CLINICAL RESEARCH

Psychological experiences of mothers of children with severe haemophilia in Iranian culture: A phenomenological study

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Introduction: Caregiving for children with haemophilia is a critical role that requires vigilance and significant lifestyle change, impacting on social activities, physical and psychological health and emotional experiences.

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A study in Iran highlights the importance of access to psychological services for mothers of boys with severe haemophilia

Aim: To explore the lived experience of mothers in Iran as caregivers of boys with severe haemophilia, focusing specifically on their psychological challenges. **Methods:** This phenomenological study forms part of a larger study exploring psychological difficulties and social interactions of mothers of boys with haemophilia (BWH) in Iran. Semi-structured in-depth qualitative interviews were conducted with the biological mothers caring for one son with severe haemophilia A or B. Interview questions focused on challenges related to treatment, medication,

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prophylaxis and their interactions with HCPs, including the mothers' feelings and coping mechanisms, and were adjusted to the Iranian cultural context. Participants were recruited from Mofid Comprehensive Care Centre for Children with Haemophilia (MCCCCH) in Tehran. Data analysis was based on van Manen's six-step framework, using MAX.QDA software (2020), to identify themes. Findings were triangulated with findings from interviews with HCPs at MCCCCH about their perceptions of the challenges the mothers experience. **Results:** Fifteen mothers of BWH were interviewed, most of whom had no or an unknown family history and no previous knowledge of haemophilia. Five themes and 27 subthemes of psychological experiences were identified. Themes included Daily emotional experiences; Challenge of acceptance; Defence mechanisms; Coping strategies (Emotion-focused and Problem-focused); and Positive expectations of the future. The most notable findings related to Daily emotional experiences and Defence mechanisms. Emotional reactions were diverse and included depression, fear and regret. Participants used a variety of defence mechanisms, including rumination and avoidance to try and overcome their situation. **Conclusion:** If informed properly about medical issues and enabled to gain insight into their psychological responses, mothers of children with haemophilia in Iran may be able to better regulate emotional complexities and handle disappointment or unrealistic expectations, thereby enhancing their quality of life. There is a need for psychological services in haemophilia care in Iran that needs to be addressed in order to better support the wellbeing of patients and their families. This psychological supportive care should be informed by culturally appropriate guidelines and could be extended to similar communities in the Middle East.

Keywords: *Haemophilia, Caregiver burden, Psychosocial factors, Motherhood, Phenomenological study, Cultural background*

Haemophilia is a sex-linked hereditary bleeding disorder related to the X chromosome as a recessive allele, resulting in a genetic deficiency in clotting factor VIII (haemophilia A) or IX (haemophilia B) [1]. Haemophilia is classified as mild, moderate or severe depending on the percentage of factor that is produced. Individuals with severe haemophilia may experience their first bleeding episode in infancy [2]. Complications in haemophilia include significant bleeding from minor injuries, and muscle and joint bleeding which can lead to musculoskeletal pain, tissue damage, muscle atrophy and permanent damage in some joints, especially the knees and ankles [3]. Mothers who carry the haemophilia gene may pass it to their sons; fathers pass the gene to their daughters. 'Carriers' may experience bleeding symptoms and have factor levels that would result in a diagnosis of mild haemophilia [4]. Haemophilia can be associated with known or unknown family histories, or might be caused by a spontaneous genetic mutation, resulting in an unexpected diagnosis.

One of the most important medical challenges for caregivers of boys with haemophilia (BWH) is administering treatment. Standard of care is replacement of the missing factor with clotting factor concentrates, either through on-demand treatment or based on a prophylactic regimen [5]. Mothers have reported functional and emotional difficulties around providing home treatment to their sons, especially repeated venepuncture and performing infusions [6]. These issues can cause them to be psychologically compelled to attend treatment centres more frequently, in addition to routine clinic appointments [6].

Caregiving for children with chronic diseases requires vigilance, continuous protection and sometimes significant lifestyle change [7]. Although it can provoke feelings of purpose and self-worth [7], most studies conducted in developed countries demonstrate that taking care of children with congenital diseases impacts significantly on social activities, family, employment, physical and psychological health, and the emotional experiences of caregivers, especially mothers [8,9,10]. Individuals affected by chronic illnesses use coping strategies in order to deal with day-to-day emotional and functional and issues, including acute and stressful situations, which can contribute to increased quality of life (QoL) [11,12]. Studies of families with children with haemophilia show cultural differences in three dimensions: coping strategies and their effectiveness on QoL [11,12], families' lived experiences [13], and accessibility of medical and healthcare services [14].

