COMMUNITY FOCUS

From shared experience to sustained leadership: a community of practice study of haemophilia society stakeholders in India

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Background: Stakeholder-led organisations play a critical role in bridging gaps in care and advocacy. Understanding the lived experiences and contributions of core facilitators within these communities is essential to strengthen their impact. **Aim:** This study explores how core facilitators collaboratively sustain a haemophilia society (HS), using the Community of Practice framework (CoP) to interpret patterns of shared purpose, collective learning, and evolving leadership in a rare disease support setting. **Methods:** An exploratory qualitative study, using in-depth, semi-guided interviews with people with haemophilia (PwH), caregivers and healthcare professionals working in voluntary, titled roles in the various HS centres of the Hemophilia Federation India, was conducted between February 2024 and January 2025. Data were analysed using a framework analysis approach, ensuring validity through member checking, reflexive journals. **Results:** A total of 22 office bearers (9 PwH, 6 caregivers, 7 healthcare professionals) participated in the study. Four overarching themes emerged: (1) Shared interest and commitment, driven by stakeholders' personal and professional ties to haemophilia; (2) Building relationships and collective identity, marked by trust, peer support, and belonging; (3) Multifaceted roles and holistic support, involving medical, psychosocial, and administrative contributions; and (4) Sustaining engagement and fostering future leadership, reflecting concerns over disengagement among PwH and leadership gaps. Applying the CoP framework post-analysis highlighted how shared learning and identity shaped the HS's evolution, underscoring the need for stakeholder-led initiatives in preventive care and community sustainability. **Conclusion:** While stakeholders shared their journey in establishing the support organisation and were optimistic about the future, this study underscores the need for emphasis on the engagement of PwH by integrating a holistic, truly sustainable approach to this progress; there must be greater inclusion of PwH in leadership, advocacy, and day-to-day activities of the HS.

Keywords: *Haemophilia, Stakeholder perceptions, Community of practice (CoP), Patient organisations, Qualitative research.*

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Haemophilia A and B are rare X-linked bleeding disorders caused by mutations in the genes encoding coagulation factor VIII (FVIII) and factor IX (FIX). Haemophilia A is more common than haemophilia B, with a global prevalence of one in 5,000 male live births compared to one in 30,000, respectively [1]. According to the National Haemophilia Registry (2019), India had 21,824 registered individuals with bleeding disorders, of which 17,606 (80.6%) were diagnosed with haemophilia A and 2,715 (12.4%) with haemophilia B [2]. The chronic nature of the disease warrants lifelong clinical care with an interprofessional collaborative and comprehensive care approach. This model of care is offered by designated multidisciplinary team of specialists and experts to ensure an overall good quality of life for people with haemophilia (PwH). Active stakeholder involvement is also a key feature of this approach, thus giving way to patient-led organisations.

The World Federation of Hemophilia (WFH) was founded in 1963 by Frank Schnabel, a person with haemophilia whose vision was to unite “hundreds of thousands” of PwH across the globe under a single organisation [3]. Likewise, the National Hemophilia Foundation (USA) was founded in 1948 by parents of an affected child [4]. These early efforts set the stage for a global network of haemophilia societies driven by those directly impacted. Today, haemophilia support networks exist in over 140 countries, usually as national member organsations (NMOs) of the WFH, and they serve as a collective voice for PwH and their families [5]. Importantly, these organisations are not solely run by PwH but typically involve interprofessional stakeholders. The Canadian Hemophilia Society (CHS), founded in 1953, includes PwH as well as various healthcare professionals (nurses, physiotherapists, social workers) in its structure [6]. This interprofessional composition reinforces comprehensive support systems for PwH.

The WFH’s model for developing sustainable national care programs is built on five key pillars: government support, care delivery, medical expertise, treatment product provision, and patient organisation involvement [6]. Establishing an effective patient organisation requires an integrated approach, engaging committed volunteers, professional staff, and supportive clinicians [6] As one WFH monograph notes, haemophilia societies must be “business-like, but compassionate”, balancing professionalism with the humanitarian ethos of a community organisation [7].

