

A person-centred intervention remotely targeting family caregivers' support needs in the context of allogeneic hematopoietic stem cell transplantation - a feasibility study

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Abstract

Purpose Allogeneic hematopoietic stem cell transplantation (HSCT) is an intensive curative treatment that increases family caregivers' burden. The aim of this study was to explore the feasibility of remotely assessing and addressing family caregivers' support needs in terms of demand and acceptability using the Carer Support Needs Assessment Tool Intervention (CSNAT-I) in the HSCT context.

Methods CSNAT-I consists of an evidence-based tool and a five-stage person-centred process. The intervention was performed remotely by two designated nurses from two HSCT centres, one before HSCT and the second 6 weeks after (November 2020 to March 2021). To capture the experiences of using CSNAT-I, interviews were conducted with family caregivers and reflections were gathered from the designated nurses.

Results Of 34 eligible family caregivers, 27 participated, 70% were partners and the rest children, siblings, or other relatives. The main support needs were: Knowing what to expect in the future and Dealing with your feelings and worries. The most frequent support actions according to CSNAT-I were psychological support and medical information. Four categories summarised family caregivers and designated nurses' experiences: CSNAT-I was relevant and became an eye opener; Nurses' experiences were important for enabling trustful CSNAT-I conversations; CSNAT-I provided family caregivers with support and a sense of security; and CSNAT-I gave family caregivers insight and enabled change.

Conclusion Both family caregivers and designated nurses experienced that using CSNAT-I in an HSCT context was feasible and had the potential to provide valuable support for most of the participating family caregivers.

Introduction

The rationale behind this study is the lack of feasible person-centred support interventions targeting family caregivers' (FC) support needs in the context of allogeneic hematopoietic stem cell transplantation (HSCT). HSCT is an intensive curative treatment for haematological malignancies, such as leukaemia, with a high risk of relapse and severe complications for patients, such as graft versus host disease and complex infections (1–3). The life situation of FC of HSCT patients is also affected and their distress is sometimes even higher than that of the patients (4, 5). They have to deal with their own worries about living with a seriously ill patient and the threat of death (6), as well as being responsible for physical and psychological support (5). FC support needs differ between individuals and also between time points during the HSCT process (7). Their individual characteristics and social context may influence their ability to provide support for the patient, which is often influenced by the patient's constantly changing health status (8). Until today few intervention studies have explored how individual support to FC in the HSCT context can increase their well-being (9, 10). However, two interventions in the USA have shown improvements. One demonstrated a decreased level of distress as an effect of eight stress management

sessions (10). The other improved self-efficacy, distress, and fatigue by delivering three problem-solving education sessions (9).

Based on interviews with FC, researchers in palliative care have developed The Carer Support Needs Assessment Tool Intervention (CSNAT-I). The intervention is specifically developed to directly assess and address practical, emotional, existential, and social support needs (11). Conversation-based assessments enable each FC to identify her/his specific support needs and prioritize the most important ones (12). The CSNAT-I has two parts: an evidence-based tool and a five-stage person-centred process. The tool includes 15 domains about the need for more support, reflecting the dual role of FC as both providers of care and persons in need of support. The five-stage process starts with an introduction to the CSNAT-I, followed by time for the FC to reflect upon support needs. In a conversation with one healthcare professional FC discuss and prioritize their support needs. The conversation results in a shared support plan to address the prioritized support needs, of which some can be directly dealt with during the meeting (11, 12). The CSNAT-I has been shown to facilitate the assessment of support needs and ensure adequate support (13, 14). It has been translated into several languages including Swedish (15) and is used internationally in palliative care.

There are both similarities and differences between a palliative care context and the HSCT context. The similarities are the complexity of the illness and associated complications, which require an advanced level of highly specialized care. The differences are that in palliative care the patient's condition deteriorates and ends in death, while in HSCT care the treatment has a curative intent and patient's medical and health status often change rapidly. There is a need for feasible person-centred support interventions targeting FC support needs in the context of HSCT. Therefore, the aim of this study was to explore the feasibility of remotely assessing and addressing family caregivers' support needs in terms of demand and acceptability using the Carer Support Needs Assessment Tool Intervention (CSNAT-I) in the HSCT context.

