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"Does my teacher know anything about my disease?": A cross sectional study to know the awareness level of teachers about hemophilia in Pakistan

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ABSTRACT

The objective is to assess the awareness level of hemophilia among schoolteachers. We used a closed questionnaire to conduct a cross-sectional study on hemophilia knowledge. Teachers of hemophiliacs students in Faisalabad took part in the study. A Cronbach's alpha was used to validate the questionnaire (a= 0.775). 9 schools having 111 teachers consented to the study. About 86.48% of the participants were female, while 13.52% were male. High school teachers accounted for 45.94%, middle school teachers for 24.32%, and preschool teachers for 29.74%. Furthermore, 33.20% of the participants had no understanding of hemophilia, 14.50 percent had a low level of information, 35% had a fair level of knowledge, and 17.30% had a high level of knowledge. Teachers in high school were the most knowledgeable about hemophilia (11.7 %). The greatest knowledge gap was in treatment, where just almost half the percentage of the teachers (47.7%) were aware of the proper treatment for hemophiliacs. One-third of the sports teachers had no idea what hemophilia was. It was found that no teacher had the ability to provide basic first aid to hemophiliacs. A large proportion of teachers at school going hemophiliacs had little or no understanding of hemophilia, and just a few teachers knew about the disease. As a result, more educational initiatives are needed to raise critical awareness.

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1. Introduction

It is an X-linked genetic bleeding disorder due to lack of clotting factors, factor VIII (haemophilia A) and IX (haemophilia B) (hemophilia B) are most frequent factors. It affects about 1 in every 5000 persons. According to the Annual Global Survey done by World Federation of Hemophilia in 2016, there were 184,723 persons who are hemophiliacs, with Asia Pacific accounting for 30% of them.

Only 10% of patients were documented in Pakistan, even though there were 20,000–25,000 haemophilia sufferers in total. It remains a high-burden disease for a variety of causes, and hemophiliacs care in many developing countries in this region remains unsatisfactory (Stonebraker et al., 2020).

With the help of society, a hemophiliac can receive the greatest and most complete care system possible (Ghosh & Ghosh, 2016; Phadnis & Kar, 2017). However, society lacks knowledge and awareness concerning haemophilia (Saxena, 2013; Williams & Chapman, 2011). Several studies have been done in poor regions to examine the haemophilia awareness

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level in certain populations such as families, nurses, and hemophiliacs patients (Mohammed, 2013).

None of these studies evaluated the level of awareness regarding disease among hemophiliac's teachers. As a result, we aimed to analyze the level of awareness among school level teachers regarding disease. Findings of this study may be useful in improving hemophilia knowledge in the society with hemophiliacs, particularly among teachers who play an important role in helping school going hemophiliacs**.**

2. Methodology

The method of investigation was cross sectional. For the study sample, baseline data was driven as part of the PhD thesis project of the author. After acquiring the permission of parents and the Hemophilia Treatment Center administration we collected data of patient's school. To meet the objectives of study we requested the schools for permission to conduct our research. Out of total 800 patients who were registered in Hemophilia Treatment Center Faisalabad, those patients were selected for the study who were school going and from Faisalabad. The respondents were not chosen at random, but rather based on the school's capacity to react to our request. In total 12 schools were contacted, 2 of them did not respond to our call, 1 refused to participate in the study. From 9 remaining schools who gave consent for the study we distributed the questionnaire to all the teachers. Out of 156 teachers, 111 consented for the study.

Researchers utilized a closed questionnaire to assess hemophilia knowledge. For all participants to understand the questionnaire, it included 14 questions written in Urdu. The tool was based on "true and false" statements to check the level of awareness. Hemophilia's Definition, Hemophilia's inheritance, Hemophilia's symptom, Hemophilia's therapy, Hemophilia's complication, and Hemophilia's physical activities associated to hemophilia were all categorized. The tool was completed anonymously by the participants, and the findings were gathered by interview during second visit.

