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CLINICAL RESEARCH

Exploring the psychosocial status and lived experiences of haemophilia carriers: a comprehensive mixed methods study

S Badagabettu, A Kurien, V Lakshmi, JA Noronha, LS George, S Govindan, DD Shroff

Introduction: Haemophilia carriers (HCs) face psychosocial challenges, including emotional distress, health concerns, and pregnancy-related issues. Understanding their needs is crucial for optimal healthcare support. This study examined the emotional impact on haemophilia carriers (HC). **Methods:** This mixed methods study employed a sequential explanatory design, beginning with a survey in the first phase, followed by a qualitative analysis in the second phase. HCs resident in Karnataka, fluent in Kannada or English, aged between 20 and 50 years, and having at least one child with haemophilia or being the daughter of a father diagnosed with haemophilia, and attending the haemophilia treatment centre at the Medical College and Hospital in Manipal, were eligible to participate. **Results:** Quantitative analysis encompassed psychosocial variables such as stress, coping, and social support; there was no significant association between stress-coping (r=-0.13, p=0.303), coping-social support (r=0.206, p=0.099), and stress-social support (r=0.216, p=0.084). However, families who had been dealing with haemophilia for a longer duration exhibited better social support (r=0.265, p=0.033). Participants with higher stress and anxiety scores were selected for qualitative interviews. Fourteen in-depth interviews were conducted, revealing six key themes.: acceptance, social support, financial security, family history, birth control, and haemophilia burden. Carrier mothers deal with acceptance issues and inherit feelings of guilt, while the burden on affected children and maternal emotional distress were palpable. **Conclusion:** This research offers valuable insights into the psychosocial wellbeing of HCs in India. It underscores the importance of holistic care, genetic education, and support systems to improve the overall quality of life for this population. By recognising the complex interplay of factors affecting HCs and their families, this study advocates for a comprehensive approach to healthcare

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J Haem Pract 2025; 12(1). doi: 10.2478/jhp-2025-0002

that considers not only the medical aspects but also psychological and social dimensions among HCs.

Keywords: *Women carries of haemophilia; Lived experience; Bio-psychosocial status; Mixed methods design; Qualitative and quantitative*

Haemophilia, a genetic disorder linked to mutations in the factor VIII (FVIII) gene (haemophilia A) or the factor IX (FIX) gene (haemophilia B), by causing deficiencies in the respective clotting factors. This leads to impaired clotting, and spontaneous and prolonged bleeding. Global birth prevalence statistics show approximately 24.6 per 100,000 males are born with haemophilia A, with severe cases comprising 9.5% of this group. For haemophilia B, the birth prevalence is approximately 5.0 per 100,000 males, with 1.5% classified as severe [1,2]. While haemophilia is generally associated with males, females can also be affected. The 2021 Global Annual Survey conducted by the World Federation of Hemophilia (WFH) identified 8,379 females globally living with haemophilia [2,3]. Research has shown that 10-15% of haemophilia carriers (HCs) may experience abnormal bleeding that often goes unnoticed and remains uninvestigated [4]. HCs experience psychosocial challenges such as misunderstanding, emotional distress, medical concern, complex family dynamics, limited support networks, and potential difficulties in career and education, despite not having severe symptoms [5].

The experiences of HC mothers remain a significant area of need and a gap in existing research studies. While there is growing awareness of the challenges faced, a comprehensive understanding of the multidimensional impact of carrier status on their lives is lacking. Current research often focuses on medical aspects, leaving gaps in the exploration of the psychological, familial, and social dimensions of their experiences. The intricate interplay between HC mothers' emotional wellbeing, family dynamics, intimate relationships, and social interactions has received limited attention. Research is needed to uncover the nuanced ways in which HC status shapes these aspects of life, including coping strategies, anxiety, fear, and uncertainty. This could encompass seeking professional help, support groups and personal resilience techniques, and the support of friends and family.

The objective of this study was to examine the psychosocial elements, particularly stress and anxiety, encountered by HCs attending the haemophilia treatment centre (HTC) at the Medical College and Hospital in Manipal, India. Through exploring HCs' personal experience, and the strategies they use to address challenges associated with their status, this research aimed to enrich understanding of the psychosocial effects on HCs and contribute insights for targeted support programmes.

KEY POINTS

- This study highlights the psychosocial challenges encountered by haemophilia carriers, emphasising the need for customised support systems to address their issues effectively.
- Factors such as acceptance, social support and financial security shape the experiences of haemophilia carriers and their families, indicating that a multifaceted approach to care is necessary.
- Comprehensive care strategies that include medical, psychological, and social support, along with genetic education, are important for improving the overall wellbeing and quality of life of haemophilia carriers and their families.
- Support from family, patient organisations, and healthcare professionals play a crucial role in facilitating knowledge acquisition among haemophilia carriers and providing emotional and practical assistance in caring for affected children.

