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Research Article

Family Caregivers' Experiences of Hospital at Home Following Allogeneic Haematopoietic Stem Cell Transplantation: A Qualitative Study

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Purpose: The use of Hospital at Home (HaH) is expanding globally, including in the context of allogeneic haematopoietic stem cell transplantation (HSCT), as an innovative care model that delivers hospital-equivalent care to patients in a home setting. The HaH model designed for HSCT relies on informal caregivers, such as next of kin or friends. Given the limited research on caregivers' perceptions of HaH, this study aimed to explore how informal caregivers of patients undergoing HSCT experienced HaH.
Method: Using a phenomenological interpretive approach, semistructured individual interviews were conducted with 14 family caregivers. Data were analysed using reflexive thematic analysis.
Results: The analysis identified three themes: (1) On the inside as a caregiver, (2) Variation in caregiver burden and (3) Appreciating normality. Caregivers valued the opportunity to be physically present and involved in caring for the patient during HSCT. Although most had to undertake an active caregiving role, they reported varying levels of involvement and distress. Caregivers also highlighted the sensation of normality that HaH fostered, emphasising that maintaining a familiar routine in the home setting was less exhausting than traditional hospital care.
Conclusion: This study found that family caregivers appreciated being physically present in HaH, experiencing a sensation of being 'on the inside' and closely sharing the patient's treatment journey, in contrast to during hospitalisation. The findings revealed diverse experiences of caregiving and associated distress, underscoring the importance of adequately preparing caregivers for their role and ensuring appropriate support.

1. Introduction

Health authorities in several countries, including Norway, regard home-based alternatives as central to achieving a sustainable, patient-centred healthcare service [1]. The use of Hospital at Home (HaH) is expanding globally, including in the context of allogeneic haematopoietic stem cell transplantation (HSCT), as an innovative care model that delivers hospital-equivalent care to patients in a home setting [2]. HSCT is an intensive treatment with curative intent, primarily for patients with haematological malignancies. Traditionally, patients undergoing HSCT are hospitalised for the first three to four weeks following transplantation to allow for close monitoring and care due to bone marrow failure and other significant treatment-related toxicities associated with chemotherapy and radiation. These

toxicities often result in severe side effects, including infections, fatigue, malnutrition, nausea and vomiting [3–6]. Most haematological patients receive intensive chemotherapy and endure prolonged hospitalisation during treatment prior to HSCT. Home-based care models aim to reduce hospital admissions and improve the patients' experiences and quality of life (QoL) [7–9].

Family caregivers of haematological patients describe the disease as a life-altering event that significantly impacts their own lives [10, 11]. Many report experiencing a profound sense of uncertainty regarding treatment outcomes, alongside concerns about both the patient's and their own future [10–14]. Caregivers often take an extensive role, providing practical and emotional support throughout the entire course of treatment [10, 11]. Studies indicate that caregivers frequently encounter high levels of psychological distress [14–16] and face challenges in balancing their own needs with the demands of caregiving [11, 15, 17].

The home-based care models have shown promise in being cost-effective and enhance QoL, while preserving long-term outcomes for haematological patients [8, 9, 18]. However, many models, including those specifically designed for HSCT, depend on informal caregivers, such as next of kin or friends, to facilitate HaH [2]. Concerns have arisen that such models may increase the responsibilities and demands placed on caregivers [15, 16, 19]. Few studies have investigated their experiences with HaH in the context of HSCT [19–21]. Given the global expansion of HaH, it is crucial to gain insight into and understand caregivers' perception of this care model. The aim of this study was to explore how informal caregivers of patients undergoing HSCT experienced HaH.

2. Methods

2.1. Design. This study had an exploratory qualitative research design, based on semistructured individual interviews and a phenomenological interpretive approach to gain insight into the phenomena underlying the informal caregivers' lived experiences with HaH [22, 23]. To ensure rigor and transparency in reporting, the study adhered to the Standards for Reporting Qualitative Research [24] (checklist provided as supporting information).

