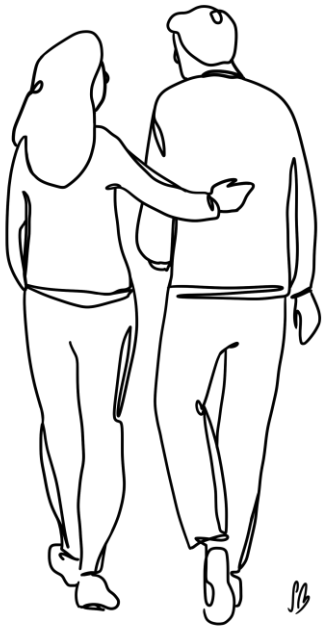
UNIVERSITY OF COPENHAGEN
FACULTY OF HEALTH AND MEDICAL SCIENCES



PhD thesis

Kristina Holmegaard Nørskov

Patient ambassador support in newly diagnosed patients with acute leukemia during the course of treatment

Perspectives and feasiblity of patient ambassador support in patients and their patient ambassadors

This thesis has been submitted to the Graduate School of Health and Medical Sciences, University of Copenhagen, Denmark on the 10 of July 2020

Patient ambassador support in newly diagnosed patients with acute leukemia during the course of treatment

Perspectives and feasiblity of patient ambassador support in patients and their patient ambassadors

PhD thesis

Kristina Holmegaard Nørskov

July 2020

Department of Haematology, Centre for Cancer and Organ Diseases, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark

Graduate program: Public Health and Epidemiology

Logo & design: Christine Meike
Illustration (front page): Selma Bess Møller

Author

Kristina Holmegaard Nørskov, M.H.Sc.

Department of Haematology, Centre for Cancer and Organ Diseases, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark

Email: kristina.holmegaard.noerskov@regionh.dk

Principal supervisor

Mary Jarden, associate professor

Department of Haematology, Centre for Cancer and Organ Diseases, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark

Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen N, Denmark

Primary co-supervisor

Dorthe Overgaard, associate professor

Department of Nursing, Faculty of Health and Technology, University College Copenhagen, Copenhagen N, Denmark

Co-supervisor

Kirsten Lomborg, professor

Department of Clinical Medicine, Aarhus University, Aarhus, Denmark

Steno Diabetes Center Copenhagen, Gentofte, Denmark

Lars Kjeldsen, head of clinic

Department of Haematology, Centre for Cancer and Organ Diseases, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark

Members of assessment committee

Chair:

Henrik Sengeløv, professor

Department of Haematology, Centre for Cancer and Organ Diseases, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark

Department of Clinical Medicine, University of Copenhagen, Copenhagen, Denmark

Opponents:

Charlotte Handberg, associate professor

Department of Clinical Medicine, Aarhus University, Aarhus N, Denmark

The Danish National Rehabilitation Center for Neuromuscular Diseases (RCFM), Aarhus C, Denmark

Helge Skirbekk, associate professor

Department of Health Management and Health Economics, University of Oslo, Oslo, Norway

Acknowledgements

This PhD was carried out at the Department of Hematology, Centre for Cancer and Organ Diseases, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark.

I would like to express my deepest gratitude to the following people who made this work possible.

To all the patients and patient ambassadors who participated in this study and who have shared their thoughts and feelings, experiences, and stories. Your valuable contributions made this study possible.

To my main supervisor, Mary Jarden, for your excellent guidance, for rewarding discussions, for always believing in me, and for encouraging me to do my best, and my co-supervisors, Associate Professor Dorthe Overgaard, Professor Kirsten Lomborg, and Head of Clinic Lars Kjeldsen, for your excellent guidance, support, encouragement, and expert advice.

To friends and colleagues in the Models of Cancer Care program for generating an inspirational and supportive environment with many rewarding discussions. A special thanks to my office mate, Iben Husted, for all our discussions and conversations about everything from peer-to-peer support to everyday family life.

To my loving husband, Christian, and our two children, Julie and Mikkel, for all their love and patience, reminding me that there is more to life than work. I love you to the moon and back!

To my parents, Stig and Jonna. Not only for their interest and support, but for letting me borrow their lovely cottage in Udsholt Strand, where most of this thesis was written.

To Director Karen Syrjala and Jean Yi for hosting me for an educational and inspiring research stay at the Fred Hutch Cancer Research Centre, Seattle, Washington, U.S.A. I look forward to our future collaboration, in new areas of supportive care.

This work was made possible through generous financial grants from the Novo Nordisk Foundation within the Models of Cancer Care program, the Aase and Ejnar Danielsens Fond and Einar Willumsen's Memorial Trust. Finally, a special thanks to LM Byg for supporting my stay at the Fred Hutch Cancer Research Centre.

Kristina Nørskov, July 2020

List of Original Papers

The thesis includes the following three papers.

Paper I Norskov, K.H., Overgaard, D., Lomborg, K., Kjeldsen, L., & Jarden, M. (2019).

Patients` experiences and social support needs following the diagnosis and initial treatment of acute leukemia: a qualitative study.
Published: *European Journal of Oncology Nursing. 2019; 41: 49–55*
doi:10.1016/j.ejon.2019.05.005

Paper II Norskov, K.H., Overgaard, D., Boesen, J., Struer, A., El-Azem, S.E.W.D., Tolver,

A., Lomborg, K., Kjeldsen, L., & Jarden. (2020). Patient ambassador support in newly diagnosed patients with acute leukemia during the initial treatment: a feasibility study.
In review: *Supportive Care in Cancer. June 25, 2020*

Paper III Norskov, K.H., Overgaard, D., Lomborg, K., Kjeldsen, L., & Jarden, M. (2020).

Patient Ambassador Support: experiences of the mentorship between newly diagnosed patients with acute leukemia and their patient ambassadors.
Published: *European Journal of Cancer Care. E-pub ahead of print. June 28, 2020*
https://doi.org/10.1111/ecc.13289

List of Abbreviations

AL	Acute leukemia
ALL	Acute lymphoid leukemia
AML	Acute myeloid leukemia
EORTC QLQ-C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire
FACT-Leu	Functional Assessment of Cancer Therapy – Leukemia HSCT
	Hematopoietic stem cell transplantation
GSE	General Self-efficacy Scale
HADS	Hospital Anxiety and Depression Scale
HCP	Health care professional
HGH	Herlev Gentofte Hospital
ID	Interpretive description
MDASI	MD Anderson Symptom Inventory
OUH	Odense University Hospital
PAM	Patient activation measure
PRO	Patient-reported outcome
QoL	Quality of life
RH	Rigshospitalet
SCT	Social comparison theory
ZUHR	Zealand University Hospital Roskilde

List of Tables

List of Figures

Table of Contents

1. Introduction

The outcome in patients with acute leukemia (AL) has improved considerably over the past four decades, masking important disparities, however, in that the outcome in the elderly or patients with relapsed or refractory AL remains poor.[1-3] Patients with AL are at increased risk of experiencing a substantial symptom burden during their treatment trajectory, many challenged physically, psychologically, and socially already from the time of diagnosis.[4,5] The acute onset of the disease, combined with the intensive treatment and an uncertain prognosis, results in a significant need for supportive care.[6-8]

Supportive care, including psychological support, rehabilitation, and social support, can prevent or reduce the adverse effects of AL and its treatment.[9] Nevertheless, there is a gap in providing supportive care despite robust emerging evidence on its effect.[9] Improved medical treatment, outpatient management of chemotherapy, and administration of patient care have made supportive care a subject of increased focus. This recognition is reflected in national cancer care programs in Europe.[10] In Denmark, the most recent program is the National Cancer Plan IV, which contains an initiative on administering treatment with chemotherapy or antibiotics in or close-by the patient's home.[11] This entails patients spending less time in hospitals than previously, which has several advantages.[12,13] Still, a report by the Danish Knowledge Centre for Rehabilitation and Palliative Care on cancer rehabilitation in Denmark emphasizes that a substantial part of the supportive care is often offered in hospitals and not in the community.[14] This creates an organizational gap in the provision of supportive care in patients with AL, highlighting the need for strategies addressing this gap in in this population.[9]

Social support has a demonstrated positive impact on psychological symptoms and health outcomes in patients with cancer.[15-22] Peer support is a type of social support that involves a cancer survivor providing psychosocial support to a cancer patient at an earlier stage in their cancer trajectory.[23,24] Most evidence on peer support is based on patients with malignant solid tumors but cannot be transferred to patients with AL.[25-28] In a Danish study, patients with AL identified a need for peer support during their disease trajectory and expressed a desire to be a peer supporter.[29] Thus, there appears to be a need for peer support, and given the increase in outpatient management or treatment outside the hospital, meeting this need can provide supportive care across sectors, independent of where patients receive treatment. The identification of this need inspired the design and conceptualization of this thesis, which aimed to generate knowledge on the experiences and social support needs of newly diagnosed patients with AL, and the feasibility of a peer support intervention in this patient group exploring their experiences with being mentored.

2. Background

2.1 Acute leukemia

The hallmark of AL is chromosomal translocations and genetic alterations involved in the differentiation and proliferation of either the lymphoid or myeloid precursor cells in the bone marrow that result in hematopoietic insufficiency.[30] AL is classified into subtypes of acute myeloid or lymphoid leukemia (AML/ALL), each with distinguishing characteristics affecting both prognosis and treatment.[31]

2.1.1 Epidemiology

AML is the most common AL in adults, with an incidence in Denmark (2018) of 230 per year and a median age of 71 years at diagnosis.[2,32,33] The overall five-year survival rate for AML is 19.3% (95% CI: 17.0-21.7) and for younger patients (<60 years) 50.4% (95% CI: 44.2-56.3).[33] ALL, the most common cancer in children, follows a bimodal distribution, with a peak in childhood (80%) and again midlife.[34] The incidence of ALL in Denmark (2018) among adults is 18 per year, and the median age at diagnosis is 50 years.[33] The overall five-year survival rate for ALL among younger patients (<45 years) is 80.0% (95% CI: 74.4-86.0), while the rate for older patients (>45 years) is 50.1% (95% CI: 43.5-56.3).[33] The majority of AL cases appears as a de novo malignancy in previously healthy individuals, although there are some predisposing factors, such as an underlying hematological disorder, the consequences of prior therapy, genetic syndromes, ionizing radiation, pesticides, certain solvents or viruses.[2,30,31]

2.1.2 Treatment trajectory

Patients with AL are treated with various combinations of high dose chemotherapy.[1,32] It is beyond the scope of this thesis to describe all treatment strategies in detail. However, it does provide a general overview of the treatment for AML and ALL. In general, chemotherapy-induced bone marrow failure is more pronounced during AML treatment, with regards to both duration and depth, leading to more infectious complications in AML compared to ALL. Corticosteroids are an important treatment modality in ALL but not in AML, leading to more steroid-associated side effects in ALL.

The treatment for AML is often carried out in two stages: induction and consolidation, with the treatment trajectory determined by patient age, risk category, and functional status.[32] Intensive chemotherapy reduces the function of the bone marrow for three to four weeks, during which there is an increased risk of infection and bleeding.[31] In curative-intended treatment, eligible patients

undergo high-dose induction chemotherapy until complete remission, followed by consolidation therapy to maintain complete remission.[31] In intermediate-risk or high-risk patients, treatment is followed by allogeneic hematopoietic stem cell transplantation (HSCT), when a donor can be identified and comorbidity and age of the patient allows.[2,31,32] The first-line treatment for ALL takes place over two to three years and comprises four phases of intensive therapy: induction, consolidation, intensification, and maintenance.[1,31] Additional treatment is directed to prevent central nervous system relapse and, in patients with a high-risk disease or persistent minimal residual disease, HSCT is recommended.[1]

Treatment with HSCT has the potential to cure malignant hematological diseases.[31,35] The treatment consists of different conditioning regimens with total body irradiation and/or chemotherapy prior to HSCT in order to eliminate the patient's bone marrow cells and suppress the immune system, either partially or completely, before donor stem cells are given to the patient.[31] After two to four weeks, the bone marrow begins to produce new blood cells, during which time the patient is at a high risk of infection and bleeding.[36] Besides chemotherapy and total body irradiation, the curative principle is graft versus leukemia, where donor t-lymphocytes find and kill the malignant cells.[31] Associated with considerable mortality due to acute toxicity, infections, and complications, the treatment has nonetheless improved considerably as a result of improved individualized pre-transplant treatment, immunosuppressive medication, and improved antibiotics and antifungal medicine, together with better donor selection.[35] A frequent complication of HSCT is graft versus host disease, which occurs in both an acute and chronic form, which considerably affects the quality of life and survival of patients.[31]

The organization of AL treatment has changed markedly during the last decade, shifting from inpatient to outpatient management, with more treatment being administered at the patients´ homes.[12,37-39] Generally, newly diagnosed patients with AL receive their first cycle of chemotherapy and experience the subsequent cytopenia during hospital admission. However, some patients are already referred to outpatient management shortly after their first cycle of treatment. International clinical practice guidelines provide recommendations on the management of AL.[40,41] Thus, the treatment trajectory is close to identical across hospitals, though minor variations exist. In Denmark, the initial treatment and management of AL take place at local hematology departments. Treatment with HSCT is performed exclusively in a highly specialized HSCT ward, which, in Zealand, is at the Department of Hematology at Rigshospitalet (RH), which serve patients from the Capital Region of Denmark, Region Zealand and South Denmark Region.

2.1.3 Symptomatology

The AL trajectory differs from most cancers because it has an acute onset, with an immediate threat to life due to the intensive treatment, which has an unpredictable clinical course and substantial symptom burden.[6,42,43] Patients with AL experience multiple symptoms at various times during their treatment. The most frequent physiological symptoms are fatigue, pain, appetite loss, nausea, and vomiting.[44] A cross-sectional study from 2013 identified an average of nine physical symptoms and two psychological symptoms, where the majority of the patients were undergoing induction chemotherapy.[6] The most prevalent psychological symptoms included insomnia, worrying, difficulty concentrating, and feeling sad, whereas lack of energy, insomnia, and pain had the highest combined rating for severity, frequency, and distress.[6] Another cross-sectional study, from 2016, found clinically significant depressive symptoms in 17.8% of newly diagnosed patients with AL, of whom 40.4% were a moderate to severe degree.[43] Research has confirmed that patients with AL report symptoms of traumatic stress, which are linked to the degree of psychical symptom burden.[42,43,45] Additionally, psychological distress is linked with increased physical adverse effects, affecting their ability to manage their self-care and adjust to everyday life.[46] Therefore, significant disease and treatment-related symptom burden may hinder recurrence to prior levels of psychological and physical functioning, limiting sustainment of their social identity, autonomy, and everyday life.[6]

2.2 Supportive care in cancer

Supportive care is a fundamental aspect of health care and involves the provision of a wide range of health care initiatives designed to meet patient needs.[47] The National Cancer Institute defines supportive care as:

"Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment."[48]

During the years, supportive care in cancer has advanced in terms of aspects focusing on well-being and quality of life, including the development of appropriate psychosocial care and the maintenance of autonomy in patients.[49,50] Advancements in supportive care practice in patients with hematologic malignancies have improved, with an increasing number of patients receiving the majority of their treatment in the outpatient setting or at home with the implementation of home-based chemotherapy treatment.[13,38,50] This is essential as patients are more involved in their

own treatment, able to sustain everyday life, are more physically and socially active and report improved quality of life (Qol).[12,13,51] Conversely, these improvements entail limited time with health care professionals (HCP) and peers with similar diagnoses and experiences during their treatment trajectory. A cross-sectional study from 2015 found that hematological cancer survivors (n=715) reported "having someone to talk to who understands and has been through a similar experience" as a significant unmet need.[52]

2.2.1 Social support

The influence of the social networks on health outcomes has been of interest for more than a century. Émile Durkheim, who postulated in late 1800 that the migration of workers in industrial areas would influence social ties, leading to a loss of social resources, identified the association between suicides and fewer social ties.[53] Since then, social integration and social support have been widely studied as an important variable that influences health outcomes.[54]

Sheldon Cohen described social support as the process in which relationships can promote and influence health and well-being.[55] The process can be categorized into two groups, one that involves the social resources an individual perceives to be available or actually provided in the context of formal or informal relationships, while the other involves the health benefits derived from participating in social groups, e.g., self-concept, feelings of self-worth, and conformity in terms of behavioral norms.[55] Social support is typically separated into perceived and received support. The former is the perception of available support if needed, while the latter is the actual recent exchange of supportive resources.[54]

In patients with cancer, a high level of social support is associated with fewer psychological symptoms, improved mental health outcomes, and perhaps changes in the immune response.[15-22] Studies of patients with hematologic malignancies indicate that patients who have greater psychological distress are more likely to report problems with social functioning.[56-59] In addition, a longitudinal study from 2019 found a positive association between social support and QoL in HSCT recipients.[21] Therefore, social support may impact health outcomes by strengthening the immune function, and by improving coping, adherence and compliance, in addition to health behavior in general.[60] A crucial psychosocial factor is the availability or provision of social support from health professionals, own social network or peers with similar diagnoses and experiences. Peers have knowledge and experience that provide them with an in-depth understanding of stressful situations and their nuances.[54] The support they provide within the context of health care is called peer support.

2.3 Peer support

Peer support is a type of social support in which the people sharing common experiences or face similar challenges provide experiential, emotional, or informational support based on shared experiences.[24,61,62] Peers have firsthand knowledge of the disease, giving them the opportunity to provide support to another peer at an early stage of the disease trajectory. This experience-based perspective is often not available to people without a personal history with the disease, including their own social network and HCPs.[25,63,64] Peer supporters feel good by helping others because they have something to give, leading to a feeling of social usefulness that is sometimes accompanied by increased status.[61,65] The peer supporter is potentially empowered because, "I can´t be helpless, if I can help someone else".[61] Thus, the peer supporter may benefit from a shift in their role as "in need of help" to "being the one helping" as a role model. This means that they profit by solving their own problems in the process of helping others.[65]

2.3.2. The historical context of peer support

Peer support is an embedded part of human behavior when responding compassionately with an urge to help when we meet others who struggle with similar problems or challenges.[61,62] Evidence of the roots of peer support reach far back into the late eighteenth century at Bicêtre Hospital in Paris, where Jean Baptiste Pussin (chief physician) was cited in 1792 in a letter to Philippe Pinel:[66]

"…As much as possible, all servants are chosen from the category of mental patients. They are at any rate better suited to this demanding work because they are usually more gentle, honest, and humane."[66] *(p.1131)*

The early development of peer support was within mental health, but the professional health care community did not begin to take an interest in it until the early twentieth cenctury,[67] for example, with the development of Alcoholics Anonymous in 1935 in Ohio, USA, with other forms of self-help groups and movements later joining in.[24] It was not until the 1970s that the mental health service user movement began, but since then, the practice of peer support has increased exponentially.[24]

In a Danish context, peer support has expanded in the last decade, primarily within mental health.[68,69] Since 2015, the Danish Social Agency has allocated large amounts of funding for local projects aimed at studying peer support in the mental health services, many of which will come to fruition in the near future.[69] Peer support is also on the agenda within the somatic area in chronic diseases, for instance, spinal cord injury, heart disease, and kidney disease. Many of these peer support services are not scientifically anchored and are often organized within patient associations

or informally at local hospital departments. It is a challenge that the peer support services in the somatic area are not organized within a larger context, similar to what is done in the mental health services. This makes it difficult to identify what peer support is available across diseases, resulting in a lack of overview of the existing knowledge in Denmark.

2.3.3 Scientific overview of peer support

In patients with cancer, the evidence of the effect of peer support is growing, and the approach increasingly is recognized as embedded in supportive cancer care.[26] Cancer patients are interested in support from other patients with similar types of cancer and treatment.[70,71] Despite the digital era, a cross-sectional study from 2018 investigating patient preferences for participating in peer support identified great interest in the more traditional forms of peer support, like one-to-one and face-to-face support.[71] Therefore, understanding the barriers and preferences peers have for participating in peer support programs is essential. A systematic review from 2015 determining the benefit of one-on-one support programs in patients with cancer found high satisfaction in all identified studies, with benefits in psychological adjustment.[26] Additionally, a meta-analysis from 2018 evaluating the effects of peer-led supportive interventions for patients with cancer found small to moderately significant improvements relative to the control group when measuring coping, emotional health, QoL, and self-efficacy.[25] Thus, several systematic reviews confirm the high satisfaction and benefits of peer support but emphasize that the interventions varied greatly in terms of disease, severity, timing, intensity, duration, and provision (e.g. face-to-face, digital, group, and one-to-one).[25-28]

A qualitative study from 2018 explored the preferences and benefits of peer support in peer supporters, patients with cancer, and their relatives, and found that the peer supporters take on a semi-professional role, providing hope and inspiration for coping through their shared experiences, supplementing the patient's own social network.[72] Simultaneously, with the increased focus on the beneficial effect of peer support in the peer recipients, a knowledge gap regarding the impact on peer supporters has been identified.[64,72,73] A cross-sectional study from 2018 investigating the well-being of volunteers, with or without a history of cancer, identified higher psychological well-being than clinical and community samples.[64] Conversely, the oncology volunteers were less satisfied with their work and reported worse psychological well-being compared with volunteers with no history of cancer.[64] Finally, several systematic reviews confirmed a lack of information on peer training, supervision, demographic characteristics on peers, screening procedures, and matching of peer dyads.[25-28] Thus it is important to monitor the perspective of the peer supporter in regard to psychosocial impact. Still, there is limited knowledge on the motivation in volunteer

supporters, especially in the context of cancer and in survivors of life-threatening illnesses. Therefore, the motivation of the peer supporters participating in this thesis was investigated parallel to conducting the three papers in this thesis. The qualitative study from 2020 exploring the motivation to volunteer as a peer supporter for newly diagnosed patients with AL found that peer supporters were motivated by the creation of meaningfulness, in terms of their own course of the disease, which was established by the new role as a peer supporter.[74] The supporter role helped them facilitate a better post-cancer recovery while simultaneously instilling hope in the support recipients.[74] Understanding the underlying mechanisms in the motivation of peer supporters is crucial to recruiting, initiating, and retaining peer supporters in peer support programs.[75] Finally, knowledge of the motivation factors strengthens the current knowledge of peer support in patients with AL and significantly impacts the development of future peer support programs.

In sum, there is scientific consensus that future research in peer support interventions should consider the intensity and timing according to patient needs as well as in selecting peer supporters in terms of specific patient needs.[25,26]

2.4 Theoretical framework

The use of a theoretical framework to guide peer led supportive interventions leads to better health outcomes.[25,76] In this thesis, two theoretical frameworks guided the author: the stress-buffering hypothesis and social comparison theory (SCT).

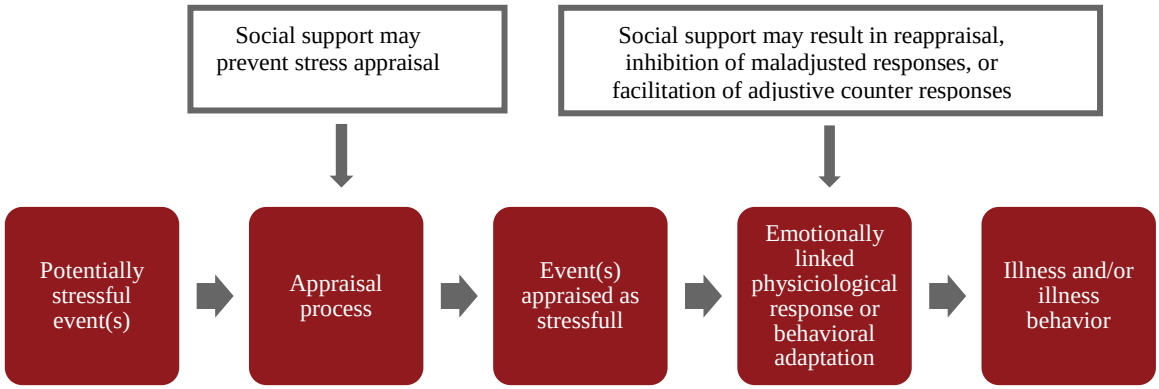
2.4.1 Stress-buffering hypothesis

One of the most influential theories explaining the positive association between social support and health outcomes is the stress-buffering model.[77] It proposes that social support protects or buffers the pathogenic effect of stressful events on coping appraisal and, thus, well-being.[55,77] The reduction of stress appraisal may be the result of the social support providing a distraction and reducing reactiveness to the stressor or healthful behavior.[77] The distinct feature in this model is that the support primarily is related to well-being in people under stress, where there has been an appraisal of the situation as threatening or demanding, without having an appropriate coping response. Stressful events challenge the coping abilities of the individual when multiple problems accumulate.[55,77]

Social support may play two possible roles in the causal association linking stress to illness (Figure 1).[77] First, social support may influence the appraisal process between the potentially stressful event and the reaction to the event.[77] Perceived social support is the perception that others will provide necessary resources, which may result in redefining the appraisal of the event as stressful

and/or strengthening the perceived coping ability preventing the event to be appraised as stressful.[77] Second, receiving a sufficient amount of social support may affect the experience of stress, resulting in a reduction or elimination of the stress reaction and the pathological outcome.[77]

Figure 1. The two ways social support interferes with the causal association linking stress to illness



The model is inspired by Cohen et.al (1985).[77]

Cohen and Willis suggest four possible resources for social support: esteem support, informational support, social companionship, and instrumental support.[77] Self-esteem support is when people experience that their self-esteem is enhanced by being accepted and valued for their worth, which may neutralize threats to self-esteem occurring under stress appraisal.[77] Informational support is the receiving of advice or guidance in defining, understanding, and coping with stressful events that help people to reappraise a stressor as benign.[77] Social companionship is when people perceive they have others with whom to attend social activities.[77] This support may reduce stress by facilitating distraction and a positive state of mind.[77] Finally, instrumental support is when material or practical resources are provided, leading to a reduction in stress by either solving a material challenge or by providing time for other activities.[77] For a buffering effect to occur, the coping requirements and the available support must match.[55]

This framework guided the design and conceptualization of the intervention in the thesis and helped the author in understanding the possible mechanisms of the impact of social support on health outcomes.

2.4.2 Social comparison theory

Leon Festinger (1954) introduced the influential development of SCT based on the premise that people are driven by a need to evaluate their abilities and opinions in order to be able to act in the world.[78] His theory has since been expanded by several theorists, with many focusing on social

comparison processes in health and illness.[79,80] In this context, SCT describes how people interpret health threats and adapt to serious illness by using comparisons with similar others to normalize their experience and reduce the threat.[80] An important aspect is an evaluation, "Can I do X?", which requires finding someone who has experience with X and learning about how they performed because their success signals the future outcome, but only if both are similar in other performances or social characteristics.[81] A distinct feature of SCT is downward and upward comparison.[82] Downward comparison theory is when people compare with someone who is in a worse state than themselves in order to cope with a threat, while upward comparison is when people compare with someone who is more fortunate than themselves, with the purpose of gaining inspiration, motivation, and information.[81] Thus, social comparison benefits various motives, including self-evaluation, self-enhancement, and common bonds.[81]

Cancer illness induces a threat to life and uncertainty about the future, causing people to use comparisons.[80] Several field studies emphasize that people want to affiliate with other people experiencing the same feelings, or who have been through the same trajectory as themselves.[80,81] This affiliation provides cognitive clarity, companionship, and experience-based information.[80,81] Some studies show that the mere fact that being able to compare with similar others improves the psychological adjustment, regardless of the type of comparison. Thus, benefits were derived with the use of either type of comparison.[81] These results have the potential to inform HCPs about effective models used in patient rehabilitation. SCT is relevant to preventive health beliefs, symptom assessment, and patient recovery and may have psychological benefits.[81]

SCT was used in this thesis to guide in understanding and interpreting the findings on patients threatened by their diagnosis with AL, as well as the benefits and challenges of peer support within a theoretical frame.

2.5 Conceptual clarification

In this thesis, peer support providers are called patient ambassadors and the peer support intervention is called patient ambassador support. A patient ambassador serves as a representative of the patient´s perspective.[24] The relationship between the patient and the patient ambassador can be seen as a mentorship, where a more experienced person helps to guide a less experienced person. The mentoring between the patient and the patient ambassador is a process that allows the informal transmission of knowledge and provision of psychosocial support during a sustained period of time.[24,83]

2.6 Rationale for the thesis

Previous research shows that newly diagnosed patients with AL experience a high disease and treatment-related symptom burden, resulting in a significant need for supportive care, although evidence on how they experience the onset of the disease and the initial treatment is lacking. In the context of improvements in outpatient management, it is paramount to gain a deeper understanding of their emotional and social well-being in coping with a life-threatening disease and to generate knowledge on their need and preferences for social support. Peer support is recognized as an approach within supportive care in patients with cancer. The existing evidence is heterogeneous regarding disease, methodology, and provision of support, but does not include patients with hematologic malignancies. AL differs from other cancer diseases in terms of the onset of the disease, intensity of the treatment, complexity of the illness, prognosis, and uncertainty about the future. As a result, existing knowledge may only be transferrable to a minor extent to patients with a life-threatening disease like AL. Therefore, the feasibility of peer support for patients with AL is warranted, which is why the results presented here will provide new knowledge on a model for supportive care that creates a partnership between peers in in the hematology setting.

3. Hypotheses

The papers in this thesis were based on the following assumptions or hypothesis:

Paper I — It was our assumption that newly diagnosed patients with AL were burdened by the acute onset of the disease and its significant symptom burden, affecting their psychological and physiological well-being, thus increasing their need for social support, especially from peers with a similar disease and experiences.

Paper II — We hypothesized that patient ambassador support was feasible and safe in newly diagnosed patients with AL and their patient ambassadors.

Paper III — It was our assumption that patients with AL and their patient ambassadors would benefit from a mentorship during patient ambassador support and, although this would cause challenges, the benefits of the support were expected to be more significant.

4. Aims

The overall aim of this thesis was to generate research-based knowledge on the feasibility of a peer support intervention in newly diagnosed patients with AL and to explore the experiences and perspectives of patients and patient ambassadors following their participation in a peer support program.

The specific aims were to:

Paper I — To explore how newly diagnosed patients with AL experience the diagnosis and the initial treatment, and to illuminate their need and preferences for social support.

Paper II — To evaluate the feasibility of patient ambassador support in newly diagnosed patients with AL during the initial treatment.

Paper III — To explore how newly diagnosed patients with AL and their patient ambassadors experience the mentorship during patient ambassador support.

5. Methods

5.1 Design

This thesis applied a multimethod design in that both qualitative and quantitative methods were used to strengthen the types of data material and to adequately answer the research aims (Table 1).[84] The three papers are included as appendices.

Table 1. Overview of study designs

	Paper I	Paper II	Paper III
Design	Qualitative	Feasibility study	Qualitative
Research methodology	Hermeneutics		Interpretive Description
Setting	RH, HGH, OUH	RH, HGH, ZUHR	RH, HGH, ZUHR
Sample (n)	18[a]	36 [a]/25[b]	28[a,b]
Data collection	Semi-structured interviews	Questionnaires	Semi-structured interviews
Test time points		Baseline, 12-week and 24-week follow-up	
Instruments		HADS, FACT-LEU, EORTC QLQ-C30, MDASI, PAM, GSE	
Data analysis	Thematic analysis	Descriptive and linear mixed effects models	Thematic analysis

[a]Patients; [b]Patient ambassadors; RH: University Hospital of Copenhagen, Rigshospitalet; HGH: Herlev and Gentofte Hospital; OUH: Odense University Hospital; ZUHR: Zealand University Hospital, Roskilde; HADS: Hospital Anxiety and Depression Scale; FACT-LEU: Functional Assessment of Cancer Therapy - Leukemia; EORTC QLQ-C30: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire; MDASI: MD Anderson Symptom Inventory; PAM: Patient Activation Measure; GSE: General Self-efficacy Scale

5.1.1 Qualitative approach

In papers I and III, qualitative methods were chosen in order to understand the human experiences and human actions in the social world and, in that way, to develop an understanding of the phenomena under study.[85] Paper I aimed to gain a deeper understanding of the experiences of newly diagnosed patients with AL and to be able to comprehend their need and preferences for social support. Paper III aimed to explore and understand the perspectives of patients and patient ambassadors of the mentorship in patient ambassador support in order to gain new knowledge and insight into this support. Hermeneutics was the theoretical approach in Paper I and interpretive description (ID) was applied as a methodological framework in Paper III.[86,87] The qualitative

interviews were analyzed using Braun and Clarke's thematic analysis approach,[88] Subsequent sections describe the qualitative research methodology and methods used.

5.1.2 Feasibility approach

In cancer research, the goal is to implement evidence-based interventions that are effective. Intervention efficacy involves testing the outcomes under ideal circumstances, which is in contrast to intervention effectiveness studies evaluating the success in real-world, non-ideal conditions.[89] The UK's National Institute for Health Research distinguishes between feasibility and pilot studies.[90,91] The former examines whether the study can be done, while the latter represents minor versions of the primary study.[90,91] Thus, feasibility studies are intended to evaluate the process of developing and implementing the intervention and to determine whether efficacy testing should be recommended.[89] The feasibility of the intervention in this thesis is relevant because no previously published studies have investigated this specific intervention within this population.[26,28]

5.2 Patient involvement

There is a growing consensus about the importance of involving patients in health care services.[92] The involvement of patients in health research is one of several ways to engage patients in health care.[93,94] Their personal experiences with disease and treatment contribute knowledge and perspectives often not available to researchers. Thus, involving patients in health research has the potential to help researchers "do the right research" and "do the research right", in an effort to improve quality, feasibility, and the translation value of research.[93] Several benefits have been described, including improved credibility of results, higher rates of enrollment and retention, securing of funding, designing of protocols, selection of outcomes, and improved translation into practice.[93,95-98] The challenges most commonly described are related to the scientific and ethical conflicts involved in the protocol design, difficulty recruiting a diverse and representative sample, disseminating research findings too early, and to the additional time and costs due to the practical aspects of involving patients in the research process.[98]

Patient involvement may help identify and prioritize topics for the research agenda. Thus, the idea and inspiration for the development of this protocol was a patient involvement study conducted at Copenhagen University Hospital, RH that examined the need for new approaches to support newly diagnosed patients with AL.[29] The study identified a need for support from other patients with a similar diagnosis but they also had the resources to help other patients going through treatment, despite their own reduced physical energy.[29]

5.2.1 Patient advisory group

The protocol of this thesis was developed after consultations with an established patient advisory group comprising volunteer patients with AL diagnosed more than one year ago and recruited from the Department of Haematology, RH; Herlev and Gentofte Hospital (HGH); and Zealand University Hospital, Roskilde (ZUHR), which serve the Capital Region of Denmark and Region Zealand. They were primarily recruited using posters and flyers at the three hematology departments. The advisory group consisted of seven members (Table 2), who met quarterly for two hours from May 2017 to October 2019.

Table 2. Overview of members of the patient advisory group

Member no.	Sex	Age in years	Diagnosis	Month since diagnosis	HSCT
1	Female	59	AML	276	Yes
2	Male	47	APL	36	No
3	Female	51	ALL	52	Yes
4	Female	51	AML	96	Yes
5	Female	39	AML	120	Yes
6	Male	69	AML	48	Yes
7	Male	27	ALL	60	No

AML: Acute myeloid leukemia; APL: Acute promyelocyt leukæmi; ALL: Acute lymphoid leukemia; HSCT: Heaemopoietic stem cell transplantation

They signed a confidentiality statement, and in collaboration, we developed a commission for the group. The purpose was to contribute to the development of the protocol, specifically in paper II, including conceptual clarification, recruitment procedures, design of the intervention, selected outcomes, and interpretation of selected data through formalized focus group interviews. More importantly, they contributed to the development of the patient ambassador training program in which they were asked to participate or teach. One patient ambassador (no. 2) participated in teaching because he had been in the patient advisory group since the beginning. In Paper I, five members of the patient advisory group were recruited to participate in a selected part of the analysis, for which they provided signed informed consent. The purpose of involving the members was to further validate the analysis and interpretation of data.

5.3 Qualitative research methodology

The research methodology is the strategy behind the use of a specific method informed by a theoretical perspective. The theoretical approach used in Paper I was Hans-Georg Gadamer´s philosophical hermeneutics, and the methodological framework used in paper III was Sally Thorne´s interpretive description (ID). In qualitative research, the pre-understanding of the researcher has a central meaning.[85,99] According to Gadamer, our understanding and interpretation of meaning will always be based on an already existing pre-understanding of the world.[86] Thus, the pre-understanding is inevitable as it is embedded in the world with understanding and meaning.[86] Thorne emphasized that the pre-understanding is an avoidable part of our understanding and knowledge as nursing researchers and can beneficially be used actively.[87] The initial pre-understanding of the author in this thesis included knowledge about the treatment and care of patients with AL as a clinical nurse specialist at the Department of Hematology, Copenhagen University Hospital, Rigshospitalet. The knowledge and professional background of the author helped in the process of framing the research aim of relevance and entailed access to the field, which was helpful in terms of gaining focus, understanding the essence of the experiences participants described, and getting the participants to elaborate on their thoughts.

5.3.1 Hermeneutics (Paper Ⅰ)

Gadamer (1900–2002) wrote in his magnus opus, *Truth and Method*, that hermeneutics is not a methodology of the human sciences and does not apply a distinct method but rather insight into how to achieve understanding and the process in which to gain new knowledge.[86] Still, Gadamer later outlined how philosophical hermeneutics might be applied as a methodology in research where science must arise from practice and be related back to practice.[100,101] According to Gadamer, humans are an interpretive being, and the human existence expresses itself through language and action.[86] The hermeneutic circle is a fundamental principle that everyone will always be a part of, and it constitutes the structure through which we understand and interpret the world.[86] It is an endless process, with a circular movement between the interpreter and the object, where the interpreter is an active partner in the creation of meaning.[102] The horizons of understanding constitute pre-understanding and prejudice. Pre-understanding is our former understanding, and prejudice is the knowledge and experience we bring to the process of our understanding of the world.[102] The fusion of horizons is the movement between the part and the whole, the subject and the object.[102] Constant interpretation of the world expands and differentiates the horizons of understanding that result in new experiences and awareness.[102] Openness and the ability to ask

questions play an important role, also if the previous understanding exceeds shifts in the horizon.[102] According to Gadamer, we need to continue to interpret and ask questions until an adequate understanding is reached.[86] Philosophical hermeneutics was chosen as the theoretical approach in Paper I because interpretation and the understanding of the world are accomplished based on what we know beforehand and because in-depth understanding of the phenomenon was sought.[100]

5.3.2 Interpretive description (Paper Ⅲ)

ID, a qualitative inductive non-categorical approach to nursing research, draws upon methodological principals developed by various social scientific traditions, such as grounded theory, naturalistic inquiry, ethnography, and phenomenology.[87] The qualitative *descriptive* in ID builds on inductive reasoning, from specific observations to generalizations of patterns or theoretical constructions, bringing the phenomena to the audience.[87] The *interpretation* in ID locates the research within human social phenomena, with inspiration from the formal interpretive hermeneutic tradition.[87] The ambition is to go beyond "pure" descriptions and seek to discover associations and patterns within the described phenomenon. The strategy for using ID is underpinned by three elements that take their point of reference in practice based on: 1) real-world origin, 2) existing knowledge and evidence, and 3) receptiveness of the audience.[87]

ID was chosen as the methodological framework for three reasons. First, the research origin is based on clinical practice. The main reason for choosing ID was that the overall thesis originated from clinical practice, since the idea and inspiration were a result of the PIRE study, where patients described their research priorities based on their experiences from clinical practice.[29] ID requires that produced knowledge is reinstated into clinical practice.[103] Paper III aims to inform and improve clinical practice, which leads to the choice of ID as a framework. Second, the researcher's foreknowledge is acknowledged. In ID, the author´s theoretical and practical knowledge within the clinical field is recognized instead of being seen as a limitation.[87] Third, ID encourages incorporating more than one perspective in the research aim. The possibility of plural perspectives in the research aim was essential because the participants described their experiences within the same social phenomenon, allowing the results to inform and be reintegrated into clinical practice to a higher degree.

Although ID studies do not contain a methodological prescription, several elements can advantageously be included.[87] These elements were implemented in the development, carrying out, and analysis of Paper III. In ID methodology, the scaffolding of the research study is of significant importance in relation to the theoretical foundation and the position of the author.[87] Due to the existence of previous literature reviews on this specific research aim, the author

conducted an updated literature search to justify the clinical relevance. The knowledge gained guided the development of the initial intervention (Paper II) and later that of the interview guide for patients and patient ambassadors (Paper III). The researcher plays an active role in the research process in qualitative research methods.[85] The researcher's pre-understanding provides a useful platform from which to design the study, and the clinical experience of the author as a clinical nurse specialist is therefore useful in orienting the research. In line with ID, the framing of this thesis included a research plan with stringent details on design and how to enter the field. Strategizing a credible study in ID includes various sampling approaches, depending on the theoretical, whole population of interest.[87] Purposive sampling was chosen to enhance maximal variation and the selection of information-rich cases.[103] There are no directives regarding sample sizes, although ID aims to use bigger sizes than traditional qualitative studies.[87] The adequate sample size used in Paper III was thus guided by information power described later in the thesis.[104] In accordance with ID, inductive concurrent data collection and analysis was applied to allow studying constructions that were socially composed.[87] As a novice qualitative researcher, the author sought a structured stepwise analysis process and, therefore, applied thematic analysis.[88] In line with ID, the data analysis began early, was immersive, and involved developing a sense of the whole. This was achieved by repeatedly listening to the interviews or reading transcriptions throughout the data analysis. Additionally, the transcripts were coded broadly to reduce premature coding and to maintain options and a general view of the material.

5.4 Setting

The empirical studies took place at four departments of hematology: Rigshospitalet (Papers I-III), HGH (Papers I-III), ZUHR (Papers II, III) and Odense University Hospital (OUH) (Paper I), which serve the Capital Region of Denmark, Region Zealand and South Denmark Region. Each of the sites has in-and out-patient wards that are connected.

The treatment trajectories of the participants in the thesis across all sites are close to identical because they follow international clinical practice guidelines on treatment and management recommendations.[40,41] Thus, the supportive care practices at the included hematology departments have, to a great extent, been managed in similar ways in a safe and feasible outpatient setting, with more treatment taking place outside the hospital in the patients' homes. Minor variations, however, were identified within the departments in terms of when the patient was transferred from in- to out-patient management. Compared to HGH, ZUHR, and OUH, RH transferred patients earlier in their treatment trajectory to out-patient management, in some cases already during induction chemotherapy. When patients are transferred to out-patient management, they receive supportive

care and their treatment together with other patients with similar diagnoses but who are in different places in their treatment trajectory. This was the case, with the exception of patients going through the initial treatment of AL, where HGH and ZUHR have treatment units that allow patients with AL to sit with other patients with similar diagnosis and who are at approximately the same place in their treatment trajectory.

5.5 Sampling and recruitment

The sample in Papers I-III in this thesis was identified from two categories of participants: patients (Papers I-III) and patient ambassadors (Papers II, III). The sampling of patients (Paper I, III) and patient ambassadors (Paper III) was planned as purposive to achieve maximal variation and information-rich interviews, just as sampling continued until diversity was reached.[87] The adequate sample size was also guided and evaluated using information power, with the impact of aim, sample specificity, applied theory, dialogue, and analysis strategy.[104] Paper II used convenience sampling, which is nonrandom sampling where participants who meet the inclusion criteria are included.[105]

Inclusion criteria applicable for all three papers were: age $\geq$18 years and able to read and speak Danish, while the exclusion criteria were: unstable medical disease (relapse, refractory disease), psychological conditions (delirium, severe depression, dementia), more than two weeks of hospitalization in intensive care unit, and transition to terminal care. The time of diagnosis was determined from the day the participant received information about the AL diagnosis. Changes in medical conditions in both types of participants were detected and registered in REDCap by the author and the project nurses at each hematology department (Paper II).

