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RESEARCH ARTICLE

A QUALITATIVE CASE STUDY ON THE MULTIDIMENSIONAL CHALLENGES OF INDIVIDUALS WITH HAEMOPHILIA-A IN HIGHER EDUCATION

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Abstract

The present study adopts descriptive case study design to document the lived experiences of haemophilic learners. A multiple Holistic case study approach was employed, wherein each case was treated as a single integrated unit of analysis. Multiple case design perceives each of the two cases as a separate unit of analysis, and patterns were drawn to find similarities and dissimilarities across the two cases. This design strengthens the research findings from being specific to a few instances to generally being valid and reliable. In multiple case studies, data collection is research-rigorous and involves multiple sources of evidence (Haemophilia A learners, parents, siblings, friends, teachers) through interviews. The results were structured based on emerging themes from the Indo-Deductive Thematic Analysis of the interviews. Further triangulation of data from multiple sources brought in the validity and reliability to the study and provided a holistic understanding making the findings more comprehensive. The study focused on understanding numerous challenges related to learners with Haemophilia-A at higher education institutions such as frequent bleeding episodes, physical constraints, social exclusion, lack of institutional support, financial burdens etc to name a few. The study also threw light on the role of their support systems in their lives to tackle these challenges. This research, thus brings to light various educational, physical, emotional, mental and social challenges faced by haemophilic individuals and also highlights the need for better policy -frameworks, guidelines and awareness amongst all stakeholders associated with haemophilic individuals.

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Introduction:-

Every person is born with some special features and attributes, which make them different from the other person. Rather it would be better to say that every person is unique and this is the reason behind intriguing variations in the human population in terms of gender, caste, color, creed, socio-economic status, physical attributes, intellectual

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levels, psychological viewpoints etc. Some people are born with or acquire certain conditions in the course of their life, which are different from the commonalities of the majority of the human population and in a way restrict the person in undertaking daily life activities, or may create additional challenges in the life of that person. These conditions are most commonly known as disabilities. Disability is an umbrella term for impairments, activity limitations, and participation restriction. It refers to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (World Health Organization's International Classification of Functioning, Disability and Health (ICF), 2001) and may occur due to various conditions like illness, infections, injuries and accidents, aging, malnutrition, environmental factors, genetic factors, etc. Some disabilities are temporary while some are life-long requiring support and medical care.

Globally there are approximately 1.3 billion disabled persons (World Health organization) representing 15% of the global population, while in India almost 2.21% of population, ie, 26.2 million people live with disabilities. The Rights to Persons with Disabilities Act (RPWD act), 2016 of India recognises 21 types of disabilities including physical , mental, intellectual disabilities, visual and hearing impairments, multiple disabilities and blood disorders.Among these disabilities, Haemophilia is a rare genetically inherited bleeding disorder that impairs the body's ability to make blood clots. It is caused due to mutation of genes causing the formation of the clotting factors. This mutation is passed down from parents to children directly following an X-linked recessive type of inheritance. The clotting proteins may be completely absent or may be present in very low levels (WHO) Haemophilia is a lifelong disorder and could be life-threatening if left untreated (World Federation of Haemophilia)

Since the disease follows an X-linked recessive type of inheritance pattern, the females having mutation on one of their X chromosomes will only become a carrier of the disease-causing gene, because females have two X chromosomes. They will only become sufferers when they have a mutation on both of their X chromosomes (which is extremely rare). While, in case of males, there is only a single X chromosome present and thus, mutation on this single X chromosome will cause disease in males. Therefore, a carrier mother will transmit the disease to half of her sons and a sufferer mother would transmit the disease to all of her sons. So, in both the conditions, the probability of males becoming sufferers is far more than females that is why, nearly all haemophilic individuals are males. Haemophilia, which finds its earliest mention in the Jewish text "Talmud" has also been famously called as the "Royal Disease" because Queen Victoria of the Royal family of Britain herself was a carrier of the disease and pedigree records show that Victoria transmitted the mutant allele to three of her nine children. The disease was passed to her daughter Alice (a carrier) and through her to her granddaughter Czarina Alexandra who was married in the Russian Imperial family. Czarina had four daughters and one son, and the son, Alexis, suffered from haemophilia. Victoria's own son Leopold was a sufferer and her daughter Beatrice (a carrier) transmitted the disease to the Royal family of Spain. Thus, the disease was passed down through descendants into various royal families of Europe (Snustad& Simmons, 1997, p.98)