In India, the Hemophilia Federation of India (HFI) has been a cornerstone of care development since it was established in 1983 by the combined efforts of PwH and affected families, leading to the development of a nationwide federation of chapters [2]. These have played a pivotal role in improving haemophilia care in India, working alongside health authorities and international partners to expand services [2].

Haemophilia societies coordinate community activities that support improved the quality of life for PwH, including camps, workshops and peer mentoring [8]. Leadership is frequently assumed by dedicated PwH, caregivers, and healthcare professionals who serve in ‘office bearer’ roles (e.g. chapter presidents, secretaries, treasurers, executive members, etc.). The key office bearers in haemophilia chapters serve as vital links between the national federation and local communities, facilitating information transfer and coordinating regional activities. They conduct education programs, provide support to newly diagnosed families, and advocate with healthcare providers and government agencies for improved treatment access. In India – as in many countries – these volunteers organise essential services, including blood camps and clotting factor distribution, and maintain PwH registries for their respective regions. Through their multifaceted roles, office bearers create sustainable community support networks that directly enhance care delivery and quality of life for PwH. While inter-professionally managed haemophilia organisations are widely recognised as essential, there is limited research on the experiences and long-term contributions of long-serving office bearers. A recent review highlighted the scarcity of published literature on the role of patient organisations in haemophilia care, underscoring that much of what is known comes from grey literature or limited case studies [8].

This study utilises the Community of Practice (CoP) framework to investigate the impact of sustained stakeholder engagement on the growth and functioning of patient organisations [9], focusing on the haemophilia societies (HS) of the HFI. A CoP is defined as a group of individuals who share a concern or passion and interact regularly to deepen their knowledge and practice [10]. In the context of the current study, application of the CoP framework allows for analysis of how shared learning, identity, and mutual support emerge within haemophilia societies and how these dynamics sustain organisational resilience. The application of this framework in stakeholder-led rare disease contexts, especially in India, remains largely unexplored.

The study seeks to generate insights that bridge a critical knowledge gap by revealing how ongoing stakeholder participation drives community-led success and shapes strategies for nurturing future advocacy leadership. While support from policymakers and hospital administrators is essential in a rare disease area such as haemophilia, haemophilia societies are primarily driven by stakeholders within the haemophilia community [2,3]. Hence, this study was designed to explore the motivation and intrinsic altruism demonstrated by various volunteer members of the HFI, who extend their support by taking on leadership roles as office bearers beyond their natural roles as PwH members, caregivers, or healthcare providers.

METHODOLOGY

Study design

The study employed in-depth, semi-structured interviews, conducted face-to-face with various stakeholders who were bearing one or the other key administrative responsibilities in various HS in India. The study was conducted over an eleven-month period, and written informed consent was taken from each participant before the interviews. Participants were given the freedom to withdraw from the study at any point. Pseudonyms have been used to link the data to ensure the identities of individual participants remain confidential.

Participant selection and recruitment

Individuals holding key responsibilities in the respective HS, or 'office bearers' (e.g. HS president, secretary, executive committee member, etc), with more than 15 years of active involvement, and who worked with the HS voluntarily, were eligible to participate in the study. These criteria ensured the inclusion of participants who could offer valuable and experience-based insights. Those with shorter involvement or who were unwilling to participate were excluded. Maximum variation purposive sampling was employed to capture diverse experiences and organisational cultures, enhancing the transferability of findings. Participants were drawn from multiple chapters of the HFI to reflect the heterogeneity of stakeholder roles.

Data collection

Timed and structured in-depth qualitative interviews were conducted in a quiet and private environment without distractions. Before the interviews, a brief orientation was provided to help participants understand the purpose of the study and provide relevant information. All interviews were conducted by the principal investigator (DS), a trained female interviewer, under the guidance of a senior researcher (DN), using a semi-structured guide with open-ended questions before exploring specific themes. The interviews were audio-recorded and transcribed verbatim; transcripts were reviewed by the other researchers (SG and SB).

