

Abstract: *The main aim of the study was to explore the perceived socio-economic burden on parents of children suffering from haemophilia and societal behavior towards patient and caregiver. A qualitative approach was utilized to narrate experiences of parenting a hemophilic child. To fulfil the said objective, 14 parents were interviewed by using sequential sampling with the help of an interview guide. All the informants included in the study were taken from Children hospital, Multan. The researcher analyzed all emerging themes from text to disseminate information. Results revealed that the majority of the parents were less educated and belonged to a middle-class background. And having a child with Haemophilia is a life-shifting phenomenon for parents. Lack of awareness regarding disease among mother caregiver was also identified as an addition to parent's miseries. Most patients were suffered from Haemophilia A, with poor health status. However, patient's caregivers were content with behavior of their family members, doctors and other medical staff. On the basis of the present findings, researcher made a recommendation to endorse patient-centred care for haemophilic patients and recognition of patient's illness and reconciliation with society.*

Key Words: Perceived Parent's Burden, Hemophilic Child, Quality of Life, Societal Behavior, Social Exclusion and Alienation, Interpretative Phenomenological Approach, Children Hospital, Multan.

Introduction

Hemophilia is a genetic sex-linked bleeding syndrome that is instigated by deficiency of clotting factor in the human body. The two types of hemophilia A and B are characterized by a dearth of clotting factor VIII and factor IX, respectively. And deficiency of these factors causes prolong bleedings [\[Nogami and Shima, 2019\]](#).

Psychosomatic condition is adversely affected by stigmatization. Most of the participants faced physical stress in the form of less productivity in any kind of work and other problems like isolation from their social circle and ambiguity of certain situations. A common false belief about people having bleeding disorder among the general public is that they consider even a minor touch can be hurtful for the patient. Hence, such patients are pampered much intensively and are not usually allowed to face any possible tough situation [\[von der Lippe, Frich, Harris, and Solbraekke, 2017\]](#).

This disorder is chronic, and the physical, as well as psychological problems associated with this disorder, are critical for both the person suffering from the disease and his family [\[Bertamino, Riccardi, Banov, Svahn and Molinari, 2017\]](#). People having

hemophilic kids have to face so many problems as their kids need extra care. From time to time, blood inoculations have to be provided, which in turn requires repeated appointments from several doctors and hospitals. These children need intensive care and control. With all these problems, such parents suffer from certain negative effects on their psyche [\[Myrin Westesson et al., 2019\]](#). As the kids need intense care, therefore parent's job, vocation, financial condition, communal life and even bodily fitness are negatively affected [\[Schwartz, Powell and Eldar-Lissai, 2017\]](#). Household management is also disturbed in such families because of the special needs of the diseased child. Other siblings of such patients face deprivation of their requirements and desires [\[Schwartz, Stark, Michael, and Rapkin, 2020\]](#).

The peril dynamics for hemophilic patient are stiffness of joints, including joints of ankle and ball and socket joints. Blood leakage from teeth, oral cavity, nasal cavity and defecation also occur, especially after circumcision [\[Zanon and Pasca, 2019\]](#).

Several researches and articles have been published regarding the impact on physical,

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psychological and economic encumbrance of guardians of hemophilic children. Most of the time, the stress of mental health of these guardians is ignored, and only financial stress is acknowledged. It is the need of the hour to study the life issues of guardian, including their living standards, public behavior and social services they are deprived of. Moreover, the perceptions of and about the parents of sick children are neglected while they are worth noticing.

This research delivers the possible indications useful for the caretakers, guardians or parents of the sick child. It also suggests precautions for the aptness of the patient's family members so that they can, in turn, provide better care to the suffering child.

Objectives of the Study

The main aim of this study was to explore.

- I. The perceived socio-economic burden on parents of children with hemophilia.
- II. Societal behavior towards patient and caregiver.
- III. Quality of life of the patients suffering with hemophilia

Methodology

Researcher adopted the following methodology to fulfil the above-mentioned objectives:

Research Design

A qualitative study was conducted to collect data from parents of hemophilic patient. The research area for the present study was The Children Hospital, Multan. Before the interview, formal permission was obtained from the respondent. Furthermore, In order to collect Socio-demographic information of respondent, a well-structured questionnaire was used. Interpretative Phenomenological Approach (IPA) was utilized to capture a profound understanding of patients and caregiver (parents) life experiences. This approach helps the researcher in integrating the pre-understanding of a particular phenomenon.