2.2. Setting. At the Department of Haematology, Oslo University Hospital (OUH), patients, based on medical suitability, compliance and cooperation, are offered HaH care during the first 28 days following HSCT. Patients are required to have an informal caregiver, such as a family member or friend aged 18 years or older, present with them at all times throughout the HaH period. Informal caregivers who participate in HaH do so voluntarily.

Caregivers' responsibilities include monitoring the patient for signs of infection and other toxicities (e.g. measuring vital signs), as well as providing support according to the patient's needs. Patients may transition to HaH the day after the transplantation. HaH takes place in a home setting (owned, rented or otherwise provided) within a 45-min drive from the hospital. An interdisciplinary team delivers hospital-equivalent care, including daily visits from a nurse who performs clinical examinations and administers treatment. Daily telephone consultations with the attending physician are mandatory, supplemented by multiple daily interactions with the HaH nurses. Hospital readmission is arranged whenever necessary, e.g., onset of infections or if the patient is unable to maintain sufficient oral intake of nutrition and medication, at the request of the patient, caregiver or medical team.

2.3. Participants and Recruitment. During the pre-transplant evaluation, the department HSCT coordinator provided written and oral information about HaH. The decision to receive HaH care was made collaboratively by the attending physician, patient and caregiver. As the HSCT coordinator maintained contact with the patient and caregiver in the pre-transplant phase and had an overview of those that had agreed to HaH care, she purposefully identified participants to the study based on the following inclusion criteria: being an informal caregiver to a patient undergoing HSCT and participating in HaH, being over the age of 18, and having the ability to communicate in Norwegian. Prior to HaH, the first author provided interested participants with additional oral and written information about the study and obtained written consent form those who wished to participate.

2.4. Data Collection. Each caregiver was interviewed once within the first weeks following the completion of HaH. As participants attended HaH at different times, the interviews were conducted between February and September 2022. The first author, a haematology nurse with experience in qualitative research, conducted all interviews. She had no prior professional or private relationship with the participants and interacted with them solely within the context of the study. Participants were given the option to choose their preferred interview method: in-person, by telephone or via video call. Although in-person interviews were preferred by the investigators, this was complicated by the fact that several caregivers returned to their homes, located across different regions of Norway, shortly after completing HaH. Consequently, telephone interviews were conducted, as participants chose and favoured this method over video calls. The interviews had an average duration of 51 min, ranging from 28 to 83 min. A semistructured interview guide was developed, founded in research, our clinical experiences, and a user group consisting of former patients and family caregivers. The topics exploring participants' experiences included adjustments to participation, implications on personal life, the caregiving role in HaH, and comparisons with traditional hospitalisation. Full interview guide is provided in the supporting information. The guide was pilot-tested in the first interview. The sequence of topics was flexible, and follow-up questions were used to validate responses and explore additional topics introduced by the participants [22]. Informational power was determined by conducting and transcribing interviews simultaneously, with no new themes emerging after 14 interviews. Data analysis followed data collection, and during this process, informational power was reassessed, concluding that no further inclusion was necessary.

2.5. Data Analysis. Reflexive thematic analysis was used to identify themes of meaning across the dataset to address the research question [23, 25]. This method was chosen for its flexibility, suitability for inductive analysis and emphasis on reflexivity, enabling critical reflection on our choice and influence [23]. The first author initiated the analysis, attaining familiarity with the dataset through verbatim transcription of the audio-recorded interviews, followed by in-depth reading of the transcripts and noting initial ideas and patterns. The dataset was then systematically and inductively coded at a semantic level, with segments of data labelled using words or phrases closely aligned with the participants' own language. The codes were ordered into preliminary categories representing patterns of shared ideas and meaning. The analytical process progressed with an active review and refinement of these categories into the final themes, which the research group agreed represented the overall story of the data [23]. An example of the analytical process is provided in Table 1. The original dataset was reappraised to validate theme development and interpretations. The research team engaged in ongoing discussions and reflections throughout the analytical process, ultimately reaching a consensus on the main themes.

