Mind and Society
A Peer Reviewed Research Journal in Humanities and Social Sciences

EMPIRICAL ARTICLE
ISSN:2277-6907
doi: 10.56011/mind-mri-133-20248

Conceptualization and Development of Quality of Life Scale for PWH Living in India

Richa Mohan[1*], Sandip Anand[2], Meera Varadarajan[3], Nita Radhakrishnan[4]

[1]*Empowering Minds Society for Research and Development, New Delhi, India.*
[2]*Department of Psychology, University of Allahabad, Prayagraj, Uttar Pradesh, India.*
[3]*Department of Clinical Hematology, Bangalore Medical College and Research Institute, India*
[4]*Department of Pediatric Hematology Oncology, SSPH&PGTI, Noida, India.*

Abstract

There is significant prevalence of haemophilia in India, with second largest number of persons with haemophilia A. Research in India includes diagnostic studies, complications and co-morbidities, prenatal diagnosis, inhibitor development, gene therapy, etc. Limited information about quality of life is available of these patients. A rare genetic condition such as haemophilia can degrade the quality of life of affected persons and their families to a great extent.The objective of the current study is to develop a scale based on variables which will best explain the quality of life of the young and adolescent patients with haemophilia in India. About 200 respondents in the age group of 15 to 40 years were interviewed and data was collected on a 5 point Likert scale. Exploratory factor analysis (EFA) followed by confirmatory factor analysis (CFA) were applied to reduce and refine the scale. With the help of EFA and CFA, we zeroed down to three dimensions for assessing the quality of life of persons suffering from haemophilia in India. The respondents in our study were extremely affected by their self esteem, their disease management ability and their family. This is a first such scale which will aid researchers and policy makers clearly identify the areas of concern to improve the lives of affected patients, specifically to Indian environment.

ARTICLE INFO

Correspondence:
Richa Mohan
richa.mohan07@gmail.com
Empowering Minds Society for Research and Development, New Delhi, India.

Dates:
Received: 17-08-2024
Accepted: 07-10-2024
Published: 15-10-2024

Keywords:
Hemophilia, Quality of life, Psychosocial, Self-esteem, Social support, Disease management, Bleeding disorders.

How to Cite:
Mohan, R., Anand, S., Varadarajan, M., Radhakrishnan, N. (2024). Conceptualization and Development of Quality of Life Scale for PWH Living in India. Mind and Society, 13(3): 59-67. doi: 10.56011/mind-mri-133-20248

Introduction

Haemophilia is a hereditary bleeding disorder, in which there is a partial or total deficiency of clotting factor in the blood (WHO, 2020). The disorder is sex-linked as it is more prominently found in males than in females. Out of the total affected population identified with haemophilia, 80% reside in developing countries (Ghosh and Shukla, 2017).

The number of prevalent cases in India is 0.9 per 1,00,000 population (Kar *et al*., 2014). India has the second largest number of patients with haemophilia A (Kar *et al*., 2014). A rare genetic condition such as haemophilia;it's symptom patterns and complication related to the disease impacts the quality of life of affected persons and their families to a great extent. In a country with population of more than one billion, the prevalence of haemophilia may seem low but the social cost of this disease is very high. The social costs of this condition and opportunities for offering genetic counseling have not been reported (Kar *et al*., 2014).

Theoretical Background and Objective

Quality of Life Assessment Scales

Quality of life (QoL) is an individual's sense of overall well-being encompassing physical, psychological, emotional, social, and spiritual dimensions (Cohen & Biesecker, 2010). QoL was a newer area of research in the field of haemophilia (Von Mackensen, 2007). However, it has become important to integrate QoL assessment with clinical and observational research in this field to justify the high costs of its lifelong management (Aledort *et al*., 2012). Conventional QoL scales focused on direct physical effects of the disease, others include dimensions such as health, social and economic, psychological and spiritual, and family (Ferrans *et al*., 2005). Disease specific QoL scales are superior to generic scales as they can detect the changes in QoL after treatment (de Vries *et al*, 2005). By the year 2013, several researchers reported to have worked on scale development for assessing health related quality of life of persons (HRQoL) with Haemophilia such as haemo-QoL, haemo-QoL-A, haem-A-QoL, A36 hemofilia-QoL. HRQoL are essential to optimize treatments and allocate resources in a cost-intensive chronic disease such as haemophilia (Remor, 2011).

