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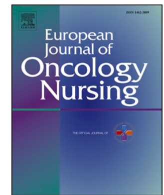

Nursing as a balancing act in allogeneic hematopoietic cell transplantation -nurses' experiences through participation in workshops

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A R T I C L E I N F O

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A B S T R A C T

Purpose: Registered nurses have a key role in supporting patients during the trajectory of allogeneic hematopoietic cell transplantation (allo-HCT). However, the circumstances for performing nursing are not previously outlined therefore the purpose of this study was to explore the conditions for nursing care in allo-HCT.
Method: An explorative design, inspired by Experienced based co-design was used to gather experiences, thoughts and visions of nursing care in allo-HCT by means of workshops. Thematic analysis was applied to analyse the data.
Result: An overarching theme that was defined from the data was *nursing as a balancing act* and illustrating conditions for performing nursing in a highly medical-technical environment. The theme included three subthemes: *Fragmented care vs holistic care* outlining how the holistic approach to care disappeared when the care became fragmented; *Proximity vs distance* illuminating the balance between seeing the patient as an independent person despite illness and the need for support; *Teamwork vs stand-alone* demonstrating the difficulties inherent in adapting to both teamwork and independence in nursing.
Conclusion: This study shows that the conditions for RNs and nursing care in allo-HCT care is to balance tasks and approach towards the patient and themselves. RNs must weigh and balance what is most important in the moment and where something else often has to be put aside. It is difficult for RNs to find the time to plan each patient's care and to support the patient in the way they see as most optimal to prepare for discharge, self-care and rehabilitation.

1. Introduction

Allogeneic hematopoietic cell transplantation (allo-HCT) is a demanding procedure that can cure an otherwise fatal diagnosis. The medical treatment, process and technology have evolved over time, resulting in increased survival (Battiwalla et al., 2017; Copelan et al., 2019). Despite those improvements for patients, the first years after an allo-HCT includes challenges, due the treatment, such as several distressing symptoms, susceptibility to infection, risk of relapse and rejection (Devins et al., 2018) as well as emotional distress and impact on health-related quality of life (Bevans et al., 2008). This may affect patients' health and wellbeing, despite the fact that the underlying disease has been treated (Park et al., 2019). This requires specialized care with high demands on both medical-technical knowledge and nursing care among registered nurses (RNs) working in allo-HCT (Fauer et al., 2019).

RNs in allo-HCT have been described as the core of the transplant procedure. They provide pharmacological and non-pharmacological care to facilitate recovery, including patient education (Bompoint et al., 2018) where supportive care is a central part of oncological nursing (Wallace et al., 2015). Patients' physical symptoms need to be assessed and treated at an early stage (Eriksson et al., 2023) and problems of a

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social, psychological and existential nature must be considered (Alfano and Rowland, 2006; Udo, 2014). The complex recovery after allo-HCT can be facilitated by means of this holistic approach (van der Lans et al., 2022). Patient's own resources should be utilized in collaboration with the healthcare staff (Ekman et al., 2011; Kitson et al., 2013). Therapeutic relationships can be described as a cornerstone for care meetings, where good and safe care is ensured based on the patient's needs (Feo et al., 2017). Here, RNs and oncology nurses have a significant opportunity to prepare and guide patients in treatment and recovery (Udo, 2014; Young et al., 2020).

