmeenheden

Formål:
At behandle patienter med akut leukæmi i cytopenifasen efter reinduktion- og kon- solidering kemoterapi i et hjemmebehandlingsregi mhp.  
- at reducere forekomst af nosokomielle infektioner,  
- at bedre ernæringsstatus for patienterne,  
- at bedre livskvalitet for patienterne  
- at fremskynde tilbagevenden til arbejdsmarkedet efter afsluttet behandling,

Definerer:
Hjemme-enheden er et tilbud til intensivt behandlede akutte leukæmipatienter hvor patienten primært opholder sig i eget hjem, men under en meget tæt og struktureret kontrol, hvor patienten møder frem mindst hver 2. dag i Hjemme-enheden. Efter afsluttet kemoterapi udskrives patienterne, såfremt almentilstanden er foreneligt hermed, mhp. genindlæggelse og blodprøvetagning i Hjemme-enheden, når pancytopenifasen forventes at indtræde. I den ambulante fase indtil patienterne bliver cytopene, følges de med blodprøvekontroller i Hjemme-enheden.  
Patienten indlægges i Hjemme-enheden, så snart trombocyttallet falder til <15 x 10⁹/L, dvs. når der er behov for trombocyttransfusion, og neutrofilletallet er <0,5 x 10⁹/L. Patienten kan også gå direkte fra sengeafsnittet (X1) til Hjemme-enheden, hvis cytopenien indtræder så hurtigt, at patienten ikke når at blive udskrevet inden. Patienten udskrives, når neutrofilletallet er >0,5 x 10⁹/L og selvforsynende med trombocytter mhp genindlæggelse til efterfølgende behandling.

Fremgangsmåde:
Patienter med leukæmi, som er i induktionsbehandling, kan ikke overgå til behandling i Hjemmeenheden. Dog kan patienter i reinduktionsbehandling overgå til hjemmeenheden efter individuel vurdering.

Patienter med akut leukæmi behandlet i Hjemmeenheden

Fremgangsmåde:
Følgende krav skal være opfyldt, for at en patient kan behandles i hjemmeregina:  
- Patienten skal være fysisk og intellektuelt egnet. De skal således kunne forstå betydningen af at have lave blodværdier og reagere på symptomer herpå med kontakt til sengeafsnittet, (eksempelvis ved feber og blødninger).  
- Patienten skal bo i maksimalt 90 min køreafstand fra OUH.  
- Patienten skal stige i trombocyttal på trombocyttransfusioner.  
- Der skal i hjemmet være en myndig pårørende tilstede i mindst 14 af døgnets 24 timer og den pårørende skal være tilstede om natten.  
- Patient skal, gerne sammen med en pårørende, have gennemført forsømte for patienter i hjemmebehandling. Dette dokumenteres i COSMIC.  
- Planter med jord bør ikke forefindes i soveværelse og de rum, hvor patienten i øvrigt opholder sig mest. Patienten bør undgå tæt kontakt med husdyr.  
- Der bør skiftes tøj dagligt og sengetøj mindst 1 gang ugentligt samt naturligvis, hvis det er kontamineret med ekskreter eller lignende. Der bør foretages ugentlig rengøring i hjemmet.  
- Patienten bør, når tallene er lave, holde sig fra havearbejde, støvende og beskidt arbejde og andet arbejde, der medfører risiko for skader på hænder og dermed infektioner.  
- Patienten skal tage dagligt bad.
Såfremt der i husstanden er personer med smitsom infektion, skal patienten indlægges i sengeafsnittet.

**Ernæring**

Hvis appetitten er nedsat, skal der laves kostplan med læge/sygeplejerske/diætist. Patienten skal ernæringsscreenes mindst x 1 ugentlig. Patienten skal af infektionshensyn undgå skimmelost, rå æg, råt kød og rå fisk. Al varm mad skal være opvarmet til en kernetemperatur på minimum 75 °C. Frugt og grønt skal være uden pletter eller skimmel og vaskes grundigt.

**Transport**

Patienten må godt køre bil selv. Ved sygetransport skal patienten have solotransport,. Hvis patienten får høj feber eller blødning, skal patienten eller pårørende ringe til afdelingen mhp. bestilling af Falck sygetransport, dvs. patienten skal ved påvirket almentilstand ikke selv køre bil eller køres til sygehuset af pårørende.

**Hjemme-enhedenes fysiske rammer og personele**


**Oplæring**

Patienter (og evt. deres nærmeste pårørende) vil blive oplært individuelt i pleje af CVK (forbindingsskift og skylning) og blodprøvetagning i henhold til afdelingens gældende instruks. CVK oplæring indledes under første konsoliderende kemobehandling og fortsættes i Hjemme-enheden. Den generelle oplæring i forholdsregler, hygiejne mm gennemføres under induktionsfasen af behandlingen, hvorunder samtlige patienter forbliver indlagt indtil de sikkert har erhvervet sig de færdigheder og den viden, der er en forudsætning for at kunne overgå til hjemmeregieri. Hjemmeenhedenes sygeplejersker forestår oplæringen. Der udarbejdes veledende patientmappe inklusiv billedmateriale og gennemførelse af undervisningen i teoretiske forhold og praktiske færdigheder samt given information (såvel mundtlig som skriftlig) vil blive konfirmeret ved dokumentation i COSMIC I forløbet af behandlingen getages undervisningen og ved løbende supervision sikres patienternes tekniske færdigheder og sygdomsmæssige forståelse. Såfremt patienterne er indlagt i sengeafsnittet pga. påvirket almentilstand, forestår oplæringen på vanlig vis blodprøvetagning.

**Kemoterapi**

Følgende regimer gives i hjemmeregieri:, Idarubicin og Novantrone som led i APL behandling. og højdosis cytosar (1 g/m² eller derover) med to daglige infusioner (givet over 4 timer med 12 timers interval) gives under indlæggelse i sengeafsnittet.

**Undersøgelser**

Kliniske og parakliniske undersøgelser af patienten gennemføres efter samme retningslinjer som, hvis patienten var indlagt, hvor fokus er rettet mod infektioner.

**Blodprøvekontrol og transfusionspolitik**
Der tages ved hvert fremmøde hæmoglobin, leukocytter, trombocytter og CRP. Mindst to gange pr. uge tages desuden væske og levertal. For hver enkelt patient fastsættes grænse for transfusion af SAG-M blod afhængigt af alder og evt. konkurrierende lidelser. Trombocytter vil profylaktisk blive transfunderet ved trombocyttal < 15 mia/l, ved pågående blødning eller feber over 38°C dog ved tal < 20 mia/l. Hvis patienten ikke stiger i trombocyttal på hverken random eller HLA-udvalgte trombocytter, kan de ikke behandles i hjemmeregi. Transfusionsgrænser angives i COSMIC under nøgleordet transfusionsgrænser. Der gives filtreret, bestrålet blod til alle patienter.

**Lav tals patienter:** Alle patienter der udskrives indtil cytopeni efter HD-behandling i M-teamet følges i hjemmeenheden indtil peni og indlæggelse eller hjemmenhedsforløb. Blodprøve-svarene vurderes ved stuegangsgående læge i hjemmenheden.

**Antibiotika**
 Ved neutrofile < 0,5 x 10⁹/L indledes profylaktisk antibiotisk behandling med
- Tbl. Moxifloxacin (Avelox) 400 mg x 1 dgl.
- Itraconazol (Sporanox) mikstur 200 mg x 2
- Tbl. Zovir (Aciclovir) 400 mg x 2.

Kan patienten ikke tage Itraconazol mikstur gives i stedet mixtur Posaconazol 400 mg x 2

Ved relaps patienter opstartes Posaconazol 400 mg x 2 i alle tilfælde

Patienter i AML17 protokollen der opstarter m-TOR skal opstartes i fluconazol 200 mg x 2.

Såfremt patienten udvikler feber >38,5 °C, anvendes følgende algoritme:

1) Patienten er alment upåvirket. I så fald kan patienten efter lægelig undersøgelse forblive i hjemmebehandlingsregi. Dog skiftes antibiotisk behandling til intravenøs
   - Ceftriaxon (Rocephalin) 4 gr x 1 og
   - Gentamycin efter skema x 1 dagligt.

Behandling med Itraconazol og Zovir fortsættes uændret.

Ceftriaxon fortsættes, indtil neutrofile er >0,5 x 10⁹/L. Efter 3 døgn erstattes Gentamycin med
   - Tbl. Ciprofloxazine (Ciproxin) 500 mg x 2 dagligt

for at undgå gennembrudsinfektion med Pseudomonas.

Dér udføres blod- og urindyrkning efter afdelingens instruks. Røntgen af thorax foretages ved febrilia.

Ved vedvarende febrilia trods Ceftriaxon i.v.i mere end 3 døgn indlægges patienten i sengeafsnittet og opstarter behandling med meronem 1g x 3 i.v.

2) Patienten er påvirket af feberen, men ikke septisk. Patienten udgår af Hjemmeenheden og, indlægges i sengeafsnittet, hvor der opstartes behandling i hht. afde-
lingens vanlige instruks i form af Tazocin og Gentamycin i.v og Avelox seponeres.

3) Patienten er septisk og der opstartes behandling med Meronem i høj dosering 2 g x 3 i.v, som evt. senere kan reduceres til 1g x 3 i.v.

Såfremt invasiv svampeinfektion mistænkes opstartes i.v. empirisk behandling efter afdelingens instruks under indlæggelse. Herunder også udredning i form af evt. HRCT, evt. BAL og s-galactomanan.

Når en patient er ovre infektionsforløb kan de genovergå til hjemmeenheden.

<table>
<thead>
<tr>
<th>Indikator(er):</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Referencer og evidens:</td>
<td></td>
</tr>
</tbody>
</table>
30. Appendix 13
Consultations in pre-scheduled time-slots at Department of Hematology, The National University Hospital, Copenhagen
### PROBLEM

I dag ses stort set alle patienter til stuegang – fremover skal de ses 2 – 3 gange til planlagt **konsulation** på en uge, men hvad er kriterierne for patienter, der **ikke** behøver at ses til konsultation?

### ÅRSAG

Der er ikke aftaler om, hvordan det besluttes, at en patient skal ses til konsultation.

### LØSNING

1. **Ved bl.pr.runde / morgentoilette ses pt af spl, som hører, om der er noget nyt, der skal handles på og tjekliste (2) udfyldes, evt. sammen med patient.**
2. **Senest kl. 8.20 afklares med koor. spl, om der skal laves om på prioriteringen af den planlagte konsultation fra dagen før.**
3. **Kl. 8.45 mødes sygepl. makkerpar til info og opgavefordeling. Daglig tjekliste (bilag 1 + 2) over hvad der skal foreligge til konsultation u.patienter og hvad der skal være styr på ved rapporteringen til den sygepl. der går konsultation.**

### HANDLINGSPLAN

1. **Ændring i velkomstpjece, afsnit om konsultation (forventningsafstemning med pt) Enhed 1: Elisabeth, Enhed 2: Kristina/Ann-Mari; Enhed 3: Anne/Maiken**
2. **Daglig tjekliste laves af læge og spl, så det sikres at nødvendige observationer / problemer videregives (bilag 1).**
3. **Tavleoversigt på patientstue – skrive op, hvornår patienten er planlagt til at ses igen. Læge min x 2/uge.**

### OPFØLGNINGSPLAN

- På tavlen er anført næste konsultation / frekvens.
- Følge op på (skema), hvor mange pt deltager i konsultation

### EFFEKT [BESKRIV: HVAD TABES OG VINDES VED LØSNINGEN?]

Det er effektivt og med bedre kvalitet for patienter og personale, så tiden kan bruges mere fokuseret på den aktuelle konsultation. Det giver et bedre overblik for patienterne, når tid for næste konsultation er kendt.
31. Appendix 14

Newsletter from IdéRiget – the pilot project of hospital-based chemotherapy at home, The National University Hospital, Copenhagen
God start for nye kemopumper: Nu kan patienter på Rigshospitalet få kemoterapi i hjemmet

Af Pernille Garde Abildgaard


Opbakningen fra direktionen har gjort, at projektet har kunnet fortsætte uden stop - til glæde for patienterne.

