

1 ***A Qualitative Case Study on the Multidimensional Challenges of Individuals with***
2 ***Hemophilia A in Higher Education.***

3
4 **Abstract:**

5 The present study adopts descriptive case study design to document the lived experiences of
6 haemophilic learners. A multiple Holistic case study approach was employed, wherein each
7 case was treated as a single integrated unit of analysis. Multiple case design perceives each of
8 the two cases as a separate unit of analysis, and patterns were drawn to find similarities and
9 dissimilarities across the two cases. This design strengthens the research findings from being
10 specific to a few instances to generally being valid and reliable. In multiple case studies, data
11 collection is research-rigorous and involves multiple sources of evidence (Haemophilia A
12 learners, parents, siblings, friends, teachers) through interviews. The results were structured
13 based on emerging themes from the **Indo-Deductive Thematic Analysis** of the interviews.
14 Further triangulation of data from multiple sources brought in the validity and reliability to the
15 study and provided a holistic understanding making the findings more comprehensive. The
16 study focused on understanding the educational, physical, emotional, mental and social
17 challenges related to learners with Haemophilia A at higher education institutions and the role of
18 their support systems in their lives to tackle these challenges.

19
20 Keywords: Haemophilic A learners, educational challenges, support systems,

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22 **INTRODUCTION**

23 Humans are one of the most diverse species on this Earth. Everyone is born with some special
24 features and attributes, which make them different from the other person. Rather it would be
25 better to say that every person is unique and this is the reason behind intriguing variations in the
26 human population in terms of gender, caste, color, creed, socio-economic status, physical
27 attributes, intellectual levels, psychological viewpoints etc.

28 Some people are born with or acquire certain conditions in the course of their life, which are
29 different from the commonalities of the majority of the human population. These conditions may
30 be physical, mental, psychological, social or emotional and in a way restrict the person in
31 undertaking daily life activities, or may create additional challenges in the life of that person.
32 These conditions are most commonly known as disabilities and may occur due to various
33 conditions like illness, infections, injuries and accidents, aging, malnutrition, environmental
34 factors, genetic factors, etc. Some disabilities are temporary while some are life-long requiring
35 support and medical care. Globally there are approximately 1.3 billion disabled persons (World
36 Health organization) representing 15% of the global population, while in India almost 2.21% of
37 population, ie, 26.2 million people live with disabilities.

38 Among these disabilities, Haemophilia is a rare genetically inherited bleeding disorder, with life
39 expectancy considerably worse in lower-income countries approximately 64%, 77% and 93% for
40 countries with upper-middle, lower-middle and low-incomes respectively, according to World
41 Bank definitions, which is due to high-treatment costs (World Federation of Haemophilia, 2019).
42 There are numerous physical, emotional, social and psychological challenges on part of the
43 patients or sufferers with hemophilia. It is difficult for the hemophiliac individuals studying in
44 educational set ups like schools, colleges, universities, etc to cope up with the unbearable pain,

45 emotional suffering, mentally challenging conditions thereby maintaining their academic
46 performance simultaneously.

47 That is why there is a need of catering the special requirements and equitable sharing of
48 resources to not only hemophilic individuals, but to all irrespective of their diversities in the
49 educational institutions, thus, calling for Inclusive Education. Inclusive education is an idea or
50 philosophy or a system that focuses on holistic development of a child in an educational setting
51 irrespective of the socio-economic background, race, gender, disabilities, geographical
52 differences, etc, thus fostering a healthy diversity, learning for all and above that to include or
53 embed all at the same place. With the new policies coming in the picture both at global and
54 national level, the idea of Inclusive education is taking shape and it has a potential to address to
55 and bring positive changes for the issues faced by hemophilic learners in the educational
56 institutions.

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58 From the review of related literature, it was observed that there is dearth of studies upon the
59 challenges faced by haemophilic learners in the higher education institutes in India and even
60 abroad, as most of the studies were focussed either upon the challenges of learners at the
61 school level or the medical challenges being faced. Also, the idea behind choosing learners in
62 college level or higher education is that with the sudden transition from adolescence to
63 adulthood, there is addition of social and emotional challenges such as insecurity, fear of
64 lagging behind with a huge syllabus due to frequent absenteeism caused due to unpredictable
65 bleeding episodes, internal psychological struggles like inferiority complex and a feeling of being
66 pitied out by peers as also highlighted in separate studies by Manikandasamy et al (2017) Along
67 with that, sports, physical activities and movements are necessary to build a good physique at
68 this stage but learners fear from engaging in sports and other physical activities or even
69 recreational activities due to a constant tension of encountering any accident or injury and the
70 excessive bleeding as a consequence (Williams & Chapman, 2011) (Silva et al, 2022) Moreover
71 at this crucial stage, there is a fear of losing out jobs and a struggling feeling of not able to
72 acquire jobs (Buckner et al, 2020) (Kar et al, 2014) Along with that there are no specific policies
73 aimed at inclusive educational setups in colleges, universities and higher educational setups,
74 hence the researchers want to study these challenges faced by the learners of haemophilia-A
75 disability and how do they deal with these challenges and what are their support systems.