In recovery after cancer, feelings of abandonment and insecurity have been expressed after completion of the treatment (Boyes et al., 2015; Corbett et al., 2018; Parry et al., 2011). Patients reported being unprepared for what can occur (Knobf, 2013; Leach et al., 2017) and concerns regarding persistent side effects and their severity as well as the impact on daily life along with the uncertainty about relapse can arise (Jefford et al., 2008). Prevalent symptoms that patients must monitor after discharge are impaired physical condition as well as cognitive, emotional problems and practical concerns (Braamse et al., 2014). Experiences and perceptions of impaired conditions may affect patients' recovery (Immanuel et al., 2019; Jones et al., 2010) and the presence of a high symptom burden at an early stage after allo-HCT, could impact recovery in terms of sick leave and a perception of low general health (Eriksson et al., 2023). Patients need information about of which symptoms to monitor and manage, but also sufficient knowledge to examine their health and perform self-care after allo-HCT (Alfano and Rowland, 2006). Furthermore, patients need support to orient themselves towards a new normal (Jim et al., 2014) in order to cope with the period after completion of treatment and resume life (Stanton et al., 2005). Existential needs must not be forgotten as severe cancer side-effects are often accompanied by existential thoughts about relapse, life and death (Udo, 2014).

How nursing care is provided to promote patients' readiness in the allo-HCT trajectory has to the best of our knowledge not previously been outlined and there has been a call for nursing interventions to prepare the patient throughout the whole process, (Grundy and Ghazi, 2009). The role of nursing care needs to be further investigated in order to develop holistic care in allo-HCT as a means of reducing uncertainty and preparing patients for extensive self-care to cope with various challenges in daily life. Thus, the purpose of this study was to explore the conditions for nursing care in allo-HCT.

2. Methods

2.1. Study design

Experience-based co-design (EBCD) is a method for developing health services and improving the quality of care using experiences from professionals (Donetto et al., 2015). The method can promote the development of nursing care by using experience from the profession where healthcare professionals, managers, patients and relatives can be invited to discuss and reflect on various topics in healthcare (Donetto et al., 2015). The present study used EBCD to collaboratively identify the content of nursing care in allo-HCT through workshops (Ørngreen and Levinsen, 2017), where RNs, head nurses and researchers shared experiences, thoughts, and visions of nursing care.

2.2. Setting

The study was performed at a 14-bed centre for allo-HCT in a university hospital in Sweden. The centre performs approximately 100 allo-HCTs annually with patients aged between 0 and 75 years. The average hospital stay was 32.5 days (2021). Thirty-two RNs were employed at the centre at the time of the study.

2.3. Data collection

2.3.1. The interview guide and workshop schedule

A semi-structured interview guide and a workshop schedule, Table 1, was developed by the research team based on the purpose of the study. The input for this was to have broad opening question to initiate the discussion. Follow-up areas were pre-formulated to elicit participants further description of the RNs work and nursing care at the ward. The opening question initiated the discussion, which then was guided by all participants through the exchange of experiences. After each workshop, the research team made an oral summary of the areas discussed. This summary was noted as a field note and brought to the next workshop to take advantage of the participants' experience and are part of the EBCD methodology (Donetto et al., 2015).

Workshop number five was planned to assess the Strengths Weaknesses Opportunities and Threats (SWOT analysis) (Teoli et al., 2021). This in accordance with EBCD's philosophy of jointly identifying problems, finding solutions but also reflecting together on mutual achievements (Donetto et al., 2015). Workshop number six was designed as a risk analysis with the intention of helping RNs to initiate change in certain areas of the content of their work, nursing care, identified during the workshops. This step within EBCD can be described as starting a change process by informing other professional groups and telling them about the change plans, why and how (Donetto et al., 2015).

2.3.2. Sampling strategy and study participants

One clinical RN became our contact RN at the unit and was responsible for service and administrative tasks concerning all workshops. Inclusion criteria to participate in the workshops was being permanently employed as a RN. The desire for identified strategic selection was requested for the later workshops, although the recruitment was based on a convenience sampling according to the RNs working at

Table 1
Questions from the interview guide.