Det har også betydet store omvæltninger for Katrine, der er gået fra at være sygeplejerske i Hæmatologisk Klinik - til at blive projektleder for implementeringen af pumperne både i egen klinik og til antibiotisk behandling i andre klinikker. Og der er rikt om hende.

"Ja, folk er begyndt at trække i mig og jeg er blevet inviteret til en hel del konferencer og seminarer, hvor jeg fortæller om kemoterapi i hjemmet og IdéRiget som helhed. Alle er meget positive og jeg har grund til at tro, at implementeringen vil blive en stor succes", fortæller Katrine og forsætter:

"Vi får så mange positive tilbagemeldinger fra patienter, der føler sig mindre sygeliggjort – og det vil få en afgørende betydning for deres helbredelse," fastslår Katrine.

Katrines fokus de næste måneder er 100% på projektet. Men det er også vigtigt at have tålmodighed, understreger hun:

"Det vigtigste de næste par måneder er, at have is i maven, have tålmodighed og ikke sætte for mange skibe i vandet på én gang. Jeg har oplært en del personale på klinikken i brug af udstyret og alle er trygge ved at bruge det. Men vi tager en langsom start, så vi er sikre på at få alle aspekter med – og forhåbentlig sikre en succes hele vejen rundt. Både for sundhedspersonalet og ikke mindst patienterne", siger Katrine.


"Med projekt IdéRiget har Rigshospitalet indsamlet ideer fra medarbejdere og testet de bedste i et intensivt innovationsforløb. For ung kræftsygeplejerske betyder det, at hun nu skal i gang med at rulle ny behandlingsform ud over hele hospitalet."

Læs hele artiklen på www.denoffentlige.dk.

IdéRiget er et projekt, der på mange måder bryder med den gængse måde at arbejde med fornyelse i offentlige organisationer. Hovedformålet med IdéRiget er at satse på de idéer, der allerede er blandt medarbejderne. Samt give medarbejderne de fornødne kompetencer og ressourcer til at gøre dem til virkelighed.

I samarbejde med DTU Business afholdte Rigshospitalets udviklingsenhed i november en videndelingskonference for alle interesserede. Og dem var der heldigvis mange af.

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Deltagerlisten bestod af både direktører, klinikchefer, forskere, overlæger og sygeplejersker fra landets øvrige regioner samt mange af landets hospitaler.

Udover præsentation af de ti idéer fra IdéRiget var der også foredrag af to af de professorer, som har undervist de 10 idémagere i forløbet, Hamish Scott fra Ashridge Business School og Simon Clathworthy fra Oslo School of Architecture and Design.

Konferencen viste, at alle ti ideer har stort potentiale – og også sagtens kan overføres til andre hospitaler. Mere herom senere i de kommende nyhedsbreve, hvor udviklingen og udrulningen af de enkelte projekter vil følges tæt.
De ti idéer fra IdéRiget

**Jordemoder Rikke Berthelsen:** Etablering af en ammeambulance-funktion som kan sikre en 24/7 rådgivning til nybagte forældre

**Sygeplejerske Caroline Find Andersen:** Udvikling af et e-værktøj som samler kalender, kommunikation og undervisning af kæftpatienter

**Bioanalytiker Helle Bendtsen:** Udvikling af et e-værktøj til planlægning, styring, kommunikation og information i forbindelse med fertilitetsbehandling

**Overlæge Helle Pappot:** Udvikling af et værktøj til patientstyret registrering af bivirkninger ved kemobehandlinger (“Patient Related Outcome Measure”)

**Afdelingslæge Juliane Theilade:** Fra ambulant fremmøde til tele/Skype konsultationer for patienter med arvelige hjertesygdomme

**Overlæge Jens Jørgen Kjer:** Patientens formodede ønske om at få et så sikkert operatív forløb som muligt gennem optimering af ny robotteknologi

**Sygeplejerske Katrine Seier Fridthjof:** Omlægning af kompleks kemoterapi – fra indlæggelse til ambulant regi. Brug af avancerede programmerbare pumper og med en omfattende patientinvolvering

**Jordemoder Signe Amanda Wenzel Nyrop:** Aflastning i eget hjem for gravide kvinder med diagnosen “truede for tidlig fødsel” og “for tidlig vandafgang”

**Sygeplejerske Søren Ebdrup:** Optimering af patientforløb for intensivpatienter gennem udvikling af en vejemetode, som ikke kræver forflytning af patienterne

**Overlæge Teit Mantoni:** Optimering af perioperative patientforløb ved stor kirurgi med særligt henblik på patienter med betydelige konkurrerende idelser og/eller dårlig almentilstand

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**IdéRiget spredes ud**

Af Peter Aagaard Nielsen, Udviklingschef

Set under ét er resultatet af IdéRiget, at det er lykkedes på 6 måneder at skabe 10 stærke innovationsløsninger, som vi kunne lægge frem for Rigshospitalets Innovation Board samtidig med, at vi har 10 godt uddannede RH innovationsfolk, som har vist, at de kan og vil. De kan bruges mange steder på Rigshospitalet.

Samtidig har IdéRiget vist, at det kan lade sig gøre hurtigt og målrettet at skabe innovation i offentlig sektor virksomheder.

Modellen kan bruges alle steder, hvor man ønsker at arbejde med velfærdsinnovation.

IdéRiget har givet genlyd mange steder – og er bl.a. blevet inviteret til Ugebrevet Mandag Morgens konference om Velfærdsinnovation i januar, fordi vi har en helt særlig metode til at drive innovative ideer frem, som er usædvanlig for store driftsvirksomheder.

Mere om dette i næste nyhedsbrev.

266 projekter fra 36 lande var indstillet og kun 31 kom gennem nåleøjet – herunder Katrines projekt om, at patienter med akut leukæmi fremover kan modtage kemoterapi i hjemmet og dermed reducere indlæggelse under forløb med kemoterapi.

"Denne mulighed gør et svært sygdomsforløb nemmere for den enkelte patient. Det har vist sig at være en ubetinget succes. Alle i Maastricht ville høre mere om vores danske erfaringer, da det åbenlyst er en god måde at sikre det bedst mulige patientforløb kombineret med, at det kræver færre sengepladser på hospitalerne", fortæller Katrine, der sammen med den Hæmatologiske afdeling på Rigshospitalet og IdéRiget nu har arbejdet koncentreret med projektet i næsten 2 år.


"Der er kun grund til at glæde sig over, at så mange i udlandet er interesseret i at arbejde videre med Katrines projekt; men også Helle Pappots projekt om patienternes e-registrering af bivirkninger ved kemoterapi skaber stor opmærksomhed", siger Peter Aagaard Nielsen og fortsætter:

"Og samtidig har man i udlandet blik for, at IdéRigets procesmodel er en robust affyringsrampe for innovative ideer af den type, som IdéRiget har leveret. I januar 2015 er der planlagt en workshop hos EIPA i Maastricht om procesmodellen. Det er en stor anerkendelse af indsats og resultater fra alle de 10 medarbejdere, som var med i IdéRigets hovedprojekt."
Kort nyt I

Arrangørerne af Start-Up weekend, der løb af stablen i november, var glade for samarbejdet med IdéRiget og mentorerne blev ligeledes rost:

"De studerende samt folk tilknyttet innovationsmiljøet ved Københavns Universitet var meget imponeret over IdéRigets koncept og resultater. Jeg kender til flere studerende som efterfølgende har fået et rigtig godt netværk i jeres miljøer", siger Masih Sina, som er medicinstuderende og med i de medicinstuderende selskab for innovation.

Mentorerne fra Rigshospitalet var bioanalytiker Helle Bendtsen, overlæge Jens Jørgen Kjær og videnbroker Line Langballe.

Kort nyt II

Et hold designere fra Københavns designskole er som en del af deres afgangsprojekt ved at designe en taske til den transportable kemo-pumpe.

Projektet kaldes "Chemo to go, please" og designerne vil gøre tasken både lidt mere elegant og lidt mere praktisk.

Gruppen har interviewet patienter og sundhedspersonale i Odense og i København, og regner med at have en prototype klar inden jul. "Nyt fra IdéRiget" vil glæde sig til at bringe et billede snarest.

Indtil videre kan du læse mere her: http://chemotogoplease.tumblr.com

Gode nyheder spredes hurtigt, og der er stor vilje til samarbejde på tværs af alle Danmarks hospitaler, når det gælder løsningen med hjemmekemo.

Det er Hæmatologisk Klinik på Rigshospitalet, der oprindeligt tog initiativ til at samle alle landets hæmatologiske afdelinger til et dialogmøde om patienternes mulighed for at få den største del af deres behandling i deres eget hjem uden tilstedeværelse af sundhedspersonale. Initiativet har nu resulteret i, at både Roskilde, Odense og Herlev nu også kan tilbyde sine patienter kemo-pumpen. Aarhus og Aalborg er ligeledes på vej.

"Der var en fantastisk stemning og synergi på møderne. Jeg brænder for, at danske patienter skal have de bedst mulige behandlingstilbud og jeg giver gerne min viden og erfaring omkring kemo-pumpane. Vi gør som Tesla – vi stiller al vores viden til rådighed, så vi i fællesskab kan gøre det endnu bedre for alle patienter i Danmark. Så nu er både Roskilde, Odense og Herlev i gang med at tilbyde deres patienter pumpen efter vores grundskema, vores planlægnings-resultater og på ryggen af vores erfaringer", siger Katrine Seier Fridthjof.

National protokol


"Det er meget perspektivrigt, at vi nu går sammen om en hurtig udbredelse af en fælles løsning og en fælles dataindsamling for denne patientgruppe", siger klinikchef Lars Kjeldsen, Hæmatologisk Klinik, Rigshospitalet og fortsætter:

"På vores seneste fælles møde opdagede vi, at vi alle sammen er modige i forhold til at afprøve nye muligheder for patienterne. Det er bare på forskellige områder. Når vi nu får lagt alt dette mod sammen, så kommer vi til at stå med et rigtigt stærkt nationalt behandlingstilbud."
En beretning om, hvordan det egentlig er at modtage kemo-terapi via pumpe…

Marc har akut leukemi, og han er også bruger af kemo-pumpen. Så i stedet for at være indlagt i måneder på Rigshospitalet, så har han kunnet gå til eksamen, gå i biffen og på restaurant.

Se f.eks. Marc’s facebook opdatering fra november.

Marc har indtil nu fået 4 kemokure og fik sin (forhåbentlig) sidste behandling i november.

3 af behandlingerne har han fået via pumpe.

Marc og Katrine har også været i TV2 Lorry og fortælle historien om kemo-pumpen og den øgede livsglæde den giver trods alvorlig sygdom.

Glæd dig til begyndelsen af 2016

I begyndelsen af januar 2016 kigger ”Nyt fra IdéRiget” lidt på udviklingen af nogle af IdéRigets projekter over det seneste år. To af projekterne blev økonomisk støttet direkte af Rigshospitalet til videreudvikling, men vi ser også på nogle af de andre projekter. Læs med i næste nummer af ”Nyt fra IdéRiget”.

”Nyt fra IdéRiget” ønsker alle en rigtig glædelig jul og et godt nyt år!
32. Paper 1
Outpatient management of intensively treated patients with acute leukemia – the patients’ perspective
Outpatient management of intensively treated acute leukemia patients— the patients’ perspective

Lene Østergaard Jepsen1,2 · Mette Terp Høybye3 · Dorte Gilså Hansen4 · Claus Wereberg Marcher1 · Lone Smidstrup Friis5

Abstract

Purpose In recent years, patients with acute leukemia (AL) have, to a greater extent, been managed in an outpatient setting where they live at home but appear every other day for follow-up visits at hospital. This qualitative article elucidates how patients with AL experience the different conditions of the inpatient and outpatient settings and how they reflect on these transitions in order to create meaning in and keep up everyday life.

