Profile Study of a School Going Child with Haemophilia

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ABSTRACT

The Rights of Persons with Disabilities Act, 2016 has specified 21 disabilities in its schedule where haemophilia has been added as one of the disability. Haemophilia is a bleeding disorder. A profile study of a school going child with haemophilia was conducted to identify the difficulties faced by the child in learning as well as carrying out day-to-day activities. A qualitative single case research design was adopted. Self designed research tools were administered to collect information. The findings revealed that there was very low or no awareness among stakeholders regarding haemophilia, its causes, symptoms, diagnosis, treatment and overall management. The child was facing lot of difficulties in learning due to his persistence absences from school and restricted participation in school activities because of his inconsistent episodes of internal or external bleeding, injuries and consecutive treatment. The school did not have any guidelines, specific educational intervention as well as individualised support programme for taking care of his health emergency, safety, education and coping with stress and pain. Teachers and parents, both, expressed their needs for training and support with regard to education and management of children with haemophilia

Keywords: *Haemophilia, disability, chronic health impairments, blood disorder, inclusive education.*

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सार

दिव्यांगजन अधिकार अधिनियम, 2016 में विभिन्न 21 प्रकार की दिव्यांगता को निर्दिष्ट किया गया है जिनमें से हीमोफिलिया एक है। हीमोफिलिया एक अधिरक्तस्त्राव की अवस्था है। एक हीमोफिलिया से प्रभावित बच्चे के समक्ष दिन-प्रतिदिन की गतिविधियों को पूरा करने में आने वाली कठिनाइयों के साथ-साथ अधिगम संबंधी चुनौतियों का अन्वेषण करने हेतु यह पार्श्व-अध्ययन किया गया । इस अध्ययन में एकल व्यक्ति-विशेष गुणात्मक अनुसंधान विधि को अपनाया गया। सूचना एकत्र करने के लिए स्वनिर्मित अनुसंधान उपकरणों का प्रयोग किया गया। इस अध्ययन से यह ज्ञात हुआ कि हीमोफिलिया के कारणों, लक्षणों, रोग-निर्धारण, उपचार और समग्र प्रबंधन के बारे में अंतर्संबंधित लोगों के बीच बहुत कम या कोई जागरूकता नहीं थी। अपनी अंत: व बाह्य रक्तस्त्रावों, जख्मों और निरंतर उपचार प्रक्रिया की वजह से वह बच्चा विद्यालय से ज्यादातर अनुपस्थित रहता और कई गतिविधियों में उसकी भागीदारी वर्जित थी, जिसके कारण सीखने में उसे कई कठिनाइयों का सामना करना पड़ रहा था। विद्यालयों में हीमोफिलिया से प्रभावित बच्चों से संबंधित विशिष्ट शैक्षिक सेवाओं व व्यक्तिगत सहायता कार्यक्रम की रूपरेखा तैयार करने-जैसी कोई दिशानिर्देश नहीं थी, जो कि बच्चे की स्वास्थ्य-संबंधी आपातकाल की स्थिति में, उसकी सुरक्षा व शिक्षा हेतु तथा उसके मानसिक तनाव और शारीरिक पीड़ा से निपटारे में सहायक हो। शिक्षकों और माता-पिता, दोनों ने ही हीमोफिलिया वाले बच्चों की शिक्षा और प्रबंधन के संबंध में प्रशिक्षण और सहायता की आवश्यकता व्यक्त की।

Introduction

While playing football, cricket, bicycling and many other games, children do get easily injured. So scratches, cuts and bumps are regular part of a child's life and generally heal with little or no care. But what if it does not heal and bleeding from cuts does not stop, then it indicates a serious concern. Children with haemophilia cannot afford to get these everyday cuts and scratches.