In Iran, qualitative studies have started to explore psychosocial issues in people with haemophilia [15,16,17], but the authors are not aware of any specific study focused on haemophilia caregivers and family challenges. Phenomenological research has been used effectively to better understand the psychosocial experience of mothers of children with haemophilia [6,13], but such research among women in developing countries is limited. Iranian culture holds views on women and motherhood based on conventional gender roles and mothers are the main caregivers of children [18]. Given the role of biological mothers in transmitting haemophilia to their sons, cultural views potentially impact the lived experience of mothers of BWH in Iran.

Using a phenomenological qualitative research method appropriate to gathering reflective insights, this study aims to explore the experience of mothers in Iran as caregivers of boys with severe haemophilia, focusing specifically on their psychological challenges. The study is part of a larger research project concerned with the psychological difficulties and social interactions of mothers of BWH in Iran.

METHODS

This phenomenological study used semi-structured in-depth qualitative interviews to collect data on experience of mothers in Iran as caregivers of boys with severe haemophilia. This type of qualitative interviewing is appropriate for gathering reflective insights and information [19].

Recruitment

Study participants were recruited from Mofid Comprehensive Care Center for Children with Haemophilia (MCCCH) in Tehran. For this type of research, it is recommended to include 5-25 participants until data saturation is achieved [20,21]. There are also recommendations to include 3 or 4 additional participants to ensure coverage of maximum variation of data [20,22].

For purposeful sampling, the inclusion criteria were: female caregivers between 18-49 years old, biological mothers of one son affected with severe haemophilia A or B and ability to come to the centre at least once a month. People with a serious psychiatric profile or who were unable to come to the centre were excluded. Selected participants were invited to interview by the supervisor head nurse of MCCCH.

Data collection

Interviews followed an interview guide, with questions based on information from literature review and consultation with experienced health care practitioners (HCPs). The guide began with general open-ended questions (e.g. Tell me about the first days of diagnosis, how did you feel then? How did you manage the new reality of having a son diagnosed with haemophilia?) and went on to focus on challenges related to treatment, medication, prophylaxis and their interactions with HCPs, including the mothers' feelings and coping mechanisms. Two caregivers were invited to participate in pilot interviews to assess the clarity and completeness of questions.

Informed consent, awareness of research purpose, interview process and withdrawal right were implemented on the basis of American Psychological Association (APA) ethical principles [23]. All interviews were conducted in person in a private room in MCCCH between May 2022 and July 2022. Interviews were conducted by a female member of the research team to take account of cultural considerations. All interviews were recorded and transcribed verbatim. The interviewer also took fieldnotes on non-verbal behaviours and emotional expressions during the interviews.

As part of the larger study, interviews were also conducted with experienced HCPs working in the clinic to better understand how they view the challenges the mothers experience. These took place after each interview with participating mothers and were referred to during data analysis. Findings from these interviews will be published elsewhere.

Data analysis

Data analysis was conducted using van Manen's six-step framework [24]. As a first step, prior to interview, the interviewer observed participating mothers when they attended clinic and communicated with HCPs to understand their medical context. The second step involved investigating the lived experiences of the mothers through interview. The third stage involved thematic analysis of the interview transcripts, enabling hermeneutic phenomenological reflection on the essential themes. Analysis was undertaken using MAX. QDA software (2020). In the fourth step, hermeneutic phenomenological writing and rewriting were undertaken, and the fifth and sixth steps focused again on the study aim and interview questions to assess the part and whole of the mothers' experiences. Data analysis was conducted by an academic psychologist at the University of Tehran (UT) and two Psychology Masters students, who coded independently. Themes were discussed among a multidisciplinary team from UT and the Shahid Beheshti University of Medical Sciences (SBMU).