Questions	Follow-up areas
Introductory question in Workshop 1 How do you want nursing care to be planned in the future?	*The goal of care?* *What do you experience as difficulties within nursing practice today?* *How do you see opportunities for development?*
Introductory question in Workshop 2 What does it mean to be a RN at the unit?	*How do you perceive nurses' work with clinical nursing care?* *The relationship with the patient - how do you create that relationship?*
Introductory question in Workshop 3 How do you experience the nursing in the ward?	*How can care planning be promoted so that the team thinks coherently?* *The relationship with the patient - how do you create that relationship?*
Introductory question in Workshop 4 What does it mean to be a RN at the unit?	*The goal of care?* *What development opportunities do you see within nursing practice?*
Introductory questions in Workshop 5 SWOT analysis What do you do well? Strength What can you improve? Weakness What opportunities are there? Opportunities What threats can you identify? Threats	
Introductory question Workshop 6 Risk analysis How do colleagues, who have not attended the workshop, may react when you express that you want to lead and develop care in the ward?	*What can happen if routines are challenged?*

the time the workshops took place and agreed to participate. No RNs participated outside working hours or on a day off. Participants could participate in several workshops if they wished and the work situation allowed it. The contact RN participated in all six workshops. The two head nurses participated in five workshops. A newly graduated RN participated in three workshops. Other RNs participated on one occasion each. The head nurses who participated in the study were RNs with extensive clinical experience in allo-HCT and worked both administratively and clinically. The research team (KH, CHL and YW) jointly participated in the discussions and led the workshop collaboration. All authors have extensive experience in haematology, oncology and allo-HCT care, and one of the authors (CHL) has high expertise in palliative care. In addition, all members of the research team had teaching skills. The research group was unknown to most of the participants, but there was some connection to the clinic in the context of research or development, but not on a regular basis.

Informed consent was obtained from the participants and the study was approved by the Swedish Ethical Review Authority (Dnr, 2020-03996) and (Dnr, 2021-03865).

2.4. Procedure of the workshops

Six workshops were performed between October 2020 and April 2021. The first two took place on site, the third via a hybrid solution, i.e. both on site and online, while workshop four, five and six were web-based, due to the pandemic. The RNs sat together on the ward, while the research team participated remotely. Three to six RNs participated in each workshop depending on staffing. One of the researchers started by informing about the purpose of the study and the workshop and informed about the voluntary nature of participation. Then all participants introduced themselves by name and contextual function. As the workshop went on, conversations flowed between the participants who shared experiences and thoughts and asked questions of colleagues and the research team.

The workshops were audio taped and workshop four, five and six recorded digitally (Lobe et al., 2020) due to the pandemic. The workshops lasted between 44 and 155 min, with a total of 448 min recorded discussions.

Field notes were kept by researcher (KH) during the workshops noted the atmosphere in the group, any disruptions and interruptions, and which topics engaged. After each workshop, the researcher (KH) wrote a summary of what was discussed. Researcher (KB), who did not participate in the workshops, first listened to the recordings then read through the summary of the discussions to highlight but also add key perspectives to what was discussed. The summary was sent to the contact RN for dissemination to the participants and to confirm that the discussion and the text were consistent. These perspectives were added in subsequent workshops.

2.5. Analysis

Thematic analysis was chosen to analyse data as this method is suitable when perceptions, experiences and knowledge in a specific environment are explored at group level (Braun and Clarke, 2006). The analysis was a reinterpretation of the data, where patterns and nuances were sought that constituted themes that answered the research question (Braun and Clarke, 2006). An inductive approach was applied, where reality was explored empirically through RNs' discussions in the workshops, with conclusions drawn through analysis of these discussions. As a first step, a familiarization process initiates thematic analysis, where the recorded material was listened to several times and careful summaries were written by researcher KH and KB. Discussions from workshop five (SWOT) and six (risk analysis) was analysed together with data from the other four workshops. Due to the exploratory nature of the study and the use of thematic analysis along with repeated listening to the workshop discussions and extensive summaries, the research team decided not to transcribe the workshop interviews verbatim (Halcomb and Davidson, 2006) except for the quotations found in the results section.

Table 2
An example of the analysis process.

