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EXPLORATION OF PERCEIVED FEARS AMONG HAEMOPHILIA PATIENTS IN PAKISTAN

Original Research

Wajeeha Shakir[1]*, Saba Zer Naz Hafsa[1]
[1]Riphah International University, Pakistan.
Corresponding Author: Wajeeha Shakir, Riphah International University, Pakistan, wajeeha.shakir5@gmail.com.

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ABSTRACT

Background: Haemophilia is a chronic genetic disorder characterized by impaired blood clotting, leading to recurrent bleeding episodes that significantly impact physical and psychological well-being. Patients often face various challenges, including social restrictions, stigma, and identity challenges, which give rise to different fears. These fears can affect their quality of life, mental health, and ability to perform daily activities. Limited research has explored the perceived fears of haemophilia patients, particularly in developing countries like Pakistan, where healthcare resources and awareness are constrained.

Objective: This study aimed to explore the perceived fears of haemophilia patients in Pakistan, evaluate their causes and effects on various life domains, and assess the pathways they adopt to cope with internal bleeding episodes using the fear-avoidance model.

Methods: A qualitative study design was employed, utilizing semi-structured interviews based on pre-developed interview guidelines. A total of 28 participants, including 20 males and 8 females aged 14 to 35 years, were recruited through snowball and convenience sampling techniques. The participants were from Rawalpindi, Lahore, Raiwind, Bahawalnagar, Gujranwala, and Hafizabad. Data collection continued until saturation was achieved, and thematic analysis was conducted following Byrne's guidelines (2021). Themes and subthemes were developed using QSR Nvivo 10 software. The fear-avoidance model was applied to assess the pathways adapted by patients during internal bleeding episodes.

Results: The study identified several fears among haemophilia patients, including fear of bleeding (6/28), rejection (4/28), injury (4/28), pain (3/28), disability (2/28), and death (2/28). Fear of treatment, illness, emotional trauma, losing social roles, and discrimination or stigma were also reported. Patients commonly employed avoidance as a coping mechanism, leading to negative consequences such as psychological distress, isolation, and disability. The findings highlighted the significant physical and mental challenges faced by patients, including social restrictions, dependence, and identity struggles.

Conclusion: Haemophilia patients in Pakistan face multifaceted challenges that give rise to various perceived fears, profoundly impacting their physical, psychological, and social well-being. The study emphasized the importance of addressing these fears through improved healthcare strategies, awareness programs, and supportive interventions to enhance the quality of life for haemophilia patients.

Keywords: Avoidance model, bleeding, hemophilia, mental health, perceived fear, psychological stress, stigma.

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INTRODUCTION

Haemophilia, a genetic disorder predominantly affecting males, arises from a deficiency in clotting factors essential for blood coagulation. This inherited condition, often linked to mutations in the X chromosome, results in prolonged bleeding even from minor injuries, posing significant risks such as joint damage, paralysis, or, in severe cases, fatal complications (CDC, 2020). The disorder is classified into haemophilia A, caused by a deficiency in clotting factor VIII, and haemophilia B, linked to factor IX, with symptoms often exacerbated by the formation of antibodies against these factors during treatment (NIH, 2023). Diagnosis typically involves blood tests to measure clotting efficiency and factor levels, while management includes factor replacement therapies using recombinant techniques or human blood, albeit with risks such as antibody resistance (CDC, 2022). Globally, haemophilia's prevalence has escalated, with the World Federation of Hemophilia (WFH) reporting over 815,100 cases as of February 2023, including 347,026 diagnosed patients and 276,900 classified as severe cases (Ndoumba-Mintya et al., 2023). In Pakistan, the WFH's 2019 data indicated the diagnosis of 2,233 patients, underscoring the increasing burden of this disorder in developing regions (1). Limited healthcare access in resource-constrained settings further compounds challenges, leaving 75% of haemophilia patients without adequate care and facing increased susceptibility to infections such as hepatitis and HIV due to unsafe blood transfusion practices (2).