The important point in the survey was whether the respondent was aware of hemophilia or had never heard of it. If a participant answered, "I don't know about" or "I've never heard of hemophilia," the quiz would be abandoned. The questionnaire contained 14 "true or false" statements. We assessed participants as having "poor" knowledge of hemophilia if they could properly answer 1–6 questions. Participants with 6–10 accurate answers were deemed to have "fair knowledge" about hemophilia, while those with 11–14 correct answers were deemed to have "excellent knowledge." With a Cronbach's alpha of 0.775, we were able to validate our questionnaire. The statistical programme for social sciences (SPSS) version 21.0 was used to analyze the data. The total and percentage were the descriptive data assessed for categorical variables.

3. Results

Twelve schools in Faisalabad were identified as having hemophiliacs, two schools did not respond, and one school declined our invitation to involve in the research. Researchers evaluated 111 schoolteachers who fully participated in the survey.

Figure 1: Social Treatment in School with Hemophiliacs

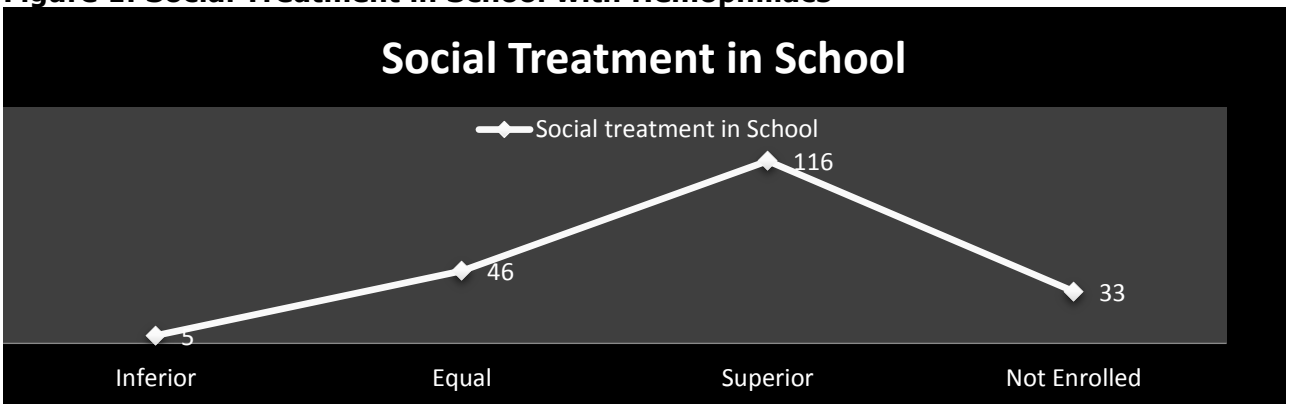


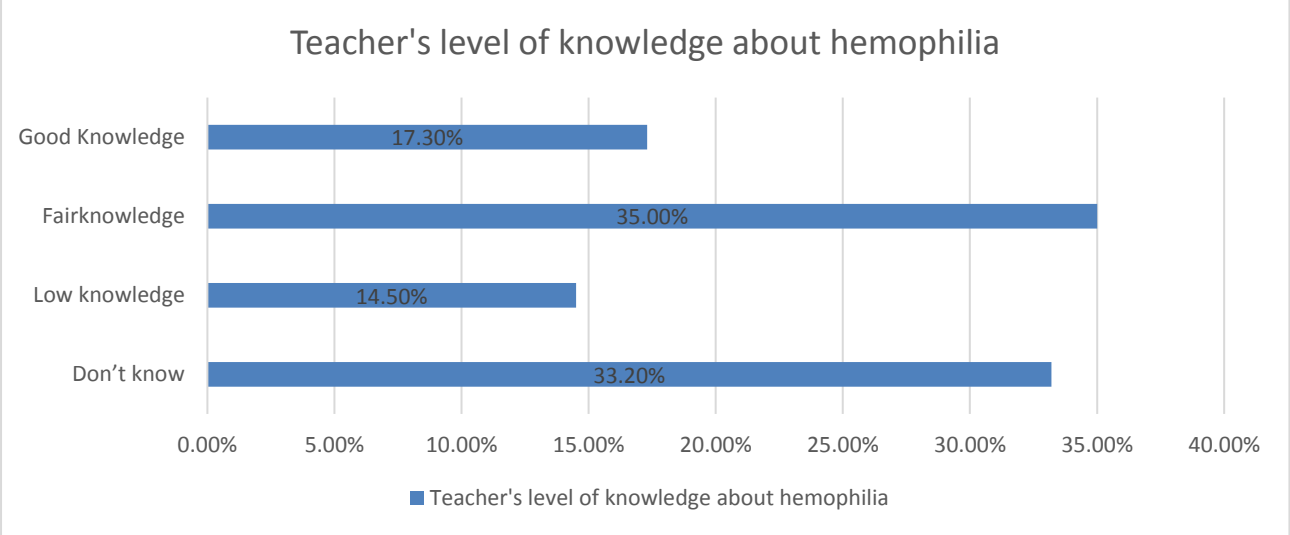
Figure 1 showed the frequency of 200 patients who shared their feelings regarding how they socially treat in their schools. The patients reported they were treated inferior 5(2.5%), equal 46(23%), superior 116(58%) and some had not enrolled in school 33(16%). This result clearly values the importance of awareness regarding hemophilia among teachers of hemophiliacs.

