



Research

“It’s the Ride of Your Life”: A Qualitative Study on Survivor Awareness and Understanding of Blood and Marrow Transplantation

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ABSTRACT

Objective: This paper describes blood and marrow transplantation (BMT) survivors' and carers' knowledge and understanding of BMT and long-term care requirements.

Methods: Semistructured, online interviews with 22 BMT survivors and 6 carers were used to collect qualitative data. Interviews were audio-recorded, transcribed verbatim, and analyzed using thematic analysis.

Results: Findings indicate the diversity of information and education received by survivors, the importance of timing in the delivery of information, and the need to provide education as an ongoing intervention in the long-term care provided.

Conclusions: The health, psychological, and functional status of BMT survivors is significantly improved by the provision of better education, understanding, and decision-making around their long-term care. Many survivors lack a good understanding of the BMT process, the late effects of BMT, and the need for and mechanism of long-term follow-up. As the number of BMT survivors increases over time, improvements in how and where education and support are provided need to be addressed to ensure adherence to recommended long-term follow-up requirements.

Implications for Nursing Practice: Nurses who work with BMT survivors should continuously reassess survivors' knowledge and understanding of their condition and provide person-centered education and resources to assist learning and treatment adherence throughout the transplant journey. Further research is necessary to explore the validity and processes of consent for BMT and establish the best model of care for long-term follow-up and education.

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Blood and marrow transplantation (BMT) is a complex medical procedure in which stem cells are used to repopulate the

hematopoietic system in patients after conditioning chemotherapy and/or radiotherapy has been administered.¹ BMT can either be autologous, where the recipient is transplanted with their cells, or allogeneic, where the recipient is transplanted with cells from another person.¹ For many patients, BMT provides the only option for long-term survival. However, survivors face serious long-term medical and psychological challenges that may impact quality of life and

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Layperson Summary

What we investigated and why

People who have received a blood and marrow transplant (BMT) require lifelong follow-up to monitor for long-term and late issues and optimize health and wellness. This study sought to investigate the experience of BMT survivors and their carers with long-term care to explore their understanding and identify what works well and areas that could be improved.

How we did our research

We undertook semistructured interviews with 22 BMT survivors and 6 carers of BMT survivors via video conference.

What we have found

We found varying levels of knowledge and understanding among the participants about long-term care needs. There were differences in how much information and resources each participant recalled receiving and how they engaged with the resources provided. The study highlighted challenges in providing information at the right time for participants.

What it means

BMT survivors are at risk of a range of late side effects and long-term health issues as a result of the BMT procedure. Given the inconsistency in understanding about and knowledge of best practice long-term care, there is a need for ongoing education to support the well-being of BMT survivors. Ensuring that the importance of long-term follow-up is regularly reinforced is vital to optimising long-term outcomes. As more people undergo BMT, survive the procedure and live longer, there is an increasing risk of loss to follow-up. This study highlights the need to explore models of care to ensure that ongoing support and education reinforce long-term care needs in this population.

each year,³ growing pressures are placed on tertiary centers and their resources. Establishing effective models for long-term care is, therefore, essential to optimize health outcomes by reducing and managing potential complications among BMT survivors.

The key to ensuring effective long-term care is empowering and educating survivors to appreciate the importance of long-term follow-up and understand its benefits.⁹ While BMT recipients are provided with a range of information about the BMT process during the acute and postacute phases,⁹ information and education about longer-term considerations and care needs varies considerably.⁸ Issues such as health literacy, survivor preferences for long-term care, and difficulties in engaging survivors who are experiencing poor emotional or psychological well-being post-BMT are also confounding factors that impact survivor motivation to participate in long-term recovery.^{7,10}

Clinical guidelines for the delivery of long-term care following BMT have been available internationally for over a decade.¹¹ However, there is still limited research in Australia relating to survivors and their carers' preferences for models of long-term care and the effectiveness of current long-term care practices. A larger study sought to explore these complex issues. This report describes BMT survivors' and carers' knowledge and understanding of the BMT process. Given the volume of data, other aspects of the larger study, such as roles and relationships with health professionals following BMT and barriers and preferences for long-term care are described elsewhere.¹²

Methods

Study Design

A qualitative descriptive study was conducted from December 2021 to March 2022. This approach facilitated in-depth exploration of participants' views and experiences. This paper was developed based on the Consolidated Criteria for Reporting Qualitative Studies (COREQ)¹³ checklist.