2.6. Ethical Considerations. The study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki [26] and approved by The Data Protection Officer at OUH (21/03590). Participation was voluntary, written informed consent was obtained and all data were handled confidentially, including de-identifying the participants with a unique code (IC1–IC14).

3. Results

3.1. Participants Characteristics. Twenty family caregivers were recruited; however, six were excluded due to either non-attendance in HaH or were lost to follow-up. Ultimately, 14 caregivers were included, five men and nine women, with a median age of 58 years (range 21–65 years) (Table 2).

3.2. Main Themes. The caregivers' experiences with HaH were identified in three themes: (1) On the inside as a caregiver, (2) Variation in caregiver burden, and (3) Appreciating normality. Quotes illustrating each theme are presented in Table 3.

3.2.1. On the Inside as a Caregiver. This theme explores caregivers' commitment to facilitating HaH and their appreciation for being physically present and actively involved in the patient's care.

Overall, the caregivers were dedicated to facilitating HaH and made the necessary practical arrangements to allocate time to participate (participants' employment situation during HaH is presented in Table 2). Many enabled HaH at the patients' request, but also because they hoped it could benefit the patients' recovery by staying in a home setting accompanied by family. At the same time, many caregivers emphasised that they wanted to participate in HaH to support and care for their loved ones during HSCT, noting that following the process from home would have been far more challenging. Many expressed gratitude that HaH provided them with the opportunity to be physically present and together with the patient during the entire treatment (Table 3, Q1 and Q2). Several contrasted this with their experiences during hospital stays, where they were limited to shorter visits, and despite maintaining contact through telephone and video calls, they found it difficult to understand what the patient was going through. Conversely, by being physically present in HaH, the caregivers observed directly the aftereffects of HSCT, gaining better insight and understanding of the patients' experiences. Additionally, many appreciated that living together allowed them and the patient to share their experiences and struggles, as well as provide better support and care for each other (Table 3, Q3–Q5).

Many caregivers felt that their ability to contribute during hospital stays was limited, as the medical team managed the primary care responsibilities. The caregivers experienced being more actively involved in HaH, appreciating having a defined role and specific tasks. One participant explained that this made her feel included in the 'care team,' working collaboratively with the physicians and nurses. Several caregivers emphasised that being physically present allowed them to care for the patient more effectively and attend to their needs. Additionally, many highlighted that the privacy offered in HaH enabled them to provide better emotional support and comfort, engage in undisturbed conversations and show affections and intimacy (Table 3, Q6 and Q7).

3.2.2. Variation in Caregiver Burden. This theme explores variations in caregivers' involvement in patient care, experiences of distress and coping strategies.

All caregivers felt well prepared for their tasks. Many mentioned being encouraged by the medical team to allow the patients to perform everyday activities, such as cooking and housecleaning, to stimulate physical activity. While many caregivers initially collaborated with the patients on these tasks, all eventually took over some or all of them as side effects increased. However, the caregivers reported varying levels of involvement, depending on the patients' individual needs. Some noted that the patients were able to care for themselves, requiring minimal assistance, while others experienced that the patient relied on substantial assistance. However, most caregivers mentioned needing to take the initiative and, at times, persuade the patient, who were reduced by fatigue, to engage in physical activity. Additionally, all caregivers described encouraging and motivating the patients, as well as preparing meals to ensure adequate nutritional intake to remain in HaH. Some caregivers, particularly those with minimal involvement, claimed not finding the stay or their responsibilities to be demanding or exhausting. Interestingly, this sentiment was also shared by many who reported providing substantial assistance

Table 1: Example of the analytical process.