Data analysis

Data were analysed using an interpretive approach, including inductive coding to address research questions. Inductive analysis involved reading transcripts, annotating the data, and accounting for participants' experiences. The themes identified were then categorised under each of the three components of the CoP framework.

This qualitative study adhered to Lincoln and Guba's guidelines to ensure methodological rigor [11]. To ensure credibility, two researchers (DS and SG) conducted data analysis independently before summarising interpretations and addressing doubts. Debriefing sessions after pilot interviews and member checking were conducted to ensure dependability. A reflexive diary was maintained for confirmability, and an audit trail of the entire research process was documented.

Ethics

Institutional Ethics Committee approval was obtained to conduct this study (KH/IEC/127/22).

RESULTS

In-depth interviews lasting between 60 and 145 minutes were conducted with 22 participants (9 PwH, 6 caregivers, 7 healthcare professionals), age range 35-74 years (mean 50 years), who had served in an office bearer role with the HS for between 14 and 25 years (mean 19.6 years). Participant characteristics are presented in Table 1.

The interviews generated rich narratives, from which four themes and nine subthemes emerged. These are categorised under each of the three components of the CoP framework (Table 2) and reflect the varied experiences and sustained involvement of stakeholders in the HS.

Theme 1: Shared interest and commitment

Reflecting the 'Domain' component of the CoP, the first theme identified was the personal and professional motivations that led stakeholders to engage with the HS.

Table 1. Participant characteristics (N=22)

PARTICIPANT	AGE	YEARS SERVED*	BACKGROUND[+]
P1	50	22	PwH
P2	39	15	HCP
P3	38	16	PwH
P4	65	25	HCP
P5	60	25	Caregiver
P5	42	18	Caregiver
P7	70	25	Caregiver
P8	65	25	Caregiver
P9	40	18	PwH
P10	48	16	Caregiver
P11	74	25	Caregiver
P12	45	19	PwH
P13	35	16	HCP
P14	56	21	PwH
P15	52	25	HCP
P16	48	14	PwH
P17	51	20	HCP
P18	55	19	PwH
P19	49	17	HCP
P20	39	16	PwH
P21	43	18	HCP
P22	40	16	PwH

* Years served at haemophilia society
[+] Stakeholder background
PwH: person with haemophilia
HCP: Healthcare professional

These individual commitments eventually merged into a shared mission aimed at addressing care gaps and building an enduring community of support. This main theme was subdivided into two subthemes: Personal and professional entry points/Initial motivations, and Emergence of a collective mission. Illustrative quotes are presented in Tables 3 and 4.

Participants commonly described their introduction to the HS as being catalysed by personal or professional exposure to the unmet needs of PwH. Many were either directly affected by the condition, had family members living with haemophilia, or had clinical or academic encounters that turned into long-term commitments. These entry points served as catalysts for long-term commitment, reshaping professional trajectories into roles of community-building within the HS. Over time, overcoming stigma and individual motivations coalesced into a shared vision, moving beyond reactive support to proactive community-building, education, and advocacy.

Theme 2: Building relationships and collective identity

The second theme (CoP component 'Community') identified a combined vision that stimulated stakeholders into collaborative advocacy and proactive healthcare initiatives. In building this cohesive community, relationships became foundational, characterised by trust, mutual emotional support, and respect, and sustaining engagement over decades. The subthemes identified were Emotional bonding and trust, and Intergenerational and peer relationships. Illustrative quotes are presented in Tables 5 and 6.

Stakeholders described the HS as more than a health initiative, but rather as something that became a place of emotional refuge and familial bonding. Many considered their roles within the HS to be akin to parenting or caretaking, extending deep affection and long-term support to PwH. The HS's success in sustaining engagement was partly attributed to its strong intergenerational relationships. Older members took on mentorship roles, ensuring that institutional memory, values, and strategies were passed down to younger participants.