Quotations	Code(s)	Memo note	Theme
"You develop a relationship with them (patients) and their relatives, but I cannot give too much of myself because then I go down the hole myself if the patient gets worse." *"Self-care, we have pushed all that away, I do not have time to wait. It's faster to do yourself than to teach or instruct".*	Relationship and care encounters Finding their own limit No time for education	*Risk of emotional burnout*	Proximity -distance Fragmented care-holistic care

The next step in the analysis involved coding the data to reflect and illustrate what RN expressed (Braun and Clarke, 2006). Example of the analysis process is presented in Table 2. When sorting the data for coding, the MAXQDA Analytics Pro 2020, release 20.4.0 was used. The third step in the data analysis was to construct preliminary themes. To facilitate the analysis, the codes were grouped so that clusters and patterns became clearer. When constructing preliminary themes, three researchers (KH, KB and CHL) were involved in the process to ensure the credibility, while the contact RN read and confirmed the themes (Tobin and Begley, 2004). In the fourth step of the data analysis, the preliminary themes were examined, and initial codes were merged into more salient themes. In phase five, one main theme and three sub-themes were identified and demarcated through analysis, discussions and scrutiny (Kiger and Varpio, 2020). The sixth step of Thematic analysis was to document the results of the analysis, where all members of the research group agreed with the presentation of the results and contributed to the text. The results were also presented to and validated by the head nurses and the contact RN at the unit.

3. Results

In total, 12 female RNs participated in the workshops. The mean age was 44 years (range from 24 to 64 years). The mean time in the nursing profession was 13.8 years with a mean time of 13 years employment at the unit (ranging from 0.7 months to 30 years). Seven RNs had a graduate degree, and five RNs had a post graduate degree.

The analysis resulted in one main theme: Nursing as a balancing act and three sub-themes; Fragmented care vs Holistic care, Proximity vs Distance and Teamwork vs Stand-alone, as outlined in Fig. 1. To illustrate RNs' experiences and perceptions covering these themes, quotations expressed by participants in the various workshops are presented.

3.1. Nursing as a balancing act

Through the RN' narratives about their role, balancing became a constant theme during the data analysis. The RNs stated that most of the tasks had a medical focus which constituted a large part of their responsibility in allo-HCT care. At the same time, RNs expressed that care planning and preparations for discharge, are important but allocated time limited space in care.

> *"We want the patient to be involved because the care is complex and they need to know what it means" Workshop no 1.*

Lack of time was a recurring feature, but although some RNs thought that there was sufficient time and that it was a matter of re-prioritize and at times put nursing before medical-technical duties.

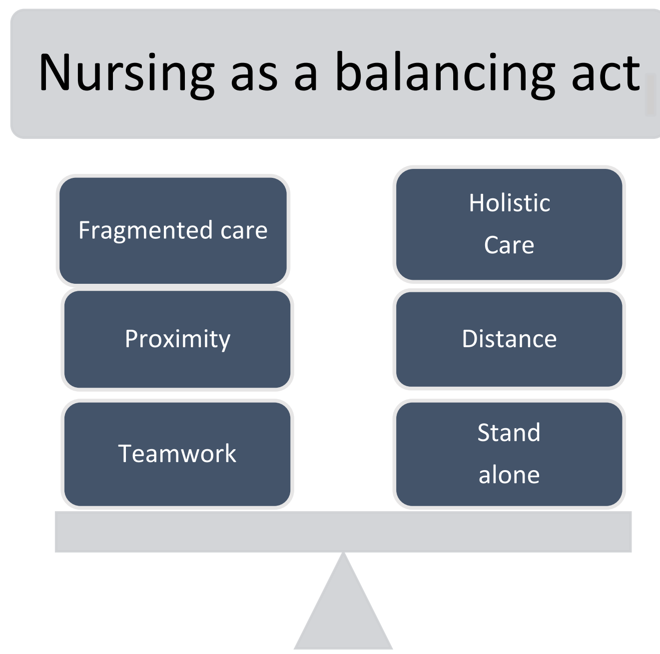

Fig. 1. Theme and sub-themes where balancing was a common denominator for nursing care in allo-HCT.