Table 1: Characteristics of respondents

Range of Age	20 – 65 years (N= 111)	
Gender	**Male**	15
	Female	96
Level of school	**Pre school**	33
	Middle school	27
	High school	51
Education level of teachers	**Masters**	7
	Bachelor level	92
	Diploma holder	4
	High school level	5
	Not say about education level	3

Table 1 summarizes the Preschool, Middle school, and High school were the three types of schools. High school has the highest percentage of students (45.94 %). Five sport teachers were also among the respondents who completed the survey.

Figure 2: Level of Awareness among Teachers about Hemophilia



Only 17.3 percent of teachers had good knowledge about the disease, 45.1 percent of whom were high school teachers. A big proportion of participants had zero to fair level of awareness of Hemophilia. Figure no 1 depicts the hemophilia knowledge among hemophiliacs' teachers. Five sport teachers took part in the research. Two of them knew nothing about hemophilia and three knew a lot about it.

Table 2: Distribution of respondents according to their correct answers and types of questions asked

No of Questions	Kinds Questions	Right Answers in (%)
1	**Hemopholia's definition**	63.3
2	**Hemopholia's symptoms**	67.7
3	**Hemopholia's inheritance**	71.12
4	**Hemopholia's treatment**	47.7
5	**Hemopholia's complications**	61.2
6	**Hemopholia's physical activity**	90.7

Each respondent who claimed that he or she was aware of hemophilia and completed the tool had their responses examined. Table 2 displays the outcome. Most teachers (90.7%)

replied correctly when asked about hemophiliacs' safe and secure physical activities. The greatest knowledge gap was in treatment, where just almost half percentage of the teachers (47.7%) were aware of the proper treatment for hemophiliacs. Moreover, it had unsatisfactory results in terms of complication and definition.

We questioned the teachers during our second visit to learn about how unusual the condition seemed to them, which led to their inability to provide first aid to hemophiliacs. Most of them were unaware that our region had only a few clinics capable of providing the necessary treatment.

4. Discussion

Hemophilia care necessitates close coordination between hemophiliac caregivers, their families, and people from a variety of professions and organizations (Ghosh & Ghosh, 2016; Phadnis & Kar, 2017). There is a lot of research available on hemophiliacs, families of hemophiliacs, and medical personnel' knowledge (Klein & Nimorwicz, 1982; Mohammed, 2013; Nazzaro, Owens, Hoots, & Larson, 2006; Van Laar, Warren, Desai, & Fogarty, 2014).