Setting and Participants

Survivor participants were recruited via the BMT databases of two hospitals in NSW, Australia, with established BMT programs. Inclusion criteria included English-speaking adults (aged >18 years) who were in remission, had undergone BMT more than 12 months earlier, and were not experiencing other life-limiting health issues. Purposive sampling was used to ensure representation from those living in metropolitan, regional, and rural areas. When BMT survivors indicated interest in participating, they were asked whether they agreed to provide their carer with information about the study. Carers who were interested in participating in the study were then able to contact the researchers if they wished to participate.

Data Collection

Semistructured interviews were conducted online using an interview schedule and prompts to elicit necessary information. This approach allowed sufficient flexibility to guide the interview while also considering and exploring issues raised by the participant. Interviews commenced by capturing demographic data, including gender, residential location, age, and transplant type. Interview questions then explored survivors' perceptions and preferences regarding long-term care, their understanding of the process of long-term follow-up following BMT, and their experiences and thoughts about shared long-term follow-up in primary care. Interviews also explored perceived barriers and facilitators in receiving long-term follow-up care in tertiary or primary care settings. The interview schedule was

decrease life expectancy. Consequently, prevention, diagnosis, and management of late effects of BMT are crucial to improving long-term outcomes.²

Patterns of BMT activity, BMT survival, and issues with BMT long-term follow-up in Australia mimic international trends.³ In Australia, BMTs are performed only in selected major urban tertiary centers with the necessary expertise, training, and resources. BMT recipients living in rural and regional areas must relocate to metropolitan areas for the transplant period and immediate follow-up.⁴ Despite the importance of post-transplant care and ongoing follow-up, large variations in the organization, delivery, and quality of long-term follow-up have been reported.^{4,5} Limitations in dedicated staffing, data management, and resources also have resulted in reliance on individual clinicians rather than a team of experts to provide long-term follow-up, which best meets the diverse and complex needs of BMT survivors.⁶ The treatment burden experienced following BMT is complicated by difficulties with access to and cost of appropriate specialist services, fragmentation of care, poor communication, and the need to navigate a complex healthcare system.^{4,6,7} Some survivors even report not being advised of the need for long-term follow-up.⁸ These factors contribute to some survivors being lost to the system, especially as more time passes since the BMT.⁴ As a consequence, many BMT survivors do not receive the comprehensive care they need to optimize their health, resulting in large variations in long-term outcomes.^{1,8} As increasing numbers of BMT are undertaken

pilot-tested, and minor adjustments were made to improve the clarity of questions and prompts. All interviews were conducted online. The timing and location of the interviews were determined by mutual agreement and participant preference. To ensure confidentiality and individual perspectives, survivors and carers were interviewed separately.

Each interview was conducted by 1 of 5 registered nurse interviewers who were experienced in cancer and hematology nursing. Participants were recruited until the interviewers felt no new information was being revealed and data saturation had been achieved. All interviews were audio-recorded, and the interviewers kept field notes.

Data Analysis

Audio-recordings were transcribed by a professional transcription company before transcripts were uploaded to NVivo Version 14 (QSR International Pty Ltd, 2014). Inductive thematic analysis, as described by Braun and Clarke,¹⁴ was used to guide the analysis. Initially, the transcripts were read and reread to gain familiarity with the data. Following this, two researchers generated the initial codes. These codes were then discussed and refined by combining them into themes. Consistent with the methods described by Braun and Clarke,¹⁴ analysis then involved (1) familiarization with the data, (2) generation of initial codes, (3) refinement of codes and combining them into themes, (4) revising and reviewing themes until consensus was reached, and (5) naming and definition of themes, followed by (6) production of the report.¹⁴

Ethics

Approval was gained from the Human Research Ethics Committees of the South Western Sydney Local Health District (Approval No. 2022/ETH01503) and the University of Wollongong prior to study commencement. All participants were provided with study information and advised of their rights to choose whether they participated in the study.

