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

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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.

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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.

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