Haemophilia occurs mainly in three different forms (Center for Disease Control and Prevention, 2023)- Haemophilia-A, the most common form which is caused by deficiency of Factor-VIII and has a prevalence of 1 in 5,000 male births globally ; Haemophilia-B (Christmas disease) caused by deficiency of Factor-IX and having a global prevalence of 1 in 25,000 male births; Haemophilia-C, the rarest and mildest among the three forms which can occur in males and females both and is more common in Ashkenazi Jews ,and is caused by deficiency of Factor-XI with a prevalence of 1 in 100,000 births (National Hemophilia Foundation, 2023) Apart from these three some rarest forms have been recently reported too like Acquired Haemophilia , an autoimmune disorder where the body develops antibodies against clotting factors, often Factor VIII (Franchini& Lippi, 2020) and Owen's disease due to deficiency of Factor-V.

The individuals suffering from Haemophilia have a life expectancy considerably worse in lower-income countries approximately 64%, 77% and 93% for countries with upper-middle, lower-middle and low-incomes respectively, according to World Bank definitions, which is due to high-treatment costs (World Federation of Haemophilia, 2019). There are numerous physical, emotional, social and psychological challenges on part of the patients or sufferers with hemophilia(Buckner et. al, 2020). It is difficult for the hemophiliac individuals studying in educational set ups like schools, colleges, universities, etc to cope up with the unbearable pain, emotional suffering, mentally-challenging conditions thereby maintaining their academic performance simultaneously. These challenges tend to become more problematic when there is a lack of societal awareness, support and even discrimination or exclusion. The Social Model theory of Oliver (1983) too emphasizes that disability is created by societal barriers, not the individual's impairment. That is why there is a need of catering the special requirements and equitable sharing of resources to not only hemophiliac individuals, but to all irrespective of their diversities in the educational institutions, thus, calling for Inclusive Education. Inclusive education is an idea or philosophy or a system that focuses on holistic development of a child in an educational setting irrespective of the socio-economic background, race, gender, disabilities, geographical differences, etc, thus fostering a healthy diversity, learning for all and above that to include or embed all at the same place. With the new policies coming in the picture both at global and national level, the idea of Inclusive education is taking shape and it has a potential to address to and bring positive changes for the issues faced by hemophiliac learners in the educational institutions.

Building upon the above background, it is important to articulate the specific need and rationale behind undertaking the present study. On reviewing the related literature, the researchers noticed a dearth of studies on haemophiliac learners particularly in the higher education institutes in India and even abroad, as most of the studies were focussed either upon the challenges of learners at the school level or the medical challenges being faced. Also, the idea behind choosing learners at college level or higher education is that with the sudden transition from adolescence to adulthood, there is addition of social and emotional challenges such as insecurity, fear of lagging behind with a huge syllabus due to frequent absenteeism caused due to unpredictable bleeding episodes, internal psychological struggles like inferiority complex and a feeling of being pitied out by peers as also highlighted in separate studies by Manikandasamy et al (2017) Along with that, sports, physical activities and movements are necessary to build a good physique at this stage but learners fear from engaging in sports and other physical activities or even recreational activities due to a constant tension of encountering any accident or injury and the excessive bleeding as a consequence (Williams & Chapman, 2011) (Silva et al, 2022)

Moreover at this crucial stage, there is a fear of losing out jobs and a struggling feeling of not able to acquire jobs (Buckner et al, 2020) (Kar et al, 2014) Along with that there are no specific policies aimed at inclusive educational setups in colleges, universities and higher educational setups, hence the researchers want to study these challenges faced by the learners of haemophilia-A disability and how do they deal with these challenges and what are their support systems. The objective behind only taking Haemophilia-A learners over other Haemophilia types is simply that there is a relatively higher prevalence of A type over other haemophilia types in India and across the globe. Also, the researchers intend to work upon learners with haemophilia-A disability because it is relatively easier to look upon or talk about someone with disability or even sympathise but to actually delve into real settings of that very person and observe the psycho-social struggles, challenges and issues, that person goes through and to go through a disease with outcomes of just a minor cut so devastating, gives the real scenario of challenges and issues of haemophiliacs, this is what motivates the researchers to undertake the study on haemophilia-A disability. The research questions that guide the study are:What are the challenges of the learners with Haemophilia-A disability at higher education institutions? And how have they dealt with these challenges?