Table 2. Thematic analysis of stakeholder participation in the haemophilia society based on the Community of Practice (CoP) framework

COP COMPONENT	THEME	SUBTHEME
Domain	**1.** Shared interest and commitment	**1.1.** Personal and professional entry Points **1.2.** Emergence of a collective action/mission
Community	**2.** Building relationships and collective identity	**2.1.** Emotional bonding and trust **2.2.** Intergenerational and peer relationships
Practice	**3.** Multifaceted roles and holistic support/Stakeholder participation and engagement	**3.1.** Advocacy, clinical care, and community outreach **3.2.** Psychosocial and economic interventions
	4. Sustaining Engagement and Fostering Future Leadership	**4.1.** PwH disengagement and dependency **4.2.** Leadership fatigue and the need for succession planning

Table 3. Supporting quotes for subtheme 1.1. Personal and professional entry points

PARTICIPANT	ILLUSTRATIVE QUOTE	INTERPRETATION
P1 (PwH)	"I am a haemophiliac since the age of 2. I knew I had to be involved when I saw what others were going through without support."	Living with haemophilia from childhood, they felt compelled to help others facing similar struggles.
P2 (Healthcare professional)	"It was during my MDS postgraduate thesis on oral health in haemophilia that I realised I couldn't look away anymore. These feelings pulled me into this organisation."	An initial academic interest in haemophilia led to lasting involvement after seeing hardships experienced by PwH.
P4 (Healthcare professional)	"We were just giving diagnoses and referring them far away to CMC Vellore. There was no local treatment. That's what moved me into action."	They described the emotional toll of diagnosing haemophilia cases without local treatment options.
P5 (Caregiver)	"There was only one vial in the hospital, and the doctors didn't even realise the boy had haemophilia until he was already on the table. That's when I knew we had to start something."	A friend's child's near-fatal misdiagnosis became a turning point that spurred them to take action.

Table 4. Supporting quotes for subtheme 1.2. Emergence of a collective mission

PARTICIPANT	ILLUSTRATIVE QUOTE	INTERPRETATION
P4 (Healthcare professional)	"We needed 30 people to register the Society, so I started writing letters to everyone we had diagnosed. That was the beginning."	Stakeholders highlighted a strong sense of collective identity that emerged organically from early grassroots efforts.
P3 (PwH)	"It started in a small room in a caregiver's house. Back then, we were only two chapters across the state."	
P12 (PwH)	"In the beginning, people were hesitant. No one wanted to take ownership. But when I saw even one person show up to the haemophilia day event I organised, it gave me the confidence that we could grow."	
P22 (PwH)	"Thirty-five years ago, parents wouldn't admit their child had haemophilia. That silence was dangerous. So we went on candle marches through the city to raise awareness."	Stigma, in particular, was seen as a major force uniting members
P8 (Caregiver)	"We could afford factors, but we knew others couldn't. That thought, 'How are others managing?' that's what birthed the Society."	Facing similar struggles, people felt a shared need to help

Table 5. Supporting quotes for subtheme 2.1. Emotional bonding and trust

PARTICIPANT	ILLUSTRATIVE QUOTE	INTERPRETATION
P8 (Caregiver)	"We are like parents to them. They call us *chetha* (brother) or *chechi* (sister), but really, we are mother and father. They come to us not just for factors but when they are mentally broken."	Frequent expressions of emotional closeness suggested that the Society created a space where members felt acknowledged, supported, and secure.
P17 (Healthcare professional)	"Here, the doctor-PwH barrier doesn't exist. They are very free with us, they laugh, cry, and share their life events openly."	An equal dynamic between clinicians and PwH emerged as a key factor.
P7 (Caregiver)	"We have a setup with ten rooms where they can come and stay. We always tell them it's like their second home not a hospital."	The creation of a physical and emotional sanctuary was also noted

Table 6. Supporting quotes for subtheme 2.2. Intergenerational and peer relationships

PARTICIPANT	ILLUSTRATIVE QUOTE	INTERPRETATION
P7 (Caregiver)	"It started in our own home, but now children are involved too. They've grown up in this community, and they understand what it means to be here."	The interactions allowed younger members to take leadership roles while staying aligned with the Society's core mission.
P13 (Healthcare professional)	"During camps, senior members naturally guide the younger ones. We ensure they learn how to handle logistics, peer interaction, even fundraising."	