> *"The time is there, but that we must dare to prioritize and ask for help, dare to prioritize the conversations. We rightly think that the medical treatment is so important, it is priority one, but I see that this patient is not doing well mentally, I have to dare to focus on that and I have to dare to ask a colleague for help. Could you please help me and relieve me with this patient who may be on some meds but is doing quite OK, so I can focus on the patient who is feeling bad even if it is not medical" Workshop no 3.*

RNs made an effort to introduce nursing in the care setting and tried to balance this by multitasking. RNs felt that they did not have time to explore the patient's own resources, which resulted in taking over full responsibility for the care with little or no patient participation. A lack of patience that affected teamwork was described, where the RNs balanced between quickly doing the job themselves, or a more planned intervention with the team. This eroded the holistic view of the patients' needs that the RNs strived for. Patients' vulnerability, where the disease challenged life, was pointed out and RNs saw themselves as significant actors in helping patients survive. RNs expressed thoughts and ideas about how care could be organized so that nursing in the form of planning and conversation would become a natural part of care. It was expressed more concretely in the sixth and final workshop.

> *"It is desirable that everyone is willing to respect and is helped to find time for these moments. This does not mean that you have to keep up with this and all other tasks, but prioritizing. Today our group will have a discharge interview or an enrollment interview" Workshop no 6.*

3.2. *Sub-theme: Fragmented care vs holistic care*

The number of pharmacological tasks, as well as rounds and administrative functions, constituted a major focus of the "nursing" that RNs described performing during each work shift. By working in a situation-oriented manner, nursing became fragmented and weakened the opportunities to engage in long-term assignments such as care planning or preparing patients for discharge or management of self-care.

> *"Self-care, we've pushed all that away, I don't have time to wait. It is faster to do it yourself than to teach and instruct the patient" Workshop no 2.*

The RNs described it as difficult to take the time to "just" talk to the patient, which they balanced by developing multitasking ability. While performing medical-technical tasks, such as administering drugs, changing dressings or connecting the patient to intravenous fluids, the time for non-pharmacological nursing, such as evaluating, conversing with or informing the patient was found. Although RNs admitted that doing two things at the same time was not an optimal solution, but it provided an opportunity to connect to the patient.

The care was described as non-holistic, i.e., that the patient's physical, mental and emotional needs were not met. One example was the discharge procedure, described as sudden, with fragmented, deficient preparation or involvement of the patient. There was a dearth of communication between RNs and physicians, where a unified view of the patient's needs and abilities after discharge was lacking despite the awareness that an incomplete discharge often meant an early readmission.

> *"We have not planned in collaboration with the patients when approaching the date when they will go home and manage for themselves. Instead, it is often: You will be discharged tomorrow. Then it will be a shock and a stressful moment for the patient How will I manage myself?" WS no 4.*

RNs identified the good collaboration between different professions as a strength in the SWOT analysis and saw this as an opportunity to develop the lagging multi-professional social meeting that took place once a week at the ward.

> *"The social round is not prioritised, often the counsellor sits alone and no one comes. It is sad. You have an opportunity to discuss the patient's well-being, prepare for discharge. However, we can update and change the structure of the social round because the discharge must be prepared well in advance. The counsellor will help to arrange practical matters, and it is important that doctors are aware of this" Workshop no 5 SWOT analysis.*

3.3. *Proximity vs distance*

RNs expressed that they saved lives, due to allo-HCT, patients were able to recover from a fatal diagnosis. Caring for patients who received this demanding treatment affected RNs who described the treatment as a journey they made together with the patient and relatives. RNs came close to the patients who ended up in a position of dependence where RNs took over the responsibility. There was no overall definition or consensus between all RNs about, what allo-HCT nursing care is. This were described as a variation between doing "everything" for the patient or refraining from doing things and instead supporting and giving more responsibility to the patient. The RNs described care situations where the patient had been seriously ill but had improved. Taking a step back and letting the patient handle certain chores independently was hard, revealing doubts about the patient's own ability and difficulties relinquishing control. Instead, RNs continued to do a great deal for patients, thus maintaining dependency. Offering the patient help with everything in a difficult situation felt good, but at the same time the RNs described it as a weakness because such actions affected the patient's autonomy.