Rigour

The Lincoln and Guba¹⁵ criteria of credibility, dependability, confirmability, and transferability were used to demonstrate rigor. Checking of transcripts and researcher debriefing demonstrated credibility. Dependability was demonstrated via an audit trail that documented decisions around study conduct. The research team's reflections during the project support confirmability. Transferability was demonstrated by providing thick descriptions that allow evaluation of the application of findings to different contexts.

Results

Twenty-two BMT recipients and 6 carers participated in the interviews (Table 1). Six (27.2%) recipients had received their transplants 5 or more years before interview. Just over half (n = 12; 54.5%) of participants were from metropolitan locations, and 59.1% (n = 13) had had an autologous transplant.

Three subthemes were developed from the major theme, *patients' and carers' knowledge and understanding of the BMT process*. (1) *Patient education and information* describes the information and resources that survivors received during their transplant journey. (2) *Understanding long-term follow-up* focuses on the participants' understanding of their long-term care. Finally, (3) *seeking their own information* reflects on the participant's ownership of seeking resources to support their long-term care.

Table 1
Demographic Characteristics

	Survivors		Carers	
	n	%	n	%
Age: Mean, \pm SD, Range	58.3 \pm 12.8	(30–80 y)	56.3 \pm 10.15	(40–65 y)
Gender				
Male	18	81.8	2	33.3
Female	4	18.2	4	66.7
Location				
Metropolitan	12	54.5	2	33.3
Regional	7	31.8	2	33.3
Rural	3	13.6	2	33.3
Disease				
Multiple myeloma	9	40.9		
Acute myeloid leukemia	5	22.7		
Non-Hodgkin lymphoma	6	27.3		
Other	4	18.2		
BMT type				
Autologous	13	59.1		
Allogeneic	8	36.4		
Both	1	4.5		
Allogeneic donor (n = 9)				
Related	6	66.7		
Unrelated	3	33.3		
Years post BMT				
\leq 2 years	12	54.5		
> 2 to < 5	4	18.2		
\geq 5 years	6	27.3		

Patient Education and Information

There was significant variation in participants' experience of the education and information received. Several participants indicated that they received comprehensive information about the BMT procedure, potential side effects, and long-term care before and soon after the transplant. This included details about available resources, the importance of vaccinations, and self-care tips. They described how this information was delivered verbally and via written materials, mainly by transplant coordinators and nurses in the BMT centers. Some participants also reported being advised to consult their general practitioners (GPs) for nonurgent concerns. Overall, many participants reported feeling well-informed and satisfied with the information they received at the time of their transplant.

Yeah, basically, they told me about the side effect, told me it may work, may not work. It doesn't work in every patient, with me it did... They told me what to expect and all that stuff like that, and that was pretty good. And yeah, how to look after myself and to do all that sort of stuff, and yeah, it was pretty good (P206).

The doctor has explained, the nurse XXXX has explained to me also. And also some tips on what to do... And also the disadvantages, the disease side effects, of the high dose chemo (P305).

A lot of it was verbal... I had phone numbers that I could ring if I had any questions (P301).

In contrast, other participants reported not understanding what was happening to them and described a lack of explanation from health professionals about both their immediate and ongoing care:

I don't have a great understanding. I just sort of catch up with my doctor and just sort of see what he says (P201).

I didn't know what I was supposed to be doing even though it says it all in the brochure (P309).

I've got no understanding of it at all (P303).