The multifaceted impact of haemophilia extends beyond physical health to encompass profound psychosocial consequences. Bleeding episodes impair mobility, disrupt daily activities, and foster social isolation due to fear of injuries and societal stigmas. Misunderstandings surrounding the disorder, such as misconceptions about its contagious nature, exacerbate discrimination and marginalization (3). Additionally, the condition often imposes economic burdens, restricts independence, and hinders life opportunities, including marriage and family planning, due to concerns over hereditary transmission (4). Psychological challenges such as anxiety, depression, and body image issues are prevalent, fueled by visible symptoms and social stigmatization (5).

Theoretical frameworks like the fear-avoidance model elucidate how haemophilia patients' experiences of chronic pain and recurrent bleeding episodes perpetuate cycles of fear, avoidance, and disability. Catastrophizing such experiences exacerbates psychological distress, while positive coping mechanisms enable better recovery and reintegration into daily life (6). Previous studies highlight the necessity for tailored interventions addressing both the physical and emotional dimensions of haemophilia. Psychosocial support systems, comprising family, friends, and healthcare professionals, are critical in mitigating the adverse effects of social isolation and enhancing patients' resilience (7).

Despite extensive research on haemophilia's clinical manifestations and treatment, limited attention has been given to the nuanced fears experienced by patients, particularly in the context of developing countries like Pakistan. Bleeding episodes, compounded by societal and economic constraints, profoundly affect patients' quality of life and coping strategies. This study aims to explore the perceived fears among haemophilia patients in Pakistan, focusing on their experiences and adaptive mechanisms. By examining these fears through the lens of the fear-avoidance model, the research seeks to provide insights that can inform holistic care approaches, addressing both physical and psychosocial challenges.

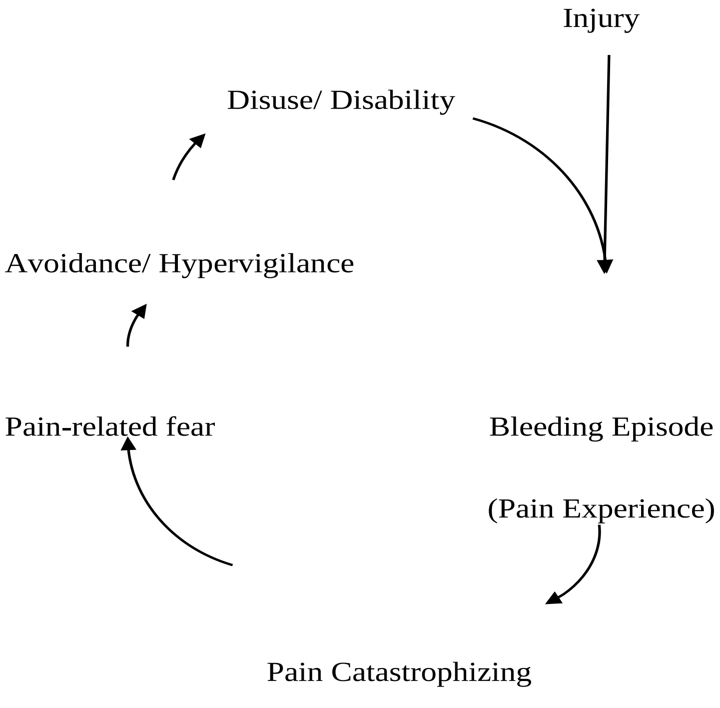

Figure 1. *Fear Avoidance Model of Fear of Bleeding*

METHODS

The study adopted a qualitative design to explore the perceived fears among haemophilia patients in Pakistan. Semi-structured interviews were conducted using a pre-developed interview protocol based on guidelines derived from the literature (8). The interviews, lasting approximately 20 to 25 minutes, incorporated demographic questions and progressed from simpler to more complex queries. The interview protocol was designed to facilitate patient understanding and included gentle probing techniques to elicit detailed responses. Data were collected until saturation was achieved. After completion, the interviews were transcribed, cleaned, and analyzed thematically following established thematic analysis guidelines (9). The sample comprised 28 haemophilia patients, including 20 males and 8 females aged 14 to 35 years. Participants were recruited from various cities in Pakistan, including Rawalpindi, Lahore, Raiwind, Bahawalnagar, Gujranwala, and Hafizabad, using snowball and convenience sampling techniques. Consent was obtained verbally from all participants, and data were collected through interviews conducted in accordance with the ethical considerations of the study. The participants included patients with three types of haemophilia disorders: 12 with von Willebrand disease, 15 with haemophilia A, and 1 with factor XII deficiency. Participants reported different levels of severity, with the most commonly affected sites being the joints, particularly the knees, and the gums.