METHODS AND MATERIALS

This study employed a sequential explanatory design carried out in two distinct phases: quantitative and qualitative (Figures 1 and 2) [6]. The rationale for study design was that the quantitative data would provide a general understanding of psychosocial variables (stress and anxiety, coping and social support) expressed by HCs and enable an exploration of patterns in psychosocial parameters across the socio-demographic characteristics of study participants. Furthermore, qualitative research would examine the lived experience of the participants in more depth. Mixed-method research enables pattern analysis, supporting and clarifying trends, processes, or explanations identified in the qualitative data [7].

This study was approved by the Institutional Ethics Committee (REF/2018/07/020990), Medical College and Hospital, Manipal, with Clinical Trial Registry of India (CTRI) registration (CTRI/2018/08/015268).

Figure 1. Visual representation of the sequential explanatory mixed methods study research design

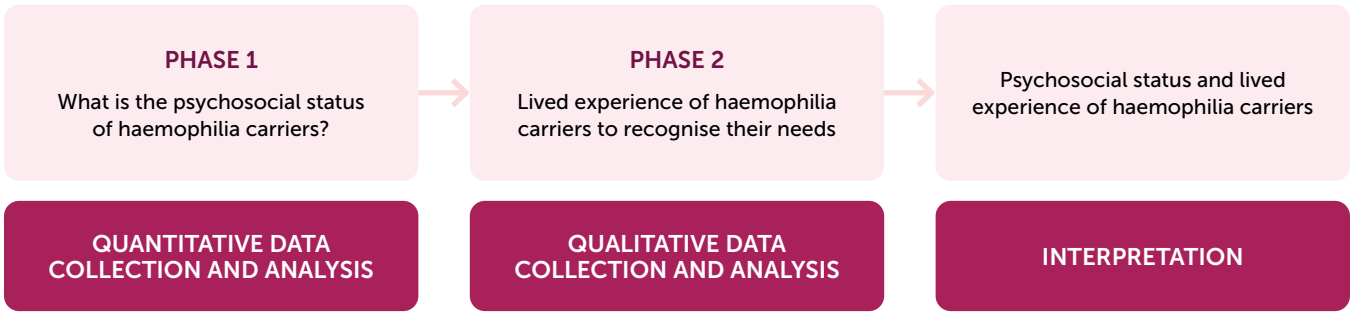

Figure 2. Detailed representation of sequential explanatory study design
Quantitative (first phase) and qualitative (second phase) research planned as a means of more meaningful results. Synthesis of quantitative and qualitative results is carried out as a final point to obtain a more detailed picture and to make the results more realistic and interpretable [16].

PHASE	PROCEDURE	PRODUCT
Quantitative data collection	• Cross-sectional study (N=72) • Purposive • Questionnaire	• Numerical data
Quantitative data analysis	• Descriptive data (frequency, percentage, correlation), R statistical computing programme	• Descriptive statistics (frequency, percentage, correlation)
Connecting quantitative and qualitative phases	• Purposeful recruitment based on typical response and maximal variation principle	• Cases (N=14) • Interview protocol
Qualitative data collection	• Purposive • Individual, in-depth, in-person, semi-structured interviews (N=14) • Explanatory design – Follow-up explanation model/Participant embedded model • Elicitation materials • Documents	• Textual data (interview transcripts, documents)
Qualitative data analysis	• Coding and thematic analysis • Within-case and cross-case themes developed • Cross-thematic analysis • R statistical computing programme	• Visual model of multiple case analysis • Codes and themes • Similar and different themes and categories • Cross-thematic matrix
Connecting quantitative and qualitative phases	• Integration of themes • Interpretation and explanation of quantitative and qualitative results	• Discussion and implications • Future research

Quantitative phase (Phase 1)

Study setting and participants

This phase was a cross-sectional survey of HCs associated with the HTC at the Medical College and Hospital, Manipal. The inclusion criteria for this phase were as follows: women who are carriers of haemophilia and reside in Karnataka; fluent in either Kannada or English; aged between 20 and 50 years; and having at least one child with haemophilia or being the daughter of a father diagnosed with haemophilia. Participation was entirely voluntary, allowing individuals the freedom to decline involvement in completing the questionnaires. Those who did not meet the inclusion criteria or who were not willing to participate were excluded. Data was gathered via administration of a validated questionnaire during visits to the HTC. Consent was obtained from the participants for quantitative and qualitative data collection. The participants were interviewed by a researcher (SB), and privacy and confidentiality were maintained throughout the process.

Data collection

Quantitative data was collected using the following research instruments.