Methods

Design

This feasibility study has a longitudinal design (Figure 1). The focus is on demand, i.e., how much the intervention is used, and acceptability, i.e., the extent to which those delivering or receiving the intervention find it appropriate, satisfying and attractive. (16).

Sample and procedure

Adult FC were consecutively included from two HSCT centres, namely Stockholm and Lund. Patients were asked by the HSCT coordinator to select a FC involved in their everyday life. With the patients' agreement, the HSCT coordinator sent the study information to the FC, who were then contacted by telephone, given oral information and invited to participate in the study. If they agreed, they were included in the CSNAT-I.

The inclusion period was from November 2020 to March 2021 and the inclusion criteria were being a FC to a patient undergoing HSCT and able to read and speak Swedish.

The CSNAT-I in the HSCT context

One designated nurse from each HSCT centre performed the CSNAT-I. They had 14 and 23 years of nursing experience respectively, had specialist training in oncology and long experience of HSCT. Both were included in the planning phase of using the CSNAT-I in the HSCT context. The CSNAT-I conversations were carried out at two time points, before transplantation and 6 weeks later when patients are usually back home again after the intensive inpatient treatment. The decision to select these two time points was based on clinical experience within the research group and earlier studies showing that these time points are demanding for the FC with uncertainty and changes in everyday life including responsibilities that often involve the need for support (7, 8). For inclusion in the study the FC had to take part in the two CSNAT-I conversations and the exit-interview.

Due to the Covid-19 pandemic the CSNAT-I had to be delivered remotely by telephone or video-visits. The CSNAT tool was sent by post to the FC before conversation 1. To document FC support needs the nurses filled in the tool for each FC during conversation 1, but this was not done during conversation 2.

Data collection

FC support needs and support plan: The Swedish CSNAT tool version 3 and its support plan were used (12, 14, 15). The tool asks the FC "Do you need more support with..." and includes 15 domains and one additional question. The response alternatives for each domain are no, a little more and quite a bit more. The support plan includes further actions required to address FC needs.

Exit interviews with FC: Semi-structured telephone interviews were conducted by one of the authors after the participant had completed the second conversation. The interviews evaluated the participants' experiences of the CSNAT-I, including whether participation had led to any changes and suggestions for improvements. The median duration of these interviews was 29 minutes (range 16-48). The answers to all questions in the exit-interview were rewritten and notes were made during and directly after the interviews.

Designated nurses' memos from conversations: After each conversation the nurses filled in a standardized written documentation form including questions about their overall reflections on the conversation, their experience of using the CSNAT-I and suggestions for improvements.

Reflective conversations with the designated nurses: After all conversations were completed, the designated nurses reflected individually on their experiences of the conversations together with one of the authors.

Data analysis

Descriptive statistics were used to describe the characteristics of the participants. Inductive qualitative content analysis was applied to the exit interviews, which were read several times (17). Open coding from the perspective of acceptability (16) was conducted by two authors. Meaning units and codes were recorded on a coding sheet and finally grouped into four categories. Qualitative content analysis was also applied to the memos and the reflective conversations with the designated nurses. All the qualitative analyses resulted in four categories, which were adjusted until consensus between all authors was achieved. Abstraction was used throughout the analysis process.

Ethical considerations

In the written and oral information, we emphasized the voluntary nature of participation, the right to withdraw from the study at any time, that data would be treated confidentially and that the identity of the participants would be protected. Ethical approval was obtained from the Regional Ethical Review Board in Stockholm, Sweden (No. 2017/11112-31/4).

Results

Out of 50 eligible patients planned for HSCT, 45 underwent transplantation, four were postponed and one died before transplantation. Among those 45 patients, six had no FC who understood Swedish, two did not allow us to invite their FC to participate, one had no FC, in one case the pre-transplantation process was too quick to enable us to ask her/him to participate and in another it was not possible to ask the patient for permission due to cognitive deficits. Thus, 34 FC were eligible for inclusion and informed about the study, of whom four declined participation and 30 accepted (88%). Of the 30 FC who accepted, three only participated in conversation 1, which resulted in a total of 27 (80%) FC, 19 from Stockholm and 8 from Lund. All conversations were conducted over the phone, except for one by video. Conversation 1 took 45–60 minutes and conversation 2 13–30 minutes. The median age of the participants was 55 years and 56% were women. Other characteristics are presented in Table 1.