76 The objective behind only taking Haemophilia-A learners over other Haemophilia types is simply
77 that there is a relatively higher prevalence of A type over other haemophilia types in India and
78 across the globe.

79 The researchers intend to work upon learners with haemophilia-A disability because it is
80 relatively easier to look upon or talk about someone with disability or even sympathise but to
81 actually delve into real settings of that very person and observe the psycho-social struggles,
82 challenges and issues, that person goes through and to go through a disease with outcomes of
83 just a minor cut so devastating, gives the real scenario of challenges and issues of
84 haemophiliacs, this is what motivates the researchers to undertake the study on haemophilia-A
85 disability. The research questions that guide the study are:

86 What are the challenges of the learners with Haemophilia-A disability at higher education
87 institutions? And how have they dealt with these challenges?

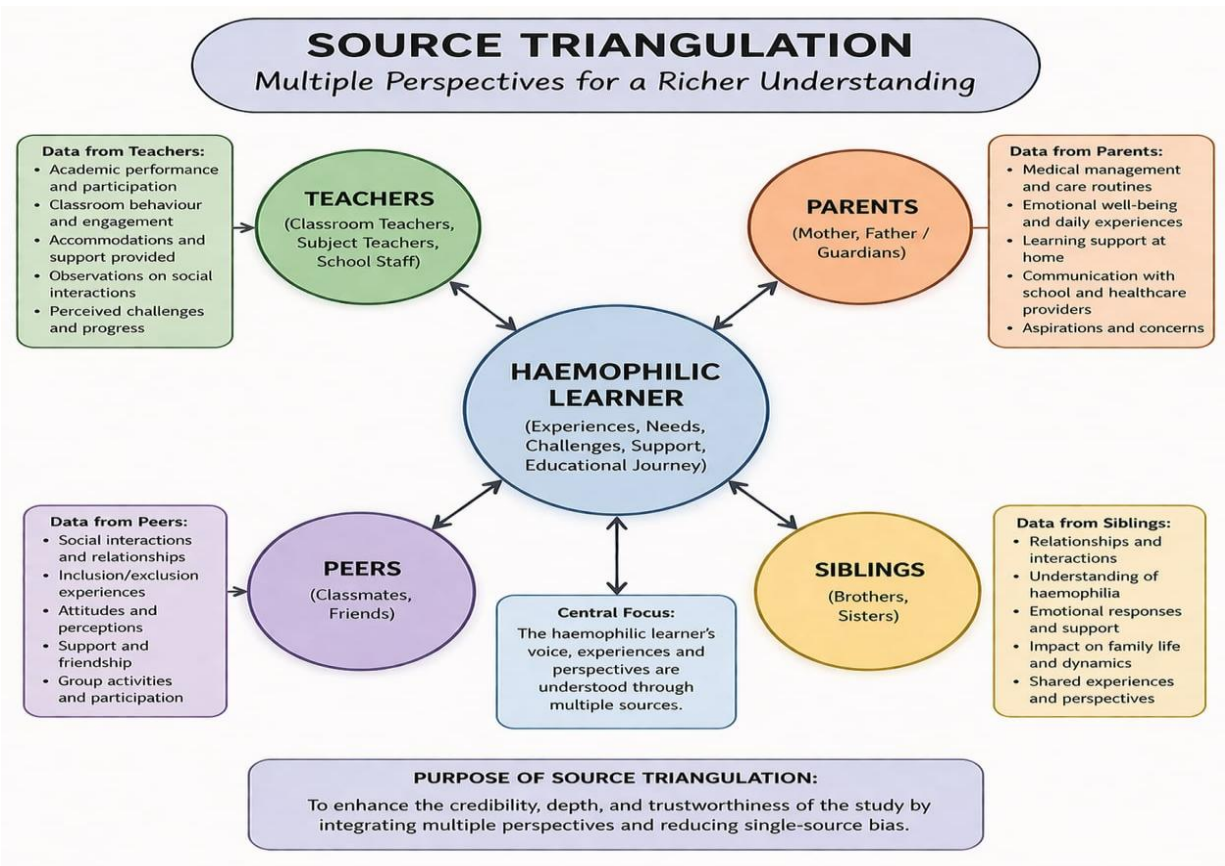
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RESEARCH METHODOLOGY

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, 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 system which forms its context. The data was collected from their support systems as well, 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.