Inclusion criteria for Paper I were that four to sixteen weeks had passed since the patient was diagnosed with AL. In Paper I, the author assessed 20 patients for eligibility, two of whom were excluded due to unstable medical conditions with refractory AL. No patients declined to participate, which means that the sample comprised 18 patients (n=8 males, n=10 females), aged 19–72 years (mean age: 52), with AML (n=13) and ALL (n=5) (Paper I, Table 2).

Inclusion criteria for Paper II were that patients had received information about their diagnosis with AL within two weeks, while patient ambassadors had to be within a minimum of one year from diagnosis with AL and in complete remission. In Paper II, 62 patients were assessed for eligibility, nine of whom were excluded due to not receiving intensive chemotherapy (n=5), had insufficient Danish (n=2), or missed study inclusion (n=2). Seventeen patients declined participation due to lack of physical or mental strength, had a large social network, had co-

morbidities, did not want to be immersed in their own disease, or did not want to be involved with unfamiliar parties. The total sample consisted of 36 patients. In all, 82 potential eligible patient ambassadors were approached, 35 of whom agreed to participate, of whom 25 were included in the intervention (Paper II, Figures 1 and 2).

Inclusion criteria for Paper III were that patients and patient ambassadors had completed participation in the intervention within the last two weeks. In Paper III, the author assessed 22 patients for eligibility, seven of whom were excluded due to unstable disease (n=1), terminal care (n=1), death (n=3), no established contact (n=1), or relapse (n=1). One patient declined to participate due to a lack of motivation, and the sample consisted of 15 patients. A total of 14 patient ambassadors were assessed for eligibility, none of whom were excluded. One patient ambassador declined to participate due to lack of motivation, and the sample consisted of 13 patient ambassadors. Overall, the sample consisted of 15 patients and 13 patient ambassadors (Paper III, Tables 3 and 4).

5.5.1 Recruitment

All eligible patients (Papers I-III) were approached and recruited by the author, either in the in- or outpatient clinic at the departments of hematology. The patients received oral and written information about the study, and all included patients provided written informed consent.

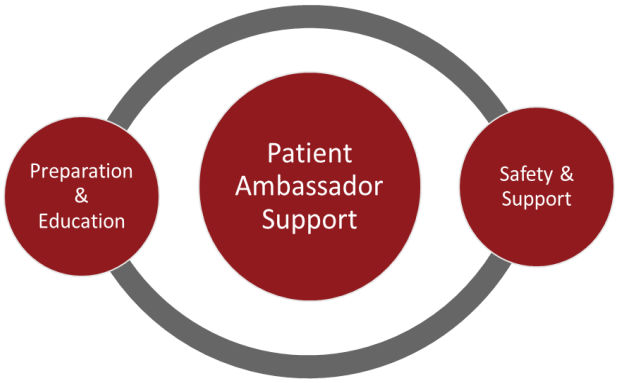
In Paper II, in cooperation with a graphic designer, the author designed a professional logo, study pamphlet, study poster, business card, and stickers (Appendix I) to send a clear signal that the study was well planned and safe to participate in, an aspect the patient advisory board assessed as important due to the patients' vulnerability. Before the intervention, all eligible patient ambassadors (Papers II, III) were recruited using two simultaneous approaches because various features of voluntariness and readiness are prevalent in the recruitment and selection process. Voluntary enrollment was crucial, while readiness was of significant importance in order to protect the patients but to also to protect them from taking on the role of patient ambassador without the necessary strength and resources. First, the primary physician and the author selected and approached eligible patient ambassadors by phone or mail, which included an invitation with a short description of the study. Second, recruitment posters and flyers were used in the hematology departments and the patient association for lymphoma, leukemia, and myelodysplastic syndrome. The majority of the enrolled patient ambassadors were recruited at their respective department of hematology through their primary physician and the author. Finally, the author screened eligible patient ambassadors who applied for enrollment for their appropriateness by doing a thorough telephone interview and in corporation with the primary physician. The screening focused on a

description of their own disease trajectory and social support needs, as well as their motivation, thoughts, and worries about being a patient ambassador. The screening did not lead to the exclusion of any patient ambassadors. Included patient ambassadors provided written informed consent, were obligated to sign a confidentiality commitment, and provided demographic information on age, sex, diagnosis, treatment, interests, work, education, and social conditions. The last-mentioned item was requested in order to obtain a good match with included patients.

5.5 Intervention

The intervention, which consisted of three components: 1) preparation and education, 2) patient ambassador support, and 3) support and safety (Figure 2), was developed based on the existing evidence and literature on peer support in cancer research and in close cooperation with the project psychologist, who has extensive experience with the education of peer supporters in psychiatry. Finally, the patient advisory board was involved in the development and planning of the intervention.

Figure 2. Components of the intervention



5.5.1 Preparation and education

The education of the patient ambassadors was crucial to ensuring that they were prepared for their new role as peer supporters and had sufficient knowledge specific to managing their new role. Thus, patient ambassadors were required to attend a six-hour educational program that was made available four times over six weeks in different locations in Zealand to ensure that they were

trained more or less simultaneously (Appendix I). To provide a well-thought-out, systematic, and well organized program, careful consideration of the didactic aspects is essential.[106] It is important that the teaching is individualized, meaningful, and makes patients feel they are learning something.[106] Hence, an educational program must be tailored to be important for the patients. Therefore, the patient advisory board contributed to the development of the educational program, specifically regarding what knowledge and resources they felt were necessary to perform the role of patient ambassador. Involving patients in the development of the program also contributed to the teaching being relevant and meaningful.

Didactics comprise the deliberations teachers have before teaching and the underlying theoretical considerations.[106] During pedagogic interventions in the health care system, applying a classic didactic model comprising the following seven considerations is useful: objectives and goals, participant prerequisites, relationship, content, teaching method, practicalities, and evaluation.[106] Table 3 describes how the educational program was implemented based on these considerations. Additionally, the educational program was developed using critical pedagogy, which holistically facilitates health education, actively engaging learners.[107] The three-phase model of pedagogy was developed based on Paulo Freire's theory on supporting learners to develop critical health literacy.[108] According the World Health Organization, Health literacy represents:

"The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions."[109]

Critical health literacy is the highest of the three levels concerning advanced cognitive skills which, together with social skills, are used for critical analysis of information.[109] This information can be used to take control over life-events and situations.[109] The three-phase model consists of: listening and naming; dialogue and reflection; and the promotion of transformative social action.[108] Listening and naming support the learners in using knowledge of their own experiences and daily life by listening and discussing.[107] Dialogue and reflection are the key components in the next phase, where the learners are encouraged to name and challenge their ideas and practices by sharing experiences and developing social progress plans to address these problems.[107] In this process the teacher becomes a co-learner who provides the learners with ownership and

engagement.[107] Finally, the promotion of transformative social action involves learners reflecting on their actions through practical training.[107]

Table 3. Overview of didactic considerations in planning of educational program

Didactic considerations	How it was implemented
Objectives and goals	The objectives and goals of the educational program were developed in cooperation with the patient advisory group and based on the principles of the three-phase model of critical pedagogy which focuses on learners engaging actively through listening, dialogue and reflection.
Participant prerequisite	The participants prerequisite was mapped during the beginning of the educational program as they were asked to describe their motivation and personal experiences being diagnosed with acute leukemia and going through treatment, and how they have needed support during this period.
Relation	The relation between the teacher and the patient ambassadors was important, and therefore all teachers participated during the whole day of teaching. This was important as the teachers wanted to hear what was important for the patient ambassadors, what was their story and what did they worry about.
Content	The patient advisory board was involved in the development of the main themes of the educational program, and in cooperation with the psychologist, who had extensive experience with peer support educational programs, the primary themes of content was developed. The content of the main themes was based on the three-phase model in that the patient ambassadors' narratives, earlier experiences, thoughts and reflections were used actively, additionally through exercises.
Teaching method	The teaching was planned based on the three-phase model which involve teaching where those who are being taught are involved actively both in discussions, sharing narratives and group exercises. In order to make sure that everyone understands and achieve the objective of the program, the teaching is organized with continuous evaluating and accumulating by using open questions following each main theme.
Practicalities	The educational program was deliberately conducted outside the hospital property which was a specific wish from the patient advisory board. The different locations were chosen because they had the suitable physical settings with round tables or multiple rooms where the it was possible to carry out group discussions. Eating lunch together was also important for the building of relations. During the lunch it was expected that the discussions and exchanging experiences would continue and therefore time was allocated for this specifically.
Evaluation	The educational program was evaluated orally and in writing following the program, and since some members of the advisory board participated in teaching, evaluation was also carried out during these meetings. Finally, the program was evaluated among the teachers at the end of each session in order to implement changes if necessary.

The educational program consisted of the following themes: fundamental principles of peer support; an update on disease and treatment; lived experience; interpersonal communication principles and methods; building supportive relationships; limits and boundaries. Table 4 provides an overview of the training program and a detailed description of the themes.

Table 4. Overview of training program for patient ambassadors

Knowledge			**Skill development**		
Fundamental principles of peer support	Update on disease and treatment – acute leukemia	Lived experience – life history and narratives	Interpersonal communication principles and methods	Building supportive relationships	Limits and boundaries
Peer support is about understanding another´s situation empathically through shared experiences. The support can occur either in a group or one-on-one, and may be emotional, informational, practical, and social. Peer support values and ethics ensure a high standard of support and add safety for both peer providers and recipients.	The curative regimens have, to a limited extent, changed, although the supportive care has improved significantly, with patients receiving the majority of their treatment in the outpatient setting. Variations in relation to when peer supporters have been through treatment for acute leukemia makes familiarity with the entire disease and treatment trajectory essential.	Life history and narratives differentiate from purposive chronological conversations and the individual's own narratives are instead important, i.e. an understanding of oneself. When lived experiences are transformed in ways that they can be used to support others in their adaptive process, which is called experience competences.	Interacting and supporting others is a normal social function. People who have already been in supporting relationships discover an ability and a desire to help others. Good communication skills are important in building supportive relationships.	The peer support relationship is about empowering the peer, who will feel hopeful about the future. Their shared experiences help establish social relationships that enable peers to cope. Their personal experiences offer an emphatic perspective on living and surviving the disease.	Peer supporters will encounter both personal and role-oriented limitations and boundaries that they will have to assess and manage. Recognizing the vulnerability of both the peer and peer supporter, it is essential, to communicate about personal limits and boundaries to create a safe and trusting relationship.
Objectives: To gain a basic understanding of peer support, what peer support can do, and how peer supporter role can be developed in practice.	*Objectives:* To ensure peer supporters have equal information on the disease and treatment trajectory of acute leukemia, allowing them to follow their peers knowing where they are on the trajectory.	*Objectives:* To adopt life history narratives through their own narratives and to listen to others life history narratives.	*Objectives*: To enhance the natural approach of the individual and their awareness of potential pitfalls and to learn various communication strategies.	*Objectives:* To increase strategies for initial meeting, create an environment based on trust and openness, establish when to share aspects of their own experiences, and how to end the relationship.	*Objectives*: To understand the role as peer supporter and the implicit limitations and boundaries, to discuss personal limits and boundaries, and to identify when boundaries have been crossed and how to respond.

The training included discussions in small groups and in plenum, where participants were encouraged to discuss and reflect on their personal goals, motivation, and concerns about volunteering as a peer supporter. The teaching was provided by the author, project nurses, and project psychologist, each with a designated teaching role. The author was responsible for providing an introduction to the study and discussing the fundamental principles of peer support, while the project nurses were responsible for providing an update on disease and treatment for acute leukemia, and the project psychologist was responsible for the rest of the program (Table 4). Patient ambassadors who had completed the training program received a thorough information dossier with a checklist of comprehensive guidelines and a list of important and relevant actions in the role of patient ambassador, in addition to an obligatory documentation tool for use during the intervention (Appendix II).

5.5.2 Patient ambassador support

The intervention with patient ambassador support involved 12 weeks of support provided by a patient ambassador to a patient newly diagnosed with AL during initial treatment. Upon receipt of written informed consent, the author immediately assigned a patient ambassador to a newly diagnosed patient after careful consideration based on specific preferences from both the patient and the ambassador regarding sex, age, type of AL, and/or other factors individually mentioned prior to inclusion. The patient ambassador was given the patient's contact information, type of AL, and a short description of where the patient was in the treatment trajectory. The patient ambassador was instructed to make initial contact within 48 hours unless otherwise agreed. Patients were asked whether they initially preferred to be contacted by text message, phone, email, or in person. During the intervention, contact between the two parties was based on the patient´s individual needs and preferences. However, personal meetings were recommended to help develop their relationship and could take place anywhere, e.g. the hospital cafeteria, the hospital ward, or at home.

The author followed up on the initial and final contact, and during the intervention if necessary, by contacting the patient ambassador. The author did an oral evaluation with the participants after the final contact between the patient and the patient ambassador. The aim of the evaluation was to give participants the opportunity to spontaneously describe their experiences with the support, providing closure to their participation. Moreover, another aim of the evaluation was to monitor the safety of the intervention by identifying any adverse events or psychological reactions that had not already been detected during the intervention. The patient ambassador followed one patient at a time but had the opportunity to initiate support for a new patient after waiting at least four weeks between two patients. Patient ambassadors worked voluntarily but received a monetary incentive

for their participation of 130 euros for travel expenses for participating in the education program, supervision network meetings, and personal meetings.

5.5.3 Safety and support

Providing a high level of safety and support for patient ambassadors during the intervention was important. Previous one-on-one, peer-to-peer studies have not included peers in this category of life-threatening illness and unpredictable long-term clinical course, which are often experienced as traumatic. Thus, applying a psychological safety net for the patient ambassadors during the intervention was crucial, which is why network meetings scheduled every six weeks with supervision from the author and the project psychologist were available. During these network meetings, patient ambassadors had the opportunity to meet the other patient ambassadors who were also long-term survivors of AL, but more importantly, they were allowed to share experiences, solve challenges, and provide mutual support. In addition, they had access to individual supervision from the psychologist during the intervention. For the same reason, utilization of the individual support and supervision from the psychologist was one of the feasibility criteria (Paper II). Every contact the psychologist, project nurses, or the author had with the participants was documented directly online via REDCap, a secure registration system.

5.6 Data collection

This thesis is based on various research methods. Participant and disease characteristics were obtained from patients, patient ambassadors, and medical records. These included: age, sex, marital status, education, employment status, disease type and status, type of treatment received, and years' post-transplant. The primary outcome in Paper II was an evaluation of feasibility, and the secondary outcome was patient-reported outcomes (PROs). Data on feasibility were collected continuously during the intervention, and PROs were collected at baseline, 12 weeks and at the 24-week follow-up.

5.6.1 Semi-structured interviews (Paper Ⅰ, Ⅲ)

Semi-structured interviews were performed using an interview guide. The process of developing the guide began with mapping the research topic's landscape in an initial literature review, which was used to identify the current evidence and theoretical and analytical categories of research.[110] The goal was to identify key conceptual domains to base development of the guide on.

In Paper I, the guide was based on theory and existing evidence. The applied theoretical framework was Cohen and Wills' stress-buffering hypothesis.[77] The current evidence was on the experiences

of cancer patients and their social support needs during treatment, complemented by the prior clinical experience of the author, in order to identify the theoretical and analytical topics of research.[4,8,44,54,111-115] The guide covered four themes related to the experience of being diagnosed with AL and the patients' need and preferences for social support (Paper I, Figure 1). The interview preceded from an open-ended question, "How did you find out you were ill?"

In Paper III, the guide was based on theory and existing evidence. The applied theoretical framework of social psychology was again Cohen and Wills' stress-buffering hypothesis,[77] and Leon Festinger's SCT,[78,116] as well as the current evidence on peer support in cancer research.[23,26-28,72,73,83,117-119] Separate interview guides were developed for patients and patient ambassadors (Paper III, Tables 1 and 2). The guide for patients covered four themes related to their experience of the mentorship program during patient ambassador support. The interview preceded from an open-ended question, "What thoughts and considerations did you have before getting in contact with your patient ambassador?" The guide for patient ambassadors covered five themes related to their experience of the mentorship during patient ambassador support. The interview preceded from an open-ended question, "What motivated you to volunteer as a patient ambassador?"

The interviews were conducted at the participants' homes, at the research facility, or at the hospital in connection with a scheduled outpatient visit. The interviews were conducted by the author, lasted between 30 to 90 minutes, were digitally recorded, and transcribed verbatim.

5.6.2 Evaluation of feasibility (Paper Ⅱ)

Feasibility studies focus on the process of developing and implementing the intervention, and eight areas of focus are described as eight feasibility criteria.[89] These criteria are acceptability, demand, implementation, practicability, adaptation, integration, expansion and limited-efficacy testing. In Paper II, we adopted the relevant feasibility criteria and assessed the criteria shown in Figure 3. Additionally, evaluations were obtained from both patients and patient ambassadors covering satisfaction and influence on a scale from 0-10, where 0 was "not at all satisfied/no influence" and 10 was "very satisfied/great influence". Finally, the patient ambassadors kept a record of frequency, type, and themes of their communication with the patient.

Figure 3. Feasibility criteria

5.6.3 Patient-reported outcomes (Paper Ⅱ)

The selection of PROs was based on an evaluation of their ability to measure the phenomena of interest, validity, and their adaptation to the sociocultural context. Moreover, we selected PROs used previously in similar studies in the population with cancer to allow comparison of results. Finally, they were selected to reflect the participants' psychological health, quality of life, symptom burden, understanding of their own health, and coping appraisal. There was no validated social support questionnaire available in Danish at the time of assessment. To cover the level of social support, we included two QoL PROs that have a social support subscale.

Psychological well-being was assessed and measured using the Hospital Anxiety and Depression Scale (HADS), which is a brief 14-item self-report measure of anxiety and depression, ranging from 0-3, divided into two subscales for depression and anxiety, each computed as the sum of seven items.[120,121] Higher scores indicate higher symptomatology, and we applied cut-off scores of ≥8 for

each subscale.[120,121] HADS has performed well in assessing the symptom severity and caseness of anxiety and depression.[121]

Quality of life was assessed using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) and the Functional Assessment of Cancer Therapy – Leukemia (FACT–Leu). EORTC QLQ-C30 is a 30-item measure with 15 domains: one global QoL domain; five functional domains (physical, role, emotional, cognitive, and social functioning); and nine symptom domains (fatigue, nausea and vomiting, pain, dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties).[122] Questions are scored on a 4-point scale ranging from 1 = "Not at all" to 4 = "Very much".[122] The domain scales are transformed into a scale of 0–100, with higher scores indicating good QoL on functional domains, and a low score indicating a low degree of symptoms for symptom domains.[122] Designed for use in cancer patients, the measure has proven to have high sensitivity and specificity in patients with cancer.[122] FACT–Leu consists of 44 items using a core set of questions (Functional Assessment of Cancer Therapy – General, FACT-G) and a cancer site-specific leukemia subscale.[123] Questions are scored on a five-point scale ranging from 0 = "Not at all" to 4 = "Very much", and items are combined into the physical well-being, social/family, emotional well-being, functional well-being, and leukemia subscale with available total scores.[123] The scale is a valid, reliable, and efficient measure designed for use in patients with acute and chronic leukemia.[123]

Symptom burden was assessed with the MD Anderson Symptom Inventory (MDASI), which is a 19-item measure assessing the severity and interference of 13 symptoms (pain, fatigue, nausea, disturbed sleep, distress (emotional), shortness of breath, lack of appetite, drowsiness, dry mouth, sadness, vomiting, difficulty remembering, and numbness) and their impact in cancer patients.[124,125] Symptoms and interference items are scored on a 10–point scale ranging from absence of the symptom to symptom is "as bad as you can imagine".[124] The interference items indicate how much the symptoms interfered with daily life (work, general activities, walking ability, relationships with others, enjoyment of life, and mood).[124]

Patients' understanding of their own health and health care was assessed using the Patient Activation Measure (PAM), which is a 13-item measurement. Patient activation is defined as "an individual's knowledge, skills, and confidence for managing their own health".[126] PAM has been extensively validated, and PAM scores have been used to divide people into groups depending on activation levels.[127] These levels have been used to tailor care to a patient's activation level measured with PAM, resulting in improved values on clinical indicators, better adherence, hospital visits, and better self-

management behavior.[127] Sum scores are graded into PAM levels 1–4, with higher levels indicating better trust and competencies to cope.

Coping appraisal was assessed with the General Self-efficacy Scale (GSE), which is a 10-item measure with responses from strongly disagree to strongly agree. This scale reflects the strength of the individual´s GSE, with higher scores indicating a greater sense of self-efficacy.[128] The scale has demonstrated high validity and reliability across various research contexts and populations.[128]

5.7 Data analysis

5.7.1 Qualitative analysis (Paper Ⅰ, Ⅲ)

Data was organized and managed by the computer software package NVivo.[129] Thematic analysis was chosen because of its flexible approach and was applied in both Papers I and III.[88,130] In paper III, the analysis was conducted across both participant groups (patients and patient ambassadors) because they described experiences related to the same social phenomenon, patient ambassador support, and because of the aim to explore their experiences of this mentorship and bring the knowledge into clinical practice. Braun and Clarke's thematic analysis approach was applied to generate data, which could be communicated transparently to clinical practice.[88]

These six levels of thematic analysis were performed in accordance with Braun and Clarke:

Level 1: Data (interviews and notes on analytical insights) were transcribed consecutively into textual data and stored in NVivo. The author listened to or read the data to become immersed with the data and its depth and breadth. This familiarization with the data enabled a search for meanings and patterns to generate initial ideas for coding. In Paper III, this process was conducted continuously as data was collected, consistent with ID methodology.

Level 2: The initial codes were generated with a constant circular revisiting of the data. The complete data set was systematically and equally analyzed with the development of organizing data into meaningful groups in a hierarchical coding structure.

Level 3: The identified codes were then sorted and collated into potential themes. This process was done manually without NVivo using a blackboard and with each code noted on a piece of paper. A thematic map was developed illustrating the relationship between codes, themes, and level of themes in relation to the overall research question. Codes that did not belong anywhere were temporarily placed in a theme

called assorted codes. In Paper III, these outliers were, according to ID methodology, of interest as the author, as an applied researcher, needed to ensure that the findings did not ignore predictable items or outliers of possible relevance. The themes were inductively generated and therefore strongly linked to the data.

Level 4: All coded data extracts were reviewed for each theme separately and appraised for demonstrating coherent patterns. Themes were refined, some collapsed, and others broken into separate themes until a coherent pattern emerged. Subsequently, the thematic map was validated in relation to the degree of its accurate reflection of the meanings that appeared in the data set as a whole. This implied that the entire data set was re-read to ensure that the thematic map was grounded in the data.

Level 5: A detailed analysis was conducted for each individual theme that evaluated the story of each theme to fit into the overall story of the entire data set and in relation to the research question.[130] In this process, potential sub-themes were identified, giving structure and hierarchy of meaning within the data.

Level 6: The final analysis and manuscript preparation was carried out, describing a concise, coherent, logical, non-repetitive story of the whole data set within and across themes and subthemes.

The analysis was carried out by the author, while Mary Jarden and Dorthe Overgaard contributed with triangulation and consensus at level four to six. In Paper I, the analysis was further validated by members of the patient advisory group at level four during a focus group interview, where the author presented preliminary themes that were discussed and commented upon by the members based on their own experiences as patients with AL. The members found the themes and subthemes recognizable compared to their own experiences, further validating the results (Paper I).

5.7.2 Statistical analysis (Paper Ⅱ)

REDCap is a secure data capture platform for managing surveys and databases. Moreover, it was applied as an online file to register contacts between patients or patient ambassadors and either the author, project nurses, or psychologist.[131,132]

The demographic and clinical characteristics of enrolled patients and patient ambassadors were summarized using numbers and percentages for categorical variables. Note that the characteristics of patient ambassadors were included only once, regardless of the number of patients they followed. Follow-up data contains only data from participants who completed the intervention. The weekly number of contacts between patient and patient ambassador, as well as the topics

discussed, was summarized graphically. PROs were summarized using mean and standard deviation at baseline, 12-week follow-up, and 24-week follow-up. Official scoring manuals were used for the computation of subscales: anxiety and depression subscales of the HADS range from 0-21, subscales and symptoms of EORTC QLQ-C30 ranges from 0 to 100. The range of subscales from FACT-Leu were physical well-being (range: 0-28), social/family (0-28), emotional well-being (0-24), functional well-being (0-28), leukemia subscale (0-68), FACT-G total score (0-108), FACT-Leu scale (0-176), and FACT-Leukemia Trial Outcome Index (0-124). Average scores of 13 items measuring the severity of symptoms and six items measuring the impact of symptoms were computed from MDASI, resulting in two scores ranging from 0 to 10. Similarly, average scores of 10 items ranging from 1 to 4 were extracted from the GSE, and sum scores of 13 items (range: 13-52) were computed from PAM and used for grading into levels 1–4. In accordance with scoring manuals, missing items were handled by computing the sum scale score only if 50% of items for a scale were answered, with the exception of the GSE sum score requiring 70% of items to be answered, and the FACT-G total score allowing for only 20% missing items. Data from one item of the FACT-Leu scale was not collected and was treated as a missing value for all participants when computing the subscale score. To analyze changes between baseline to the 12-week follow-up and 12-week to 24-week follow-up, a linear mixed-effect model was used with a random effect of the participant and fixed effect of assessment time (baseline, 12-week follow-up, and 24-week follow-up). The Wald test was used to test the hypothesis that changes equal zero. P-values <0.05 were used to determine statistical significance. IBM SPSS Statistics for Windows version 25 and R were used to carry out data analysis.[133]

Sample size justification

When planning a clinical trial, it is important to consider and determine the sample size needed to be able to answer the trial research question.[134] The sample size should neither be too large or too small, and the sample size justification depends on whether the endpoint is dichotomous compared to continuous. Billingham et al. recommend in two-arm feasibility trials with a continuous endpoint, a median sample size of 30 in each arm.[135] Due to the prognosis and significant symptom burden in patients with AL, which result in the risk of high attrition, we determined that a sample size of 35 was sufficient in each group of participants.[135]

5.8 Ethical considerations

The three papers (I–III), were conducted in accordance with the Declaration of Helsinki and approved by the Joint Ethics Committee of the Capital Region of Denmark (approval no. H-17012104) and are registered with the Danish Protection Agency (VD-2017-176). The hospital wards and clinics signed a written cooperation agreement, and the studies were presented to the ward management and staff prior to inclusion of participants. Written information about the three studies was available at the wards, just as the preliminary status and information were presented regularly.

The ethical principles of autonomy, non-maleficence, and justice form the basis of the ethical considerations in this thesis.[136] Informed consent protects the autonomy of participants, and it is paramount that the researcher provides full information about the study to allow participants to freely choose whether they want to participate in the study.[136] Eligible participants in all three studies were contacted in person by the author and informed, orally and in writing, with emphasis on the voluntary nature of participation, about their right to withdraw and confidentiality. Written consent was obtained from all participants, and patient ambassadors also signed a confidentiality statement. The autonomy was further strengthened by the fact that the author was not involved in their treatment, reducing the power imbalance. The participants were informed that the author was a PhD student and a clinical nurse specialist on leave, which meant they would not encounter the author in a professional context regarding their treatment. True voluntary participation might have been jeopardized as the majority of eligible patient ambassadors were invited by their primary physician but to receive further information about participation in the study (Paper II), they had to independently initiate contact with the author. Therefore, all patient ambassadors who applied for enrollment were screened for suitability.

The participants can be seen as vulnerable, and participation in a research study while having or having had a life-threatening disease could put an extra strain on patients and patient ambassadors. In addition, the principles of non-maleficence in research were considered due to the presence of the risk of psychologically indirect harm, for example, the stirring up of painful feelings or memories.[136] Although research has shown that being given the opportunity to share experiences in the illness trajectory is valuable and offers positive benefits.[137,138] Thus, several steps were taken to minimize the risk of harm and to respond to any harm that might occur during the study. In Papers I and III, the participants chose the time and place for the interview, and with respect to their physical condition, the interviews were postponed or discontinued if they were too tired or unwell. Moreover, participants were prepared for the interview as they were given brief information about the themes in the interview guide in advance. In Paper II, the psychological

health of the patients and patient ambassadors was of great importance, and it was essential that they did not suffer unnecessary distress as a result of their participation in the intervention. Therefore, patients were assessed for eligibility in close collaboration with their primary nurse and physician. Upon receipt of written consent, time was set aside to hear their story and about their life situation to gather information to ensure a good match with the patient ambassador. In addition, patient ambassadors were prepared for their new role through the obligatory group training program, with a focus on both knowledge and skills, and had the option of attending supervision from a psychologist with other patient ambassadors, or individually. Finally, participants were closely observed so that any adverse events during the trial were responded to immediately. Common to all three studies was a debriefing at the end of either the interview or the intervention to ensure that participants did not experience any distress or have any concerns that needed further attention.

6. Results

The main findings in Papers I–III are presented separately, but the full versions of each paper are available in the appendices. A comprehensive model presented below, was developed to illustrate the coherence of the findings and the overall aim of this thesis.

6.1 Paper Ⅰ

Three main themes and two subthemes were identified when exploring the experiences of newly diagnosed patients with AL in terms of their diagnosis and the initial treatment, illuminating their need and preferences for social support.

Jolted by the diagnosis

The acute onset of the disease was experienced as a traumatic shock with a loss of control over their own life. Normality was replaced with uncertainty about the future, emotional reactions, and concerns that they had difficulty sharing with their own social network. The degree of their symptom burden determined the amount of strength they had to participate in social activities.

Loss of personal autonomy

Participants experienced the loss of personal, bodily, and social control, leading to difficulty in maintaining control over their own life. The rapid initiation of treatment and recommendations from HCPs was perceived as uncontrollable, resulting in a loss of autonomy.

Restoring normality in everyday life

The feeling that their life was on hold resulted in them striving for normalcy, which was accomplished by doing things the way they did previously, taking one day at a time, and by restoring control over their own life by being more involved in their own course of treatment.

Facing a new social identity

Adapting to the transition of being a cancer patient and losing parts of their own social identity was difficult and affected their social roles. The impact of AL affected their ability to fulfill their social roles, leading to guilt towards their own social network. When improvements occurred in disease and well-being, they had a need to reestablish their social network and social roles.

A lifeline of hope

Social support was experienced as lifesaving, inducing hope for the future. Social support from HCPs was challenged by their lack of presence at the clinic. Their own social network had a

significant role by offering support on emotional and practical issues. Experienced-based support from other patients with AL was beyond the scope of HCPs and their own social network. They wanted confirmation on their emotional reactions, as well as the confirmation that survival was possible from someone who had been through the same experiences and trajectory.

6.2 Paper Ⅱ

The main findings in Paper II were based on four feasibility criteria: acceptability, practicability, safety and support, and resource utilization (Figure 4). The secondary outcomes were the clinical outcomes assessed by QoL, symptom burden, self-efficacy, and patient activation.

Figure 4. Evaluation of feasibility

Acceptability

Of the 62 potentially eligible patients, nine were excluded because they did not meet requirements for inclusion and 17 declined participation, mainly due to physical and/or psychological distress, they had enough support from their own network, co-morbidities, did not want to become immersed in their own disease, or did not want to involve unfamiliar parties in their situation. In total, 36 patients agreed to participate, after which four were lost to follow-up due to transition to terminal care (n=1), death (n=2), and withdrawal (n=1). In all, 32 patients completed the intervention (Paper II, Figure 1).

Of the 82 eligible patient ambassadors, 47 declined to participate by not responding to the invitation letter. In total, 35 patient ambassadors agreed to participate, ten of whom were not enrolled in the intervention for the following reasons: relapse (n=3), physical condition (n=1), withdrawal of consent (n=2), or did not match a patient during the intervention (n=4). Overall, 25 patient ambassadors were enrolled, 10 of whom participated more than once. After enrollment, six were subsequently lost to follow-up due to relapse (n=1) or their patient died, was transferred to terminal care, or withdrew, and a total of 24 completed the intervention (Paper II, Figure 2).

Patients and patient ambassadors reported the extent to which they were satisfied with the support (Figure 5). To a great extent, patients were satisfied with the intervention, whereas the level of satisfaction among patient ambassadors fluctuated more. Most patients found that the support from their patient ambassador had positively influenced their disease and treatment trajectory (Figure 6).

Figure 5. Satisfaction with intervention in patients and patient ambassadors

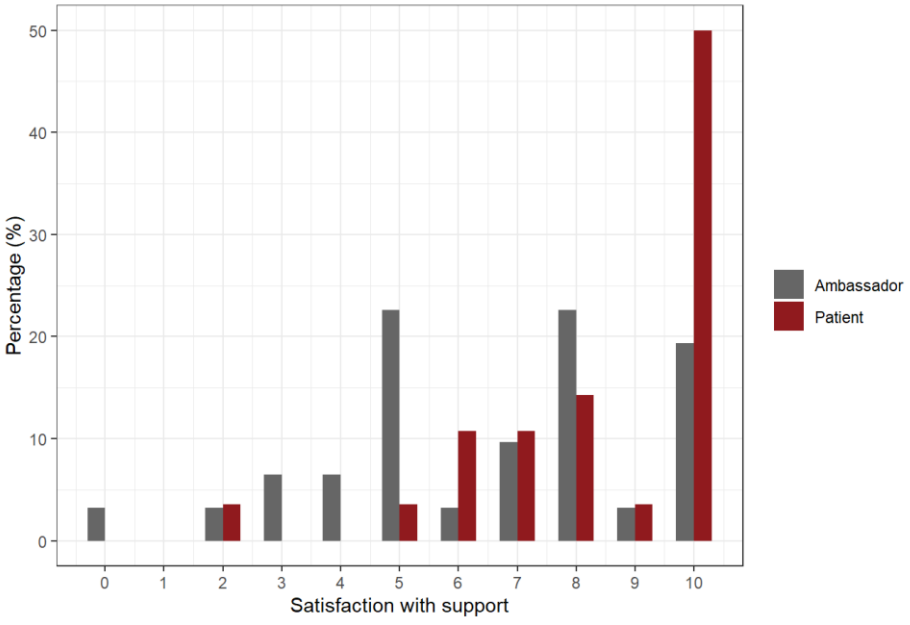
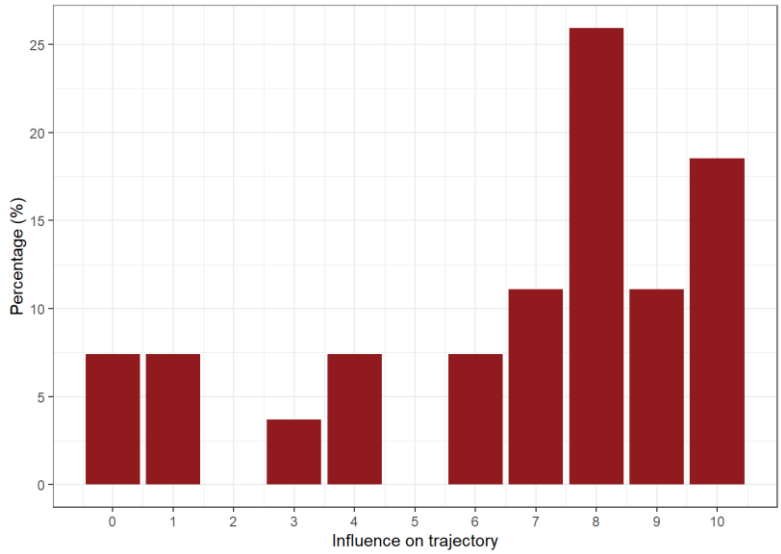


Figure 6. Influence on patient´s disease and treatment trajectory

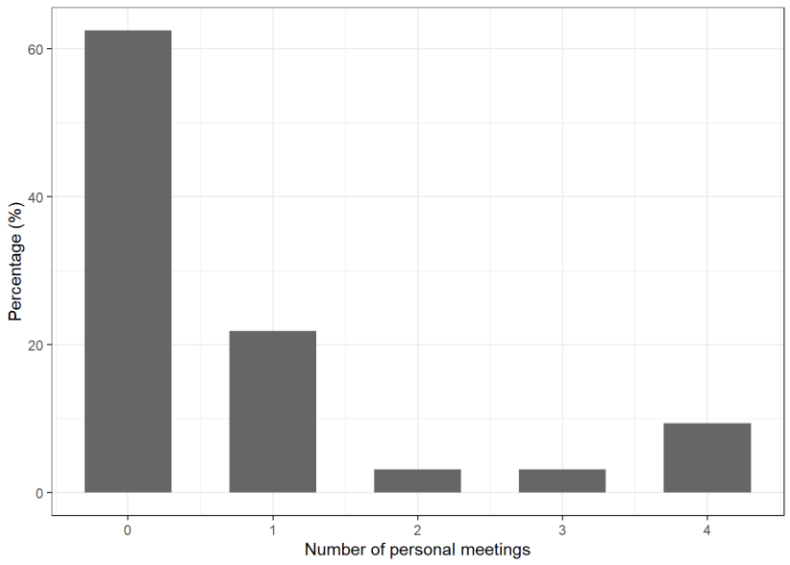


Practicability

All patient ambassadors who agreed to participate attended the educational program prior to the intervention. They reported high satisfaction with the program, which they found useful in regard to what they experienced (86.6%) and provided them with enough information and knowledge about their role as peer supporters (93.3%). Ten network meetings were conducted during the intervention, with 3 to 13 patient ambassadors attending each meeting. Overall, 19 out of 35 patient ambassadors participated in one (n=4), two (n=3), three (n=2), four (n=3), five (n=1), six (n=4), and seven (n=2) network meetings. Of these patient ambassadors, two were not enrolled in the intervention because they did not match a patient during the intervention. Therefore, 17 of the 25 patient ambassadors participated in at least one network meeting.

Patients and patient ambassadors made 404 contacts during the intervention, with a mean of 12.6 contacts per dyad. The most used type of contact was text message and phone calls, with a decreasing number of contacts during the intervention, though with a slight increase at the end of the period (Paper II, Figure 3). Personal meetings were less frequent due to: patients lacking the strength and energy, hospitalization, a weakened immune system, many visits from their own network, geographical distance, or personal preferences. A total of 9.3% had the recommended four personal meetings during the 12-week period (Figure 7). Throughout the intervention, treatment was the most common topic discussed, followed by everyday life/family and side effects/complications (Paper II, Figure 3). The remaining topics comprised less than 25% of the contacts during the period.

Figure 7. Distribution of personal meetings



Safety and support

We did not encounter any unexpected adverse events throughout the intervention, and no patient ambassadors required individual support from the project psychologist. Instead, they primarily found support at network meetings (76.5%) because they needed to talk with others and hear their experiences with their role as a patient ambassador, managing challenges in establishing the relationship with the patient, and coping when the patient's treatment failed. Sixteen participants (only patient ambassadors) initiated contact with the author during the intervention, dispersed as follows: one contact (n=7), two contacts (n=2), three contacts (n=3), four contacts (n=2), and six contacts (n=1). Reasons for having contact with the author were primarily an evaluation of or challenges with establishing the relationship, death of the patient, or the patient was unsure of whether to stay in the intervention.

Resource utilization

Figure 8 shows the resources spent on coordination and the operational cost of the patient ambassador program over 18 months.

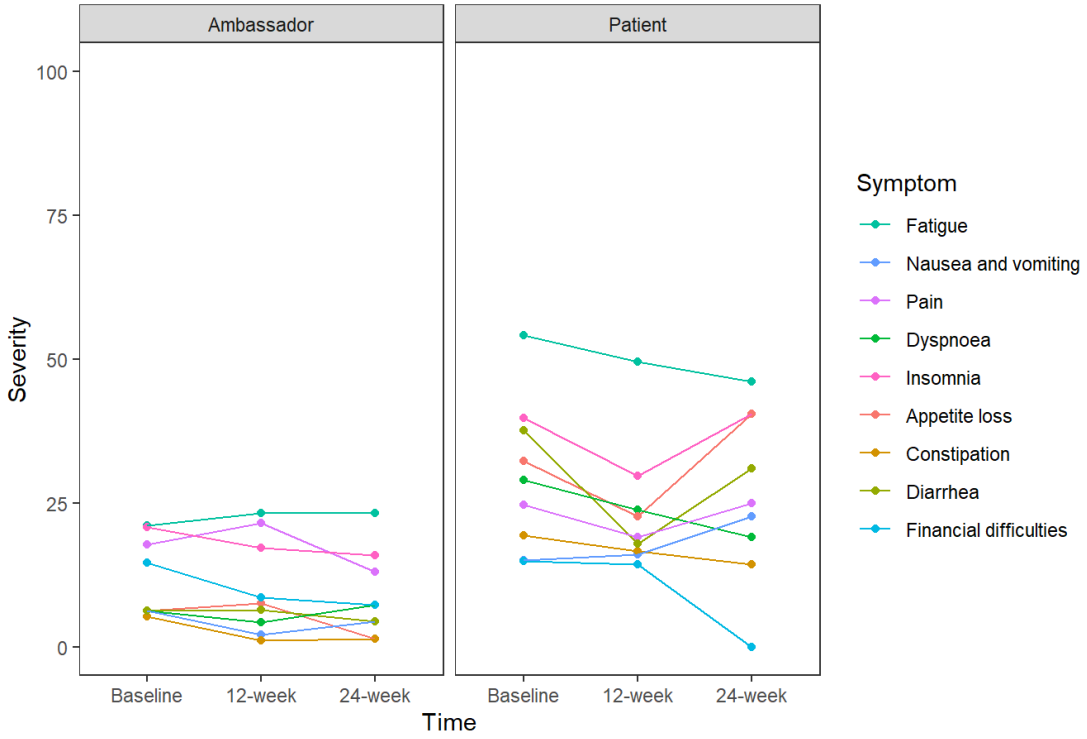
Figure 8. Overview of resource utilization

Clinical outcomes

For the secondary outcomes, the findings showed that patients improved in all summarized symptoms and QoL scores over time (Paper II, Table 2). Specifically, patients reduced their anxiety level at baseline from above the cut-off score (>8) to below the cut-off point by the 12-week follow-up (p=0.007). Additional statistically significant improvements were found from baseline to the 12-week follow-up for global health (p=0.047), role functioning (p=0.014), cognitive functioning (p=0.044), functional well-being (p=0.014), and patient activation level (p=0.021). Figures 9 and 10 show the severity of specific symptoms in both patients and patient ambassadors.

In patients (Figure 9), all symptoms decreased from baseline to 12 weeks (diarrhea: p=0.03) and then increased to baseline level or above, except fatigue, constipation, dyspnea, and financial difficulties, which all decreased over time. In patients (Figure 10), there was a tendency towards a reduction (dry mouth: p= 0.01, sleep: p=0.024) or unchanged level from baseline to 12 weeks, which by the 24-week follow-up had either increased or remained unchanged. Conversely, numbness/tingling increased over time (baseline,12-week follow-up (p=0.029), 12-week to 24-week follow-up (p=0.009).

Figure 9. Symptoms assessed by the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire



In patient ambassadors, the overall trend showed no significant change in clinical outcomes (Paper II, Table 3) over time, except in emotional well-being (p=0.004) from baseline to the 12-week follow-up. Beyond the unchanged tendency, the results shown in Figures 9 and 10 illustrate the severity of specific symptoms. Figure 10 shows a trend towards a small non-significant increase from baseline to the 12-week follow-up, which normalized to baseline level by the 24-week follow-up.

