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Lived Experiences of Patients after Peripheral Blood Allogeneic Hematopoietic Stem Cell Transplantation: A mixed-method study

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ABSTRACT:

Background: Recovery after allogeneic peripheral blood stem cell transplantation (PBSCT) is often evaluated through clinical endpoints, yet survivors also manage persistent bodily, emotional, family, and financial challenges after discharge. This study explored the lived experiences and supportive care needs of adult PBSCT survivors in Egypt. Methods: A qualitative-dominant exploratory mixed-method design was used in hematology and bone marrow transplantation outpatient clinics. Sixty adult survivors completed a demographic and clinical data sheet to contextualize the sample. A purposively selected subsample of 20 survivors completed three qualitative contacts: one in-person interview and two follow-up telephone calls. Interviews were audio-recorded, transcribed verbatim in Arabic, translated for reporting, thematically analyzed, and interpreted alongside descriptive findings. Results: Participants were 19-55 years old (mean 38.6 +/- 9.2); 56.7% were male, 66.7% were married, 63.3% reported inadequate income, and 45.0% reported post-transplant complications. Six themes were identified: living in a fragile body; uncertainty as a daily companion; rebuilding life and roles; coping through meaning and discipline; support gaps and financial strain; and the healthcare relationship. Conclusion: Post-PBSCT survivorship was clinically and socially complex. Follow-up care should extend beyond complication surveillance to include fatigue assessment, symptom guidance, family-inclusive support, financial awareness, culturally meaningful coping, and clear communication pathways.

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Figure 1. Graphical abstract summarizing the study context, survivorship experiences, and supportive care needs.

1. INTRODUCTION

Peripheral blood allogeneic hematopoietic stem cell transplantation (PBSCT) is commonly evaluated through biomedical endpoints such as engraftment, relapse, graft-versus-host disease, treatment-related complications, and survival. These outcomes are indispensable, yet they do not fully describe what it means to live after transplantation. For many survivors, discharge from intensive transplant care does not mark the end of vulnerability; it begins a prolonged period in which the body feels altered, ordinary symptoms become emotionally charged, and daily life must be rebuilt under persistent uncertainty. Recent qualitative evidence confirms that allogeneic hematopoietic stem cell transplantation survivors often experience fatigue, disrupted self-image, fear of relapse, social withdrawal, altered roles, and difficulty reconstructing normal life after treatment (Almutairi et al., 2025; Ruan et al., 2024, 2026).

This survivorship reality has direct relevance for transplant nursing and supportive follow-up care. Post-transplant follow-up is not limited to detecting complications or reinforcing medication schedules. It also requires interpretation of symptoms, psychological containment, family-inclusive education, and sustained support for self-management. Contextual analyses of follow-up after allogeneic hematopoietic stem cell transplantation have emphasized that survivors and clinicians need care pathways that respond to practical, informational, emotional, and digital support needs (Leppla et al., 2020). Broader nursing literature similarly highlights that education and patient engagement are central to helping individuals participate safely in self-management and survivorship decision-making (Oakley and Ream, 2024).

The Egyptian post-transplant context deserves particular attention. Outpatient survivorship may unfold within households affected by travel costs, medication expenses, income disruption, dense family involvement, and variable access to continuous nursing support. In such settings, recovery is not simply a biological trajectory; it is negotiated through economic capacity, family protection, spiritual meaning, and the quality of communication with healthcare professionals. Although international studies have increasingly addressed transplant survivorship, patient-centered evidence from Middle Eastern and North African outpatient settings remains limited. A recent Saudi qualitative study underscored the multidimensional nature of adult survivorship after hematopoietic stem cell transplantation (Almutairi et al., 2025), but Egyptian patients may experience different service structures, financial pressures, and household dynamics.

To our knowledge, little is known about how Egyptian PBSCT survivors experience recovery and supportive care needs during outpatient survivorship, particularly within the social, financial, and family contexts that shape everyday life after transplantation. This qualitative-dominant exploratory mixed-method study aimed to explore the lived experiences and supportive care needs

of adult survivors after peripheral blood allogeneic hematopoietic stem cell transplantation in Egypt. Descriptive demographic and clinical data from a broader survivor sample were used to contextualize the qualitative findings; no inferential analyses or person-level comparisons were undertaken.