Carers noted that during the early recovery period, the altered cognition of the BMT survivor impacted their ability to understand the information provided:

His cognition was certainly affected in those first few months when he was feeling really crook and steadily getting worse. His level of understanding wasn't what it normally is. It's back there now, but it wasn't when he was unwell (C201).

I do remember at some point through the process, sending him [carer's partner] [to the specialist] with a list of questions, though... I do remember at one point going "Here's the list of questions you need to ask today, because this is the stuff that we've been thinking about." Because otherwise he'd get there and he'd forget. And then we'd be like "Oh, did you ask this?" he goes "Oh, no, I forgot" (C401).

Understanding Long-Term Follow-Up

Some participants described how "a lot of it's not explained [long-term tests]. It's like wait and see, type things" (P301). While others expressed that too much information was seen as unnecessarily worrying:

I don't take anything more than a week or two at a time, just way too confronting; for me, anyway (P101).

I don't know if my challenges were because of my doctor or whether—because I read other people have probably more informative hematologists. But again, it's just her style and if it works, I guess if I don't need to worry, then I don't need to know the nitty-gritty of everything because I really don't understand all the bits and pieces... (P309).

Many participants acknowledged that they might have been given the information at the time of the BMT, however, several reported focusing on 'surviving' immediate treatment rather than contemplating the future beyond the immediate situation.

... not much has gone wrong so I haven't wanted to know too much, and there's not much you've got to know about having the stem cell except hang on and fight like hell. That's the bottom line; it's the ride of your life (P101).

Look, I don't really recall to be honest. After the transplant I was very much concerned in just getting to my two weeks, two-month segment, until I got to the stage where they started the injections to get my immune system up. And once that started going OK, I don't think I looked health-wise that far forward, I was only looking in small jumps (P205).

For others, BMT was a "very stressful and overwhelming time" (C301) and they struggled to recall the information they had received and/or acknowledged not reading it thoroughly.

I just remember before the transplant a booklet about like before transplant and I think he did receive something... I don't remember (C303).

I've got a drawer full of written material here. Like what the medications do and what the side effects could be. And what to look out for. I didn't read a lot of that because I sort of think if you get it in your mind, this can happen, do you know what I mean (P102)?

I got a pamphlet that I sort of flipped through... I sort of tried to be... ignorance is bliss. I didn't look too heavily at it at the time (P201).

As I said, we all got the booklets and paperwork, and my wife, she read up a lot of it, where I didn't. You know, I just sort of, well, no, I've got to have the treatment, I've got to get this done... I didn't read a thing on it. Maybe I did. I flicked through a few things. But I think the more I flicked, the more I looked through things, the more it upset me (P304).

While pamphlets and written information were referred to by many participants, most described not having read the materials in detail and many had long discarded the materials.

I might have [received written information]. I haven't read it. If I've got any problems, I'd rather ring someone, I'm not a bookworm. I remember the purple bag that you get, that's got all the information in that. If I did get it, I didn't read it (P302).

And there possibly was other paperwork telling me the standard post stuff. But as I said, it's two years ago, and that paperwork's long gone to the bin (P202).

Participants suggested a number of strategies to optimize adherence with long-term follow-up including a written timeline or plan, reminders and follow-up calls for appointments, and regular checks by BMT staff to ensure that patients and carers had received and understood information previously provided to them about BMT:

You're like, OK, that's [BMT] all done, and then you just think that's the end of it. So maybe just a letter later on to just reiterate. OK, this is what we need you to have at this, this, and this. And if you experience this, this, and this, then you go here, here, and here (C301).

When I got the stem cell, I got a sheet. It was like a run sheet when this is going to happen (P201).

It would have been nice for my hematologist or her department to say all right, this is your program for the next 12 months now unless something changes. But I guess they don't do that maybe? They just wait to see if anything changes in your blood when you have your next appointment (P309).

Seeking Their Own Information

Some participants described how they had been proactive in seeking out information regarding follow-up:

I also participate in webinars through the Leukemia Foundation, and they've been brilliant, spot on... I know my doctor said, "Don't do Dr Google" but sometimes you need to. You want to find more information (P301).