India has enacted the Rights of Persons with Disabilities (RPwD) Act in 2016. This Act proclaims to ensure full and effective participation of children (persons) with disabilities and their inclusion in society without any discrimination and respect the rights of children with disabilities to preserve their identities. Inclusive Education is defined in this Act as a 'system of education wherein students with and without disabilities learn together and the system of teaching and learning is suitably adapted to meet the learning needs of different types of students with disabilities'. The RPwD Act, 2016 has specified 21 disabilities in its schedule where Haemophilia has been added as one of the disability under

the category 'disability caused due to chronic blood disorders'. Haemophilia is incurable, rare and genetic blood disorder in which blood does not clot normally and properly due to the lack or defectiveness of a specific Factor VIII, a clotting protein which helps in clotting after bleeding occur. When blood can't clot properly, excessive bleeding externally and internally occurs after any injury or damage. Incidence of 1 per 10,000 births progressing to chronic disability and premature mortality has been reported in studies. Indian haemophilia (bleeding disorder) registry has close to 20,000 haemophilia patients all over the country (Phadke, 2011; Ghosh and Shukla, 2017), though its estimated number swell near 50,000–100,000 (Kar, et al, 2014 and Ghosh and Shukla, 2017), when availability of investigative techniques, i.e., coagulation laboratories are available across 750 districts in the country (Ghosh and Shukla, 2017). Haemophilia can be mild, moderate and severe depending on the factor availability in the blood. Mild to severe complications include internal bleeding leading to swelling, risk of organ failure due to bleeding, easy bruising, targeted joints, damaging joints, numbness and pain of limbs, bleeding that does not stop after biting lip, nosebleed, tooth extraction, scratch and/ or paper cut. Having a disorder like this, affects the education of children while going through treatment and management of the disorder. High treatment cost of the disease leads to financial burden that also results in poor maintenance of regular treatment as well as child's physical inability to attend classes regularly in schools. These challenges directly or indirectly affect the education of children. So, the school life of children and their participation in school activities in school are also considered as an important yardstick for their quality of life. Keeping the complications of these children in view and the impact of the disorder on education of the child affected by the haemophilia, a study was conducted.

Objectives

1. To study the nature and severity of haemophilia in the child causing disability.
2. To identify the difficulties faced by the child with disability due to haemophilia in learning as well as carrying out day-to-day activities.

Research Method

Research Design

The design of this study was qualitative (single case design) in the nature.

Sample

A child with haemophilia studying in an elementary school of Dang District in the State of Gujarat, his parents, two teachers and a health care provider were interacted for in depth study to investigate the implications of haemophilia on learning and day to day functioning of the child and the family.

Research Tools

For collection of the information from primary sources, five research tools, i.e., Child Profile Sheet, Information schedule for Parents, Child and Health Care Providers and a Questionnaire for Teachers were designed. Child Profile Sheet was used to obtain information about the child with haemophilia. It consisted of nine sections for obtaining detailed information on socio-demographic clinical profile of the child. This profile sheet was used in collecting disease related specific information, present complications, previous consultations, record of investigations, childhood history, nature of physical illness, immunisation history, daily routine of the child, school history, play profile, familial composition and family history of this disease, social and neighbourhood ecology, specific management problems faced by the parents and parental report of the child. Interview Schedule for Parents was used to collect information regarding the child's health, education and overall management of the disorder. This interview schedule had 29 items with 10 open ended items restricted to record responses in maximum four to five sentences and 19 yes/no type items with space to query reasons for 'yes/no' responses. Interview Schedule for Child was also used to collect information from the child regarding his own health, education and his engagement in day to day activities. This interview schedule had 15 items with nine open ended items restricted to record responses in maximum four to five sentences and six yes/no type items exploring specific reasons for 'yes/no' responses. Interview Schedule for Health Care Providers was used to collect information from the treating doctor regarding

the child's health, his illness, treatment and overall management of the disorder. This interview schedule had 18 items with eight open ended items restricted to record responses in maximum four to five sentences and ten yes/no type items having spaces to enquire reasons for 'yes/no' responses. Questionnaire for teachers was used to collect information regarding the child's education and his participation in school activities. This questionnaire had 19 items with eight open ended items restricted to record responses in maximum four to five sentences and eleven yes/no type items having spaces to enquire reasons for 'yes/no' responses. The items and questions of all the tools were distributed unevenly across the tool in order to minimise the mental set and carry over effects. These research tools were reviewed jointly by a team of registered medical practitioners, trained in treatment of haemophilia and other blood disorders, licensed rehabilitation practitioners, trained in education and rehabilitation of children with disability and group of educationists, sociologists and psychologists, who had more than twenty years of experiences in their respective field. The items or questions appeared ambiguous or in which there was poor agreement among the different reviewers were reworded or replaced with more suitable items or questions. Content validity for the questionnaire was further established through detailed discussion with medical practitioners, rehabilitation professionals, social workers, teachers and clinical counsellors.