According to our knowledge, no research has been done on hemophiliacs' teachers' hemophilia knowledge. Teachers spend ample time with their hemophiliac students, and many activities at school might cause bleeding, which can be life-threatening. In our study, nearly half of the teachers at hemophiliacs had no awareness of hemophilia. Our findings are consistent with previous research that found a dearth of understanding about hemophilia in a variety of groups, including hemophiliacs and their families. Thirty Pakistani hemophiliacs, ranging in age from 8 to 37 years old and with varying levels of education, had low hemophilia knowledge (Hoseini, Valizadeh, Zamanzadeh, Fallahi, & Behtash, 2014; Karimi, Zarei, Haghpanah, & Zahedi, 2016; Mantik, Gunawan, & Wowiling, 2020; Novais, Duclos, Varin, Lopez, & Chamouard, 2016; Pandey, Panigrahi, Phadke, & Mittal, 2003; Salih, 2014).

A study found that French hemophiliacs and their informal carers lacked adequate knowledge and abilities when it came to hemophilia drugs and their management. Nonetheless, an ancient study in the United States (US) found that family members of hemophiliacs had strong overall awareness regarding hemophilia, with mothers of hemophiliacs doing best of all (Klein & Nimorwicz, 1982).

Interestingly, two studies in Iraq found that nurses who care for hemophilic children lacked hemophilia knowledge (Mantik et al., 2020; Salih, 2014). The amount of knowledge was significantly connected with age, level of education, experience, and training. An international survey of hematologists revealed a knowledge gap in hemophilia care (Van Laar et al., 2014).

We found that hemophiliacs' teachers were knowledgeable with the fundamentals of hemophilia. However, a large majority of individuals were unaware of the initial hemophilia treatment and basic first aid. Only a few hemophiliacs' sport teachers took part in our research. One-third of them had no idea what hemophilia was. This could make it difficult to conduct safe physical activities for school going hemophiliacs. According to a national survey of hemophiliac teens in the United States, 60% of respondents avoided strenuous activities to manage their disease. Moreover, a quarter of the participants did not do any regular moderate physical activity (Nazzaro et al., 2006).

Nonetheless, a study found that physical activity in school going hemophiliac children does not increase the exposure of advancement of bleeding in joints in the presence of regular prophylaxis treatment and better management. Physical activity is advised as a preventative approach, with physical activity being avoided only when a bleeding episode has occurred (Ross, Goldenberg, Hund, & Manco-Johnson, 2009).

Teachers in this study had no understanding of hemophilia, which is an issue. Due to this problem, education and training are required. Experience and studies have shown that continuing to improve educational activities aimed at hemophiliacs, carers, the community, and health staff is necessary. The approach must be a patient-centered one and based on the feedback from respondents. Hemophiliac societies have previously played a significant role in

the success of hemophiliacs and associated family education in low-income countries (Pandey et al., 2003; Phadnis & Kar, 2017).

Following the information we provided, the hemophilia organization in our area organized several events to combat the lack of awareness. To begin they invited every school, where their registered hemophiliacs are studying, to an annual hemophilia meeting which was also attended by parents and hemophiliacs. The activities comprised a hemophilia educational programme, basic training in hemophilia management, and the distribution of a hemophilia practical book.

Teachers were also involved in the hemophilia society's campaign by spreading hemophilia information in schools via flyers. To succeed, teachers had to overcome numerous challenges posed by culture, stigma, and societal judgment.

5. Conclusion

Hemophilia is an uncommon coagulation illness that very few people are aware of. Teachers who work with patients with hemophilia (PWH) play an important role in assisting school going hemophiliacs. There have been few studies on the disease's knowledge among hemophiliacs' teachers.

One third of the sports teachers had no idea what hemophilia was. It was found that no teacher had the ability to provide basic first aid to hemophiliacs. A large proportion of teachers at school going hemophiliacs had little or no understanding of hemophilia, and just a few teachers knew about the disease. As a result, more educational initiatives are needed to raise critical awareness.

Hemophiliacs' teachers' knowledge of the disease is lacking. We need to improve hemophiliacs instructors' access to information related to hemophilia and its basic first aid. Sports and physical activity teachers need to be encouraged to have some sort of awareness regarding the bleeding disorders. So that hemophiliac children's school going age is productive and healthy.

There were some flaws in this research. We have yet to conduct an evaluation of the hemophilia educational programme because just a few hemophiliacs' teachers participated.