We get a lot of information from other myeloma websites with other patients that have sort of been through it and have been through it more than once, and you get to sort of understand. We both signed up and you read up on the patients, the people who've got the myeloma and you read their partners' what they're saying and what they have to do (C304).

Several participants described an awareness of what they or their carers could do to optimize their health and well-being in the long term, although it was not always clear where this information was obtained.

Every day I go for a walk and that's sort of my get away from the home a bit where I go walk three or four hours a day... I'll tell you something, man, the main thing is I believe that [and] the diet is very important. The mental, as in positive, mentally you've got to be positive (P204).

I'm not a fanatic, I'm not a vegetarian or anything like that... [but] we eat well... we hardly ever eat out... I prepare all the meals at home and I believe that the quality of our food has played a big role in [partner] recovery and maintaining our health (C302).

Discussion

This study demonstrates that BMT survivors and their carers frequently lack understanding about the need for long-term follow-up post-BMT despite efforts by their transplant centres to educate them about BMT. It is unclear how much of this "knowledge deficit" is because of failures in the education process, insufficiency of

educational resources, or failure to account for the challenges associated with learning complex health information in the context of serious and life-threatening illness. The fact that inadequate understanding of the importance of long-term follow-up may reduce adherence is an important finding because this misunderstanding may compromise the validity of consent during all stages of care. There is also increasing evidence that empowering survivors improves their post-transplant outcomes.^{7,16,17} Given the increasing transplant activity worldwide and the growing numbers of patients surviving and living longer, there is an urgent need to develop and test models of care to improve post-transplant education and support.¹⁸

Most participants in this study remembered receiving written and/or verbal information from health professionals at the BMT center before or immediately after their transplant. However, many described not feeling able to discuss the content within the written materials further with their health care provider at the time, and then many also discarded the resources. This suggests that an ongoing education strategy is required to ensure that the right information is given at the right time and is accessible for people to engage in when they are ready. While there is increasing use of technology to support patient education at a time that suits the user, there has been limited evaluation of this in BMT survivors.¹⁹ Future research should examine how technology could reach survivors geographically to ensure adequate follow-up and/or be provided with educational resources.

A key message from this study was the prominence of the BMT center staff in patient education and support. Few participants described receiving education or information in the post-transplantation phase or from primary care professionals. This is concerning given the nature of BMT follow-up, which includes regular reviews of survivors' quality of life and health status by multiple health professionals across various settings. Pidalact et al¹⁷ raise the importance of seamlessly integrating education into the spectrum of long-term care provided to survivors, arguing that this ultimately leads to timely identification of psychosocial needs and/or physical interventions when required to improve quality of life. This finding emphasizes that more needs to be done to develop relationships and shared care models between BMT centers and primary care practices to clarify roles and ensure that all health professionals can positively contribute to building capacity for long-term self-management among BMT survivors and their carers.

Many participants in this study expressed reluctance to seek detailed information about the trajectory after. These participants preferred to follow their treating doctors' advice on a short-term basis, rather than be anxious or depressed about what might happen. This is consistent with the findings of Fadem and Mikesell,²⁰ who described how BMT doctors were consistently challenged by the need to provide sufficient information to patients so that they were appropriately informed while ensuring that they were not overwhelmed or psychologically harmed by the information disclosed. They also highlighted the significant impact of the unpredictability of BMT outcomes and specific complications and the challenges this created for patient education.²⁰ Given that appropriate health literacy is necessary not only for ensuring treatment adherence but also for building capacity for self-management,²¹ there is a need to review current strategies for patient education and test innovative models to promote health literacy in this group.