Table 1
 Characteristics of the participating FC (n = 27)

FC age, years, Md [min-max]	55 [22–73]
FC gender, n (%)	15 (56)
Female	12 (44)
Male	
FC country of birth, n (%)	23 (85)
Sweden	4 (15)
Elsewhere	
FC relationship to patient, n (%)	19 (70)
Partner	4 (15)
Child	2 (7)
Sibling	2 (7)
Other (Cousin, friend)	
Cohabiting with the patient, n (%)	18 (67)
Yes	9 (33)
No	
Education, n (%)	14 (51)
Lower (elementary or secondary school)	13 (49)
Higher (college/university)	
Occupational situation	11 (41)
Working full-time	4 (15)
At home due to HSCT for more than 4 weeks*	2 (7)
Disability pension/sick leave due to other reason	7 (26)
Old age pension	3 (11)
Other (housewife, jobseeker, student)	

* Have been on sick leave or in receipt of a disease carrier allowance due to COVID-19.

FC age, years, Md [min-max]	55 [22–73]
Time from patient’s diagnosis to start of the CSNAT-I intervention	10 (37)
3–5 months	9 (33)
6–11 months	8 (30)
> 12 months (range 17–156 months)	
* Have been on sick leave or in receipt of a disease carrier allowance due to COVID-19.	

Support needs and support actions in the HSCT context

The number of support needs reported by FC in conversation 1 varied widely: zero (n = 4), one (n = 6), two (n = 4), four (n = 4), five (n = 2) and more than six (n = 7). The main support needs were: Knowing what to expect in the future; Dealing with your feelings and worries; Knowing who to contact; and Talking with your relative about their illness (Fig. 2). A support plan was set up in 78% (21 out of 27) of the first conversations, while in 22% (6 out of 27) there was no need for further action (Table 2). The actions concerned advice about how to seek psychological support (n = 14) or medical treatment for themselves (n = 2), medical information about the patient from a physician (n = 9) or patient organisation (n = 4), or how to arrange home care (n = 4).

Table 2

Planned support actions in each of the CSNAT-I domains documented in the support plan in conversation 1.

CSNAT domain	Action plan	Number
1. Understanding your relative's illness	Talk to the patient's doctor	5
	Participate in the enrolment/discharge talk	3
	Use information on the patient organisation website	3
	Contact the patient organisation for relatives	1
2. Having time for yourself in the day	Continue contact with social worker	1
	Referral to the social worker	1
	Increase help from other relatives	1
	Take a walk outside the home by on her own	4
3. Managing you relative's symptoms	Referral to the social worker	1
	Referral to ASIH that can manage the patient's medicines	1
	Talk to the patient's doctor to understand medications	1
4. Your financial, legal or work issues	Follow-up during the second conversation	1
	Referral to the social worker	2
	Contact your own doctor in primary care	1
	Contact a relative who can help	1
5. Providing personal care for your relative	Contact the municipality for home care	1
6. Dealing with your feelings and worries	Remain in contact with the social worker	1
	Referral to the social worker	7
	Contact the patient organisation for relatives	2
7. Managing relationships	Referral to the social worker at ASIH	1
8. Knowing who to contact if you are concerned	Pointed out who can be contacted at the ward or out-patient clinic	2
	Pointed out that one can always phone the hospital chaplain	1

CSNAT domain	Action plan	Number
9. Looking after your own health	Contact your own primary care doctor to obtain a sick leave certificate for yourself	1
		1
	Take 10 minutes for yourself each day	1
	Become physically active again with support from a physiotherapist	1
	Contact a doctor with experience of naprapathy to obtain help for own pain	
10. Equipment to help care for your relative		0
11. Your beliefs and spiritual concerns	Will search for someone else to talk to in addition to social worker	1
	Contact the hospital chaplain	1
12. Talking with your relative about his or her illness	Referral to the social worker	5
	Contact the patient organisation for relatives	1
	Contact the hospital chaplain	1
	Talk to the healthcare personnel at the ward	1
13. Practical help around the home or elsewhere	Contact the municipality for home care	2
	Talk to healthcare personnel at the ward before discharge	1
	Engage the family more for practical help	1
14. Knowing what to expect in the future	Participate in continuous contact with the patient's doctor and nurses	3
		1
	Use information on patient organisation website	2
	Contact the patient organisation for relatives	3
	Participate in the admission talk	1
	Referral to the social worker	2
	Information about normal procedure and side-effects	2
15. Getting a break from caring overnight		0