Research Methodology:-

A descriptive case study design was used to document the two haemophilic individuals, in detail capturing what happened and the real-life context around them. The study aims to identify the challenges of the learners with Haemophilia-A disability at higher education institutes with respect to; Educational, Physical, Emotional, Mental and Social challenges. It also aims to study the support system (parents, siblings, peers and teachers) of the learners with Haemophilia-A disability at higher education institutes. Here, in this study the cases are the Haemophilia A learners in higher education institutions. The two cases were purposely selected based on their availability, access and readiness to provide data and studied progressively. Both the cases of Haemophilic A learners are the units of analysis. The study aimed to describe characteristics, behaviours or situations as they naturally occurred for haemophilic learners. Each of the two (haemophilic individuals) acted as a separate and unique case, in this holistic multiple case study, along with their environment and support systems which form its context and are integrated with the case. The data was therefore collected from the support systems too, including their parents, teachers, siblings and peers. Semi-structured Interview was the primary means of data collection, allowing flexibility in questions but also retaining some control to enforce some consistency in dealing with similar essential issues such as stressors and coping mechanisms. Since this study employed multiple holistic case study methods, therefore, in-depth interviews of learners with haemophilia-A disability were conducted along with their support systems consisting of their parents, siblings, teachers and peers without which the context of the case cannot be understood. It involved multiple sources of evidence through interviews. Field notes prepared by the researchers further strengthened the interview findings.

The interviews were conducted in the real settings of the learners as well as their support systems and all ethical considerations were taken into account during the process. Written as well as verbal consents were obtained from the participants. Confidentiality was maintained throughout the research process. All participant data have been anonymized, the findings being presented with the intent of contributing to academic understanding, not to stigmatize any individual or group. Transcripts were prepared from the interviews and data was reduced and organised and then analysed using a hybrid inductive–deductive thematic analysis approach, integrating both data-driven and theory-driven coding as proposed by Fereday and Muir-Cochrane (2006). Certain preconstructs had been identified using existing theories and literature and used for making the interview schedule while certain newer themes and codes emerged from the interview (as shown in Table 1, codes , categories and themes were derived for haemophilics and likewise separately for their support systems too). After thematic analysis, results were subjected to triangulation to obtain multiple perspectives and to enhance the credibility of the findings of the study.