Consistent with other studies of BMT survivors, we found that the stress experienced by survivors and their carers resulting from their disease diagnosis and/or relapse, BMT, and ongoing follow-up affected their capacity to absorb information or to want to learn more. Our findings are similar to a study by Wrona-Polańska²² of leukemia patients who received BMT, where personal resources of individuals, including a strong sense of coherence, sense of control, and positive self-esteem, were important factors impacting their capacity

to cope with the challenges of BMT and on-going care.²² They also reported that promoting a pro-health personality considerably enhanced effective stress management and, at the same time, buffered negative stress effects.²² In a separate study, Heinonen et al²³ found that lack of information about BMT was one of a cluster of stressors identified by BMT survivors that negatively affected their quality of life. In contrast, some survivors in our study stated that the availability of huge volumes of information on the internet did not relieve stress but rather exacerbated it. These findings suggest that the provision of general written information about BMT will need to be supplemented with (1) an individualized approach that best meets the needs of each survivor and their carer/s; (2) is tailored to the specific post-BMT circumstances of the survivor; (3) takes into account the survivor's social, relational, occupational and economic circumstances; and (4) is consistent with the survivor's capacity and preferences for mode of information delivery.⁷

Findings from this study indicate that participants received varying amounts of support and had differing levels of understanding of their long-term health needs. This was partly due to different organizational structures and availability of services but also reflected individual characteristics and willingness to be informed about BMT long-term care. As poor levels of understanding and unwillingness to adhere to protocols are likely to impact long-term health outcomes, there is a need to structure programs of education and individualized support across all BMT centers and primary health care services to meet the needs of increasing numbers of BMT survivors requiring long-term follow-up.

Limitations

This study has several limitations. First, although the sample size allowed data saturation to be reached and allowed the researchers to obtain a snapshot of different participants' views and experiences following BMT, it cannot be assumed that the findings of this study can be generalizable to different populations or settings. Second, the sample was located in two local health districts in a well-resourced state in Australia, with access to specialist and long-term care in metropolitan centers. Findings may have been very different for survivors living in other regions or those from priority populations, such as those for whom English is not their first language or those with socioeconomic disadvantage. Finally, most participants in this study were less than 5 years post-BMT, with over half having received their transplant in less than 2 years. A further study focusing on the long-term care of survivors more than 5 years post-BMT may reveal further considerations. Additionally, this period overlapped with the COVID-19 pandemic, which may have affected the delivery of usual care.

Conclusion

Evidence tells us that the health, psychological and functional status of BMT survivors is significantly improved by the provision of better education, understanding and decision-making around their long-term care. This study has demonstrated that some survivors lack understanding of the BMT process, the late effects of transplant, and the need for and mechanism of long-term follow-up. As both the population of BMT survivors grows and their post-transplant life expectancy lengthens, improvements in how and where education and support are provided need to be addressed to ensure adherence to approved long-term follow-up requirements and the optimization of long-term survival.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

CRediT authorship contribution statement

Gemma McErlean: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Christine Ashley:** Writing – review & editing, Writing – original draft, Formal analysis, Conceptualization. **Anisha Pradhan:** Writing – review & editing, Investigation, Data curation, Conceptualization. **Alana Paterson:** Writing – review & editing, Conceptualization. **Gai Farnham:** Writing – review & editing, Conceptualization. **Fran Owen:** Writing – review & editing, Conceptualization. **Anne-Marie Watson:** Writing – review & editing, Conceptualization. **Peter Presgrave:** Writing – review & editing, Conceptualization. **Vanessa Yenson:** Writing – review & editing, Conceptualization. **Ian Kerridge:** Writing – review & editing, Conceptualization, Supervision, Methodology, Formal analysis. **Elizabeth Halcomb:** Writing – review & editing, Conceptualization, Supervision, Methodology, Formal analysis.