To promote reliability and validity, findings from the analysis were triangulated with findings from the HCP interviews and rechecked with the head of MCCCH (a professor of paediatric haematology), the supervisor

Table 1. Socio-demographic characteristics of participating mothers of sons with severe haemophilia (n=15)

VARIABLE	NUMBER (%)
Mother as the main caregiver	15 (100%)
Nationality	
Iranian	13 (87%)
Afghani	2 (13%)
Age of mother	
Mean	37.6 years
Range	30-45 years
Age of child with severe haemophilia	
Mean	10.5 years
Range	6-14 years
Age of child at diagnosis	
Mean	5.8 months
Range	3-20 months
Family history of haemophilia	
Known family history	4 (26%)
No/unknown family history	11 (74%)
Previous knowledge of haemophilia	
Had knowledge about haemophilia before child's diagnosis	4 (26%)
No knowledge about haemophilia before child's diagnosis	11 (74%)
Prophylaxis administration	
Mother administers prophylaxis	12 (80%)
Prophylaxis administered at hospital	3 (20%)
Adjustments for child's safety within the home	
Safety protocols in place	9 (60%)
No safety protocols in place	6 (40%)
Education level of mother	
Associate degree	1 (7%)
Master's degree	2 (13%)
Bachelor's degree	2 (13%)
Diploma	6 (40%)
Elementary school	2 (13%)
Illiterate	2 (13%)

head nurse and the primary general physician of MCCCH, focusing particularly on perceptions of the mothers' psychological challenges.

Ethical approval

This study was evaluated and approved by the SBMU Research Ethics Committee at SBMU, approval ID IR.SBMU.RICH.REC.1401.009.

RESULTS

Fifteen mothers of BWH (representing 20 percent of total registered BWH at MCCCH) were interviewed. Four had a family history or previous knowledge of haemophilia before their child's diagnosis. All usually attended the centre on a monthly basis. The average duration of interviews was 60 minutes (range 40-97 minutes). Data saturation was attained after 12 interviews, but further interviews were conducted to ensure coverage of maximum variation of data.

Table 1 shows sociodemographic characteristics of participants and their children.

Five themes and 27 subthemes relating to the psychological experiences of mothers of boys with severe haemophilia were identified (Table 2). The themes included: Daily emotional experiences, Challenge of acceptance, Defence mechanisms, Coping strategies, and Positive expectations for the future. Daily emotional experiences and Defence mechanisms were the most notable findings.

Daily emotional experiences

Daily emotional experiences refer to the phenomenology of emotionally relevant events, affective reactions, and associated cognition [25]. Emotions occur in combination and are difficult to distinguish, but during interviews participants indicated specific emotions including fear, anxiety, distress, guilt, disappointment, depression, embarrassment, shame, regret, anger and hate because of haemophilia-related challenges.

Fear, anxiety and associated psychosomatic symptoms were often related to hypervigilance and overprotection, especially after a child's diagnosis.

> *"I'm so stressed and get nervous fast due to the smallest things, sometimes I feel pain in my fingers and my body is shaking because of stress."* [Participant 5]

As 'carriers' of the haemophilia gene, most participants considered themselves responsible for their children's current and future suffering and challenges, and some reported feelings of guilt and sadness.

Caregiver responsibilities caused some restriction in mothers' daily activities and impacted their personal lives, which resulted in some experiencing depression and disappointment.

> *"My daily activities are restricted noticeably because all of my time is spent on my son and it makes me more depressed and I know this depression is too major, nothing can make me happy and I'm so apathetic about everything,*

Table 2. Overview of themes and sub-themes relating to the psychological experiences of mothers of boys with severe haemophilia in Iran

THEME	SUB-THEMES	
Daily emotional experiences	Depression	
	Hate	
	Regret	
	Disappointment	
	Sadness	
	Shame	
	Anger	
	Embarrassment	
	Anxiety	
	Guilt	
	Fear	
Challenge of acceptance	Acceptance	
	Non-acceptance	
Defence mechanisms	Rumination	
	Idealisation of children	
	Avoidance	
	Withdrawal	
	Splitting	
Coping strategies	Emotion-focused strategies	Emotional drain
		Daily activities for wellbeing
	Problem-focused strategies	Medical migration
		Consulting with medical staff
		Childbearing after having a boy with haemophilia
		Consulting with a psychologist
Positive expectations for the future	Educational positive expectations	
	Medical positive expectations	
	General positive visualisation of the future	

> *even the smallest things make me cry and I don't care about my body anymore and it doesn't matter to me whether I'm fat or thin and how I look."* [Participant 3]

Some mothers mentioned engaging in relaxing activities, such as using social media, to help relieve their feelings. However, they sometimes felt these conflicted with cultural values and were embarrassed about this.