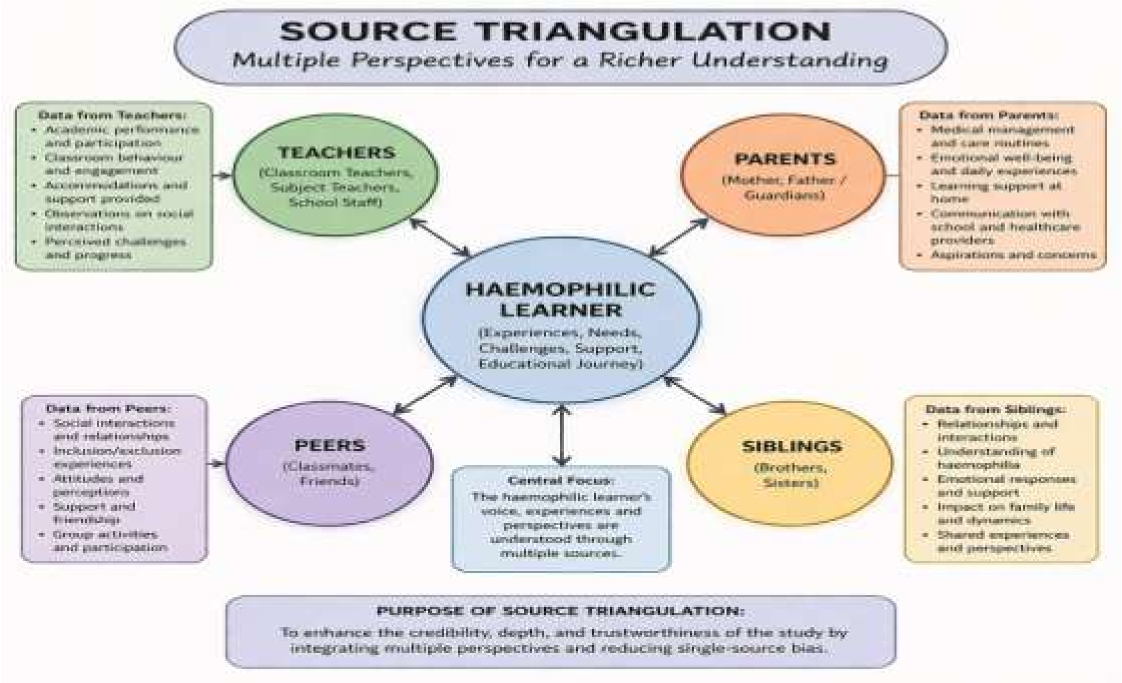

Fig 1- Figure showing source triangulation for multiple perspectives and a richer understanding

Results of the Study:-

The present study highlighted various challenges associated with the haemophilic individuals

Table1: Table showing derived themes, categories and codes from in-depth interviews of both haemophilic cases

THEMES	CATEGORIES	CODES
1. DIAGNOSIS AND EARLY EXPERIENCES OF HAEMOPHILIC LEARNERS	DIAGNOSIS OF THE DISEASE	Early diagnosis in infancy
		Late diagnosis due to lack of facilities
	LACK OF AWARENESS AND PANIC	Misinterpretation of symptoms
		Family panic
		Lack of knowledge

	EARLY CHILHOOD RESTRICTIONS	Reliance on local/alternative practices
		Isolation in childhood
		Overprotection by family
		Limited interaction with peers
. 2. MEDICAL MANAGEMENT AND TREATMENT-RELATED CHALLENGES	TREATMENT TYPES AND EVOLUTION	Factor replacement therapy
		Antibody therapy-newer advancement
		Lack of treatment in remote areas initially
	EFFECTIVENESS OF TREATMENT	Reduction in bleeding frequency
		Improved mobility and functioning
	ACCESSIBILITY AND COST ISSUES	Limited availability in government hospitals
		Rural vs urban differences in medical facilities
		High costs of medication
	TREATMENT BURDEN AND ADDITIONAL CAUTION	Frequent hospital visits
		Need for emergency preparedness
		Difficulty during travelling
3. PHYSICAL CHALLENGES AND LIFESTYLE MODIFICATIONS	PHYSICAL CHALLENGES	Inability to participate in sports
		Avoidance of strenuous activities
	MOBILITY LIMITATIONS	Joint pain and swelling
		movement difficulties
	LIFESTYLE MODIFICATIONS	Need for planning activities
		Avoidance of risk situations
4. PSYCHOLOGICAL IMPACT AND COPING	EMOTIONAL DISTRESS AND SELF-PERCEPTION	Feelings of why me
		Mental burden
	STIGMA AND DISCRIMINATION	Exclusion during childhood
		Misconception of contagious disease
		Teacher over protection

	SOCIAL SUPPORT SYSTEMS	Family support
		Peer assistance
		NGO and community support
	ACCEPTANCE AND COPING MECHANISMS	Adaptation over time
		positive reframing
		Resilience
5.EDUCATIONAL CHALLENGES AND INSTITUTIONAL SUPPORT	ATTENDANCE AND ACADEMIC DISRUPTIONS	Missing classes and exams
		backlogs and delays
		Interrupted education
	LACK OF INSTITUTIONAL PROVISIONS	No formal accommodations
		lack of emergency protocol
		insufficient flexibility
	TEACHER AND PEER SUPPORT	Informal support
		Flexibility in assignments
		Emotional encouragement
	NEED FOR INCLUSIVE PRACTICES	Requirement of extra leaves
		need for understanding from educators
6. FUTURE CONCERNS, ASPIRATIONS AND FINANCIAL BURDENS	CAREER AND MOBILITY CONCERNS	limitations in studying abroad
		employment challenges
	FEAR OF GENETIC TRANSMISSION AND FAMILY LIFE	Concern about children
		Partner-related worries
		High treatment costs
		Dependency on aid
	HOPE FOR FUTURE CURE	Expectations from medical advancements
		Optimism

The above themes reveal the various challenges faced by haemophilic learners:

Educational Challenges:

Haemophilic learners experience frequent absenteeism due to bleeding episodes and medical needs, leading to academic disruption. Subject B faced serious academic setbacks such as continuous backlogs in each semester and even discontinuation of courses due to physical constraints created by haemophilia disability (As reported by Subject B "had three backlogs…could not attend classes";"had to take drop from my B.Tech. course")Lack of formal institutional support (e.g., no structured provisions for haemophilia) was evident. Both the teachers had also revealed during the interview that there is a lack of institutional guidelines. Though teachers and peers provided informal academic support such as extra time, notes, and flexibility, these aren't sufficient; these findings bring to light that still there is a lack of formally defined institutional policies for disorders like haemophilia.

Physical and Medical Challenges:-

Haemophilia requires continuous medical management and preparedness (e.g., carrying medicines, regular injections). The individuals suffering from haemophilia have to carry injections at their homes and while travelling to some other places. Subject B revealed during the interview "I cannot just start travelling because I have to plan a lot. I have to pre plan everything. Then I can only go. And also I have to always carry with me emergency medications"Despite advancements in treatment, accessibility and affordability remain major concerns. High treatment costs that too at regular intervals decreases the affordability of the treatment for everyone. One of the parents revealed that approximately 30% of his salary went into availing medicines for the treatment (as reported by parent of Subject A "It is very costly. It is very expensive treatment, government support is there, but still, almost 30% of my salary goes into that. And if somebody is poor, then it is difficult for them. Really!")Frequent bleeding episodes restrict participation in physical activities and affect mobility. The subjects revealed that they had to restrict their participation in sports activities despite their interest, because of fear of getting hurt. Even their support systems didn't allow them to participate to prevent any unforeseen possibilities.

Emotional and Psychological Challenges:-

Learners experience fear, anxiety, and emotional distress, especially related to injury and uncertainty. Daily activities like driving, walking could have a severe impact not only physically but psychologically driven by fear of getting hurt. In this study too, a sibling of the subject revealed that her brother had a fear of driving because of the possibility of getting hurt ("he had a fear of driving") Feelings of isolation, inferiority, and being "different" were observed. Initial reactions, mindsets and stigmas by society members led to feelings of isolation, however with time and awareness, these societal members emerged as major support systems for the learners.Over time learners develop resilience and adaptive coping strategies. Both the learners revealed that they have well adapted to live with the disease and they are ok with the disease (Subject A revealed that "I think of haemophilia. Now, I'm used to it" while Subject B revealed "It's normal now, like I do not feel a lot, but yeah, it is there, and I have accepted it"

Social Challenges and Inclusion:-

Social participation is often restricted due to safety concerns. The study highlights that initially after diagnosis of the disease learners were often restricted from playing or moving outside by their parents and teachers in order to prevent them from getting hurt.While peers are generally supportive, inconsistencies in inclusion were noted. Not everybody is equally supportive or equally unsupportive. Awareness among peers enhances inclusion and reduces stigma. Peer group efforts and efforts by teachers too brought about inclusion in the classroom setting of which haemophilic learners are part of. As revealed by the subjects in this study and a common existing issue that bullying in colleges is quite common especially among males, but in their case, they never faced anything like that because of peer group and classroom inclusivity(Subject B describes "Right from 2007 I am staying alone outside my house due to academic purposes. So, I have colleagues, college classmates, hostel mates, all those friends, and they have been very supportive to me, and because of them, you know, I never felt actually that I have been isolated or something like that. They have been very supportive to me, providing notes or helping me out with this hemophilia thing, physically, mentally, emotionally, to whatever extent they can do. So yes, I am lucky in that sense")

Family and Financial Burden:-

Families face significant financial strain due to expensive treatment. In the study the individuals as well as their parents have stated multiple times during the interviews that the treatment costs are too high for a middle-class person to deal with. Parents adopt protective behaviors, sometimes leading to restricted independence. Parents are often seen to prevent them from going outside, sometimes bringing the need to differentiate between overparenting and care.Awareness and accessibility of government schemes are limited. In the Indian context, availing any scheme or benefits require a lot of paperwork which makes the whole process nearly inaccessible (As highlighted by one of the parents "Daftarkechakkarkaatateraho"implying that one has to visit government offices multiple times in order to avail any scheme.Moreover there is less awareness regarding the existing schemes as well amongst parents as well as teachers. Therefore, there is a felt need to work in the direction of awareness about the disease and existing policies for it. However, several social groups like the Haemophilia society of India and its district chapters not only helped the individuals and their families to get access to medical aids easily and injections on discounts but also served as a ray of hope during times of financial crises.