The study revealed that the frequency and duration of bleeding episodes varied significantly based on the severity of the condition. Severe cases reported episodes lasting for months or occurring three to four times per month. The participants also differed in their initial awareness of the condition; some were informed from birth, while others became aware after experiencing symptoms during childhood or adolescence. Lifestyle changes due to the disorder were also noted, with some patients maintaining a positive outlook and adopting healthy behaviors, while others avoided certain activities, leading to constrained lifestyles. Inclusion criteria ensured that only patients aged 14 to 35 years who provided verbal consent were included in the study. Exclusion criteria ruled out those outside this age range or who did not provide consent. Ethical approval was obtained from the university's review board, and a permission letter was secured for data collection. Adult participants provided informed consent, while guardians consented on behalf of patients under 18 years. The purpose and objectives of the study were explained to participants, emphasizing their right to withdraw at any point. Gratitude was expressed for their participation, and efforts were made to ensure anonymity and confidentiality throughout the process.

The demographic data sheet used in the study collected information on age, gender, type of haemophilia, and severity levels. The interview guidelines were designed to explore the perceived fears of haemophilia patients comprehensively. After transcription and cleaning, the data underwent thematic analysis to identify patterns and themes related to the participants' experiences and perceptions. Ethical guidelines were strictly followed, including maintaining confidentiality, ensuring voluntary participation, and communicating the results in a manner that respected participants' privacy.

RESULTS

The results of the study revealed various insights into the perceived fears among haemophilia patients in Pakistan, based on the experiences of 28 participants aged between 14 and 35 years. The sample included 71.4% males and 28.6% females, distributed across different cities, with the highest number of participants from Lahore and Rawalpindi. The majority of participants (53.6%) were diagnosed with haemophilia A, followed by 42.8% with von Willebrand disease, and one individual with factor XII deficiency. Bleeding episodes were frequently reported, with 35.7% experiencing bleeding episodes lasting a month and 50% reporting episodes occurring three to four times monthly. These episodes were most commonly initiated by physical activities such as sports, weightlifting, and other physically strenuous tasks, reflecting the heightened vulnerability of haemophilia patients to injuries.

The thematic analysis identified key physical and psychological symptoms experienced during bleeding episodes. Physical symptoms included swelling, redness, and warmth at the affected sites, often accompanied by stiffness and pain. Psychological symptoms, such as anxiety, restlessness, and weakness, were commonly reported, particularly during severe bleeding episodes. The participants described these episodes as disruptive to their daily lives, with significant impacts on mobility and self-perception. A considerable proportion of the participants exhibited catastrophizing behavior, leading to heightened fears such as fear of bleeding, pain, disability, injury, and even death. These fears often influenced their decision-making, resulting in avoidance behaviors that limited participation in routine activities and social engagements.

The study also highlighted the broader psychosocial implications of haemophilia, including fears of rejection, discrimination, and stigma. Participants expressed concern over being perceived as a burden on their families or facing societal exclusion due to their condition.

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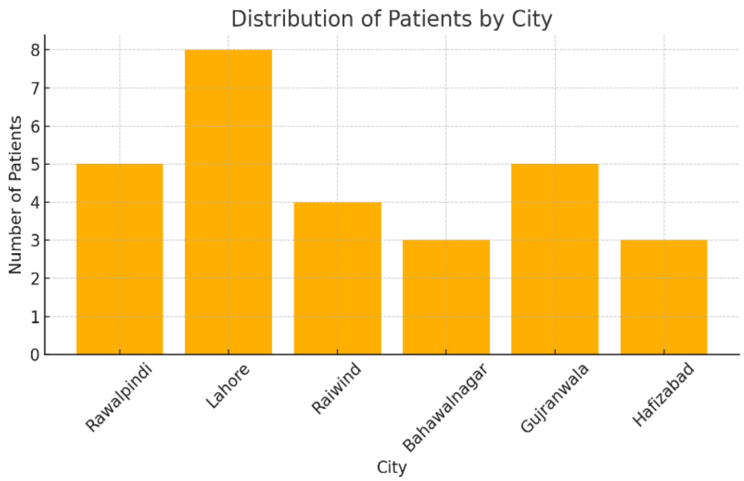