Process and Analysis

Respondents were selected through sequential sampling. The number of informants (e.g. 14) was not pre-determined. The reason for not including more informants after the 12th interview is that researcher gathered sufficient and rich material, and no more new information was attained. However, the researcher interviewed two more informants to make sure the saturation point. Interviews lasted 30-40 minutes. In the first stage, the researcher maintained rapport with the

participant by greetings and informal conversation and then began interviewing the participant. Interviews were recorded, and important points were also noted during the interview. The researcher assign a unique code (ID numbers) to each transcript to ensure transparency and confidentiality. Data were analyzed by using Thematic Analysis. In order to identify themes researcher listens to recordings and read transcripts, meanwhile noted important points. After that, all the emerging themes were clustered together. The validity of the context was checked by two PhD scholars and one research analyst. The researcher used the original verbatim of the respondent throughout the paper in order to express the respondent's views.

Results and Discussion

Informants Characteristics

The researcher conducted 14 in-depth interviews; all caregivers were females (100%). Only those females were included in the sample who were carriers and have at least one hemophilic child. Before the interview, permission was granted from all of the participants through written informed consent. In order to have variation in the sample, females belonged to different age groups were interviewed, having an age range [20-45 years]. Among them, mostly [10] females belonged to age range [30-35] years, only two participants fall in the age category [20-25 years], and the rest of the two females belonged to age category [40-45 years]. Most of the participants were illiterate or having primary level qualification with poor economic background with a minimum salary range [11%] 10000-15000, and the maximum salary was 30000 [only one participant], the higher level of education among all participants was Graduation [only one participant]. More than half of the participants [8%] were engaged in various tasks for earning purpose like thread cutting worker [1%], embroidery work, e.g. needlework [2%], woollen shawl making, however, only in the winter season [1%], labor, e.g. harvest crops [2%] and Maids in houses [2%]. While remaining were house wife's [6%]. Slightly more than half [8%] of caregivers lived in a joint family system, having a number of children [max: 06-min: 01]. The majority of the females [8%] having 2 to 3 children, a few have 6 children [4%], and one female has one child while the rest of the one has 5 children.

Financial and Psycho-Social Burden on Parents

The first emerging theme illustrates the financial and Socio-psychological burden faced by parents of hemophilic patients. Parents of hemophilic children

deal with a multitude of demands and practical issues [Westesson, Wallengren, Baghaei and Sparud-Lundin, 2018]. And personal suffering is one of the consequences of having a child with chronic disease. This 'personal suffering' would term as 'burden'. Parental burden comprised of objective or practical problems (e.g. frequent hospital visits, time management for child treatment, extreme care and supervision, least time for their own leisure as well as for work and economic distress) and subjective or Psychological problems (disturbed relations with family and spouse, anxiety, depression, missed dreams and hope) [Pilapil, Coletti, Rabey, and DeLaet, 2017].

Financial Burden

Most of the respondents reported that disease adversely impacts their financial condition as the majority of the respondents belonged to a low-class background and cannot afford such an expensive treatment. They do not have enough money for treatment medicines, feel difficulty in transportations, arrangement of blood and hospital visits. Thus they borrow money from relatives and friends to meet the expenses.

"Our relatives abused us in many ways, particularly when we are not able to pay back their money that we have borrowed for the treatment...not only this they said that your child would never recover. You are just wasting your money on a victim child (expressions of great disappointment)... You can't even imagine... how much pain these words are...and...you know how hard these words hit, particularly when you are already going through a dreadful situation" (ID-3).

Participants (four) revealed that they have to make frequent visits to the hospital for checkup, and treatment which directly impacts their employment conditions. As mostly patient's fathers were temporary job holder or daily wagers. So they remained absent from their work or on short leave. This leads them to lose their jobs, as reported by one of the participants.

"My husband was a daily wager...you know it is very difficult for a daily wager to manage treatment expenses of a hemophilic child...my husband lost his job due to remain absent from work...This impacts not only on our child's treatment but also on our lives and on our families too... Employers should cooperate with us and should understand our miseries" (ID-14).

"We sold out our animals (cows) to meet the expenses of treatment of our child. Those animals were the source of our livelihood. Now we have only

one animal and no source of income besides this. This adds to our miseries. My elder daughters left school because we are not able to afford their education expenses...Sometimes we are not able to manage food for our family, but we manage medicines and treatment for our victim child" (ID-3).