The results indicated an overall trend in symptom severity, with patients reporting higher symptom severity than patient ambassadors. Regardless, the most frequent symptom in both patients and patient ambassadors was fatigue. The interference of symptoms with activity, mood, work, relationships with others, walking, and enjoyment of life also showed a similarly higher interference in patients compared to patient ambassadors, although both improved over time (Figure 11).

Figure 10. Symptoms assessed by MD Anderson Symptom Inventory

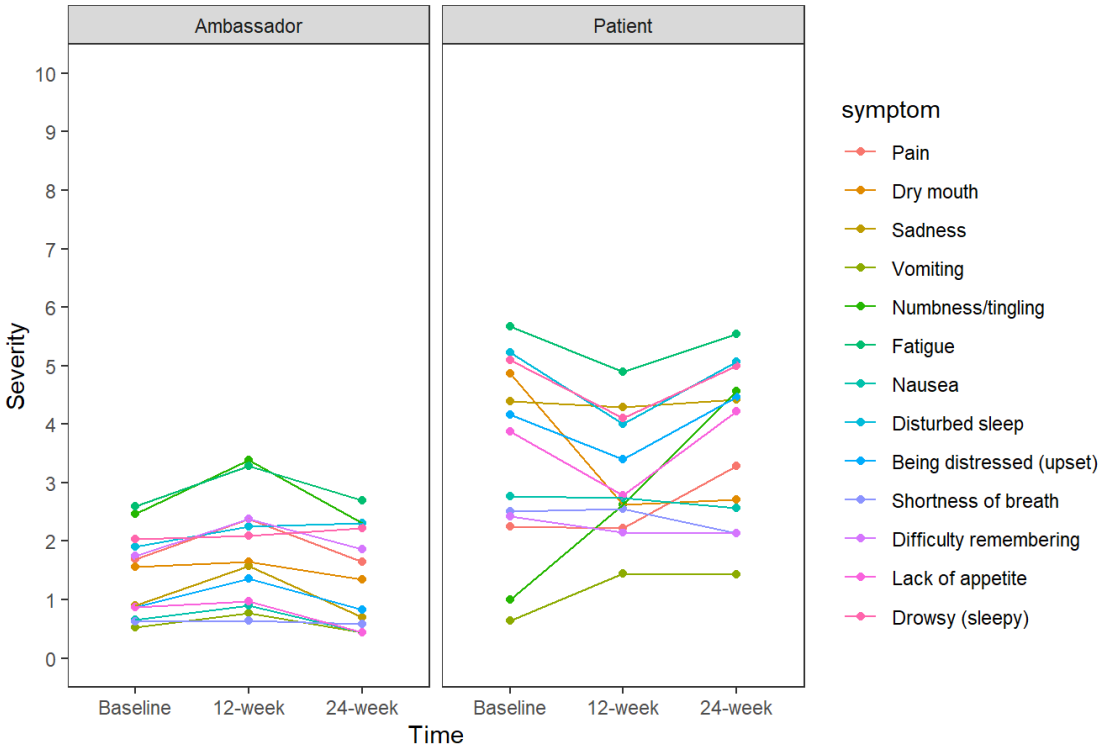
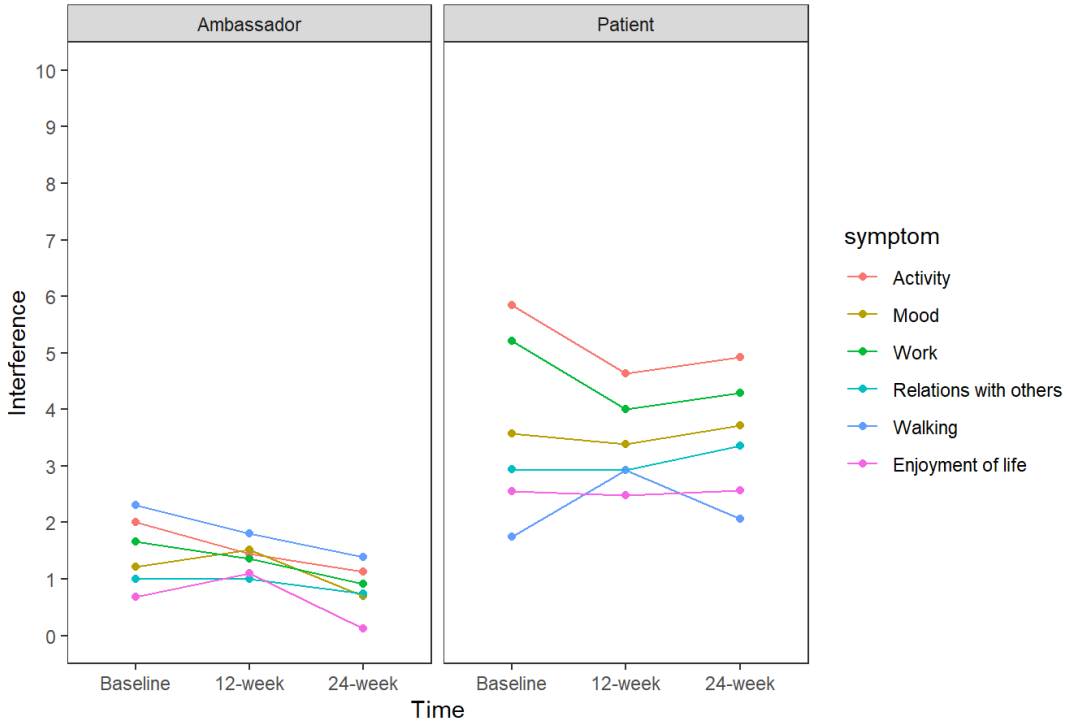


Figure 11. Symptom interference assessed by MD Anderson Symptom Inventory



6.3 Paper III

Four main themes and three subthemes were identified in the exploration of how newly diagnosed patients with AL and their patient ambassadors experienced the mentorship during patient ambassador support.

Exchanging life experiences

The impact of AL determined which knowledge and experiences patients requested from their patient ambassadors. Simultaneously, patient ambassadors shared knowledge and experiences that they had needed during their own trajectory. The patients expressed a need for support during three phases of recovery: initial treatment, HSCT, and survivorship.

Individualized support

The support was individualized by the patient ambassador in proportion to the impact of AL, social conditions, and personal preferences. Regardless, high satisfaction with the support was independent of the frequency of contact during the intervention. Text messages were the most used form of contact, although they required greater reflection by the patient ambassadors.

A meaningful return

Patient ambassadors were motivated, either because they had experienced the same support during their own trajectory or because they had experienced an unmet need for peer support. Helping others by having a positive impact on their trajectory and situation resulted in their own disease trajectory became meaningful.

Existential cohesion

Shared experiences between patients and patient ambassadors induced existential cohesion and equality, serving to help the relation evolve. Some participants wanted to continue the relationship throughout their trajectory, while some patient ambassadors were afraid it would become an emotional burden.

Interreflection

Patients and patient ambassadors reflected themselves in each other's lives, which, for patients, resulted in hope for the future and, for patient ambassadors, in helping them put their life into perspective. Mutual reflection was only possible if a good match was made between the patient and the patient ambassador. A crucial factor was being in the same place in life, followed by treatment trajectory and sex.

Terms and conditions

Entering the mentorship on unequal terms and conditions caused challenges in establishing the relationship, different levels of expectations, not having a clear sense of the significance of the support, and inappropriate exchanges of knowledge. Supervision with the psychologist during network meetings helped patient ambassadors deal with these challenges.

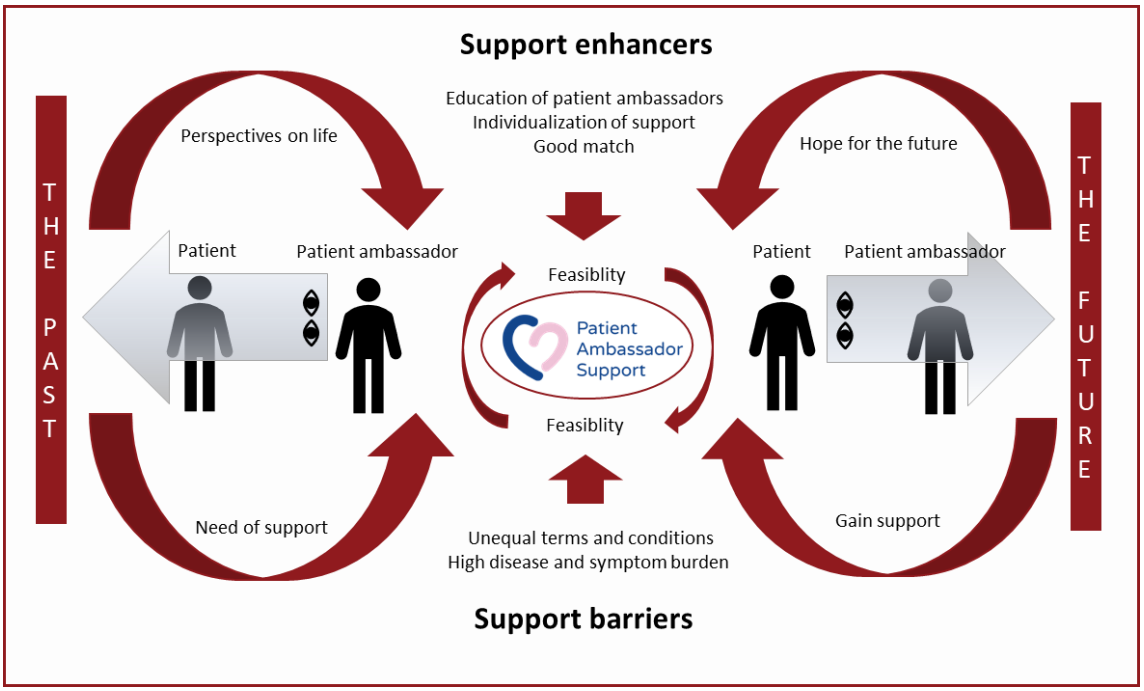
Break in journey

Patients and patient ambassadors were aware of the underlying premise that their mentorship could end prematurely due to relapse, the transition to palliative care, or death. Despite this, they thought the support was too important for other patients not being given the opportunity.

6.4 A comprehensive model of patient ambassador support

The comprehensive model developed for patient ambassador support illustrated in Figure 12 demonstrates the cohesion between the findings in Papers I–III. The model shows that, in order to understand the experiences and perspectives of the patients and patient ambassadors, the approach must be bipartite in two dyads, where either the patient or patient ambassadors are in focus.

Figure 12. Comprehensive model of patient ambassador support



The patients gained hope for the future by mirroring their experiences in those of the patient ambassadors, causing them to realize it was possible to manage and get through the treatment, which added support. Simultaneously, patient ambassadors gained perspectives on life by mirroring their own past experiences in those of the patients, causing them to realize how far they had come in their own recovery, increasing their own need for support. The feasibility of patient ambassador support is affected by central support enhancers and support barriers. The support is enhanced by sufficiently educating patient ambassadors, by providing individualized support, and by achieving a good match. Conversely, the inevitable inherent terms and conditions related to their diagnosis with AL and the high disease and symptom burden are significant barriers to the feasibility of the support.

7. Discussion

The discussion is divided into two sections. First, the main findings will be discussed based on the comprehensive model of patient ambassador support (Figure 12) in the context of the existing evidence and the chosen theoretical frameworks: stress-buffering hypothesis and SCT. The second section discusses the methodological considerations of the three papers.

7.1 Discussion of the findings

This thesis expands our understanding of the experiences patients with AL have following their diagnosis and initial treatment, and their need and preferences for social support. Moreover, in addition to contributing to the existing evidence on peer support in patients with cancer, it is, to our knowledge, the first study to investigate peer support in patients with AL. The main findings demonstrate that peer support was feasible and safe and that it benefited both the patient and patient ambassador. Although some challenges were identified, these were manageable if patient ambassadors were provided with sufficient support. The following components of the comprehensive model of patient ambassador support (Figure 12) will frame the discussion of findings: hope for the future, life in perspective, need of support, feasibility, support enhancers, and barriers.

7.1.1 Hope for the future

The findings emphasized that newly diagnosed patients with AL experienced extensive changes in their lives in terms of significant physical, psychological, and social distress already from the time of diagnosis (Paper I). The poor prognosis further intensified their distress, increasing their need for social support that would enhance hope and facilitate coping in living with a life-threatening illness (Paper I). This is consistent with previous studies highlighting this population as particularly influenced by the acute onset and the significant disease and treatment-related symptom burden. [4,114,115,138,139] Additionally, our findings (Paper I) stressed the importance of this impact on increasing their need for social support, specifically from other patients with similar diagnoses and experiences. Experience-based support has the distinct ability to provide patients with emotional and informational support that conveys hope for the future and ways of coping, an aspect that is beyond the scope of health professionals and people's own social network.[83] In Paper III, this was confirmed when patients stressed the importance of shared experiences, which resulted in a mirroring in the patient ambassador's life situation, leading to a feeling of hope. The model in Figure 12 illustrates that patients were able to believe in the possibility of survival and a future

due to interreflection with the patient ambassador, which induced hope. People can use comparisons when facing life-threatening situations by having contact with others in similar situations, often someone in better health than themselves or further along with treatment.[80] The model in Figure 12 clearly shows that patients used upward social comparisons to positively impact their belief in being able to cope with their new life situation by comparing themselves with those who had survived the disease and treatment. However, some studies describe the downward comparison in patients with cancer, where patients instead compare themselves with others who are in a worse situation than themselves, resulting in feelings of being in a less threatening situation.[80,81] This comparison is mainly possible between people in similar situations and places along the treatment trajectory, which explains why this was not described by patients with respect to their patient ambassadors (paper III). The importance of establishing hope in patients with cancer is well described in the literature.[140,141] Due to the significant impact of the disease and treatment of AL, increasing hope in this population is pivotal and may potentially improve the ability of patients to cope with their situation. In patients with cancer, sharing experiences with others during peer support has been shown to decrease isolation and increase hope.[23,142] Thus, providing peer support for patients with AL may induce hope, enhancing their capacity to adapt to the life-threatening disease AL.

7.1.2 Life in perspective

The findings clearly show that the trajectory of AL distinguishes itself from other cancers due to the acute onset of the disease, the intensity of treatment, and the long-term neutropenia that alters the patient's social identity and social life (Paper I). Consistently, this impact postpones their resumption of work, studies, and the ability to obtain a normal social life.[4,5] The findings indicated that sharing these experiences motivated the patient ambassadors to support others going through the same difficult experiences that as they did (Paper III). This is consistent with our qualitative study from 2020 exploring the motivation of the patient ambassadors prior to their enrolment in the educational program (Paper II).[74] The findings emphasized that patient ambassadors were motivated by helping others in a situation they had previously experienced.[74] They were hoping for their own disease trajectory to become meaningful, which potentially would facilitate a better recovery.[74] Similarly, the patient ambassadors gained the experience of their own pathway becoming more meaningful, consequently helping them to help others in making their disease and treatment trajectory less challenging by using their experience-based knowledge (Paper III). Thus, by supporting others, the patient ambassadors gained perspective on their own life (Paper III).

Knowledge on the perspectives of the peer supporter within the context of cancer is limited.[26,73] A qualitative study from 2018 found that peer supporters addressed that working as a peer supporter met their own needs for social contact while simultaneously making them feel useful.[72] Similarly, another qualitative study from 2013 found that peer supporters gained closure while carrying out the role of peer supporter, which addressed the therapeutic aspect of peer support for the provider.[73] Based on the model (Figure 12), patient ambassadors reflected their own past experiences in the current experiences of the patients, helping them to gain perspective on their own life which, in turn, helped them realize what they had been through and how far they had come. They advantageously may have used social comparison to others in a similar situation to evaluate themselves in this process.[80] As illustrated in the model, they may use downward comparison, where evaluating against someone who is perceived to be in an inferior position is decisive in order to be able to put their own disease trajectory into perspective, helping them to achieve a feeling of how far they actually had come in their survivorship. Additionally, it could be argued that comparisons potentially also took place between the patient ambassadors during the educational program and the network meetings, which could be either downward or upward comparisons, depending on their position in their disease trajectory and recovery.[80] This may, in part, explain why the patient ambassadors participated, to a great extent, in these meetings with a high level of satisfaction (Paper II and III). Moreover, the meetings provided a forum where they were able to use comparisons but, more importantly, where they had a social community of like-minded people. This is especially important since many long-term survivors of AL have increasingly limited contact with the health care system and survivorship support.[143,144] Regardless, the ability to use comparisons plays a decisive role if the differences between people are not too significant, highlighting the importance of a good match between patients and patient ambassadors, but also in regard to conducting the educational program and network meetings.[82]

The provision of peer support may benefit the recovery and survivorship of long-term survivors of AL, though providing support and gaining perspectives on their life increased their need for support.

7.1.3 Need of support

Support for the patient ambassador was important for various reasons (Paper III). First, there is the potential psychological strain of re-experiencing previous traumatic events during their disease trajectory. Second, the unpredictable course of the disease may increase worry about cancer recurrence. Third, feelings of uncertainty about being a good patient ambassador may arise. There is increasing consensus on the importance of support for the peer supporter as essential for the

success of the delivery of support.[26,64,145,146] Most studies investigating peer support offer some degree of support or training for the peer supporter, although there is great variation in the content and frequency of this support.[26,64,145,146] A meta-analysis from 2018 evaluating the effects of peer-led interventions in patients with cancer found that the training of peers ranged from two to 48 hours.[25] More importantly, few studies have examined peer supporters' need for support when carrying out their role. [26,64,145,146]

The educational program for patient ambassadors was developed in cooperation with the patient advisory group, which may contribute to the high acceptability of the intervention and satisfaction with the content of the educational support (Paper II). This highlights the importance of involving patients in the development of similar peer support programs as differences will inevitably arise, depending on the disease population. A qualitative study from 2013 exploring the benefits and challenges of cancer peer supporters highlighted the importance of education and support but argued that it should be viewed in proportion to the risk of professionalization.[73] Similarly, a qualitative study from 2018 described peers as portraying themselves as professional helpers and as seeing themselves as more professional in respect to other volunteers and fellow patients.[72] Still, the peer supporters developed these semi-professionals norms following their training to protect them and to act as boundaries in the social interaction with the peer support recipients.[72] Thus, educational support is essential; however, there is a critical balance that must be struck between providing knowledge and support to the peer supporter without turning them into professionals. The patient ambassadors stressed that being able to participate in regular network meetings with a psychologist and other peer supporters entailed a limited need for individual support (Paper III). They emphasized the importance of regular meetings as being their own social peer support network. Knowledge on the provision of regular network meetings during peer support in the context of cancer is limited.[64,73] Yet, in the Danish peer support programs within mental health, network meetings are an established part of programs.[68,69] They offer different levels of education for peer supporters and have established national network groups, where peers have the opportunity to participate in network meetings, lectures on related topics, and to be part of a social forum for peer supporters.

Overall, support for the peer supporter is pivotal for various reasons. First, the safety and mental health of the peer supporter, the quality of support provided to the patient and, finally, the feasibility of the mentorship between the peers.[64,73]

7.1.5 Feasibility

Patient ambassador support is a supportive care intervention demonstrated to be feasible and safe in newly diagnosed patients with AL (Paper II). In Paper I, the findings stressed the importance of social support in newly diagnosed patients, which may explain why the mentorship between peers was found feasible in Paper II. From a theoretical point of view based on the stress-buffering hypothesis (Figure 1), social support (patient ambassador support) buffers or protects against the effect of stressful events (the diagnosis with AL) on the patients coping appraisal and, hence, their well-being.[55] According to this theory, patient ambassador support may play two roles in the stress-buffering pathway. First, the support may prevent or reduce the stress appraisal as the patient ambassador is living proof that it is possible to survive and cope with the long-term treatment trajectory. Second, the support may reduce the appraisal of being diagnosed with AL by providing a distraction, reduced reactiveness to the traumatic event of having a life-threatening diagnosis, or helpful healthful behavior.

Cohen and Willis suggest four resources of support, and the findings in Paper III indicate that the patient ambassadors potentially are able to provide all four resources: esteem support, informational support, social companionship, and instrumental support.[55] For this buffering effect to occur, the patient's coping needs and the resources within the patient ambassadors need to match.[55,77] This highlights the importance of elucidating the patient's needs in order to find a patient ambassador who has the available resources, for instance, in relation to being in the same place in life, having small children, or living alone. Regardless, the stress-buffering hypothesis was developed based on the assumption that people are under stress and appraise a situation as threatening or demanding without having the available coping responses.[55] This underlines the importance of providing patient ambassador support to patients who appraise their situation as threatening or demanding and as being without the necessary coping responses. As the findings emphasized, most patients appraised the diagnosis with AL and the subsequent treatment as threatening and demanding; however, some may have had the necessary coping responses available (Paper I). This could derive from previous experiences with cancer or similar diseases, either in themselves or in close relatives. Nevertheless, the findings in Papers II and III indicated that the majority of patients benefitted from the support regardless of available resources, although it could be argued that some of those who refused to participate in the study did so as a result of having the necessary coping resources. This is consistent with a meta-analysis from 2018 evaluating the effects of peer-led interventions in patients with cancer, where patients with a low level of psychological distress who were not receptive to receiving social support, or who had adequate support, were less likely to report psychosocial benefits.[25]

Overall, the mentorship between patients and patient ambassadors was feasible. This is consistent with previous peer support intervention studies involving patients with cancer, where findings highlight satisfaction with the support among both supporters and recipients.[26-28,145,146] The findings in this thesis demonstrated a high recruitment and low attrition rate among both patients and patient ambassadors, which is significant given their prognosis and high level of distress, disease, and symptom burden (Paper II). A systematic review from 2019 describing the experiences and impact of peer support in people with advanced cancer found that this population frequently used peer support programs, but that the programs were rarely specifically designed to accommodate their needs.[146] Conversely, the patient ambassador support program in this thesis was specifically designed and developed to meet the needs of patients with AL by already involving the patient advisory group in the development of the protocol. The majority of peer support studies are conducted within gendered diagnoses, e.g. breast and prostate cancer. [26-28,145,146] The remaining studies differ from the findings in Paper II regarding sex as several of these studies report an overrepresentation of females in both peer support providers and recipients.[146] Conversely, the findings demonstrated an equal gender distribution among the participants (Paper II). This may be explained by the design of the intervention, which was individualized regarding the provision and frequency of contact, which could be argued to address the male gender preferences to a higher degree.

Support enhancers and barriers were encountered, some of them specific to this population, which also justifies this thesis.

7.1.4 Support enhancers and barriers

The feasibility of patient ambassador support was influenced by specific elements that either enhanced or impeded the support (Figure 12). The findings in Papers II and III emphasized that educating patient ambassadors, the match between the peers, and individualization of the support enhanced the provision of support. Simultaneously, this was challenged by a high disease and symptom burden, and unequal terms and conditions.

The educational support for the patient ambassadors was essential as it helped them prepare for their upcoming role and contributed to their clarification of being mentally ready. Thus, the educational program was developed in cooperation with the psychologist and patient advisory board (Paper II) by using a classic didactic model and critical pedagogy.[106,107] Because some patient ambassadors still experienced some degree of disease and symptom burden, the length of the educational program was carefully organized in proportion to their abilities. Hence, great variations exist in the amount and quality of educational support given to peer supporters.[25] This

may highly impact the possibility of being able to compare peer support studies and may be an explanatory factor as to why some effect studies are un able to prove the significant effect of peer support in patients with cancer.[25,26,145,146]

The match between the patient and patient ambassadors was crucial for the feasibility and success of the support (Papers II and III). This is consistent with the general evidence of peer support, highlighting that it is important for both sets of peers to be able to recognize their own life situation and treatment trajectory within their counterpart.[25-28] Therefore, in respect to the model in Figure 12, reflection on the past or the future is only possible if the match is appropriate. This is consistent with SCT, which emphasizes that comparisons are not possible if the difference between people is too significant.[82] Consequently, performing a sufficient match according to the peer's diagnosis, treatment, and life situation will facilitate comparisons between peers and, subsequently, enhance the support.

Individualized support appeared to be fundamental in carrying out patient ambassador support (Papers II and III). Concurrently, the findings in a mixed-method study from 2010 investigating which peer support models people with colorectal cancer preferred showed that half of the participants equally wanted either one-to-one telephone support or face-to-face support, with both methods of communication seen as acceptable and with a high level of satisfaction.[147] This contradicts the methodology in most previous studies investigating peer support interventions, where the provision of support was predefined in relation to both the provision and frequency of contact between peers.[26,64,145,146] The explanation for this has mainly been related to the aim of investigating the effect of peer support in these studies, which necessitates specific delivery of the intervention. When providing individualized support, it may be difficult to elucidate which part of the intervention was responsible for the effect identified. However, the provision of individualized patient ambassador support increased the opportunity for patient-centered care. Nevertheless, the need for individualized support may be especially pronounced in patients with AL due to their life-threatening prognosis, severity of symptom burden, and unpredictable disease trajectory.

Severity of the disease and symptom burden was a potential barrier for the feasibility of patient ambassador support as it challenged their ability to initiate and maintain contact (Paper II and III). These findings have, to our knowledge, not been described in previous systematic reviews of peer support in patients with cancer, underlining this challenge as especially pronounced in this population.[25-28,145,146] Thus, peer support may not be relevant for all patients with AL during the initial treatment but should be an option along their treatment trajectory. However, the findings also indicated that the high disease and symptom burden potentially increased their need of social

support, including peer support (Paper I), which underlines the necessity of managing these barriers when providing peer support. Of further importance is that the findings stressed the extensive impact of the disease and treatment on their physical, psychological, and social well-being already from the time of diagnosis (Paper I). It is essential to provide peer support to patients with AL as it has the potential to lessen their symptoms and to promote the return to prior levels of functioning and, in this way, to sustain the social identity and everyday life of the patient.[6]
Unequal terms and conditions are an aspect that has not been described in peer support studies within populations with cancer.[25-28,145,146] In Paper II, some patient ambassadors experienced that their patient died during their support. They described feeling enormous empathy toward the relatives and did not want the situation to deprive others from receiving this support (Paper III). Several studies emphasized that, despite the risk of the patients becoming critically ill or dying, peer supporters were not overwhelmed and it was important for them to continue their work.[26,64,73]
In Papers II and III, a reversed situation was encountered when a patient ambassador relapsed and was excluded because she had to resume intensive chemotherapy treatment. In respect to SCT, it could be argued that this situation contradicted their mutual comparisons, especially for the patient, which could result in difficulty maintaining hope for the future. Still, it turned out that their existential cohesion (Paper III) was so strong that it resulted in a more equitable relationship.

The feasibility of patient ambassador support was enhanced when providing patient ambassadors with sufficient education when they were matched with and provided support to patients according to their individual needs and preferences. Regardless, one aspect that was impossible to modify was their unequal terms and conditions, although the findings emphasized (Paper III) that education and continuous support from the network meetings reduced these challenges and potential barriers.

7.2 Discussion of the methods

This thesis generated results using both qualitative and quantitative methods, which is why the methodological considerations are discussed separately.

7.2.1 Methodological considerations in the qualitative studies (Paper Ⅰ, Ⅲ)

The sample size was determined by using information power which is a concept developed to guide an adequate sample size in qualitative studies (Papers I and III). Five specific items were relevant to include when determining whether the size of the samples had sufficient information power: the aim of the study, the specificity of the sample, applied theory, quality of the dialog, and the analysis strategy.[104] The samples were purposive, which enhanced maximal variation within

the participant experiences.[85] The methodological approach will be discussed in light of the concept of trustworthiness, as described by Lincoln and Guba, and used to evaluate the credibility, dependability, transferability, and confirmability of the results.[148]

Credibility is achieved through reliable descriptions of participant experiences, generating findings that are trustworthy and enhanced by creating optimal conditions for conducting the interviews and using an appropriate methodology.[148] The participants were carefully informed about the studies, chose where they wanted the interview to be conducted, and a sufficient amount of time was allocated to establish a feeling of confidence between the interviewer (the author) and the participant. The interviews were collected retrospectively, which may threaten the credibility of the findings, although such memories are often independent of time and instead increase the ability to reflect (Paper I).[149] Conversely, the interviews in Paper III were conducted relatively close to the participants' experiences of the phenomenon under study. It could be argued that a more retrospective approach would have produced a more reflexive perspective. However, considering the unpredictability of the disease and treatment trajectory, the aim was to capture their uninfluenced and spontaneous experiences and perspectives, which ultimately enhanced the credibility of the results.

Overall, two methodologies, Hans-Georg Gadamer´s philosophical hermeneutics and Sally Thorne´s ID, were chosen as the theoretical approach and framework for Papers I and III, respectively, just as using and applying these methodologies enhanced the credibility. In hermeneutics, the hermeneutic circle is a continuous process aimed at creating meaning and understanding.[86] This dialectic movement between the interpreter and the object may have enhanced the credibility in Paper I because the process continued until an understanding was reached.[86] In ID, several features affected the credibility of the findings in Paper III. The stepwise preliminary analytical approach, beginning when carrying out the interviews, guided the author in remaining focused and on where to go next. The findings were further strengthened by coding large sections of 5-10 lines, making it possible to maintain the ability to see the patterns and continuously going back to the source to ensure consistency, which also enhanced the trustworthiness of the findings. Interviews were applied as the data source in Papers I and III, and according to ID, using multiple data sources strengthens credibility. Possible examples of additional data sources are focus group interviews during network meetings with patient ambassadors and diary entries by patients during their mentorship. This would potentially have expanded the knowledge and understanding of the mentorship during patient ambassador support. However, the author did participate in all network meetings to gain further insight into the

experiences of patient ambassadors and also carried out individual interviews and evaluations with all patients and patient ambassadors. Thus, this knowledge was, to some degree, applied during interpretation of the interview data as it was part of the author's pre-understanding of the phenomenon.

Dependability is based on freedom from bias and enhanced by using triangulation in the research process.[148] Dependability was sought by discussing the methods used during the research process with the other authors and by employing triangulation in the data analysis (Papers I and III). In Paper I, the data analysis was further validated by members of the patient advisory board.

Confirmability refers to the degree of neutrality and is strengthened by clearly describing the analysis process and the interaction between quotations and the findings.[148] This was done using Braun and Clark's thematic analysis to describe each step carefully to secure a transparent analytical process and by using patient quotations to illustrate participant experiences (Papers I and III). In qualitative research, the subjectivity and involvement of the interviewer is a premise that is embedded in the hermeneutics and ID of the chosen methodologies. The pre-understanding of the author was acknowledged when going into the field and eased access due to her knowledge of the hospital, the roles, routines, and traditions and, in particular, her familiarity with the treatment and disease trajectory of the participants. However, the pre-understanding may potentially have caused blind spots, which the author acknowledged and was aware of in the analysis and interpretation of the data by continuously asking the question, "What else might there be to see and how would I know that?".[85,87] Thus, the use of triangulation with the other authors in the analysis process further strengthened the confirmability.

Transferability relates to the extent to which the findings can be applied to other settings and populations.[148] This was attained by including a sample from a hospital setting that is representative of the population the papers aimed to explore (Papers I and III). Although maximal variation was not achieved within the distribution of sex as the sample had more women than men (Paper III). This was due to the characteristics of eligible newly diagnosed patients with AL in the feasibility trial in this specific period of enrolment. Still, the variation was achieved in relation to age, diagnosis, and patient and ambassador experiences. Moreover, transferability was achieved by providing transparent descriptions of the setting, sample, collection of data, and the process of analysis. ID is oriented toward improving clinical practice, which may lead some researchers to adapt their findings to bring knowledge back to practice. The ID framework was useful as the orientation to clinical practice guided and helped the author to stay focused by continually being

aware of what knowledge led to the purpose of this study and what knowledge is needed to improve practice (Paper III).

7.2.2 Methodological considerations in the quantitative study (Paper Ⅱ)

One of the strengths of this study includes the longitudinal design for recruiting participants from multiple hematological departments across regions in Denmark. This is further bolstered because the design and intervention were developed based on recommendations from the patient advisory group that was established comprising former patients with AL. This advisory group participated in the majority of the research process, from developing the protocol to evaluation of the intervention. Three advisory board members also participated in the patient ambassador educational program and performed the role of patient ambassador. This occurred due to the non-randomized feasibility design, which enhanced the possibility of discussing and evaluating the feasibility of the intervention from a general perspective. Overall, the involvement of the patient advisory group improved the quality, feasibility, and translational value of this thesis.

According to Shadish, Cook, and Campbell, all designs include potential threats to the validity of the study, which is why these consequences will be discussed in the following sections: statistical conclusion validity, internal validity, and external validity.[150]

Statistical conclusion validity

Statistical conclusion validity is related to three essential concepts: type II error, type I error, and the significance of the findings.[151] Type II refers to the risk of false negative findings, which can be improved either by a larger sample size or by reducing the amount of error.[151] The primary goal was the evaluation of feasibility, and the sample size was determined on that fundamental basis. Still, criticism could be levelled against the sample size in the analysis of secondary outcomes, which lacked in power; however, it is important to emphasize that the purpose of including the secondary outcomes was descriptive. Type I error refers to the risk of obtaining false positive results, which is most often controlled by choosing a significance level of 0.05.[151] There is a high risk of type I errors, which should be emphasized, as p-value <0.05 was applied to an explorative study with multiple outcomes and assessment times. The practical value or importance of the findings is referred to as clinical significance.[150] Results indicating statistically significant differences may not always indicate meaningful differences to the individual patient.[151] In the analysis of the secondary outcomes, several significant improvements were identified, although it is difficult to determine if these changes are meaningful to the individual patient. Some evidence exists indicating that on the EORTC QLQ-C30, differences of 10 points or more are proposed as

clinically significant.[152] Therefore, it could be argued that the improvements in patients related to global health and role functioning are clinically important improvements. Regardless, these improvements are mean values for the group and not individual changes. Thus, it would be more accurate to investigate how many individuals experienced a change of 10 points for whom the changes were clinically important.

Internal validity

Internal validity is related to the degree to which the study is carried out in such a way that it measures what it was designed to measure and results in findings that are trustworthy.[99] A non-randomized feasibility design was chosen for various reasons: first, because it allowed the author to test the intervention in more patients; second, because no previous studies had investigated peer support in patients with AL; and, finally, because of the risk of life-threatening complications and significant disease and treatment-related symptom burden in this patient group. The internal validity is threatened by the endogenous change that is changes within the person, for instance, spontaneous remission.[150] The newly diagnosed patients with AL recovered spontaneously in the period from baseline to 12 weeks, although the opposite could be a possibility in this population. Interfering events, other than the experimental intervention, may also reduce internal validity.[151] In this case, the population with AL is, regardless of being a patient or a patient ambassador, at increased risk of experiencing interfering events, for instance, relapse or complications, affecting the internal validity of this study. There is a risk of attrition bias, which occurs if intervention dropouts are a biased subset, resulting in limitations of the representativeness for the population under study.[99] There were missing data due to attrition, incomplete data collection, and exclusion of participants. This was, to some degree, expected in this population due to their significant disease and treatment burden and prognosis. The amount of missing data was primarily related to the 24-week follow-up, and the primary outcome was measured between baseline and the 12-week follow-up. Thus, with the overall aim in mind, these circumstances did not threaten the validity of the primary outcome of this study. Nevertheless, by the 24-week follow-up, the remaining participants may differ from those who left the study and may lead to overestimation of the sum scores at that time point.

External validity

External validity refers to the degree to which the results may be generalized over time, settings, or populations.[99] The intervention in Paper II was inspired by patients, developed in corporation with patients, performed by former patient ambassadors for newly diagnosed patients, which

greatly underpins a high external validity. In non-randomized designs, selection bias is caused by a non-random imbalance, where individuals are selected for inclusion based on specific criteria, resulting in characteristics which differentiate from the target population.[99] The chosen criteria resulted in exclusion of patients who were critically ill, did not speak Danish, were not receiving intensive chemotherapy, and who had been diagnosed more than two weeks earlier. This may have caused bias as the exclusion of these patients, who potentially would have benefitted from participating in the study, may have caused the study population to be less representative of the target population, affecting the external validity of the findings. Hence, the representativeness of the participants is one aspect of external validity and concerns to what degree the sample represents the population to which the findings are generalized.[99] In the recruitment of patient ambassadors, 35 of the 82 eligible individuals were enrolled to the study, while in patients, 36 of the 53 eligible were enrolled. Information on non-participants was not collected, which is why it has not been possible to confirm whether they were comparable, ruling out non-response bias. The sample did include patients who were primarily not living alone and who were well educated, although the number of patients who declined to participate was small and therefore should not impact the external validity. For the clinical setting to maintain external validity, study settings must be representative.[99] Minor variations were identified at the sites, such as when patients were transferred to outpatient management with home-based chemotherapy. These variations entail differences in the amount of time the patients had with HCPs and other patients with AL during their treatment. In light of the non-randomized design and the aim of feasibility, these differences should not have a significant impact on the conclusions and are instead important within a clinical implicational perspective. The aspect of replication is important for external validity because the generalizability is attained when replicated in multiple sites.[99] Thus, the findings in Paper II enhanced the external validity because they were replicated at the three sites.

8. Conclusions

The overall aim of this thesis was to generate research-based knowledge on the feasibility of a peer support intervention in newly diagnosed patients with AL. Additionally, it was to explore the experiences and perspectives of patients and patient ambassadors following their participation in a peer support program. This is the first study to investigate peer support in newly diagnosed patients with AL by evaluating the feasibility of patient ambassador support and by exploring the mentorship during this support from the perspectives of the patients and their patient ambassadors.

Based on the findings in Paper I–III, the following conclusions can be drawn:

First, receiving the life-threatening diagnosis of AL had an extensive impact on the everyday life of patients, already from the time of diagnosis, which affected their participation in social activities. They needed to reestablish daily life activities in order to restore normality, which was challenged by the significant disease and treatment burden and poor prognosis, resulting in reactions and concerns that they had difficulty sharing with their own social network. This increased their need for social support from their own social network, health professionals, and peers with a similar disease and experiences that increased hope and enabled coping in living with a life-threatening disease. Support from peers had a unique ability to induce hope because they were able to compare their emotions and experiences with others similar to themselves and to recognize the possibility of survival and coping with treatment.

Second, patient ambassador support was feasible in newly diagnosed patients with AL during their initial treatment. The intervention was acceptable, with high satisfaction among both patients and patient ambassadors. The educational program was successful and corresponded to the experiences of performing the role of patient ambassador. No unexpected adverse events were encountered, which was attributable to the network meetings, which functioned as the patient ambassadors' own peer support network, where they could exchange experiences both as patient ambassadors and former patients. The patient ambassadors provided individualized support based on the patient's disease and symptom burden as well as preferences, resulting in few participants carrying out the recommended number of personal meetings. The conversations between the participants were most often on topics related to treatment, complications, and everyday life or family.

Third, the mentorship benefited both the patients and the patient ambassadors. The patients requested knowledge and experiences from their patient ambassadors based on the impact AL had

on their lives. The patient ambassadors experienced that their own trajectory became meaningful due to helping others by sharing their experiences with the disease and treatment. The mentorship resulted in the development of existential cohesion, which enabled mutual interreflection, where patient ambassadors gained perspectives on life and patients realized that they had opportunities and hope for a future. The feasibility of this mentorship was enhanced by the education of patient ambassadors, individualized support, and a good match. Conversely, the disease and symptom burden, as well as the unequal terms and conditions, were barriers that necessitated supervision.

Finally, despite the intensity of treatment, the complexity of the illness, and the prognosis, it was demonstrated that patient ambassador support was feasible in newly diagnosed patient with AL, and that these results provide new knowledge on a comprehensive model of patient ambassador support. The findings can help guide practice in developing a supportive care program incorporated in the hematology setting and provided across sectors, creating a collaboration between patients and patient ambassadors, supporting them in their survivorship cancer care continuum.

9. Future perspectives

9.1 Implications for clinical practice

The findings of this thesis provide several recommendations and implications for clinical practice.

First, assessing the patient's social network is essential already from the time of diagnosis with the aim of identifying available social resources and of helping to strengthen or expand the existing social network. This could potentially be carried out by supporting patients in activating their social network when diagnosed with a life-threatening illness like AL, by initiating increased support from HCPs in the clinical setting, or by initiating support from a patient ambassador. The findings highlight that the psychosocial impact of AL is considerable already from the time of diagnosis, and these patients may not be disease-fee for long periods, emphasizing the importance of supportive care interventions to begin during the initial treatment (Paper I).

Secondly, patient ambassador support should be seen as a supplement to the existing supportive care services available to patients with AL. Potentially, some HCPs may feel threatened in that the patient ambassadors are a resource that could provide care at little or no cost. Conversely, patient ambassadors may feel threatened by the authority of HCPs. Thus, it is pivotal to facilitate respectful cooperation between patient ambassadors and HCPs to generate a platform for comprehensive cancer care. Regardless, implementing patient ambassador support in clinical practice requires an infrastructure where nurses play an important role in recruiting, training, supervising, and maintaining patient ambassadors and conducting program evaluation. Nurses will always be an integral part of supportive care in cancer, which is why they will inevitably play an important role in the movement of patient ambassador support.

Thirdly, Collecting information about why patients and patient ambassadors drop out of patient ambassador support programs is proposed because this information may explain some of the weaknesses of such programs. Moreover, this information may reveal important aspects of optimal matching or important issues that should be incorporated into the educational program and network meetings.

Fourthly, consistent with previous studies, the findings in this thesis suggest that patient ambassadors must receive the necessary support, both from an educational program specifically developed for the purpose of educating patient ambassadors, and continuous support through network meetings and the possibility of initiating contact with HCPs when needed. It is therefore

recommended to initiate a patient ambassador support organization that could provide and facilitate collaboration through networks between patient ambassadors, hospitals, and the designated departments. Such an organization could benefit from having a role and impact in providing cancer care and as being an accepted part of the team of HCPs.

Fifthly, the findings indicated that patient ambassador support was relevant along the initial cancer care trajectory. Consistently, findings from other studies emphasize that many patients with cancer experience that their need for support continues after treatment has ended as the psychological challenges lie within the resumption of everyday life activities.[143,153] This also highlights the importance of being more holistic in the clinical approach and considers patient ambassador support as a part of the supportive care during treatment and survivorship in all phases of the continuum. This is needed to avoid low referral rates as a barrier to success as some patients are often not aware of the available support, while others are reluctant to seek support. This is of further importance due to the improvements in outpatient management as patients are spending increasingly less time at the hospital and receive treatment at home.

Finally, the findings from this thesis provide new knowledge that aims to guide practice in implementing future initiatives involving patient ambassador support that are potentially transferable and valuable in a broader context of patients with life-threatening illnesses.

9.2. Implications for research

The findings in this thesis provide several recommendations and implications for future research.

First, further research is needed to investigate the effects of peer support in patients with AL by using a robust, sufficiently powered, theoretically underpinned, and evaluative study design. The findings in this thesis do not provide, however, insight into specific characteristics, for instance, sex, age groups, or level of social network. Further research is required to gain knowledge on peer support within these groups and, in that way, to be able to target the support specifically based on their needs and preferences.

Secondly, research is needed to elucidate the impact of providing support and specifically explore the finding that patient ambassadors perceived their support as being less effective than did the patients. This will improve our knowledge on the benefits and challenges for the peer support providers and inform the further development educational programs for patient ambassadors.