Codes	Preliminary categories	Identified theme
Wanted to be present during the long treatment It would have been worse, stressful and terrible not being there Tougher not being there, I wanted to be with the one I love	Devoted to enable and participate	On the inside as a caregiver
Opportunity to live and be together while patient is undergoing treatment Cannot be close or support the patient when they are hospitalised Different impression being present than just talking on Skype Being together, gained understanding of what the other is going through	Physical presence facilitated the ability to support, care, and comprehend	
Taking care of the patient: Comfort, talk, help, provide care Being there means a lot—to encourage and look after You do not provide care in the hospital in the same way Positive to motivating and helping her	Actively involved in providing care	

Table 2: Participants' characteristics.

	$n = 14$
Gender	
Male	5
Female	9
Age median (range)	58 (21–65)
Relationship status to patient	
Wife	4
Husband	3
Partner (female)	2 (2)
Parent (father/mother)	4 (1/3)
Child (male)	1 (1)
Education (highest)	
High school	4
Collage/university 3 years	5
Collage/university ≥ 5 years	5
Attendance in hospital at home	
Alone	10
Shared with second caregiver	4
Hospital at home facilities	
Own home	3
Department-provided apartment	10
Borrowed apartment from family	1
Employment situation during HaH	
Retired/disabled/out of work	3
Student	1
Full-time	2
Partially on sick leave during HaH	2
Full sick leave	2
Leave with pay/unpaid/vacation	4
Interview	
In person	4
By phone	10

(Table 3, Q8–Q10). Nevertheless, others found the caregiving role challenging. Two male and four female caregivers reported mental and physical exhaustion during and after HaH, explaining that much of their time was spent caring and monitoring the patients. Some female caregivers also acknowledge neglecting their own well-being, particularly their nutritional needs (Table 3, Q11). Several caregivers expressed a need for breaks during the stay. At the same time, some found that work, visits from family and friends, and activities like listening to music or knitting, helped them to disconnect. Four participants attended HaH with a second caregiver and valued sharing responsibilities and having the possibility to leave the home. Several also mentioned intentionally going for long, fast walks during the nurses' visits to take care of themselves and ventilate from the situations (Table 3, Q12 and Q13).

3.2.3. Appreciating Normality. This theme explores caregivers' appreciation for preserving a sense of normality in a home environment.

Although the caregivers found that the circumstances and the patient's condition defined the time in HaH, all appreciated the resemblance of living an almost normal everyday life, with the ability to maintain familiar routines. Many emphasised that this contributed to a sense of normality. Spouses and partners of the patients valued sharing their familiar daily life together, in contrast to the unfamiliar experiences of living apart during hospital stays. The four caregivers who had the opportunity to work remotely appreciated maintaining close-to-normal work routines. Overall, all caregivers valued relaxing in their homes or a homelike environment, being grateful for the avoidance of stress and time spent commuting to visit the patients, as they would have during hospital admissions (Table 3, Q14 and Q15).

4. Discussion

Our study explored informal caregivers' experiences with HaH following HSCT and found that they highly valued the opportunity to be physically present and involved in the patient's care. While caregivers had to take an active caregiving role, they reported varying levels of involvement and distress. All caregivers appreciated the sense of normality afforded by HaH, emphasising maintaining aspects of a familiar daily life.

The family caregivers highlighted that being physically present in HaH enabled them to be there for the patient while also gaining a better understanding of what the patient was going through, in contrast to when they were hospitalised. 'Being present' is central to the interpersonal aspect of both caregiving and care receiving [27, 28]. The appreciation expressed by our caregivers suggests that HaH may provide caregivers with the opportunity to be on the 'inside', sharing the patient's treatment journey, rather than feeling 'outside' and disconnected, as they may during hospitalisation.