FC and designated nurses' experiences of the CSNAT-I

The CSNAT-I was relevant and became an eye opener

Both FC and designated nurses described that using the CSNAT tool provided a structure, which facilitated a good conversation. The designated nurses experienced that the FC were well prepared and believed it had worked well both when FC had completed the tool before the conversation or together with them during the conversation. Many FC highlighted that going through all domains provided them with a new insight into what support they might need throughout the HSCT-process, which was described as “a kind of eye opener” and as a recognition of what might arise in the future.

The domains in the tool were relevant, although some FC, especially those not living with the patient, stated that the domains “Getting a break from caring overnight” and “Practical help in the home” were not relevant. This was also supported by the nurses. Some of the FC commented that the domain “Beliefs or spiritual concerns” felt odd. Only a few of the FC felt the domains were not relevant and some FC appreciated an explanatory description of the domains in relation to the HSCT-process.

Most of the FC experienced the conversations as “timely” which was confirmed by the nurses. Most FC mentioned that they were content with one follow-up conversation, but a few FC would have appreciated an additional follow-up conversation, which the nurses also identified in a few cases. The nurses reflected on the fact that the content of the conversations had a different focus, i.e., the first conversation often had a focus on “Understanding the illness”, “Expectations for the future” and “Knowing who to contact”. In the second conversation, the support needs identified during the first conversation were followed up and the focus was on dealing with practicalities, such as coping with various restrictions. The nurses experienced that the FC took the lead in the second conversation.

Nurses’ experiences were of importance to enable trustful CSNAT-I conversations

All FC identified several factors of importance for creating trust in the nurses, i.e., the nurses’ high level of competence and extensive experience of HSCT, their ability to have these conversations, as well as their professional and personal qualities. The nurses were described as being easy to talk to and being professional yet personal. The designated nurses also highlighted the fact that their experience and knowledge of HSCT-nursing made them comfortable and confident to have these conversations. They emphasised the need to have a genuine interest in listening. They expressed that an active listening approach had developed from their knowledge, experience and conscious choice of a humble attitude towards the life situation of FC.

Both FC and designated nurses reported that conducting the conversations over the phone was positive, worked well and enabled them to build a trustful relationship despite being unable to see each other. Several FC mentioned the advantage of not having to go to the hospital. However, those who had difficulties with the Swedish language would have preferred face-to-face conversations and several FC expressed a wish for video-based conversations. The designated nurses reported a disadvantage of being unable to read body language or interpret reactions and emotions during the conversations. This was

especially problematic when a FC cried or shared something sensitive, as it was impossible to show care and provide comfort through their own body language.

The CSNAT-I provided FC with support and a sense of security

All the FC expressed and appreciated that the conversations had focused on their life situation and needs. The conversations were about how the FC was doing, her/his thoughts and worries. Many of the FC expressed that they had initially believed that they did not need support, but that during the conversations it became obvious that they felt worse than they had thought. They experienced that the conversations were supportive and derived great benefit from them. The FC expressed that the conversations fulfilled another function compared to the information from doctors, i.e., focus on them as individuals. The FC felt relieved and more at peace after the conversations. For many, this was the first time that focus was exclusively on their life situation and needs, which they expressed as valuable and a good feeling, adding that they appreciated being listened to. The conversations gave them opportunities to ask questions, receive information and reflect and discuss situations in life, with a focus on their needs as a FC, while the patient was not present. The support from the nurses during the conversations also included practical aspects and advice, such as information about support available for FC, for example sick leave, and what to think about during the rehabilitation when the patient returned home. However, some of the FC expressed that they had no need for these conversations. Nevertheless, both designated nurses felt that most of the FC were satisfied after the conversations. Even the FC who did not have any support needs expressed that the conversations per se had been rewarding.