References

Ghosh, K., & Ghosh, K. (2016). Management of haemophilia in developing countries: challenges and options. *Indian Journal of Hematology and Blood Transfusion, 32*(3), 347-355. doi:https://doi.org/10.1007/s12288-015-0562-x

Hoseini, F. A., Valizadeh, L., Zamanzadeh, V., Fallahi, S., & Behtash, M. R. (2014). Knowledge, attitudes and practices of preventing complications among adolescents with severe hemophilia. *Thrita, 3*(2), e8758.

Karimi, M., Zarei, T., Haghpanah, S., & Zahedi, Z. (2016). Evaluation of knowledge of patients with hemophilia regarding their diseases and treatment in Iran. *Turkish Journal of Hematology, 33*(4), 355-370.

Klein, R. H., & Nimorwicz, P. (1982). The relationship between psychological distress and knowledge of disease among hemophilia patients and their families: A pilot study. *Journal of Psychosomatic Research, 26*(4), 387-391. doi:https://doi.org/10.1016/0022-3999(82)90012-5

Mantik, M. F. J., Gunawan, S., & Wowiling, S. (2020). Knowledge about hemophilia among teachers of patients with hemophilia in Indonesia. *Pediatric Hematology Oncology Journal, 5*(3), 126-129. doi:https://doi.org/10.1016/j.phoj.2020.06.003

Mohammed, A. O. (2013). Assessment of Mothers Knowledge and Practices with Hemophilic Children type A at Azadi Teaching Hospital in Kirkuk City. *Iraqi National Journal of Nursing Specialties, 26*(2), 35-48.

Nazzaro, A.-M., Owens, S., Hoots, W. K., & Larson, K. L. (2006). Knowledge, attitudes, and behaviors of youths in the US hemophilia population: results of a national survey. *American journal of public health, 96*(9), 1618-1622.

Novais, T., Duclos, A., Varin, R., Lopez, I., & Chamouard, V. (2016). Treatment-related knowledge and skills of patients with haemophilia and their informal caregivers. *International journal of clinical pharmacy, 38*(1), 61-69. doi:https://doi.org/10.1007/s11096-015-0207-z

Pandey, G. S., Panigrahi, I., Phadke, S. R., & Mittal, B. (2003). Knowledge and attitudes towards haemophilia: the family side and role of haemophilia societies. *Public Health Genomics, 6*(2), 120-122.

Phadnis, S., & Kar, A. (2017). The impact of a haemophilia education intervention on the knowledge and health related quality of life of parents of Indian children with haemophilia. *Haemophilia, 23*(1), 82-88. doi:https://doi.org/10.1111/hae.13070

Ross, C., Goldenberg, N. A., Hund, D., & Manco-Johnson, M. J. (2009). Athletic participation in severe hemophilia: bleeding and joint outcomes in children on prophylaxis. *Pediatrics, 124*(5), 1267-1272. doi:https://doi.org/10.1542/peds.2009-0072

Salih, Y. A. (2014). The Perspective of the Pediatric Nurses toward Hemophilia in the Teaching Hospitals of Kirkuk city. *kufa Journal for Nursing sciences, 4*(3), 1-8.

Saxena, K. (2013). Barriers and perceived limitations to early treatment of hemophilia. *Journal of blood medicine, 4*, 49-56. doi:https://doi.org/10.2147/JBM.S43734

Stonebraker, J. S., Bolton-Maggs, P. H., Brooker, M., Evatt, B., Iorio, A., Makris, M., . . . Pierce, G. F. (2020). The World Federation of Hemophilia Annual Global Survey 1999-2018. *Haemophilia, 26*(4), 591-600. doi:https://doi.org/10.1111/hae.14012

Van Laar, E. S., Warren, C., Desai, J., & Fogarty, P. F. (2014). Knowledge Gaps in the Management of Hemophilia Among Hematologists/Oncologists. *Blood, 124*(21), 4831. doi:https://doi.org/10.1182/blood.V124.21.4831.4831

Williams, K. A., & Chapman, M. V. (2011). Social challenges for children with hemophilia: Child and parent perspectives. *Social work in health care, 50*(3), 199-214.