> *"A weakness is that RNs are bad at laying the foundation for the future, that the patient should feel ready to be discharged. Instead, we do things for the patient that they can actually handle themselves" Workshop no 5 SWOT analysis.*

RNs described the close relationship as something satisfactory and that they wanted to support the patients in their vulnerable situation. Tension arose if treatment was not effective, the patient relapsed or developed a severe complication. In such situations, being too close was perceived as troublesome because it negatively affected both the RN and the whole healthcare team giving rise to a mixture of sadness and failure. Building relationships was described as a balancing act between closeness and distance, in order to avoid the feeling of defeat, especially

if the patient died. Despite the challenges of maintaining a balance without being harmed, most of the RNs perceived these relationships with patients and relatives as something positive, rewarding and a reason to work at the unit.

3.3.1. Teamwork vs stand alone

The teamwork was mostly described as well-functioning, but certain aspects required further development. Due to the high workload and time pressure the teamwork ceased to function. Several RNs expressed that it was difficult to keep up with all the work during a work shift and balanced between working alone and in the team. In addition, the RNs expressed that it was challenging to ask for help as everyone had their share of work and that nobody wanted to burden a colleague by asking for help. The group was described as impatient, where the RN preferred to do the work on their own in order to get it finished. The more inexperienced RNs expressed reluctance to relinquish control of "their" patients and felt a need to do everything for them. During the SWOT analysis, opportunities to develop and improve teamwork were identified, such as new way of working like developing bedside rounds. The nurses felt that RN colleagues were mostly positive to change work in the department and that the nursing assistants were very supportive. Still, RNs could perceive a threat that physicians did not really appreciate changes but that this could be overcome by good argumentation for the cause.

> *"The care is medically technical complex but it is also complex in nursing, conversations, training in communication and others. We don't have time to embrace caregiving, catch the conversation and listen in, the urgency means we don't have time to stop and take it in. We need to find strategies to find solutions and facilitate situations, but does the RN have to solve everything?" Workshop no 5 SWOT analysis.*

4. Discussion

The overall theme *Nursing as a balancing act* illustrates RNs' difficulties in providing nursing care in a constant flow of pharmacological assignments. The work is largely medically oriented, which might not be surprising as an allo-HCT requires extensive medical interventions. However, this can affect other basic nursing issues, such as establishing relationships, communicating, care planning based on individual needs, preparing and enabling relevant self-care after discharge. These issues seem to weigh a little lighter and medical care weighs more heavily and little attention is paid to these activities within nursing care (Feo and Kitson, 2016). If the RN is to work holistically, with planning in a person-centred way, the balance between tasks should be stabilized.

RNs communication with patients took place during the performance of medical duties, which is problematic as communication is an essential part of nursing and promotes care meetings, i.e., a deeper interaction between the RN and patient, where the latter can reveal thoughts to an attentive RN (Holopainen et al., 2019). If the climate is conducive, RNs can prepare and educate the patient during these caring encounters where RNs pedagogical skills are considered important (Friberg et al., 2007). Information and preparation need to be continuous and repetitive and take place before discharge (Handberg and Maribo, 2020). Communication is a part of nursing where patients have expressed that their needs are not being met, including self-care and education (Chaboyer et al., 2021).