UNDER PEER REVIEW



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117 Fig 1- Figure showing source triangulation for multiple perspectives and a richer understanding
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119 **RESULTS OF THE STUDY**

120 The present study highlighted the challenges associated with the Haemophilic individuals
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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
		Misinterpretation of symptoms
	LACK OF AWARENESS AND PANIC	Family panic
		Lack of knowledge

	EARLY CHILHOOD RESTRICTIONS	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

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	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	EMOTIONAL DISTRESS AND SELF-	Feelings of why me

COPING	PERCEPTION	
		Mental burden
	STIGMA AND DISCRIMINATION	Exclusion during childhood
		Misconception of contagious disease
		Teacher overprotection
	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

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The findings revealed 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. Teachers and peers provided informal academic support such as extra time, notes, and flexibility. This finding brings to light that still there is a lack of formally defined institutional policies for disorders like haemophilia.

Physical and Medical Challenges

139 Haemophilia requires continuous medical management and preparedness (e.g., carrying
140 medicines, regular injections). The individuals suffering from haemophilia have to carry
141 injections at their homes and while travelling to some other places. Subject B revealed during
142 the interview *"I cannot just start travelling because I have to plan a lot. I have to pre plan
143 everything. Then I can only go. And also I have to always carry with me emergency
144 medications"*

145 Despite advancements in treatment, accessibility and affordability remain major concerns. High
146 treatment costs, that too at regular intervals decreases the affordability of the treatment for
147 everyone. One of the parents revealed that approximately 30% of his salary went into availing
148 medicines for the treatment (as reported by parent of Subject A *"It is very costly. It is very
149 expensive treatment, government support is there, but still, almost 30% of my salary goes into
150 that. And if somebody is poor, then it is difficult for them. Really!"*)

151
152 Frequent bleeding episodes restrict participation in physical activities and affect mobility. The
153 subjects revealed that they had to restrict their participation in sports activities despite their
154 interest, because of fear of getting hurt. Even their support systems didn't allow them to
155 participate to prevent any unforeseen possibilities.

156 **Emotional and Psychological Challenges**

157 Learners experience fear, anxiety, and emotional distress, especially related to injury and
158 uncertainty. Daily activities like driving, walking could have a severe impact not only physically
159 but psychologically driven by fear of getting hurt. In this study too, sibling of the subject revealed
160 that her brother had a fear of driving because of possibility of getting hurt (*"he had a fear of
161 driving"*)

162 Feelings of isolation, inferiority, and being "different" were observed. Initial reactions, mindsets
163 and stigmas by society members led to feelings of isolation, however with time and awareness,
164 these societal members emerged as major support systems for the learners.

165 Over time, learners develop resilience and adaptive coping strategies. Both the learners
166 revealed that they have well adapted to live with the disease and they are ok with the disease
167 (Subject A revealed that *"I think of haemophilia. Now, I'm used to it"* while Subject B revealed
168 *"It's normal now, like I do not feel a lot, but yeah, it is there, and I have accepted it"*)

169 **Social Challenges and Inclusion**

170 Social participation is often restricted due to safety concerns. The study highlights that initially
171 after diagnosis of the disease learners were often restricted from playing or moving outside by
172 their parents and teachers in order to prevent them from getting hurt.

173 While peers are generally supportive, inconsistencies in inclusion were noted. Not everybody is
174 equally supportive or equally unsupportive.

175 Awareness among peers enhances inclusion and reduces stigma. Peer group efforts and efforts
176 by teachers too brought about inclusion in the classroom setting of which haemophilic learners
177 are part of. As revealed by the subjects in this study and a common existing issue that bullying
178 in colleges is quite common especially among males, but in their case, they never faced
179 anything like that because of peer group and classroom inclusivity

180 (Subject B describes *"Right from 2007 I am staying alone outside my house due to academic
181 purposes. So I have colleagues, college classmates, hostel mates, all those friends, and they
182 have been very supportive to me, and because of them, you know, I never felt actually that I*

183 *have been isolated or something like that. They have been very supportive to me, providing*
184 *notes or helping me out with this hemophilia thing, physically, mentally, emotionally, to whatever*
185 *extent they can do. So yes, I am lucky in that sense”)*

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187 **Family and Financial Burden**

188 Families face significant financial strain due to expensive treatment. In the study the individuals
189 as well as their parents have stated multiple times during the interviews that the treatment costs
190 are too high for a middle class person to deal with.