Thirdly, research is warranted to demonstrate which outcomes are appropriate for assessing the effectiveness of peer support in patients with cancer. Most peer support studies assess physical or psychological symptoms, coping, and QoL, which results in a variety of outcome measures. Few randomized trials have found small effects of peer support in patients with cancer.[25] This may be explained by the mentioned methodology, with multiple outcomes, or it might be explained by the use of inappropriate outcomes. Still, many of these outcomes were not described by patients or patient ambassadors in this thesis. It has been suggested that more immediate outcomes are more applicable, such as the availability of social support.[25] Thus, it is recommended to include outcomes described by patients and patient ambassadors that concern their feeling of being understood, not feeling isolated, increased hope, and feeling of meaningfulness (Paper I). Regardless, due to the immediate significant symptom burden in patients with AL, it is highly relevant to demonstrate a clinically significant effect and thus establish a supportive care intervention that reduces the symptom burden in this patient group.

Fourthly, it is important to investigate the frequency and duration of support as the question still remains unanswered regarding the "dose" required to produce effective outcomes and to obtain maximal benefit in recipients and providers. Findings from others peer studies emphasize that the support may not be effective for newly diagnosed patients with cancer as distressed people may be reluctant to meet their peers and discuss their experiences. As a result, the findings suggest that the timing should be individualized.[154] Moreover, it could be relevant to examine their motivation for receiving peer support at recruitment, because when people are not open to receiving support, it may reduce the potential psychosocial impact and thus the effectiveness of the findings.

Finally, most studies have investigated the effect of peer support provided either by telephone, face-to-face, or in groups. Thus, taking a more pragmatic and individualized approach would also be relevant when designing future peer support studies in patients with cancer to increase the external validity of the findings. The findings showed that this is also necessary because patients have different preferences regarding support, and they are, to varying degrees, affected by the disease and treatment. In addition, the findings demonstrated that patients with AL requested patient ambassador support across the disease and treatment trajectory. Thus, research is needed to explore patient need and preferences for peer support across the cancer continuum in this population.

10. Summary

10.1 English summary

AL is a malignant hematological disease with considerable morbidity and mortality. The acute onset of the disease followed by intensive chemotherapy treatment results in a significant disease and treatment-related symptom burden. Social support has a beneficial effect on well-being by improving adherence with treatment, enhancing coping, and reducing symptoms. Peers with a similar disease and experiences can provide support beyond the scope of HCPs and the patient's own social network. Knowledge on the experiences of newly diagnosed patients with AL will generate a deeper understanding of their need for social support, as will investigating the feasibility of how a peer-to-peer support intervention may impact the well-being of patients and their coping with a life-threatening disease.

This Ph.D. thesis consists of three papers with the following aims: to explore how newly diagnosed patients with AL experience the diagnosis and the initial treatment, and to illuminate their need and preferences for social support (Paper I); to evaluate the feasibility of patient ambassador support in newly diagnosed patients with AL during the initial treatment (Paper II); and to explore how newly diagnosed patients with AL and their patient ambassadors experience the mentorship during patient ambassador support (Paper III).

In Paper I, the methodology included a qualitative design with semi-structured interviews to explore the experiences of 18 newly diagnosed patients with AL. In Paper II, a multicenter single-arm feasibility study was applied comprising 12 weeks of support to newly diagnosed patients (n=36) provided by patient ambassadors (n=25). The feasibility criteria were acceptability, practicability, safety and support, and resource utilization. In Paper III, a qualitative design with semi-structured interviews was used to explore experiences of the mentorship during patient ambassador support in 28 patients and patient ambassadors. A thematic analytic approach was used in Papers I and III.

In Paper I, patients experienced the acute onset of disease as traumatic, affecting autonomy and everyday life. This required restoring normalcy and re-establishing daily life activities while managing a new social identity as a cancer patient. This increased their need for social support from their own social network, HCPs, and other patients with a similar disease and experiences to facilitated coping with a life-threatening disease. Paper II demonstrated that patient ambassador support was feasible in newly diagnosed patients with AL during their initial treatment and in their

patient ambassadors. The support was carried out with no unexpected adverse events and with high satisfaction among both patients and patient ambassadors. In Paper III, the analysis revealed mutual benefits experienced by both the patients and patient ambassadors during their mentorship. The support was individualized according to patient needs and preferences, and their shared experiences created an existential cohesion that enabled mutual interreflection. This mirroring led to a sense of hope in patients and a perspective on life in patient ambassadors. The mentorship was challenged by the impact of AL in patients and by the terms and conditions faced due to AL, which also affected the educational program and supervision during network meetings for patient ambassadors.

The overall conclusion of this thesis is that the intensity, complexity, and prognosis of AL induce a need of social support and that especially support from peers is unique and beyond the scope of HCPs and their own social network. Patient ambassador support is feasible in this population, and the findings led to the development of a comprehensive model of patient ambassador support. The findings can guide practice in aiming to develop a supportive care program for patients with life-threatening cancer and lead to the creation of collaboration between patients and patient ambassadors with the aim of supporting them in their survivorship continuum of care. These steps can help newly diagnosed patients gain faith in the future and patient ambassadors gain new perspectives on life.

10.2 Danish summary (Resumé)

Akut leukæmi er en hæmatologisk kræftsygdom med betydelig sygelighed og dødelighed. Sygdommens akutte begyndelse efterfulgt af intensiv kemoterapibehandling resulterer i en betydelig sygdoms- og behandlingsrelateret symptombyrde. Social støtte har en gavnlig effekt på velvære ved at forbedre adhærens, øge mestring og reducere symptomer. Patienter med samme diagnose og oplevelser kan yde en særlig erfaringsbaseret støtte, som ofte ikke er mulig for sundhedsprofessionelle og eget socialt netværk. Viden om hvordan ny diagnosticerede patienter med akut leukæmi oplever deres sygdom og forløb vil skabe en dybere forståelse af deres behov for social støtte, og undersøgelse af gennemførbarheden af en støtte intervention mellem patienter vil kunne påvirke deres velvære og mestring af en livstruende sygdom.

Denne PhD afhandling består af tre artikler med følgende formål; (Artikel I) at undersøge hvordan ny diagnosticerede patienter med akut leukæmi oplever at få diagnosen og den initiale behandling, samt at belyse deres behov og præferencer for social støtte, (Artikel II) at evaluere

gennemførbarheden af patient ambassadør støtte til ny diagnosticerede patienter med akut leukæmi gennem deres initiale behandling, (Artikel III) at undersøge hvordan ny diagnosticerede patienter med akut leukæmi og deres patient ambassadører oplever patient ambassadør støtte forløbet.

I artikel I var metodologien et kvalitativt design med individuelle semi-strukturerede interviews af ny 18 diagnosticerede patienter med akut leukæmi. Artikel II bestod af et multicenter en-armet feasibility design bestående af 12-ugers patient ambassadør støtte til ny diagnosticerede patienter med akut leukæmi (n=36) udført af patient ambassadører (n=25). Kriterier for gennemførbarhed var accepterbarhed, gennemførlighed, sikkerhed og støtte samt ressourcer. I artikel III, blev et kvalitativt design anvendt med 28 individuelle semi-strukturerede interviews for at undersøge patienter og patient ambassadørers oplevelser af deres forløb med patient ambassadør støtte. En tematisk analytisk tilgang blev anvendt i artikel I and III.

I artikel I oplevede patienter sygdommens akutte begyndelse som traumatisk, hvilket påvirkede deres autonomi og hverdagsliv. Dette nødvendiggjorde en genoprettelse af normalitet og reetablering af dagligdags aktiviteter imens en ny social identitet som kræftpatient blev mestret. Dette øgede deres behov for social støtte fra eget socialt netværk, sundhedsprofessionelle og andre patienter med samme diagnose og oplevelser, hvilket faciliterede mestring af at leve med en livstruende sygdom. Artikel II demonstrerede, at patient ambassador støtte var gennemførbart hos ny diagnosticerede patienter med akut leukæmi under deres initiale behandling og deres patient ambassadører. Støtten blev givet uden uventede følgevirkninger og med stor tilfredshed hos både patienter og patient ambassadører. I artikel III viste analysen, at patienter og patient ambassadører oplevede gensidig fordel af mentorordningen. Støtten var individualiseret ud fra patientens behov og præferencer, og deres fælles oplevelser skabte en eksistentiel samhørighed som muliggjorde interreflektion. Denne spejling førte til en følelse af håb hos patienter og nyt perspektiv på livet hos patient ambassadører. Mentorordningen var udfordret af patientens belastningsgrad fra sygdom og behandling samt begge parters betingelser og vilkår som følge af akut leukæmi, hvilket forstærker behovet for uddannelsesprogrammet og supervision gennem netværksmøder for patient ambassadører.

Den overordnede konklusion for denne afhandling er, at intensiteten, kompleksiteten og prognosen for AL øger behovet for social støtte, og særligt støtte fra ligesindede anses som unik og ikke mulig for sundhedsprofessionelle og eget socialt netværk. Patient ambassadør støtte er gennemførbart hos denne population, og fundene har ført til udviklingen af en helhedsorienteret model for patient ambassadør støtte. Resultaterne kan guide praksis med det formål, at sammensætte et tilbud

indenfor den støttende behandling til patienter med livstruende kræft, og skabe et unikt samarbejde mellem patienter med det formål at støtte dem i deres overlevelseskontinuum af behandling og rehabilitering. Herved kan nye patienter opnå en tro på at en fremtid er mulig, og patient ambassadører kan få nye perspektiver på livet.

11. References

1. Malard F, Mohty M. Acute lymphoblastic leukaemia. *Lancet.* 2020;395(10230):1146-1162.
2. De Kouchkovsky I, Abdul-Hay M. Acute myeloid leukemia: a comprehensive review and 2016 update. *Blood cancer journal.* 2016;6(7):e441.
3. Shallis RM, Wang R, Davidoff A, Ma X, Zeidan AM. Epidemiology of acute myeloid leukemia: Recent progress and enduring challenges. *Blood reviews.* 2019;36:70-87.
4. Tomaszewski EL, Fickley CE, Maddux L, et al. The Patient Perspective on Living with Acute Myeloid Leukemia. *Oncology and therapy.* 2016;4(2):225-238.
5. Koehler M, Koehler K, Koenigsmann M, Kreutzmann N, Fischer T, Frommer J. Beyond diagnosis: subjective theories of illness in adult patients with acute myeloid leukemia. *Hematology (Amsterdam, Netherlands).* 2011;16(1):5-13.
6. Zimmermann C, Yuen D, Mischitelle A, et al. Symptom burden and supportive care in patients with acute leukemia. *Leukemia research.* 2013;37(7):731-736.
7. Manitta V, Zordan R, Cole-Sinclair M, Nandurkar H, Philip J. The symptom burden of patients with hematological malignancy: a cross-sectional observational study. *Journal of pain and symptom management.* 2011;42(3):432-442.
8. Albrecht TA, Boyiadzis M, Elswick RK, Jr., Starkweather A, Rosenzweig M. Symptom Management and Psychosocial Needs of Adults With Acute Myeloid Leukemia During Induction Treatment: A Pilot Study. *Cancer nursing.* 2017;40(6):E31-e38.
9. Stein Kaasa FMK, Faith Mwangi-Powell, Gary Rodin. Supportive care in cancer: new directions to achieve universal access to psychosocial, palliative, and end-of-life care. *The Lancet Global Health,*. 2018;Volume 6, Supplement 1.
10. Kristiansen M, Adamsen L, Brinkmann FK, Krasnik A, Hendriksen C. Need for strengthened focus on cancer rehabilitation in Danish municipalities. *Danish medical journal.* 2015;62(4):5045.
11. *Patienternes Kræftplan: Kræftplan IV [The Patient´s Cancer Plan: National Cancer Plan IV].* Copenhagen: Regeringen [Danish Government];2016.
12. Fridthjof KS, Kampmann P, Dunweber A, et al. Systematic patient involvement for homebased outpatient administration of complex chemotherapy in acute leukemia and lymphoma. *British journal of haematology.* 2018;181(5):637-641.
13. Vaughn JE, Buckley SA, Walter RB. Outpatient care of patients with acute myeloid leukemia: Benefits, barriers, and future considerations. *Leukemia research.* 2016;45:53-58.
14. Thuesen J RK, Frausing S, Tang HL, Broby TM. *Kræftrehabilitering i Danmark– kortlægning af praksis på hospitaler og i kommuner.* The Danish Knowledge Centre for Rehabilitation and Palliative Care (REPHA);2017.
15. Applebaum AJ, Stein EM, Lord-Bessen J, Pessin H, Rosenfeld B, Breitbart W. Optimism, social support, and mental health outcomes in patients with advanced cancer. *Psycho-oncology.* 2014;23(3):299-306.
16. Deno M, Tashiro M, Miyashita M, et al. The mediating effects of social support and self-efficacy on the relationship between social distress and emotional distress in head and neck cancer outpatients with facial disfigurement. *Psycho-oncology.* 2012;21(2):144-152.
17. Kornblith AB, Herndon JE, 2nd, Zuckerman E, et al. Social support as a buffer to the psychological impact of stressful life events in women with breast cancer. *Cancer.* 2001;91(2):443-454.
18. Leung J, Pachana NA, McLaughlin D. Social support and health-related quality of life in women with breast cancer: a longitudinal study. *Psycho-oncology.* 2014;23(9):1014-1020.

19. Haugland T, Wahl AK, Hofoss D, DeVon HA. Association between general self-efficacy, social support, cancer-related stress and physical health-related quality of life: a path model study in patients with neuroendocrine tumors. *Health Qual Life Outcomes.* 2016;14:11.
20. Weber BA, Roberts BL, Yarandi H, Mills TL, Chumbler NR, Wajsman Z. The impact of dyadic social support on self-efficacy and depression after radical prostatectomy. *Journal of aging and health.* 2007;19(4):630-645.
21. Liang Y, Wang H, Niu M, Zhu X, Cai J, Wang X. Longitudinal Analysis of the Relationships Between Social Support and Health-Related Quality of Life in Hematopoietic Stem Cell Transplant Recipients. *Cancer nursing.* 2019;42(3):251-257.
22. Lutgendorf SK, Sood AK, Anderson B, et al. Social support, psychological distress, and natural killer cell activity in ovarian cancer. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology.* 2005;23(28):7105-7113.
23. Pistrang N, Jay Z, Gessler S, Barker C. Telephone peer support for women with gynaecological cancer: recipients' perspectives. *Psycho-oncology.* 2012;21(10):1082-1090.
24. Watson EM, S. *Peer support in mental health.* UK: Red Globe Press 2019.
25. Lee MK, Suh SR. Effects of Peer-Led Interventions for Patients With Cancer: A Meta-Analysis. *Oncology nursing forum.* 2018;45(2):217-236.
26. Meyer A, Coroiu A, Korner A. One-to-one peer support in cancer care: a review of scholarship published between 2007 and 2014. *European journal of cancer care.* 2015;24(3):299-312.
27. Macvean ML, White VM, Sanson-Fisher R. One-to-one volunteer support programs for people with cancer: a review of the literature. *Patient education and counseling.* 2008;70(1):10-24.
28. Hoey LM, Ieropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. *Patient education and counseling.* 2008;70(3):315-337.
29. Piil K, Jarden M, Pii KH. Research agenda for life-threatening cancer. *European journal of cancer care.* 2019;28(1):e12935.
30. Terwilliger T, Abdul-Hay M. Acute lymphoblastic leukemia: a comprehensive review and 2017 update. *Blood cancer journal.* 2017;7(6):e577.
31. Hoffman RB, EJ. Silberstein, LE. Heslop, H. Weitz, J. Anastasi, J. *Hematology - Basic Principles and Practice.* 7 th ed: Elsevier; 2018.
32. Blackburn LM, Bender S, Brown S. Acute Leukemia: Diagnosis and Treatment. *Seminars in oncology nursing.* 2019;35(6):150950.
33. Afdeling for Cancer og Cancerscreening RKKR. *Dansk Akut Leukæmi Database & Myelodysplastisk Syndrom Database: National årsrapport 2018.* Regionernes Kliniske Kvalitetsudviklingsprogram;2018.
34. Paul S, Kantarjian H, Jabbour EJ. Adult Acute Lymphoblastic Leukemia. *Mayo Clinic proceedings.* 2016;91(11):1645-1666.
35. Singh AK, McGuirk JP. Allogeneic Stem Cell Transplantation: A Historical and Scientific Overview. *Cancer research.* 2016;76(22):6445-6451.
36. Ogonek J, Kralj Juric M, Ghimire S, et al. Immune Reconstitution after Allogeneic Hematopoietic Stem Cell Transplantation. *Frontiers in immunology.* 2016;7:507.
37. Nissim R, Rodin G, Schimmer A, et al. Finding new bearings: a qualitative study on the transition from inpatient to ambulatory care of patients with acute myeloid leukemia. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer.* 2014;22(9):2435-2443.
38. Walter RB, Taylor LR, Gardner KM, Dorcy KS, Vaughn JE, Estey EH. Outpatient management following intensive induction or salvage chemotherapy for acute myeloid leukemia. *Clinical advances in hematology & oncology : H&O.* 2013;11(9):571-577.

39. Moller T, Nielsen OJ, Welinder P, et al. Safe and feasible outpatient treatment following induction and consolidation chemotherapy for patients with acute leukaemia. *European journal of haematology.* 2010;84(4):316-322.
40. Hoelzer D, Bassan R, Dombret H, Fielding A, Ribera JM, Buske C. Acute lymphoblastic leukaemia in adult patients: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of oncology : official journal of the European Society for Medical Oncology.* 2016;27(suppl 5):v69-v82.
41. Heuser M, Ofran Y, Boissel N, et al. Acute myeloid leukaemia in adult patients: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of oncology : official journal of the European Society for Medical Oncology.* 2020.
42. Rodin G, Deckert A, Tong E, et al. Traumatic stress in patients with acute leukemia: A prospective cohort study. *Psycho-oncology.* 2018;27(2):515-523.
43. Gheihman G, Zimmermann C, Deckert A, et al. Depression and hopelessness in patients with acute leukemia: the psychological impact of an acute and life-threatening disorder. *Psycho-oncology.* 2016;25(8):979-989.
44. Albrecht TA. Physiologic and psychological symptoms experienced by adults with acute leukemia: an integrative literature review. *Oncology nursing forum.* 2014;41(3):286-295.
45. Nissim R, Zimmermann C, Minden M, et al. Abducted by the illness: a qualitative study of traumatic stress in individuals with acute leukemia. *Leukemia research.* 2013;37(5):496-502.
46. Galway K, Black A, Cantwell M, Cardwell CR, Mills M, Donnelly M. Psychosocial interventions to improve quality of life and emotional wellbeing for recently diagnosed cancer patients. *The Cochrane database of systematic reviews.* 2012;11:Cd007064.
47. Fitch MI. Supportive care framework. *Canadian oncology nursing journal = Revue canadienne de nursing oncologique.* 2008;18(1):6-24.
48. National Cancer Institute (NCI). Dictionary of Cancer Terms: supportive care https://www.cancer.gov/publications/dictionaries/cancer-terms/def/supportive-care. Accessed April 27, 2020
49. Klastersky JA, Fontaine C, Force obotBSCT. Editorial: Supportive care in cancer patients: a constantly evolving field. *Current Opinion in Oncology.* 2019;31(4):257-258.
50. Cannas G, Thomas X. Supportive care in patients with acute leukaemia: historical perspectives. *Blood transfusion = Trasfusione del sangue.* 2015;13(2):205-220.
51. Sive J, Ardeshna KM, Cheesman S, et al. Hotel-based ambulatory care for complex cancer patients: a review of the University College London Hospital experience. *Leukemia & lymphoma.* 2012;53(12):2397-2404.
52. Hall AE, Sanson-Fisher RW, Lynagh MC, Tzelepis F, D'Este C. What do haematological cancer survivors want help with? A cross-sectional investigation of unmet supportive care needs. *BMC research notes.* 2015;8:221.
53. Tsai AC, Papachristos AV. From social networks to health: Durkheim after the turn of the millennium. Introduction. *Social science & medicine (1982).* 2015;125:1-7.
54. Uchino BN, Bowen K, Carlisle M, Birmingham W. Psychological pathways linking social support to health outcomes: a visit with the "ghosts" of research past, present, and future. *Social science & medicine (1982).* 2012;74(7):949-957.
55. Cohen SU, LG. Gottlieb, BH. *Social support measurement and intervention. A guide for health and social scientists.* New York: Oxford University Press; 2000.
56. Margolis M, Austin J, Wu L, et al. Effects of Social Support Source and Effectiveness on Stress Buffering After Stem Cell Transplant. *International journal of behavioral medicine.* 2019;26(4):391-400.

57. Rini C, Redd WH, Austin J, et al. Effectiveness of partner social support predicts enduring psychological distress after hematopoietic stem cell transplantation. *Journal of consulting and clinical psychology.* 2011;79(1):64-74.
58. Wells KJ, Booth-Jones M, Jacobsen PB. Do coping and social support predict depression and anxiety in patients undergoing hematopoietic stem cell transplantation? *Journal of psychosocial oncology.* 2009;27(3):297-315.
59. Hochhausen N, Altmaier EM, McQuellon R, et al. Social support, optimism, and self-efficacy predict physical and emotional well-being after bone marrow transplantation. *Journal of psychosocial oncology.* 2007;25(1):87-101.
60. Pinquart M, Hoffken K, Silbereisen RK, Wedding U. Social support and survival in patients with acute myeloid leukaemia. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer.* 2007;15(1):81-87.
61. Riessman F. Restructuring help: A human services paradigm for the 1990s. *American Journal of Community Psychology.* 1990;18(2):221-230.
62. Penney D. Defining "peer support": Implications for Policy, Practice and Research. 2018; https://www.ahpnet.com/AHPNet/media/AHPNetMediaLibrary/White%20Papers/DPenney_Defining_peer_support_2018_Final.pdf. Accessed May 18, 2020.
63. Campbell HS, Phaneuf MR, Deane K. Cancer peer support programs-do they work? *Patient education and counseling.* 2004;55(1):3-15.
64. Meyer A, Moran C, Fitzpatrick T, Ernst J, Korner A. Oncology Volunteers: The Effect of a Personal Cancer History on Compassion and Psychological Well-Being. *Clinical journal of oncology nursing.* 2018;22(4):398-406.
65. Riessman F. The "helper" therapy principle. *Social Work.* 1965;10(2):27-32.
66. Weiner D. The apprenticeship of Philippe Pinel: a new document, “Observations of Citizen Pussin on the Insane”. *The Americal journal of psychiatry.* 1979;36:1128-1134.
67. Davidson L, Bellamy C, Guy K, Miller R. Peer support among persons with severe mental illnesses: a review of evidence and experience. *World Psychiatry.* 2012;11(2):123-128.
68. Korsbek LP, L. Peer support in the mental health services settings -what are the effects? . *Tidsskrift for psykisk helsearbeid.* 2016;4(12):288-304.
69. korsbek L. How to Recover? Recovery in Denmark: A Work in Progress. *Journal of Recovery in Mental Health.* 2017;1(1).
70. Park HY, Kim MJ, Kim JY, et al. Could Peer Support Programs Be a Good Resource for Managing the Unmet Needs of Cancer Patients? *Journal of cancer education : the official journal of the American Association for Cancer Education.* 2019;34(5):950-957.
71. Boyes A, Turon H, Hall A, Watson R, Proietto A, Sanson-Fisher R. Preferences for models of peer support in the digital era: A cross-sectional survey of people with cancer. *Psycho-oncology.* 2018;27(9):2148-2154.
72. Skirbekk H, Korsvold L, Finset A. To support and to be supported. A qualitative study of peer support centres in cancer care in Norway. *Patient education and counseling.* 2018;101(4):711-716.
73. Pistrang N, Jay Z, Gessler S, Barker C. Telephone peer support for women with gynaecological cancer: benefits and challenges for supporters. *Psycho-oncology.* 2013;22(4):886-894.
74. Myrhoj CB, Norskov KH, Jarden M, Rydahl-Hansen S. The motivation to volunteer as a peer support provider to newly diagnosed patients with acute leukemia - A qualitative interview study. *European journal of oncology nursing : the official journal of European Oncology Nursing Society.* 2020;46:101750.
75. Skaalvik EM, Skaalvik S. *Motivation for læring : teori og praksis.* Frederikshavn: Dafolo; 2015.

76. Suh SR, Lee MK. Effects of Nurse-Led Telephone-Based Supportive Interventions for Patients With Cancer: A Meta-Analysis. *Oncology nursing forum.* 2017;44(4):E168-e184.
77. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychological bulletin.* 1985;98(2):310-357.
78. Festinger L. A Theory of Social Comparison Processes. *Human Relations.* 1954;7(2):117-140.
79. Wheeler LS, J. A History of Social Comparison Theory. In: *Social Comparison, Judgment, and Behavior.* Oxford University Press; 2020.
80. Tennen H, McKee T, Affleck G. Handbook of Social Comparison Theory and Research. In: *Social Comparison Processes in Health and Illness.* Springer Science+Bussiness Media; 2000:443-483.
81. Suls J. Social Comparison Processes: Implications for Physical Health. In: *The Oxford Handbook of Health Psychology.* Oxford University Press; 2011.
82. Suls J, and Ladd. Wheeler. *Handbook of Social Comparison Theory and Research.* New York: Springer Science+Business Media; 2000.
83. Dennis CL. Peer support within a health care context: a concept analysis. *International journal of nursing studies.* 2003;40(3):321-332.
84. Albert HB, JD. Designing Multimethod Research. In: *The Oxford Handbook of Multimethod and Mixed Methods Research Inquiry.* Oxford University Press; 2015.
85. Kvale S, Brinkmann S. InterView: Learning the Craft of Qualitative Research Interviewing. In. Thired ed: Sage, New Delhi; 2015.
86. Gadamer H. *Truth and Method.* Bloomsbury Publishing Plc; 2013.
87. Thorne S. *Interpretive Description: Qualitative research for applied practice* New York Routledge; 2016.
88. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology.* 2006;3(2):77-101.
89. Bowen DJ, Kreuter M, Spring B, et al. How we design feasibility studies. *American journal of preventive medicine.* 2009;36(5):452-457.
90. National Institute for Health Research. NIHR evaluation, Trials and Studies Coordination Centre: Glossary. https://www.nihr.ac.uk/glossary?letter=F&postcategory=-1. Accessed April 21, 2020.
91. Orsmond GI, Cohn ES. The Distinctive Features of a Feasibility Study: Objectives and Guiding Questions. *OTJR : occupation, participation and health.* 2015;35(3):169-177.
92. Coulter A. *Engaging Patients In Healthcare* Open University Press; 2011.
93. Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. *BMC health services research.* 2014;14:89.
94. Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, et al. Patient and service user engagement in research: a systematic review and synthesized framework. *Health expectations : an international journal of public participation in health care and health policy.* 2015;18(5):1151-1166.
95. Ennis L, Wykes T. Impact of patient involvement in mental health research: longitudinal study. *The British journal of psychiatry : the journal of mental science.* 2013;203(5):381-386.
96. Sullivan P, Goldmann D. The promise of comparative effectiveness research. *Jama.* 2011;305(4):400-401.
97. Pii KH, Schou LH, Piil K, Jarden M. Current trends in patient and public involvement in cancer research: A systematic review. *Health expectations : an international journal of public participation in health care and health policy.* 2019;22(1):3-20.
98. Brett J, Staniszewska S, Mockford C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health expectations :*

an international journal of public participation in health care and health policy. 2014;17(5):637-650.
99. Polit F, Beck C. *Nursing research: Generating and Assessing Evidence for Nursing Practice* Eleventh edition ed: Wolters Kulwer; 2020.
100. McCaffrey G, Raffin-Bouchal S, Moules NJ. Hermeneutics as Research Approach: A Reappraisal. *International Journal of Qualitative Methods.* 2012;11(3):214-229.
101. Gadamer H, Palmer R. *The Gadamer Reader: a Bouquet of the Later Writings.* Evaston,ill: Northwestern University; 2007.
102. Barthold LSG. *Gadamer's Dialectical Hermeneutics.* Lanham: Md: Lexington Books; 2010.
103. Thorne S, Kirkham SR, O'Flynn-Magee K. The Analytic Challenge in Interpretive Description. *International Journal of Qualitative Methods.* 2004;3(1):1-11.
104. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative health research.* 2015.
105. Etikan I. Comparison of Convenience Sampling and Purposive Sampling. *American Journal of Theoretical and Applied Statistics.* 2016;5:1.
106. Christensen S, Jensen B. *Didaktik og patientundervisning.* København: Gads Forlag; 2003.
107. Matthews C. Critical Pedagogy in Health Education. *Health Education Journal.* 2014;73(5):600-609.
108. Romas JS, M. *Theoretical Foundations of Health Education and Health Promotion* Sudbury: MA: Jones & Bartlett Learning; 2012.
109. Nutbeam D. Health promotion glossary. *Health promot Int* 1998;13(4).
110. Crabtree BF, Miller WL. *Doing Qualitative Research.* SAGE publications; 1999.
111. Albrecht TA, Rosenzweig M. Distress in patients with acute leukemia: a concept analysis. *Cancer nursing.* 2014;37(3):218-226.
112. Uchino B P. *Social support and physical health: understanding the health consequences of relationships.* New Haven: Yale University Press; 2004.
113. Hall A, D'Este C, Tzelepis F, Lynagh M, Sanson-Fisher R. Factors associated with haematological cancer survivors experiencing a high level of unmet need across multiple items of supportive care: a cross-sectional survey study. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer.* 2014;22(11):2899-2909.
114. Koehler M, Koenigsmann M, Frommer J. Coping with illness and subjective theories of illness in adult patients with haematological malignancies: systematic review. *Critical reviews in oncology/hematology.* 2009;69(3):237-257.
115. Koenigsmann M, Koehler K, Regner A, Franke A, Frommer J. Facing mortality: a qualitative in-depth interview study on illness perception, lay theories and coping strategies of adult patients with acute leukemia 1 week after diagnosis. *Leukemia research.* 2006;30(9):1127-1134.
116. Suls J, Miller R. Social comparison theory and research: an overview from 1954. In: *Social Comparison Processes.* London John Wiley & Sons; 1977:1-17.
117. Rudy RR, Rosenfeld LB, Galassi JP, Parker J, Schanberg R. Participants' perceptions of a peer-helper, telephone-based social support intervention for melanoma patients. *Health communication.* 2001;13(3):285-305.
118. Ussher J, Kirsten L, Butow P, Sandoval M. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social science & medicine (1982).* 2006;62(10):2565-2576.
119. Legg M, Occhipinti S, Ferguson M, Dunn J, Chambers SK. When peer support may be most beneficial: the relationship between upward comparison and perceived threat. *Psycho-oncology.* 2011;20(12):1358-1362.

120. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta psychiatrica Scandinavica.* 1983;67(6):361-370.
121. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *Journal of psychosomatic research.* 2002;52(2):69-77.
122. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute.* 1993;85(5):365-376.
123. Cella D, Jensen SE, Webster K, et al. Measuring health-related quality of life in leukemia: the Functional Assessment of Cancer Therapy--Leukemia (FACT-Leu) questionnaire. *Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research.* 2012;15(8):1051-1058.
124. Cleeland CS, Mendoza TR, Wang XS, et al. Assessing symptom distress in cancer patients: the M.D. Anderson Symptom Inventory. *Cancer.* 2000;89(7):1634-1646.
125. Williams LA, Garcia Gonzalez AG, Ault P, et al. Measuring the symptom burden associated with the treatment of chronic myeloid leukemia. *Blood.* 2013;122(5):641-647.
126. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health services research.* 2004;39(4 Pt 1):1005-1026.
127. Rademakers J, Maindal HT, Steinsbekk A, Gensichen J, Brenk-Franz K, Hendriks M. Patient activation in Europe: an international comparison of psychometric properties and patients' scores on the short form Patient Activation Measure (PAM-13). *BMC health services research.* 2016;16(1):570.
128. Johnston M WS, Weinman J. *Measures in Health Psychology: A User's Portfolio.* UK: Windsor: NFER-NELSON; 1995.
129. QSR International Pty Ltd. Version 10. NVivo qualitative data analysis Software. 2015.
130. Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods.* 2017;16(1):1609406917733847.
131. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: Building an international community of software platform partners. *Journal of biomedical informatics.* 2019;95:103208.
132. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)-a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of biomedical informatics.* 2009;42(2):377-381.
133. The R project for statistical computing. https://www.R-project.org/. Accessed April 25, 2020.
134. Whitehead AL, Julious SA, Cooper CL, Campbell MJ. Estimating the sample size for a pilot randomised trial to minimise the overall trial sample size for the external pilot and main trial for a continuous outcome variable. *Statistical methods in medical research.* 2016;25(3):1057-1073.
135. Billingham SA, Whitehead AL, Julious SA. An audit of sample sizes for pilot and feasibility trials being undertaken in the United Kingdom registered in the United Kingdom Clinical Research Network database. *BMC medical research methodology.* 2013;13:104.
136. Beauchamps T, Childress J. *Principles of biomedical ethics.* Oxford: Oxford University Press 2001.
137. Friis LS. *Sygdomsopfattelse og behandlingserfaring hos intensivt behandlede patienter med akut myeloid leukæmi.* Odense: Det Sundhedsvidenskabelige Fakultet, Syddansk Universitet; 2003.

138. Jepsen LØ. *Outpatient management of acute leukemia patients. The experiences of patients and their relatives*. Odense: Det Sundhedsvidenskabelige Fakultet, Syddansk Universitet; 2016.
139. Papadopoulou C, Johnston B, Themessl-Huber M. The experience of acute leukaemia in adult patients: a qualitative thematic synthesis. *European journal of oncology nursing : the official journal of European Oncology Nursing Society.* 2013;17(5):640-648.
140. Chi GC. The role of hope in patients with cancer. *Oncology nursing forum.* 2007;34(2):415-424.
141. Butt CM. Hope in adults with cancer: state of the science. *Oncology nursing forum.* 2011;38(5):E341-350.
142. Proserpio T, Ferrari A, Lo Vullo S, et al. Hope in cancer patients: the relational domain as a crucial factor. *Tumori.* 2015;101(4):447-454.
143. Watts TE, Bower J. Still lost in transition: a qualitative descriptive study of people's experiences following treatment completion for haematological cancer in Wales, UK. *Ecancermedicalscience.* 2019;13:985.
144. Raphael D, Frey R, Gott M. Psychosocial distress in haematological cancer survivors: An integrative review. *European journal of cancer care.* 2017;26(6).
145. Kowitt SD, Ellis KR, Carlisle V, et al. Peer support opportunities across the cancer care continuum: a systematic scoping review of recent peer-reviewed literature. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer.* 2019;27(1):97-108.
146. Walshe C, Roberts D. Peer support for people with advanced cancer: a systematically constructed scoping review of quantitative and qualitative evidence. *Current opinion in supportive and palliative care.* 2018;12(3):308-322.
147. Ieropoli SC, White VM, Jefford M, Akkerman D. What models of peer support do people with colorectal cancer prefer? *European journal of cancer care.* 2011;20(4):455-465.
148. Lincoln Y, Guba E. *Naturalistic Inquiry.* Newbury Park: Sage; 1985.
149. Persson L, Hallberg IR, Ohlsson O. Survivors of acute leukaemia and highly malignant lymphoma--retrospective views of daily life problems during treatment and when in remission. *Journal of advanced nursing.* 1997;25(1):68-78.
150. Shadish WC, TD. Campbell DT. *Experimental and qasi-experimental designs for generalized causal inference.* Vol 2nd ed. Boston MA:Houghton Mifflin; 2002.
151. Barker CP, N. Elliott, R. *Research Methods in Clinical Psychology. An introduction for students and practitioners.* Third Edition ed: Wiley Blackwell 2016.
152. Maringwa J, Quinten C, King M, et al. Minimal clinically meaningful differences for the EORTC QLQ-C30 and EORTC QLQ-BN20 scales in brain cancer patients. *Annals of oncology : official journal of the European Society for Medical Oncology.* 2011;22(9):2107-2112.
153. Lobb EA, Joske D, Butow P, et al. When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. *Patient education and counseling.* 2009;77(1):103-108.
154. Lee R, Lee KS, Oh EG, Kim SH. A randomized trial of dyadic peer support intervention for newly diagnosed breast cancer patients in Korea. *Cancer nursing.* 2013;36(3):E15-22.

12. Appendices

Paper I Patients` experiences and social support needs following the diagnosis and initial treatment of acute leukemia: a qualitative study.
Norskov, K.H., Overgaard, D., Lomborg, K., Kjeldsen, L., & Jarden, M.

Paper II M. (2020). Patient ambassador support in newly diagnosed patients with acute leukemia during the initial treatment: a feasibility study.
Norskov, K.H., Overgaard, D., Boesen, J., Struer, A., El-Azem, S.E.W.D., Tolver, A., Lomborg, K., Kjeldsen, L., & Jarden.

Paper III Patient Ambassador Support: experiences of the mentorship between newly diagnosed patients with acute leukemia and their patient ambassadors.
Norskov, K.H., Overgaard, D., Lomborg, K., Kjeldsen, L., & Jarden, M.

Appendix I: Project logo and recruitment material

Appendix II: Patient ambassador educational training program

Appendix III: Patient ambassador information dossier

Appendix IV: Co authorship declarations

PAPER I

Patients` experiences and social support needs following the diagnosis and initial treatment of acute leukemia – a qualitative study

Kristina Norskov,
Dorthe Overgaard, Kirsten Lomborg,
Lars Kjeldsen & Mary Jarden

European Journal of Oncology Nursing 41 (2019) 49–55

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Patients' experiences and social support needs following the diagnosis and initial treatment of acute leukemia - A qualitative study

Kristina Holmegaard Nørskov[a,*], Dorthe Overgaard[b], Kirsten Lomborg[c], Lars Kjeldsen[a], Mary Jarden[a,d]

[a] Department of Hematology, Rigshospitalet, Blegdamsvej 9, 2100, Copenhagen Ø, Copenhagen University Hospital, Denmark
[b] Metropolitan University College, Tagensvej 18, 2200, Copenhagen N, Denmark
[c] Department of Clinical Medicine, Aarhus University, Paalle Juul-Jensens Boulevard 82, 8200, Aarhus N, Denmark
[d] Department of Public Health, Blegdamsvej 3B, 2200, Copenhagen N, University of Copenhagen, Copenhagen, Denmark

ARTICLE INFO

Keywords:
Acute leukemia
Acute myeloid leukemia
Acute lymphatic leukemia
Qualitative interviews
Autonomy
Social support
Peer support

ABSTRACT

Purpose: This study explores how newly diagnosed patients with acute leukemia (AL) experience the diagnosis and the initial treatment, and their need and preferences for social support.
Methods: Explorative semi-structured individual interviews were carried out in patients with AL (n = 18) four to sixteen weeks post diagnosis. Thematic analysis was used to analyze the qualitative interview data.
Results: Identified themes were 1) Jolted by the diagnosis, and subtheme Loss of personal autonomy; 2) Restoring normality in everyday life, and subtheme Facing a new social identity; and 3) A lifeline of hope. Being newly diagnosed with AL was experienced as traumatic, which negatively affected personal autonomy and everyday life. There was a pressing need to restore a sense of normality in everyday life while managing a new social identity as a cancer patient. Social support from family, friends and other patients were invaluable and experienced as an important lifeline.
Conclusion: Receiving a life threatening diagnose and undergoing chemotherapeutic treatment had a negative impact on everyday life which required re-establishing daily life activities. This increased the need for social support which had a distinct role in facilitating the patients' coping strategy.
Clinical implications: It is important to support and strengthen the patient's social network from the time of diagnosis. Future studies should examine the feasibility and benefit of experienced-based social support from peers (former patients) to patients with AL.

1. Introduction

Acute Leukemia (AL) is a life-threatening hematological malignancy associated with considerable morbidity and mortality (Arber et al., 2016; Ferrara and Schiffer, 2013). AL trajectory differs from most other cancer forms in having an acute onset followed by an intensive treatment regimen which is often complicated by serious infections and a substantial symptom burden (Ferrara and Schiffer, 2013). A significant disease and treatment-related symptom burden can impede return to prior levels of functioning and result in a limitation of everyday activities during and after treatment (Zimmermann et al., 2013). Advancements in medical treatment and supportive care have improved overall 1-year survival (Bray et al., 2018; Manitta et al., 2011; Tomaszewski et al., 2016). There is a trend towards treating patients with hematological malignancy with homecare-based chemotherapy (Ferrara and Schiffer, 2013; Fridthjof et al., 2018; Nissim et al., 2014).

Living with AL challenges the patients' physical, psychological and social wellbeing from the time of diagnosis (Koehler et al., 2011; Tomaszewski et al., 2016). A qualitative synthesis from 2013 (Papadopoulou et al., 2013) found that patients with AL used different coping strategies to make sense of and accommodate the illness in their everyday life. Yet, there is limited evidence on the experiences of adults with newly diagnosed acute leukemia. Previous research on the supportive care needs of patients with hematological disease including AL has demonstrated several unmet needs (Boyes et al., 2015; Hall et al., 2014). Most studies are quantitative cross-sectional surveys focusing on the physical and psychological symptoms and their associated supportive care needs.

* Corresponding author.
E-mail addresses: Kristina.holmegaard.noerskov@regionh.dk (K.H. Nørskov), doov@phmetropol.dk (D. Overgaard), kl@clin.au.dk (K. Lomborg), lars.kjeldsen.01@regionh.dk (L. Kjeldsen), mary.jarden@regionh.dk (M. Jarden).

https://doi.org/10.1016/j.ejon.2019.05.005
Received 22 November 2018; Received in revised form 15 May 2019; Accepted 30 May 2019

Social support can potentially lessen the strains posed by AL and at the same time improve autonomy (Papadopoulou et al., 2013). This is consistent with the 'buffering model' (Cohen and Wills, 1985) which describes social support as having beneficial effects on well-being. The model posits that social support protects people from the potential influence of stressful events. Several studies support the influence of social support on improving adherence with treatment and enhancing coping and health behavior (Cohen and Herbert, 1996; Pinquart et al., 2007; Shinn et al., 1977). From a biological perspective evidence links social support to a strengthened immune function, improved neuroendocrine function and better survival in patients with AML (Cohen and Herbert, 1996; Pinquart et al., 2007; Shinn et al., 1977). Limited evidence exists on social support needs of patients with AL throughout the course of treatment. This is important in the new context of improved medical treatment, management of chemotherapy and administration of patient care.

The purpose of this qualitative study was to explore how newly diagnosed patients with AL experience the diagnosis and the initial treatment, and to illuminate their need and preferences for social support. Knowledge from this study will strengthen the existing expertise of health professionals by generating a deeper understanding of the experiences of newly diagnosed patients with AL, and therefore have a significant impact on the patients emotional and social well-being as well as ability to cope with a life-threatening disease.

2. Methods

This exploratory qualitative interview study was based on a semi-structured interview guide (Fig. 1).

2.1. Participants

The study was conducted at the Departments of Hematology at University Hospital of Copenhagen, Rigshospitalet, Herlev and Gentofte Hospital and University Hospital of Odense. The sample included 18 newly diagnosed patients with acute leukemia (AL) including Acute Myeloid Leukemia (AML) and Acute Lymphatic Leukemia (ALL) who were approached by the primary investigator Kristina Holmegaard Nørskov (KHN) at the in- or out-patient clinic in the period of June 2017 to January 2018.