Methods Qualitative semi-structured individual interviews twice with each AL patient focusing on the outpatient setting, impact on everyday life, responsibility and the home were performed. Twenty-two patients were interviewed the first time, and 15 of these were interviewed the second time. The data were analyzed in an everyday life relational perspective.

Results Outpatient management facilitates time to be administered by the patients and thereby the possibility of maintaining everyday life, which was essential to the patients. The privacy ensured by the home was important to patients, and they accepted the necessary responsibility that came with it. However, time spent together with fellow patients and their relatives was an important and highly valued part of their social life.

Conclusions Approached from the patient perspective, outpatient management provided a motivation for patients as it ensured their presence at home and provided the possibility of taking part in everyday life of the family, despite severe illness and intensive treatment. This may suggest a potential for extending the outpatient management further and also for patient involvement in own care.

Keywords Acute leukemia · Outpatient · Everyday life · Rehabilitation · Qualitative study

Introduction

Curative chemotherapy treatment regimens for acute leukemia (AL) have changed little over the last several decades, while supportive care practices have developed significantly. In recent years, many patients with AL have been managed in a safe and feasible outpatient setting where they live at home but appear often at follow-up visits at the hospital [1–4].

Previous research has shown that people living with a life-threatening disease could benefit from engaging in everyday activities because continued involvement serves not only a functional purpose but is also essential in maintaining meaning of life [5–7]. Everyday activities, however, are often highly restricted and difficult to maintain while admitted to hospital [8]. Outpatient management has been described as an advantage for social, emotional and role functioning during and following treatment for AL and with an improvement of quality of life in general [2, 9]. Despite recent changes to the organization of AL treatment, it still consists of periods of
both inpatient and outpatient management, asking the patient to relate to the different frameworks that this provides. As inpatient, large amounts of time are spent waiting for services and care from providers placing inpatients in a constant waiting position [10]. Even though inpatients receive social visits, they have been found to suffer social isolation playing no part of the everyday routines of the family [10]. Further, privacy is often compromised by limited space and shared bedrooms in inpatient settings [11]; however, studies have found that this may also facilitate valuable social exchange between patients, if the interpersonal dynamics are good [10, 11].

The transitions between inpatient and outpatient management in AL treatment are increasingly important and a serious domain of care. Only one qualitative study [12] has, to our knowledge, studied the transition from hematologic inpatient to outpatient. It described how acute myeloid leukemia (AML) patients, in response to the transition from inpatient to outpatient, had to readjust their expectations, experienced a shift in responsibility and a simultaneously growing desire to understand the long-term plan, and furthermore redefining their sense of self. The existing knowledge focuses on feasibility, quality of life and infections, which underlines the importance of more research-based knowledge of the AL patients’ experience of the transition from inpatient to outpatient, as well as the everyday life perspective of outpatient management.

This qualitative article, based on interviews, elucidates how patients with AL experience the different conditions of the inpatient and outpatient settings and how they reflect on these transitions in order to create meaning in and keep up everyday life.

**Methods**

**Design**

This article is based on data from consecutive, individual patient interviews at two given time points conducted as a part of a larger qualitative study. The larger study combined participant observation in the home unit (HU) (outpatient setting), consecutive, individual patient interviews at three different times and group interviews with their relatives.

Interviews were conducted as semi-structured on the basis of an interview guide. The four key topics covered in the interview guide (outpatient setting, impact on everyday life, responsibility, the home) were inspired by the participant’s observation in the HU, conducted by the first author. There was one main question to each topic, and according to the answer of the patient, five to 13 questions were added to facilitate a talk covering the topic sufficiently.

**Participants**

To be included in the study, patients had to match the standard requirements for outpatient management in the HU and additionally be able to understand and speak Danish. Twenty-six patients were included consecutively from May 2013 to August 2014 (Fig. 1, Enrollment of study participants). The time for the first individual interview was scheduled in accordance with the patients’ transition to outpatient management. Interviews were conducted in the HU as soon as possible after starting in the HU. Time of the second interview was scheduled to follow the end of outpatient management in the HU setting, where 15 patients were interviewed in their homes immediately after finishing HU management approximately 4 months after the first interview. The exact interview time varied in accordance with the individual trajectories of each patient. The two interview time points were chosen to enable us to explore and elucidate the transitions between inpatient and outpatient management. The first interview lasted 30–90 min (mean of 60 min). The second interview lasted 40–115 min (mean of 80 min). All interviews were conducted by the first author, digitally recorded and transcribed verbatim by a secretary. Demographic characteristics are shown in Table 1.

**Treatment setting**

Each year, the Department of Hematology, Odense University Hospital receives approximately 60 newly diagnosed AL patients from the Region of Southern Denmark including 45 receiving curative intended chemotherapy. Following the first treatment cycle and pancytopenia period, around 75% of these patients will be managed in the HU. The HU consists of two separate rooms situated in conjunction to the department. The main room is designed with a small table and soft chairs where the patients and their relatives sit. A bed in the middle of the room functions as a couch for interactions between the nurse and the patients. In front of the room, there are two computer workstations for the nurses. The room is furthermore equipped with a television, some magazines, a refrigerator with cold beverages and a small table with coffee and snacks for the patients. There is no wall decoration, and the overall design is sterile and hospital-like. The smaller adjacent room is used for consultations with the doctor and for patients who need to rest. The HU typically hosts 6 to 8 patients and relatives for 3 to 8 h between 8.00 am and 4.00 pm. During visits, all patients are seen by a doctor.

For safety reasons, all patients are required to fill in treatment diaries, measure temperature and blood pressure, and also take prophylactic antibiotics. All patients have a tunneled central venous catheter, which they or
their relatives draw blood samples from, change the dressing of and flush. Patients are instructed to avoid any contact with persons carrying an infection and places where many people are gathered. At home, the whole family should intensify the hygienic precautions and eschew mould.

Analysis

The analysis of the interview data took an inductive approach to extract meaningful content across the material from the perspective of the patients. Following transcription, the data analysis was conducted as a four-step process, inspired by the approach described by Miles and Huberman [13]. First, the interviews were read several times to gain an overall understanding and sense of the material. Second, specific text pieces were identified as the content and context related to each other and to the aim of the study. Third, descriptive codes were produced and assigned to the text. Finally, the text was condensed into categories. The NVivo 10 computer programs assisted this process of organizing and coding the material.

The analysis aimed to address the key issues of transitions between inpatient and outpatient management, with a particular focus on how the everyday life of patients was shaped and affected by these conditions. To further support our analytical exploration, we brought the material into a dialogue with the theoretical framework of everyday life. Taking this social constructivist approach, everyday life according to Bech-Jørgensen [14] is in its simplicity ‘the life we live every day’ and emerges as an interaction between conditions and the ways people manage within it. This provided an analytical way of understanding how patients engage and interact with the different conditions and structures they are subjected to during treatments.

Table 1 Demographic characteristics of study participants (n=26)

<table>
<thead>
<tr>
<th>Sample characteristics</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male 13 (50 %)</td>
</tr>
<tr>
<td></td>
<td>Female 13 (50 %)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>(mean 56.7; range 26–74)</td>
</tr>
<tr>
<td>&lt;60</td>
<td>13 (50 %)</td>
</tr>
<tr>
<td>≥60</td>
<td>13 (50 %)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married or common-law relationship 19 (74 %)</td>
</tr>
<tr>
<td>Single/divorced</td>
<td>3 (11 %)</td>
</tr>
<tr>
<td>Unknown</td>
<td>4 (15 %)</td>
</tr>
<tr>
<td>Education</td>
<td>Unskilled workers 4 (15 %)</td>
</tr>
<tr>
<td></td>
<td>Skilled workers 14 (55 %)</td>
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<tr>
<td></td>
<td>Further education 4 (15 %)</td>
</tr>
<tr>
<td></td>
<td>Unknown 4 (15 %)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Acute myeloid leukemia (AML) 18 (69 %) (3 relapses)</td>
</tr>
<tr>
<td></td>
<td>Chronic myeloid leukemia (CML) 1 (4 %)</td>
</tr>
<tr>
<td></td>
<td>Chronic myelomonocytic leukemia (CMML) 1 (4 %)</td>
</tr>
<tr>
<td></td>
<td>Refractory anemia with excess blasts (RAEB) 2 (8 %)</td>
</tr>
<tr>
<td></td>
<td>Other myeloid leukemia 1 (4 %)</td>
</tr>
<tr>
<td></td>
<td>Acute lymphoblastic leukemia (ALL) 3 (11 %)</td>
</tr>
<tr>
<td>Time from diagnosis to the first interview (weeks)</td>
<td>Mean 8.6; range 3–15 (n=22)</td>
</tr>
<tr>
<td>Time from diagnosis to the second interview (weeks)</td>
<td>Mean 19.7; range 13–28 (n=15)</td>
</tr>
<tr>
<td>Treatment status at time of the first interview</td>
<td>(n=22)</td>
</tr>
<tr>
<td>1 course of chemotherapy</td>
<td>5 (23 %)</td>
</tr>
<tr>
<td>2 courses of chemotherapy</td>
<td>13 (59 %)</td>
</tr>
<tr>
<td>3 or more courses of chemotherapy</td>
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</tr>
<tr>
<td>5 or more courses of chemotherapy</td>
<td>2 (12 %)</td>
</tr>
<tr>
<td>Awaiting a allogeneic hematopoietic stem cell transplantation</td>
<td>16 (73 %)</td>
</tr>
</tbody>
</table>

Fig. 1 Enrollment of study participants

* HSCT= allogeneic hematopoietic stem cell transplantation

Assessed for eligibility (n=32)

Excluded (n=6)
  • Declined to participate (n=5)
  • Let out by mistake (n=1)

Included (n=26)

Lost to follow-up (n=4)
  • Died (n=2)
  • Withdraw informed consent (n=2)

First time interview (n=22)

Lost to follow-up (n=7)
  • Non-responder to invitation (n=2)
  • No time span before HSCT* (n=5)

Second time interview (n=15)

* HSCT= allogeneic hematopoietic stem cell transplantation

Table 1

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<tr>
<td>Awaiting a allogeneic hematopoietic stem cell transplantation</td>
<td>16 (73 %)</td>
</tr>
</tbody>
</table>
Results

The patients are highly valued for being able to maintain everyday life and routines throughout the treatment trajectory, and that life, as closely as possible, resembled life before the diagnosis of AL.

‘Having been able to maintain my everyday life as much as was actually possible, I think, mentally meant everything to the course of my illness in the end. It may still go in the wrong direction and end badly, once I’m all done with my treatment here, but it’s what we talked about, the quality of life.’ (Patient 23)

Similar psychosocial concerns and challenges were predominant in the inpatient and outpatient conditions, but studying the transition between conditions elucidated how similar concerns may have different expressions in everyday life of the patients depending on the setting. Four main categories emerged through our analysis that reflected the predominant issues that were put in perspective by the transition between inpatient and outpatient treatment: (1) everyday activities, (2) privacy, (3) social relations and (4) patient involvement in care.

Everyday activities

Alternative to being at the hospital 24/7, everyday life as an outpatient consisted of both days at home and days of follow-up visit at the HU. Patients and relatives could more freely plan their own time and make schedules that enabled them to maintain everyday life routines (Table 2, quote 2). Most patients described it as satisfactory to contribute to everyday life of the family, engaging in everyday tasks (Table 2, quote 3). Patients considered their visits to the HU as a tiresome activity, which should claim little time as much as possible. They experienced the time at the hospital as time they could have spent at home. The staff recognized this, which was reflected by their practice of calling the doctor as soon as a patient was ready for consultation to minimize waiting (Table 2, quote 4).

Inpatient days, in contrast, consisted of different necessary tasks and activities that often required interaction with other people and largely occurred on the terms of the department. This left the patients no possibility for individual planning of their time. Patients pointed out differences between days with or without chemotherapy, but independent of that, inpatients used a huge amount of time every day waiting to have their blood drawn, a variety of examinations, treatments to be given, food, ward rounds etc. Being constantly available to the professionals prevented the patients from doing things independently, for example being physically active (Table 2, quote 5).