Profile Study of Participant

An eleven years old normal appearing pleasant hemophilic male child belonging to tribal rural lower socio-economic class, studying in Class VI in an elementary school of Dang District in the State of Gujarat in India was selected for this study. His previous history revealed that during infancy, once he fell down from bed and had a bump on his forehead. Local doctor made a cut on it for blood flow and bleeding stopped normally at that time. He was first diagnosed with haemophilia at the age of four years after a bleeding episode in which bleeding did not stop consecutively for eight days after a minor cut by a blade on the right side of nose. At that time, he was taken to local doctors who were not aware of disorder. Later he was taken to Civil Hospital which is around 150 km away from his home and doctor diagnosed him with Haemophilia A, Factor VIII deficient. His family members were already aware of some of the symptoms of haemophilia disorder as child's cousins were suffering

from the same disease and leading a manageable life. The child had one elder brother who had not shown any signs and symptoms of haemophilia and never underwent any test to rule out haemophilia too. Maternal grandfather also had Haemophilia. Child's mother and aunt were sisters and married in the same family to younger and elder brother respectively, both were carrier of the disorder as established in a medical report. Since, the child's father was aware of some of the symptoms already, hence while admitting the child in the present school, father explained headmaster and other teachers about the disorder and ask them to take extra care of this child. He requested his teachers not to bother much if he did not do well in studies. As per father's verbatim, 'teachers used to take care of child like a fragile glass'. He previously got admission in Eklavya Model Residential Schools (EMRS) after passing the state level examination for admission in Class VI of EMRS. He was staying in the hostel of EMRS but as he regularly required Factor VIII four times in a month, he had to withdraw himself from the school and hostel. He was a bright, intelligent and curious student and used to ask a lot of questions while in class as reported by his teachers and father, though he was facing various challenges in his day-to-day life. He used to remain absent from classes for around 12–15 days in a month to attend medical interventions for his disorder during which he always missed out most of the parts of his syllabus, resulting lower achievement than the expected level. He showed poor academic achievements almost in all subjects, as reported. Parents were worried about his learning, academic achievements and his future since he was a bright child otherwise. There were no special provisions or plans prepared either by the school or by the teachers to cover up his missed out syllabus. He was dependent on his classmates' class-notes only. He could not sit for long periods of time in the class. His wrist and elbow joints used to get frozen while writing continuously and sometimes bulged up. He could not afford to miss his examination due to risk of failure. He was always fearful of being retained in same class for the next year in case he would fail, or his school would be changed as happened earlier. During examination, whether he had pain or in the need of Factor VIII of the blood, he used to appear in his examination and never tried to escape from attempting to write examination paper because of his illness. After finishing his examination paper, he used to leave for hospital to receive Factor VIII infusion, if required. He also abstained from playing sports due to the fear of getting a

bleeding episode. Even a little pat on his shoulder by friends while playing used to develop swelling in those areas and ended up with requirement of Factor VIII infusion. He did not participate in most of the school activities as his classmates. His school was around 1.5 km away from his home and he had to walk down to reach the school. He could not carry his own school bag on his shoulders since due to weight of the bag he could develop swelling and it sometimes, became an emergency case for immediate Factor VIII infusion. He could not stand for long period of time (more than half an hour) constantly. He could not walk continuously and travel for a long distance otherwise swelling usually appears in his both feet. His favourite hobby was cycling but due to this disorder, he used to avoid cycling. Swelling was present around his ankle joints of the left leg during case work up and limping while walking was also observed. He could not consume mid-day-meal within the limited time period, since he was facing difficulty in chewing and swallowing the food items due to affected jaws because of the disorder.