Inclusion criteria were patients ≥18 years old, between four to sixteen weeks post diagnosis of AL receiving chemotherapy, who provided informed written consent and were able to understand, speak and read Danish. The exclusion criteria were cognitive disorders and unstable medical conditions e.g. dementia or refractory disease as these conditions could potentially influence the experience of the disease and needs of social support in a different way. Patients eligibility were assessed by KHN who is a clinical nurse specialist with special knowledge of hematological malignancy. They were recruited by purposeful sampling strategy and eligible patients were introduced to the study by KHN.

2.2. Data collection

The interview guide was based on the current evidence and prior clinical experience to identify the theoretical and analytic categories for the topics of research (Albrecht et al., 2016; Hall et al., 2013; Meyer et al., 2015; Tomaszewski et al., 2016; Uchino B, 2004). The guide covered four main topics related to the experience of being diagnosed with AL and the need for social support (Fig. 1). The sequence of questioning during the individual interviews allowed for flexibility according to the informant's responses (Crabtree and Miller (1999). Floating prompts (silence, eyebrow flash, reflective summary etc.) were used to keep the story flowing (Crabtree and Miller, 1999). Respondents had the choice of being interviewed at home or at the hospital, however, all informants chose to be interviewed at the hospital in connection with a scheduled outpatient visit. All interviews were conducted by KHN. The interviews lasted between 30 and 70 min, were digitally

Topic	Research question	Interview question
	Introduction question	How did you find out you were ill?
The initial period after diagnosis	How is the initial period experienced after the diagnosis of acute leukemia?	What has your experience been of the initial period following your diagnosis, and the beginning of your treatment?
		Which physical symptoms have you experienced since you received your diagnosis and started treatment?
		What emotional reactions have you experienced since you received your diagnosis and started treatment?
	Which physical, psychological or social changes and/or symptoms are experienced during the initial period of treatment of acute leukemia?	Have you had any symptoms as a result of these emotional reactions?
		Have you experienced any practical challenges in the initial period following your diagnosis and since you started treatment, and if so, which?
		What impact has this had on your daily life?
		Have you experienced any change in your social life? – has there been any change in other´s behaviour towards you in a social context?
Coping with the new situation	How do patients with acute leukemia cope with their diagnosis, and intensive chemotherapy treatment?	In what way have you been able to deal with becoming ill?
		What has helped you to deal with becoming ill?
		What is the hardest thing for you at the present time?
The need for social support	What kind of social support is needed in the initial period after being diagnosed with acute leukemia?	What kind of support did you need in the initial period after you were diagnosed with acute leukemia?
		Can you describe what you have done when/if you have needed support during this period?
		Which daily tasks did you need help with after you started treatment? Were you able to do them yourself or did you receive assistance?
		Who did you talk to when/if you needed support, and what have they helped you with? Did you ask for help yourself?
		What do you discuss with healthcare professionals, and what do you feel you cannot talk to them about?
		What have you missed the most since you became ill?
The need for support from other patients	To what extent is there a need for contact to, and support from, other patients with the same diagnosis?	Have you talked to other patients about your diagnosis during your treatment?
		If yes, who has taken the initiative? yourself, healthcare professionals or other patients?
		What areas concerning your illness have you discussed?
	What influence/effect does talking to other patients have?	How often have you talked to other patients about your illness and the course of disease?
		Have these been planned conversations or spur-of-the moment chats, and how did you get in touch?
		How has it helped you to talk to other patients?
		If no, what considerations have stopped you from talking to other patients?

Fig. 1. Interview guide.

recorded, and transcribed verbatim.

A pilot interview was carried out to assess the respondents understanding and acceptance of the content and sequence of the questions. The interview guides' topics and questions were not changed after the pilot interview.

2.3. Ethical considerations

This study was approved by The Joint Ethics Committee of the Capital Region of Denmark (approval no. H-17012104) and is registered by the Danish Protection Agency (VD-2017-176). Each informant received written and verbal information regarding the study including the right to withdraw from the study and assurance of confidentiality according to the principles for research stated in the Helsinki Declaration. Written informed consent was obtained before the interview.

2.4. Patient representatives

The current study is part of an ongoing multiple-site research project investigating a supportive care intervention in patients newly diagnosed with AL. Within this program, a patient advisory board (PAB) was established by recruiting patients with AL who were diagnosed > one year ago. Patients as partners in health science contribute with a different knowledge and perspective than health professionals (HP) due to their personal experiences. Research may then become more relevant for patients when the research focus is on issues of importance to patients (Brett et al., 2014; Domecq et al., 2014). Patient representatives in this study were recruited from the PAB (n = 5). They were approached by KHN, and all signed informed consent. The purpose of involving the patient representatives was to further validate the analysis and interpretation of the data, carried out by the researchers.

2.5. Data analysis

Data were managed by the computer software package NVivo version 11 (QSR International Pty Ltd. Version 10, 2012). The analysis was carried out by three researchers (KHN, DO, MJ). Thematic analysis was used to search for themes and patterns by examining and analyzing the data for detail (Braun and Clarke, 2006). The analysis was performed in six levels. At level one the transcribed data were read several times, and initial ideas were noted to become familiarized with the data. Interesting features of data were then coded, and initial codes were generated in level two. The analysis process proceeded by coding the data, identifying potential subthemes and themes and finally defining and naming the themes. The final analysis and writing was carried out in level six (Nowell et al., 2017). The six levels of analysis were carried out by KHN, while DO and MJ contributed with triangulation and consensus on coding and themes in level four to six. An example of the analysis process is provided in Table 1. Further, the analysis was validated by patient representatives (n = 5) at level four during a focus group which lasted 85 min and was digitally recorded. KHN presented the preliminary identified themes, which were discussed individually and transversely. The patient representatives commented on and discussed the themes based on their own experiences as patients. As a result, the themes and their interrelationship were recognizable which in turn validated the identified themes and subthemes, and this contributed to a deeper understanding of content in the analysis.

3. Findings

Twenty patients were assessed for eligibility, thereafter two were excluded due to unstable medical conditions with refractory AL. No patients declined to participate, and therefore a total of eighteen patients (referred to as informants) were included in the study, and the characteristics are summarized in Table 2. Informants were men

Table 1
Thematic analysis process (example).

Code: Control					
Level 1	Level 2	Level 3	Level 4		
Quotation	Code and interpretation	Potential themes	Identified subtheme	Overarching theme	
"We will just take your body away from you, and we will pour gallons of poison into you." (ID 16)	Loss of personal freedom, Loss of control over own body and choices regarding treatment	Lack of decision making Loss of control	Loss of personal autonomy	Jolted by the diagnosis	
"Well, I can see and feel that I am not myself. When I look in the mirror and into my own eyes, I don't look the same, it's kind of a blurry image in front of me." (ID 15)	Does not feel like himself anymore Unable to recognize himself physically and mentally	Changed personality Changed body image			
"My body reacted totally strange. I was afraid of my body because I could not recognize myself." (ID 2)	Alienated from own body causing anxiety Loss of control over own body	Alienated from own body			

(n = 8) and women (n = 10), aged 19–72 years (mean 52) with AML (n = 13) and ALL (n = 5). Time since diagnosis was between 4 and 16 weeks. No patterns emerged between the different treatment or socio-demographic characteristics and specific disease experiences.

Three overarching themes emerged from the analysis: 1) Jolted by the diagnose and subtheme Loss of personal autonomy; 2) Restoring normality in everyday life and subtheme Facing a new social identity; and 3) A lifeline of hope.

3.1. Jolted by the diagnose

Receiving the diagnosis was experienced as sudden and incomprehensible because of the short transition from feeling healthy to having a life-threatening disease.

> "It was like a bus that drove in front of you and stopped your life, and you were stripped of everything." (ID1

The normal aspects of life were set aside and replaced with uncertainty about the future. This was perceived as a traumatic change and a sudden loss of control over their own lives. They described being in a state of shock focusing primarily on survival.

> "You didn't have time to think. You just went into survival mode." (ID 12)

The informants felt the need to focus more on their physical condition than on their emotional well-being. Once the immediate shock of the diagnosis had passed, emotional reactions as worry, negative thoughts, fear of dying, guilt about being sick, and family concerns occurred.

The risk of infections, because of a weakened immune system, intensified their fear of dying. They described feeling alone with their thoughts of death and had difficulty talking with their family about this because of the need to hold on to the belief that they would survive. Talking about death was perceived by several as an acceptance or awareness of not believing in survival.

Lack of physical energy determined whether they had mental energy for social activities and in that way increased feelings of loneliness and isolation during periods of a high physical symptom burden.

> "I am not allowed to take the bus, train or go shopping. No doubt about it … life is becoming quieter now." (ID 13)

3.1.1. Subtheme: loss of personal autonomy

The informants experienced loss of personal, bodily and social control leading to loss of independence and difficulty in maintaining control over their new life situation. Receiving the diagnosis and starting treatment was experienced as incontrollable because everything happened so quickly and decisions about treatment were already made for them.

> "We will just take your body away from you and pour gallons of poison into you." (ID 16)

The recommendations from the HPs were not always experienced as actual choices but rather perceived as a further loss of personal autonomy.

> "All my personal freedom is just taken away from me, and now you come and tell me what I should be eating, and which exercises I should do … Just stop it. I'll decide for myself. Everything has been taken away from me … I cannot choose." (ID 16)

Physical and mental changes were described to such a significant degree that they didn't recognize themselves, feeling foreign to their own body and mind. One young man described his own image as unrecognizable.

> " Well, I can see and feel that I am not myself. When I look in the mirror and into my own eyes, I don't look the same, it's kind of a blurry image in front of me." (ID 15)

They experienced unexpected physical challenges as alopecia and loss of muscle function. Undergoing these changes impacted their experience of being seriously ill. Not being able to predict how their body reacted to the treatment promoted anxiety.

> "My body reacted totally strange. I was afraid of my body." (ID 2)

3.2. Restoring normality in everyday life

Everyday life was characterized by frequent hospital appointments, hospitalization and social constraints due to a reduced immune system which led to a more quiet and isolated life. Life was perceived as being put 'on hold'. A young girl was confronted with the fact that she hadn't been a part of the life around her.

> "When you begin to get your strength back you start to discover that life around you and other people's lives have continued." (ID 18)

There was a need to feel a sense of normalcy in their lives. This was accomplished by creating a space that was 'free of disease' where they could talk about and do things as before they were diagnosed with AL. They described a desire to restore some of the lost control by being more involved in and taking responsibility for their own course of treatment. Requesting information and increasing their knowledge about the disease and treatment supported self-management of their disease and helped them regain control. Further, taking 1 day at a time and carrying out everyday activities as previously were helpful coping strategies that assisted them in regaining control and feeling a sense of optimism.

> " I've actually taken it bit by bit. At the beginning we took one hour at a time. Then it went to one day and when the good news started coming, then we could start taking a few days at a time". (ID17)

3.2.1. Subtheme: facing a new social identity

The informants experienced losing fragments of their social identity while involuntarily gaining a new identity as a cancer patient. Adapting to this transition was difficult.

> "But I do not consider myself to be a cancer patient, I suppose? This is something I dream, it is not real. This is not me. I think it's a little weird that it's inside my body." (ID 10)

Change in physical appearance e.g. loss of hair, weight loss, contributed to compound their identification as a cancer patient. Some had difficulty accepting their self-image while socializing with others.

> "I didn't feel sick, really, but as soon as you lose your hair you realize that you are seriously ill, especially when everyone else can see it too." (ID 17)

Being a cancer patient affected their social roles with family and friends and in working life. The physical and psychological impact of the disease reduced their ability to fulfill daily roles, which for some led to feelings of guilt towards family and friends. They found the transition difficult, from being in control and helping others to loss of independence and being in need of help from others.

> "I don't really have a role anymore … I've been a very active person. I cannot do that anymore … you just sit around like a vegetable. I do not have the energy to play with my daughter." (ID 12)

As treatment-effect occurred, and their physical and emotional wellbeing improved, they expressed a need to reestablish contact with friends, co-workers or other social network. This facilitated recognizable social roles and reduced the feeling of being ill.

3.3. A lifeline of hope

The informants described a need for and an ongoing use of social support from HPs, social network (family, friends, colleagues) and other patients with AL (peers). The diverse support was experienced as life-saving and induced hope for the future.

Support from HPs was perceived as valuable in terms of practical and treatment-related issues. However, due to lack of time and availability in the outpatient clinic, HPs supported to a lesser degree social and psychological issues.

Support from their social network was experienced as crucial during treatment. Several described being overwhelmed by the unconditional support from family, friends and colleagues. They were thankful to have a supportive social network that helped with emotional issues and practical tasks such as cleaning, transportation, shopping and cooking. The informants described that their social network took on two different types of emotional supportive roles; one role facilitated positive and important reflections on their new life situation as a cancer patient, and the other role provided space when there was a need to create distance from the disease. Both types of emotional support were experienced as invaluable.

> "Because I'm sick …. It's just hell every day. Virtually every day it's hell. So, there is no doubt, if I hadn't had them (family) then I would have stopped treatment". (ID 12)

Support from other patients with AL was unique, because sharing personal experiences was an aspect beyond the scope of HPs and their own social network. They shared experiences about symptoms, practical details regarding treatment and how they managed their life situation. Many described an increasing need to talk to other patients with AL as they recovered from the shock of the diagnosis. They wanted to hear positive stories and have their feelings and reactions to the disease and treatment confirmed from someone who was experiencing the same and was doing well at the same time. This provided hope for the future and a belief in being able to cope with the treatment.

> "It might have been great with such a lifeline, where you could reach out for some good things, and gain hope for the future". (ID 15)

The similarity of the disease experience including sharing the same diagnosis, uncertain prognosis and undergoing highly invasive treatment was important for understanding and handling the challenges, they were facing. However, some informants did not wish to talk to other patients as they feared it would become too emotionally stressful to listen to other patients' stories and experiences.

4. Discussion

The aim of this qualitative study was to explore how newly diagnosed patients with AL experience the diagnosis and the initial treatment, and to illuminate their need and preferences for social support. We found there were extensive changes in the patients' lives already from the time of diagnosis that were further intensified by a restricted everyday life centered around frequent hospital appointments, hospitalization and environmental limitations. Additionally, due to the poor prognosis of AL, there was a further increased distress concerning uncertainty about the future and fear of dying. The diagnosis and treatment caused significant emotional and social distress, which increased the need for support from their social network and/or other patients with AL. Moreover, social support was experienced as irreplaceable in keeping hope and a positive focus which facilitated coping with a life-threatening illness.

The modern health care system has evolved from a paternalistic approach towards a patient-centered care model that aims to individualize care according to each patients' needs, values and preferences. However, despite patients' increasing active involvement, physicians and healthcare professionals maintain a dominant role in the healthcare system (NHS., 2012). We found the acute onset of the disease with AL and lack of influence on decisions and recommendations during the intensive treatment regimen to intensify the experience of loss of autonomy because of difficulty maintaining control over their new life situation. This is comparable with the findings from a qualitative thematic synthesis (2013) exploring the experiences of AL in adult patients, and the results identified loss of personal control, independence and normality in everyday life (Papadopoulou et al., 2013). Supporting patients in being active in their own treatment starting from the time of diagnosis could potentially strengthen the patient's autonomy and reduce distress. Recent initiatives of active involvement of patients, such as shared decision-making (SDM), increase patient's involvement in their own course of treatment (NHS., 2012). The essence of SDM include recognition that a decision needs to be made, readiness to make a decision and the identification of the decision outcome (NHS., 2012). In a systematic review (2012) evaluating the effectiveness of interventions to improve HPs' adoption of SDM as seen by patients, concluded that SDM increased the patients' knowledge and confidence in making decisions (Legare et al., 2012). To implement SDM in clinical practice, HPs should understand the components of SDM and the potential benefits and challenges. Although the process of SDM is further complicated in the provision of hematological treatment and care by the high level of uncertainty and weighing risks of different treatments with potential benefits. Additionally, the treatment and care of patients with AL often occur over an extended period and is often in constant change depending on the patient's response to treatment and physical wellbeing (Ferrara and Schiffer, 2013; Zimmermann et al., 2013). Conversely, some HPs have been found to doubt the use of SDM as some patient's don't want to be involved in decisions regarding their treatment. Others claim they are already using SDM, though, evidence from patient surveys and our results indicate the opposite (Coulter, 2010). Therefore, workshops focusing on the components of SDM should be provided for HPs with the aim of increasing knowledge and extend instruments on the use of SDM which may act as a catalyst and support in the adoption of SDM in routine clinical practice.

Living with AL challenges the patients physical, psychological and social wellbeing already from the time of diagnosis, as the patient must expand their social context to include the health care context (Papadopoulou et al., 2013; Tomaszewski et al., 2016). Consistently, the informants in our study expressed that daily tasks were replaced by hospital routines where treatment and environmental restrictions resulted in a more quiet and isolated life. The environmental restrictions caused by the long-term neutropenia is mostly based on non-evidence-based recommendations which in different ways restrict the possibility of restoring normality in everyday life. Modifications to these restrictive recommendations as well as more efficient treatment/care pathways during time spent at the hospital would potentially help patients maintain everyday life with an earlier return to their social life. This is important as informants in this study experienced being involuntarily part of a new social identity as a cancer patient, which led to changes in social roles. In particular, these characteristics distinguishes patients with AL from other cancer patients, as the intensity of the treatment and ensuing long-term neutropenia postpone resumption of work, studies or social life (Koehler et al., 2011; Tomaszewski et al., 2016). We found the changed life conditions, routines and social roles increased a need to regain control by carrying out everyday activities. Helping patients maintain their everyday life is crucial to sustain their social identity and social roles within their family and network. This finding is comparable with a qualitative study (2011) exploring coping strategies in patients with AML which found the "adaptation to the role as a patient" constituted a reintegration of coping strategies where focus was on familiar everyday activities (Koehler et al., 2011). Implementing delivery of home-care based advanced chemotherapy and outpatient handling of the treatment induced pancytopenic phase in patients with AL has been shown to help patients that are involved in

their own treatment, to sustain everyday life, be more physically active and allows patients to spend more time with family and friends, prepare and eat meals at home, and sleep in their own bed (Fridthjof et al., 2018; Moller et al., 2010; Vaughn et al., 2016). In addition, studies using home-care based chemotherapy administration indicate improvements of quality of life as well as reduction of hospitalization and infections (Fridthjof et al., 2018; Sive et al., 2012). This emphasizes the necessity of increasing attention to the use of early delivery of home-care based advanced chemotherapy in patients with AL as the possible beneficial outcomes include sustaining social identity, autonomy and everyday life throughout treatment.

The impact of AL and the intensive treatment regimen increased the need for social support from HPs, social network (family/friends) and other patients with AL (peers). Social support was emphasized as an important aspect in facilitating helpful coping strategies during the course of treatment. Social support can potentially prevent and reduce the pathogenic psychological impact of AL and increase the level of autonomy (Papadopoulou et al., 2013). Social support may have beneficial effects on well-being as social support protects people from the influence of stressful events (Cohen and Wills, 1985). Additionally, evidence link higher levels of available social support to better survival in patients with AML (Pinquart et al., 2007). In our study, the different types of social support received from HPs, own social network and peers, complemented each other and further strengthened the coping process in these patients. The HP's in the context of clinical practice should analyze and map patient's accessibility of social support already from the time of diagnosis with the purpose of strengthening the existing social network. Moreover, patients with limited access to social support may be more vulnerable and at higher risk of psychosocial distress, and therefore in need of increased support from HPs in the clinical practice.

A qualitative study (2003) exploring AML patients' need for information found that patients with AL were interested in how other patients had experienced and coped with their illness and treatment, and how it could influence their social life (Friis et al., 2003). This is consistent with our findings, where informants described that conversing with other patients helped them believe they could manage the challenges of the disease and treatment. It gave them hope for the future and increased engagement in their own life.

Experience-based support from peers can give patients a unique feeling of being understood, which HPs and own social network cannot offer. A systematic review (2008) examining peer support programs for people with cancer concluded that peers can provide information, advocacy, practical and psychosocial support (Hoey et al., 2008). In general, these studies suggest that regardless of the way peer support was delivered, having contact with other people with cancer assisted current cancer patients in practical, social and emotional ways. It has also been suggested that peer support can positively impact the psychological adaptation to a cancer diagnosis and treatment or help patients to reframe their appraisals of their situations and improve coping responses (Hoey et al., 2008; Meyer et al., 2015). Sharing experiences is the essence of peer support, an aspect beyond the scope of HPs and own social network (Dennis, 2003). In the clinical practice HPs should develop and support initiatives focusing on strengthening and establishing experienced-based support from peers early in the course of treatment. This could be carried out by creating a social setting that facilitates safe social gathering between patients. This is especially important in patients identified with reduced access to social support. However, there is lack of evidence on peer-to-peer support in patients with hematologic malignancy. Future studies should examine whether this type of social support is feasible and safe in patients with newly diagnosed AL. Additionally, in this context it is pivotal to determine the beneficial effect on the psychological wellbeing in both newly diagnosed and peers with AL.

Our findings generate increased understanding of the experiences of newly diagnosed patients with AL and add comprehension to the basis on which clinical recommendations to people with newly diagnosed AL are made. Furthermore, it highlights the need for HPs to be attentive that the psychosocial impact of AL is substantial already from the time of diagnosis. There is emerging consensus that psychosocial interventions should begin from the time of diagnosis especially in hematologic cancer survivors who may not be disease-free for long periods of time. This would potentially enhance long-term outcomes and improve quality of life (Bugos, 2015).

4.1. Methodological discussion

'Information power' was used to guide and evaluate the adequate sample size of the study (Malterud et al., 2015). Our sample specificity was dense because of the specified target group including newly diagnosed patients with AL. All interviews were rich in information and certain findings included knowledge that was not previously known to us, which strengthens the credibility of the results (Malterud, 2001). In addition, variation in age, gender and type of diagnosis is obtained which strengthens transferability of the results (Malterud, 2001). Trustworthiness and credibility was strengthened through researcher triangulation in the analysis of the data (Crabtree and Miller, 1999; Malterud, 2001). Further, validation of the identified themes was carried out with patient representatives. Limitations of this study include the retrospective nature of the data regarding the experience of diagnosis and initial treatment since patients were interviewed 5–16 weeks from the time of diagnosis. However, the findings are considered valuable as the nature and truthfulness of such memories is independent of time, and the ability for reflection may be greater after the acute phase (Persson et al., 1997). Finally, these findings are limited to the experience of patients during the initial period of diagnosis and treatment, and future studies should explore the experience of patients further along the trajectory of the disease.

5. Conclusion

The findings of this study bring knowledge to how newly diagnosed patients with AL experience the diagnosis and treatment. The rapid transition from feeling healthy to having a life-threatening disease resulted in a traumatic shock where everyday life was centered around frequent hospital appointments, hospitalizations and environmental restrictions. Feelings of loss of control over life required a re-establishment of normalcy by regaining independence and coping with a new social identity. Social support from family, friends, colleagues and other patients with AL (peers) were considered as a lifeline, helping them to actively manage their new life situation and regain hope. Attention to initiatives that support and strengthen the social network in newly diagnosed patients with AL is crucial. Future studies should examine the feasibility of peer-to-peer support interventions in patients with AL.

Declarations of interest

The authors declare no conflict of interest.

Acknowledgement

The authors are grateful for the participation of patients and staff at the Department of Hematology at Copenhagen University Hospital, Rigshospitalet, Herlev and Gentofte Hospital and Odense University Hospital, Denmark. This study is part of the Models of Cancer Care Research Program at Copenhagen University Hospital and funded by the Novo Nordisk Foundation.

References

Albrecht, T.A., Boyiadzis, M., Elswick Jr., R.K., Starkweather, A., Rosenzweig, M., 2016.

Symptom management and psychosocial needs of adults with acute myeloid leukemia during induction treatment: a pilot study. Cancer Nurs. https://doi.org/10.1097/ncc.0000000000000428.
Arber, D.A., Orazi, A., Hasserjian, R., Thiele, J., Borowitz, M.J., Le Beau, M.M., Bloomfield, C.D., Cazzola, M., Vardiman, J.W., 2016. The 2016 revision to the World Health Organization classification of myeloid neoplasms and acute leukemia. Blood 127, 2391–2405. https://doi.org/10.1182/blood-2016-03-643544.
Boyes, A.W., Clinton-McHarg, T., Waller, A.E., Steele, A., D'Este, C.A., Sanson-Fisher, R.W., 2015. Prevalence and correlates of the unmet supportive care needs of individuals diagnosed with a haematological malignancy. Acta Oncol. (Stockh.) 54, 507–514. https://doi.org/10.3109/0284186x.2014.958527.
Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3, 77–101.
Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R.L., Torre, L.A., Jemal, A., 2018. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J. Clin. 68, 394–424. https://doi.org/10.3322/caac.21492.
Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., Suleman, R., 2014. A systematic review of the impact of patient and public involvement on service users, researchers and communities. Patient 7, 387–395. https://doi.org/10.1007/s40271-014-0065-0.
Bugos, K.G., 2015. Issues in adult blood cancer survivorship care. Semin. Oncol. Nurs. 31, 60–66. https://doi.org/10.1016/j.soncn.2014.11.007.
Cohen, S., Herbert, T.B., 1996. Health psychology: psychological factors and physical disease from the perspective of human psychoneuroimmunology. Annu. Rev. Psychol. 47, 113–142. https://doi.org/10.1146/annurev.psych.47.1.113.
Cohen, S., Wills, T.A., 1985. Stress, social support, and the buffering hypothesis. Psychol. Bull. 98, 310–357.
Coulter, A., 2010. Do patients want a choice and does it work? BMJ 341, c4989. https://doi.org/10.1136/bmj.c4989.
Crabtree, B.F., Miller, W.L., 1999. Doing Qualitative Research. SAGE Publications.
Dennis, C.L., 2003. Peer support within a health care context: a concept analysis. Int. J. Nurs. Stud. 40, 321–332.
Domecq, J.P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J.P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Dabrh, A.M., Murad, M.H., 2014. Patient engagement in research: a systematic review. BMC Health Serv. Res. 14, 89. https://doi.org/10.1186/1472-6963-14-89.
Ferrara, F., Schiffer, C.A., 2013. Acute myeloid leukaemia in adults. Lancet 381, 484–495. https://doi.org/10.1016/s0140-6736(12)61727-9.
Fridthjof, K.S., Kampmann, P., Dunweber, A., Gorlov, J.S., Nexo, C., Friis, L.S., Norskov, K.H., Welinder, P.C., Moser, C., Kjeldsen, L., Moller, T., 2018. Systematic patient involvement for homebased outpatient administration of complex chemotherapy in acute leukemia and lymphoma. Br. J. Haematol. 181, 637–641. https://doi.org/10.1111/bjh.15249.
Friis, L.S., Elverdam, B., Schmidt, K.G., 2003. The patient's perspective: a qualitative study of acute myeloid leukaemia patients' need for information and their information-seeking behaviour. Support. Care Canc. 11, 162–170. https://doi.org/10.1007/s00520-002-0424-6.
Hall, A., D'Este, C., Tzelepis, F., Lynagh, M., Sanson-Fisher, R., 2014. Factors associated with haematological cancer survivors experiencing a high level of unmet need across multiple items of supportive care: a cross-sectional survey study. Support. Care Canc. 22, 2899–2909. https://doi.org/10.1007/s00520-014-2264-6.
Hall, A., Lynagh, M., Bryant, J., Sanson-Fisher, R., 2013. Supportive care needs of haematological cancer survivors: a critical review of the literature. Crit. Rev. Oncol.-Hematol. 88, 102–116. https://doi.org/10.1016/j.critrevonc.2013.03.008.
Hoey, L.M., Ieropoli, S.C., White, V.M., Jefford, M., 2008. Systematic review of peer-support programs for people with cancer. Patient Educ. Counsel. 70, 315–337. https://doi.org/10.1016/j.pec.2007.11.016.
Koehler, M., Koehler, K., Koenigsmann, M., Kreutzmann, N., Fischer, T., Frommer, J., 2011. Beyond diagnosis: subjective theories of illness in adult patients with acute myeloid leukemia. Hematology 16, 5–13. https://doi.org/10.1179/102453311x12902908411599.
Legare, F., Turcotte, S., Stacey, D., Ratte, S., Kryworuchko, J., Graham, I.D., 2012. Patients' perceptions of sharing in decisions: a systematic review of interventions to enhance shared decision making in routine clinical practice. Patient 5, 1–19. https://doi.org/10.2165/11592180-000000000-00000.
Malterud, K., 2001. Qualitative research: standards, challenges, and guidelines. Lancet 358, 483–488. https://doi.org/10.1016/s0140-6736(01)05627-6.
Malterud, K., Siersma, V.D., Guassora, A.D., 2015. Sample size in qualitative interview studies: guided by information power. Qual. Health Res. https://doi.org/10.1177/1049732315617444.
Manitta, V., Zordan, R., Cole-Sinclair, M., Nandurkar, H., Philip, J., 2011. The symptom burden of patients with hematological malignancy: a cross-sectional observational study. J. Pain Symptom Manag. 42, 432–442. https://doi.org/10.1016/j.jpainsymman.2010.12.008.
Meyer, A., Coroiu, A., Korner, A., 2015. One-to-one peer support in cancer care: a review of scholarship published between 2007 and 2014. Eur. J. Cancer Care 24, 299–312. https://doi.org/10.1111/ecc.12273.
Moller, T., Nielsen, O.J., Welinder, P., Dunweber, A., Hjerming, M., Moser, C., Kjeldsen, L., 2010. Safe and feasible outpatient treatment following induction and consolidation chemotherapy for patients with acute leukaemia. Eur. J. Haematol. 84, 316–322. https://doi.org/10.1111/j.1600-0609.2009.01397.x.
NHS, 2012. Measuring Shared Decision Making: A Review of the Research Evidence. A Report for the Shared Decision Makirng Programe. In Partnership with Capital Group Plc. Capital Park, Cambridge, UK.
Nissim, R., Rodin, G., Schimmer, A., Minden, M., Rydall, A., Yuen, D., Mischitelle, A., Fitzgerald, P., Lo, C., Gagliese, L., Zimmermann, C., 2014. Finding new bearings: a qualitative study on the transition from inpatient to ambulatory care of patients with acute myeloid leukemia. Support. Care Canc. 22, 2435–2443. https://doi.org/10.1007/s00520-014-2230-3.
Nowell, L.S., Norris, J.M., White, D.E., Moules, N.J., 2017. Thematic analysis: striving to meet the trustworthiness criteria. Int. J. Qual. Methods 16https://doi.org/10.1177/1609406917733847. 1609406917733847.
Papadopoulou, C., Johnston, B., Themessl-Huber, M., 2013. The experience of acute leukaemia in adult patients: a qualitative thematic synthesis. Eur. J. Oncol. Nurs. 17, 640–648. https://doi.org/10.1016/j.ejon.2013.06.009.
Persson, L., Hallberg, I.R., Ohlsson, O., 1997. Survivors of acute leukaemia and highly malignant lymphoma–retrospective views of daily life problems during treatment and when in remission. J. Adv. Nurs. 25, 68–78.
Pinquart, M., Hoffken, K., Silbereisen, R.K., Wedding, U., 2007. Social support and survival in patients with acute myeloid leukaemia. Support. Care Canc. 15, 81–87. https://doi.org/10.1007/s00520-006-0114-x.
QSR International Pty Ltd, 2012. NVivo Qualitative Data Analysis Software. Version 10. .
Shinn, M., Caplan, R.D., Robinson, E.A., French Jr., J.R., Caldwell, J.R., 1977. Advances in adherence: social support and patient education. Urban Health 6, 20–21 57-29.
Sive, J., Ardeshna, K.M., Cheesman, S., le Grange, F., Morris, S., Nicholas, C., Peggs, K., Statham, P., Goldstone, A.H., 2012. Hotel-based ambulatory care for complex cancer patients: a review of the University College London Hospital experience. Leuk. Lymphoma 53, 2397–2404. https://doi.org/10.3109/10428194.2012.694430.
Tomaszewski, E.L., Fickley, C.E., Maddux, L., Krupnick, R., Bahceci, E., Paty, J., van Nooten, F., 2016. The patient perspective on living with acute myeloid leukemia. Oncol. Ther. 4, 225–238. https://doi.org/10.1007/s40487-016-0029-8.
Uchino B, P., 2004. Social Support and Physical Health, Understanding the Health Consequences of Relationships (Current Perspectives in Psychology). Yale University Press, NH.
Vaughn, J.E., Buckley, S.A., Walter, R.B., 2016. Outpatient care of patients with acute myeloid leukemia: benefits, barriers, and future considerations. Leuk. Res. 45, 53–58. https://doi.org/10.1016/j.leukres.2016.03.011.
Zimmermann, C., Yuen, D., Mischitelle, A., Minden, M.D., Brandwein, J.M., Schimmer, A., Gagliese, L., Lo, C., Rydall, A., Rodin, G., 2013. Symptom burden and supportive care in patients with acute leukemia. Leuk. Res. 37, 731–736. https://doi.org/10.1016/j.leukres.2013.02.009.

European Journal of Oncology Nursing 42 (2019) 162

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Erratum

Erratum to "Patients experiences and social support needs following the diagnosis and initial treatment of acute leukemia - A qualitative study" [Eur. J. Oncol. Nurs. 41 (2019) 49–55]

Kristina Holmegaard Nørskov[a,*], Dorthe Overgaard[b], Kirsten Lomborg[c], Lars Kjeldsen[a], Mary Jarden[a,d]

[a] Department of Hematology, Rigshospitalet, Blegdamsvej 9, 2100, Copenhagen Ø, Copenhagen University Hospital, Denmark
[b] Metropolitan University College, Tagensvej 18, 2200, Copenhagen N, Denmark
[c] Department of Clinical Medicine, Aarhus University, Paalle Juul-Jensens Boulevard 82, 8200, Aarhus N, Denmark
[d] Department of Public Health, Blegdamsvej 3B, 2200, Copenhagen N, University of Copenhagen, Denmark

The publisher regrets that Table 2 was missed in the publication of this article. Table 2 is available below.

ID	Gender	Age in years	Marital status	Number of children	Level of education	Diagnosis	Time from diagnosis to interview (weeks)
	Male 8 (44,4) Female 10 (55,55)	52 (mean) 19-72 (range)	Married 8 (44.44) Not married 7 (38.88) In a relationship 2 (11.11) Widowed 1 (5.55)		5 (mean) 3-8 (range)	AML 13 (72.22) ALL 5 (27.77)	11 (mean) 4-16 (range)
ID 1	Male	44	Married	1	Level 6	AML	16
ID 2	Female	37	Not married	0	Level 6	ALL	6
ID 3	Female	59	In a relationship	0	Level 7	AML	12
ID 4	Female	63	Not married	2	Level 3	AML	14
ID 5	Male	70	Widowed	3	Level 5	ALL	7
ID 6	Male	51	In a relationship	1	Level 3	AML	14
ID 7	Male	70	Married	2	Level 6	AML	12
ID 8	Female	71	Married	2	Level 5	AML	8
ID 9	Male	72	Married	2	Level 6	AML	11
ID 10	Female	69	Married	2	Level 5	AML	6
ID 11	Female	52	Married	0	Level 6	AML	6
ID 12	Male	34	Not married	2	Level 4	ALL	15
ID 13	Female	72	Married	2	Level 6	AML	10
ID 14	Female	66	Married	2	Level 6	AML	7
ID 15	Male	21	Not married	0	Level 5	ALL	14
ID 16	Male	38	Not married	2	Level 8	AML	5
ID 17	Female	21	Not married	0	Level 5	AML	14
ID 18	Female	19	Not married	0	Level 5	APL	16

ID: Personal identification number; level of education: is based on the International Standard Classification of Education (ISCED). ISCED 2011 has nine education levels, from level 0 to level 8. Level 0: Early childhood education; Level 1: Primary education; Level 2: Lower secondary education; Level 3: upper secondary education; Level 4: Post-secondary non-tertiary education; Level 5: short-cycle tertiary education; Level 6: Bachelors or equivalent level; Level 7: Masters or equivalent level; Level 8: Doctoral or equivalent level. AML: Acute Myeloid Leukemia; ALL: Acute Lymphatic Leukemia. Unless otherwise stated, data are shown as number of informants (N) with the percentage in parentheses (%).

The publisher would like to apologise for any inconvenience caused.

DOI of original article: https://doi.org/10.1016/j.ejon.2019.05.005
* Corresponding author.
E-mail addresses: Kristina.holmegaard.noerskov@regionh.dk (K.H. Nørskov), doov@phmetropol.dk (D. Overgaard), kl@clin.au.dk (K. Lomborg), lars.kjeldsen.01@regionh.dk (L. Kjeldsen), mary.jarden@regionh.dk (M. Jarden).

https://doi.org/10.1016/j.ejon.2019.08.004

1462-3889/

PAPER II

Patient ambassador support in newly diagnosed patients with acute leukemia during the initial treatment – a feasibility study

Kristina Norskov,
Dorthe Overgaard, Jannie Boesen,
Anne Struer, Sarah Elke Weber Due El-Azem,
Anders Tolver, Kirsten Lomborg,
Lars Kjeldsen & Mary Jarden

Patient ambassador support in newly diagnosed patients with acute leukemia during the initial treatment: a feasibility study

Patient Ambassador Support for Acute Leukemia Patients

Authors

Corresponding:

1) Kristina Holmegaard Nørskov (a), M.H.Sc. (Ph.D. student)
   Kristina.holmegaard.noerskov@regionh.dk
   +45 22648697

Co-Authors:

2) Dorthe Overgaard (b), Ph.D., M.Sc.N., associate professor, DOOV@kp.dk
3) Jannie Boesen (c), R.N., Jannie.Boesen@regionh.dk
4) Anne Struer (d), R.N., astu@regionsjaelland.dk
5) Sarah Elke Weber Due El-Azem (d), R.N., sare@regionsjaelland.dk
6) Anders Tolver (e), Ph.D., MSc,tolver@math.ku.dk
7) Kirsten Lomborg (f,g), Ph.D., M.Sc.N, professor, kirsten.elisabeth.lomborg@regionh.dk
8) Lars Kjeldsen (a), Ph.D., M.D., head of clinic, lars.kjeldsen.01@regionh.dk
9) Mary Jarden (a,h), Ph.D., head of research, associate professor, mary.jarden@regionh.dk

a) Rigshospitalet, Copenhagen University Hospital, Department of Haematology, Blegdamsvej 9, 2100 Copenhagen Ø, Denmark

b) University College Copenhagen, Tagensvej 18, 2200 Copenhagen N, Denmark

c) Herlev Hospital, Department of Hematology, Borgmester Ib Juuls Vej 1, 2730 Herlev, Denmark

d) Zealand University Hospital, Department of Hematology, Roskilde, Sygehusvej 10, 4000 Roskilde, Denmark

e) University of Copenhagen, Data Science Laboratory, Department of Mathematical Sciences, Universitetsparken 5, 2200 Copenhagen N, Denmark

f) Aarhus University, Department of Clinical Medicine, Paalle Juul-Jensens Boulevard 82, 8200 Aarhus N, Denmark

g) Steno Diabetes Center Copenhagen (SDCC), Department of Clinical Research, Niels Steensens Vej 2, 2820 Gentofte, Denmark

h) University of Copenhagen, Department of Public Health, Blegdamsvej 3B, 2200 Copenhagen N, Copenhagen, Denmark

Abstract

Purpose

This study investigated the feasibility of patient ambassador support in newly diagnosed patients with acute leukemia during their initial treatment.

Methods

A multicenter single-arm feasibility study that included patients newly diagnosed with acute leukemia (n=36) and patient ambassadors previously treated for acute leukemia (n=25). Prior to the intervention, all patient ambassadors attended a six- hour group training program. In the intervention, patient ambassadors provided 12 weeks of support for patients within two weeks of their diagnosis.

Results

Patient ambassador support was feasible and safe in this population. Patients and patient ambassadors reported high satisfaction with the individually adjusted support, and patients improved in psychosocial outcomes over time. Patient ambassadors maintained their psychosocial baseline level, with no adverse events, and used the available support to exchange experiences with other patient ambassadors and to manage challenges.

Conclusion

The patient ambassador support program is feasible and has the potential to be a new model for care incorporated in the hematology clinical care setting, creating an active partnership between patients and former patients. This may strengthen the existing supportive care services for patients with acute leukemia.

Clinical trial registration number: NCT03493906, April 11, 2018.

Keywords

Peer support, Patient ambassador, Acute leukemia, Supportive care, Feasibility, Psychosocial

Acknowledgments

We are grateful to the patients who participated in this study. We also acknowledge the volunteer participation of the patient ambassadors and their passion for helping other patients with AL by sharing their experiences. This study is part of the Models of Cancer Care Research Program at Copenhagen University Hospital, Rigshospitalet, funded by Novo Nordisk Foundation.

Declarations

Funding
This study was supported by the Novo Nordisk Foundation (grant number NNF17OC0030072).

Conflict of interest
The authors declare that they have no conflict of interest.

Ethics approval
This study, which was approved by Copenhagen University of Hospital's ethics committee (58097, 19-04-2017), adheres to the tenets of the declaration of Helsinki.

Consent to participate
Informed consent was obtained from all individual participants included in the study.

Consent to publish
The participants provided informed consent regarding publishing their data in this article.

Availability of data and material
Not applicable.

Code availability
Not applicable.

Authors' contributions (CRediT Taxonomy)
Funding acquisition: Kristina Holmegaard Nørskov, Mary Jarden; Conceptualization: Kristina Holmegaard Nørskov, Dorthe Overgaard, Lars Kjeldsen, Mary Jarden; Methodology: Kristina Holmegaard Nørskov, Dorthe Overgaard, Anders Tolver, Kirsten Lomborg, Lars Kjeldsen, Mary Jarden; Investigation: Kristina Holmegaard Nørskov, Jannie Boesen, Anne Struer, Sarah Elke Weber Due El-Azem; Data curation: Kristina Holmegaard Nørskov, Anders Tolver, Mary Jarden; Formal analysis: Kristina Holmegaard Nørskov, Anders Tolver, Mary Jarden; Resources: Kristina Holmegaard Nørskov, Mary Jarden; Software: Kristina Holmegaard Nørskov, Mary Jarden; Supervision: Mary Jarden, Dorthe Overgaard, Lars Kjeldsen, Kirsten Lomborg; Validation: Dorthe Overgaard, Anders Tolver, Kirsten Lomborg, Lars Kjeldsen, Mary Jarden; Visualization: Kristina Holmegaard Nørskov, Mary Jarden; Writing – original draft: Kristina Holmegaard Nørskov; Writing – review & editing: Dorthe Overgaard, Jannie Boesen, Anne Struer, Sarah Elke Weber Due El-Azem, Anders Tolver, Kirsten Lomborg, Anders Tolver, Mary Jarden.

Introduction

Acute leukemia (AL) is a malignant hematological disease with a rapid onset which, in curative treatment regimens, is followed by intensive high-dose chemotherapy, risk of life-threatening complications, and a significant symptom burden [1-4]. Through the last decade, curative regimens for AL have only improved to a limited extent [1], while supportive care has improved significantly, with an increasing number of patients receiving the majority of their treatment in the outpatient setting [5-8]. These improvements are crucial, but they involve spending limited time with health professionals and in contact with other patients with AL during treatment.

Being diagnosed with a life-threatening disease like AL, which comprises an unpredictable long-term clinical course, can be a traumatic experience, and many patients report high levels of psychological distress [2,9-11]. In a previous study, we identified that newly diagnosed patients with AL experienced feeling jolted by the diagnosis and uncertainty about the future [12]. Moreover, they considered social support, including support from other patients with AL, as a lifeline because it had the potential to help them actively manage their situation and, more importantly, regain hope [12].