While time was important in both treatment conditions and patients spent a lot of time waiting on procedures to be performed, time in the outpatient setting seemed to have another dimension, as it was experienced by the patients as their own time, in contrast to inpatient time, which was purely hospital time.

Privacy

Patient privacy as outpatients was guarded by the domestic sphere of the home. During visits to the HU, privacy was not explicitly requested by the patients. Consultations with the doctor at the HU took place in a separate room but afterwards, patients often freely shared their news with fellow patients.

This contrasted the situation as inpatient, where consultations during ward rounds often took place with a roommate present behind a curtain (Table 3, quote 6). The absence of privacy as an inpatient impacted the patients. The shared bedroom made patients seek out spaces in the hospital outside the department (Table 3, quote 7).

It was remarkable that the high, everyday privacy of outpatients was freely negotiated in the HU, where they chose to share private details about their treatment and illness. For inpatients to obtain brief moments of privacy, they sought it in other (public) places in the hospital.

Social relations

The key issue in everyday social life as outpatients was the presence at home, which strengthened the sense of being a part of the family and kept up normal family relations (Table 4, quote 8). Being at home made it possible to participate in the social life of the family and not feeling estranged, which was often a consequence of inpatient treatment.

As mentioned above, patients found visits to the HU a time-consuming and tiresome activity. However, they tried to make the best of it, and with time, it became an important and highly valued part of their social life during outpatient treatment. They described the atmosphere as relaxed, informal and confident. This also included their relatives (Table 4, quote 9). In this context, the patients did not view waiting time as an issue, as they experienced time as simultaneously used for treatment and socialization (Table 4, quote 10).

This contrasted the modest patient relationships established during inpatient periods, where privacy seemed to have a higher priority than social engagement with fellow patients. Although some inpatients described good interpersonal dynamics with their roommates, it never reached the familiar level of social interactions in the HU.

Many outpatients established close relationships and met at private events, even after finishing the treatment.

Visits during treatment from family and friends were welcomed both as inpatient and outpatients, but the patients, in
general, felt more relaxed receiving visits in their home environment. Coordinating visits at home was easier, and the patients could control the conditions of visits, such as their duration.

Social interactions with fellow patients showed an impact from the transition between inpatient and outpatient management with a suffering social relationship as inpatient.

**Patient involvement in care**

The patients were generally surprised to realize that the staff expected them to take an active part in their medical treatment. Particularly as outpatients, they had to manage the special precautions and take responsibility for their own care. To many patients, this seemed like an overwhelming responsibility until they returned home to realize that they were fully capable of handling it. The patients took pride in following the precautions as closely as possible, but did however recognize that the precautions limited everyday life (Table 5, quote 11).

Involvement of patients in their own care seemed to influence their interpretation of personal responsibility for the treatment outcome. They might blame themselves for getting common complications such as neutropenic fever (Table 5, quote 12). As outpatients, they sensed this responsibility 24/7, which meant that the management concept was constantly of concern, and the special precautions were always valid. Although it required an effort from the patients, this was not viewed as a burden, as the alternative would be hospitalization, which was considered worse (Table 5, quote 13).

Inpatients, however, did not feel the same responsibility. They had only few tasks to perform, and it was easy to get help, if needed (Table 5, quote 14).

Both inpatients and outpatients had to take precautions and perform certain everyday tasks. However, the sense of responsibility for the management of own care was experienced to a much higher degree by outpatients, in the context of their own home, without health care professionals around.

**Discussion**

This study described how patients with AL experience the different conditions in inpatient and outpatient settings, and how they reflected on the transitions in order to create meaning and keep up important everyday life practices.

Time was experienced differently during inpatient and outpatient management. Where inpatients’ days were governed by time, scheduled by the practice and availability of the staff, outpatient time was split by the intervening period in the HU with a gradual shift to predominant use of time at home. That is important as the patients described how outer controlled time yields a feeling of being constantly at the disposal of others, preventing them from everyday activities and essentially not being in control of their own lives.

In the light of this, patients may potentially benefit from a shift in clinical focus from outer to inner controlled time during both inpatient and outpatient treatments. This could provide inpatients the possibility to maintain their own everyday life practices, to some extent. If examinations and ward rounds

---

**Table 2** Sample statements from participants: everyday activities

<table>
<thead>
<tr>
<th>Quote</th>
<th>Patient</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>15</td>
<td>‘I actually do the same things as I used to, but I do them slower, and I may only manage half.’</td>
</tr>
<tr>
<td>3</td>
<td>24</td>
<td>‘It is a satisfaction [to take part in everyday life] because it is not agreeable to me to just sit in the couch and watch all those series [on television] all day long. […] being part of everyday life.’</td>
</tr>
<tr>
<td>4</td>
<td>18</td>
<td>‘I just want to go home, right, because when your counts are low, wow, you are tired the next day [after visits in the HU], right. You are completely done.’</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>‘I don’t think you have time for it [Physical activity]. You have to be present when the doctor is here, ‘cause I don’t think he’ll come searching for you three or four times.’</td>
</tr>
</tbody>
</table>

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**Table 3** Sample statements from participants: privacy

<table>
<thead>
<tr>
<th>Quote</th>
<th>Patient</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>15</td>
<td>‘It is not insignificant when you have 5 x 2 meters right? Who is behind the curtain.’</td>
</tr>
<tr>
<td>7</td>
<td>15</td>
<td>‘Completely depending on my wellbeing – If I was feeling good I got a requisition and we took our meals at the patient hotel. My husband and I did that a few times when we got visit here [at the hospital]. And then privacy was ensured because over there you just found a corner where you could sit and hang for hours if you wanted. We did that some times. It was a way to get some privacy. But it was only possible in the periods when I felt good; otherwise I simply didn’t have the strength for it.’</td>
</tr>
</tbody>
</table>
took place in brief pre-scheduled time periods, and patients learned the different self-care procedures (e.g. central venous catheter-care) early on in the course of treatment, the number of interactions would be reduced, making it possible for inpatients to maintain individualized daily rhythms [15].

As outpatient, privacy was guarded at home. This motivated patients to engage in social life in the HU, openly discussing subjects concerning their condition that they would often not bring up with roommates as inpatients. While the physical environment of the HU stimulates conversation, through soft chairs and tables, the shared bedrooms used by inpatients hold no incitement for conversation, but demarcate through soft chairs and tables, the shared bedrooms used by physical environment of the HU stimulates conversation, often not brought up with roommates as inpatients. While the discussing subjects concerning their condition that they would ed patients to engage in social life in the HU, openly everyday life activities as when reaching the possibility of managing own time. The activities of concern to AL patients are not much different from those of healthy people. This is in accordance with previous arguments that the everyday life world is the most meaningful for patients facing an unfamiliar circumstance [16]. Normal everyday tasks, which require physical activity, are not equivalent to hard training but a natural way of using the body actively. When at home, such activities are not recognized as physical training by HU patients, but according to Bech-Jørgensen, unnoticed activities are part of everyday life [17].

Our study showed that patients struggle with the responsibility of the situation, which was in line with observations among AML patients by Nissim et al. [12]. The responsibility for different procedures (e.g. central venous catheter-care) frightened many patients initially, but once learned and performed a few times, patients felt confident. Additionally, they valued self-control that was achieved through these self-care practices, which is in line with earlier research of AL patients

<table>
<thead>
<tr>
<th>Quote</th>
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<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>21</td>
<td>‘You form a family-like relationship with those you meet. Oftentimes you’ve met as inpatients and then you meet in the HU, and well… it’s like it is a little family out here [in the HU] because we follow each other.’</td>
</tr>
<tr>
<td>9</td>
<td>10</td>
<td>‘Well we talk about… a lot of it concerns our illness. How were your counts [blood counts] the last time? Well, they were like… How were your counts, and like that and how were… yeah, gosh Jens are you here now, we hadn’t seen you, we thought so and so, you know – and where were you… So 75 % of conversation concerns illness. Leukemia in general, right, which I find quite natural. And then there are ummm wives and children and grandchildren and traveling and vacation. And what was on TV yesterday? And ohhh are you reading that book at the moment, right? And this was in the newspaper yesterday, and so on, right. Like common conversation.’</td>
</tr>
<tr>
<td>10</td>
<td>24</td>
<td>‘I’m there when they come home from school, right. I’m there for dinner. I’m there to say good night, when they need a bath and when they are doing homework and all those everyday stuff that you do as a family. That I’ll say means a whole lot.’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quote</th>
<th>Patient</th>
<th>Statement</th>
</tr>
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<tbody>
<tr>
<td>11</td>
<td>23</td>
<td>‘Well, you don’t go home and start eating honey or blue cheese as you usually do. You don’t go out gardening and you don’t start helping out with the reconstruction of the bathroom your brother is doing upstairs. […] So in a way they [the special precautions] have influenced my behavior – but it’s been – interfering with manageable areas.’</td>
</tr>
<tr>
<td>12</td>
<td>23</td>
<td>‘I try to maintain as much of an everyday life as is possible - ummm, necessarily within the limits the HU has outlined for it to be so clean and don’t do this and that. But when I believe in it and find it to be sensible and fair then I would also defend doing it because I also know who is to blame if it goes wrong – that’s me.’</td>
</tr>
<tr>
<td>13</td>
<td>15</td>
<td>‘It is a great deal that has to be managed and planned I think. It surprised me. It also surprised me that I find it hard or challenging at times. When I was working I could have had a hectic day from 8 am to 3 – 4 pm but then I would come home and there was just something new on the agenda – a change. That doesn’t happen now [as a patient in the HU]. It all runs 24/7.’</td>
</tr>
<tr>
<td>14</td>
<td>1</td>
<td>‘You have to do your bed as inpatient if you are able to because it is good to your arms. In the beginning I thought: now just stop. That’s your [the nurse] job. But I had second thoughts since.’</td>
</tr>
</tbody>
</table>
When patients are unwell, they have a need for care and security, as provided by the inpatient setting. They lack the incentive for personal involvement and self-management. The overwhelming responsibility for own care experienced when shifting to outpatient management may be reduced if the patients become familiar with the procedures through supervised training and guidance during admission. Such initiatives would have the additional benefit of securing more inner time for the patients.

Being engaged in everyday life practices and procedures together with family and fellow patients seems to heighten the general level of activity of the patients. Thereby, the outpatient management could be suggested as having a potential of supporting rehabilitation to this severely ill group of patients.

All study participants received curative intended chemotherapy and were evaluated as suitable candidates for outpatient management. The weakest patients were missing, including those living alone without a social network to support them. The advantages of outpatient management of AL described in this study may not be applicable for patients with limited resources. Our engagement of the theoretical framework of everyday life in the analytical work allows an analytical generalization, which is common for qualitative research.

In conclusion, the findings of this study contribute to our understanding of how patients with AL experience the different conditions in the inpatient and outpatient settings, and the transition between them. This study showed that outpatient management facilitates time administrated by the patients and thereby the possibility of maintaining everyday life practices to a higher extent, which was very important to all patients. Time spent together with fellow patients became an important and highly valued part of social life during outpatient management. Privacy ensured at home was important to patients, and they accepted the necessary responsibility, precautions and procedures that came with it. With few exceptions, outpatient management provided motivation for patients to engage in everyday life despite severe illness and intensive treatment.

The conditions in the inpatient setting may be improved substantially, and the transition to outpatient management may benefit by supervised training and guidance during admission, to make patients familiar with the procedures reducing the otherwise overwhelming responsibility.

Acknowledgments The authors wish to thank all the patients who participated in the study for their valuable contributions in 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 the 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.