> *"Chatting with others on social media makes me better, I know this is not good for me because it's my weakness and I shouldn't do it but afterwards I feel better emotionally."* [Participant 13]

Some participants who were aware of their carrier status before their child was born reported regret due to uncertainty about terminating their pregnancy, citing that this was due to cultural and religious reasons. These feelings were compounded by seeing how their children suffered with their haemophilia. Some also felt angry, particularly about having to impose restrictions on BWH in the family to accommodate other members of the family.

Challenge of acceptance

Acceptance of their child's haemophilia diagnosis was a significant psychological challenge for the mothers in this study. 'Acceptance' refers to an individual's compliance with the reality of a situation and recognition of a condition without trying to change it or denying it.

Over half of participants said they overcame this challenge and gradually accepted the difficulties associated with their child's haemophilia diagnosis. However, there were also instances of denial and fruitless endeavours to change the reality of their child's condition.

> *"I cannot accept my son's haemophilia and his major bleedings. So, my partner took us to Mashhad (a religious city in Iran) and carried him on his shoulders to the holy shrine for several times for getting my son's healing from God but something did happen for me, my tears are coming and I can't stop crying, I'm always begging and asking this crucial question: God, how long does this child needs to suffer and what should I do? I'm really desperate."* [Participant 8]

For seven participants, acceptance was impacted by disease aggravation, such as their child suffering permanent damage to the knee joint as a result of bleeding, or personal crises, including the loss of family members.

Defence mechanisms

Five defence mechanisms were reported by participants: idealisation, avoidance, splitting, withdrawal and rumination. Avoidance and rumination were most often applied.

Some mothers used idealisation, attributing exaggerative positive qualities to their children.

> *"He is so punctilious, if he sits here next to you, he will immediately get what you are going to say and also, he is so responsible and committed and patience about other's mistakes."* [Participant 1]

Three mothers demonstrated idealistic expectations and attitudes about treatment methods in developed countries, expressing enthusiasm for therapeutic migration. Most of these therapeutic attitudes focused on the future and related to recovery of disabilities through short-term treatment or a definite remedy for permanent joint damage.

Some mothers used avoidance to dismiss unpleasant thoughts or feelings, or keep themselves from facing facts, people or places. While confronting some difficulties, some used a 'splitting' mechanism, drawing a distinction between good and bad parts of their situation (unit object).

> *"The problem is just the presence of the disease, not my son himself."* [Participant 11]

Some mothers used a withdrawal mechanism, taking back what they had said about their experiences and escaping from reality to fantasy.

> *"Thank God, well there are some issues in every family, which naturally includes us, but maybe we don't have anything right now. In the beginning we had, yes, but not now."* [Participant 10]

Participants also described using rumination, distracting themselves with repetitive and more acceptable thoughts.

> *"I talk to myself all the time like I'm crazy and think about the past and review it and try to fix the problems in my mind."* [Participant 12]

Coping strategies

The coping strategies employed by participants fell into two categories: **emotion-focused coping strategies,** where they attempted to regulate their feelings and emotional responses, and **problem-focused coping strategies,** where they coped with stress by confronting it directly and actively attempted to modify the situation [26].

Two types of emotion-focused coping strategies were referred to. Some mothers attempted to introduce regular, pleasurable daily activities to enhance their wellbeing. Others used an 'emotional drain' strategy, in which after experiencing powerful emotions for a while, they undertake actions which reveal them.

> *"Most of the time, I'm an aggressive person and scream or say whatever comes to my mind and cry, then I get relaxed."* [Participant 6]

Among the problem-focused strategies described, four participants referred to medical migration, specifically relocating to the Iranian capital, Tehran, from their home town/city or country so that they could access better services. Some mothers had sought therapeutic advice from HCPs, and some mothers had consulted psychologists and psychiatrists about family issues related to haemophilia.

Some mothers reported struggles and challenges around pregnancy and childbearing after having a child with haemophilia. In some cases, they tried to prevent pregnancy, and some chose to terminate a pregnancy to avoid the risk of passing the haemophilia gene to another child.