Table 7. Supporting quotes for subtheme 3.1. Advocacy, clinical care, and community outreach

PARTICIPANT	ILLUSTRATIVE QUOTE	INTERPRETATION
P7 (Caregiver)	"There were 2,000 PwH in our state, and the politicians didn't even know what haemophilia was. We had to educate MLAs and get them to ensure medicine availability. It was a long fight."	The senior office bearers served as healthcare facilitators, educators, and negotiators, advocating for resource mobilisation.
P21 (Healthcare professional)	"We called all schools and colleges and asked them to arrange awareness sessions. We covered both scientific and psychosocial aspects. This wasn't a one-time thing it became part of our routine."	Community outreach was carried out through physiotherapy sessions, school and college awareness drives, and direct educational campaigns.
P19 (Healthcare professional)	"Some PwH don't stay in touch or come to the Society, so we go to their homes, sit with them, talk to their families. That personal connection is key."	Regular home visits also played a significant role. These efforts illustrated how community care extended beyond clinical spaces and into the lives of PwH.

Table 8. Supporting quotes for subtheme 3.2. Psychosocial and economic interventions

PARTICIPANT	ILLUSTRATIVE QUOTE	INTERPRETATION
P8 (Caregiver)	"Many PwH don't disclose their condition before marriage, leading to family issues. We intervene, mediate, and support them emotionally and legally if required."	The range of support extended from pre-marital counselling to financial aid.
P15 (Healthcare professional)	"We give Rs. 10,000 loan without interest so that they can start a small shop or phone booth. They repay when they can. It's not charity, it's empowerment." (P10)	
P13 (Healthcare professional)	"We conduct beach camps for children, and group activities during camps. The laughter, the bonding it heals something deeper than medicine can." (P10)	Participants emphasised how crucial emotional encouragement was for well-being.

Theme 3: Multifaceted roles and holistic support

The third identified theme (CoP component 'Practice') emphasised the stakeholders' engagement in multifaceted roles, including advocacy, clinical interventions, and community outreach, expanding into economic empowerment and psychosocial support, thus demonstrating the holistic support mechanisms essential for addressing diverse needs within the haemophilia community. Stakeholders also undertook significant operational responsibilities without formal training, reflecting their adaptability and proactive learning approach. This contributed to both tangible healthcare improvements and strengthened community resilience, highlighting sustained dedication and collective efficacy. Illustrative quotes are presented in Tables 7 and 8.

Stakeholders wore multiple hats, from educators and fundraisers to care coordinators and policy advocates. They organised camps, negotiated with policymakers, and introduced preventive care, and described themselves as playing pivotal roles in bridging gaps between PwH, healthcare systems, and policymakers. Beyond medical care, the HS intervened deeply in the social and emotional lives of PwH and their families.

Theme 4: Sustaining engagement and fostering future leadership

While the analysis employed the three core elements of the CoP – Domain, Community, and Practice – one additional thematic category emerged inductively from the participants' narratives. This theme reflected critical issues of organisational sustainability and community evolution. As the HS matures, participants expressed concern over sustaining long-term engagement and ensuring a transition towards patient-led leadership. Illustrative quotes are presented in Tables 9 and 10.

Many stakeholders highlighted that as access to treatment improved through government schemes, the involvement of PwH in society activities declined. The various benefits by the government allowed PwH to receive factor concentrates directly, leading some to reduce their participation in community-led programs. Some PwH began to withdraw from active roles, leading to concerns about long-term engagement.