Compliance with ethical standards

Informed consent Informed consent was obtained from all individual participants included in the study. Throughout the manuscript, an ID number identifies participants, and synonyms are used in the quotes to preserve confidentiality. The study was approved by The Regional Scientific Ethical Committees for Southern Denmark (S-20122000 86) and the Danish Data Protection Agency (J. No. 2008-58-0035). Permission to conduct the study was obtained from the Department of Hematology, Odense University Hospital, where the study took place. The first author had no professional medical interaction with the participants during the study period, but has formerly been employed as a physician in the department. Participation in research while undergoing treatment for a serious illness puts strain on patients. We sought, in this study, to pay attention to this by minimizing the extra time they needed to invest. Inclusion was handled solely by the first author to avoid a possible sense of pressure on patients if they were recruited by the regular staff. We recognize that research is always a relational endeavour with implications for the life of its participants.

Conflict of interest The authors declare that they have no competing interests.

References


33. Paper 2
Rehabilitation during intensive treatment of acute leukemia including allogenic stem cell transplantation – a qualitative study of patient experiences
Rehabilitation during intensive treatment of acute leukemia including allogenic stem cell transplantation – a qualitative study of patient experiences

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Abstract

Purpose

Physical, psychological and social functioning is affected substantially by a diagnosis of acute leukemia (AL) and its treatment. The lacking immune system as part of the pancytopenia makes the group of AL patients special in relation to rehabilitation. How AL patients treated with curative aim, including HSCT, assess their physical, psychological and social capability during and following treatment and health initiatives supporting their rehabilitation is elucidated.

Methods

As the final interview, in a line of three conducted as part of a larger qualitative study, we conducted qualitative, semi-structured individual patient interviews with 16 patients, six months after end of treatment.

Results

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. Patients struggled with anxiety and the need for
progress in treatment and well-being to feel well. Unexpectedly it demanded an effort of the patients to get back a meaningful social life. Six months after end of treatment patients still had to prioritize activities and were not able to keep up everyday life as they used and wanted to.

Conclusions
AL patients suffered physically, mentally and socially throughout the whole illness trajectory. Room for improvement of rehabilitation initiatives are pointed out. For example that physical activity through daily tasks is manageable by the patients and underlines why the future concepts to a higher degree should encourage that. Regular needs assessment may improve that changes of health and motivation are addressed during the illness trajectory.

Keywords
Rehabilitation, acute leukemia, everyday life, qualitative study

Introduction
Physical, psychological and social functioning is affected substantially by a diagnosis of acute leukemia (AL) and its treatment [1]. The lacking immune system as part of pancytopenia makes the AL patients special. Rehabilitation, such as physical exercise and social engagement may support patients’ quality of life and their return to daily life after end of treatment. However, physical exercise may seem overwhelming without persistent encouragement, especially for patients with low energy levels due to pancytopenia and long periods in bed. Furthermore patients may be hindered in social engagement due to restrictions outlined in the treatment regimen [2]. Rehabilitation refers to focused initiatives and efforts supported by health professionals but is also used to describe the process in which the patient has to reframe a sense of self, following intensive cancer treatment [3]. However, it is not well described which kind of needs intensively treated, fragile AL patients have and how to meet their needs.
Although the literature is rather sparse regarding AL and rehabilitation a few studies have shown that physical exercise is feasible and safe to AL patients even with critical cytopenia due to intensive chemotherapy and have beneficial effects on physical performance, fatigue and quality of life [4-8]. A six week supervised exercise and health counselling intervention to AL patients undergoing chemotherapy during outpatient management showed physical, functional, psychosocial and symptom benefits of the patients [9]. For patients with hematological malignancies undergoing allogenic hematopoietic stem cell transplantation (HSCT) exercise interventions have also shown significant benefits without reporting any unexpected or negative effects [10].

Studies have shown that health related quality of life of hematological cancer patients are lowered mainly by reduced role functioning, insomnia and fatigue [11,12]. The association between impaired quality of life and unmet needs are generally strong for cancer patients [13]. Patients report unmet needs early and later on in the cancer trajectory regarding several aspects of life. Psychologist counselling, physical rehabilitation, sexual and financial areas and practical help have been found to be of concern and vary with age, gender and cancer diagnosis [14,15]. Due to fear of death and social stigmatization a range of cancer survivors express needs of psychosocial rehabilitation [16].

The existing knowledge underlines a range of beneficial effects of physical activity, even for cytopenic patients and unmet needs according physical and psychosocial support. However, research-based knowledge of how AL patients experience needs and interventions addressing their rehabilitation during the illness trajectory is sparse but required to meet the needs of this special, fragile group of patients in the future.

This qualitative article, based on interviews, elucidates how AL patients treated with curative aim, including HSCT, assess their physical, psychological and social capability during and following treatment and health initiatives supporting their rehabilitation.
Material and methods

Design

This article is based on data from individual patient interviews with 16 patients, six months after end of treatment. The interview was the third and final interview in a line of three, conducted as part of a larger qualitative study, which combined participant observation in the outpatient setting, individual patient interviews, and group or individual interviews with their relatives [17].

Semi-structured interviews were conducted on the basis of a thematic interview guide [2]. The first topic was ‘impact on everyday life practices’ where rehabilitation issues where covered with questions such as ‘Try to describe your present physical capability and how you reached that level’. The question was repeated for social and mental well-being. The second topic ‘the home’ explored daily life at home and the roles of the family whereas the third topic ‘hygiene’ covered how the intensified hygiene requirements affected everyday social life.

Participants

Participants were Danish speaking AL patients intensively treated with curative aim. All were managed in the outpatient setting, the Home Unit (HU) at the Department of Hematology, Odense University Hospital (OUH) and subsequently followed in the outpatient clinic at OUH or had HSCT at the National University Hospital, Copenhagen or at Aarhus University Hospital [2].

Twenty-six patients were included consecutively from May 2013 to August 2014, of which 16 took part in this third interview (Figure 1). Table 1 shows demographic characteristics. The interview was conducted in the patients’ home six months after end of treatment. The interviews lasted from 40 to 115 minutes with a mean of 68 minutes. All interviews were digitally recorded and transcribed verbatim by a secretary.
Setting

Each year the Department of Hematology, OUH receives about 45 newly diagnosed AL patients who are candidates of curative intended chemotherapy. The course of treatment contains periods as inpatient and periods as outpatient where they live at home and appear at follow-up visits every second day [2].

The HU was situated next to the hematological department, OUH. Both inpatients and outpatients could use the fitness facilities located within the department whenever they wanted. Twice a week a physiotherapist was present for one hour to support patients showing up. During the course of treatment patients could by request be referred to a physiotherapist, a psychologist, a chaplain or a medical social worker at the department.

For patients to be transplanted a pre-visit at the hospital of transplantation included a consultation with a physiotherapist and instructions in simple exercises to do during the course of transplantation. During isolated periods of treatment an exercise-bike was present in the bed-room.

The Danish Cancer Society had counsellors close to treatment settings for patients and relatives. Furthermore, patients could always contact their general practitioner.

The responsibility of rehabilitation following treatment was held by the local municipality. The municipalities have different rehabilitation offers and cancer knowledge due to different population and geographic size [18].

Analysis

The study took outset in the World Health Organization definition of rehabilitation [19], but simultaneously acknowledged that rehabilitation in the context of this study was an analytical approach to the social, physical and existential challenges facing AL patients, and not a structural or organizational intervention as such. In this article we look at the configuration of rehabilitation needs as experienced by the patients and draw attention to possible contextual factors that need to be taken into account. Furthermore, AL patients’
experience of potential rehabilitation initiatives. To further support our analytical exploration, the theoretical framework included International Classification of Functioning, Disability and Health (ICF) [20].

Data analysis took an inductive approach and was an ongoing process of four steps inspired by Miles and Huberman [21]. First, the interviews were transcribed and read several times to gain an overall understanding of the material. Secondly, specific text pieces were identified as the content and context related to each other and the study aim. Thirdly, descriptive codes were produced and assigned. Finally, the text was condensed into categories. The computer program, NVivo 10 supported data organization, coding and retrieval.

**Ethics**

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

**Results**

Patients did not use the word ‘rehabilitation’ about the process of regaining physical, mental and social functioning. Rehabilitation was therefore an analytical condensation of the AL patients’ assessments of their capability and experiences of supportive initiatives. Subcategories of physical activity, mental well-being and social activity were constructed.

To many of the patients the organization of the everyday life practices was a first step. This process began when coming home after hospitalization the first time and continued through the illness trajectory. They described how they had lacked the energy to go through a full day’s program, and at time of interview had escalated activities from twice a week to every second day and from one to five hours. The pace was still
slow in all activities and a nap in the afternoon was often needed. Projects without a deadline were preferred (Table 2, quote 1).

House-keeping tasks, such as cutting the grass or vacuuming the house which would have been no problem prior to the illness were ‘physically demanding’ now, challenged them substantially and greatly impacted their daily life. This was expected during the course of treatment but six months after the patients had expected to be ‘back to normal’.

**Physical activity**

Nearly all patients 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. Elastic bands were handed out by the physiotherapist at OUH, and the simple exercises instructed in at the hospital were used by many patients (Table 3, quote 1).

Ending chemotherapy, a handful of patients exercised more intensively in a fitness center, doing bike rides of 50 kilometers, swims of 1000 meters or three to four kilometers running. They wanted to get back their usual physical strength and fitness but also aimed to be prepared if the AL relapsed (Table 3, quote 2).

Referral from hospital to municipality for rehabilitation happened if and when they or their doctor came to think about it. Waiting time from referral to start was usual. The exercise offered in the municipalities was training in a class with other patients, one hour twice a week for six to twelve weeks. Everyone experienced to be the only patient with AL/HSCT and at the end of the period many were told to be ‘too good’ to continue in the class. Disappointment regarding the enthusiasm and competences of the health care professionals in the municipality was apparent (Table 3, quote 3).

None were satisfied with their physical status six months after end of treatment being less capable than expected. Thinking back it had been too easy to ‘escape’ the physiotherapist during hospitalization. Shifting to the outpatient setting they did not remember having been encouraged to be physically active. In the first interviews [2] the patients described how they prioritized to socialize with fellow patients in the
outpatient setting to the detriment of physical training. In line with the first interviews they still not participated 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 as described previously [17]. Activities that were part of their everyday life were not considered as training.

Regardless of treatment status the patients experienced little focus on physical activity from the health care professionals. The outcome of training programs in the municipality was low, and surprisingly the patients often were ‘too good’ to continue the course, which mis-matched their motivation to continue and dissatisfaction of own physical capability at time of last interview. The lack of physical capability still prevented the patients from engaging in everyday life activities as they used and wanted to but none of the them challenged the municipality to optimize their training offer.

**Mental well-being**
The treatment and the physical capability strongly influenced the mental well-being of the patients. It was mentally challenging in periods when not feeling better or when physical symptoms caused uncertainty (Table 4, quote 1).

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, patients found. Another way was to talk to family members or friends, which all used to varying extent. They also used talking to fellow-patients as a coping strategy, especially while in the HU, but also when they happened to meet each other later on at the hospital.

AL had challenged their identity and security that were shaped by work or social activities, which raised the existential question to many patients: Who am I – besides being a leukemia patient? (Table 4, quote 2). Patients believed that the illness trajectory ended up with survival. The stepwise prolongation experienced by everyone due to unexpected occurrences was mentally draining. Furthermore it was hard never to be
provided a ‘cured-date’. As an alternative some patients marked 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 where survival and physical issues had first priority. Later on, it was a barrier to describe their illness trajectory once again.

Mental well-being was influenced by the flow in treatment and their 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.

**Social activity**

As previously described the social life of patients suffered while they were inpatients, while outpatient management allowed for more time spent together with fellow patients, which became an important and highly valued part of their social life [2].

The difference between friends and familiar people became more apparent as time went by. Losing contact to persons counted as friends was a mental strain (Table 5, quote 1). As the trajectory proceeded patients wanted the conversation to turn from illness and treatment into everyday things and the future. They could no longer cope with too much talk of illness (Table 5, quote 2).

The treatment precautions meant that patients only saw few people at a time and that nearly all social activity should take place at home or in hospital. Returning to a more normal social life after end of treatment was overwhelming and unexpectedly demanding (Table 5, quote 3).