Various scales have been found in the literature to assess quality of life of patients with hemophilia (Gringery& Von Mackenson, 2008). Physical health being one of the key indicators of state of life or quality of life of affected persons, research shows there are other factors that influence the quality of life of affected people. The existing scales consist of variables such as treatment options, physical health, feelings, self-perception, sports and leisure, work and school, treatment, future, family planning and relationships, social support systems apart from disease specific related measures (Ferreira *et al*., 2013). An investigation of physical performance in haemophilic patients invariably focused on body perception in addition to mobility, strength & coordination, endurance as an important dimension of performance (Von Mackensen *et al*., 2010). Most of the above-mentioned studies have been done in the context of developed nations. However, quality of life in developing countries, is shaped by resource constraints, collectivistic values, role of family and other social support which become more important for any affected individual to lead a relatively good quality of life, apart from state of physical health.

Social Support and Quality of Life

The majority of HRQoL studies have overlooked the role and impact of psychosocial variables such as social support, coping, and self-efficacy on the HRQoL of haemophilia patients (Shah, 2016). In contrast, various other researchers have revealed strong correlations and importance of psychosocial factors in determining an individual's QoL.

Families with children suffering from haemophilia experience stress in terms of emergency care, treatment and precautions to be observed in daily living. Caregivers of children with haemophilia had lower HRQoL compared to the general population, especially caregivers of children with inhibitors reported lower HRQoL and an increased burden (Lindvall, 2013).

A study of haemophiliacs in Austria concluded that most of the Austrian haemophiliacs share a sound family environment, suggesting that they are highly capable of coping with their chronic disease which was indicated by good scores for role-emotional and mental health (Hartl *et al*., 2008). It is well known in many cross-cultural studies that role of family is different across cultures.

Self Esteem and Quality of Life

The domains of 'feelings' and 'view of yourself' have been found in haemophilia scale development studies (Wyrwich *et al*., 2015).The HERO study pointed out that haemophilia affected persons and their family suffer from anxiety about their future (HERO-S, 2020). More often, PWH do feel insecure,inadequate, and unequal to their peers. A study from India clearly pointed out a lack of self esteem amongst young and adolescent patients (Mohan *et al*., 2021).

Disease Management

Good management of a chronic condition, is related to disease knowledge and complications associated with the condition and the preventive

behaviours that can improve these complications (Nazzaro *et al*., 2006). In cases where the disease is discovered in adolescent years or later, the affected person may be less familiar with haemophilia management, leading to lower self-efficacy related to their disease and higher likelihood of relying on their haemophilia treatment centre (HTC) for their care (Buckner *et al*., 2017). However, knowledge about management of the disease gives the patient as well as their family a good HRQoL

Objective of the study

Given the background, the objective of our current study is to conceptualize and validate a scale to measure the quality of life of the young and adolescent patients with haemophilia in developing countries like India. The scale is based on parameters affecting quality of life other than physical health.

The current study is in continuation of a previous study (Mohan *et al*., 2020) wherein we tried to assess the knowledge, attitude and behaviour of persons with Haemophilia.

Methods

Scale Development

Step 1: Conceptual Development and Item Generation

- We followed the steps as suggested by Hinkin (1995). First, we conducted a comprehensive review of the literature to identify all the factors which influence the quality of life of people with haemophilia (Table 1).
- Second,an indepth discussions with researchers and medical practitioners was carried out. Next,the list of factors collated from literature was shared with the two groups - medical practitioners and people suffering from haemophilia (two different age groups- young cohort 14–21 years and elder cohort 22–40 years). They were asked to add more factors affecting quality of life of affected persons as per their opinion and experience. The list was further elaborated to 100 items after the first round of feedback.
- Third, in the next step, the medical practitioners were asked to mark the importance of each factor(on a scale of 1–5). Factors which were rated about 3 were considered to be affecting the quality of life more than other factors.

At the end of this process, consensus was reached for 82 items which were finalized to develop a structured questionnaire.

Step 2: Dimension development

The items were segregated into three sections: knowledge, emotions and behaviour of haemophilia patients.

The knowledge section (24 items) was about technical knowledge about the disease its management.

The emotions section (33 items) was about the feelings of affected people with family support, perceived financial burden, self-esteem, future and career, perceived infrastructural support (provided by hospitals and Government).

Questions in behaviour section (25 items) were related to preventive and curative behaviour of respondents at the time of bleeding.