Table 9. Supporting quotes for subtheme 4.1. Patient disengagement and dependency

PARTICIPANT	ILLUSTRATIVE QUOTE	INTERPRETATION
P9 (Caregiver)	"Earlier, they had to come to us for factors. Now they go directly to the Karunya shops. We only see them during camps."	Stakeholders felt that many PwH continued to see the Society as a service provider rather than a shared space
P4 (Healthcare professional)	"They thank us, but they don't take any initiative. They still act like it's our responsibility, not theirs."	
P5 (Healthcare professional)	"We want them to come forward asking for dental check-ups or physio, not just arrive during emergencies."	

Table 10. Supporting quotes for subtheme 4.2. Leadership fatigue and the need for succession planning

PARTICIPANT	ILLUSTRATIVE QUOTE	INTERPRETATION
P11 (Caregiver)	"The president is 74. Everything depends on him. If something happens, we don't know what will happen to this Society."	Concerns about centralised leadership and the lack of succession planning.
P5 (Caregiver)	"We need someone who can write to HFI in English and Hindi. Right now, we don't have anyone." (P11)	Barriers to leadership included low confidence, poor communication skills, and limited professional independence among potential successors.
P10 (Caregiver)	"Even after we conducted training programs, the youth still didn't ask how the Society runs or how we fund our work. They attend, they clap, but they don't lead."	
P2 (Healthcare professional)	"They're not lazy it's just that they suffer so much already. We need to keep reinforcing their strengths until they believe in themselves."	Despite these challenges, participants expressed hope that reinforcement and mentorship could change this trajectory.

The burden of sustaining the HS continues to fall on a small number of ageing leaders. Participants voiced anxiety over the lack of structured leadership pipelines and the unwillingness or inability of younger members to step into key roles. Recommendations offered by participants included creating robust mentorship programs, encouraging younger generations' participation, and advocating for continuous professional training and capacity building.

In sum, the stakeholders' narratives reflect a compelling journey marked by deep personal convictions, significant professional commitments, and a collective vision for enhanced care. These rich narratives are intertwined with insightful reflections on successes, struggles, and strategic imperatives crucial for the society's continued relevance and effectiveness. The HS, through the eyes of its dedicated stakeholders, emerges as an embodiment of sustained collective action, driven by compassion and unyielding dedication towards transforming the lives of PwH and their families

DISCUSSION

This study aimed to explore stakeholder perspectives among office bearers within the HSs of the HFI. We used the CoP framework to illuminate how collective motivations, relationships, and activities influence organisational sustainability. Analysis generated four interconnected themes aligned with CoP components – Domain, Community, and Practice – and finally, Sustaining engagement and fostering future leadership. The CoP framework elucidated the interplay between personal motivations, community relationships, and stakeholder practices in sustaining engagement. It further demonstrated how shared interests and applied roles underpin trust and enable effective leadership within haemophilia patient organisations.

The HS office bearers in our study were bound together by their commitment to improve the lives of PwH. This convergence of personal and professional entry points created a united domain of practice. Every member shares a common interest in haemophilia management, forming the basis of mutual commitment and understanding within the community [7]. Such a shared domain ensures that all stakeholders – PwH, family members, and healthcare professionals – speak a "common language" of dedication to haemophilia care, facilitating collaboration from the outset [12]. Recognising and accommodating stakeholders' diverse motivations enhances their fulfilment, encourages sustained engagement, and strengthens organisational outcomes [13,14]. Studies consistently indicate that intrinsic motivators such as personal fulfilment, meaningful relationships, and a sense of calling yield stronger organisational commitment than extrinsic rewards like financial compensation [15,16,17,18]. Our findings affirm that when haemophilia societies prioritise internal motivators, they cultivate committed and proactive leadership.

Building upon this strong shared domain, office bearers foster a community of relationships and commitment, emotional bonds, and relational trust, which emerged as critical in sustaining stakeholder engagement. In our study, stakeholders described how HS office bearers successfully transformed the organisation from merely an advocacy group to a supportive 'second family' for PwH, their caregivers and families. This finding aligns with prior research, where PwH and caregivers universally described haemophilia associations as essential sources of emotional support [8]. Additionally, the value of intergenerational relationships through peer mentoring was clearly demonstrated, enabling experienced stakeholders to impart essential leadership skills and institutional knowledge to newer members[19,20].