Six months after the end of treatment the energy level of patients was still impaired. Patients thus had to choose for themselves what to participate in and social activities were in competition with practical tasks, physical activity and work (Table 5, quote 4).
The patients described how it was unexpectedly demanding to regain a meaningful social life. They wanted to focus on the future with input from the outside. No one experienced or expected that social life had the attention of professional intervention.

**Discussion**

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

Patients did not exercise as much as they wanted to. That seems in line with a long hematological tradition avoiding physical training during cytopenia periods even though a recent study shows that patients may be able to attend physical training and benefit from this during treatment [9]. A questionnaire study with 451 mixed cancer patients looked into given information on physical training. Oncological patients felt better informed compared to hematological patients which raised the question that health care professionals were biased with regards to whom they considered suitable for physical activity [22]. In our study six months after end of treatment patients did not remember that there might have been attention to physical activity during the course of treatment. At the same time they described the refusal of the physiotherapist’s training offer and their prioritization the social life in the HU [2]. It was a deliberate choice showing that the patients’ attitude towards training changed during the treatment period. They exuded no motivation for physical training during the first part of the illness trajectory but were highly motivated after end of treatment. At that time the municipality did not offer training matching their needs and only few patients managed to follow their own training program at that time.

It is interesting that there is a difference between the patients’ attitudes and concrete actions regarding physical training during the treatment course. The individual responsibility of the patients in line with the late modern society leaves no other explanations possible to avoid stigmatization, than that lack of attention from the health care professionals was the reason.
Few patients called for easier access to psychologists but the majority found no reason for that since they felt sufficiently supported by family, friends and health care professionals. This is in line with a questionnaire study among 132 mixed hematological and oncological patients [23]. Internationally, systematic needs assessment has been recommended as a part of routine cancer care [19] which may uncover substantial needs and changes of the health and motivation in the patients that would otherwise not be addressed. However, none of the patients in our study have had their needs assessed because it was not yet implemented in the department. Another explanation of the sparse demand of psychological support may be that the weakest patients were not recruited for this study, had left the study, or that more existential problems surface later.

The patients had to prioritize to care for themselves even though it sometimes caused emotional limbo, which has also been described in a focus group interview study among mixed cancer patients [16]. Social reintegration unexpectedly required an effort, and they had to challenge themselves step-by-step. None seemed to expect professional help and no one stated that they should have been informed of the social challenges that could occur. This gives the impression that the patients made no connection between their social life and the possibility for support for this by professional interventions, e.g. as part of general rehabilitation efforts in line with the definition [19] and ICF-model [20].

**Limitations**

The relatively small number of participants in this study makes it difficult to generalize to the wider population of hematological cancer patients. The theoretical framework of rehabilitation may thus strengthen the possibility for analytical generalization [24]. The majority of patients received a HSCT as the final treatment entity but the study left no room for differentiation between those with and without. In a rehabilitation perspective ‘six months after intensively treatment for AL’ seems a short time. New data after one year or longer may show additional aspects for the longer perspective for example late mental or existential problems. The patients showed a high degree of self-preservation instinct during the illness trajectory, which may indicate a selection of patients who wanted to participate in the study.
**Perspectives**
This study has several implications for future patients. The patients wished the rehabilitation process to begin shortly after treatment start. This is in line with all rehabilitation recommendations and a focus to maintain instead of catching up lost capabilities[25,26].

An enhanced understanding of the importance of physical activity by the patients to secure the performance on days where symptoms or bad mood is present is important. Especially, that minor everyday activities, such as change of linen help against loss of muscle and capability. Simple exercises should be introduced shortly after start of treatment and be supervised through treatment, whatever the setting. This may support continuity and activities across different hospitals, home and municipality initiatives improving wellbeing and quality of life among patients.

Referral to a psychologist may be important for a minor group of patients. This study supports that preparation to reaction patterns and mental distress might be appreciated by the majority.

To optimize patients’ social life the treatment initiated precautions should have a thorough evaluation of the evidence. A revision may decrease the impact on everyday life and thereby patient and family wellbeing.

**Conclusion**
In conclusion, the findings of this study bring new knowledge of how AL patients treated with curative aim 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 experienced no matching training offer when motivation for being active came after end of treatment. Mentally the patients struggled with anxiety and the need of progress in the treatment and rehabilitation process to feel well. Talking to family and friends was experienced as a good way of addressing mental problems. The precautions stipulated by the hospitals
restricted social life and unexpectedly demanded an effort of the patients to get back a meaningful social life.

Room for improvement of rehabilitation initiatives has been pointed out. Regular needs assessment may improve that changes of health and motivation are addressed during the illness trajectory.

**Acknowledgements**

The authors wish to thank all the patients who participated in the study for their valuable contributions in 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.

**Conflicts of interest:** The authors declare that they have no conflict of interest.

**References**

17. Jepsen LØ HM, Hansen DG, Marcher CW, Friis LS. (2015) Outpatient management of intensively treated acute leukemia patients - the patients’ perspective.9
### Table 1 Demographic characteristics of study participants (n=16)

<table>
<thead>
<tr>
<th>Sample characteristics</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Description</td>
</tr>
<tr>
<td>Male</td>
<td>9 (56 %)</td>
</tr>
<tr>
<td>Female</td>
<td>7 (44 %)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>(mean 55.1; range 26-74)</td>
</tr>
<tr>
<td>&lt; 60</td>
<td>8 (50 %)</td>
</tr>
<tr>
<td>≥ 60</td>
<td>8 (50 %)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Description</td>
</tr>
<tr>
<td>Married or common-law relationship</td>
<td>13 (81 %)</td>
</tr>
<tr>
<td>Single/divorced</td>
<td>3 (19 %)</td>
</tr>
<tr>
<td>Education</td>
<td>Description</td>
</tr>
<tr>
<td>Unskilled workers</td>
<td>2 (12 %)</td>
</tr>
<tr>
<td>Skilled workers</td>
<td>10 (63 %)</td>
</tr>
<tr>
<td>Further education</td>
<td>4 (25 %)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Description</td>
</tr>
<tr>
<td>Acute myeloid leukemia (AML)</td>
<td>11 (69 %) (3 relapse)</td>
</tr>
<tr>
<td>Chronic myeloid leukemia in myeloid blast crisis (CML)</td>
<td>1 (6 %)</td>
</tr>
<tr>
<td>Chronic myelomonocytic leukemia (CMML)</td>
<td>1 (6 %)</td>
</tr>
<tr>
<td>Refractory anemia with excess blasts (RAEB)</td>
<td>1 (6 %)</td>
</tr>
<tr>
<td>Acute lymphoblastic leukemia (ALL)</td>
<td>2 (13 %)</td>
</tr>
<tr>
<td>Time from diagnosis to third interview (weeks)</td>
<td>Mean 51.9 ; range 40-72</td>
</tr>
<tr>
<td>Treatment status</td>
<td>Description</td>
</tr>
<tr>
<td>Outpatient Clinic follow-up</td>
<td>3 (19 %)</td>
</tr>
<tr>
<td>Allogenic hematopoietic stem cell transplantation, National University Hospital, Copenhagen</td>
<td>8 (50 %)</td>
</tr>
<tr>
<td>Allogenic hematopoietic stem cell transplantation, Aarhus University Hospital</td>
<td>2 (12 %)</td>
</tr>
</tbody>
</table>
Second line therapy,  
Odense University Hospital 3 (19 %)

Table 2 Sample statements from participants

<table>
<thead>
<tr>
<th>Quote</th>
<th>Patient</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>25</td>
<td>‘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.’</td>
</tr>
</tbody>
</table>

Table 3 Sample statements from participants: Physical activity

<table>
<thead>
<tr>
<th>Quote</th>
<th>Patient</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10</td>
<td>‘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.’</td>
</tr>
<tr>
<td>2</td>
<td>18</td>
<td>‘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.’</td>
</tr>
<tr>
<td>3</td>
<td>23</td>
<td>‘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.’</td>
</tr>
</tbody>
</table>
Table 4 Sample statements from participants: Mental well-being

<table>
<thead>
<tr>
<th>Quote</th>
<th>Patient</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>19</td>
<td>‘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.’</td>
</tr>
<tr>
<td>2</td>
<td>23</td>
<td>‘Principally you are a lot because of you training and the background you have and what you do.’</td>
</tr>
<tr>
<td>3</td>
<td>25</td>
<td>‘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.’</td>
</tr>
<tr>
<td>Quote</td>
<td>Patient</td>
<td>Statement</td>
</tr>
<tr>
<td>-------</td>
<td>---------</td>
<td>-----------</td>
</tr>
<tr>
<td>1</td>
<td>21</td>
<td>‘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.’</td>
</tr>
<tr>
<td>2</td>
<td>25</td>
<td>‘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.’</td>
</tr>
<tr>
<td>3</td>
<td>18</td>
<td>‘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.’</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>‘And then I was at work yesterday morning and in the afternoon I should have been to a co-worker’s 60th 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.’</td>
</tr>
</tbody>
</table>
Figure 1: Enrollment of patients

Assessed for eligibility (n=32)

Excluded (n=6)
  • Declined to participate (n=5)
  • Left out by mistake (n=1)

Included (n=26)

Lost to follow-up (n=4)
  • Died (n=2)
  • Withdrew informed consent (n=2)

First time interview (n=22)

Lost to follow-up (n=7)
  • Non-responder to invitation (n=2)
  • No time span before HSCT* (n=5)

Second time interview (n=15)

Lost to follow-up (n=6)
  • Non-responder to invitation (n=3)
  • Died (n=2)
  • Severely ill inpatient (n=1)

Third time interview (n=16)

* HSCT = allogeneic hematopoietic stem cell transplantation
34. Paper 3
Living with outpatient management as spouse to intensively treated patients with acute leukemia
Living with outpatient management as spouse to intensively treated acute leukemia patients

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Abstract

Objectives

Spouses have a key position in the treatment of patients with acute leukemia (AL) who are increasingly managed securely in an outpatient setting. Patients live at home but appear at the hospital every second day for follow-up visits. Patients must adhere to specific precautions while at home because of a lacking immune system, which influence the life of the whole family.

This qualitative article, based on individual and group interviews with spouses to AL patients in curative intended treatment, elucidates how spouses experience the challenges arising during outpatient management. The aim is to illustrate how the caregiver role affects everyday life of the family.

Methods

Qualitative semi-structured group interviews (six participants) and individual interviews (five participants) with spouses to AL patients were conducted at different time points during the whole course of treatment.

Theories of everyday life serve as the theoretical framework for this article.

Results

The spouses described their experiences as being in a constant state of vigilance and attention as a consequence of the sense of responsibility they felt during outpatient management. This made them experience their role as a burden. Furthermore the spouses found that the health care professionals took their efforts and engagement for granted, which added to their feeling of outpatient management as a
burden. The social life of the spouses suffered substantially due to the precautions that were instated in the home. However, relations in the family were reported to be strengthened.

**Significance of results**
To counter additional psychosocial burdens to relatives instigated by the outpatient treatment regimens, the health care system should develop ways to engage the relatives, without adding to their sense of burden. This could apply not only to relatives of AL patients but to the relatives of other severely ill patients as well.

**Keywords**
Spouses, acute leukemia, everyday life, qualitative study, outpatient management

**Introduction**
The closest relative has a key position in the treatment of patients with acute leukemia (AL) who are increasingly managed in an outpatient setting. How this influences the everyday life and psychosocial well-being of the relative to this special group of patients is however not well understood. For months patients live at home but appear at the hospital every second day for follow-up visits (Walter et al., 2013). The concept of outpatient management has become standard way of managing AL patients during the last five years in Denmark and is an alternative to be inpatient. AL patients are highly vulnerable to infections and severe bleedings for three to five weeks after each cycle of chemotherapy. Adaption to the often rapidly changing health status of the patients is challenging for the close relatives and comes into conflict with planning and maintaining everyday life, in particular in families with younger children (Blindheim et al., 2013, Melcher et al., 2015).