The support system (parents, siblings, peers, teachers) of the learners with Haemophilia-A disability and their roles:

Role of Teachers:-

Teachers have basic awareness and adopt inclusive practices like flexible teaching and emotional support. Teachers not only act as important stakeholders but they also bring inclusivity in the classroom by adapting their classroom practices and teaching styles. Teacher of Subject A herself revealed "Ipromote inclusivity by creating awareness among students about empathy, respect, and individual differences"However, lack of professional training and institutional guidelines is a major gap. In this study too, both the teachers revealed that due to lack of guidelines, institutional support and training programmes it is nearly impossible to maintain complete inclusivity in the classroom and foster healthy learning.

Role of Siblings and Peers:-

Siblings act as emotional supporters and caregivers, often adjusting their own routines. The individuals suffering from disability not only find a companion in them but also, share their stories of distress and personal feelings. Being of the same age group they have mutual understanding and cooperation for each other.Peers provide academic and emotional support, helping learners cope with absenteeism. Peers do not act as mere note-providers but they provide constant support to the sufferer individuals in college as well as at home too, often taking them to hospital and being present in any emergency condition. However, both groups highlighted the need for greater awareness and structured support.

Future Concerns and Aspirations of the Haemophilic cases:-

Learners expressed concerns about career, employment, financial stability, and genetic transmission. One constant view emerged out of both the interviews, ie, family or marital life in future. Due to the unpredictability and fatal nature of the disease, the major concern is genetic transmission of disease in the next generation. This brings out that due to the disorder not only one but several lives could be affected, highlighting concern and future scopes for such individuals. Despite challenges, hope for medical advancements (e.g., gene therapy) was evident but due to the ethical considerations of cures like gene therapies, it again raises a question how and when it will fully become a reality in the future course of time.

Discussion:-

Haemophilia or the Royal disease of British empire, which is a X-linked recessive disorder, caused by a single copy of recessive X gene where fathers pass a single X-chromosome to their daughters making them carriers but a male getting an X always becomes a sufferer (Snustad& Simmons,1997, p.98) accounting for a higher prevalence in males globally. Apart from being a genetic disorder caused due to mutation and inheritable in nature, this disease also acts as a physiological disorder where the gene coding for factor VIII or simply clotting factor gets mutated and the person with this mutation being devoid of clotting factor, may suffer from excessive bleeding even during a minute injury. Along with that there are other physiological issues making life of such individuals challenging. The present study was conducted to find out the various challenges faced particularly by haemophilic learners at higher education institutions.

The study employed a multiple holistic case study method under descriptive case study design and the findings of this study revealed that haemophilic individuals suffer through a lot of challenges including educational, social, mental, emotional etc. The findings of this study attempt to answer the set research questions bringing out the challenges faced by haemophilic learners at higher education institutions and how they have been able to cope up with those challenges with the help of their support systems in their environment such as their parents, teachers, siblings and peers. The findings reveal numerous challenges which came to light through verbatim of the Haemophilic individuals as well as their different support systems including physical challenges such as frequent bleeding episodes, mobility issues, inability to participate in sports etc. along with psychological and emotional challenges including fear of getting hurt, exam stress, future concerns etc. The study also highlighted how support systems' constant care and nurture help the individuals combating social challenges and initial feelings of exclusion and isolation.

The findings of this study truly align with existing literature and extend the understanding of haemophilia in higher education contexts. One of the most reported issues by the samples in this study was found to be Academic disruptions due to unpredictable and frequent bleeding episodes which goes in alignment with the study by Kar et al (2014) The issue of academic disruption due to absenteeism supports the findings of this study highlighting the negative impact of frequent bleeding episodes on educational attainment as reported in other such studies by Shapiro et al. (2001) and Buckner et. al (2020) The emotional distress and psychological challenges observed in both the learners correspond with studies emphasizing anxiety, fear, and reduced quality of life among haemophilic individuals which aligns with the findings of the study by Manikandasamy et al.(2017)