> *"I didn't notice how I got pregnant and as soon as I figured it out, I had an abortion."* [Participant 8]

Table 3. Further supporting quotes for themes identified in the psychological experiences of mothers of boys with severe haemophilia in Iran

THEME		SUB-THEMES
Daily emotional experiences		*"I consider myself guilty. So, I must do my best for my son's future till he grows up perfect and healthy."* [Participant 10]
		"Sometimes I say to myself, I wish I didn't give birth to such a person who has to endure these challenges because of my wrong decision, however abortion was like killing my own child." [Participant 1]
		"I agree that I get angry fast especially when he is nervous. I try to be relaxed and negotiate with him in these situations, but after five minutes when I see him not calming down I shout eventually." [Participant 14]
Challenge of acceptance		*"In the first two years after diagnosis, I had no normal life, especially in my relationship with my husband, but I noticed it cannot continue like this and I asked myself if there is a problem, what else do you want to do? So, I faced with difficulties and started again, then I coped with these problems gradually."* [Participant 12]
Defence mechanisms		*"I always try not to think about the annoying situation and distract my thoughts with something else."* [Participant 3]
Coping strategies	Emotion-focused strategies	*"I like to watch movies or read books and sometimes I do so during the physiotherapy sessions."* [Participant 12]
		"We used to live in Arak and because of my son's illness, we moved to Tehran." [Participant 14]
	Problem-focused strategies	*"We came to this centre and the head nurse explained all I needed to know and answered my questions to take care of my son."* [Participant 11]
		"I realised something is not right so I preferred to visit a psychologist and he/she gave some practical recommendations." [Participant 15]
Positive expectations for the future		*"My only dream is about my children's education. I wish to see them in the best scientific positions, which I couldn't achieve it myself because of imposed restrictions by culture on women in my town. I specially encourage my affected son to study hard. Because of haemophilia, all physical job is prohibited for him."* [Participant 7]

Positive expectations of the future

Most participants described feeling responsible for their son's future status, and some emphasised having a positive perspective about the years to come. These positive expectations were therapeutic, academic and general.

Some mothers said they have a generally positive image of the future and visualise it as a dream.

> *"My son will take his engineering certificate, I will buy my pleasant apartment and all of my goals will be fulfilled, especially my favourite vacations. In the next five years I will never worry about my son's medicine and we will go on every trip that we want together."* [Participant 8]

All positive expectations were somehow related to the therapeutic situation, but some focused more on medical issues.

> *"I told him don't worry, this disease is treatable and will definitely improve as you get older, you can also prevent your gene's mutation by innovative treatments, so everything is fine."* [Participant 8]

Education was presented by some mothers as a major achievement in their son's life and a way to overcome some of the constraints (e.g. limitations on physical activities) associated with their haemophilia. For some, positive educational expectations also compensated for deficits in their own lives, for example those linked to cultural views about women's education in some rural areas in Iran.

Further supporting quotes for each of the themes are provided in Table 3.

DISCUSSION

As 'carriers' of the haemophilia gene, the mothers who participated in our study experience issues and complications related to marriage, pregnancy and childbirth, and providing care for their children with haemophilia [6,27]. These issues and complications often resulted in a need for psychological support. Studies in Europe have demonstrated that transmission of sex-linked genetic disorders like haemophilia may cause feelings of guilt and self-blame in parents, especially in mothers [6,27,28,29]. Our study similarly found that mothers experience feelings of guilt and consider themselves responsible for their child's condition, and as a result they significantly reduce their personal daily activities to protect their sons. This may also contribute to escalating intense emotions such as anxiety, anger, depression, regret and embarrassment. However, the role of Iranian culture in the lived experiences of mothers of BWH in our study is also important and needs to be clarified.

One of the most impactful features of Iranian culture found in our study relates to conventional gender roles. Mothers are the main caregivers of children and are responsible for caring for the family, while fathers are financial providers and make most important family decisions [18,30]. Expressing emotions is not always culturally acceptable – for example, it is generally not appropriate for women to express feelings of anger or regret about having a child – and there continues to be an expectation that women will dedicate themselves to their children and husbands. In our study, daily emotional experiences and attempts to relieve the stress of challenges posed by caring for a child with haemophilia sometimes left mothers feeling embarrassed and 'weak', as reported by one participant who found comfort in using social media – in some regions of Iran, the secret use of social media is condemned for married women as a cultural prohibition. In this context, understanding the lived experiences of Iranian mothers of BWH is crucial, and there is an urgent need for an adapted guideline for HCPs and psychology teams caring for families affected by haemophilia to enable effective services for both mothers and BWH.