Studies including relatives of other types of patients and settings have shown that the caregiver role, assuming responsibility and being taken into account and treated with respect by the professionals, made close relatives feel empowered (Nygårdh et al., 2011). A challenging balance for close relatives between managing their own needs and meeting the needs for support and care of the patient, has been pointed
out (Ervik et al., 2013). Relatives reported a higher average number of concerns than patients themselves; concerns which were focused on family issues and unmet needs regarding information on medical treatment and supportive care for the patient (Dodd et al., 1992, Adams et al., 2009, Friis et al., 2003).

The existing knowledge of the experiences of the relatives as intensively involved caretakers during outpatient management of AL patients is sparse and insufficient to further qualify the programs and to ensure an endurable trajectory for the relatives.

This qualitative article, based on individual and group interviews with spouses to AL patients in curative intended treatment elucidates how spouses experience the outpatient management. The aim is to illustrate how the caregiver role affects their everyday lives.

**Methods**

**Design**

This article is based on data from individual and group interviews with relatives of AL patients in curative treatment conducted as a part of a larger qualitative study. The larger study combined participant observation in the Home Unit (HU) (outpatient setting), individual patient interviews at three different times, and group or individual interviews with their relatives (Jepsen et al., 2015). In-depth interviews were used to obtain insight into people’s life situation, experience, views and attitudes (2010). The analysis focused on everyday life during outpatient management for AL in the perspective of the close relatives.

**Participants**

Invited participants were Danish speaking relatives to intensively curative intended treated AL patients managed in the HU at the Department of Hematology, Odense University Hospital. A relative was defined, as the person living with the patient during outpatient treatment, and who in collaboration with the patient, was responsible for meeting the obligations of the HU. Relatives were invited to participate in the study after agreement with the patient. Eleven relatives, who all turned out to be spouses, were included from March to November 2014 (Figure 1). Demographic characteristics are shown in table 1.
**Recruitment and data collection**

We invited relatives to the 26 patients included in the larger study. Two group interviews included two and four spouses, respectively, and were conducted in a separate room at the HU. In addition five spouses were interviewed individually as they were not able to attend the scheduled group interviews. The spouses chose the location of the individual interviews (two at the hospital and three at their homes). The time from patient diagnosis to spouse interview varied from seven to fifty weeks.

Topics covered in all interviews were predetermined and formulated as five questions:

1) Try to give examples of how everyday life is experienced as a relative to a patient in the Home Unit?

2) Which things/tasks came with being a relative to a patient in the Home Unit?

3) What has it meant to your home that your spouse has been patient in the Home Unit?

4) If I say the word ‘hygiene’, what do you think?

5) How do you, as a relative, experience the Home Unit concept?

Topics were inspired by participant observation previously conducted at the HU by the first author as part of the larger qualitative study. The interviews lasted from 60 to 90 minutes with a mean of 75 minutes. All interviews were conducted by the first author, digitally recorded, and transcribed verbatim by a secretary.

**Setting**

Each year the Department of Hematology, Odense University Hospital receives about 45 newly diagnosed AL patients from the Region of Southern Denmark who are candidates of receiving curative intended chemotherapy. Following the first treatment cycle about 75 % of these patients will be managed in the HU during the periods of pancytopenia. The course of treatment for the patients contains periods as inpatient where the spouse is welcome to visit the patient, and periods as outpatient where the patients live at home and appear at follow-up visits in the HU every second day (Figure 2).

An important prerequisite for being managed in the HU is that a relative is present at home at night. Due to safety precautions patients also have to measure temperature, blood pressure, take prophylactic
antibiotics and record their overall wellbeing in diaries. All patients have a tunneled central venous catheter from which they or their close relatives draw blood samples, and do the cleaning routines of changing the dressing and flushing. Patients are instructed to avoid any contact with persons carrying an infection (including close family members) and avoid places where crowds gather such as grocery stores, public transport and social events. At home, the whole family should intensify the hygienic precautions and eschew mold. Patients must abide by the precautions 24/7.

Upon enrolment in the outpatient program the patient and the spouse have a formal meeting with a nurse who clarifies the precautions, the need for collaboration on tasks and procedures and the principles of the HU.

Analysis

The purpose of the data analysis was to extract meaningful content from the experiences of the spouses, addressing the specific aims of this study. Data analysis was an ongoing process performed in four steps as described by Miles and Huberman (Miles et al., 2014):

1) The transcribed interviews were read several times to get an overall understanding
2) Text fragments were identified where the content and context related to each other and to the aim of the study
3) Descriptive codes were made
4) The descriptive codes were condensed into categories

Data presented many examples, tasks and concerns of everyday life. All interview data was organized, coded and retrieved using the computer program NVivo 10.

Theories of everyday life constitute the analytical framework of this work. Everyday life is in its simplicity ‘the life we live every day’, according to Bech-Jørgensen and emerges from an interaction between everyday structure and circumstances and the ways people manage within these (Bech-Jørgensen, 1993). The everyday life and the surrounding world are largely taken for granted, as we create routines to be
reproduced and repeated in continuous interaction with others, which also happens in the life of AL patients and their spouses. The life world is not private for any individual but rather it is ‘a world of our common experiences’ (Schutz and Luckmann, 1974). We assume with this outset that the experiences of patients managed in the HU and their spouses are intertwined and inseparable as individuals.

Ethics

All participants provided written informed consent. Throughout the manuscript an ID-number identifies participants, and synonyms are used in the quotes to preserve their confidentiality. The study was approved by The Regional Scientific Ethical Committees for Southern Denmark (S-20122000 86) and the Danish Data Protection Agency (J. no. 2008-58-0035). Permission to conduct the study was obtained from the Department of Hematology, Odense University Hospital, where the study took place. It was conducted in accordance with the Declaration of Helsinki II. We recognize that research is always a relational endeavor with implications for the life of its participants. The first author had no professional medical interaction with the participants during the study period.

Results

The profound challenge to the everyday life of the family was a predominant issue. Accounts from the spouses of AL patients, focused on the category of everyday life, were organized into four descriptive categories: responsibility, challenging partnership, the family, and social network. The spouses noted that the changes were out of their control, which may have caused a different approach to the whole situation than if they had decided to change thing themselves. It was imposed on them.

Responsibility

Spouses were keen to act and assume responsibility when necessary. They experienced feelings of additional responsibility when the patient-status shifted from inpatient to outpatient, accompanied by the particular precautions specified by the HU for the patient’s time at home. It was described as a huge job to
keep up with the precautions. A key issue was that the house had to be prepared before the patient came home from the hospital with meticulous cleaning and all potted plants removed (Table 2, quote 1).

It was a demanding responsibility for the spouses to observe and react adequately to sudden symptoms of the patients, like fever or bleedings. Spouses and patients did not always agree on when to discuss symptoms with the hospital staff. At all hours they could call the Department to discuss a situation and ask for advice, but still they had to make independent decisions at home (Table 2, quote 2).

The spouses stressed how important it was that the nurses on call were positive and confident and gave instructions in accordance with previous information received, because otherwise it caused uncertainty and insecurity. They experienced that the health care professionals were serious about their concerns and discussed issues in a productive manner. However, the weight of the responsibility and the impact on everyday life surprised them (Table 2, quote 3).

It was remarkable that the weight of responsibility surprised the spouses even though they felt well informed. This speaks to the pervasive impact of outpatient management on the psychosocial well-being of the spouses, where the structural demands of caregiving add additional burden to their everyday life.

**Challenging partnership**

All spouses described how the patient had been emotionally affected during treatment. Patients were more short-tempered and experienced sudden uncontrollable episodes of crying. The spouses described how they tried to cope with these powerful emotional changes (Table 3, quote 1).

The extra precautions and the medical tasks that characterized everyday life of the partnership (e.g. caring for the central venous catheter) placed the spouses in a nurse-like role. This was accepted by spouses as the natural order in the situation, though it often challenged their relationship when the patient did not behave as advised by the health care professionals (Table 3, quote 2).
The prescribed medication was administrated by the spouse in all but one case and it was considered an important and complex task. The other procedures were often more equally shared between patient and spouse, but the spouse expressed a strong desire that the patient would be more responsible and take on more of the effort to get things done (Table 3, quote 3).

Spouses experienced that patients were mostly not able to think about anything other than themselves and getting through their illness. This left the responsibility, the caretaking and the communication with their children in the hands of the spouses (Table 3, quote 4).

The natural order of the partnership was challenged by the psychosocial changes of the patients. Furthermore, the caregiver role of the spouses created an unequal distribution of the responsibility and the medical tasks, which caused conflicts between them.

**The family**

In families with young children the spouse felt torn between the patient and the children, whereas grown-up children were experienced as partners in managing the fear, thoughts and practical things like keeping the house and garden (Table 4, quote 1).

With the patient at home, young children had to organize their play-dates according to the blood test results of the parent, as not to attract unnecessary infections to the house. Children were very alert to the movements and well-being of the ill parent, noticing and measuring the severity by little things, such as if they were present to read a bed time story (Table 4, quote 2).

Relations in the family between the patient and their spouse, their children, their grandchildren and their siblings were strengthened during the trajectory of AL. The spouses were delighted and emphasized this as one of the few good things that followed from the cancer (Table 4, quote 3).

Despite all the hurdles that appeared during the course of treatment the spouses experienced that relations of the family network were strengthened. The age of the children, however, seemed to be crucial
to how the children were perceived. The spouses either saw them as resources, helping out with structural needs in everyday family life, or as vulnerable beings who needed extra attention and care because of the situation, adding to the strain on the spouses.

**Social network**
The patient was at the center of attention from all sides and their needs had first priority. All spouses found that self-evident, but as the course of treatment prolonged they could not keep neglecting their own needs. They expressed that family and friends were very important relations as a means of creating a personal space away from the patient and as an outlet to express their feelings and fears, which they did not want to share with the patient (Table 5, quote 1).

Having the patient live at home with the intensified hygiene standards and other precautions, affected the normal social life of the whole family. All members learned to live and act in accordance with the patients’ blood counts and be very alert when numbers were low. This often prevented having guests in the home (Table 5, quote 2).

Furthermore, the spouses felt uncomfortable leaving the patient home alone and felt that it was unfair to the patient if they participated in a gathering with family or friends. As a result, they rarely did. The spouses expressed a need of their social network for supportive reasons, but at the same time they were so conscientious to respect the precautions stated by the HU that it hampered their social life.

**Discussion**
The caregiver role and the new responsibility, to a great extent, influenced the spouses’ everyday life and changed the structure of the partnership during outpatient management. Indeed the spouses had a hard time constantly being on call to assist the fragile AL patients.

The individualization in late modern society makes individuals, to an exceedingly high extent, responsible for their own health. This has carried over to the health care system, where patients are expected to take
responsibility for their own life including their illness and thereby to take an active part in the treatment hereof (Lupton, 1997, Glasdam et al., 2015, Vallgarda, 2007). The outpatient management of AL patients is an example of that. However, this study illustrates how difficult it is to make severely ill AL patients meet these expectations leaving the spouses to be the ones who actually take over management of and responsibility for the complex course of treatment.

A prerequisite for the outpatient management was that the health care professionals found the patient and spouse suitable for it. In this way the spouses were unknowingly required to take on the caregiver role, and their readiness and the spouses had the impression, that their efforts were taken for granted by the health care professionals. None of the spouses ever questioned or refused the caregiver tasks, although it was overwhelming and stressful. It seems that the spouses themselves expected to be responsible, active caregivers trying to live up to an unspoken late-modern ideal of relatives of cancer patients (Mol, 2008).

This study found that the overwhelming and pivotal role of the relative in ensuring the coherence of the outpatient care was similar to findings to a phenomenological interview study with 12 relatives to colon cancer patients in a fast-track program (Norlyk and Martinsen, 2013). It is noteworthy, that fast-track surgery is a program of shorter duration (Norlyk and Martinsen, 2013) contrary to the AL trajectory, which may indicate that the duration of treatment is not the key issue. This speaks to the point of a difference between the information provided by health care professionals and knowledge actually required and acquired by patient and spouse. The health care system may provide thorough information but the patient and the spouse need to live with and experience outpatient management before they can truly understand how profoundly the everyday life of the whole family is changed and challenged by the treatment.