Demographic proforma:

The demographic form included information on individual HCs and their affected children. For HCs, this included age, education, working status, yearly income, family history of haemophilia, birth control measures, and reported bleeding symptoms. The child outcome variables included diagnosis, haemophilia severity, treatment, number of visits to the HTC, reason for hospital visit /hospitalisation, and educational level of the affected child.

Self-administered bleeding assessment tool (Self-BAT):

We used the ISTH self-BAT tool, a validated 14-item bleeding symptom assessment tool for inherited bleeding disorders [8]. Each domain scores from 0 (absence of bleeding symptoms) to 4 (symptoms requiring extensive medical intervention), and the overall bleeding score is determined by summing the scores for all domains. An abnormal bleeding score has been determined for men >3 and for women >5 [8,9] and is used clinically to assess bleeding frequency.

Stress and anxiety scale:

A non-validated tool was developed by the study investigators, comprising 21 items representing the physical, psychological, and social dimensions experienced by HCs, measured by the stress and anxiety scale, with 14 items scored reverse. Participants were asked to rate the extent to which they experienced each state over the past week on a 4-point Likert scale. The scale was scored into mild, moderate, severe stress and anxiety categories, and sub-scale scores were derived by totalling the scores. Total stress and anxiety scores were categorised as mild (score-0-28), moderate(score-29-56), and severe(score-57-84), and the reliability was established by the researcher with Cronbach's alpha = 0.74.

Self-reported Brief Coping Orientation to Problems Experienced (Brief-COPE) Inventory:

Assessing coping strategies among HCs, the Brief-COPE questionnaire had 28 items (14 dimensions) and used a 4-point Likert scale ranging from "I have not been doing this at all (score 1)" to "I have been doing this a lot (score 4)" [10]. Cronbach's alpha overall scale was 0.89, while the Intraclass Correlation Coefficient (ICC) was 0.876 [11].

Multidimensional Scale of Perceived Social Support (MSPSS):

The MSPSS comprises 12 items on a 7-point Likert-type scale ranging from very strongly disagree (1) to very strongly agree (7). The Internal consistency of the scale was .84 (95% CI = 0.83-0.86) [12,13].

The questionnaires were completed during face-to-face interviews with the participants. The time taken for the interviews was 35 to 45 minutes. The quantitative focus included variables (stress, anxiety, coping mechanisms, and social support). Qualitative data gathered during this phase established foundational insights into these psychosocial aspects.

Qualitative phase (Phase 2)

Lived experience refers to the expression of HCs' feelings in response to the research question and was assessed by a semi-structured interview schedule (Appendix), interpreted through thematic analysis.

Study participants

A maximum variation approach was used to purposively sample participants for the qualitative study. Participants for the qualitative strand were selected based on quantitative results (participating in the initial quantitative data collection) to facilitate improved insights and interpretations [14]. Participants who had moderate and high scores (29-56 and 57-84, respectively) for stress and anxiety were enrolled for the second phase of the qualitative study.

Table 1. Sample characteristics of haemophilia carriers (N=72)

SAMPLE CHARACTERISTICS	NUMBER (N)	PERCENTAGE (%)
Age of haemophilia carrier (mean = 48.96 years)		
20-30 years	7	9.7
31-40 years	34	47.2
41-50 years	17	23.6
51-60 years	14	19.4
Education		
Illiterate	10	13.8
School education	28	38.8
Pre-university education and above	34	47.2
Working status		
Unemployed	55	76.3
Employed	17	23.6
Yearly income (INR)		
Less than 200,000	66	91.6
>200,000-9,99,999	6	8.3
Family history of haemophilia		
Yes	33	45.8
No	39	54.2
Birth control measures		
Yes	29	40.2
No	43	59.7
Bleeding symptoms reported		
Yes	42	58.3
No	30	41.6
Number of children with haemophilia		
One child	66	91.6
Two or more than children	6	8.4

Data collection

Participants were interviewed by a qualified doctoral researcher experienced in conducting qualitative interviews. The interviews were audio recorded and transcribed by one of the researchers (DS), and meaningful units, sub themes and main themes were identified. This process was continued until data saturation was reached. The process continued until data saturation was achieved. For final validation, the themes were reassessed to ensure alignment with the initial interpretation and comprehensive understanding. Patterns and key concepts emerged as the themes and relationships between the themes were developed.

Integration of quantitative and qualitative data

Data was integrated by linking the qualitative data to the quantitative results. Combining the data provided a broader and more comprehensive view of the participants' responses and the research question. The point of integration was done at the quantitative and qualitative results; a joint display matrix is shown in Table 4 [15,16]. Thematic analysis was then used to identify themes which emerged from the data within the categories. Two researchers (DS, VLR) coded the data into the framework separately. Four researchers (SB, DS, LS, VLR) compared the findings and came to a consensus on any discrepancies which did not demonstrate a significant difference.