2. MATERIALS AND METHODS

2.1 Design

A qualitative-dominant exploratory mixed-method design was employed. The qualitative component provided the primary analytic strand because the research question focused on lived experience and supportive care needs. The quantitative component described demographic, social, and clinical characteristics of the sample and was used to contextualize, not statistically test, the qualitative findings. Accordingly, no inferential statistical testing or correlational claims were made. Reporting was informed by the Standards for Reporting Qualitative Research (SRQR) and the Good Reporting of A Mixed Methods Study (GRAMMS) principles (O'Brien et al., 2014; O'Cathain et al., 2008).

2.2 Setting

The study was conducted in hematology and bone marrow transplantation outpatient clinics affiliated with governmental and private hospitals in Egypt. Recruitment occurred in routine follow-up settings where recipients were contacted during the survivorship phase after transplantation.

2.3 Participants and recruitment

Eligible participants were adult men and women aged 18-55 years who had undergone PBSCT 1-3 years earlier, were medically stable at the time of outpatient follow-up, were alert and oriented, spoke Arabic, and consented to participate. Patients with severe graft-versus-host disease, severe infection, relapse, or significant physical or cognitive impairment were excluded because the study focused on survivorship rather than acute clinical deterioration.

Purposive sampling was used to recruit participants who could provide rich accounts of recovery after transplantation. Sixty participants completed the structured demographic and clinical data sheet. From this group, 22 survivors were purposively invited for qualitative interviews to ensure variation in sex, age, time since transplantation, and complication history. Twenty participants completed the planned three contacts and were included in the final qualitative analysis. Recruitment continued until thematic saturation was achieved, whereby no substantially new concepts or themes emerged from successive interviews. This sampling strategy prioritized depth, variation, and interpretive richness over numerical representativeness.

2.4 Data collection tools

Tool I: Demographic and clinical data sheet. This structured sheet collected personal and social data, including age, sex, marital status, education, occupation, income adequacy, number of co-residents, housing conditions, availability of a private room, ventilation, and exposure to birds, animals, or plants at home. Clinical items included diagnosis, time since transplantation, history of previous transplantation, family history of transplantation, post-transplant complications, and prior knowledge about transplantation.

Tool II: Semi-structured interview guide. The interview guide included open questions addressing perceived changes in physical and psychological health, the trajectory of recovery, quality of life, coping strategies, psychological concerns, available support, experiences with healthcare providers, and suggestions for improving post-transplant care. Optional probes were used to clarify meanings, elicit examples, and deepen participant narratives.

2.5 Data collection procedure

After obtaining institutional and administrative approvals, eligible participants were approached individually during outpatient follow-up visits. Recruitment took place after the clinical encounter or during waiting periods to avoid disrupting care. The study was conducted in Arabic. Written informed consent was obtained before participation.

For the qualitative subsample, data collection occurred over three contacts. The first contact was conducted in person in the outpatient clinic, where the structured data sheet was completed and the first interview was undertaken in a private area whenever feasible. Two follow-up telephone calls were then conducted to clarify meanings, explore additional experiences remembered after returning home, and allow participants to speak more openly about issues that had not emerged during the

clinic-based interview. Interviews lasted approximately 30-60 minutes, were audio-recorded with permission, and were transcribed verbatim in Arabic. Field notes were maintained during data collection and were used to support interpretation of interview data. Quotations selected for reporting were translated into English with attention to conceptual equivalence rather than literal word-by-word translation.

2.6 Trustworthiness and reflexivity

Several strategies supported qualitative rigor. Repeated contact with participants allowed clarification and elaboration of earlier accounts. Audio recording and verbatim transcription preserved the participants' wording. Transcripts were read repeatedly, codes were compared across interviews, and candidate themes were discussed between the authors until a coherent thematic structure was agreed. Theme development was checked against the transcripts several times to ensure that the final interpretation remained grounded in the data. The authors also reflected on their clinical nursing backgrounds during analysis to avoid reducing participants' experiences to biomedical events alone.