Psycho-Social Burden

Almost all participants described certain symptoms they feel as a consequence of their child's ill health, and it negatively impacts their social and psychological well-being. Respondents feel depression (4), anxiety (2), frustration (5) and health issues (10) too. Moreover, their social life (10) is also disturbed due to their hemophilic child.

"Having a hemophilic child is really frustrating; I have domestic issues with my husband... feelings of hopelessness cause anxiety in me. And I went through a condition of trauma which affects not only my marital life but my personal and social life as well" (ID-11).

Cutter et al. (2019) demonstrated that having a hemophilic child affects marital relations between husband and wife.

Most of the participant reported that their child's condition affects their health adversely as they remain awake the whole night when their child go through pain full treatment (blood transfusion) or have bleed episodes. This nevertheless had a negative impact on the mother caregiver quality of sleep but also impacted badly her health.

"I have to spend sleepless nights... due to my child's poor health ...and it a matter of my routine. I avail only few hour for sleep and rest. I am also suffering from blood pressure. So not having proper rest made my health more worse...but I never take care of my health...I just want to look after my child and want to see him healthy and sound" (ID-2).

The majority of the respondents reported that nature of their genetic makeup or being a mother of hemophilic child negatively influence their mental health. Especially when they have to face medical and social barriers to extend their family (family planning), as one of the respondents said:

"Our Doctor advised us to limit our family. If I conceive, there are 100 % chances the child would be hemophilic so we have to restricted our family and could not have more babies. I have only one child son (hemophilic). You are fertile but could not have more babies...it breaks you and made your whole life awful" (ID-8).

Six of the respondents reported feelings of

social exclusion and alienation which is the result of limited out door mobility of parents especially mother caregiver. Having no time or less time for social gatherings, limited interaction with relatives and friends and less social contacts negatively affect social life of parents and create anger and frustration.

"You know...being a parent of a hemophilic child is not that much easy. You have to sacrifice all the time and made compromises at each and every stage of your life...you have to skip many family gatherings and social events as well...you just confined yourself at your home...Sometimes I felt that I am living in lifelong and life-threatening confinement..." (ID-4).

Social Stigmatization

Under the theme of stigmatization, researcher uncover stigmatization at two levels that are; at family level and at societal level. During interview, researcher also explore the experiences of discrimination faced by respondents due to their condition. [Exploring extend of discriminatory behavior was not included in the purpose of present study, However, during interview some of the respondents share the experiences of discrimination, especially at school, So the Researcher also added some of their quotes].

All informants conveyed that they were content by the patient's father's behavior. They reported that their husband love their child and took all the responsibility for the treatment.

"He did everything for his child, he love him, play games with him, despite facing problems in meeting all the expenses of treatment he managed it any how" (ID-6)

They also described about their good relationship with their spouse. However, three participants reported that sometimes husbands taunt them for giving birth to a sick child, and mother in law also use humiliating words for them and curse them One of the participants described that when it was diagnosed for the first time that she is carrier her husband and mother in law react intensely worse:

"I do remember about a year back, when I was diagnosed as carrier I get upset due to behavior of family members (husband and mother in law). They blamed me for all the hell what we were going through. My husband feel so negative and made me feel guilty by saying that you bring this misfortune in our family. My mother in law often taunt me and complaining me for having this disease" (ID-4)

Mostly participants stated a pleasant

relationship of patient with siblings and friends. One of the participant described that his sisters took good care of her brother and play with him. Most mothers reported that their child has a very good and friendly relationship with his peers. They are very cooperative, took care of their child, and play games carefully. However, one participant reported that his siblings often fight with the patient:

"Sometimes my two elder daughters fight with their hemophilic brother, because I give more time to him and do more care of him and they feel jealousy and show sibling rivalry. I do not feel good and my son also get upset due to his sisters misbehavior" (ID-2)

The same participant (ID-2) also made complaint about his peers by saying that they want to stay away from my child, and do not have a friendly relationship with him. She also narrated a mishap of fighting at school:

"One day, at school, my child had a fight with his classmate because his mate make fun of his bleeding disorder, and then they had fought, his mate beat him badly, such fights are dangerous for my child, he gets injured and it leads toward bleeding. A teacher rescue my child and provide first aid. After this incidence, I remain worried all the time when he went to school due to behavior of classmates" (ID-2)

Another participant shared the same views and informed that:

"My child is so lonely, without any friend...because no one wants to be his friend and have bleeds like him (tears in her eyes)" (ID-9)

All informants conveyed that they come across a certain degree of stigmatization regarding their child condition. And they face various stereotypes that still exist in our society. Informants reported that when they have to interact with the general population, whether in a social gathering or during travel or shopping, they faced lots of misconceptions and people use to stigmatize them in different ways. A very common misconception regarding the hemophilic patient is that they must have HIV [a contagious disease], and thus they are reluctant to sharing things and touching the patient (ID-2, 4, 9, 11, 14).