Peer support may benefit not only the person being supported but also the supporter [13]. Peers possess an understanding and a first-hand experience of the disease and its treatment, and may provide support to a peer who is at an earlier stage of treatment or recovery [14]. Social comparison theory may partially explain the beneficial influence of peer support [15]. Comparisons with others in a similar situation to oneself can normalize the experience, provide positive role modelling, reduce the threat, and aid in coping with the new challenges [16]. In peer support programs, the peer supporter may also find comparisons helpful because they put their own disease trajectory and life-experiences into perspective [13,17]. The evidence of the effect of peer support programs in patients with cancer is growing [18,19]. A review of one-to-one peer support programs in cancer care substantiate the beneficial effect on the psychosocial adjustment and the resulting high participant satisfaction with peer support [19]. Yet, due to the potential vulnerability of peer supporters, it is suggested that future research monitor the effect of their psychosocial state and elucidate the potential impact on patients and peer supporters [19,17].

Patients with AL request research that focuses on interventions in which former patients treated for AL support new patients with AL [20]. There is no evidence to date on the feasibility of a one-to-

one peer support intervention in patients with AL [18,19]. The existing research can only be transferred, to a limited extent, to patients with AL. Thus, due to acute onset, the intensity of treatment regimens often complicated by serious infections, and the risk of substantial symptom burden, it is relevant to investigate this type of social support in patients with AL. In the present study, a peer supporter is a former patient previously treated for AL who was named a patient ambassador (PA).
This study was conducted to investigate the feasibility of patient ambassador support (PAS) in newly diagnosed patients with AL during initial treatment.

Material and methods

Study design

This multicenter single- arm feasibility study was conducted at three hematology departments in Denmark: Rigshospitalet, Herlev/Gentofte Hospital and Zealand University Hospital, Roskilde. The intervention included a 12-week PAS program for newly diagnosed patients with AL during their initial treatment with high-dose chemotherapy.

Participants and procedures

The study included two categories of participants: patients and PAs.

Eligibility criteria:

- Patients >18 years and included within the first two weeks from time of diagnosis with acute myeloid leukemia or acute lymphatic leukemia if intensive chemotherapy treatment was planned.
- PAs >18 years, previously diagnosed and treated for AL with intensive chemotherapy, at least one year since diagnosis, and in complete remission.

Participants were excluded if they did not understand, read and speak Danish, and if they had an unstable medical disease or any cognitive/psychiatric disorders.

Recruitment
PAs were recruited voluntarily from October 2017 to January 2018 using posters and flyers at the hematology departments and the Patient Association of Lymphoma, Leukemia and Myelodysplastic Syndromes, or they were selected and then approached by phone or mail by their primary hematologist in cooperation with the primary investigator (KHN), who screened eligible PAs for

their suitability in a telephone interview. The PAs received a monetary incentive of 130 euro to cover transport expenses. The project nurse and KHN approached and recruited patients from February 2018 to June 2019 at the inpatient or outpatient clinic. Eligible participants received oral and written information from KHN. Included participants then provided written informed consent prior to inclusion and the PAs also signed a confidentiality agreement. Exclusion criteria for the participants were: relapse (PAs), psychological conditions (delirium or severe depression), hospitalization in intensive care unit for more than two weeks, or transition to terminal care.

Intervention

Preparation for the intervention

Prior to the intervention, the PAs attended a specially tailored six-hour program carried out by KHN, the project nurse, and the project psychologist. The program included an introduction to the study, an overview of the disease and treatment regimes, and information and training on psychological issues and communication skills. There were discussions in small groups and in plenum on their personal goals, motivation, and concerns about volunteering. Upon completion of the training program, they received an information dossier with a checklist and guidelines, which included a list of relevant actions for PAs to take, and a tool to document the intervention.

PAS program

PAs provided 12-weeks of support to patients newly diagnosed with AL. Included patients and PAs were matched by KHN immediately upon receipt of their informed content according to sex, age, type of AL, and/or other factors individually expressed prior to the intervention. The PA initiated contact with the patient within 48 hours, either by phone (conversation/text message), e-mail, or a face-to-face meeting, depending on the individual patient's needs. However, face-to-face meetings were recommended for the purpose of developing a relationship. PAs followed one patient at a time, with a minimum of four weeks between patients. KHN followed up on the initial and final contact, and during the intervention, if necessary.

Support and safety

During the intervention, the PAs could attend network meetings with supervision every six weeks with KHN and the psychologist. If requested, the psychologist also provided individual supervision during the intervention.

Outcome measures

Primary outcome

Feasibility was assessed based on the following criteria: acceptability, practicability, and safety and support [21,22]. Evaluations were also obtained from patients and PAs. Finally, the PAs kept a record of the frequency, type, and themes in their communication. Participant and disease characteristics were obtained from the patient and PA, and from medical records.

Secondary outcome

Participants filled out electronic or paper versions of patient-reported outcome questionnaires at baseline and at the 12 and 24-week follow-up. Psychological well-being was assessed and measured using the Hospital Anxiety and Depression Scale (HADS) [23], while quality of life (QOL) was assessed using the Functional Assessment of Cancer Therapy – Leukemia (FACT-LEU) [24] and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) [25]. Symptom burden was assessed using the MD Anderson Symptom Inventory (MDSAI) [26], while the Patient Activation Measure (PAM) [27,28] was used to gauge the patients' understanding of their own health and health care, and coping appraisal was assessed with the General Self-Efficacy Scale (GSE) [29].

Statistical analysis

REDCap was used to collect and manage survey data and as an online record to register all contacts from participants with KHN, project nurses, and the psychologist [30,31]. A sample size of 30 is recommended for feasibility trials. Due to the prognosis and significant symptom burden in patients with AL, they have a risk of high attrition, which is why we set a sample size of 35 in each group of participants [32]. The demographic and clinical characteristics of participants were summarized using numbers and percentages for categorical variables. PA characteristics were included once, regardless of the number of patients they followed. Follow-up data only contains data from participants who have completed the intervention. Patient-reported outcome measures were summarized using mean and standard deviation (SD). Official scoring manuals including guidelines for handling missing answers were used for computation of subscale scores. Data from one item of the FACT-LEU scale was not collected and is treated as a missing value for all participants when computing the subscale score. A linear mixed-effect model with random effect of participants and fixed effect of assessment time was used to analyze changes between baseline to 12-week follow-up and between the 12 and 24-week follow-up. The Wald test was used to test the hypothesis that

changes equal zero. P-values <0.05 were used to determine statistical significance and the data analysis was carried out using IBM SPSS Statistics for Windows version 25 and R [33].

Results

Participant characteristics

In total, 36 patients and 24 PAs were included (Table 1). Females made up 58.3% of patients and 50% of Pas, while the age range was 21-77 (mean age, patients: 54.5 years; PAs: 51.5 years). PAs were slightly more frequently married or living with a partner compared to patients. Acute myeloid leukemia was the most frequent diagnosis in both patients (66.7%) and PAs (50.0%). A little less than half (44%) of the PAs were more than four years from their AL diagnosis, and 68% had undergone allogeneic hematopoietic stem cell transplantation.

Feasibility criteria

Acceptability

A total of 53 eligible patients were approached (Fig. 1), 36 of whom were accepted for participation, and 17 of whom declined participation, mainly due to: a lack of physical and/or psychological strength to participate; already had enough support from own network; co-morbidities; did not want to become immersed in their own disease; and did not want to involve unfamiliar parties in the course of their disease and treatment. Four patients were lost to follow-up due to transition to terminal care (n=1), death (n=2), and withdrawal (n=1). In total, 32 patients completed the intervention. A total of 82 eligible PAs were approached (Fig. 2), 35 of whom agreed to participate, and 25 of whom were enrolled in the intervention. After enrollment, six PAs were lost to follow-up due to relapse, their patient died, was transferred to terminal care, or withdrew. In total, 24 PAs completed the intervention, and 12 participated more than once. Patients and PAs were largely satisfied with the intervention, with 96.3% of patients (n=27) and 80.6% of PAs (n=31) reporting a satisfaction level of $\geq$5 out of 10. The intervention also had an acceptable influence on the patient's disease and treatment trajectory, with 74.0% reporting $\geq$5 out of 10 points.

Practicability

All 35 enrolled PAs participated in the mandatory educational six-hour program prior to the intervention. The PA course was reported useful (86.6%) in proportion to what they experienced,

and the majority (93.3%) reported receiving enough information and knowledge about their new role. Throughout the intervention, 10 network meetings were held, with participation at each meeting reaching three to 13 PAs.

Meeting personally with patients was challenging, primarily because of the patients' lack of strength, hospitalization, reduced immune system, many visits from their own social network, or geographical distance. Only 9.3% had four personal meetings during the intervention, 3.1% had three meetings, 3.1% had two, 21.9% one, and 62.5% none. There were 404 contacts between patients and Pas, with a mean of 12.6 contacts per dyad. The number of contacts was decreasing during the intervention, with a small increase at the end of the period (Fig. 3). Our data shows that text messages and telephone conversations were used the most to make contact. Fig. 4 provides an overview of the distribution of conversation topics between participants during the intervention, with treatment the most common, followed by side effects, complications, everyday life, and family.

Safety and support

None of the PAs needed individual support from the project psychologist and they only initiated contact with health professionals during the intervention. There were 16 PAs who initiated contact with KHN, interspersed as follows: one contact (n=7), two contacts (n=2), three contacts (n=3), four contacts (n=2), and six contacts (n=1). Reasons for contact were: evaluation of initiating the relation; challenges in establishing the relationship: death of patient; and patient unsure of whether to stay in the intervention. PAs primarily found support in network meetings (76.5%), KHN (23.5%), and their spouse (17%). Reasons for seeking support were: the need to talk with others and hear their experiences with the role of PA; managing challenges in establishing the relationship with the patient; and coping when the patient's treatment failed. No unexpected adverse events occurred during the intervention.

Clinical outcome

We studied multiple patient-reported outcome variables, which are listed for patients in Table 2 and for PAs Table 3. An overall trend showed that patients improved in all sum scores over time, from baseline to week 24. The patient's mean score was above the cut-off score (>8) for anxiety at baseline, but improved by 12-week follow-up, scoring below the cut-off point. For patients, statistically significant improvements from baseline to 12-week follow-up were found for anxiety (p=0.007), global health (p=0.047), role functioning (p=0.014), cognitive functioning (p=0.044), functional well-being (p=0.014), and patient activation level (p=0.021). Conversely, PAs did not

change significantly over time in any of the clinical outcomes, with the exception of emotional well-being (p=0.004) from baseline to 12-week follow-up.

Discussion

Discussion of results

To our knowledge, this is the first study to investigate one-to-one peer support intervention in newly diagnosed patients with AL. The findings demonstrate that PAS was feasible and safe in this population, with high acceptability and satisfaction among both patients and PAs. However, there were challenges related to the wide amount of variation in how the support was provided, and in terms of the high disease and treatment-related symptom burden, emphasizing the importance of individualizing support in clinical practice. Support for the PAs was an indispensable aspect of the PAS program.

This study demonstrated that PAS can be conducted in patients with AL undergoing intensive chemotherapy. Similar to other studies exploring peer support in cancer populations, we found the intervention to be acceptable, with high satisfaction among both patients and PAs [18,19]. This may be explained by the benefits of social comparison processes, which play a pivotal role in understanding of how people interpret health threats, understand their own health risks, and adapt to serious illness [16]. People facing a life-threatening disease may be compelled to use comparison as a way to counteract these issues [34]. Studies have revealed that patients with cancer prefer contact with, and information about, other cancer patients whose health is better than their own [35-37]. This upward social comparison may positively impact newly diagnosed patients during peer support because they can clarify what has happened (and is happening) to them, be assured by those who have survived the disease and treatment, and share their experiences with others [35-37].
In contrast, PAs may use downward comparisons to evaluate themselves against those perceived to be in poorer health, in this case the patients, to put their own disease trajectory into perspective [34]. Regardless, if the difference between people is too significant, it may result in alienation, with no possibility of comparison [16]. Therefore, matching in peer support interventions is of great importance to achieve successful comparison between two peers. In our study, we matched participant preferences as closely as possible, which may explain the low dropout rate and the high satisfaction among both groups of participants.

Our results showed that patients improved over time in most psychosocial outcomes, which is consistent with other longitudinal studies examining QOL and psychological health in patients with

AL throughout the treatment trajectory [38-40]. Although scores improved over time, the results were still significantly lower compared to normative data [41]. This highlights the importance of developing and undertaking interventions that improve QOL and psychosocial outcomes in patients with AL. Interestingly, PAs who maintained their psychosocial origin had QOL levels that were equal to or better than normative data [41]. This indicates two important perspectives to recognize in peer support interventions. First, PAs may benefit from their role as a peer supporter, and the role becomes a part of their own long-term psychological recovery. This has been confirmed in previous studies where peer supporters achieve a positive impact by putting their own disease trajectory and life experiences into perspective [13,17,19]. Second, PAs represent a selected group of peers who are psychologically robust, which is important as those who wish to participate are best suited for the role of peer supporter.

Several systematic reviews have examined the impact of peer support in cancer populations [18,19,42,43]. However, depending on the cancer population, there is contradictory evidence on the provision of peer support [18]. Our results suggest that PAS in patients with AL should be provided individually as patients have different needs that change over time, depending on their disease trajectory and symptom burden. These results are in line with the general perspective of patient-centered care, which focuses on the individual's particular health care needs and preferences [44].

Due to the peer supporter's history of cancer and thus risk of increased vulnerability, monitoring their psychosocial status is imperative [18]. Our results demonstrate that psychosocial status in PAs does not change over time during their role as peer supporters, and none of the PAs took advantage of the opportunity to speak individually with the psychologist. This result should be viewed in the light of the tremendous effort we put into preparing and supporting the PAs throughout the intervention. In line with this, a qualitative study (2013) exploring the experiences of peer supporters found no adverse consequences but emphasized the importance of providing support and training [17].

There is an indication that peer supporters perceive their support as being less effective and supportive than the peer support recipients did [43]. This potential discrepancy may explain why the PAs in the present study were less satisfied compared to the patients. Similar results were found in a previous qualitative study exploring the experiences of cancer patients and their peer supporters that showed that peer supporters found it challenging to strike the right balance between their own need to help and the patient's need for help [13]. In a recent qualitative study, the motivation of PAs was explored and showed that their own disease course became meaningful, which facilitated a better

recovery [45]. Therefore, taking their motivation and potential challenges into account is essential when training of the peer supporters.

Discussion of methods

The strengths of this study include the longitudinal design and inclusion of three centers, with a close monitoring of feasibility and the psychosocial well-being of all participants. Limitations include that participants were primarily not living alone and were well-educated, which may limit the representativeness of our findings. Patient demographic data on non-participants was not collected, which is why we cannot confirm their comparability. However, only a small number of patients declined participation due to having a sufficient social network. We encountered missing data at 24 weeks, mostly in patients, although this was expected to some degree due to their prognosis and significant symptom burden. This may have led to an overestimation of the sum scores at this time point.

Clinical implications

Based on our results, we recommend that PAS supplement the existing supportive care service available to patients with AL. The PAs are not educated health care professionals, which is why it is essential that they receive the necessary education and support organized by an established network with collaboration between PAs, hospitals, and departments. Evidence is lacking on the timing, type, and duration of peer support, though many studies have assessed outcome measures such as coping, QOL, and psychological states without finding significant effects [18,19]. This might suggest that these outcomes are not appropriate for assessing the effectiveness of peer support, and more immediate outcomes such as availability of social support could be more applicable in future research. Finally, the evidence to date is based on an examination of peer support provided either face-to-face, by telephone or as a group support. Our findings highlight the importance of providing the support individually, which makes it even more difficult to determine the effect of the different ways the support can be provided. Regardless, taking this approach is imperative to obtain high representativeness to initiate meaningful support that accommodates a broad group of patients.

Conclusion

This study demonstrates that PAS in newly diagnosed patients with AL during the initial treatment was feasible and safe. Patients and PAs reported high satisfaction with individual peer support, and

patients improved in their psychosocial outcomes over time. PAs maintained their psychosocial baseline levels, with no adverse events, and used the available support to exchange experiences with other PAs. The findings of this study have the potential to impact psychosocial supportive care in patients with AL by informing the development of integrated psychosocial interventions. Our results are based on a sample of participants with AL, and future research is needed to confirm these results in patients and survivors with other hematological malignancies and cancers.

Conflict of interest

The authors declare that they have no conflict of interest.

The corresponding author have full control of all primary data and agree to allow the journal to review their data if requested.

References

1. Short NJ, Rytting ME, Cortes JE (2018) Acute myeloid leukaemia. Lancet 392 (10147):593-606. doi:10.1016/s0140-6736(18)31041-9

2. Zimmermann C, Yuen D, Mischitelle A, Minden MD, Brandwein JM, Schimmer A, Gagliese L, Lo C, Rydall A, Rodin G (2013) Symptom burden and supportive care in patients with acute leukemia. Leukemia research 37 (7):731-736. doi:10.1016/j.leukres.2013.02.009

3. Terwilliger T, Abdul-Hay M (2017) Acute lymphoblastic leukemia: a comprehensive review and 2017 update. Blood cancer journal 7 (6):e577. doi:10.1038/bcj.2017.53

4. De Kouchkovsky I, Abdul-Hay M (2016) Acute myeloid leukemia: a comprehensive review and 2016 update. Blood cancer journal 6 (7):e441. doi:10.1038/bcj.2016.50

5. Moller T, Nielsen OJ, Welinder P, Dunweber A, Hjerming M, Moser C, Kjeldsen L (2010) Safe and feasible outpatient treatment following induction and consolidation chemotherapy for patients with acute leukaemia. European journal of haematology 84 (4):316-322. doi:10.1111/j.1600-0609.2009.01397.x

6. Walter RB, Taylor LR, Gardner KM, Dorcy KS, Vaughn JE, Estey EH (2013) Outpatient management following intensive induction or salvage chemotherapy for acute myeloid leukemia. Clinical advances in hematology & oncology : H&O 11 (9):571-577

7. Cannas G, Thomas X (2015) Supportive care in patients with acute leukaemia: historical perspectives. Blood transfusion = Trasfusione del sangue 13 (2):205-220. doi:10.2450/2014.0080-14

8. Fridthjof KS, Kampmann P, Dunweber A, Gorlov JS, Nexo C, Friis LS, Norskov KH, Welinder PC, Moser C, Kjeldsen L, Moller T (2018) Systematic patient involvement for homebased outpatient administration of complex chemotherapy in acute leukemia and lymphoma. British journal of haematology 181 (5):637-641. doi:10.1111/bjh.15249

9. Albrecht TA, Boyiadzis M, Elswick RK, Jr., Starkweather A, Rosenzweig M (2016) Symptom Management and Psychosocial Needs of Adults With Acute Myeloid Leukemia During Induction Treatment: A Pilot Study. Cancer nursing. doi:10.1097/ncc.0000000000000428

10. Albrecht TA, Rosenzweig M (2014) Distress in patients with acute leukemia: a concept analysis. Cancer nursing 37 (3):218-226. doi:10.1097/NCC.0b013e31829193ad

11. Gheihman G, Zimmermann C, Deckert A, Fitzgerald P, Mischitelle A, Rydall A, Schimmer A, Gagliese L, Lo C, Rodin G (2016) Depression and hopelessness in patients with acute leukemia: the psychological impact of an acute and life-threatening disorder. Psycho-oncology 25 (8):979-989. doi:10.1002/pon.3940

12. Norskov KH, Overgaard D, Lomborg K, Kjeldsen L, Jarden M (2019) Patients' experiences and social support needs following the diagnosis and initial treatment of acute leukemia - A qualitative study. European journal of oncology nursing : the official journal of European Oncology Nursing Society 41:49-55. doi:10.1016/j.ejon.2019.05.005

13. Skirbekk H, Korsvold L, Finset A (2018) To support and to be supported. A qualitative study of peer support centres in cancer care in Norway. Patient education and counseling 101 (4):711-716. doi:10.1016/j.pec.2017.11.013
14. Ussher J, Kirsten L, Butow P, Sandoval M (2006) What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. Social science & medicine (1982) 62 (10):2565-2576. doi:10.1016/j.socscimed.2005.10.034
15. Festinger L (1954) A Theory of Social Comparison Processes. Human Relations 7 (2):117-140. doi:10.1177/001872675400700202
16. Suls J, Miller R (1977) Social comparison theory and research: an overview from 1954. In: Social Comparison Processes. John Wiley & Sons, London pp 1-17
17. Pistrang N, Jay Z, Gessler S, Barker C (2013) Telephone peer support for women with gynaecological cancer: benefits and challenges for supporters. Psycho-oncology 22 (4):886-894. doi:10.1002/pon.3080
18. Hoey LM, Ieropoli SC, White VM, Jefford M (2008) Systematic review of peer-support programs for people with cancer. Patient education and counseling 70 (3):315-337. doi:10.1016/j.pec.2007.11.016
19. Meyer A, Coroiu A, Korner A (2015) One-to-one peer support in cancer care: a review of scholarship published between 2007 and 2014. European journal of cancer care 24 (3):299-312. doi:10.1111/ecc.12273
20. Piil K, Jarden M, Pii KH (2019) Research agenda for life-threatening cancer. European journal of cancer care 28 (1):e12935. doi:10.1111/ecc.12935
21. Orsmond GI, Cohn ES (2015) The Distinctive Features of a Feasibility Study: Objectives and Guiding Questions. OTJR : occupation, participation and health 35 (3):169-177. doi:10.1177/1539449215578649
22. Bowen DJ, Kreuter M, Spring B, Cofta-Woerpel L, Linnan L, Weiner D, Bakken S, Kaplan CP, Squiers L, Fabrizio C, Fernandez M (2009) How we design feasibility studies. American journal of preventive medicine 36 (5):452-457. doi:10.1016/j.amepre.2009.02.002
23. Zigmond AS, Snaith RP (1983) The hospital anxiety and depression scale. Acta psychiatrica Scandinavica 67 (6):361-370
24. Cella D, Jensen SE, Webster K, Hongyan D, Lai JS, Rosen S, Tallman MS, Yount S (2012) Measuring health-related quality of life in leukemia: the Functional Assessment of Cancer Therapy--Leukemia (FACT-Leu) questionnaire. Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research 15 (8):1051-1058. doi:10.1016/j.jval.2012.08.2210
25. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JC, et al. (1993) The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. Journal of the National Cancer Institute 85 (5):365-376
26. Cleeland CS, Mendoza TR, Wang XS, Chou C, Harle MT, Morrissey M, Engstrom MC (2000) Assessing symptom distress in cancer patients: the M.D. Anderson Symptom Inventory. Cancer 89 (7):1634-1646

27. Hibbard JH, Stockard J, Mahoney ER, Tusler M (2004) Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health services research 39 (4 Pt 1):1005-1026. doi:10.1111/j.1475-6773.2004.00269.x
28. Rademakers J, Maindal HT, Steinsbekk A, Gensichen J, Brenk-Franz K, Hendriks M (2016) Patient activation in Europe: an international comparison of psychometric properties and patients' scores on the short form Patient Activation Measure (PAM-13). BMC health services research 16 (1):570. doi:10.1186/s12913-016-1828-1
29. Johnston M WS, Weinman J (1995) Measures in Health Psychology: A User's Portfolio. Windsor: NFER-NELSON, UK
30. Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, McLeod L, Delacqua G, Delacqua F, Kirby J, Duda SN (2019) The REDCap consortium: Building an international community of software platform partners. Journal of biomedical informatics 95:103208. doi:10.1016/j.jbi.2019.103208
31. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG (2009) Research electronic data capture (REDCap)-a metadata-driven methodology and workflow process for providing translational research informatics support. Journal of biomedical informatics 42 (2):377-381. doi:10.1016/j.jbi.2008.08.010
32. Billingham SA, Whitehead AL, Julious SA (2013) An audit of sample sizes for pilot and feasibility trials being undertaken in the United Kingdom registered in the United Kingdom Clinical Research Network database. BMC medical research methodology 13:104. doi:10.1186/1471-2288-13-104
33. The R project for statistical computing. R Foundation for Statistical Computing. https://www.R-project.org/. Accessed April 25 2020
34. Guyer JV-J, Thomas. (2018) Upward and downward social comparisons: A brief historical overview. In: V. Zeigler-Hill TKS (ed) Encyclopedia of Personality and Individual Differences. Springer International Publishing
35. Moulton A, Balbierz A, Eisenman S, Neustein E, Walther V, Epstein I (2013) Woman to woman: a peer to peer support program for women with gynecologic cancer. Social work in health care 52 (10):913-929. doi:10.1080/00981389.2013.834031
36. Mirrielees JA, Breckheimer KR, White TA, Denure DA, Schroeder MM, Gaines ME, Wilke LG, Tevaarwerk AJ (2017) Breast Cancer Survivor Advocacy at a University Hospital: Development of a Peer Support Program with Evaluation by Patients, Advocates, and Clinicians. Journal of cancer education : the official journal of the American Association for Cancer Education 32 (1):97-104. doi:10.1007/s13187-015-0932-y
37. Lee R, Lee KS, Oh EG, Kim SH (2013) A randomized trial of dyadic peer support intervention for newly diagnosed breast cancer patients in Korea. Cancer nursing 36 (3):E15-22. doi:10.1097/NCC.0b013e3182642d7c
38. Alibhai SM, Breunis H, Timilshina N, Brignardello-Petersen R, Tomlinson G, Mohamedali H, Gupta V, Minden MD, Li M, Buckstein R, Brandwein JM (2015) Quality of life and physical function in adults treated

with intensive chemotherapy for acute myeloid leukemia improve over time independent of age. Journal of geriatric oncology 6 (4):262-271. doi:10.1016/j.jgo.2015.04.002
39. Moller T, Adamsen L, Appel C, Welinder P, Stage M, Jarden M, Hjerming M, Kjeldsen L (2012) Health related quality of life and impact of infectious comorbidity in outpatient management of patients with acute leukemia. Leukemia & lymphoma 53 (10):1896-1904. doi:10.3109/10428194.2012.676169
40. Jarden M, Moller T, Christensen KB, Kjeldsen L, Birgens HS, Adamsen L (2016) Multimodal intervention integrated into the clinical management of acute leukemia improves physical function and quality of life during consolidation chemotherapy: a randomized trial 'PACE-AL'. Haematologica 101 (7):e316-319. doi:10.3324/haematol.2015.140152
41. Nolte S, Liegl G, Petersen MA, Aaronson NK, Costantini A, Fayers PM, Groenvold M, Holzner B, Johnson CD, Kemmler G, Tomaszewski KA, Waldmann A, Young TE, Rose M (2019) General population normative data for the EORTC QLQ-C30 health-related quality of life questionnaire based on 15,386 persons across 13 European countries, Canada and the Unites States. European journal of cancer (Oxford, England : 1990) 107:153-163. doi:10.1016/j.ejca.2018.11.024
42. Campbell HS, Phaneuf MR, Deane K (2004) Cancer peer support programs-do they work? Patient education and counseling 55 (1):3-15. doi:10.1016/j.pec.2003.10.001
43. Macvean ML, White VM, Sanson-Fisher R (2008) One-to-one volunteer support programs for people with cancer: a review of the literature. Patient education and counseling 70 (1):10-24. doi:10.1016/j.pec.2007.08.005
44. Flagg AJ (2015) The role of patient-centered care in nursing. The Nursing clinics of North America 50 (1):75-86. doi:10.1016/j.cnur.2014.10.006
45. Myrhoj CB, Norskov KH, Jarden M, Rydahl-Hansen S (2020) The motivation to volunteer as a peer support provider to newly diagnosed patients with acute leukemia - A qualitative interview study. European journal of oncology nursing : the official journal of European Oncology Nursing Society 46:101750. doi:10.1016/j.ejon.2020.101750

Fig. 1 Flowchart on patients

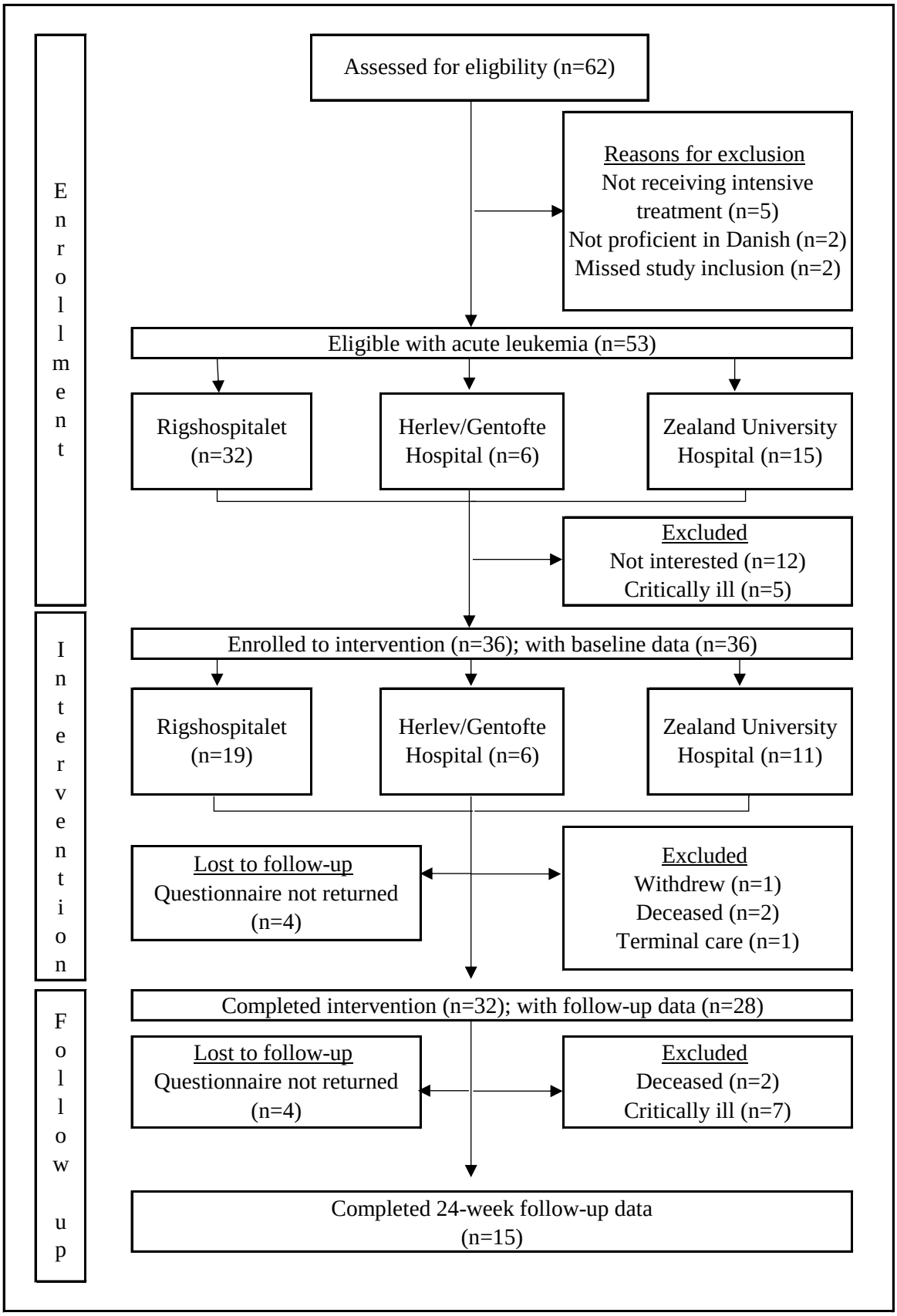


Figure 2 Flowchart on patient ambassadors

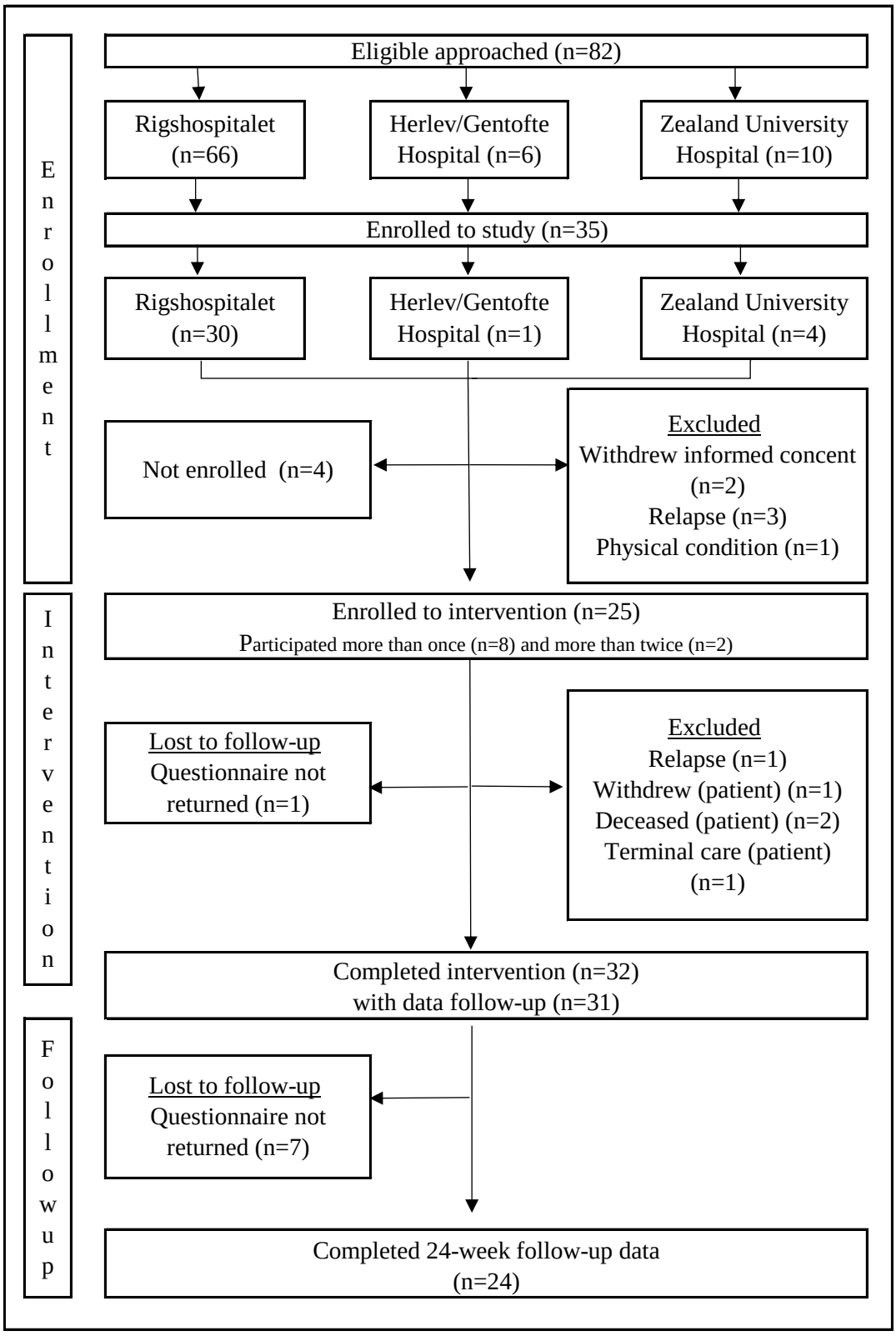


Fig. 3 Contacts between participants

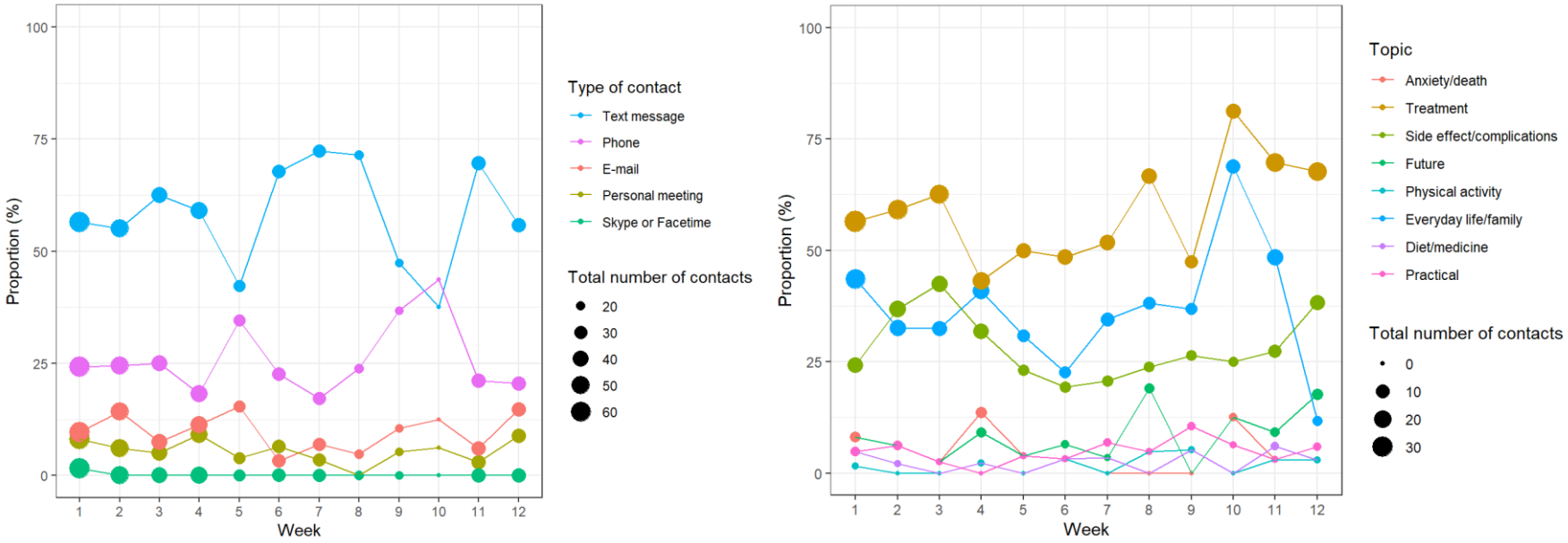


Table 1

Demographic and Clinical Characteristics of Study Participants

Characteristic	Patients N=36 Value	Ambassadors N=24 Value
Gender, female n (%)	21 (58.3)	12 (50.0)
Age, mean (range)	54.5 (27-77)	51.5 (21-76)
Education, n (%)		
No high school degree	4 (11.1)	1 (4.2)
High school degree	1 (2.7)	3 (12.5)
2-year college	13 (36.1)	6 (25.0)
4-year college	9 (25.0)	9 (37.5)
Master´s degree or higher	7 (19.4)	5 (20.8)
Occupation, n (%)		
Salaried employee	17 (47.2)	11 (45.8)
Unemployed	0	0
Retired employee	15 (41.7)	8 (33.3)
Sickness benefits	2 (5.6)	2 (8.3)
Undergoing education	2 (5.6)	3 (12.5)
Marital status, n (%)		
Married or cohabitating	25 (69.4)	19 (79.2)
Single, separated, divorced, or widowed	10 (27.8)	5 (20.8)
Unknown	1 (2.8)	0
Diagnosis, n (%)		
Acute lymphatic leukemia	11 (30.6)	8 (33.3)
Acute myeloiod leukemia	24 (66.7)	12 (50.0)
Other	1 (2.8)	4 (16.7)
Treatment, n (%)		
DA 3+10	18 (50.1)	
FLAG-IDA	3 (8.3)	
NOPHO	8 (22.2)	
Other	7 (19.4)	
Years post AL diagnosis, n (%)		
<2		7 (29.2)
2-4		7 (29.2)
>4		10 (41.6)
Allogeneic HSCT, n (%)		16 (66.6)
Years post HSCT, n (%)		
< 2		7 (43.7)
2-4		3 (18.7)
> 4		6 (37.5)

DA 3+10: Daunorubicin - Ara-C; FLAG-IDA: Fludarabine, Cytarabine, Idarubicin and G-CSF; NOPHO: Nordic Society of Pediatric Haematology and Oncology; HSCT: hematopoetic stem cell transplantation.