Teachers of the present school were not aware about the disorder and did not know about emergency remedies if required, though father had explained to child's teachers, headmaster and classmates during admission. Teachers expressed their need for training on education and management of children with haemophilia in schools and other similar disorders. Frequency of bleeding episodes occurs 2–3 times in a month; 500 mL quantity of Factor VIII was required through infusion, but generally 250 mL remained available at the hospital (as reported) due to the shortage or unavailability of factor. Every time parents had to make request to avail 500 mL of Factor VIII. Child had to travel for more than 4 hours in a public bus to get factor injected or sometimes ended up getting no infusion due to unavailability of Factor VIII in the hospital. He and his family were found struggling for availing Factor VIII, spending money, time and energy again and again. Sometimes he used to get irritated and angry due to his disorder and became obstinate during pain episodes. While in severe pain, the child used to cry a lot, scream and start crawling on the floor. Now he started developing self coping mechanism to live with the disease. He tried to avoid taking risk of any physical injury on his own. He used to share his feeling of stress with his peers. His classmates started visiting his home in the evening hour almost daily. They used to play simple and easy indoor games together and also share the activities of the class

with the child and his parents. Parents were assisting the child in learning activities at home as his classmate started sharing the class-notes and activities. Parents, after intervention of School Management Committee and resource teacher, were maintaining regular contact with his teachers for ensuring his participation in classroom activities. They tried to collect his homework during his period of absentees to cover up the missed out syllabus. However, due to poor financial condition, parents were found struggling with their daily hassles of livelihood. Family could not afford specific food suggested by the doctor. Commutation expenses and visit to doctor did cost them 4–5 thousands monthly, for meeting these expenditure father had to take financial help from acquaintance due to his low economic status. Father was not satisfied with the treatment due to the unavailability of factor remained in spite of his and family effort for requesting the medical fraternity in the hospital.

Discussion

World Health Organisation considers disability, not just a health problem, but it is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. People with disabilities may face difficulties while interacting with persons, objects or activities in his immediate environment. It requires interventions to remove these environmental and social barriers. For a long time children with disabilities were studying in secluded schools and then in separate classes after movements towards integrate them in regular schools. After enforcement of the Right of Children to Free and Compulsory Education Act, 2009 in India, education became fundamental right of every student including children with disability in inclusive setup as endorsed in the Rights of Persons with Disabilities Act 2016. Haemophilia is one of the disabilities caused due to chronic blood disorders. Haemophilia is rare and inherited bleeding disorder where blood does not clot normally after internal or external bleeding usually affecting only male but transmitted by women to their male children. Although the genetic basis of this disorder has been well studied in India, data on the number of individuals, trends of the disorder in India, have not been properly reported. Available data and studies are mainly from the field of medical science related to treatment procedures. Very limited studies are available in literature

on challenges faced by these children from socio-psychological and educational perspectives. There is very low or no awareness among the health care providers, parents, teachers and community at large regarding haemophilia, its causes, symptoms, diagnosis, treatment and overall management. Referring to this study family was not aware of the causes of haemophilia that it is inherited; mother could be the carrier of the disorder, which could have been pretested or prescreened before birth of the child while having two other persons in the family already suffering from haemophilia. Females are rarely severely affected or suffer the symptoms. They are the carrier of the disorder. Ghosh and Shukla (2017) quoted in their study not to forget carrier mothers, sisters and daughters and occasional female sufferers of this disease. The manifested child and the family were found suffering and struggling for Factor VIII due to its unavailability in the hospital as quoted in earlier study as 'high cost low volume disease' (Ghosh et al., 2008). Human body have 13 clotting factors which help in clotting blood and having defective or lack of Factor VIII and IX, causes haemophilia. There are mainly two types of haemophilia, Haemophilia A where Factor VIII is deficient and Haemophilia B where Factor IX is deficient. General indication is bleeding, which is often spontaneous into joints and soft tissues (Barr et al., 2002). Children are more prone to bleeding due to movement oriented activities.

Availability of medical product is a one of the major problem in many countries (Shapiro et al., 2001). In this case too, it was found that the lack of resources, even in the metro city like Mumbai, seem to be an important cause of mismanagement in health, causing adverse impact on education and the whole life of the affected child as reported in many studies. From educational point of view, managing education of haemophilic child seems challenging. The effect of haemophilia on the educational aspect has also been interest of researchers. Haemophilia can result in a wide range of physical, social, and academic activities among school-aged children (Shapiro et al., 2001). Here in this case the child lost his residential school facility due to his bleeding disorder. His previous residential school as well as the present government school did not have any specific guideline for taking care of such children's health, safety and security. He had to change his school from residential set up of EMRS to general government school due to this blood disorder.