An invisible hyper-awareness was a consistent state of being, apparent all the time, also when spouse and patient were apart. Spouses continuously checked and observed the patient day and night being anxious that the patient would contract an acute infection. Aspects of being alert and constantly monitoring patients have likewise been shown in a qualitative interview study with 17 partners and daughters of
chronic heart failure patients in an outpatient clinic (Strøm et al., 2015). It is natural to be alert in acute situations but with a patient suffering a long-term illness it seems to become a persistent state. This study suggests that such persistent alertness accounts for a large part of the spouses’ experience of burden. As a consequence of outpatient management of AL patients the observation part of treatment is transferred to the spouses, and they are not able to act as health care professionals, who are educated to differentiate between observing and being alert. And perhaps most importantly, they can never ‘just be relaxed’.

Empowerment is a process of mobilization and enhancement of an individuals’ own resources to enable them to feel in control of their own lives, to meet their own needs and solve their problems (Gibson, 1991). The process encompasses both the individual, institutional, organizational and social responsibilities. The possibility of refusing is not part of the concept. Creating a sense of empowerment in the spouses during the long and strenuous treatment trajectory is central, as it may provide a sense of everyday life as accomplished despite the uncertainty of treatment. The results of this study, however suggest that spouses did not feel well prepared to take on the tasks expected of them by patients, hospital and society. This in turn countered their ability to feel empowered by the outpatient management.

The feeling of responsibility and burdensome “work” experienced by the spouses was increased when they did not find the patient to be committed to the precautions outlined by the HU. However, the quality of the partnership between patient and spouse seemed highly important in this respect, as a sense of empowerment did seem to arise from the outpatient management in couples that managed to develop a sense of ‘we’ in relation to management; understanding management as a joint effort and venture. This corresponds to what is shown for relatives to patients with pre-dialysis chronic kidney disease in a qualitative interview study exploring empowerment in outpatient care as experienced by these family members (Nygårdh et al., 2011). The study described how being an involved participant, trusting in the health-care staff and having confirming encounters were central to the feeling of empowerment in relatives as well as patients.
Outpatient management seemed to contribute to the strengthening of the relations across the family, as it made it possible for the patient to spend more time with the family. This was valued by spouses as beneficial to the patient and the family as a whole. Previous focus group research with 16 relatives of mixed cancer patients from non-HU settings have also found that the relative came closer to the patient by spending greater amounts of time together and that it gave strength and meaning to the life of the relatives, even though it was hard to watch the suffering of the patients (Blindheim et al., 2013).

One randomized controlled trial with a complex intervention for caregivers to cancer patients found significantly better understanding of symptoms and side effects and that their information needs were more frequently met (Tsianakas et al., 2015). Confidence in coping improved, but the emotional wellbeing showed no difference from the control group. Focus group interviews with caregivers and health care professionals concluded that the intervention was accepted and feasible. Overall, the relatives may profit from specifically tailored interventions and specific focus from the health care professionals.

The interview method used in the study may have favored women (8 out of 11 participants) but no gendered variation was seen in the statements in our relatively small material. Based on the small size of participants in this study, it is not possible to generalize. However, our analytical engagement of a theoretical framework of everyday life allows for an analytical generalization to be made, which is common for qualitative research (Halkier, 2011).

The late-modern anticipations of patients and caregivers for self-care and responsibility in relation to own treatment is a key characteristic of outpatient management like the HU studied here. Based on the findings of this study, we find that spouses should to a higher degree be included as a focus point for the information initially given about the structure and demands of outpatient treatment. The health care professionals should pay attention to the spouses’ perspective and be aware of their burdensome role and give them a change to question the demands of the caregiver role.
Specific focus from the health care professionals on spouses and their particular challenges and needs is essential to ensure a sense of empowerment of the spouses and keep them resourceful and supportive to the patient throughout the illness trajectory. Ways to proceed with this could be a supportive/educative DVD, an accompanying booklet and group consultations inspired by the study by Tsianakas (Tsianakas et al., 2015).

Not all precautions taken in outpatient management are evidence based. A clinical reassessment of those could lead to a reduction in precautions, which in turn could relieve some burdens from the caregiving spouse, resulting in a better social life for the whole family.

Future interventions by health care professionals may support the relatives in identifying resources that they cannot find on their own. This is of the utmost importance in a time when outpatient management has become the state of the art treatment option in the case of AL and is to be introduced to other patient groups in the future.

In conclusion, this study contributes to our understanding of how spouses to AL patients in curative intended treatment experience the challenges arising during outpatient management in the perspective of everyday life. The study illustrates how the responsibility of the caregiver role affects everyday life of the whole family. The spouses had the impression that the health care professionals took their efforts for granted and the role as caregivers could not be questioned. The social life of the spouses suffered substantially due to the precautions stipulated by the HU and the expectations of time consuming and close collaboration between spouses and health care professionals. The partnership was challenged, but relations in the family seemed strengthened during the course of treatment.

The spouses’ caregiver role during outpatient management may be experienced as less burdensome if focus from the health care professionals is obtained.
Acknowledgements
The authors wish to thank the spouses of patients with AL who participated in the study for their valuable contributions in 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.

References


*Clin Adv Hematol Oncol, 11, 571-7.*
<table>
<thead>
<tr>
<th>Sample characteristics</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (27 %)</td>
</tr>
<tr>
<td>Female</td>
<td>8 (73 %)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 60</td>
<td>7 (64 %)</td>
</tr>
<tr>
<td>≥ 60</td>
<td>4 (36 %)</td>
</tr>
<tr>
<td><strong>Relationship to the patient</strong></td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>3 (27 %)</td>
</tr>
<tr>
<td>Wife</td>
<td>8 (73 %)</td>
</tr>
<tr>
<td><strong>Families with children (years)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 18</td>
<td>2 (18 %)</td>
</tr>
<tr>
<td>≥ 18</td>
<td>8 (73 %)</td>
</tr>
<tr>
<td>No children</td>
<td>1 (9 %)</td>
</tr>
<tr>
<td><strong>Time from patient diagnosis to relative interview (weeks)</strong></td>
<td>Mean 27.4; range 7-50</td>
</tr>
<tr>
<td><strong>Education</strong></td>
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<td>Skilled worker</td>
<td>6 (55%)</td>
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<td>5 (45%)</td>
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<tr>
<td><strong>Employment status</strong></td>
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</tr>
<tr>
<td>Retired</td>
<td>3 (27 %)</td>
</tr>
<tr>
<td>On leave because of partner's illness</td>
<td>1 (9 %)</td>
</tr>
<tr>
<td>On leave because of own illness</td>
<td>3 (27 %)</td>
</tr>
<tr>
<td>Quote</td>
<td>Spouse</td>
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<tr>
<td>1</td>
<td>10</td>
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<td>Quote</td>
<td>Spouse</td>
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</table>
| 1     | 8      | ‘I think, going through the procedures they [the patients] do, then you [the patients] can get a little – well – it takes less to – for you to get annoyed and such. You get more edgy and I think you can sense that. And that’s probably just how it is and then you just have to – well, hold your tongue’  
Group interview. Spouse to a man with acute myeloid leukemia. |
| 2     | 10     | ‘They [the health care professionals] can’t be blamed that they have a self-willed patient who once in a while does things he is not allowed to because now his patience can’t be stretched any further. That is where we had the largest conflicts. It is when he has done something that he is not allowed to do, then I get all hysterical because… I’ll be damned if he gets ill again, gets some bacterial infection.’  
Individual interview. Spouse to a man with relapse of acute myeloid leukemia. |
| 3     | 6      | ‘That’s what Thomas always says, “she will take care of it” – and I gladly do that, but I just don’t always want to – it’s just once in a while – then you become so full of it because then there are injections and then there is changing of this and that and then there are pills and it is a 100 times during that day – well, yeah, it’s not worse than that, but there is just so much, and then there is also just a bit with the blood sugar when steroids are given. It is just constantly every two or three hours something has to happen. And then just now and then you sigh deeply and say: Could you at least just once in a while try to take over a bit? ‘But are you tired of me?’ yes – no, that’s not what it’s about, right… But I’m also knocked over a bit… but then I take another round and try to steel myself again, right.’  
Group interview. Spouse to a man with acute lymphoblastic leukemia. |
| 4     | 7      | ‘Because the first time she was picked up [by the ambulance] I remember, when she was lying on the stretcher and was about to enter the ambulance. Then you stand there beside her, and then she says -looking me deeply in the eyes, then she says: ‘Now you are the one to take care of our children’. It really trickled down my spine. And I think I have a fairly good and strong mind.’  
Group interview. Spouse to a woman with relapse of acute myeloid leukemia. |
<table>
<thead>
<tr>
<th>Quote</th>
<th>Spouse</th>
<th>Statement</th>
</tr>
</thead>
</table>
| 1     | 11     | ‘She [daughter] has also spent much time at home with me, whenever it was possible. And she wants to – also on weekends with her boyfriend, and they have all been like that. [...] It was good to be together when dad was over there [at the hospital], right. [...] That has been really good, because we’ve talked much about it with each other, all the time and every time something happened.’
   Individual interview. Spouse to a man with acute myeloid leukemia.                                                                                                                                                                                                                                                                                                                                                     |
| 2     | 10     | ‘Just when he [the patient] got home he was standing there looking at the stairs and I could hear how he sighed and fought to ascend the stairs. To him it was climbing of the highest caliber. [...] Fourteen days later or something like that, then suddenly the oldest [boy] said: ‘Dad, have you recovered?’ [...] And Johan said no and asked why. ‘Well, you could follow me up the stairs this time’. So he registered this – and he notices a lot.’
   Individual interview. Spouse to a man with relapse of acute myeloid leukemia.                                                                                                                                                                                                                                                                                                                                  |
| 3     | 2      | ‘Well, a trajectory like this also does some marvelous things, as Jacob and his two siblings have developed the closest, most loving relationship that you can imagine. And now that he has also opened up to his grandchildren, really he has never been caring much for the kids. The boys, the kids, our children, it’s always been mommy. […] Really, it’s a new world that’s opened up to him, I must say. A good world. A world where he really feels that he means a lot to the family if just he allows himself to.’
   Individual interview. Spouse to a man with chronic myelomonocytic leukemia.                                                                                                                                                                                                                                                                                                                                 |
<table>
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<tr>
<th>Quote</th>
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<td>1</td>
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<td>‘The ill gets constant care, the ill all the time gets: ‘Oh you are so good at this, and well, and are told how marvelous it is and so on and so forth’ but the one standing at the sideline… […] What I want to say is that it’s not particularly easy to be a relative. And then it is really good that you have a network, and you have… In my case not friends but my family.’</td>
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<td>Individual interview. Spouse to a man with chronic myelomonocytic leukemia.</td>
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<td>Actually we don’t think that we have had many visits because, well first it was winter. And now with grandchildren, right, they catch all kinds of infections in school and kindergarten. […] And our daughter, she understood that very well and she didn’t think that they should come here if there was the least to worry about. And Christmas we celebrated by ourselves at home because, well his numbers were very low and then we wouldn’t risk anything. We had a nice Christmas on our own.’</td>
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<td>Group interview. Spouse to a man with acute myeloid leukemia.</td>
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Figure 1: Enrollment of relatives

Included patients (n=26)

Lost to follow-up (n=4)
- Died (n=2)
- Withdrew informed consent (n=2)

 Relatives assessed for eligibility (n=22)

Lost to follow-up (n=11)
- Not spouses (n=2)
- Declined to participate (n=2)
- Non-responder to invitation (n=6)
- Interviewed with patient (n=1)

Included relatives (n=11)

Group interview (n=8)
Individual interview (n=5)

Figure 2: Course of AL treatment

C= chemotherapy as inpatient; HU= Home Unit; Out.= outpatient follow-up; A-HSCT= allogenic hematopoietic stem cell transplantation