2.7 Pilot study

A pilot study was conducted with three participants to evaluate the clarity of the interview questions, feasibility of the interview sequence, and practicality of field procedures. These cases were used to refine the process and were excluded from the main analysis.

2.8 Ethical considerations

Ethical approval was obtained from the Faculty of Nursing, Cairo University Institutional Review Board (IRB No. 2019041701), and official permissions were obtained from the participating settings. The study was conducted in accordance with the principles of the Declaration of Helsinki. Participation was voluntary, and participants were informed of their right to refuse or withdraw at any time without consequences for their care. Study materials were coded rather than named, identifying information was removed from transcripts, and audio recordings and transcripts were stored securely. Audio recording occurred only after written informed consent had been obtained.

2.9 Data analysis and integration

Quantitative data were analyzed descriptively using frequencies, percentages, means, standard deviations, and medians with interquartile ranges where appropriate. These data were used to describe the participant group and provide context for the qualitative interpretation. They were not used for hypothesis testing.

Qualitative analysis involved repeated reading of transcripts, line-by-line coding, comparison of codes across interviews, development of categories, and refinement of themes. Integration occurred at the interpretation stage. The descriptive quantitative data clarified the personal, social, and clinical context in which the themes were expressed, while the qualitative findings explained how those characteristics were experienced in daily life. A joint display was developed to make this integration explicit.

3. RESULTS AND DISCUSSION

3.1 Recruitment and participant profile

During recruitment, 80 PBSCT recipients were approached in outpatient follow-up clinics. Sixty-eight agreed to initial screening. Eight did not meet the inclusion criteria, and four declined participation. Sixty participants provided written consent and completed the descriptive component. Of these, 22 were invited to participate in qualitative interviews; 20 completed the three scheduled contacts and were included in the qualitative analysis, while two were excluded due to incomplete follow-up.

The broader descriptive survivor sample comprised 60 adults who completed the demographic and clinical data sheet. This dataset was used to characterize the outpatient survivorship context in which the qualitative interviews were conducted. Twenty purposively selected survivors completed the three planned qualitative contacts and formed the interview sample used for thematic analysis.

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Table 1. Demographic, social, and clinical profile of the broader descriptive survivor sample (n = 60).

Variable	Category/Unit	n	% / Mean +/- SD
Age (years)	Mean +/- SD (range)	60	38.6 +/- 9.2 (19-55)
Sex	Male	34	56.7
	Female	26	43.3
Marital status	Single	16	26.7
	Married	40	66.7
	Divorced	3	5.0
	Widowed	1	1.6
Education	Illiterate	5	8.3
	Read and write	7	11.7
	Secondary/Diploma	18	30.0
	Technical institute	10	16.7
	University	20	33.3
Occupation	Not working	15	25.0
	Student	3	5.0
	Manual work	18	30.0
	Office work	24	40.0
Income adequacy	Adequate	22	36.7
	Inadequate	38	63.3
Co-residents	Median (IQR)	60	4 (3-6)
Housing type	Apartment	44	73.3
	Room	16	26.7
Private room	Yes	32	53.3
	No	28	46.7
Good ventilation	Yes	41	68.3
	No	19	31.7
Birds/animals at home	Yes	19	31.7
	No	41	68.3
Plants at home	Yes	14	23.3
	No	46	76.7
Diagnosis	AML	18	30.0
	ALL	10	16.7

	Lymphoma	12	20.0
	Aplastic anemia	6	10.0
	MDS	8	13.3
	Other	6	10.0
Time since PBSCT	1 year	18	30.0
	2 years	22	36.7
	3 years	20	33.3
Prior transplant history	Yes	6	10.0
	No	54	90.0
Family member transplant history	Yes	4	6.7
	No	56	93.3
Post-transplant complications	Yes	27	45.0
	No	33	55.0
Prior information about transplantation	Yes	33	55.0
	No	27	45.0

Notes: AML = acute myeloid leukemia; ALL = acute lymphoblastic leukemia; IQR = interquartile range; MDS = myelodysplastic syndrome; PBSCT = peripheral blood allogeneic hematopoietic stem cell transplantation.