Thies (1999) had reported that around 58 per cent of school children with chronic conditions routinely remain absent from school and 10 per cent miss more than 25 per cent of the year. This child was also unable to attend the classes regularly due to bleeding episodes and consecutive treatment protocols supporting the findings of earlier studies too, highlighting higher rates of absenteeism in school children suffering from hemophilia than others (Markova and McDonald, 1980; Woolf et al., 1989; Colgrove et al., 1994) and inconsistencies between student's ability and academic achievement as they progress through higher classes (Olch D., 1971). A Multicenter Hemophilia Growth and Development Study (HGDS) report provided insight on interconnection between long-term hospitalisation and poor achievement test scores in reading as well as spelling, resulting lower achievement than the expected level based on IQ (Loveland et al., 1994) of the child. Most of the times in spite of being in school, this child missed out a number of school activities to participate, especially physical (e.g., movement) in nature restricting his opportunities to learn by different modes and means supporting the findings of Irwin and Elam, 2011 that chronically ill children can experience various multiple issues associated to their illness that interfere with school activities. Children with hemophilia may be generalised to other chronic health impairments and associated conditions to some extent, contributing to school absenteeism, interfering with physical function, and the child's ability to take part in regular tasks of childhood (Shapiro et al., 2001).

It was reported that teachers did not have any individualised support programme as recommended in the RPwD Act, 2016; as seen in the report of Department of Education, Government of UK that there was no specific programme of educational intervention existed in schools for such children with persistent absences (DoE, 2019). Persistent absence from schools by children with chronic disease could certainly interfere with children's educational and social development as reported in earlier studies also (Weitzman M, 1986). Children with such chronic health impairments could have remarkable impact on the academic performance due to waxes and wanes in attendance, lack of ability to engage in standardised measures, and poor performance on assessments due to low school participation. The child and family did not get any educational support from teachers and schools. The child used to feel isolated causing low self esteem and low level of confidence. This study has

raised an important interconnection between the number of bleeding episodes experienced and scholastic achievement in a school-aged child with severe hemophilia as found in earlier study (Shapiro et al., 2001). Moreover, the high treatment cost of the disease leads to financial burden that also results in poor maintenance of regular treatment as well as child's physical inability to attend classes regularly in schools. Subsidised treatment services were of limited availability causing significant out of pocket expenditure for parents affecting quality of life of the child and the whole family.

Conclusion and Recommendations

Disability is a form of social diversity. Society, therefore, has responsibility to educate and take care of children with disabilities. Every child with or without disability has the right to get equal educational opportunities to achieve his or her academic potential. Haemophilia is a chronic blood disorder causing disability, where cure is not attainable due to limited resources. There are limited systematic epidemiological data on Haemophilia. Treatment is prolonged, unpleasant and repetitive. The treatment processes affect a child's physical and mental health, education and life satisfaction. Today's researchers are more concern about the child's education and quality of life and are trying to improve their life standards by different medical as well as educational intervention options. There is an urgent need to develop specific guidelines for school on educational intervention and individualised support programme for these children with chronic health impairments. Sensitisation of teachers on haemophilia is utmost important. Capacity building of the in-service teachers through nationwide programme is also the need of the hour. This is also required to revisit the pre-service teacher education programmes both in the area of general teacher education programme regulated by National Council of Teacher Education as well as in special teacher education programme regulated by the Rehabilitation Council of India. Beside these, community awareness programme may also be organised at local level so that the community would be aware of the needs and strengths of the affected child and mobilise resources (may be through E-village, medical home, etc.) to the family. The health care system may introduce digital platform to notify the availability of the resources and factors, particularly in such type of cases. Today, it becomes essential for educationists and rehabilitation professional to develop educational assessment measures to

determine the learning and other needs of these children so that an appropriate educational intervention programmes can be developed in order to prepare them to confront independently with each and every situation appear their life.

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