The CSNAT-I gave FC insight, preparedness and enabled change

When the FC recalled the CSNAT-I during the exit-interviews, they realized that they had gained new insights. They had learned about how they were actually feeling and what support they needed, e.g., the need to take care of oneself and ask for help. They had also gained new knowledge about the transplantation process and the patient's situation, which led to reduced or more balanced worries about things that might happen later. The intervention also made it possible for them to focus on non-medical aspects, such as how to relate to the situation and that they as FC are important for the patient. They described feeling more prepared for the transplantation process with a sense of participating in the patient's care. The feeling of preparedness mainly concerned being mentally prepared. For some, the CSNAT-I had led to a personal change in their life situation, and they understood that they needed help. These changes involved dealing with grief, contacting a social worker for psychological support and prioritizing their own needs, such as time for themselves, physical exercise and sufficient sleep during the night. However, a few did not make any changes after the conversations, despite the fact that most appreciated the conversations focusing on them as FC.

Discussion

This feasibility study conducted in an HSCT context shows that the demand from FC to participate in CSNAT-I was high. Furthermore, it demonstrated a high acceptability both among designated nurses and participating FC. Participants described not only appreciating the conversations, but also being provided with support and a sense of security. Several FC experienced gaining insights, preparedness and in some cases the intervention enabled them to make changes in their life. In summary, implementing the CSNAT-I in HSCT general practice is clearly acceptable.

Almost 80% of eligible FC participated in the intervention. Including FC in interventions during the patient's transplantation process (18) has been previously reported as challenging. However, we believe that our design facilitated FC participation, i.e., the nurses were flexible concerning the time points for the conversations, the conversations were conducted remotely, and FC were not asked to fill in any further questionnaires. Most FC were partners, but it was interesting to note that not all patients chose their partner to be the FC in the study. This was probably because they did not want to burden their partner any further and in some cases the partner was also ill and unable to be a FC.

In the present study, all FC and designated nurses were satisfied with the CSNAT-I, including the remotely conducted conversations and the chosen time points for them. In general, the first conversation was longer than the second one, which is in line with the developers' intention (13, 14), as the first includes assessment, delivery of support and documentation, while the second is a follow-up. The results highlight the fact that the CSNAT tool works as a conversation-based assessment between FC and healthcare professionals in an HSCT-context. The person-centred process gave FC the opportunity to gain new insights and receive proactive support. Many participants described that they realised during the first conversation that the patient's health could deteriorate during and after the HSCT, which increased their preparedness. This finding is very positive, as our earlier study shows that preparedness does not decrease over time among FC in the HSCT context (19). The insight gained by FC in the present study was mainly related to two of the domains in the CSNAT tool, namely caring for the patient during the night and giving practical help to the patient at home. It is interesting to note that these were the domains that both FC and designated nurses found irrelevant in the first conversation. This was especially reported by FC who did not live with the patient and was not expecting to be involved in such care. However, all domains in the tool were used in an HSCT context by some of the FC both in this and in our earlier study (7), indicating that FC have support needs in all domains.

The results show that the designated nurses' extensive experience of HSCT care and their ability to provide psychosocial support was highly appreciated by FC. The importance of the abilities of the healthcare professional conducting the conversations is also highlighted in another CSNAT-I feasibility study among FC of patients with Chronic Obstructive Pulmonary Disease, who stated that the interventionists' demeanor, relational skills and knowledge were more important than her/his profession (20). In the present study, the nurses' medical knowledge and experience seem to be important to FC, indicating that nurses are an appropriate professional category to conduct the CSNAT-I in HSCT care. Furthermore, we believe that after adequate training the CSNAT-I can also be used to enable more novice nurses to perform this intervention as intended.

In our context, FC described that participating in the CSNAT-I gave them a sense of security. The support plans of more than half of the FC included a need for more psychological support for themselves. This is related to the fact that in the HSCT context the greatest problem for FC is the sense of uncertainty, especially due to the unknown prognosis of the transplantation (6) and that lack of information, incomplete understanding of the treatment and disease, as well as the difficulties coping with the precariousness of daily life increase such uncertainty (21–23). Furthermore, the need to prioritize themselves including seeking psychosocial support was described by FC as an eye opener, which is also reported in other feasibility studies using the CSNAT-I (24, 25). Although FC have a personal responsibility to ask for and receive support, we believe that support resources could be offered in connection with the CSNAT-I conversation.