References

1. Dyer G. *The Experience of Long-Term Survival Following Allogeneic Blood and Marrow Transplant (BMT) in New South Wales (NSW), Australia in Faculty of Medicine*. Sydney, NSW, Australia: University of Sydney; 2019.
2. Rotz SJ, et al. International recommendations for screening and preventative practices for long-term survivors of transplantation and cellular therapy: a 2023 update. *Transpl Cell Ther*. 2024.
3. McCaughan GJ, et al. Trends and outcomes in Australia and New Zealand in autologous stem cell transplantation in older patients with multiple myeloma: an Australasian Bone Marrow Transplant Recipient Registry Study. *Transpl Cell Ther*. 2021;27(3):S399–S401.
4. Dyer G, et al. What they want: inclusion of blood and marrow transplantation survivor preference in the development of models of care for long-term health in Sydney, Australia. *Biol Blood Marrow Transpl*. 2016;22(4):731–743.
5. Hashmi S, et al. Lost in transition: the essential need for long-term follow-up clinic for blood and marrow transplantation survivors. *Biol Blood Marrow Transpl*. 2015;21(2):225–232.
6. ACI New South Wales Centre for Clinical Innovation. *Clinical Guidelines: Blood and Marrow Transplant. Long-Term Follow Up*. Sydney, NSW: Agency for Clinical Innovation; 2016.
7. McErlean G, et al. Long-term treatment burden following allogeneic blood and marrow transplantation in NSW, Australia: a cross-sectional survey. *J Cancer Surv*. 2022;16(2):432–444.
8. Dyer G, et al. Adherence to cancer screening guidelines in Australian survivors of allogeneic blood and marrow transplantation (BMT). *Cancer Med*. 2016;5(7):1702–1716.
9. Armato K, Weisbrod B. BMT patient education: consistency and understandability in a complex population; creating a standardized patient education process for blood and marrow transplant, a single institution experience in an academic medical center. *Biol Blood Marrow Transpl*. 2019;25(3): S83–S83.
10. Amonoo HL, et al. Beyond depression, anxiety and post-traumatic stress disorder symptoms: qualitative study of negative emotional experiences in hematopoietic stem cell transplant patients. *Eur J Cancer Care*. 2020;29(5):e13263.
11. Majhail NS, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation. *Bone Marrow Transpl (Basingstoke)*. 2012;47(3):337–341.
12. McErlean G, Ashley C, Pradhan A, et al. A qualitative study on blood and marrow transplant recipients' perceptions of health professional roles following BMT and preferences for ongoing care. *J Cancer Surviv*. 2024. <https://doi.org/10.1007/s11764-024-01658-4>. Epub ahead of print. PMID: 39153048.
13. Tong A, Sainsbury P, Craig J. Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357.
14. Braun V, Clarke V. *Thematic Analysis: A Practical Guide*. London: SAGE Publications; 2022.
15. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Beverly Hills, CA: Sage Publications; 1985.
16. Brice L, et al. Haematopoietic stem cell transplantation survivorship and quality of life: is it a small world after all? *Supp Care Cancer*. 2017;25(2):421–427.
17. Pidala J, Anasetti C, Jim H. Health-related quality of life following haematopoietic cell transplantation: patient education, evaluation and intervention. *British journal of haematology*. 2010;148(3):373–385.
18. Majhail NS, et al. National Survey of Hematopoietic Cell Transplantation Center Personnel, Infrastructure, and Models of Care Delivery. *Biol Blood Marrow Transplant*. 2015;21(7):1308–1314.
19. Nascimento AAdA, et al. Educational technologies used to teach self-management after hematopoietic stem cell transplantation: a scoping review. *Texto Contexto-Enfermagem*. 2023;32: e20220170.
20. Fadem S, Mikesell L. Patient and provider perspectives on the impacts of unpredictability for patient sensemaking: implications for intervention design. *J Patient Exp*. 2022;9: 23743735221089460.
21. Papadakos JK, et al. Health literacy and cancer self-management behaviors: a scoping review. *Cancer*. 2018;124(21):4202–4210.
22. Wrona-Polańska H. Subjective health and its predictors in leukaemia patients after bone marrow transplantation. *Contemp Oncol (Poznań, Poland)*. 2023;27(2):90–94.
23. Heinonen H, et al. Stress among allogeneic bone marrow transplantation patients. *Patient Educ Couns*. 2005;56(1):62–71.