A significant finding, mirroring the observation by Wilson et al. [12], was that the caregivers desired to support and care for the patient during HSCT. Other studies similarly report that caregivers found meaning in facilitating HaH to be with and care for their relatives [29, 30]. A natural desire to care for others lies in the concept that caregiving is essentially a moral and fundamental human practice [27, 31, 32]. The motivation to provide care can arise from external influences, such as social expectations or sense of obligation, or internal influences related to personal choice, emotions and a sense of usefulness [33, 34]. Given the reliance on informal caregivers to facilitate home-based care models, as highlighted in our study, caregivers may feel a sense of obligation to participate. Williams [35, 36] identified commitment as a source to caregiving, characterised by enduring responsibilities grounded in love or obligation, prioritising the patient and their well-being. This aligns with our findings, suggesting that an internal and natural desire to support and care for relatives during illness and treatment motivates caregivers to participate in HaH.

Consistent with the findings of Bergkvist et al. [20], caregivers reported having an active role in HaH. Furthermore, our caregivers valued the defined role and tasks, which enhanced their sense of inclusion in the 'care team' alongside the medical team. A recent study reported that family caregivers to HSCT patients felt they were a necessary yet invisible part of the care team, receiving little acknowledgement for their contribution and limited attention

Table 3: Participants quotes illustrating each theme.

Quotation number	Theme 1: on the inside as a caregiver
Q1	IC6, son: It has meant a lot to me that I was able to help her because that it is what I wanted. I want her to get better, and if she needs help, I will be there to assist her. I felt I could do that better in 'hospital at home', especially when it came to supporting her and being there for her.
Q2	IC8, father: I am very glad that I was able to be there and did not bring work with me. I made an important priority, and it was only a few days, but so important. (If his son had been admitted in hospital for the entire treatment) [. . .] It would have been awful. I would have felt sick to my stomach all the time. Even though I would have been there, I would not have been there, because I would have just visited him at the hospital for a few hours every day.
Q3	IC9, mother: [. . .] It would have been worse, and I would have been much more worried and anxious if I had not been there. I am very glad that I was able to be there and be close. We had daily contact on FaceTime with those at home because they wanted to know how it was going, but I did not have to be the one to call because I was there, so I did not have that worry because I knew what we were facing in that moment.
Q4	IC4, husband: It has been quite interesting because I gained a different impression of the entire process. Instead of just seeing her on Skype and talking to her, I had a closer look and experienced the whole process firsthand. It is a tough journey she has gone through, and I got a completely different impression and gained a better understanding of what she has gone through. [. . .] I feel I have benefited from this because, instead of simply asking, 'Oh, are you feeling unwell?', I now understand why and have gained insight into how seriously ill she has been.
Q5	IC13, wife: It has meant a lot because you see what your partner is going through. As a caregiver, when your partner is hospitalised and tells you, 'No, everything is fine', you know them well enough to recognise whether things are fine or not. I have been with him the whole illness process, and he has also immediately noticed if I have been upset. It has been very important for the relationship and for us, and that we have been in this together. He is the one who has been sick and got this disease, but we have been in this together.
Q6	IC7, mother: There should be a system in hospitals to give caregivers a defined role, but there is not. [. . .] luckily, we are allowed to visit, but at other hospitals there are visiting hours [. . .] and that makes you feel like you are a bit in the way. What was so great about 'hospital at home' was that we were given a role and responsibilities, and then we no longer felt like we were in the way.
Q7	IC11, wife: It has meant a lot to me because I felt that I was contributing and helping him. When he is in the hospital, others take care of him, so as a caregiver you do not do much beside provide support. In the apartment I did things for him and took care of him, so I felt like I was contributing with something.
	Theme 2: variation in caregiver burden
Q8	IC12, husband; There was little for me to follow up other than being present. She took care of herself [. . .] I did not feel it as a heavy responsibility, but that was also because she was quite fine and functioning well.
Q9	IC1, husband: I had to try to get her to take pills and to eat. Getting her to understand that she needed to drink and get nutrition, so I became a bit of a nag. Even though she understood that I did it with good intentions, I had to do it in a calm way, but it was difficult sometimes. The worst part was food and drink [. . .] it required patience.
Q10	IC14, mother; [. . .] They said that he should manage everything on his own, and that I should be there as an observer, but that was not the case because he could not have managed to be on his own. He was far too weak and tired. He was not taking care of himself. I was not just an observer, but it was not a problem, but he could not have been there alone.
Q11	IC3, wife: I did not think about myself [. . .] when he did not eat I did not eat either. I would eat chocolate and unhealthy things as a convenient solution. I did not think about myself, like taking a shower, I would do that when he was asleep. So yeah, I adapted everything to his needs.
Q12	IC6, son: [. . .] I started to feel tired. I was a bit exhausted. It was nice that my father came so that I did not have to be there alone, so that someone else was there too. It was good to not be there alone all the time.
Q13	IC5, wife: I was dependent on that walk every day and it was an important part of the day because it allowed me to recharge and get energy to be there, and be the person I wanted to be for him.