191 Parents adopt protective behaviors, sometimes leading to restricted independence. Parents are
192 often seen to prevent them from going outside , sometimes bringing the need to differentiate
193 between overparenting and care.

194 Awareness and accessibility of government schemes are limited. In the Indian context, availing
195 any scheme or benefits require a lot of paperwork which makes the whole process nearly
196 inaccessible (As highlighted by one of the parents “*Daftar kechakkarkaataateraho*” Moreover
197 there is less awareness regarding the existing schemes as well amongst parents as well as
198 teachers. Therefore, there is a felt need to work in the direction of awareness about the disease
199 and existing policies for it.

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201 **The support system (parents, siblings, peers, teachers) of the learners with Haemophilia-** 202 **A disability**

203 **Role of Teachers**

204 Teachers have basic awareness and adopt inclusive practices like flexible teaching and
205 emotional support. Teachers not only act as important stakeholders but they also bring
206 inclusivity in the classroom by adapting their classroom practices and teaching styles. Teacher
207 of Subject A herself revealed “*Ipromote inclusivity by creating awareness among students about*
208 *empathy, respect, and individual differences”*

209 However, lack of professional training and institutional guidelines is a major gap. In this study
210 too, both the teachers revealed that due to lack of guidelines, institutional support and training
211 programmes it is nearly impossible to maintain complete inclusivity in the classroom and foster
212 healthy learning.

213 **Role of Siblings and Peers**

214 Siblings act as emotional supporters and caregivers, often adjusting their own routines. The
215 individuals suffering from disability not only find a companion in them but also, share their
216 stories of distress and personal feelings. Being of the same age group they have mutual
217 understanding and cooperation for each other.

218 Peers provide academic and emotional support, helping learners cope with absenteeism. Peers
219 do not act as mere note-providers but they provide constant support to the sufferer individuals
220 in college as well as at home too, often taking them to hospital and being present in any
221 emergency condition.

222 However, both groups highlighted the need for greater awareness and structured support.

223 **Future Concerns and Aspirations**

224 Learners expressed concerns about career, employment, financial stability, and genetic
225 transmission. One constant view emerged out of both the interviews, ie, family or marital life in
226 future. Due to the unpredictability and fatal nature of the disease, the major concern is genetic

227 transmission of disease in the next generation. This brings out that due to the disorder not only
228 one but several lives could be affected, highlighting concern and future scopes for such
229 individuals.

230 Despite challenges, hope for medical advancements (e.g., gene therapy) was evident but due to
231 the ethical considerations of cures like gene therapies, it again raises a question how and when
232 it will fully become a reality in the future course of time.

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235 **DISCUSSION**

236 Haemophilia or the Royal disease of British empire, which is a X-linked recessive disorder,
237 caused by a single copy of recessive X gene where fathers pass a single X-chromosome to
238 their daughters making them carriers but a male getting an X always becomes a sufferer
239 (Snustad& Simmons,1997,p.98) accounting for a higher prevalence in males globally. Apart
240 from being a genetic disorder caused due to mutation and inheritable in nature, this disease
241 also acts as a physiological disorder where the gene coding for factor VIII or simply clotting
242 factor gets mutated and the person with this mutation being devoid of clotting factor, may suffer
243 from excessive bleeding even during a minute injury. Along with that there are other
244 physiological issues making life of such individuals challenging. The present study was
245 conducted to find out the various challenges faced particularly by haemophilic learners at higher
246 education institutions. The study employed a multiple holistic case study method under
247 descriptive case study design and the findings of this study revealed that haemophilic
248 individuals suffer through a lot of challenges including educational, social, mental, emotional etc.
249 The findings of this study attempt to answer the set research questions bringing out the
250 challenges faced by haemophilic learners at higher education institutions and how they have
251 been able to cope up with those challenges with the help of their support systems in their
252 environment such as their parents, teachers, siblings and peers. The findings reveal numerous
253 challenges which came to light through verbatim of the Haemophilic individuals as well as their
254 different support systems including physical challenges such as frequent bleeding episodes,
255 mobility issues , inability to participate in sports etc. along with psychological and emotional
256 challenges including fear of getting hurt, exam stress, future concerns etc. The study also
257 highlighted how support systems' constant care and nurture help the individuals combating
258 social challenges and initial feelings of exclusion and isolation.