Support from family and HCPs was important to study participants. Family members participate in daily routines and family rituals, which enabled the mothers to realise that life goes on with the presence of haemophilia. This supported their acceptance of haemophilia over time, alongside continuous constructive interactions with the care centre, receiving adequate information from experienced HCPs and facilitation of treatment actions such as prophylaxis. Medical aspects such as prophylaxis can represent a burden due to the need for frequent regular injections and increased visits to the treatment centre for parents with young children [13]. Mothers who took part in our study usually attended the comprehensive care centre (CCC) on a monthly basis despite most administering treatment at home, which is indicative of how much their child's haemophilia occupies and impacts their lives. Similar to other literature, participants accepted the need for these therapeutic activities, treated them as a new family activity in addition to other existing family routines and rituals, and thereby protected how the family functions [6,31,32].

In common with other developing countries, limited numbers of medical centres and experienced HCPs in some provinces, alongside constraints on medical resources impact haemophilia care in Iran [14,33]. Three mothers in our study mentioned their decision to migrate to Tehran to benefit from proper medical services. Despite the challenges this involved – including the impact on family and personal support networks – they felt this would solve their problems and, over time, improve their life satisfaction. Participants also referred to medical restrictions in other Middle Eastern countries that are culturally close to Iran [34,35], highlighting the role of socio-cultural barriers to receiving proper medical services and psychological support.

Participants' belief in better access to better care services in developed countries is based on reality [14,33], but some mothers had idealistic expectations that this could soon include a treatment that would result in recovery from haemophilia-related disability or reverse permanent joint damage, which does not correspond with current medical reality. Psychologically, it seems that these idealistic expectations are a kind of unconscious intrapsychic defence used to avoid and inhibit emotions like depression which are caused by their experience of caring for a child with severe haemophilia.

A number of defence mechanisms were used by the mothers in our study, but they were not always completely aware of them and a lack of insight was observed. Defence mechanisms, including idealisation, are mental operations that keep painful thoughts and effects out of awareness (out of focus) [36]. These operate in a mostly automatic manner, are pervasive and are used in the absence of insight, but when overused can become rigid and impair mental health. This contrasts with the more agentic use of emotion- and problem-focused strategies used by some mothers, which focused on emotional palliation and logical problem solving respectively [26].Gaining insights into personal defence mechanisms can help to promote psychological functioning [37], and psychotherapies can be effective in increasing insights [38]. Some mothers in our study reported seeking advice from a psychologist as a problem-solving coping strategy. This again amplifies the need for providing psychological guidelines and services in CCCs.

Limitations

Due to the qualitative methods used for this study, there are limitations related to the generalisability of the results, both to developed countries and other less developed countries, and to caregivers attending healthcare facilities other than MCCCH in Tehran and in other provinces of Iran. The study also focused on mothers of BWH, and did not consider the psychological processes of other family members, such as fathers and siblings. It is suggested for future studies to pursue research in this area. Due to the large population of Afghan refugees and immigrants in Iran [39] and considering the limited coverage of insurance for them in the Iranian healthcare system [40], it is also important for further studies to focus on refugees and immigrants with BWH and their biopsychosocial challenges.

CONCLUSION

The mothers of boys with severe haemophilia in our study had little information about the disorder until after their child's diagnosis. They experienced emotional reactions including depression, fear and regret, and used defence mechanisms including rumination and avoidance to overcome their situation, alongside problem-focused and emotion-focused strategies, which may have had inconsistent efficacy. If mothers of children with severe haemophilia are informed about medical issues and gain insight about their psychological experiences, they may be able to mediate emotional complexities and prevent disappointment or unrealistic wishes, thereby enhancing their QoL. At the present time, there is little in the way of access to experienced psychologists in Iranian CCCs, but there is a need for psychological services in haemophilia care in Iran that needs to be addressed.

Supportive care for congenital bleeding disorders requires an interdisciplinary approach that responds to physical, social and psychological needs, with the aim of improving QoL among affected people and their family members [41,42]. It is important that other HCPs working in CCCs in Iran increase their knowledge of the psychological needs of haemophilia caregivers to improve the therapeutic relationship [6] and enable them to better support the wellbeing of patients and their families. Psychological support should be culturally appropriate, informed by research-based guidelines, and could be extended to similar communities in the Middle East. Studies that facilitate understanding of the psychological difficulties experienced by mothers of BWH, and other family members, should be used to inform the development of these guidelines and future psychological services.

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

The authorship contribution of current study is as follows: AE and MF designed the research method and FF conducted the project. BH and PE contributed to project executive support and coordination with participants. AE, FF and ZS analysed the data. FF and AE wrote the manuscript. JAR was the counsellor of the research team. All authors agreed the manuscript.

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