Table 3: Continued.

	Theme 3: appreciating normality
Q14	IC5, wife: [. . .] It normalised the situation we were in, which was not normal, but we still felt the positive aspect of being able to cook together, eat and be in the same room, where he read and I knitted, things that took us back to the normality of what we have at home.
Q15	IC10, wife: [. . .] you feel like you must visit, but it is exhausting living far away [. . .] I had to be there for a few hours when I first came to visit, and then the whole day would go by. When I came home, I would think about all the things I needed to do, but I felt so drained after spending the day in hospital. Therefore, I would rather bear that burden at home instead of driving back and forth visiting him.

to their own needs [21]. Family caregivers are a valuable resource, possessing both knowledge of and a close relationship with the patient, which may enhance the quality of care provided [35]. Actively involving family caregivers and establishing a collaborative relationship in both the HaH and hospital settings could benefit not only patients and the medical team but also improve the caregivers' sense of acknowledgement and inclusion as an active and integral resource in the patient's treatment journey.

HaH models have been criticised for potentially placing an inappropriate burden on informal caregivers by requiring them to take an active role in patient care [37]. Research have demonstrated that caregivers do indeed assume an active role in such settings [19, 21, 30, 38, 39]. Our findings align with this, but also shows that our participants experienced varying levels of involvement in the caregiving role. HSCT patients are expected to develop treatment-related side effects and thus require assistance, but often in an unpredictable and shifting manner [40, 41]. Caregivers of haematological patients encounter a range of unanticipated events and must remain flexible as their tasks and responsibilities shift in response to the patient's clinical changes [11, 21]. This can explain our findings and suggest that caregivers participating in HaH should be adequately prepared and have realistic expectations regarding the demands they may encounter, the potential distress and the evolving nature of their tasks and responsibilities.

Family caregivers report experiencing distress and exhaustion during and after HaH [19, 38, 39], as demonstrated in our study. Caregivers of haematological patients report difficulties in maintaining self-care and balancing their own needs with those of the patient [10–12, 42]. Our findings suggest that these types of sacrifices and challenges may persist in HaH. Ko et al. [29] observed that sharing caregiving responsibilities among family members was common, and consistent with Jenkelowitz et al. [19], we found that caregivers valued the opportunity to take breaks, disconnect and prioritise self-care during HaH. These insights highlight the necessity for healthcare professionals to provide follow-up support for HaH caregivers, with particular attention to the risks of caregiver burden and burnout, while recognising that HaH itself may contribute and increase stress levels.

In alignment with findings from other studies, caregivers found living with the patient more convenient, as it eliminated the need to commute to the hospital [29, 30, 39]. Additionally, as previously reported, our caregivers valued the sense of normality and ability to maintain a more familiar, everyday routine [19, 20, 29, 39, 43]. These findings suggest that HaH may reduce some level of stress and reduce disruptions in the lives of family caregivers.