3.2 Qualitative findings

Six interrelated themes were identified. They demonstrate that survivors experienced recovery as a prolonged, embodied, social, and relational process rather than as a single clinical endpoint.

3.2.1 Living in a fragile body

Participants consistently described fatigue, weakness, diminished stamina, and fluctuating physical capacity. Recovery was not presented as linear. Survivors moved between better and worse days, and their bodies often felt unfamiliar or unreliable. Activities that appeared ordinary to others, such as walking, climbing stairs, or completing household tasks, could become unexpectedly tiring. This bodily fragility also affected identity because participants felt that others sometimes judged them as recovered before they felt recovered themselves.

"People may think I look better, but my body is still the same. It can feel like a long journey when you walk a short distance."

"Some mornings I wake up tired before the day even starts, and that makes me feel like I am not fully recovered yet."

3.2.2 Uncertainty as a daily companion

Uncertainty was not confined to scheduled investigations or follow-up visits. Many participants described a continuing habit of monitoring their bodies for danger. A mild fever, unfamiliar pain, unusual tiredness, or an unexpected physical sensation could immediately revive fear of relapse or complications. Several participants felt that they were living in the present while mentally preparing for possible bad news.

"Any new pain makes me overthink. I do not deal with it as a simple symptom; my mind goes directly to relapse."

"Even when I am happy with my family, part of me is waiting for the next test result."

3.2.3 Rebuilding life and roles

Participants attempted to re-enter family, work, and social roles, but this process was gradual and uneven. Returning to normal life was often imagined as a sign of recovery, yet survivors encountered reduced energy, diminished confidence, and altered expectations from others. Family protection was valued, but it could also feel ambivalent if it limited autonomy or reinforced a sense of permanent vulnerability.

"I wanted to go back to my normal role at home and at work, but I realized I was returning with a different energy and a different self."

"My family was trying to protect me, but sometimes that protection made me feel that I was no longer trusted to live normally."

3.2.4 Coping through meaning and discipline

Coping combined spiritual meaning with practical discipline. Participants described prayer, Qur'an recitation, gratitude, and trust in God as sources of emotional steadiness. These spiritual resources were closely connected to daily practices such as taking medication on time, observing food precautions, maintaining hygiene, and protecting themselves from infection. In this sense, coping was not passive acceptance; it was an active routine through which survivors tried to restore control.

"What keeps me stable is remembering God, praying, and telling myself to take recovery one step at a time."

"I became very strict with my medicines, food, and hygiene because discipline gives me a sense of safety."

3.2.5 Support gaps and financial strain

Financial strain was one of the most difficult aspects of post-transplant life. Participants spoke not only about medication and investigations but also about transportation, lost income, repeated visits, and the pressure of being ill within a household already carrying economic responsibilities. Emotional support was also perceived as inconsistent. Several survivors did not primarily ask for more technical instructions; they wanted continuity, listening, and recognition that recovery remained heavy after transplantation had formally ended.

"The transplant ended, but the expenses did not end. Every visit and every medicine adds another pressure to the house."

"Sometimes I do not need advice first; I need someone to listen and understand how heavy this period feels."

3.2.6 The healthcare relationship

Participants attached strong significance to how healthcare professionals communicated during follow-up. Calm explanation, reassurance, and the opportunity to ask questions reduced anxiety, particularly around investigations and new symptoms. Conversely, fragmented instructions left some participants uncertain about what was expected, what was dangerous, and when they should seek help. The healthcare relationship therefore shaped not only satisfaction with care but also perceived safety at home.

"When the doctor or nurse explains things calmly, I feel safer and more able to manage what is happening."

"Sometimes I leave the visit with new instructions but still with unanswered questions."

3.3 Mixed-method integration

Integration of the descriptive quantitative profile with the qualitative findings showed that the main themes were not isolated narratives; they were grounded in the social and clinical conditions of the sample. Table 2 presents this integrated interpretation.

Table 2. Contextual interpretation of qualitative themes using descriptive data from the broader survivor sample.