A strength of this feasibility study is that it was based on quite a large sample, was undertaken in two HSCT centres at two different geographical locations and that the two designated nurses were involved in the planning process of delivering the CSNAT-I in the HSCT context. However, having such dedicated nurses delivering the intervention makes it unique and a possible limitation is that the nurses might have been evaluated rather than the effects of the intervention itself.

In conclusion, both FC and designated nurses experienced that using CSNAT-I in the HSCT context was feasible. The intervention had the potential to provide most of the FC with both direct and proactive support. This study also highlights a need for further psychosocial support among FC.

Declarations

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Code availability: Not applicable

Authors' contributions: All authors contributed to the study conception and design. Material preparation was performed by Annika M Kisch, Karin Bergkvist and Jeanette Winterling. Data collection was performed by Annika M Kisch, Karin Bergkvist, Jeanette Winterling, Sólveig Adalsteinsdóttir and Christel Wendt, and analysis was performed by Annika M Kisch, Karin Bergkvist and Jeanette Winterling. The first draft of the manuscript was written by Annika M Kisch, Jeanette Winterling and Karin Bergkvist. All authors commented on previous versions of the manuscript and read and approved the final manuscript

Ethics approval: Ethical approval was obtained from the Regional Ethical Review Board in Stockholm, Sweden (No. 2017/1112-31/4).

Consent to participate: All participants gave their oral and written consent to participate in the study. After received oral and written information about the study

Consent for publication: All of the authors approved the manuscript and agreed on publication