Within the CoP framework, Practice encompasses various stakeholders' multifaceted roles and shared activities [10]. In this study, HS leaders extended their responsibilities beyond administrative roles, simultaneously acting as advocates, educators, counsellors, and program managers. This holistic practice addresses the diverse medical, psychosocial, and economic needs associated with haemophilia. Literature on rare disease communities emphasises the vital role patient organisations play in advocacy, outreach, and education [21]. Likewise, frameworks for chronic disease management recommend comprehensive psychosocial interventions, highlighting the positive impact these practices have on patient quality of life and adherence to care [22,23]. Our study reinforces these findings by demonstrating how stakeholders' integrated roles significantly enhance both organisational efficacy and outcomes.

Despite clear strengths, the study identified challenges that could threaten the sustainability of these organisations, including patient disengagement, dependency, and leadership fatigue. Existing research emphasises that leadership fatigue can lead to decreased organisational effectiveness if proactive measures for succession are not in place [23]. Our findings underline the critical importance of structured succession planning, including active recruitment and mentoring of emerging leaders, to ensure seamless leadership transitions and continued organisational vitality. Facilitators such as structured stakeholder feedback, co-design of interventions, individualised training, and incentives for sustained participation can help address these challenges effectively [24,25,26]. Ensuring the continued renewal of the organisation – by attracting new members, nurturing inclusive relationships, and systematically transferring skills and responsibilities. – will be essential to preserving and advancing the significant gains already achieved in haemophilia care and advocacy.

The CoP framework provided a comprehensive lens, through which we could understand how HS stakeholders' shared interests, relationships, and practices converge to sustain meaningful participation and effective leadership. These findings highlight not only the strengths inherent in such organisations but also the necessity of deliberate strategies for leadership continuity and stakeholder engagement. For patient organisations addressing complex health conditions, fostering intrinsic motivation, community connectedness, holistic practice, and structured succession planning is paramount to ensuring their long-term impact and sustainability.

Limitations

A limitation of this study is the recall bias exhibited by the participants, as the interview questions were taking them to very old situations. This was primarily because most participants had been associated with their respective HS for more than 20 years. This limitation was mitigated to a certain extent by encouraging participants to recall concrete events; for instance, by looking through archived documents that serve as cherished memories or meaningful souvenirs. Nevertheless, some degree of retrospective bias may remain and should be considered while interpreting the findings.

CONCLUSION

Our study emphasised the importance of a community-led haemophilia care model in India through a CoP lens. Our findings underscore that even in low-income settings, collaboration among diverse stakeholders has strengthened haemophilia care through a shared learning community, which ultimately improves the lives of PwH. Additionally, integrating a holistic, truly sustainable approach to this progress, there must be greater inclusion of PwH in leadership, advocacy, and day-to-day activities. Encouraging the active participation of PwH will not only enhance ownership but also bridge the existing gap between service providers and recipients. Future research should continue to explore how fostering inclusive leadership and peer-driven engagement will be crucial to ensuring that society/patient organisation remains adaptive, resilient, and truly patient-centred.

ACKNOWLEDGEMENTS

Conflict of interest

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

Consent

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

Author contributions

DS: Conception and design, implementation of the project, acquisition of data, analysis and interpretation of data, and drafting of the manuscript.

SG: Conception and design, acquisition and data, analysis and interpretation of data, critical review of the manuscript, and supervision of the project.

SB: Conception and design, analysis of the data, and critical review of the manuscript.

DN: Conception of the study design, supervision of the project, critical review of the results, analysis and manuscript.

Funding

This project did not receive any funding from any agencies in the public, commercial, or not-for-profit sectors.

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HOW TO CITE THIS ARTICLE:
Shroff DD, G S, B S, Nayak DM. From shared experience to sustained leadership: a community of practice study of haemophilia society stakeholders in India. *J Haem Pract* 2025; 12(1): 126-135. *https://doi.org/10.2478/jhp-2025-0017*