Qualitative theme	Relevant descriptive context	Integrated interpretation for follow-up care
Living in a fragile body	45.0% reported post-transplant complications; survivors were 1-3 years post-PBSCT.	Persistent fatigue and bodily vulnerability may remain clinically

		meaningful well beyond the early transplant period.
Uncertainty as a daily companion	55.0% reported prior information about transplantation, yet uncertainty remained common in interviews.	Information before transplantation does not necessarily meet evolving survivorship needs during outpatient recovery.
Rebuilding life and roles	66.7% were married; 70.0% were working, including 30.0% in manual work.	Survivorship support should address work capacity, family expectations, and graded role resumption.
Coping through meaning and discipline	Participants described spiritual and practical routines across interviews.	Care can acknowledge faith-based coping while reinforcing safe self-management practices.
Support gaps and financial strain	63.3% reported inadequate income; repeated outpatient follow-up was required.	Financial pressure should be assessed as part of survivorship care rather than treated as a background issue.
The healthcare relationship	Participants relied on follow-up communication to interpret symptoms and risks.	Clear, calm, and consistent communication functions as a safety intervention in outpatient survivorship.

3.4 Discussion

This qualitative-dominant exploratory mixed-method study shows that adult PBSCT survivors in Egypt did not experience recovery as a simple return to normal life. Survival was essential, but it did not automatically restore bodily confidence, role continuity, financial stability, or emotional safety. Even 1-3 years after transplantation, participants described fatigue, vigilant self-monitoring, altered family and work roles, financial pressure, and dependence on the quality of follow-up communication. These findings are consistent with recent qualitative and review evidence indicating that allogeneic hematopoietic stem cell transplantation survivorship is a prolonged adaptive process rather than a discrete post-treatment stage (Almutairi et al., 2025; Ruan et al., 2024, 2026).

The first major contribution of this study is its emphasis on bodily fragility as a social as well as physical experience. Fatigue was not described only as a symptom; it changed what participants could do, how they judged themselves, and how others interpreted their recovery. This aligns with qualitative evidence showing that post-transplant survivors frequently struggle with physical limitation, changed self-perception, and difficulty resuming ordinary activities (Ruan et al., 2024; Vinette and Bilodeau, 2021). In this sample, however, fatigue was especially entangled with household responsibilities and employment concerns. Survivors were often expected to resume previous roles while still living with a body they did not fully trust.

Uncertainty was also more pervasive than an episodic fear related to investigations. Participants described uncertainty as an everyday orientation toward the body. New pain, fever, or tiredness could be interpreted through the lens of relapse or complications. This finding supports the argument that survivorship care after transplantation should include anticipatory guidance about expected symptoms, warning signs, and practical thresholds for seeking help. Without such guidance, patients may convert every bodily change into a private crisis. Contextual work on allogeneic hematopoietic stem cell transplantation follow-up similarly indicates that survivors require more continuous support for managing symptoms, information, and self-care at home (Leppla et al., 2020).

The theme of rebuilding life and roles extends existing evidence by highlighting the ambivalent meaning of family protection. Family involvement was a central source of care, but protection could also limit autonomy when survivors were treated as permanently fragile. This is particularly important in family-oriented cultures where caregiving is collective and close. Nurses can help families distinguish supportive protection from overprotection by providing realistic guidance on graded activity, infection precautions, safe role resumption, and emotional adjustment.

Coping through meaning and discipline further reflects the cultural embeddedness of survivorship. Participants used prayer, Qur'an recitation, gratitude, and trust in God to make sense of their experience, but these spiritual resources were not detached from practical self-management. They were linked to medication adherence, hygiene, food precautions, and symptom monitoring. Recent discussions of patient engagement in hematopoietic stem cell transplantation emphasize the need to position survivors as active partners in long-term care (Schoemans et al., 2024). The current findings suggest that, in culturally congruent practice, engagement may be strengthened when education recognizes both spiritual meaning and disciplined self-care as legitimate survivorship resources.