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Figures

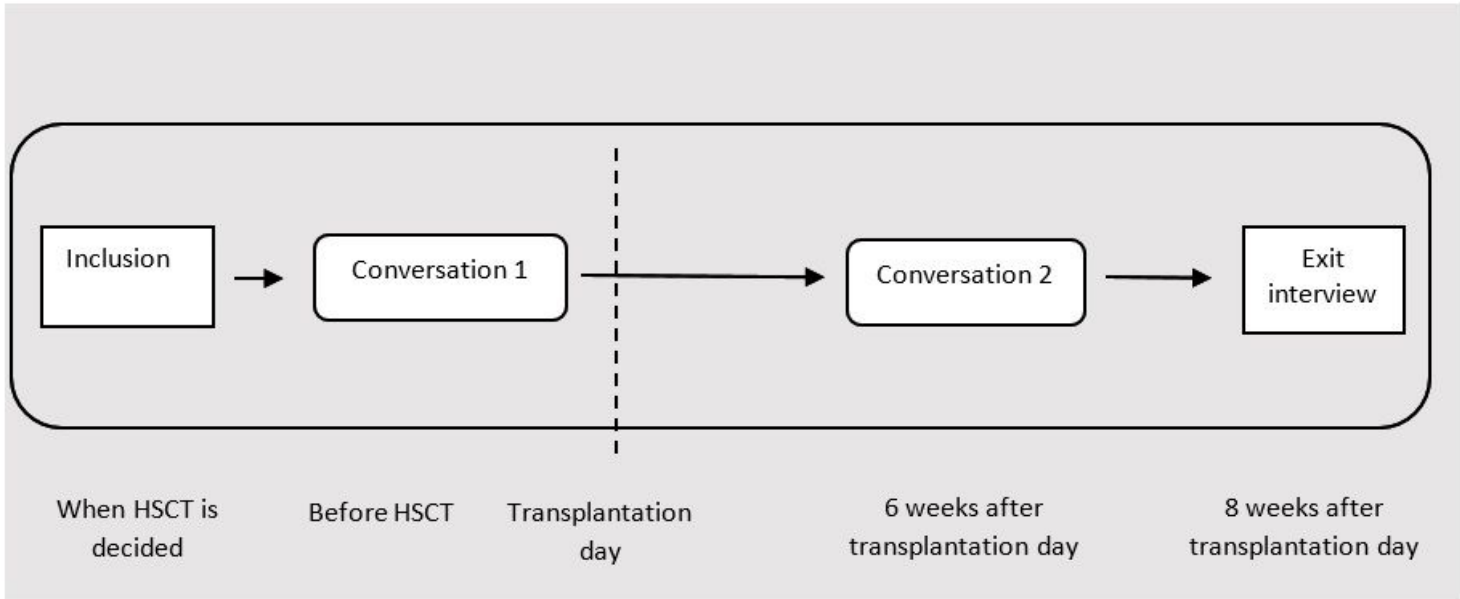


Figure 1

Design of the feasibility study using CSNAT-I in the HSCT context

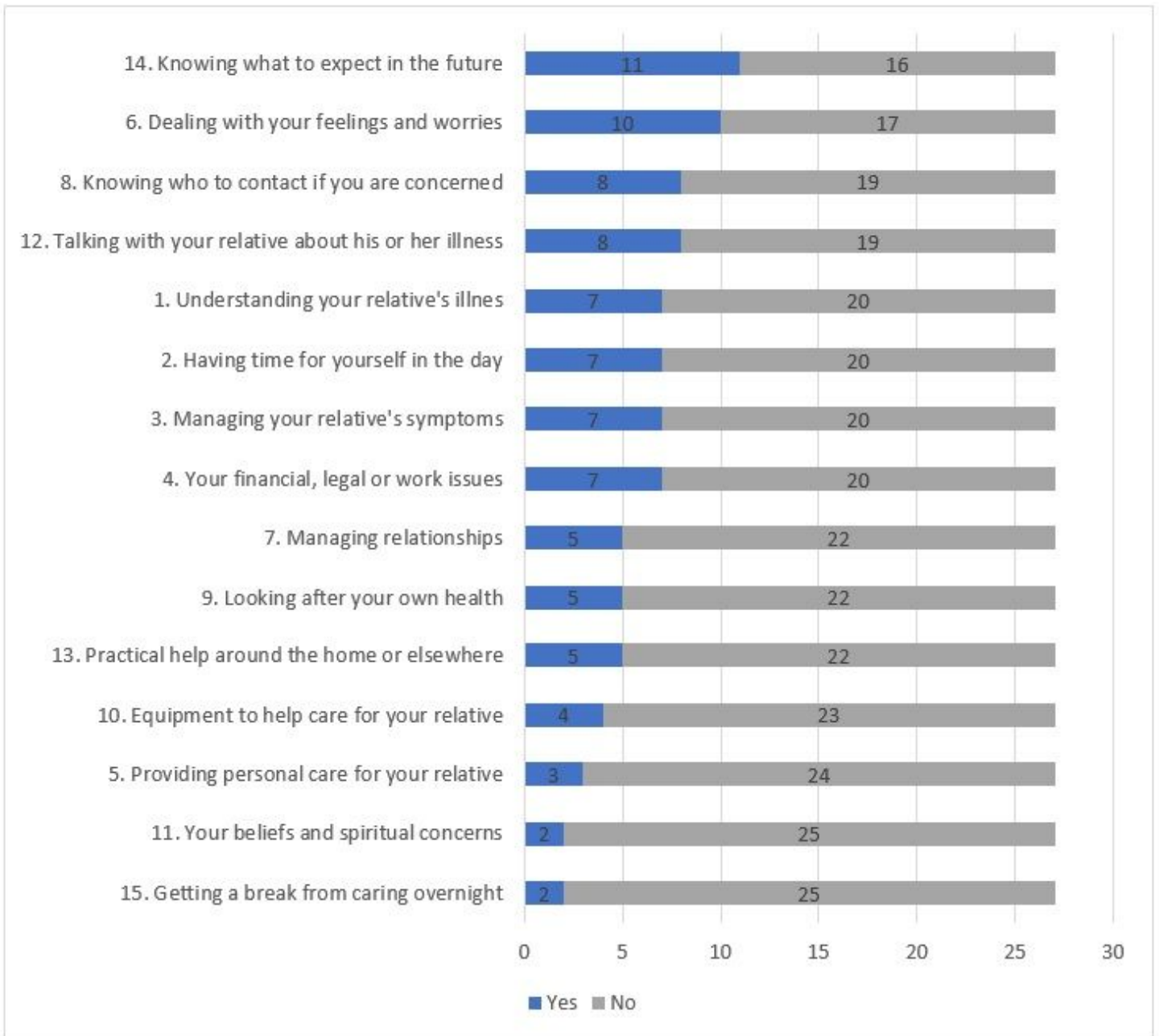


Figure 2

Number of family caregivers expressing more support needs listed in the CSNAT-I during conversation 1 (n=27)