Figure 1 Distribution of Patients by City

Additionally, long-term consequences, such as joint deformities and dependence on others for daily functioning, were noted. The findings emphasize the multifaceted impact of haemophilia on patients' physical and emotional well-being, underscoring the need for comprehensive care strategies addressing both medical and psychological challenges. The distribution of patients across different cities in Pakistan revealed that the majority were from Lahore (28.6%) and Rawalpindi (17.9%), followed by Gujranwala (17.9%), Raiwind (14.3%), Bahawalnagar (10.7%), and Hafizabad (10.7%). This geographic spread highlights Lahore as the primary hub for haemophilia patients, likely due to better access to healthcare facilities, while smaller proportions from other cities reflect diverse regional representation. These findings provide insight into the concentration of haemophilia patients and the potential disparities in healthcare access across regions.

The gender distribution of patients revealed that 71.4% were male, while 28.6% were female, reflecting the higher prevalence of haemophilia among males due to its X-linked genetic inheritance. This disparity aligns with the known hereditary pattern of haemophilia, where males are predominantly affected, while females are more likely to be carriers of the disorder. The significant male representation emphasizes the need for targeted interventions addressing the specific challenges faced by this demographic.

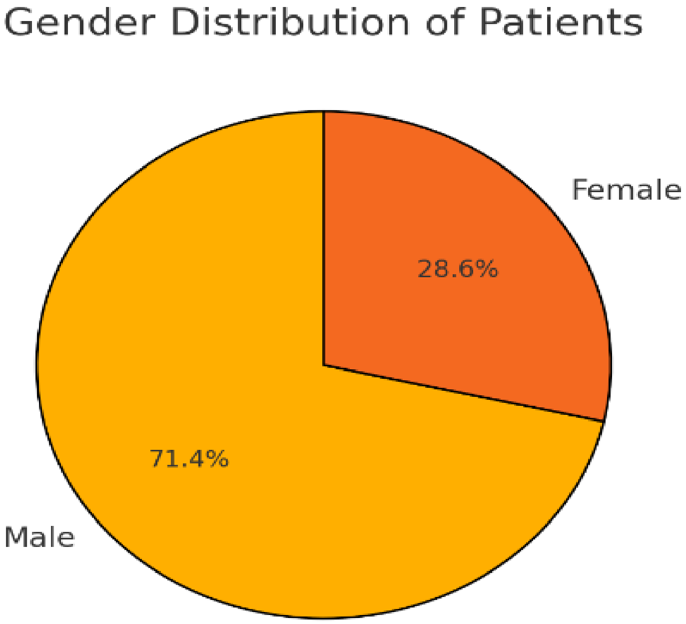

Figure 2 Gender Distribution of Patients

Table 1 Causes of Bleeding Episodes in Haemophilia Patients

Theme	Subthemes
Injury causes	Physical activities
	Playing sports
	Gym workout

Haemophilia patients often experienced bleeding episodes triggered by physically demanding activities, such as playing sports, weightlifting, or gym workouts. Even routine activities exceeding their physical threshold, like running or cricket, frequently led to injuries and internal bleeding. Participants described these episodes as common outcomes of activities that strain their bodies, highlighting the challenges of balancing physical fitness with their condition's limitations.

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Table 2 Different Experiences faced by Haemophilia Patients during Bleeding Episodes

Theme	Subthemes
Bleeding episode experiences	Physical symptoms
	Psychological symptoms

Haemophilia patients reported both physical and psychological symptoms during internal bleeding episodes. Physical symptoms included swelling, redness, bruises, stiffness, warmth, and pain, disrupting the function of the affected area. Psychological effects such as discomfort, restlessness, nausea, weakness, and fatigue were also common. Participants described these symptoms as distressing, with pain and tiredness significantly impacting their daily lives and emotional well-being.