Statistical analysis

We used descriptive statistics to analyse responses and respondent characteristics, summarising data as proportions with binomial 95% CIs. Qualitative data analysis was performed using Jamovi version 2.3.21 (R platform).

RESULTS

Sample characteristics

Seventy-two HCs participated in the study (Table 1). Thirty-four participants (47.2%) were aged between 31 and

Table 2. Sample characteristics of children with haemophilia in the families of participating haemophilia carriers (N=80)

SAMPLE CHARACTERISTICS	NUMBER (N)	PERCENTAGE (%)
Age		
<12years	39	48.7
13-24yrs	33	41.3
>25yrs	8	10.0
Education		
1st -8th (school)	22	27.5
9th-12th (pre-university)	38	47.5
College degree	11	13.7
Advanced degree	9	11.2
Diagnosis		
Haemophilia A	62	77.5
Haemophilia B	18	22.5
Haemophilia severity		
Mild	11	13.7
Moderate	21	26.2
Severe	48	60.0
Treatment regimen		
On demand	80	100
Prophylaxis	0	0
Number of visits to the centre/Year		
< 5/year	49	61.2
5-10 times/year	22	22.5
> 10 times/year	9	22.5
Reason for hospital visit/hospitalisation		
Major bleeds (joint bleeds, gastro-intestinal (GI) bleeds, intracranial (IC) bleeds, iliopsoas bleeds)	17	21.2
Minor bleeds (haematuria, bleeding from minor injury)	63	78.7

40 years, 33 (45.8%) had a family history of haemophilia, 66 (91.6%) had one child with haemophilia. Twenty-eight (38.8%) had a school education; the majority (n=-55; 76.3%) were unemployed; 91.6% (n=66) had a yearly income of less than INR 2,00,000, (USD 2,413).

Twenty-nine (40.2%) HCs used one or more (permanent or temporary) birth control measures of whom 29 (40.2%) favoured tubectomy. Most HCS (n=42; 58.3%) reported abnormal bleeding symptoms. Twelve (28.5%) reported at least two bleeding symptoms, including heavy menstrual bleeding and ecchymotic patches; five had a BAT score of >5 and required blood transfusion, and one underwent hysterectomy post-delivery.

None of the participants had undergone evaluations of clotting factor levels of FVIII or FIX.

Eighty children of HCs were reported in the study (Table 2). Thirty-nine (48.7%) HCs had children aged under 13 years; 38 (47.2%) children were in pre-university level education. The majority of children (n= 62; 77.5%) had haemophilia A, 18 of whom (60%) had a severe form. Forty-nine (61.2%) visited the treatment centre less than five times a year; the primary reason for their visits was minor bleeding (n=63; 78.7%).

Psychosocial variables

To explore the psychosocial aspects of the study participants, 65 participants were considered for further exploratory analysis. Based on age at diagnosis and the current age of the people with haemophilia (PWH) evaluated in the study, seven were excluded as outliers. This ensured homogeneity in the study population.

Based on inferential analysis of the data obtained from participants, it is pertinent to note that there was no relationship between stress and the coping strategies (r=-0.13, p=0.303) used by them. Furthermore, there was a poor relationship between coping strategies and social support, which was not statistically significant

Table 3. Characteristics of interview participants (N=14)

PARTICIPANT ID	AGE	CARRIER STATUS	MEMBER(S) OF FAMILY WITH HAEMOPHILIA	AGE OF AFFECTED CHILD/REN (AND DIAGNOSIS)	NO. OF CHILDREN	CARRIER STATUS KNOWN PRIOR TO HAVING A SON WITH HEMOPHILIA
P1	25	Obligate	Brother & son	3 (HA)	2 (1 male; 1 female)	No
P2	31	Obligate	Brother & son	6 (HA)	2 (1 male; 1 female)	No
P3	35	Possible	Son	6 (HB)	1 (male)	No
P4	35	Obligate	Two sons	14,12 (HB)	3 (male)	No
P5	32	Obligate	Father, brother, son	9 (HB)	1 (male)	No
P6	36	Obligate	Brother & son	12 (HA)	2 (male)	No
P7	38	Obligate	Father, brother, son	14 (HB)	3 (1 male; 2 female)	No
P8	30	Possible	Son	6 (HA)	2 (1 male; 1 female)	No
P9	30	Possible	Son	11 (HB)	2 (1 male; 1 female)	No
P10	38	Obligate	Brothers (N=2), cousin, son	14 (HA)	2 (1 male; 1 female)	No
P11	31	Obligate	Father, son	12 (HA)	1 (male)	No
P12	41	Possible	Son	15 (HA)	2 (male)	No
P13	28	Possible	Son	12 (HA)	2 (1 male; 1 female)	No
Pt14	32	Possible	Son	13 (HA)	2 (1 male; 1 female)	No

HA: Haemophilia A
HB: Haemophilia B

(r=0.206, p=0.099). A similar phenomenon was observed in the context of stress and social support (r=0.216, p=0.084). However, the study revealed a stronger level of social support for HCs and families who had been dealing with haemophilia for a longer duration (r=0.265, p=0.033), indicating an enriched social network, and also underscoring that the level of social support is not determined solely by age. Demographics of the interviewed participants are shown in Table 3; a joint display of results from the integrated quantitative and qualitative study is in the Appendix (Table 4).