Table 2 Patient-reported outcomes in patients

Variables	Baseline (N=36)		12-week follow-up (N=28)		24-week follow-up (N=15)		Baseline to 12-week follow-up			12-week to 24-week follow-up		
	N	Mean (SD)	*N*	Mean (SD)	*N*	Mean (SD)	Change (s.e.)	95% CI	P-value	Change (s.e.)	95% CI	P-value
HADS												
Anxiety (0-21)	*35*	8.2 (3.8)	*28*	6.2 (4.4)	*15*	6.8 (3.7)	-2.1 (0.7)	[-3.6; -0.6]	0.01*	0.0 (0.9)	[-1.8; 1.9]	0.98
Depression (0-21)	*35*	7.3 (4.3)	*28*	5.5 (3.9)	*15*	6.2 (4.5)	-1.3 (0.7)	[-2.7; 0.1]	0.07	0.7 (0.9)	[-1.1; 2.5]	0.46
MDASI												
Core (0-10)	*35*	3.5 (1.9)	*27*	3.1 (2.5)	*14*	3.7 (2.2)	-0.3 (0.5)	[-1.2; 0.6]	0.52	0.7 (0.6)	[-0.4; 1.9]	0.21
Interference (0-10)	*35*	3.7 (2.5)	*28*	3.4 (3.0)	*14*	3.5 (2.6)	-0.1 (0.6)	[-1.3; 1.0]	0.85	0.5 (0.7)	[-1.0; 1.9]	0.54
EORTC QLQ-C30												
Global Health (0-100)	*35*	40.5 (22.5)	*27*	55.6 (27.8)	*14*	61.3 (30.4)	11.5 (5.6)	[0.1; 22.8]	0.05*	6.0 (7.2)	[-8.5; 20.5]	0.41
Physical functioning (0-100)	*33*	67.5 (24.4)	*28*	70.5 (23.5)	*14*	71.9 (23.7)	-1.6 (5.0)	[-11.7; 8.5]	0.76	0.6 (6.3)	[-12.2; 13.4]	0.93
Role functioning (0-100)	*31*	28.5 (31.4)	*28*	51.2 (34.5)	*13*	57.7 (33.8)	20.8 (8.1)	[4.4; 37.2]	0.01*	5.0 (10.2)	[-15.8; 25.7]	0.63
Emotional functioning (0-100)	*34*	71.5 (21.5)	*28*	74.1 (21.2)	*14*	71.6 (22.5)	0.9 (3.8)	[-6.9; 8.8]	0.81	-1.5 (4.9)	[-11.5; 8.5]	0.76
Cognitive functioning (0-100)	*34*	72.5 (21.3)	*28*	81.0 (18.0)	*14*	82.1 (19.0)	9.0 (4.3)	[0.3; 17.8]	0.04*	-0.4 (5.5)	[-11.6; 10.8]	0.94
Social functioning (0-100)	*34*	53.9 (36.0)	*28*	63.1 (28.5)	*14*	66.7 (39.2)	9.9 (6.8)	[-3.9; 23.6]	0.15	-0.9 (8.7)	[-18.5; 16.7]	0.92
FACT-Leu												
Physical well-being (0-28)	*34*	17.6 (5.6)	*28*	19.6 (7.1)	*14*	18.6 (8.4)	1.6 (1.4)	[-1.3; 4.6]	0.26	-1.2 (1.9)	[-5.0; 2.5]	0.51
Social/familily well-being (0-28)	*34*	21.9 (4.1)	*28*	21.2 (5.3)	*14*	21.7 (5.6)	-0.6 (0.6)	[-1.8; 0.7]	0.35	0.4 (0.8)	[-1.2; 1.9]	0.66
Emotional well-being (0-24)	*35*	16.1 (4.8)	*28*	16.8 (4.3)	*14*	16.6 (5.2)	0.2 (0.7)	[-1.3; 1.7]	0.76	0.8 (1.0)	[-1.1; 2.8]	0.4
Functional well-being (0-28)	*34*	11.2 (5.8)	*28*	25.5 (6.7)	*13*	16.6 (8.6)	3.5 (1.4)	[0.8; 6.3]	0.01*	0.6 (1.8)	[-3.0; 4.3]	0.73
FACT-G (0-108)	*33*	66.9 (15.9)	*28*	73.1 (18.2)	*13*	74.0 (23.3)	4.1 (3.0)	[-2.0; 10.1]	0.18	0.1 (4.0)	[-7.9; 8.2]	0.97
Leu subscale (0-68)	*35*	42.9 (11.7)	*28*	47.4 (9.2)	*14*	44.5 (12.3)	3.5 (2.2)	[-1.0; 7.9]	0.13	-2.6 (2.9)	[-8.4; 3.2]	0.36
FACT-Leu scale (0-176)	*33*	110.1 (26.7)	*28*	120.5 (26.4)	*13*	118.9 (34.8)	7.2 (5.0)	[-3.0; 17.3]	0.16	-2.9 (6.6)	[-16.3; 10.4]	0.66
TOI (0-124)	*33*	72.1 (21.6)	*28*	82.5 (21.2)	*13*	80.2 (28.6)	8.0 (4.6)	[-1.3; 17.3]	0.09	-3.9 (6.1)	[-16.1; 8.4]	0.53
PAM												
Sum score (13-52)	*31*	37.6 (4.5)	*24*	40.1 (6.7)	*14*	39.0 (6.7)	2.2 (1.3)	[-0.5; 5.0]	0.11	-0.4 (1.6)	[-3.7; 3.0]	0.82
Niveau (1-4)	*31*	2.2 (1.0)	*24*	2.9 (0.9)	*14*	2.4 (1.2)	0.6 (0.3)	[0.1; 1.1]	0.02*	-0.4 (0.3)	[-1.0; 0.3]	0.25
GSE												
Average score (1-4)	*34*	2.8 (0.6)	*28*	3.0 (0.7)	*13*	2.8 (0.7)	0.2 (0.1)	[-0.1; 0.4]	0.22	-0.1 (0.2)	[-0.5; 0.2]	0.37

HADS: Hospital Anxiety and Depression Scale a 14-item measure with higher scores indicating higher symptomatology (cutoff scores>8 for each item), MDASI: MD Anderson Symptom Inventory a 19-item measure and assesses the severity of 13 symptoms and their impact in cancer patients, EORTC QLQ-C30: European Organisation for Reseearch and Treatment of Cancer Quality of Life Questionaaire a 30-item measure; FACT-Leu: Functional Assessment of Cancer Therapy - Leukemia a 44-item measure; FACT-G: physical, social/family, emotional and functional well-being; FACT-leu: FACT-G and Leu subscale; TOI, trial outcome index: physical, functional well-being and Leu subscale; PAM: Patient Activation Measure a 13-item measure, with sum scores graded into PAM levels 1-4, with higher levels indicating better trust and competencies to cope; GSE: General Self-Efficacy Scale a 10-item measure, with higher scores indicating greater sense of self-efficacy, Range of score listed after each variable, SD: standard deviation; s.e.: standard error; 95% CI: 95% confidence interval; any available data from patients who did not complete the intervention is included in baseline summaries; *p <0.05

Table 3 Patient-reported outcomes in patient ambassadors

Variables	Baseline (N=36)		12-week follow-up (N=31)		24-week follow-up (N=24)		Baseline to 12-week follow-up			12-week to 24-week follow-up		
	N	Mean (SD)	*N*	Mean (SD)	*N*	Mean (SD)	Change (s.e.)	95% CI	P-value	Change (s.e.)	95% CI	P-value
HADS												
Anxiety (0-21)	*36*	3.6 (2.4)	*31*	3.1 (2.9)	*24*	3.3 (3.0)	-0.4 (0.5)	[-1.4; 0.7]	0.46	0.4 (0.6)	[-0.7; 1.5]	0.51
Depression (0-21)	*36*	2.0 (1.7)	*31*	2.0 (2.1)	*24*	2.0)2.1)	-0.1 (0.3)	[-0.7; 0.5]	0.67	0.2 (0.3)	[-0.5; 0.9]	0.6
MDASI												
Core (0-10)	*36*	1.5 (1.5)	*31*	1.8 (1.8)	*23*	1.4 (1.6)	0.4 (0.3)	[-0.2; 1.0]	0.18	-0.5 (0.3)	[-1.1; 0.2]	0.16
Interference (0-10)	*36*	1.4 (2.0)	*31*	1.4 (2.0)	*23*	0.8 (1.3)	-0.1 (0.4)	[-0.9; 0.6]	0.73	-0.6 (0.4)	[-1.5; 0.2]	0.14
EORTC QLQ-C30												
Global Health (0-100)	*36*	80.3 (15.6)	*31*	78.2 (19.1)	*23*	80.8 (18.0)	-1.4 (2.2)	[-5.8; 3.1]	0.54	1.1 (2.5)	[-3-8; 6.1]	0.66
Physical functioning (0-100)	*36*	85.6 (20.8)	*31*	86.1 (17.2)	*23*	87.5(16.9)	1.3 (1.9)	[-2.5; 5.1]	0.51	1.56 (2.1)	[-2.8; 5.8]	0.48
Role functioning (0-100)	*36*	87.5 (20.8)	*31*	84.9 (20.8)	*23*	82.6 (25.4)	-0.6 (3.1)	[-6.7; 5.5]	0.85	-2.3 (3.5)	[-9.2; 4.6]	0.51
Emotional functioning (0-100)	*36*	90.7 (13.3)	*31*	92.5 (12.8)	*23*	96.0 (7.9)	1.9 (2.3)	[-2.7; 6.7]	0.4	2.2 (2.6)	[-3.0; 7.5]	0.4
Cognitive functioning (0-100)	*36*	87.0 (18.3)	*31*	84.4 (19.7)	*23*	86.2 (17.9)	-2.1 (1.9)	[-6.1; 1.8]	0.29	1.2 (2.2)	[-3.3; 5.7]	0.61
Social functioning (0-100)	*36*	86.6 (19.8)	*31*	88.2 (17.8)	*23*	87.7 (20.9)	1.5 (2.8)	[-4.1; 7.2]	0.59	0.1 (3.2)	[-6.2; 6.5]	0.97
FACT-Leukemia												
Physical well-being (0-28)	*36*	24.6 (3.0)	*31*	24.3 (3.9)	*23*	24.9 (3.7)	-0.1 (0.5)	[-1.1; 0.9]	0.89	0.6 (0.6)	[-1.1; 0.9]	0.89
Social/familily well-being (0-28)	*36*	22.3 (4.4)	*31*	22.4 (4.7)	*23*	21.0 (6.4)	0.1 (0.8)	[-1.5; 1.7]	0.9	-1.4 (0.9)	[-3.1; 0.4]	0.12
Emotional well-being (0-24)	*36*	21.4 (2.5)	*31*	20.8 (2.5)	*23*	21.1 (2.3)	-1.0 (0.3)	[-1.6; -0.3]	<0.01*	0.4 (0.4)	[-0.3; 1.1]	0.26
Functional well-being (0-28)	*35*	23.0 (4.7)	*31*	23.1 (4.4)	*23*	22.3 (6.3)	0.1 (0.6)	[-1.2; 1.3]	0.93	-1.0 (0.7)	[-2.4; 0.4]	0.15
FACT-G (0-108)	*35*	91.3 (11.8)	*31*	90.5 (11.5)	*23*	89.4 (16.2)	-1.1 (1.6)	[-4.3; 2.1]	0.51	-1.3 (1.8)	[-5.0; 2.3]	0.46
Leu subscale (0-68)	*36*	59.1 (6.8)	*31*	59.0 (6.2)	*23*	59.1 (8.3)	-0.4 (0.9)	[-2.1; 1.4]	0.67	-0.1 (1.0)	[-2.0; 1.9]	0.96
FACT-Leu (0-176)	*35*	150.3 (17.5)	*31*	150.0 (17.0)	*23*	148.5 (23.4)	-1.6 (2.0)	[-5.7; 2.5]	0.43	-1.4 (2.3)	[-6.0; 3.2]	0.54
TOI (0-124)	*35*	106.6 (12.6)	*31*	106.4 (12.5)	*23*	106.3 (16.7)	-0.7 (1.5)	[-3.6; 2.3]	0.65	-0.5 (1.7)	[-3.8; 2.9]	0.78
Patient Activation Measure												
Sum score (13-52)	*36*	44.0 (7.6)	*28*	44.1 (7.5)	*23*	45.3 (4.8)	0.1 (1.4)	[-2.7; 2.8]	0.96	2.0 (1.5)	[-1.1; 5.1]	0.2
Niveau (1-4)	*36*	3.3 (1.0)	*28*	3.3 (1.0)	*23*	3.6 (0.6)	0.1 (0.2)	[-0.3; 0.5]	0.74	0.3 (0.2)	[-0.1; 0.7]	0.16
General Self-Efficacy Scale												
Sum score (1-4)	*36*	3.4 (0.5)	*31*	3.4 (0.6)	*23*	3.4 (0.6)	-0.0 (0.1)	[-0.2; 0.1]	0.61	0.0 (0.1)	[-0.1; 0.2]	0.66

HADS: Hospital Anxiety and Depression Scale a 14-item measure with higher scores indicating higher symptomatology (cutoff scores>8 for each item), MDASI: MD Anderson Symptom Inventory a 19-item measure and assesses the severity of 13 symptoms and their impact in cancer patients, EORTC QLQ-C30: European Organisation for Reseearch and Treatment of Cancer Quality of Life Questionaaire a 30-item measure; FACT-Leu: Functional Assessment of Cancer Therapy - Leukemia a 44-item measure; FACT-G: physical, social/family, emotional and functional well-being; FACT-leu: FACT-G and Leu subscale; TOI, trial outcome index: physical, functional well-being and Leu subscale; PAM: Patient Activation Measure a 13-item measure, with sum scores graded into PAM levels 1-4, with higher levels indicating better trust and competencies to cope; GSE: General Self-Efficacy Scale a 10-item measure, with higher scores indicating greater sense of self-efficacy, Range of score listed after each variable, SD: standard deviation; s.e.: standard error; 95% CI: 95% confidence interval; any available data from patients who did not complete the intervention is included in baseline summaries; *p <0.05

PAPER III

Patient Ambassador Support: experiences of the mentorship between newly diagnosed patients with acute leukemia and their patient ambassadors

Kristina Norskov,
Dorthe Overgaard, Kirsten Lomborg,
Lars Kjeldsen & Mary Jarden

Received: 24 January 2020 | Revised: 26 May 2020 | Accepted: 10 June 2020

DOI: 10.1111/ecc.13289

ORIGINAL ARTICLE

European Journal of Cancer Care WILEY

Patient ambassador support: Experiences of the mentorship between newly diagnosed patients with acute leukaemia and their patient ambassadors

Kristina Holmegaard Nørskov[1] | Dorthe Overgaard[2] | Kirsten Lomborg[3] | Lars Kjeldsen[1] | Mary Jarden[1,4]

[1]Department of Hematology, Rigshospitalet, Copenhagen University Hospital, Copenhagen, Denmark

[2]University College Copenhagen, Copenhagen, Denmark

[3]Department of Clinical Medicine, Aarhus University, Aarhus, Denmark

[4]Department of Public Health, University of Copenhagen, Copenhagen, Denmark

Correspondence
Kristina Holmegaard Nørskov, Department of Hematology, Rigshospitalet, Blegdamsvej 9, 2100 Copenhagen Ø, Copenhagen University Hospital, Denmark.
Email: Kristina.holmegaard.noerskov@regionh.dk

Funding information
This research was undertaken, in part, thanks to funding from the Novo Nordisk Foundation.

Abstract

Objective: The study explores how newly diagnosed patients with acute leukaemia and their patient ambassadors experience the mentorship during the patient ambassador support programme.

Methods: Explorative semi-structured individual interviews (n = 28) were carried out in patients with acute leukaemia (n = 15) and their patient ambassadors (n = 13). Interpretive description was the methodological framework used for the thematic analysis of the qualitative interview data.

Results: Identified themes were as follows: (a) exchanging life experiences (subthemes: individualised support and a meaningful return); (b) existential cohesion; (c) interreflection; and (d) terms and conditions (subtheme: break in journey). Patients experienced a feeling of being understood, the cohesion leading to hope and a feeling of being able to cope with their situation. Patient ambassadors experienced a sense of meaningfulness and gratitude for life.

Conclusions: Patients and patient ambassadors experienced benefits from the individualised support. Their shared experiences created a connection and mutual mirroring, which led to a sense of hope and gratitude for life. Initiatives that introduce peer-to-peer support in newly diagnosed patients with acute leukaemia as part of treatment and in daily clinical practice are crucial. Future studies should further examine the feasibility of peer-to-peer support interventions along the trajectory of acute leukaemia.

KEYWORDS

acute leukaemia, mentorship, patient ambassador, peer support, qualitative interviews, social support

1 | INTRODUCTION

Acute leukaemia (AL), a malignant disorder of haematopoietic stem cells, is associated with morbidity and mortality (Short, Rytting, & Cortes, 2018). AL is classified into subtypes of acute myeloid or lymphoid leukaemia (AML/ALL) (Hoffman, Silberstein, Heslop, Weitz, & Anastasi, 2018). AML is the most common AL in adults with an incidence in Europe of 5.06 patients per 100.000 people (Roman et al., 2016). ALL has a bimodal distribution with a peak in childhood and then again in midlife with an incidence in Europe of 1.28 patients per 100.000 people.(Hoelzer et al., 2016). The trajectory has an acute onset followed by a significant disease and treatment-related symptom burden, with a risk of developing psychological distress impacting quality of life (Ferrara & Schiffer, 2013; Leak Bryant, Lee Walton, Shaw-Kokot, Mayer, & Reeve, 2015; Short et al., 2018; Zimmermann et al., 2013). The psychological morbidity following AL can influence recovery and adaptation of the illness in everyday life (Manitta, Zordan, Cole-Sinclair, Nandurkar, & Philip, 2011).

Social support is defined as a multidimensional construct that refers to the psychological and material resources available to individuals through their interpersonal relationships (Cohen & Wills, 1985). The most influential theoretical perspective on social support and health outcomes indicates that social support protects people from the influence of stressful events (Cohen & Herbert, 1996; Cohen & Wills, 1985).

Social support increases adherence to treatment and improves health behaviour (Pinquart, Hoffken, Silbereisen, & Wedding, 2007; Shinn, Caplan, Robinson, French, & Caldwell, 1977). In patients with cancer, increased level of social support is associated with fewer psychological symptoms, improved well-being and quality of life (Kornblith et al., 2001; Liang et al., 2019; Papadopoulou, Johnston, & Themessl-Huber, 2013).

One-to-one peer support is social support that involves a cancer survivor providing emotional and experience-based support to a patient in an earlier stage of treatment or recovery than the provider of peer support (Pistrang, Jay, Gessler, & Barker, 2012, 2013; Ussher, Kirsten, Butow, & Sandoval, 2006). Peers have the unique opportunity of providing experienced-based informational, emotional and practical support beyond the scope of health professionals and their own social network (Dennis, 2003). People giving help profit through self-development by solving their own problems in the process of helping others (Riessman, 1965). A 2015 systematic review (Meyer, Coroiu, & Korner, 2015) found that peer-to-peer support led to benefits in psychological adjustment, self-efficacy and high satisfaction with and acceptance of the support in patients with cancer. Yet, the included studies were exclusively quantitative. Additionally, few studies have focused on the peers' experiences of mentorship in one-to-one interventions, especially in relation to the perspective of the provider of peer support (Pistrang, Jay, Gessler, & Barker, 2013).

The existing evidence on peer-to-peer support within cancer is based on other malignancies than haematology, primarily breast and prostate cancer (Hoey, Ieropoli, White, & Jefford, 2008; Meyer et al., 2015). Because of the disease and treatment-related symptom burden posed by AL, the existing research can, only to a limited extent, be transferred to patients with AL, creating a lack of research and evidence in peer-to-peer support interventions for the AL patient group. In the current study exploring the experiences of a peer support intervention, a peer support provider is named a patient ambassador.

The purpose of this study was to explore how newly diagnosed patients with AL and their patient ambassadors experience the mentorship during patient ambassador support as a means to gain new knowledge and insight into this unique support.

2 | METHODS

Interpretive description (ID) is applied as a methodological framework in this explorative qualitative study with the objective of informing and improving clinical practice (Thorne, 2016). ID combines aspects from traditional qualitative methods and with its inductive approach focuses on applied science within health science discipline (Thorne, Kirkham, & O'Flynn-Magee, 2004).

2.1 | Setting

This study is part of a feasibility intervention trial investigating patient ambassador support in newly diagnosed patients with AL (ClinicalTrials.gov identifier: NCT03493906). The trial comprises a 12-week support intervention for newly diagnosed patients with AL provided by patient ambassadors. Patients are included within the first two weeks from time of diagnosis. A patient ambassador in this study is defined as having previously been diagnosed with and treated for AL and is in complete remission. Patient ambassadors have attended an obligatory one-day preparatory educational course and had the opportunity to attend regular network meetings with supervision from a psychologist. Patients and ambassadors were encouraged to engage in four personal meetings during the intervention; however it was not a requirement.

2.2 | Participants and procedures

The sample is based on a purposive strategy to achieve maximal variation and information-rich interviews, which is why sampling continued until diversity was reached (Thorne, 2016). Participants were approached by the primary investigator, KHN, within two weeks after completing patient ambassador support in the period of June 2018 to January 2019. Inclusion criteria were patients and patient ambassadors who had participated in and completed the intervention within the last two weeks and who were able to understand, speak and read Danish. The exclusion criteria were cognitive disorders and unstable medical conditions. The sample consisted of 28 participants comprising 15 patients and 13 patient ambassadors,

with one patient ambassador interviewed twice while having two separate mentorships.

2.3 | Data collection

Separate semi-structured interview guides were developed for patients and for patient ambassadors, based on an evaluation of the existing literature, to identify the theoretical and analytic categories for the topics of research (Tables 1 and 2). The participants had the choice of being interviewed at home (n = 4), at the research facility (n = 8) or at the hospital in connection with a scheduled outpatient visit (n = 16). All interviews were conducted by KHN, lasted 30–90 min, were digitally recorded and transcribed verbatim.

2.4 | Data analysis

Consistent with ID methodology, data analysis was conducted continuously as interviews were transcribed as the study progressed (Thorne, 2016). Notes on analytical insights were generated from concurrent reflections during data collection and used in the process of analysis (levels one and two). Data were organised and managed by NVivo qualitative data analysis software, version 11 (QSR International Pty Ltd. Version2015, 2015). Thematic analysis was carried out by three researchers: KHN, DO and MJ.(Braun & Clarke, 2006) The analysis comprised six levels (Figure 1) (Nowell, Norris, White, & Moules, 2017). KHN carried out the six levels, while DO and MJ contributed with triangulation and consensus on coding and the themes at levels four to six.

3 | FINDINGS

Thirty-seven participants were screened, and seven patients were excluded. Reasons for exclusion are as follows: too ill (n = 1), palliative care (n = 1), death (n = 3), no established contact (n = 1) and relapse (n = 1). Of the eligible participants approached, one patient and one patient ambassador declined participation due to lack of motivation. The number of participants included was 28, comprising patients (n = 15) and patient ambassadors (n = 13). Tables 3 and 4 present the characteristics of the patients and patient ambassadors. Women made up 67% in patients and 69% in patient ambassadors; age range was 27–73 (mean age, patients: 49 years, patient ambassadors: 51 years); AML was the most frequent diagnosis in patients (73%) compared to patient ambassadors (54%).

The analysis identified four overarching themes: (a) exchanging life experiences (subthemes: individualised support and a meaningful

TABLE 1 Patient interview guide

Topic	Research questions	Interview questions
Expectations prior to patient ambassador support	What thoughts and expectations do the patient have in relation to receiving patient ambassador support?	What thoughts and considerations did you have before getting in contact with your patient ambassador? What expectations did you have prior to having contact with your ambassador? Were these expectations met? Did you experience any discrepancies between your expectations and what you experienced?
Experiencing patient ambassador support	How does the patient experience the patient ambassador support?	How did your contact with your patient ambassador begin? How did you experience the progression of the actual contact? Who took the initiative? What type of contact did you have? What type of contact did you have the most? Which type of contact do you prefer? What type of experience worked the best or worst for you? How often did you have contact with your patient ambassador? How was the match between you and your patient ambassador? How did you experience your relationship with your patient ambassador? What did you talk about during your conversations? What personal experiences from the patient ambassador did you ask about? What specifically worked well? Which conversations were particularly significant? What was difficult/challenging about having a patient ambassador? What did you do when it became difficult or challenging? What conversations were particularly difficult? What do you think about how the program ended?
The significance of the support	What significance does the support have for the patient?	What significance has it had for you to have a patient ambassador during your course of treatment (physically, psychologically, socially, symptoms)? Did you seek support from anyone else besides your ambassador? *If yes*, who (e.g. a psychologist or priest)?
The optimal patient ambassador support programme	What is the optimal patient ambassador support program?	Did you lack any information or knowledge from your patient ambassador or the primary investigator? To what extent was your patient ambassador sufficiently prepared for his or her role as ambassador? From your experience, what would you consider to be the optimal patient ambassador support program? (context, matching, amount of contact, content)

TABLE 2 Patient ambassador interview guide

Topic	Research questions	Interview questions
The role as ambassador	How does the ambassador experience his or her role in the supportive and mentoring relationship with the patient?	What motivated you to volunteer as a patient ambassador? Did your motivation change during or after the program ended? What thoughts and considerations did you have regarding the patient ambassador role? What expectations did you have to your role as patient ambassador? Were these expectations met? Did you experience any discrepancies between your expectations and what you experienced?
Patient ambassador support	How does the ambassador experience the patient ambassador support?	How did your contact with the patient begin? How did you experience the progression of the actual contact? What type of contact did you have? What type of contact did you have the most? What type of contact did you experience worked the best or worst? What was your preference? How often did you have contact with your patient? How was the match between you and your patient? How did you experience your relationship with the patient? What did you talk about during your conversations? What personal experiences did you share? What specifically worked well? Which conversations were particularly of value to the patient (from your perspective)? What was difficult during the program? What did you do when it was difficult? Which conversations were particularly difficult? Did you experience the need to contact to the patient's relatives? What did you think about how the 12-week program ended?
The value of the role as ambassador	What value does the support have for the patient ambassador?	What value did it have for you to be patient ambassador?
The need for support as patient ambassador	To what extent is there a need for support as a patient ambassador?	Did you experience a need for support as a patient ambassador? *If yes*, what type of support did you need and from whom? Did you participate in the patient ambassador support network meetings? *If yes*, what impact did these meetings have on you as a patient ambassador? What was especially helpful from these meetings? *If no*, why did you not participate in the meetings? Did you receive support elsewhere?
The optimal patient ambassador support programme	What is the optimal patient ambassador support program?	How was the patient ambassador training program useful compared to what you experienced? Was there any information, knowledge or support lacking during the program? If yes, explain. How do you think the patient ambassador support program can be improved?

return); (b) existential cohesion; (c) interreflection; and (d) terms and conditions (subtheme: break in journey).

3.1 | Exchanging life experiences

The impact of AL and its treatment on the patient's well-being determined the type of knowledge and experiences they requested from the patient ambassadors. Some requested information and advice on their treatment, symptoms or side effects, and others expressed a need for support in managing social issues in both family and working life, as well as in handling the practical challenges in everyday life.

> I asked her about her social life, because you become isolated when the treatment lasts so long. I stopped working, and that's why I need a social network. She gave me some ideas and inspiration for doing something different.
>
> (P11)

Patients expressed a need for support during three phases of treatment: initial treatment, stem cell transplantation and survivorship. The patient ambassadors exchanged experiences with the patients that they had had a need for during their own treatment.

3.1.1 | Individualised support

The patient ambassadors coordinated and initiated the support. The content and type of support was individualised depending on the degree of symptom burden, treatment side effects, social conditions and personal preferences. The type of contact (text message, telephone or face to face) was chosen by the patient which was by text message in the beginning. This type of contact was experienced as less committing, created emotional distance and showed consideration for the patients vulnerable and burdened situation.

> One, you don´t feel up to par; two, you're tired; three, you feel sick; and four, you don't look that great. Then

> you just don't feel like having people stop by. Then a text message is great, because it's non-committal and neutral. But it still gives you the feeling that there's someone thinking of you.
>
> (P7)

Conversely, some patient ambassadors experienced the use of text messages required increased reflection. Contact varied from a single long telephone conversation to weekly contact. Satisfaction with the support was independent of the frequency of contact; the patients described the intervention had significant impact on how they had managed their situation. A young man described how the support had an impact on his everyday life:

> He also had two small children at the time and was torn away from his family life and unable to be present. Asking him how they managed everyday life and solved these challenges was very useful. You need to gain control of practical tasks before you can adapt to what's happening to you.
>
> (P3)

3.1.2 | A meaningful return

The patient ambassadors were motivated by having experienced the same support during their own trajectory, and others had experienced an unmet need for this support. They were motivated by the desire that their experiences might help and have a positive impact on certain aspects of life for others in their current situation.

> I actually think it's been a nice thing to think about. All the bad experiences, they can be turned into something positive.
>
> (A6)

Sharing life experiences was meaningful, because doing so might help make the illness pathway easier.

> There's an important message in helping each other. This has been my greatest motivation. It means a lot; it's difficult to put into words. It's not only helping others, but it also helps you to give.
>
> (A8)

For these reasons, following and supporting others in their pathway had a therapeutic effect on the patient ambassadors.

3.2 | Existential cohesion

Existential cohesion arose in the relationship between patients and patient ambassadors in consequence of their shared experiences with the disease and treatment. This cohesion allowed a unique sharing and mutual reflection on life experiences which evolved into a relationship. The patient ambassador's advice was respected, because it was based on personal experience.

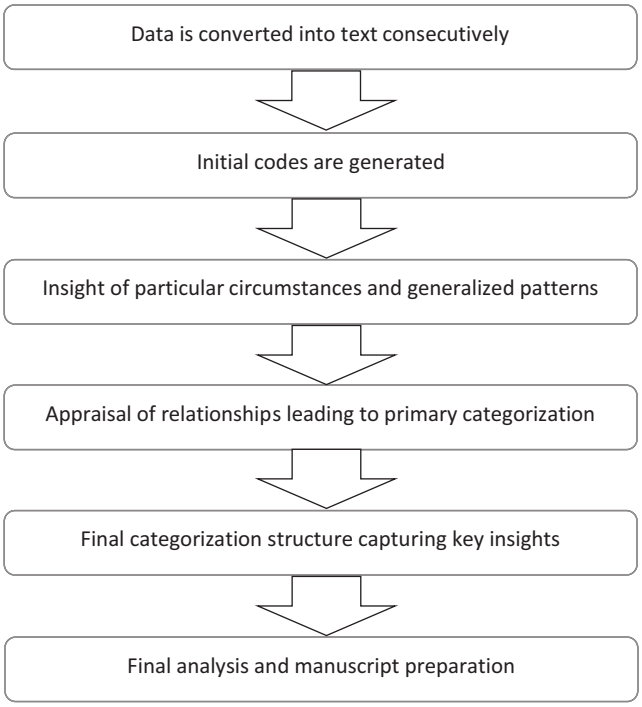


FIGURE 1 Illustration of the analysis process. A model on thematic data analysis framed by the interpretive description methodology (Thorne, 2016)

> My own friends' responses do not have the same effect on me as his do. He knows exactly what it's like.
>
> (P11)

This aspect also presented new opportunities to talk about life and the future with someone who understood their thoughts and feelings.

They expressed a willingness to continue their relationship because of a shared desire to stay abreast of one another's lives and because the patients were interested in continuing the relationship throughout the treatment trajectory.

> But how does my story end? It seems a bit strange to stop abruptly. We've talked a lot recently, and then suddenly it would end. It's nice to be followed all the way through.
>
> (P8)

Conversely, some patient ambassador's preferred not to have this kind of relationship with their mentee, because they were afraid the disease would worsen someday, creating too much of an emotional burden to continue the relationship.

TABLE 3 Patient characteristics

ID	Gender	Age in years 49 (mean) 27–73 (range)	Diagnosis	Marital status	Level of education 5.6 (mean) 3–7 (range)
P1	Male	27	ALL	In a relationship	Level 7
P2	Female	28	ALL	In a relationship	Level 7
P3	Male	31	ALL	Married	Level 6
P4	Male	32	AML	In a relationship	Level 5
P5	Male	33	ALL	Married	Level 6
P6	Female	33	AML	Single	Level 6
P7	Female	40	AML	Single	Level 6
P8	Female	50	AML	Married	Level 3
P9	Male	51	AML	Married	Level 7
P10	Female	59	AML	Single	Level 5
P11	Female	68	AML	Married	Level 7
P12	Female	70	AML	Married	Level 5
P13	Female	70	AML	Married	Level 6
P14	Female	72	AML	Married	Level 5
P15	Female	73	AML	Married	Level 5

Note: Level of education, is based on the International Standard Classification of Education (ISCED). ISCED 2011 has nine education levels, from level 0 to level 8.

Abbreviations: ALL, Acute Lymphatic Leukaemia; AML, Acute Myeloid Leukaemia; ID, Personal identification number; Level 0, Early childhood education; Level 1, Primary education; Level 2, Lower secondary education; Level 3, upper secondary education; Level 4, Post-secondary non-tertiary education; Level 5, short-cycle tertiary education; Level 6, Bachelors or equivalent level; Level 7, Masters or equivalent level; Level 8, Doctoral or equivalent level.

TABLE 4 Patient ambassador characteristics

ID	Gender	Age in years 51 (mean) 26–75 (range)	Diagnosis	Month since diagnosis 40 (mean) 18–90 (range)	Bone marrow transplant	Marital status	Level of education 5.6 (mean) 4–7 (range)	Number of patients supported
A1	Male	26	ALL	71	Yes	Single	Level 7	1
A2	Female	29	AML	27	Yes	In a Relationship	Level 6	1
A3	Male	39	ALL	24	Yes	Married	Level 4	2
A4	Male	41	ALL	60	No	Married	Level 5	2
A5	Female	46	AML	44	No	Married	Level 5	1
A6	Female	46	AML	27	Yes	Married	Level 5	3
A7	Female	49	ALL	19	Yes	Single	Level 7	2
A8	Female	49	AML	74	Yes	Married	Level 4	1
A9	Female	53	AML	27	Yes	Married	Level 5	2
A10	Female	66	ALL	90	Yes	Married	Level 6	2
A11	Male	70	ALL	26	Yes	Married	Level 5	1
A12	Female	75	AML	20	No	Widowed	Level 7	1
A13	Female	75	AML	18	Yes	Widowed	Level 7	1

Note: Level of education, is based on the International Standard Classification of Education (ISCED). ISCED 2011 has nine education levels, from level 0 to level 8.

Abbreviations: ALL, Acute Lymphatic Leukaemia; AML, Acute Myeloid Leukaemia; ID, Personal identification number; Level 0, Early childhood education; Level 1, Primary education; Level 2, Lower secondary education; Level 3, upper secondary education; Level 4, Post-secondary non-tertiary education; Level 5, short-cycle tertiary education; Level 6, Bachelors or equivalent level; Level 7, Masters or equivalent level; Level 8, Doctoral or equivalent level.

3.3 | Interreflection

Their shared experiences with the disease and treatment enabled mutual reflection. Uncertainty about the future increased the patients' need to mirror themselves in their patient ambassador which resulted in feelings of hope. Meeting someone who has completed treatment and returned to everyday life gave patients strength and hope for the future.

> It was nice to meet someone who had come out on the other side. That's just what I needed him for. He was my beacon.
>
> (P1)

The patient ambassadors also reflected themselves in the patients, helping to put their own lives into perspective realising how far they had come in their disease trajectory, creating gratitude for life.

It was important for the patient and patient ambassador to be matched according to type of AL, gender and family relationships. Being in the same phase of life was a crucial factor in terms of recognisability and the interreflection of life. A good match between the patient and the patient ambassador was essential in establishing the relationship. A well-aligned match increased the likelihood that the patient ambassadors experienced thoughts and emotions related to their own course of treatment, though not of an emotionally burdensome nature.

3.4 | Terms and conditions

Patients and patient ambassadors entered into the mentorship on unequal terms and conditions. This induced challenges with establishing the relationship due to the patient's vulnerable situation, with some indicating that this challenged their ability to share experiences and feelings with a stranger. The impact of their symptom burden reduced the amount of energy they had to establish and maintain contact, affecting the ability to have face-to-face meetings.

> When I was well and at home, there were many practical and social things to do. When I was feeling sick, I didn't have the strength. We had contact during those in-between periods.
>
> (P9)

Regardless, patients experienced the onset of illness as appropriate in relation to their current need for support.

They experienced different levels of expectations prior to establishing their relationship. The patient's vulnerable situation made it difficult for them to recognise their needs, causing them to accept all the help they could get, with very few expectations which were often fulfilled. Ambassadors, on the other hand, had more time to prepare and raise their expectations. One patient ambassador stated:

> I just think I had expected and imagined myself being an oracle, someone who could generously share my experiences and help that person having a less difficult course of treatment.
>
> (A3)

Some ambassadors said that they did not have a clear sense of whether their role had been significant to the patient. Therefore, receiving patient feedback was crucial regarding having their expectations met.

> The patients and patient ambassadors were in different illness and survivorship phases, increasing the risk of an inappropriate exchange of knowledge. "When somebody asks about your disease, it's like pressing a button. I almost blew her over, and now realize I should have shut up."
>
> (A10)

Supervision helped them to deal with any potential challenges and meeting other ambassadors also imparted a feeling of solidarity, helping them not feel alone as a long-term survivor of AL.

3.4.1 | Break in journey

One premise that both groups were aware of was the patient's risk of treatment resistance and the ambassador's risk of relapse. A few mentorships ended prematurely, because the patients were either transferred to palliative care or died. Despite this experience, the patient ambassador wished to mentor a new patient because they felt they still had experiences to share.

> Of course, you get emotionally involved, but it doesn't go that deep. What hit me the most was when her husband wrote me that evening to tell me she was gone.
>
> (A6)

Another patient ambassador experienced a relapse during the intervention, causing the patient concern because of the ambassador's function as a role model. The worry did not persist, however, and the new circumstances meant that they took a more equal role.

4 | DISCUSSION

Our findings provide important insight into patient ambassador support in newly diagnosed patients with AL and their patient ambassadors, shedding light on the benefits and challenges of this support. We found that both patients and patient ambassadors experienced substantial benefit from the support. Patient ambassadors experienced the mentorship as meaningful, and due to their mutual

existential cohesion, both groups were able to mirror each other's experiences, creating hope and gratitude for life. An important issue to point out in terms of initiating patient ambassador support is that the patient ambassador relationship is based on unequal. We found that individualised support was essential as a result of the symptom burden and personal preferences.

Research has identified several mechanisms linking social support to health outcomes (Ditzen & Heinrichs, 2014; Pinquart et al., 2007). The stress-buffering model predicts the level of social support needed to buffer the effects of stressful events in a person's life. In this model, social support is beneficial, because it decreases the negative effects of stress on health outcomes (Cohen & Herbert, 1996; Cohen & Wills, 1985). Our previous research indicates that newly diagnosed patients with AL consider social support, especially from other patients with AL, as a lifeline, helping them to actively manage their new life situation and to regain hope (Norskov, Overgaard, Lomborg, Kjeldsen, & Jarden, 2019). The present study identified various benefits derived from patient ambassador support that may explain the mechanisms linking social support with improved health outcomes in both peer recipients and peer supporters.

Patients experience feelings of uncertainty and a threat to their existence when diagnosed with cancer. A literature review (2007) identified hope as an important factor in the lives of newly diagnosed patients with cancer (Chi, 2007). Hope can help patients deal with uncertainty of their cancer diagnosis (Butt, 2011). Our study consistently indicated that shared experiences result in mutual mirroring, leading to a feeling of hope and belief in their ability to cope with their situation. These findings are comparable with a qualitative study (2012) exploring experiences in peer support recipients that found decreased isolation and increased hope in patients receiving support from peers with a similar cancer diagnosis (Pistrang, Jay, Gessler, & Barker, 2012). Similar results were found in a recent cross-sectional study (2015) exploring the determinants of hope in patients with cancer, showing that patients who shared their experiences with others were more hopeful (Proserpio et al., 2015). Hope can enhance the capacity of patients with AL to adapt to the life-threatening disease (Chi, 2007). Our results emphasise that social support enhances hope which, in patients with AL, is crucial because of the often long and fluctuating treatment trajectory.

In accordance with previous research, our results showed that supporting others was meaningful and gave a new perspective on their own lives which led to self-development (Pistrang et al., 2013; Riessman, 1965; Skirbekk, Korsvold, & Finset, 2018). This is consistent with the results of a qualitative study (2012) exploring the experience of peer supporters, where supporters gained closure (Pistrang et al., 2013). The patient ambassador role becomes a part of their own long-term psychological recovery and also represents self-support for the supporter. This is an important aspect since many of the patient ambassadors were long-term survivors with limited contact to the health care system and survivorship support. Thus, implementing patient ambassador support has a significant impact on recovery and survivorship in long-term survivors of AL (Margolis et al., 2019).

We identified the match between the patient and patient ambassador to be of pivotal importance for the success of the mentorship. Being in the same phase in life was a critical factor in terms of mirroring life experiences. Similar results have been identified in earlier peer-to-peer studies in patients with cancer (Pistrang et al., 2013; Skirbekk et al., 2018). According to social comparison theory, peer support can validate the patient's own feelings, concerns and experiences by using comparisons to cope, to reduce the threat and to find ways to meet challenges (Suls & Miller, 1977). Conversely, we found that a good match increased the patient ambassadors' reflections on their own trajectory, with past emotions returning, causing some patient ambassadors needing support. However, support from regular network meetings was sufficient to manage these emotions. For this reason, when initiating patient ambassador support, it is essential to have a comprehensive diverse patient ambassador corps to successfully match participants. But, more importantly, it is pivotal to prioritise and arrange regular network meetings, so patient ambassadors have the opportunity to receive supervision.

The AL disease and treatment trajectory is characterised by causing a significant symptom burden challenging the patient's physical, psychological and social well-being with supportive care needs that vary during the trajectory of treatment (Hall, Sanson-Fisher, Lynagh, Tzelepis, & D'Este, 2015; Tomaszewski et al., 2016; Zimmermann et al., 2013). Our results suggest that peer-to-peer support should be adjusted individually due to variations in symptom burden, supportive care needs and personal preferences regarding type of contact. Importantly, we found that patients with a high symptom burden had difficulty maintaining contact with their patient ambassador even though they needed the support. However, despite limited contact, they experienced that the support had a positive impact on how they managed their situation. This emphasises that individualised support is important as patients' needs and preferences vary along the disease trajectory.

We identified some challenges as a result of the patients and patient ambassadors being on unequal terms and conditions. Despite the risk of becoming critically ill or dying, they agreed that the support was unique and that the unequal conditions should not be considered a barrier for others. This is consistent with a qualitative study (2012) in women with gynaecological cancer, where peer supporters receiving the news of their patient's death would do it again (Pistrang et al., 2013). An updated systematic review (2015) on one-to-one peer support in cancer care found similar results and reported that peers who experienced challenges in their role did not feel overwhelmed by their duties, if they had access to supervision (Meyer et al., 2015). It is crucial to include this aspect in the patient ambassador's preparation and education when implementing this type of support in clinical practice.

4.1 | Methodological discussion

We used information power to guide and evaluate the study's adequate sample size (Malterud, Siersma, & Guassora, 2015). Consistent

with the ID approach, our sample was purposive, which enhanced maximal variation and the selection of information-rich cases (Thorne et al., 2004). Limitations include that the sample had more women than men as a consequence of the characteristic of eligible participants diagnosed with AL in the feasibility trial in this specific time period from which the participants in the present study were enrolled. The unequal distribution of gender among patient ambassadors was due to the patient's preference for same gender in matching. Our findings do not provide insight into specific demographic characteristics, for example, young adults, sex, level of social network. We recommend that future research focus on these specific characteristics to gain further knowledge about this support and to enhance its applicability in clinical practice. These findings are limited to the experience of peer-to-peer support in patients and their ambassadors during the initial period of diagnosis and treatment. Consequently, future studies should explore the experiences of support further along the disease trajectory.

4.2 | Conclusion

The findings provide new knowledge on how the mentorship between newly diagnosed patients with AL and their patient ambassadors is experienced during patient ambassador support. The experience-based knowledge that was exchanged was influenced by how affected the patient was by their symptom burden, life situation and treatment, which meant the support was highly individualised. Shared experiences resulted in a sense of cohesion and mutual mirroring that created feelings of hope and gratitude for life. Supervision of patient ambassadors through network meetings was of crucial importance for managing potential challenges. One-on-one peer-to-peer support in newly diagnosed patients with AL as part of treatment and in daily clinical practice is important and deserves greater attention. Future studies should examine the feasibility of peer-to-peer support interventions during the survivorship trajectory of AL and in patients with other haematological malignancies.

4.3 | Practice implications

Our findings provide useful insights for future initiatives involving peer-to-peer support and are potentially transferable and valuable to a broader context of patients with cancer or other life-threatening diseases when implementing peer-to-peer support in clinical practice. These results stress the importance of social support from peers with first-hand experience of the disease and treatment.

ACKNOWLEDGEMENTS

We are grateful for the participation of patients and acknowledge the volunteer participation of the patient ambassadors involved in this study. Their passion for helping other patients by sharing their experiences was inspiring. This study is part of the Models of Cancer Care Research Program at Copenhagen University Hospital.

CONFLICT OF INTEREST

None.

ETHICAL APPROVAL

This study is registered with the Danish Protection Agency (no. VD-2017–176). Each informant received written and verbal information on the study and assurance of confidentiality according to the principles for research stated in the Helsinki Declaration. Written informed consent was obtained before interviews.