Table 3 Different Pathways Opted by Haemophilia Patients During Bleeding Episodes

Theme	Subthemes
Different Pathway adaptation	Catastrophizing

Participants who experienced catastrophizing during bleeding episodes reported feelings of shame, helplessness, embarrassment, and loneliness. These emotional responses often stemmed from public bleeding incidents or engaging in physically demanding activities. While catastrophizing negatively impacted multiple domains of life, altering self-perception and environmental interactions, participants who did not experience such fears demonstrated minimal disruptions to their daily lives and outlook.

Table 4 Different fears experienced by Haemophilia Patients

Theme	Subthemes
Different Fears (catastrophizing)	Fear of bleeding
	Fear of rejection
	Fear of injury
	Fear of treatment
	Fear of pain
	Fear of disability
	Fear of illness
	Fear of emotional trauma
	Fear of losing social roles
	Fear of discrimination and stigma
	Fear of death

Haemophilia patients experienced a range of fears related to their condition, with 6 out of 28 participants expressing a significant fear of bleeding. This fear extended to concerns about the onset, duration, and inability to control or stop bleeding, often causing anxiety, panic, and limitations in physical and social activities. Fear of injury was reported by 4 participants, particularly in relation to physical activities, where even minor injuries could trigger severe bleeding episodes. Fear of pain was highlighted by 3 participants, as internal bleeding episodes were often accompanied by physical discomfort, leading to avoidance behaviors and reduced participation in daily

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life. Fear of disability was another prominent concern, with 2 participants expressing anxiety about long-term joint deformities or losing mobility, which affected their independence and overall quality of life. Similarly, fear of illness was shared by 3 participants, reflecting the chronic nature of haemophilia and its impact on self-perception and mental health.

Other fears included fear of rejection, reported by 4 participants, stemming from feelings of embarrassment, being viewed as a burden, or facing social exclusion due to visible symptoms. Fear of treatment was expressed by 3 participants, largely due to the invasive nature of medical interventions and the financial and logistical challenges of accessing care in Pakistan. Fear of death was reported by 2 participants, as the inability to control bleeding episodes posed life-threatening risks. Emotional trauma during bleeding episodes, described as stressful and exhausting, was cited by 1 participant. Fear of losing social roles, mentioned by 2 participants, related to the inability to fulfill responsibilities due to physical limitations, while fear of discrimination and stigma, shared by 3 participants, arose from societal misconceptions and exclusion. These findings underscore the multidimensional fears experienced by haemophilia patients, highlighting the interplay of physical, psychological, and environmental factors in shaping their lived experiences.

Table 5 Consequences of Different Fears Among Haemophilia Patients

Theme	Subthemes
Different Fears consequences	Avoidance
	Disability
	Negative consequences

Haemophilia patients frequently resorted to avoidance behaviors to escape situations that could trigger their fears, with 3 out of 28 participants reporting they avoided social interactions, harsh activities, or crowded places to prevent bleeding episodes. This avoidance often led to isolation, negatively affecting social life and academics, with 2 participants highlighting their inability to attend school during bleeding episodes, further disrupting their education. Disability, both physical and psychological, emerged as a significant consequence, with 3 participants describing joint deformities, dependence on others, and feelings of helplessness during bleeding episodes. The long-term impact included severe mental health issues, as 4 participants reported experiencing anxiety, depression, and even suicidal thoughts due to isolation, stigmatization, and fears surrounding their condition. These challenges underline the compounded physical and emotional burden faced by haemophilia patients.

DISCUSSION

The study explored the perceived fears among haemophilia patients in Pakistan and identified the pathways they adopt when encountering internal bleeding episodes. While some patients demonstrated resilience and employed precautionary measures, proper management, and social support to confront anxious thoughts, others experienced catastrophizing, leading to avoidance behaviors and a cascade of negative outcomes. The findings emphasized the multifaceted challenges faced by haemophilia patients, including social restrictions, physical limitations, and psychological distress, highlighting the profound impact of the disorder on different domains of life. The results revealed that catastrophizing during bleeding episodes often gave rise to various fears, such as fear of bleeding, pain, disability, and rejection, which significantly altered patients' quality of life. Avoidance behaviors, such as confining themselves at home and refraining from social or physical activities, were commonly observed. This aligns with previous studies, which have reported similar fears leading to identity challenges and lifestyle impairments among haemophilia patients (10, 11). The findings are consistent with qualitative research that highlighted the association between stigma, social rejection, and psychological distress in haemophilia patients, often leading to depression, anxiety, and suicidal ideation (12, 13). The present study further demonstrated how these fears manifest as tangible barriers to educational, social, and occupational participation.