Acceptance of haemophilia

Participants had accepted a variety of changes in their daily lives due to their child being diagnosed with haemophilia and their need for lifelong treatment for bleeding episodes. Participants were aware of the support offered through the Indian patient organisation (Hemophilia Federation) and found this to be valuable, continuous and available at all time points. HCs demonstrated their confidence by being able to manage their child.

> *"Of course, my son has haemophilia, which has had a depressing effect on my life, but after some time being part of a patient organisation, I gained confidence to manage my life and face the problem." (P1)*

In their journey of acceptance of haemophilia, some individuals (n=4) had 'given up' due to the limits of daily life and the burden of modifying health behaviours.

J Haem Pract 2025; 12(1). doi: 10.2478/jhp-2025-0002

"I felt I didn't want my life... I used to never sleep... if he was in pain or bleeding, I had to be awake most of the night... it was difficult to care for him... I went through a lot of difficulties and hardships during that time. But now that this is my fate, what else can I do?" (P10)

Social support

HCs reported that social support from various people in their lives (husband, relatives, teachers, friends, patient organisation) helped them to cope, acting as an intervention in awareness, self-esteem, guilt, and grief. They also stated that someone was concerned about their feelings, and they were shown positive regard. Social support in various forms aided HCs (n=12) through showing that they are valued and that there is someone to cry on.

"My husband was always encouraging. Nobody has ever pointed out that my son has haemophilia. They have assisted me in every way possible. My husband advises me not to be tensed. He always tells me that." (P14)

"My son has haemophilia, which my relatives partially blame [on me]... but my husband was encouraging hence, I didn't find it difficult..." (P12)

"When my child was young, we have received continuous support from patient organisation. I only wished to have simple life with better health." (P2)

"Whenever I request that my friends accompany me to the hospital when my child factors and treating bleed, they do so... so, they support while my husband is away from home." (P5)

Financial security and education

Financial security is an important aspect of chronic disease management. When participants had a child with haemophilia and this became a financial burden, they felt a desire to support their partner financially but felt helpless and needed to take special care of their child.

"Now I must take care of my child hence I cannot go to work." (P10)

"My day just goes in dropping and picking him up from the school. It is difficult to go to work." (P5)

Despite being educated and self-sufficient after marriage, some HCs did not continue to work. They believed they were financially secure, but having a child with haemophilia increased the financial burden for treatment as well as the responsibility of caring for the child.

"I was working as an accountant when I was required to leave the job due to my child's increasing health problems. They did call me back to rejoin, but I am bound with responsibilities of taking care of my child." (P10)

Role of family history

Family history is an important risk factor in haemophilia, and it is critical to document the diagnosis of rare genetic disorders with clear patterns of inheritance. Some participants admitted that they were unaware of their family history of haemophilia and would have taken precautions if they had known sooner (n=4).

"I was so disappointed when my younger sister died from excessive bleeding after delivery, and my brother had similar symptoms where I was unaware of the disease. When I was young, I used to see similar bleeding symptoms in my father, and he died from bleeding." (P7)

"My mother used to say that your father probably had it as well... His legs used to swell at joints, and he used to apply 'lepa' (a herbal paste) to reduce the swelling... going to hospital wasn't available back then... my mother didn't have it... my father's blood would have it, and that's how I got it... how that's I feel... I wish I had known about it." (P10)

One significant finding regarding the status of carriers was that none of the participants knew their potential carrier status, despite eight families having multiple affected individuals (Table 3).

"When I was small my elder brother died from bleeding due to fall from height which caused an injury on his leg." (P2)

"When I had my second child, we discovered that both of our children have haemophilia." (P4)

Birth control measures

When it came to reproductive decisions, HCs lacked reproductive autonomy and were under pressure from

their families to have a second child. All 14 participants had a first child with haemophilia.

> *"I did not want another child, but family members advised me to have another, even though I was aware of my carrier status and the risks associated with having another haemophilic child. ... My family members said that once we've seen the pain, let's see it again... I had an intuition it would be a girl, and she is seven years old now, while the boy is 12. She is active and intelligent... even my son is intelligent and active, besides being haemophilic." (P9)*

When it came to personal choices, participants said they would prefer to have a child without haemophilia (n=9). Most did not have reproductive autonomy, but two decided not to have further children, and six underwent tubectomy:

> *"I don't want one more child to suffer and face difficulties." (P2)*

Haemophilia burden

When a child with haemophilia has a sibling, the burden becomes more visible, making it difficult to care for the unaffected children due to the increased importance placed on the affected child. This may lead to sibling rivalry. Additionally, the burden imposed by functional limitations in a child with haemophilia frequently causes mothers to overwork and quality of life is affected.