ORCID

Kristina Holmegaard Nørskov https://orcid.org/0000-0002-1055-9161

REFERENCES

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Butt, C. M. (2011). Hope in adults with cancer: State of the science. *Oncology Nursing Forum*, *38*(5), E341–E350. https://doi.org/10.1188/11.onf.e341-e350

Chi, G. C. (2007). The role of hope in patients with cancer. *Oncology Nursing Forum*, *34*(2), 415–424. https://doi.org/10.1188/07.onf.415-424

Cohen, S., & Herbert, T. B. (1996). Health psychology: Psychological factors and physical disease from the perspective of human psychoneuroimmunology. *Annual Review of Psychology*, *47*, 113–142. https://doi.org/10.1146/annurev.psych.47.1.113

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310–357. https://doi.org/10.1037/0033-2909.98.2.310

Dennis, C. L. (2003). Peer support within a health care context: A concept analysis. *International Journal of Nursing Studies*, *40*(3), 321–332. https://doi.org/10.1016/S0020-7489(02)00092-5

Ditzen, B., & Heinrichs, M. (2014). Psychobiology of social support: The social dimension of stress buffering. *Restorative Neurology and Neuroscience*, *32*(1), 149–162. https://doi.org/10.3233/rnn-139008

Ferrara, F., & Schiffer, C. A. (2013). Acute myeloid leukaemia in adults. *Lancet*, *381*(9865), 484–495. https://doi.org/10.1016/s0140-6736(12)61727-9

Hall, A. E., Sanson-Fisher, R. W., Lynagh, M. C., Tzelepis, F., & D'Este, C. (2015). What do haematological cancer survivors want help with? A cross-sectional investigation of unmet supportive care needs. *BMC Research Notes*, *8*, 221. https://doi.org/10.1186/s13104-015-1188-7

Hoelzer, D., Bassan, R., Dombret, H., Fielding, A., Ribera, J. M., & Buske, C. (2016). Acute lymphoblastic leukaemia in adult patients: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology*, *27*(suppl 5), v69–v82. https://doi.org/10.1093/annonc/mdw025

Hoey, L. M., Ieropoli, S. C., White, V. M., & Jefford, M. (2008). Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling*, *70*(3), 315–337. https://doi.org/10.1016/j.pec.2007.11.016

Hoffman, R. B., Silberstein, E. J., Heslop, L. E., Weitz, J. I., & Anastasi, J. (2018). *Hematology – Basic principles and practice* (7th ed.). Amsterdam, the Netherlands: Elsevier.

Kornblith, A. B., Herndon, J. E. 2nd, Zuckerman, E., Viscoli, C. M., Horwitz, R. I., Cooper, M. R., … Holland, J. (2001). Social support as a buffer to the psychological impact of stressful life events in women with breast cancer. *Cancer*, *91*(2), 443–454. https://doi.org/10.1002/1097-0142(20010115)91:2<443:aid-cncr1020>3.0.co;2-z

Leak Bryant, A., Lee Walton, A., Shaw-Kokot, J., Mayer, D. K., & Reeve, B. B. (2015). Patient-reported symptoms and quality of life in adults with acute leukemia: A systematic review. *Oncology Nursing Forum*, *42*(2), E91–E101. https://doi.org/10.1188/15.onf.e91-e101

Liang, Y., Wang, H., Niu, M., Zhu, X., Cai, J., & Wang, X. (2019). Longitudinal analysis of the relationships between social support and health-related quality of life in hematopoietic stem cell transplant recipients. *Cancer Nursing*, *42*(3), 251–257. https://doi.org/10.1097/ncc.0000000000000616

Malterud, K., Siersma, V. D., & Guassora, A. D. (2015). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Manitta, V., Zordan, R., Cole-Sinclair, M., Nandurkar, H., & Philip, J. (2011). The symptom burden of patients with hematological malignancy: A cross-sectional observational study. *Journal of Pain and Symptom Management*, *42*(3), 432–442. https://doi.org/10.1016/j.jpainsymman.2010.12.008

Margolis, M., Austin, J., Wu, L., Valdimarsdottir, H., Stanton, A. L., Rowley, S. D., … Rini, C. (2019). Effects of social support source and effectiveness on stress buffering after stem cell transplant. *International Journal of Behavioral Medicine*, *26*(4), 391–400. https://doi.org/10.1007/s12529-019-09787-2

Meyer, A., Coroiu, A., & Korner, A. (2015). One-to-one peer support in cancer care: A review of scholarship published between 2007 and 2014. *European Journal of Cancer Care (Engl)*, *24*(3), 299–312. https://doi.org/10.1111/ecc.12273

Norskov, K. H., Overgaard, D., Lomborg, K., Kjeldsen, L., & Jarden, M. (2019). Patients' experiences and social support needs following the diagnosis and initial treatment of acute leukemia – A qualitative study. *European Journal of Oncology Nursing*, *41*, 49–55. https://doi.org/10.1016/j.ejon.2019.05.005

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), 1609406917733847. https://doi.org/10.1177/1609406917733847

Papadopoulou, C., Johnston, B., & Themessl-Huber, M. (2013). The experience of acute leukaemia in adult patients: A qualitative thematic synthesis. *European Journal of Oncology Nursing*, *17*(5), 640–648. https://doi.org/10.1016/j.ejon.2013.06.009

Pinquart, M., Hoffken, K., Silbereisen, R. K., & Wedding, U. (2007). Social support and survival in patients with acute myeloid leukaemia. *Supportive Care in Cancer*, *15*(1), 81–87. https://doi.org/10.1007/s00520-006-0114-x

Pistrang, N., Jay, Z., Gessler, S., & Barker, C. (2012). Telephone peer support for women with gynaecological cancer: Recipients' perspectives. *Psychooncology*, *21*(10), 1082–1090. https://doi.org/10.1002/pon.2005

Pistrang, N., Jay, Z., Gessler, S., & Barker, C. (2013). Telephone peer support for women with gynaecological cancer: Benefits and challenges for supporters. *Psychooncology*, *22*(4), 886–894. https://doi.org/10.1002/pon.3080

Proserpio, T., Ferrari, A., Vullo, S. L., Massimino, M., Clerici, C. A., Veneroni, L., … Mariani, L. (2015). Hope in cancer patients: The relational domain as a crucial factor. *Tumori Journal*, *101*(4), 447–454. https://doi.org/10.5301/tj.5000366

QSR International Pty Ltd., Version 10 (2015). *NVivo*. https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

Riessman, F. (1965). The "helper" therapy principle. *Social Work*, *10*(2), 27–32.

Roman, E., Smith, A., Appleton, S., Crouch, S., Kelly, R., Kinsey, S., … Patmore, R. (2016). Myeloid malignancies in the real-world: Occurrence, progression and survival in the UK's population-based Haematological Malignancy Research Network 2004–15. *Cancer Epidemiology*, *42*, 186–198. https://doi.org/10.1016/j.canep.2016.03.011

Shinn, M., Caplan, R. D., Robinson, E. A., French, J. R. Jr, & Caldwell, J. R. (1977). Advances in adherence: Social support and patient education. *Urban Health*, *6*(4), 20–21, 57–29.

Short, N. J., Rytting, M. E., & Cortes, J. E. (2018). Acute myeloid leukaemia. *Lancet*, *392*(10147), 593–606. https://doi.org/10.1016/s0140-6736(18)31041-9

Skirbekk, H., Korsvold, L., & Finset, A. (2018). To support and to be supported. A qualitative study of peer support centres in cancer care in Norway. *Patient Education and Counseling*, *101*(4), 711–716. https://doi.org/10.1016/j.pec.2017.11.013

Suls, J., & Miller, R. (1977). *Social comparison theory and research: An overview from 1954. In* Social Comparison Processes (pp. 1–17). London: John Wiley & Sons.

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice*. New York, NY: Routledge.

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, *3*(1), 1–11. https://doi.org/10.1177/160940690400300101

Tomaszewski, E. L., Fickley, C. E., Maddux, L., Krupnick, R., Bahceci, E., Paty, J., & van Nooten, F. (2016). The patient perspective on living with acute myeloid leukemia. *Oncology and Therapy*, *4*(2), 225–238. https://doi.org/10.1007/s40487-016-0029-8

Ussher, J., Kirsten, L., Butow, P., & Sandoval, M. (2006). What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science and Medicine*, *62*(10), 2565–2576. https://doi.org/10.1016/j.socscimed.2005.10.034

Zimmermann, C., Yuen, D., Mischitelle, A., Minden, M. D., Brandwein, J. M., Schimmer, A., … Rodin, G. (2013). Symptom burden and supportive care in patients with acute leukemia. *Leukemia Research*, *37*(7), 731–736. https://doi.org/10.1016/j.leukres.2013.02.009

How to cite this article: Nørskov KH, Overgaard D, Lomborg K, Kjeldsen L, Jarden M. Patient ambassador support: Experiences of the mentorship between newly diagnosed patients with acute leukaemia and their patient ambassadors. *Eur J Cancer Care*. 2020;00:e13289. https://doi.org/10.1111/ecc.13289

Appendices

Appendix I: Project logo and recruitment material

Appendix II: Patient ambassador educational program

Appendix III: Patient ambassador information dossier

Appendix IV: Co-authorship declarations

Patient
Ambassadør
Støtte

BLIV EN STØTTE FOR EN MED AKUT LEUKÆMI

Brug din egen erfaring med akut leukæmi og gør en forskel for en anden patient. Som patientambassadør lytter og støtter du en anden, som netop har fået stillet diagnosen.

Vil du høre mere om projektet, og hvordan du bliver patientambassadør? Så tag en folder og kontakt sygeplejerske, ph.d. studerende og projektansvarlig

Kristina Holmegaard Nørskov på mobil 61 69 87 10 eller email: kristina.holmegaard.noerskov@regionh.dk.

Patient Ambassadør Støtte er et tilbud som indgår i et forskningsprojekt i samarbejde med:

KØBENHAVNS UNIVERSITET

REGION Herlev og Gentofte Hospital

REGION Rigshospitalet

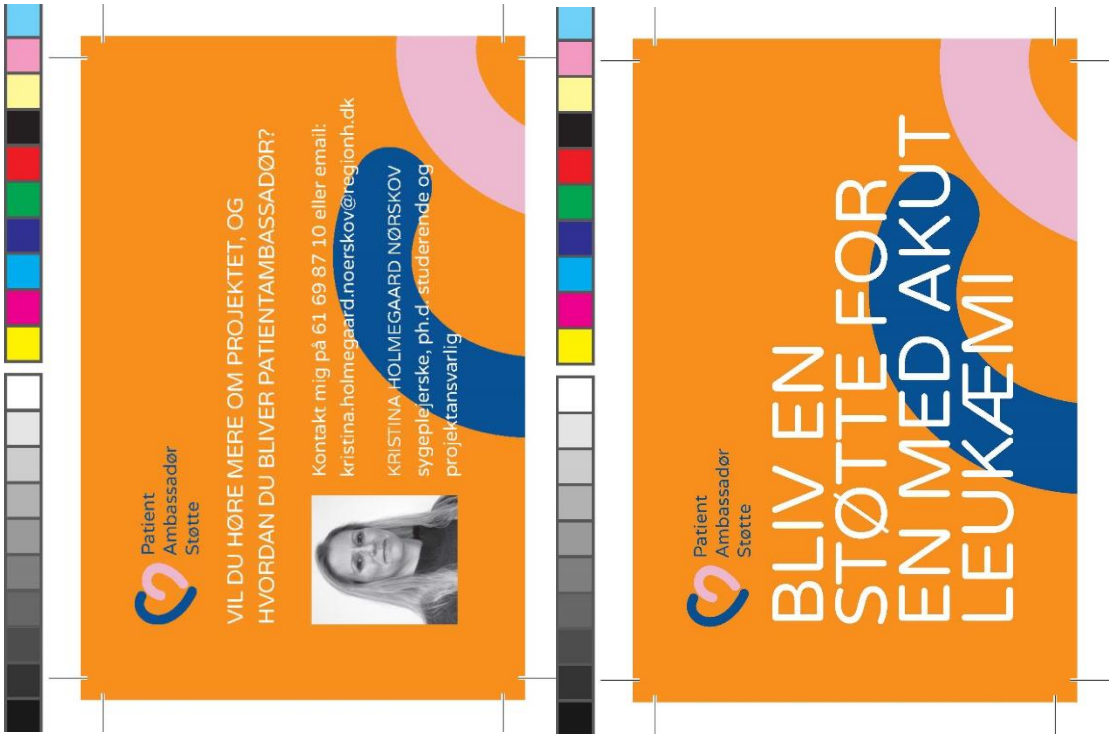
Models of Cancer Care

REGION SJÆLLAND – vi er til for dig

LyLe

novo nordisk fonden

Business card



TRANSPORT OG ØKONOMI

Patientambassadører må selv betale transport-udgifter i forbindelse med de aftalte møder. Som frivillig patientambassadør modtager du i stedet et gavekort på 1000 kr. som tak for din tid og deltagelse i projektet.

Ønsker du at høre mere om, hvad det indebærer at være patientambassadør, så kontakt mig venligst her:

KRISTINA HOLMEGAARD NØRSKOV
sygeplejerske, ph.d. studerende

mobil: 61 69 87 10
e-mail: kristina.holmegaard.noerskov@regionh.dk

Rigshospitalet
Forskningenheden afsnit 7831
Tagensvej 22, 3 sal.
2200 København N

Tilbuddet indgår som et forskningsprojekt i samarbejde med Københavns Universitet og hæmatologiske afdelinger på Rigshospitalet, Herlev og Gentofte Hospital samt Sjællands Universitetshospital Roskilde.

Projektet er støttet af Novo Nordisk Fonden og gennemføres i perioden november 2017 til november 2019.

design og layout: christinemeike.dk

Patient
Ambassadør
Støtte

BLIV EN STØTTE FOR EN MED AKUT LEUKÆMI

Brug din egen erfaring med akut leukæmi og gør en forskel for en anden patient.

Patient Ambassadør Støtte er et projekt for nydiagnosticerede patienter med akut leukæmi. Formålet med projektet er at udvikle og afprøve tilbuddet under behandlingsforløbet tidligt efter diagnosen. Projektet har fokus på, at øge den syges følelsesmæssige velvære og evnen til at håndtere egen sygdom samt reducere symptomer og bivirkninger under behandlingen.

HVAD ER EN PATIENTAMBASSADØR?

- En patientambassadør er en person, som selv har eller har haft akut leukæmi for mere end ti måneder siden.
- En patientambassadør arbejder som frivillig og ønsker at dele og bruge sine egne erfaringer i støtteforløbet.

HVAD ER EN PATIENTAMBASSADØRS FUNKTION?

- En patientambassadør skal være interesseret i at lytte og støtte en anden, som netop har fået stillet diagnosen med akut leukæmi.
- Du er ambassadør i 12 uger og kan mødes med patienten både personligt, via telefon, e-mail, sms, FaceTime, Skype eller Messenger etc.

HVORFOR VIL DU GERNE VÆRE PATIENT-AMBASSADØR?

- Du vil gerne have muligheden for at gøre en forskel for én, som netop har fået stillet diagnosen.
- Du har lyst og overskud til at bruge din egen erfaring og indsigt med sygdommen til at inspirere, motivere og støtte et andet menneske i samme situation.
- Du har lyst til at blive en del af et netværk med andre patientambassadører, som mødes og deler erfaringer om støtteforløbet.

HVAD FORVENTES AF EN PATIENT-AMBASSADØR?

- Det forventes, at du deltager i et kursus for ambassadører af 6 timers varighed.
- Det forventes, at du kort og enkelt gør rede for hver kontakt, der har været mellem patienten og dig.

HVORDAN MATCHER MAN PATIENT OG PATIENTAMBASSADØR?

- Patienter og patientambassadører bliver matchet efter deres indbyrdes ønsker.

STØTTE TIL PATIENTAMBASSADØRER

- Som patientambassadør skal du deltage på en kursusdag som varer 6 timer og afholdes i enten København, Hillerød eller Roskilde. Dato, tid og sted for kurserne oplyses, når du tager kontakt til den projektansvarlige.
- Vi afholder netværksmøder for patient-ambassadører, hvor du mødes og deler erfaringer og oplevelser med andre ambassadører.
- Der vil være mulighed for, at du får supervision af en psykolog mens du er patientambassadør.

Patient Ambassadør Støtte til ny diagnosticerede patienter med akut leukæmi gennem deres behandling

Kursusprogram for patient ambassadører

Program

10.00 – 10.35	Præsentationsrunde
10.35 – 10.55	Introduktion til "Patient Ambassadør Støtte" *Kristina Nørskov, projekt ansvarlig*
10.55 – 11.05	Pause: kaffe og te
11.05 – 11.15	Ambassadør netværk og støtte muligheder *Kristina Nørskov, projektansvarlig*
11.15 – 11.30	Perspektiver på rollen som patient ambassadør *En kommende patient ambassadør*
11.30 – 11.45	Update på behandlingsforløbet for akut leukæmi *Rebecca Reetz, Sygeplejerske,*
11.45 – 12.45	Frokost
12.45 – 14.00	Rollen som ambassadør *Sabrine Friis, Psykolog*
14.00 – 14.15	Pause: kaffe, te og sødt
14.15 – 15.30	Rollen som ambassadør *Sabrine Friis, Psykolog*
15.30 – 16.00	Afrunding og udlevering af ambassadør materiale

Dato, tid og sted:

3 marts kl. 10-16
Rigshospitalets forskningsenhed
Tagensvej 22, 3 sal (afsnit 7831)
2200 København N
(Der er elevator og gratis parkering foran indgangen)

E-PROOF til godkendelse

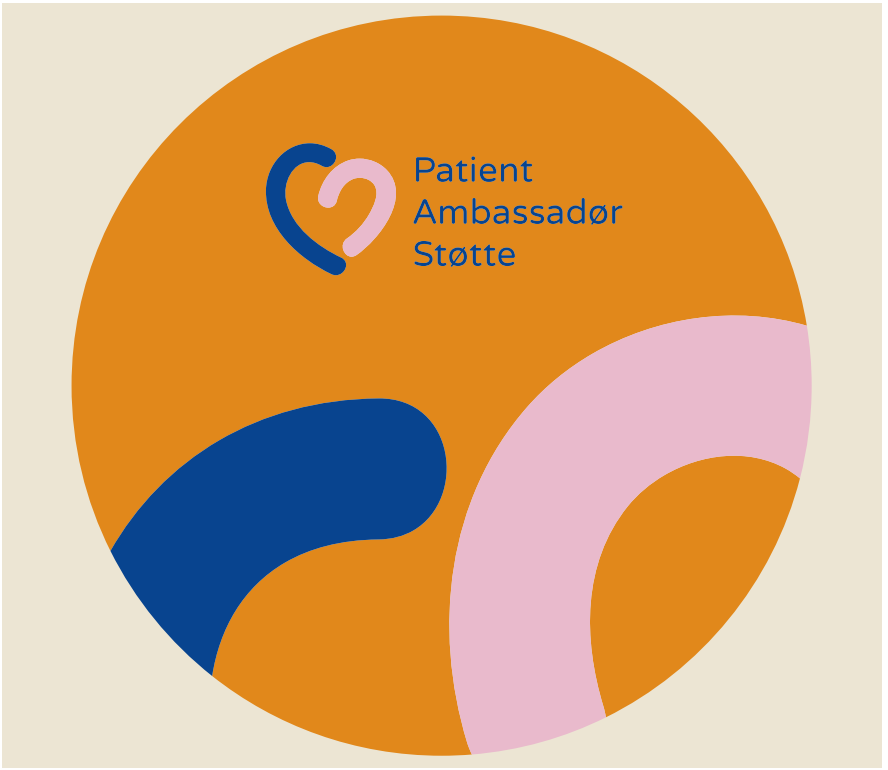
15/12/17, 15:26:03

Order Number	: 1652605
Customer Reference	: 1328 Patientstøtte muleposer
Article	: Carolina cotton Tote

Wilke Promotion A/S

Wilke Promotion
PROFILBEKLÆDNING - REKLAMEARTIKLER - FIRMAGAVER

Logo:



Imprint size (mm)	: 120 x 120
Trykfarver	: Underlayer,Pantone 671 C,Pantone 144 C,Pantone 294 C.
Imprint method	: Transfer extra fast
Trykposition	: foran;
Article	: NATURAL 11941100 100pcs

Sticker for information dossier

Patient ambassadør støtte

Information til patient ambassadøren

Hvorfor et tilbud om Patient Ambassadør Støtte?
Efter diagnosen med akut leukæmi oplever mange en fuldstændig forandring af deres livssituation. Patient Ambassadør Støtte er en type social støtte, hvor mennesker, som har levet med sygdommen, kan være en unik og effektiv ressource for ny diagnosticerede patienter. Det at dele sine oplevelser er essensen af patient ambassadør støtte. Især kort efter at diagnosen er stillet og den første tid under behandlingen, kan denne støtte være en stor hjælp. Det at tale med andre, der har været igennem behandlingen, kan give håb og bedre håndtering af sygdommen.

Et forskningsprojekt!
Patient Ambassadør Støtte er et tilbud til patienter med akut leukæmi, og er en del af et ph.d. forskningsprojekt under Københavns Universitet og Model of Cancer Care forskningsprogram, Finsencenteret, Rigshospitalet. Der er behov for systematisk at få vurderet betydningen af Patient Ambassadør Støtte hos patienter med akut leukæmi under deres behandling. Formålet med projektet er at udvikle og afprøve tilbuddet under behandlingsforløbet tidligt efter diagnosen. Målet er at øge følelsesmæssigt velvære og patienternes evne til at håndtere deres egen sygdom, samt at reducere symptomer hos patienter under deres behandling. Projektet gennemføres på tre hospitaler på Sjælland henholdsvis Rigshospitalet, Herlev Hospital og Sjællands Universitetshospital, Roskilde.
Projektet påbegynder i november 2017 og forventes af afslutte i november 2019. Det forventes at i alt 35 patienter og patient ambassadører gennemfører et forløb af 12 uger under projektperioden.

Hvad er en patient ambassadør?
En patient ambassadør er en person, som selv har eller har haft akut leukæmi for mere end 12 måneder siden. En patient ambassadør er en frivillig person, som ønsker at støtte en anden patient med ny opdaget akut leukæmi.

Hvad er din funktion som patient ambassadør?
Som patient ambassadør lytter, støtter og vejleder du en anden, som netop har fået stillet diagnosen indenfor de sidste to uger. Du er tilknyttet patienten i en periode på 12 uger, hvor I anbefales at mødes minimum 4 gange ansigt til ansigt, udover kontakt via telefon, e-mail, sms etc. Det personlige møde kan foregå på hospitalet, ved et cafébesøg, en gåtur i området, eller måske kan en træningssituation også være en god ramme for en snak.

Hvorfor vil du gerne være patient ambassadør?

- Du vil gerne have muligheden for at gøre en særlig forskel hos én, som netop har fået stillet diagnosen.
- Du har lyst og overskud til at bruge din egen erfaring og indsigt med sygdommen til at inspirere, motivere og støtte et andet menneske i samme situation.
- Du har lyst til at blive en del af et netværk af andre patient ambassadører, som mødes og deler erfaringer om dette arbejde.

Hvad forventes af dig som patient ambassadør?

- Det forventes, at du deltager i et kursus for ambassadører af 6 timers varighed. Efter kurset underskriver du en fortrolighedserklæring. Dette skyldes, at samtalerne mellem dig og patienten skal være fortrolige.
- Det forventes, at du gør rede for hver kontakt, der har været mellem patienten og dig. Dokumentationen er enkel og skal belyse samtalernes sted, hyppighed, varighed og indhold.
- Du forventes som ambassadør, at deltage i netværksmøder og eventuel gøre brug af psykolog-supervision, hvis der er et særligt behov herfor. Det er dit ansvar, at kontakte den projektansvarlige, hvis der er behov for supervision, problemer i kontakten med patienten eller andre forhold, som kan have indflydelse på den fortsatte deltagelse i projektet. Ved slutningen af patient ambassadør forløbet vil nogle ambassadører blive individuelt interviewet omkring deres oplevelse.

Hvordan matches du med patienten?

Du og patienten får mulighed for at fortælle den projektansvarlige, hvilke præferencer I har for jeres match med hinanden. Der vil derfor ved optagelse i projektet blive indhentet oplysninger om alder, diagnose, interesser, uddannelse, sociale og geografiske forhold eller andre faktorer, som kan have betydning for den enkelte. I aftaler og underskriver en enkel forventningsaftale om jeres fremtidige forløb, særligt med hensyn til hvornår og hvor ofte I må kontakte hinanden.

Hvad hvis det ikke fungerer mellem dig og patienten?

Du og patienten kan til enhver tid kontakte den projektansvarlige, hvis der opstår problemer i samarbejdet. Særligt hvis det har betydning for ønsket om fortsat at deltage i projektet. Herved kan det blive nødvendigt at finde en ny ambassadør til den pågældende patient.
Hvis der opstår ændringer af sygdomsmæssig karakter hos en af parterne, - ændringer, som kan påvirke det videre forløb, kan det blive nødvendigt, at forløbet må afbrydes. Beslutningen herom tages af den projektansvarlige, som i forvejen af en af parterne er gjort bekendt med situationen.

Støtte til dig som patient ambassadører

<u>Kursus for ambassadører</u>

Alle patient ambassadører skal deltage i et én dags kursusprogram på 6 timer som inkluderer temaerne:

- Introduktion til projektet
- Praktiske forhold
- Rammer for ambassadøren
- Rollen som ambassadør
- Psykiske redskaber, herunder reaktioner og aktiv lytning
- Workshop

Der vil ligeledes være diskussion af patient ambassadørernes personlige mål og usikkerhed ved at deltage i projektet. Det er væsentligt at opretholde og tilpasse sine egne erfaringer og grænser. Det er vigtigt at være bevidst omkring sin egen rolle som lyttende patient ambassadør, som kun bruger sine egne erfaringer, når patienten giver udtryk for at ville høre om det. Der bliver også diskuteret hvis sygdomstilstanden ændres hos enten patienten eller dig selv. Alle patient ambassadører modtager et certifikat og en mappe med materiale, når kurset er gennemført.
Kurset vil foregå i København, Hillerød og Roskilde. Dato, tid og sted for kurser oplyses ved at tage kontakt til den projektansvarlige.

Ambassadør Netværk

Der vil blive afholdt netværksmøder for patient ambassadører, hvor man mødes og deler erfaringer og oplevelser. Den projektansvarlige vil deltage i møderne sammen med en psykolog med særlig erfaring indenfor Patient Ambassadør Støtte. Der vil til nogle netværksmøder være mulighed for at arrangere oplægsholdere efter ambassadørernes ønsker. Emner der diskuteres ved hvert netværksmøde er:

- Hvordan gør vi?
- Hvad er svært?
- Hvad fungerede godt?
- Hvad kan vi gøre for at bedre forløbet?

Supervision/samtale

Der vil være mulighed for at du kan få supervision / samtale med psykolog under patient ambassadør forløbet. Supervision udføres af en erfaren psykolog med mange års erfaring indenfor støtte til patienter med akut leukæmi. Psykologen kan kontaktes indenfor fastsatte rammer, og behovet for supervision skal være i relation til arbejdet som frivillig patient ambassadør.

Transport og økonomi

Du må som patient ambassadør selv betale transportudgifter i forbindelse med de aftalte møder med patienten. Idet man arbejder som frivillig vil du i stedet modtage et gavekort på 1000 kr. som tak for din tid og deltagelse i projektet.

Har du yderligere spørgsmål kan du altid kontakte:

Projektansvarlig:	Kristina Holmegaard Nørskov, sygeplejerske ph.d. studerende
Mobil:	61 69 87 10
E-mail:	kristina.holmegaard.noerskov@regionh.dk
Adresse:	Rigshospitalet Forskningenheden afsnit 7831 Tagensvej 22, 3 sal. 2200 København N

Hvad gør jeg hvis…

Hvad gør jeg hvis jeg selv bliver alvorlig syg?
Du skal kontakte projektansvarlig Kristina Nørskov, hvis du bliver syg under et forløb som patient ambassadør, og hvor du er i tvivl om du kan fortsætte din deltagelse i projektet. Vi drøfter i samarbejde med din kontaktlæge om du kan fortsætte som aktiv patient ambassadør. Efterfølgende vil projektansvarlig Kristina Nørskov kontakte patienten du er ambassadør for hvis det vurderes at jeres forløb skal afsluttes før tid.

Hvad gør jeg hvis jeg ikke kan få kontakt med patienten?
Du kan i første omgang kontakte den person, som patienten har udnævnt som kontaktperson. Hvis du stadig har problemer med at få kontakt med patienten, bedes du kontakte projektansvarlig Kristina Nørskov.

Hvad gør jeg hvis samarbejde og kommunikation med patienten ikke fungerer?
Hvis der er problemer med jeres samarbejde og kommunikation, som har betydning for om du vil fortsætte som patient ambassadør, bedes du kontakte projektansvarlig Kristina Nørskov.

Hvad gør jeg hvis patienten fortæller mig informationer, som jeg føler skal videre til en tredje part?
Hvis du føler, at du får givet nogle informationer, som du er i tvivl om hvad du skal eller bør gøre ved, bedes du kontakte projektansvarlig Kristina Nørskov eller projektsygeplejersken på det hospital, hvor patienten er tilknyttet (se praktiske oplysninger i ambasadørmappen).

Hvad gør jeg hvis jeg bliver ked af det, og følelser om mit eget forløb fylder for meget?
Hvis du bliver ked af det, som følge af din funktion som patient ambassadør og har brug for en at snakke med kan du kontakte vores psykolog, som er tilknyttet projektet (se praktiske oplysninger i ambasadørmappen).

Hvad gør jeg hvis jeg ikke vil være ambassadør længere?
Hvis du efter nøje overvejelser beslutter, at du ikke længere ønsker at være patient ambassadør bedes du kontakte projektansvarlig Kristina Nørskov. Er du i et aktivt forløb som patient ambassadør anbefaler vi, at du også selv kontakter patienten og afslutter jeres forløb.

Hvad gør jeg hvis jeg har en masse tanker og oplevelser fra et møde/en samtale med patienten, som jeg må dele med en anden?
Hvis du har brug for én at snakke med, kan du altid kontakte vores frivillige psykolog (se praktiske oplysninger i ambasadørmappen). Du må også meget gerne skrive dine tanker og oplevelser ned i dagbogsnotaterne. Det kan sommetider hjælpe at skrive sine tanker og oplevelser ned, og du kan senere hen læse dem igen. Du kan ligeledes snakke med andre ambassadører om dine tanker og oplevelser på netværksmøderne.

Praktiske oplysninger

Projektansvarlig
Kristina Holmegaard Nørskov, Sygeplejerske ph.d. studerende
Forskningenheden 7831
Tagensvej 22, 3 sal
2200 København N
Telefon: 61 69 87 10
E-mail: kristina.holmegaard.noerskov@regionh.dk

Projektsygeplejerske Rigshospitalet
Klara Lundstrøm Jørgensen, Sygeplejerske
Hæmatologisk Afdeling 4041/4043
Blegdamsvej 9
2100 København Ø
Telefon: 35 45 40 41
E-mail: klara.lundstroem.joergensen@regionh.dk

Projektsygeplejerske Herlev og Gentofte Hospital
Janni Boesen
Hæmatologisk Afdeling L 24 etage
Herlev Ringvej 75
2730 Herlev
Telefon: 38 68 39 07
E-mail: Jannie.Boesen@regionh.dk

Projektsygeplejerske Sjællands Universitetshospital Roskilde
Anne Struer / Sarah Elke
Hæmatologisk Afdeling
Vestermarksvej 9, 1
4000 Roskilde
Telefon: 47 32 48 86
E-mail: astu@regionsjaelland.dk eller sare@regionsjaelland.dk

Psykolog
Beatriz Reino
Telefon: 42 72 85 22
E-mail: beatrizreino@gmail.com
Fra mandag til fredag efter kl.18

Psykolog
Sabine Friis
Telefon: 20 43 25 95
E-mail: kontakt@sabinefriis.dk

ID: RH-A-1

Kontakt mellem ambassadør og patient

Dato/ årstal	**Varighed af samtale (minutter)**	**Hvordan havde i kontakt** (eks. Sms, Skype, e-mail, telefonsamtale)	**Samtalens indhold** (eks. Familieliv, bivirkninger, fremtiden)

ID: RH-A-1

Personligt møde mellem ambassadør og patient

Dato/ årstal	**Varighed af møde (minutter)**	**Sted for mødet** (eks. Rigshospitalet, en café, en gå tur)	**Samtalens indhold** (eks. Familieliv, bivirkninger, fremtiden)

Postcard (A5)

Themes on the postcard are from a brainstorm at a meeting with the patient advisory board

GRADUATE SCHOOL OF HEALTH AND MEDICAL SCIENCES
UNIVERSITY OF COPENHAGEN

PHD-THESIS
DECLARATION OF CO-AUTHORSHIP

The declaration is for PhD students and must be completed for each conjointly authored article. Please note that if a manuscript or published paper has ten or less co-authors, all co-authors must sign the declaration of co-authorship. If it has more than ten co-authors, declarations of co-authorship from the corresponding author(s), the senior author and the principal supervisor (if relevant) are a minimum requirement.

1. Declaration by	
Name of PhD student	
E-mail	kristina.holmegaard.noerskov@regionh.dk
Name of principal supervisor	Mary Jarden
Title of the PhD thesis	Patient ambassador support in newly diagnosed patients with acute leukemia during the initial treatment

2. The declaration applies to the following article	
Title of article	Patients` experiences and social support needs following the diagnosis and initial treatment of acute leukemia – A qualitative study
Article status	
Published ☒ Date: May 2019	Accepted for publication ☐ Date:
Manuscript submitted ☐ Date:	Manuscript not submitted ☐
If the article is published or accepted for publication, please state the name of journal, year, volume, page and DOI (if you have the information).	European Journal of Oncology Nursing. 2019; 41: 49–55 doi:10.1016/j.ejon.2019.05.005

3. The PhD student's contribution to the article ***(please use the scale A-F as benchmark)*** Benchmark scale of the PhD-student's contribution to the article **A.** Has essentially done all the work (> 90 %) **B.** Has done most of the work (60-90 %) **C.** Has contributed considerably (30-60 %) **D.** Has contributed (10-30 %) **E.** No or little contribution (<10 %) **F.** Not relevant	**A, B, C, D, E, F**
1. Formulation/identification of the scientific problem	A
2. Development of the key methods	B
3. Planning of the experiments and methodology design and development	B
4. Conducting the experimental work/clinical studies/data collection/obtaining access to data	A
5. Conducting the analysis of data	B
6. Interpretation of the results	A
7. Writing of the first draft of the manuscript	A
8. Finalisation of the manuscript and submission	A
Provide a short description of the PhD student's specific contribution to the article.[i] Kristina Holmegaard Nørskov has essentially done most of the work for this paper including, study design, analysis, interpretation, writing the manuscript and submission.	

4. Material from another thesis / dissertation[ii]	
Does the article contain work which has also formed part of another thesis, e.g. master's thesis, PhD thesis or doctoral dissertation (the PhD student's or another person's)?	Yes: ☐ No: ☒
If yes, please state name of the author and title of thesis / dissertation.	
If the article is part of another author's academic degree, please describe the PhD student's and the author's contributions to the article so that the individual contributions are clearly distinguishable from one another.	

5. Signatures of the co-authors[iii]

	Date	Name	Title	Signature
1.	25/6-20	Dorthe Overgaard	Associate professor	Dorthe Overgaard
2.	25.6.20	Kirsten Lomborg	Professor	Kirsten Lomborg
3.	25/6 20	Lars Kjeldsen	Head of Clinic	
4.	8/7-20	Mary Jarden	Associate professor	Mary Jarden
5.				
6.				
7.				
8.				
9.				
10.				

6. Signature of the principal supervisor

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.
Date: 8/7-20
Principal supervisor: Mary Jarden Mary Jarden

7. Signature of the PhD student

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.
Date: 9/7-20
PhD student: Kristina Nørskov Kristina Nørskov

Please learn more about responsible conduct of research on the Faculty of Health and Medical Sciences' website.

[i] This can be supplemented with an additional letter if needed.
[ii] Please see Ministerial Order on the PhD Programme at the Universities and Certain Higher Artistic Educational Institutions (PhD Order) § 12 (4):
"Any articles included in the thesis may be written in cooperation with others, provided that each of the co-authors submits a written declaration stating the PhD student's or the author's contribution to the work."
[iii] If more signatures are needed please add an extra sheet.

GRADUATE SCHOOL OF HEALTH AND MEDICAL SCIENCES
UNIVERSITY OF COPENHAGEN

PHD-THESIS
DECLARATION OF CO-AUTHORSHIP

The declaration is for PhD students and must be completed for each conjointly authored article. Please note that if a manuscript or published paper has ten or less co-authors, all co-authors must sign the declaration of co-authorship. If it has more than ten co-authors, declarations of co-authorship from the corresponding author(s), the senior author and the principal supervisor (if relevant) are a minimum requirement.

1. Declaration by	
Name of PhD student	Kristina Holmegaard Nørskov
E-mail	kristina.holmegaard.noerskov@regionh.dk
Name of principal supervisor	Mary Jarden
Title of the PhD thesis	Patient ambassador support in newly diagnosed patients with acute leukemia during the initial treatment

2. The declaration applies to the following article	
Title of article	Patient ambassador support in newly diagnosed patients with acute leukemia during the initial treatment: a feasibility study
Article status	
Published ☐ Date:	Accepted for publication ☐ Date:
Manuscript submitted ☒ Date: May 2020	Manuscript not submitted ☐
If the article is published or accepted for publication, please state the name of journal, year, volume, page and DOI (if you have the information).	Supportive Care in Cancer

3. The PhD student's contribution to the article ***(please use the scale A-F as benchmark)*** Benchmark scale of the PhD-student's contribution to the article **A.** Has essentially done all the work (> 90 %) **B.** Has done most of the work (60-90 %) **C.** Has contributed considerably (30-60 %) **D.** Has contributed (10-30 %) **E.** No or little contribution (<10 %) **F.** Not relevant	**A, B, C, D, E, F**
1. Formulation/identification of the scientific problem	A
2. Development of the key methods	B
3. Planning of the experiments and methodology design and development	B
4. Conducting the experimental work/clinical studies/data collection/obtaining access to data	B
5. Conducting the analysis of data	B
6. Interpretation of the results	A
7. Writing of the first draft of the manuscript	A
8. Finalisation of the manuscript and submission	A

Provide a short description of the PhD student's specific contribution to the article.[1]
Kristina Holmegaard Nørskov has essentially done most of the work for this paper including, study design, analysis, interpretation, writing the manuscript and submission.

4. Material from another thesis / dissertation[ii]	
Does the article contain work which has also formed part of another thesis, e.g. master's thesis, PhD thesis or doctoral dissertation (the PhD student's or another person's)?	Yes: ☐ No: ☒
If yes, please state name of the author and title of thesis / dissertation.	
If the article is part of another author's academic degree, please describe the PhD student's and the author's contributions to the article so that the individual contributions are clearly distinguishable from one another.	

5. Signatures of the co-authors[iii]

	Date	Name	Title	Signature
1.	24/6-20	Dorthe Overgaard	Associate professor	Dorthe Overgaard
2.	3/7-20	Jannie Boesen	Clinical Nurse Specialist	
3.	24/6-20	Anne Struer	Clinical Nurse Specialist	
4.	24/6-20	Sarah Elke Weber Due El-Azem	Clinical Nurse Specialist	
5.	26-6-20	Anders Tolver	Statistician	Anders Tolver
6.	25.6.20	Kirsten Lomborg	Professor	Kirsten Lomb
7.	29/6 20	Lars Kjeldsen	Head of Clinic	
8.	8/7-20	Mary Jarden	Associate professor	Mary Jarden
9.				
10.				

6. Signature of the principal supervisor

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.
Date: 8/7-20
Principal supervisor: Mary Jarden Mary Jarden

7. **Signature of the PhD student**
I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge. Date: 9/7 -20 PhD student: Kristina Nørskov Kristina Nørskov

Please learn more about responsible conduct of research on the Faculty of Health and Medical Sciences' website.

---

[i] This can be supplemented with an additional letter if needed.

[ii] Please see Ministerial Order on the PhD Programme at the Universities and Certain Higher Artistic Educational Institutions (PhD Order) § 12 (4):
"Any articles included in the thesis may be written in cooperation with others, provided that each of the co-authors submits a written declaration stating the PhD student's or the author's contribution to the work."

[iii] If more signatures are needed please add an extra sheet.

GRADUATE SCHOOL OF HEALTH AND MEDICAL SCIENCES
UNIVERSITY OF COPENHAGEN

PHD-THESIS
DECLARATION OF CO-AUTHORSHIP

The declaration is for PhD students and must be completed for each conjointly authored article. Please note that if a manuscript or published paper has ten or less co-authors, all co-authors must sign the declaration of co-authorship. If it has more than ten co-authors, declarations of co-authorship from the corresponding author(s), the senior author and the principal supervisor (if relevant) are a minimum requirement.

1. Declaration by	
Name of PhD student	Kristina Holmegaard Nørskov
E-mail	kristina.holmegaard.noerskov@regionh.dk
Name of principal supervisor	Mary Jarden
Title of the PhD thesis	Patient ambassador support in newly diagnosed patients with acute leukemia during the initial treatment

2. The declaration applies to the following article	
Title of article	Patient ambassador support: experiences of the mentorship between newly diagnosed patients with acute leukemia and their patient ambassadors.
Article status	
Published ☒ Date: June 28, 2020	Accepted for publication ☐ Date:
Manuscript submitted ☐ Date:	Manuscript not submitted ☐
If the article is published or accepted for publication, please state the name of journal, year, volume, page and DOI (if you have the information).	European Journal of Cancer Care. E-pub ahead of print. June 28, 2020 https://doi.org/10.1111/ecc.13289

3. The PhD student's contribution to the article ***(please use the scale A-F as benchmark)*** Benchmark scale of the PhD-student's contribution to the article A. Has essentially done all the work (> 90 %) B. Has done most of the work (60-90 %) C. Has contributed considerably (30-60 %) D. Has contributed (10-30 %) E. No or little contribution (<10 %) F. Not relevant	**A, B, C, D, E, F**
1. Formulation/identification of the scientific problem	A
2. Development of the key methods	B
3. Planning of the experiments and methodology design and development	A
4. Conducting the experimental work/clinical studies/data collection/obtaining access to data	A
5. Conducting the analysis of data	B
6. Interpretation of the results	A
7. Writing of the first draft of the manuscript	A
8. Finalisation of the manuscript and submission	A
Provide a short description of the PhD student's specific contribution to the article.[i] Kristina Holmegaard Nørskov has essentially done most of the work for this paper including, study design, analysis, interpretation, writing the manuscript and submission.	

4. Material from another thesis / dissertation[ii]	
Does the article contain work which has also formed part of another thesis, e.g. master's thesis, PhD thesis or doctoral dissertation (the PhD student's or another person's)?	Yes: ☐ No: ☒
If yes, please state name of the author and title of thesis / dissertation.	
If the article is part of another author's academic degree, please describe the PhD student's and the author's contributions to the article so that the individual contributions are clearly distinguishable from one another.	

5. Signatures of the co-authors[iii]

	Date	Name	Title	Signature
1.	25/6-20	Dorthe Overgaard	Associate professor	Dorthe Overgaard
2.	25.6.20	Kirsten Lomborg	Professor	Kirsten Lomborg
3.	25/6/20	Lars Kjeldsen	Head of Clinic	
4.	8/7-20	Mary Jarden	Associate professor	Mary Jarden
5.				
6.				
7.				
8.				
9.				
10.				

6. Signature of the principal supervisor

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.
Date: 8/7-20
Principal supervisor: Mary Jarden Mary Jarden

7. Signature of the PhD student

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.
Date: 9/7-20
PhD student: Kristina Nørskov Kristina Nørskov

Please learn more about responsible conduct of research on the Faculty of Health and Medical Sciences' website.

[i] This can be supplemented with an additional letter if needed.
[ii] Please see Ministerial Order on the PhD Programme at the Universities and Certain Higher Artistic Educational Institutions (PhD Order) § 12 (4):
"Any articles included in the thesis may be written in cooperation with others, provided that each of the co-authors submits a written declaration stating the PhD student's or the author's contribution to the work."
[iii] If more signatures are needed please add an extra sheet.

PhD thesis

Kristina Holmegaard Nørskov

Patient ambassador support in newly diagnosed patients with acute leukemia during the course of treatment

Perspectives and feasiblity of patient ambassador support in patients and their patient ambassadors