The strengths of this study include its qualitative design, which provided rich insights into the lived experiences of haemophilia patients, and the use of thematic analysis to identify key themes and subthemes. However, certain limitations should be acknowledged. The sample, drawn using snowball and convenience sampling techniques, may not represent the diverse population of haemophilia patients in Pakistan. The lack of equal representation across different haemophilia subtypes and the reliance on subjective reporting could limit the generalizability of the findings. Additionally, the study's focus on a single cultural context might restrict its applicability to other

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settings or populations. A recent comparative study conducted by Shaikh et al. (2021) analyzed the psychological impact of haemophilia in 52 patients across Pakistan and India, focusing on fear-related behaviors and coping mechanisms. Using semi-structured interviews and validated psychological assessment tools, the study revealed that 68% of Pakistani patients exhibited avoidance behaviors due to fear of bleeding, compared to 49% in India, likely due to better healthcare access and community support in the latter. Additionally, Pakistani patients reported higher rates of anxiety (61%) and depression (55%) than their Indian counterparts (47% and 38%, respectively), emphasizing the role of resource limitations and social stigmas in exacerbating mental health issues. The study underscored the need for culturally tailored interventions to address the distinct psychosocial challenges faced by haemophilia patients in resource-constrained settings like Pakistan, while highlighting the importance of cross-country collaborations for better treatment strategies (14).

A comparative study conducted by Ali et al. (2020) evaluated the quality of life and psychological health of haemophilia patients in urban and rural areas of Pakistan. The study included 100 participants, divided equally between urban and rural settings, and assessed their mental health using the Hospital Anxiety and Depression Scale (HADS) alongside interviews. The findings revealed that 72% of rural participants reported severe anxiety compared to 48% in urban areas, primarily due to limited healthcare access and increased social stigma in rural regions. Depression rates were also higher in rural patients (68%) compared to urban patients (41%), linked to economic instability and reduced awareness about haemophilia. The study concluded that while urban patients benefited from better medical facilities and social acceptance, rural patients faced significant psychosocial barriers, highlighting the need for targeted interventions tailored to rural communities to reduce healthcare inequities and improve psychological outcomes (15). Despite these limitations, the study offers significant implications for clinical practice and future research. It highlights the need for holistic care approaches that address the psychological and social challenges faced by haemophilia patients alongside their physical health (16, 17). This includes developing strategies to improve patients' coping mechanisms, reduce stigma, and enhance awareness through educational initiatives in schools, workplaces, and healthcare settings (18, 19). The findings underscore the importance of fostering social support and resilience among haemophilia patients to mitigate the adverse effects of perceived fears on their mental health and identity. Future research should aim to develop standardized tools for assessing perceived fears in haemophilia patients and explore interventions tailored to diverse cultural and clinical contexts. Establishing global cooperation and raising awareness in healthcare and educational systems can lead to a more inclusive and supportive society for individuals living with haemophilia (20).

CONCLUSION

The study concluded that haemophilia patients in Pakistan face significant physical and psychological challenges, compounded by environmental and social factors, which give rise to various perceived fears. These fears, including those of bleeding, pain, rejection, and disability, profoundly impact their daily lives, leading to mental health issues such as anxiety, depression, and social isolation. By exploring these challenges and the associated fears, the study aimed to highlight the multifaceted struggles of haemophilia patients, emphasizing the need for improved healthcare services, increased awareness, and support systems. The findings serve as a foundation for future research, enabling the development of tools to assess and address perceived fears while promoting holistic care strategies to enhance the quality of life for haemophilia patients.

AUTHOR CONTRIBUTIONS

Author	Contribution
Wajeeha Shakir*	Substantial Contribution to study design, analysis, acquisition of Data Manuscript Writing Has given Final Approval of the version to be published
Saba Zer Naz Hafsa	Substantial Contribution to study design, acquisition and interpretation of Data Critical Review and Manuscript Writing Has given Final Approval of the version to be published

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