> *"As a mother, I feel terrible and have no idea what to do when my son is in pain. I can't afford to ignore their needs... Being a parent and seeing my child bedridden is a different kind of pain and suffering." (P4)*

> *"I feel if he was normal things would be much better." (P9)*

> *"I feel guilt and then when my son can't play, and the other children play. He has to simply sit... I feel a lot pain in my heart... we do have difficulties, but we don't tell him." (P11)*

> *"When I see other children, I am saddened and discouraged because my child is unable to go and play. He is missing his childhood." (P11)*

DISCUSSION AND CONCLUSION

This study aimed to explore and understand how HCs were psychosocially affected how their lives changed, and how they managed with being a carrier over time. Stress, anxiety, acceptance, social acceptability, and feelings of guilt have been observed in the parents of children who have a chronic illness [17]. Our study findings show that active coping and acceptance have a positive relationship with wellbeing and a negative relationship with stress and anxiety. These findings are consistent with previous research suggesting that active coping and acceptance can be viewed as adaptive coping [6,18].

Most HCs accepted the challenges they face daily after having a child with haemophilia and how their lives change, though these aspects are often unknown to them before the child is diagnosed. They accepted their new reality, including the need for emergency care due to traumatic or spontaneous bleeding, financial difficulties, social constraints, strained family relationships, emotional problems, and psychological stress [6]. Nevertheless, parents of children affected by haemophilia face difficult challenges imposed by this pathology, often without prior knowledge. Alongside the challenges referred to, the centre of family attention may be focused on the child with haemophilia, neglecting other siblings and relatives who may feel abandoned. Family plans and programmes may be upset or changed by bleeding episodes, resulting in a feeling of instability and uncertainty within the family [21]. Mothers of children with haemophilia have been reported to have higher levels of depression and anxiety than fathers [22], possibly caused by guilt at being the genetic carrier, and this may manifest as an intense and over-protective mother/ child relationship.

Social situation was an influencer in our study and revealed a strong connection between the patient support group, which facilitated knowledge acquisition, and HTC members who encouraged the carrier's partners and families to care for the child [19]. Based on a qualitative research approach, these findings can and should be interpreted as one contribution to a more insightful understanding of the phenomenon of being a carrier of haemophilia and the mother of a child with haemophilia [20]. Social support plays a pivotal role in helping HC mothers navigate the complex emotional and social challenges associated with their condition, including coping with anxiety, fear, and uncertainty in family and interpersonal relationships. However, it is the obligation of health care providers to assist carriers in making informed decisions in the best interests of the individual family, while keeping the child in mind.

Being a HC may have a psychosocial impacts and affect reproductive choices. In a study of reproductive choices in haemophilia carriers of known or suspected carrier status in the Netherlands, none of the carriers had made a conscious choice not to have children, although five carriers who had had one or more children subsequently chose not to have further children [23]. Most of the participants enrolled in our study appear to have a second child despite the risks associated with haemophilia. However, our findings also emphasise the pressure on HCs to deliver a healthy child as one reason behind this phenomenon.

Other significant findings included the reporting of bleeding symptoms in HCs, e.g. *"I lost my sister due to unexpected bleeding after vaginal delivery. Despite our best efforts, we couldn't save her. Now, her son, who has haemophilia B, is in our care"* (P7). Similar reports describe excessive bleeding that ranges from mild to severe or life-threatening [24]. The assessment of bleeding severity in HCs might be influenced not only by personal bleeding experiences, but also the severity of symptoms and the extent of children affected in the family [25].

Limitations

Our study had some limitations. The sample size estimated for quantitative data collection was not reached due to factors related to the COVID pandemic, including restrictions on to travel to households. The study was conducted from one HTC and results may not be generalisable to other centres.

Relevance for clinical practice

Based on the findings of this study, it is evident that tailored support programmes are essential to address the psychosocial challenges faced by HCs. A comprehensive approach to care—integrating medical, psychological, and social support—is paramount for effective management. This can be achieved through a holistic strategy that includes targeted interventions to address emotional challenges, alongside genetic education and counselling, enabling carriers to make informed decisions. Additionally, collaborative efforts, such as joint educational programming between clinical care teams and patient advocacy organisations, could enhance awareness, support, and management strategies for individuals and families affected by haemophilia. By incorporating these strategies into clinical practice, healthcare providers can optimise the wellbeing of HCs and their families, promote holistic care, and improve overall health outcomes.