More distressing situations emerged out in this particular study that due to frequent bleeding episodes, the learner had to drop-out from the college, this finding goes in alignment with the study of Karet. al (2014) The study also reinforces the importance of family and social support, consistent with previous research indicating that strong support systems enhance resilience and coping (Dickmen et. al, 2024) However, the present study uniquely highlights: The lack of structured institutional support in higher education, where most support is informal rather than policy-driven. The present study also highlights the role of NGOs as support system particularly, The Haemophilia Society of India and its local chapters distributed throughout the country, in not only providing social support but extending their services by providing medical aids such as injections and factor proteins at a lower cost. This finding goes hand in hand with the findings of Ghosh et. al(2015) and Saxena et. al (2014) The critical role of siblings, which is often underexplored in existing literature but the present study touches this dimension, bringing further scope for studying the role of peers as a support system for haemophilic individuals. The study also highlights the gap between awareness and implementation, particularly in teacher training and government schemes, as reflected in the similar studies of Singh & Mukherjee (2017) Thus, the findings emphasize that haemophilia is not merely a medical condition but a biopsychosocial challenge, affecting all aspects of a learner's life.

Conclusion:-

The study concludes about the two cases, Subject A and B:

Subject A: A 23-year-old Microbiology graduate student who comes from a well to do family background and is the youngest amongst his siblings. He got diagnosed with Haemophilia (moderate type) during infancy. The study found out that his primary educational challenges are frequent absenteeism and missing out on important classes at college leading to stress, anxiety and fear. His parents, siblings and peers act as his primary support systems taking care of him not only at college but at home. However, initially because of lack of awareness about his disability there were episodes of social exclusion with his peers, teachers at institutional level but now his peers and teachers have also emerged as his major support systems, maintaining an inclusive setup for him inside the institution. His sibling and parents (sister) acts as his major support system at home, not only providing care but also emotional support to tackle difficult situations. His major future concerns emerged out to be his unpredictable health condition and personal life due to the genetic inheritability of the disease.

Subject B: A 36-year-old PhD student in Community Sciences who is a severe haemophilic case. He got diagnosed with the disease at the age of 10. The study found out that his primary educational challenges match with another subject, i.e. frequent absenteeism due to which he had so many gaps and dropouts in his educational journey. Coming from a rural lower middle class agricultural family, financial impacts of haemophilia and its treatment have been a major challenge for him and his family. However, with time his parents and especially his peers have emerged out as his biggest support systems. As revealed by him, he has been living outside his city just from 17 years of age and his peers have emerged as his support taking care in his frequent hospitalisations and treatment. Being subjected to social exclusion and stigma during his childhood, he has coped up with mental and emotional challenges and has developed a very positive attitude for life, working for society. However, like subject A his major future concerns remain personal responsibilities for his family and unpredictable outcomes of haemophilia disease.
For both cases, NGOs like Haemophilia society have emerged as major social support systems not only helping them with medical aids but emotionally and psychologically too.

The study concludes that haemophilia significantly affects learners across educational, physical, emotional, and social domains. While medical advancements have improved survival and management, the challenges in educational settings remain substantial. Academic disruptions are primarily due to health-related factors rather than cognitive limitations while missing important classes and frequent absenteeism act as major hurdles in academic aspirations of the learner.Emotional and psychological challenges are deeply intertwined with physical conditions. Fear and anxiety arising from physical and academic constraints can hinder their mental well-being.However, support systems (family, teachers, peers and siblings) play a crucial role in coping and resilience. They not only create a healthy social environment for the individuals with haemophilia but help them combat with different challenges. They also maintain inclusivity in institutions, class and even society. Institutional and policy-level gaps hinder effective inclusion. Lacunae in institutional guidelines for specific needs of the haemophilic individuals create hindrances in maintaining inclusivity in the academic and social setup.

Overall, the study emphasizes the urgent need for a holistic, inclusive, and structured approach that integrates medical care, educational support, and psychosocial interventions to ensure the well-being and success of haemophilic learners in higher education. Though there exists acts like RPWD 2016 and others to name a few, there seems to be a need to address challenges faced by individuals with invisible and unpredictable disorders like Haemophilia. There is a high time when each and every one of us should realise the need for inclusivity in each and every institution in order to build a healthy human society to live in.

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