"People inevitably linked bleeding disorder with HIV".

"You know, in social gatherings, people avoid shaking hands with a person having bleeds, and people think they have HIV too (ID-9)".

Participants reported that they face lots of public misconceptions like;

"Oh, we can't share the same plate or mug with an HIV patient... They are also reluctant to share a toilet seat with HIV patient" (ID-14)

Results from the theme mention above show consensus with the previous studies as there are so many misconceptions regarding bleeding disease among the general public. As [Goffman \(1963\)](#) uphold that the greatest degree of social stigma is when an individual is supposed as accountable for having an illness, and the illness is incurable and progressive, and it was not fully understood by the public. Similarly, the disease of hemophilia fits into this standards.

Education, Physical and Social well-being

Quality of life of patient was investigated under the themes physical and social well-being and education, which focused on physical and social dimension of health and on educational activities of patients. [Fischer et al, 2016](#) investigated that disease is not the sole factor which negatively influence QOL of hemophilic patient, demographic features, personality and financial status also effect patient's life.

Physical well being

Most respondents narrated that the Health status of patients was not good due to which physical functioning of patient was also disturbed. They are not able to perform their daily routine tasks by themselves due to severe pain in joints. They often had not only severe joint pain but also had pain in the elbow and knee. And they had bleeding episodes in case of external injury which have a direct impact on their physical well-being. In the condition of bleeds in joints they have limited mobility. This all made most of the patients dull and lethargic. Patients suffering with hemophilia A have injected factor VIII injections [sometimes at home by mother caregiver]. This pain full treatment cause a condition of trauma in many patients.

"My child frequently has bleeding episodes...bleeds with severe pain in joints, knees and elbow...and this pain make him unable to move anywhere" (ID-1)

As far as patient's quality of sleep is concern, most of the respondents claim that their children have good quality of sleep. However, only two of the respondents (ID-6 and ID-10) reported poor quality of sleep of patient. They also narrated that when their child had bleeding episodes or pain in joint they remain disturbed at night or can't be able to sleep whole night. This worsen their condition more, and they missed their school, also remained dull and sluggish in the next day.

Education

Patient school life and social life was disturbed due to bleeding episodes. They can only participate in indoor games, went government schools due to financial problems and have limited friend circle.

"My child has frequent bleeds in knees, ankles, and joints, and it affects his mobility. And affects all aspects of life. He missed his school many times, he is not able to complete the syllabus on time, can't play outdoor games. Our Doctor has restricted my child to play outdoor games like football, cricket etc. I remained worried about his future and career" (ID-6).

One of the mother respondents described that:

"I wish...like other children...my child also took part in extra-curricular activities and games at school...but I hide my feelings because I know such activities are dangerous for my child". (ID-14).

These results are aligned with a previous study by [Chu et al, 2018](#), who identified problems in physical health and mobility as a consequence of bleeding episodes.

Social-Well being

Patient's Social life is also disturbed due to his illness. Most of the patients have few friends and less participation in social activities.

"My child is so mischievous, he insists me to let him go outside and let him play with other children but I did not allow him to went outside and play games, because I remain worried about his health and if he get injured external bleeding started which is very pain full and I don't want to see my child in pain". (ID-5).

Conclusion

From the above discussion it was concluded that majority of the respondents belonged from poor families and faced financial stress due to their ill child. Researcher found that Physical and mental health of parents was also affected badly and they were physically and socially stigmatized by both family and society which tend to lead them alienation. It was also evident that patient went through severe pain and trauma due to internal and external bleeding episodes. The disease also had a negative impact on patient's mobility, physical health, outdoor activities and school life too.

Recommendations

On the basis of current findings researcher-made following recommendations

- Educate and aware general public in order to

eliminate misconceptions regarding bleeding disorder

- Government should made policies to facilitate patient's family to reduce their financial burden
- Hospital administration should refer patients and patient's families to Psychiatrist and

occupational therapist to provide them assistance regarding their mental health

- More research is needed to create self-management intervention for patients to made them empower

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