Financial strain was one of the clearest contextual findings. The descriptive profile showed that 63.3% of participants reported inadequate income, while the interviews illustrated how costs continued after transplantation through medication, investigations, transportation, and disrupted work. Financial toxicity is now recognized as a significant survivorship burden across cancer populations (Mols et al., 2020). In this Egyptian sample, financial strain did not appear as an abstract socioeconomic variable; it shaped how patients experienced follow-up, family stress, and the moral burden of illness within the household. Assessments that ignore financial strain may therefore miss a major determinant of survivorship distress.

Finally, the healthcare relationship emerged as a practical component of safety. Participants valued calm explanation, continuity, and the opportunity to ask questions. They also described leaving visits with instructions but unresolved uncertainty. This supports recent nursing literature emphasizing patient education, engagement, and communication as central elements of care rather than optional supportive activities (Marklund et al., 2025; Oakley and Ream, 2024). In post-transplant follow-up, communication may reduce distress by helping survivors interpret symptoms accurately and act appropriately.

The study's methodological contribution should be understood carefully. The quantitative strand was descriptive and contextual. It was not designed or analyzed to produce statistically generalizable conclusions. Its value lies in showing the social and clinical background against which the qualitative accounts were produced. The primary contribution is therefore interpretive and practice-oriented: it clarifies how adult PBSCT survivors make sense of recovery and what kinds of support may be needed in outpatient survivorship care.

3.5 Implications for follow-up care

Post-PBSCT follow-up should include routine assessment of fatigue, uncertainty, coping difficulties, informational needs, family-role adjustment, and financial strain. Survivors may benefit from structured written guidance explaining common expected symptoms, red-flag symptoms, infection precautions, medication routines, and when to contact the transplant team.

Family-inclusive education is particularly important. Families should be helped to support recovery without unnecessarily restricting autonomy. Health professionals can also normalize the non-linear nature of recovery, reinforce safe graded activity, and create opportunities for survivors to ask questions after leaving the clinic. Where resources permit, telephone follow-up or nurse-led survivorship contact may reduce uncertainty and improve continuity after outpatient visits.

3.6 Limitations

This study was conducted in selected Egyptian outpatient settings using purposive sampling, which may limit transferability to other transplant centers or healthcare systems. The quantitative sample was modest and was intentionally analyzed descriptively; therefore, the findings should not be interpreted as statistically generalizable or as evidence of associations between participant characteristics and outcomes. The qualitative analysis included only participants who completed all three contacts, so the perspectives of survivors with incomplete follow-up may be underrepresented. Some accounts were retrospective, and recall bias is possible. Patients with severe graft-versus-host disease, relapse, severe infection, or significant impairment were excluded, meaning that the findings mainly reflect the experiences of medically stable survivors in the post-transplant survivorship phase. The descriptive and qualitative components were integrated at the group level; therefore, the findings should not be interpreted as person-level associations between individual characteristics and interview experiences.

4. CONCLUSION

Adult survivors after PBSCT in this Egyptian study did not move directly from treatment to normal life. Recovery was prolonged, uneven, and shaped by fatigue, uncertainty, altered roles, spiritual and practical coping, financial pressure, and the quality of follow-up communication. The findings support a broader model of post-transplant survivorship care that combines

clinical surveillance with symptom interpretation, emotional containment, family-inclusive education, financial awareness, and culturally meaningful support for self-management.

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AUTHOR CONTRIBUTIONS

Shaimaa Raafat ALI: Conceptualization, methodology, investigation, data curation, formal analysis, writing - original draft. Ehsan Ahmed YAHIA: Conceptualization, methodology, supervision, validation, formal analysis, writing - review and editing. Both authors read and approved the final manuscript.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

ETHICS STATEMENT

Ethical approval was obtained from the Institutional Review Board of the Faculty of Nursing, Cairo University (IRB No. 2019041701). Official permissions were obtained from the participating settings. Written informed consent was obtained from all participants before enrolment. The study was conducted in accordance with the principles of the Declaration of Helsinki.

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DATA AVAILABILITY STATEMENT

The qualitative data include sensitive interview material from a small clinical population and are not publicly available. De-identified data supporting the findings of this study are available from the corresponding author upon reasonable request and subject to institutional ethical approval.

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