4.1. Limitations and Strengths. With an awareness that our clinical experiences in haematology, HSCT and working with this caregiver group introduce personal bias, we consistently maintained a reflexive attitude [23] throughout the study, particularly during data analysis, critically reflecting on our assumptions, interpretations and understanding. Telephone interviews offered flexibility to interview caregivers for whom in-person interviews were not feasible. However, the lack of face-to-face interaction and the absence of non-verbal communication, such as facial expressions and body language, which are essential components of communication [44], may have constrained our understanding of participant's descriptions and emotions, potentially affecting data quality. Through conscious awareness of these limitations, we carefully engaged in active listening and strategically used follow-up questions to ensure that, despite conducting telephone interviews, we obtained rich and detailed data.

We acknowledge that our participants represent a selected group of family caregivers who willingly participated in HaH. Additionally, their experiences are specific to the HSCT setting at a single transplant centre, which may not fully reflect the experiences of all informal caregivers, thereby limiting the generalisability of our findings. Nonetheless, a strength of our study lies in the participants' detailed descriptions, which provided valuable insight into and a deeper understanding of their commitment to HaH and their experiences with the caregiving role in this context, as well as in the traditional hospital setting. We believe our findings hold transferable value for other healthcare services and HaH models, offering important insight into this innovative approach to healthcare delivery.

5. Implications for Clinical Practice

Informal caregivers play a crucial role in HaH, potentially easing pressure on healthcare systems. The findings demonstrate aspects that should be considered when implementing HaH to ensure well-being and support of caregivers. Caregivers should receive structured guidance, including clear information, adequate training on how to

effectively support patients, and be prepared for varying levels of involvement based on the unpredictability of the patients' health condition. To ensure their well-being, healthcare professionals should provide follow-up support during and after HaH to help caregivers navigate challenges and process stressful experiences. Encouraging multiple caregivers to share responsibilities, especially during critical periods, may reduce burnout and allow for self-care.

In hospital settings, healthcare professionals should actively integrate caregivers into the treatment process through structured involvement plans to enhance their sense of inclusion, and recognise them as a valuable resource in the patient's recovery journey. Future research is needed to explore caregivers' experiences within the hospital setting in order to gain a better understanding of their needs and optimise the support offered to them in this setting.

6. Conclusion

Our study found that HaH provided family caregivers of HSCT patients with the opportunity to be physically present and involved in the patient's care, experiencing a sense of being 'on the inside' and closely sharing the patient's treatment journey, in contrast to during hospitalisation. While most caregivers had to undertake an active caregiving role, they reported varying levels of involvement and distress. Caregivers valued the sensation of normality offered by HaH, highlighting that maintaining a familiar routine in a home setting resulted in less exhaustion compared to traditional hospital care. These findings suggest that healthcare professionals should adequately prepare caregivers for their roles, including the potential demands and associated distress, and provide ongoing support and follow-up care to the caregivers during and after HaH. Studies on the long-term impact of the caregiving burden in haematology are warranted. Longitudinal qualitative studies could shed light on caregivers' mental and physical health, and well-being over time. Investigating factors that contribute to positive caregiving experiences may help identify elements that promote personal growth, emotional rewards and a sense of fulfilment that may arise from the caregiver role.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Conflicts of Interest

S.C.T.S., H.S.W., G.E.T., T.G.-D. and A.E.M. are employees at the Department of Haematology, Oslo University Hospital. The other author declares no conflicts of interest.

Author Contributions

All authors designed the study. S.C.T.S. was responsible for data collection, analyses and writing of the original manuscript. H.S.W., L.F. and A.E.M. contributed to supervision, and A.E.M. was project administrator. G.E.T. and T.G.-D. contributed to resources, project administration, and funding. All authors edited, read and approved the final manuscript.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.
Supporting Information 1. Checklist-standards for reporting qualitative research.

Supporting Information 2. Interview guide.

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