ACKNOWLEDGEMENTS

Consent

Informed consent has been obtained from the participants in the study reported in this paper.

Disclosures

The authors have advised no interests that might be perceived as posing a conflict or bias.

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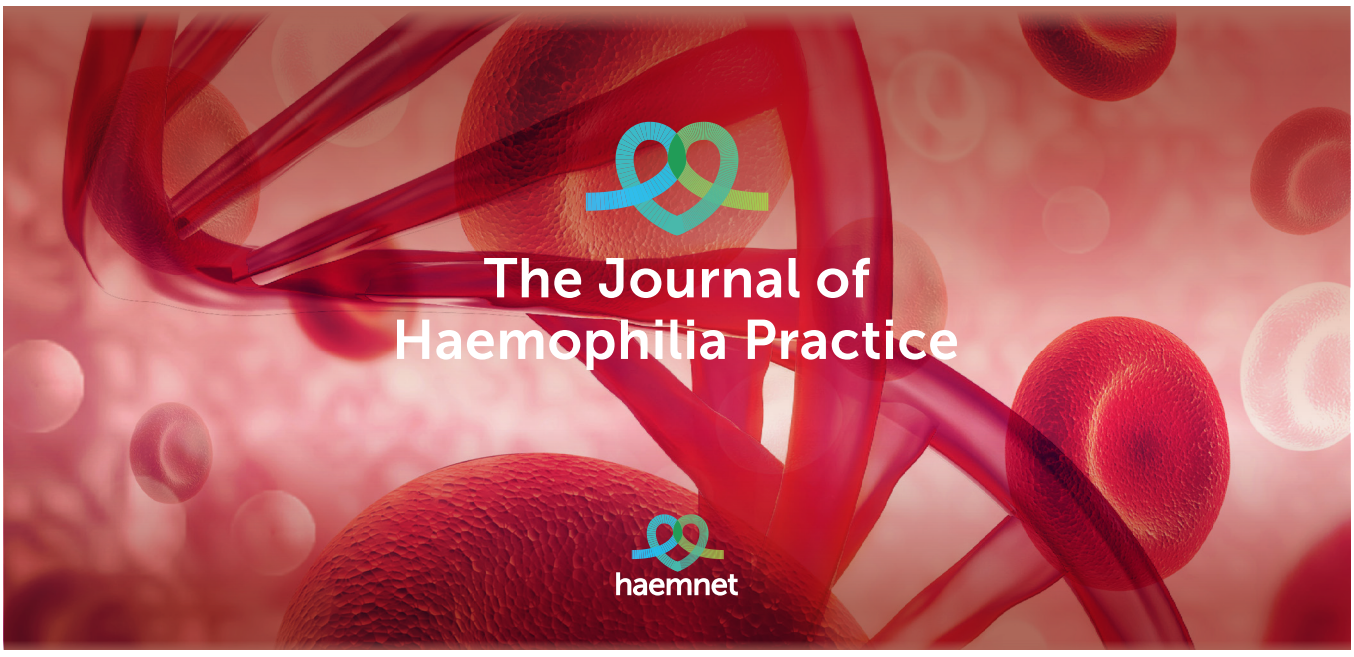
CORRECTION
The keywords in this article were updated on 22 May 2025 following a proofing oversight.

HOW TO CITE THIS ARTICLE:
Badagabettu S, Kurien A, Lakshmi V, Noronha JA, George LS, Govindan S, Shroff DD. Exploring the psychosocial status and lived experiences of haemophilia carriers: a comprehensive mixed methods study. *J Haem Pract* 2025; 12(1): 34-47. *https://doi.org/10.2478/jhp-2025-0002*



APPENDIX

Qualitative interview schedule

Instruction: The semi-structured interview will be started by asking the following questions. The next question is prompted as the questions are discussed, and the interview is audio recorded.

1. Can you tell me about you and your family?
2. Could you please elaborate on your daily routines?
3. At what age was your child diagnosed with haemophilia?
   Probe: Early days of haemophilia
4. Were you aware that you were a carrier of haemophilia?
   Probe: If yes, how did you experience your journey as a carrier?
5. Did you receive support from others?
   Probe: Family, peers, and patient organisation
6. What are the problems you encounter, and how do you handle them?
   Probe: financial, daily issues, personal, and family
7. Describe how you see yourself and your future.
8. Did you feel like having another child?
9. What do you envision for your future? Do you want to add anything?