259 The findings of this study truly align with existing literature and extend the understanding of
260 haemophilia in higher education contexts. One of the most reported issue by the samples in this
261 study was found to be Academic disruptions due to unpredictable and frequent bleeding
262 episodes which goes in alignment with the study by Kar et al(2014) The issue of academic
263 disruption due to absenteeism supports the findings of this study highlighting the negative
264 impact of frequent bleeding episodes on educational attainment as reported in other such
265 studies by Shapiro et al.(2001) and Buckner et. al (2020) The emotional distress and
266 psychological challenges observed in both the learners correspond with studies emphasizing
267 anxiety, fear, and reduced quality of life among haemophilic individuals which aligns with the
268 findings of the study by Manikandasamy et al.(2017) More distressing situations emerged out in
269 this particular study that due to frequent bleeding episodes, the learner had to drop-out from the
270 college, this finding goes in alignment with the study of Kar et. al (2014) The study also

271 reinforces the importance of family and social support, consistent with previous research
272 indicating that strong support systems enhance resilience and coping(Dickmen et. al, 2024)
273 However, the present study uniquely highlights: The lack of structured institutional support in
274 higher education, where most support is informal rather than policy-driven.The present study
275 also highlights the role of NGOs as support system particularly, The Haemophilia Society of
276 India and its local chapters distributed throughout the country, in not only providing social
277 support but extending their services by providing medical aids such as injections and factor
278 proteins at a lower cost. This finding goes hand in hand with the findings of Ghosh et. al(2015)
279 and Saxena et. al (2014)

280 The critical role of siblings, which is often underexplored in existing literature but the present
281 study touches this dimension, bringing further scope for studying the role of peers as a support
282 system for haemophilic individuals. The study also highlights the gap between awareness and
283 implementation, particularly in teacher training and government schemes, as reflected in the
284 similar studies of Singh & Mukherjee (2017)

285 Thus, the findings emphasize that haemophilia is not merely a medical condition but a
286 biopsychosocial challenge, affecting all aspects of a learner's life.

287

288 **Conclusion**

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

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

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303 **Subject B:** A 36 year old PhD student in Community Sciences who is a severe haemophilic
304 case. He got diagnosed with the disease at the age of 10. The study found out that his primary
305 educational challenges match with another subject,ie, frequent absenteeism due to which he
306 had so many gaps and dropouts in his educational journey. Coming from a rural lower middle
307 class agricultural family, financial impacts of haemophilia and its treatment have been a major
308 challenge for him and his family. However with time his parents and especially his peers have
309 emerged out as his biggest support systems. As revealed by him, he has been living outside his
310 city just from 17 years of age and his peers have emerged as his support taking care in his
311 frequent hospitalisations and treatment. Being subjected to social exclusion and stigma during
312 his childhood, he has coped up with mental and emotional challenges and has developed a very
313 positive attitude for life, working for society. However like subject A his major future concerns

314 remain personal responsibilities for his family and unpredictable outcomes of haemophilia
315 disease.

316 For both cases , NGOs like Haemophilia society have emerged as major social support systems
317 not only helping them with medical aids but emotionally and psychologically too.

318 The study concludes that haemophilia significantly affects learners across educational, physical,
319 emotional, and social domains. While medical advancements have improved survival and
320 management, the challenges in educational settings remain substantial . Academic disruptions
321 are primarily due to health-related factors rather than cognitive limitations while missing
322 important classes and frequent absenteeism act as major hurdles in academic aspirations of the
323 learner.

324 Emotional and psychological challenges are deeply intertwined with physical conditions. Fear
325 and anxiety arising from physical and academic constraints can hinder their mental well-being.
326 However, support systems (family, teachers, peers) play a crucial role in coping and resilience.
327 They not only create a healthy social environment for the individuals with haemophilia but help
328 combat them with different challenges. They also maintain inclusivity in institutions, class and
329 even society.

330 Institutional and policy-level gaps hinder effective inclusion. Lacunae in institutional guidelines
331 for specific needs of the Haemophilic individuals create hindrances in maintaining inclusivity in
332 the academic and social setup.

333 Overall, the study emphasizes the urgent need for a holistic, inclusive, and structured approach
334 that integrates medical care, educational support, and psychosocial interventions to ensure the
335 well-being and success of haemophilic learners in higher education.

336 **Acknowledgments**

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338 their participation and contribution in the interviews. The researchers also extend their gratitude
339 towards parents ,teachers ,siblings and peers of the subjects for their valuable time and
340 cooperation.

341

342 **Conflict of interests**

343 The researchers declare that there is no conflict of interests.

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