When the deeper interaction between RN and the patient is sparse, the knowledge of the patient's individual abilities and desires but also fears and anxieties is lacking. Due to illness, the patient ends up in a vulnerable situation and need help with issues that cannot be handled independently (Angel and Vatne, 2017). In allo-HCT, the isolation is one limiting factor that considerably affects the patient's ability to be autonomous. The dependence contributes to power becoming asymmetrical in care situations where the patient needs or becomes dependent on someone, for example the RN (Ozaras and Abaan, 2018; Sellman, 2005; Strandberg and Jansson, 2003). High workload and time pressure can lead RNs to view the patient as a passive recipient of care (Leplege et al., 2007) rather than a partner in the care team (Ekman et al., 2011). This was expressed in the sub theme *Proximity vs Distance,* where RNs described difficulties to step back giving tasks to the patient, as part of the rehabilitation and preparation for life after discharge. RNs acknowledged that it saved time to perform the chores on their own compared to teaching, informing and listening. A high workload may contribute to patients becoming more dependent than necessary with little time for RNs to support the development of autonomy (Candela et al., 2020; Lindberg et al., 2014).

In order to provide the right individual support, care should be based on the patient's individual needs, but also promote collaboration between healthcare professionals and patients. Partnership, documentation and the patient's narrative constitute the foundation of Person-centred care (PCC) and the structure of work with a holistic perspective. PCC can promote trust building through the development of an informal relationship between patients and healthcare professionals (Wolf et al., 2017). Working according to a person-centred approach within allo-HCT should contribute to increased preparation for life after transplantation, designed according to the patient's needs, opportunities and wishes, where pharmacological and non-pharmacological nursing care are equally important for the patient's recovery.

4.1. Methodological considerations

It might be a limitation that this is a single center study with a limited number of participants, although this created a high interactivity between the RNs as they knew each other and the study is, to our knowledge, a first attempt to describe conditions of nursing care in allo-HCT. Twelve female RNs out of the 31 RNs employed at the unit participated, which is fewer than expected and can constitute a limitation of the study. However, the pandemic affected the opportunities for RNs to participate when the staffing situation was strained, and these six small groups workshops provide opportunities for in-depth discussion and close cooperation. According to the EBCD, it is an evolution in the process of creating smaller co-design groups (Donetto et al., 2015). The decision to ask head nurses to participate in workshops was deliberate as they have mandate to take the results further to the management team. During the workshops, it was observed and noted in field notes if the presence of the head nurses could be perceived negatively by other participants but was not judged to disturb in an unwanted way.

The EBCD (Donetto et al., 2015) provides a basis for capacity building to create space for nursing care, in this study by means of workshops as a co-creative forum to discuss, share and learn to develop allo-HCT nursing. To reduce the possible impact of the researchers' pre-understanding and interpretations on the data and analysis, reflexivity was used in every phase of the analysis, from data collection to the presentation of the results (Braun and Clarke, 2006; Malterud, 2001).

5. Conclusion

This study shows that the conditions for RNs and nursing care in allo-HCT care is to balance tasks and approach towards the patient and themselves. RNs must weigh and balance what is most important in the moment and where something else often has to be put aside. It is difficult for RNs to find the time to plan each patient's care and to support the patient in the way they see as most optimal to prepare for discharge, self-care and rehabilitation.

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CRediT authorship contribution statement

Katarina Holmberg: Conceptualization, Formal analysis, Writing – original draft, review and editing draft, final approval. **Karin Bergkvist:** Conceptualization, Formal analysis, Writing – review & editing, final approval. **Solveig Adalsteinsdóttir:** Writing – review & editing, final approval. **Yvonne Wengström:** Conceptualization, Writing – review & editing, final approval. **Carina Lundh Hagelin:** Conceptualization, Formal analysis, Writing – review & editing, final approval, Supervision, Project administration, Funding acquisition.

Declaration of competing interest

Declaration of competing interest No conflict of competing interest applies to this study.

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