Table 4. Joint display of quantitative and qualitative findings to develop meta-inferences

THEME	QUANTITATIVE FINDINGS	QUALITATIVE FINDINGS	META-INFERENCES
Acceptance	Based on Spearman's Correlation analysis, there is no statistically significant relationship between stress-coping (r=-0.13, p=0.303), coping-social support (r=0.206, p=0.099) and stress-social support (r=0.216, p=0.084)	Empowerment (n=2/14) *"I have attended sessions conducted by hemophilia society and I feel courageous to handle the disease now."* Self-reflection (n=4/14) *"I used to pray to God. but then when I see others, I feel we are better, what else could be done..."* Resilience (n=1/14) *"I never imagined; my child would get this disease. For his good health, I must be strong..."* Adaptation over time (n=3/14) *"I used to get tensed and sit and cry at night ...now that's my life I got used to it..."*	• HCs express a feeling of being able to accept their condition due help from the patient organisation • HCs have accepted the reality of lifelong disease • Participation in support groups increases HCs' confidence and knowledge
Social support	Based on Spearman's Correlation analysis, there is a mild positive statistically significant relationship between disease duration and social support (r=0.265, p=0.033). This indicates better social support for families who have been affected by haemophilia/ which have included people with haemophilia for a longer duration.	Support from husband/partner/teacher (n=4/14) *"My husband always says that 'I am there, right, do not take any stress' ...he is very supportive."* Support from haemophilia community (n=2/14) *"I have attended sessions conducted by haemophilia society and I feel courageous to handle the disease now."* Spouse support (n=1/14) *"He used to restrict me to go to the hospital but now it is not like that, he supports me..."* Increased family care and support (n=3/14) *"After knowing that he has this disease everyone takes care of him."* Family/friends (n-2/14) *"I get always support from my friends... today he/ she has accompanied me to visit centre."*	• HCs discussed the enduring support they received from husbands, friends, community, and the patient organisation, which has helped them cope over time.

THEME	QUANTITATIVE FINDINGS	QUALITATIVE FINDINGS	META-INFERENCES
Financial security	Based on the Mann Whitney U test, there is no statistically significant difference in the average scores of stress level (p=0.367), coping (p=0.675) and social support (p=0.684) across family income. Based on the Mann Whitney U test, there is no statistically significant difference in the average scores of stress level (p=0.202), coping (p=0.295) and social support (p=0.899) across working status of mothers.	Job sacrifice (n=2/14) *"Due to my marriage, I left the job..."* Financial constraints (n=2/14) *"Now I must take care of him so. I cannot go to work."* Work-life Imbalance and employment challenges (n=4/14) *"...My day just goes in dropping and picking him up from the school. It is difficult to go to work"*	• Leaving a job is not purely because of the disease burden • HCs feel their professional growth has stopped due to having children
Role of family history	Based on the Mann Whitney U test, there is a statistically significant difference in the average scores of coping (p=0.019) across family history of haemophilia (Yes/No). However, this phenomenon is not observed in the case of stress (p=0.099) and social support (p=0.338).	Lack of awareness and hidden family medical history (n=2/14) *"They didn't say anything... it was a great shock... mother's elder son had it... I do not even know...I did not even see him... Only my mother was aware... He expired at the age of 18... We did not know anything and couldn't really understand anything."* Missed opportunity for Informed decision-making (n=4/14) *"She got married when I was very young, and she never told me...otherwise, I could have tested and had my child aborted, and then we found out when my child was diagnosed with haemophilia after asking she said that even her kids have."*	• HCs spoke about the reluctance of family members to discuss haemophilia
Birth control measures	Based on Mann Whitney U test, there is no statistically significant difference in the average scores of stress (p=0.052), coping (p=0.837), and social support (p=0.280) across the decisions taken on birth control measures.	[Emotional struggle in expanding the family (n=2/14) *"It is difficult to see one more child with the same disease..."* Family influence on reproductive decisions (n=2/14) *"Family said having one more child which would be disease-free would-be better."*	• Having another child in spite of knowing the risk
Education	Based on the Kruskal-Wallis test, there is no statistically significant difference in the average scores of stress (p=0.397), coping (p=0.869), and social support (p=0.427) across education levels.	Marriage impacts on education (n=??/14) *"I got married and then I could not continue." (Healthcare professional)* *"I was into accounts for six months. After that I got married. Then I did not go to continue." (Finance professional)*	• HCs opted not to continue their profession due to marriage

THEME	QUANTITATIVE FINDINGS	QUALITATIVE FINDINGS	META-INFERENCES
Haemophilia burden	Based on the Kruskal-Wallis test, there is no statistically significant difference in the average scores of stress (p=0.397), coping (p=0.869), and social support (p=0.427) linked with the child's haemophilia severity. Based on the Mann-Whitney U test, there is no statistically significant difference in the average scores of stress (p=0.128), coping (p=0.080), and social support (p=0.234) across haemophilia type.	Family support in managing haemophilia (n=2/14) *"My son is suffering a lot …the members at home take care of him very well."* Emotional impact of restricted activities (n=4/14) *"He feels bad that he cannot go out to play."*	• HCs feel they do not have a normal life