The selected items were a comprehensive list, representing concerns of both the age groups.

Step 3: Item purification

Cronbach's alpha of the scale was recorded to be 0.836. A stepwise process was followed to improve the reliability of the scale (Hair & Anderson, 2010; Malhotra and Dash, 2010). 'Cronbach's alpha if item deleted' was run ten times to arrive at Cronbach's alpha of 0.902 and a total of 45 items were retained out of 82.

To explore the relationship between the remaining set of variables, exploratory factor analysis was applied using principal axis factoring (PAF) method, using SPSS. Factorability of data was verified using Kaiser–Meyer–Olkin (KMO) test of sampling adequacy and Bartlett's test of sphericity (Hair *et al*., 2010).

A stepwise process was followed to extract meaningful factors. Initially, 14 factors were extracted which explained the total variance of 69%. Though the variance explained was high enough, it was difficult to identify 14 factors which would explain the quality of life of people with haemophilia. There were several factors with single items, which needed to be dropped in order to follow the rule of minimum three items per factor.

Table 1: Conceptual, dimensional and item development

Steps	*Description*	*Results*
Conceptual development and item generation	Literature Review 10 Focus Group Discussions with Persons with Haemophilia In-depth interviews with medical practitioners working with Haemophilia	Obtained understanding about factors influencing quality of life from the perspective of Stakeholders Aided in conceptualization and item generation. Delphi technique, based on expert opinion helped in establishing construct validity of our scale.
Dimension Development	Representativeness and readability assessment Survey of PWH (n = 200)	82 items identified
	Dimensional and generalizability assessment	Weak items, nongeneralizable items revised or eliminated from initial pool; pool reduced to 45 items
		Cronbach's alpha with item deleted used to establish reliability of our scale.
Item Purification	EFA factor loadings and item-to-total correlations to reduce scale	Reduced to 15 items Three dimensions identified
Scale finalization	Theory and literature revisited, conducted CFA with above data using three dimensions	CFA confirms strength of the scale with 15 items (3 dimensions); see Table below

We then limited the number of factors to be extracted to 8 and then to 6, 5, 4 and finally 3.

Following parameters were used to zero down to the final solution. (Hair & Anderson, 2010; Carpenter, 2018)

- ***Rotation method***

Varimax rotation with Kaiser normalization was used to clearly identify the factors which were emerging.

- ***Factor loadings***

Factor loading of 0.4 or more was fixed a-priori.

- ***Cross loadings***

The final solution should have minimum number or no cross loadings

- ***Minimum three items under one factor***

An important reason for zeroing down to three factors was to have minimum three items under one factor.

- ***Communalities of items***

Items which showed communalities lower than 0.4 were further dropped.

The remaining 15 items were grouped under three factors.

Step 4: Scale Finalization

Confirmatory factor analysis (CFA) was conducted in PLS SEM software, using the same set of data to identify the relationships between the latent constructs and observed variables. CFA is conducted to minimize the difference between the observed and estimated covariance matrices (Hair & Anderson, 2010;Schreiber *et al*., 2006;Raja *et al*., 2020).

Target Population

Young persons with haemophilia in the age group of 15 to 45 years, enrolled with Haemophilia Treatment Center and Haemophilia Societies were the target respondents.

Sample Size

Sample size of 200 was estimated using the formula (Malhotra and Dash, 2010):

$$n = \frac{z^2 * \hat{p}(1-p)}{\varepsilon^2},$$

Where z is the z score, ε is the margin of error, N is the population size, p̂ is the population proportion

In the sample only haemophilics in the age group of 15 to 40 years and living in India, were included. The sample excluded those PWH who were not residing in India, and/or were less than 15 years or more than 40 years old. Only 15 to 40 years old were included to ensure sample homogeneity. However,no gender specific criteria was used for exclusion. A total of 200 questionnaires were filled by our target respondents. Out of 200, 169 questionnaires were found to be complete and suitable for analysis, which were finally included in the study.

The questionnaire prepared after step 1 was administered to 200 respondents. 169 responses were used to conduct analysis, mentioned in step 3 and 4.

Data Collection Procedure

Field instructors who were attuned to dealing with haemophilia patients facilitated data collection. The field instructors were medical volunteers engaged with NGO working with persons with haemophilia. The instructors explained the research objectives to the respondents and translated the questionnaire in the language understood by the target population. The tool was translated in two languages - Hindi and Kannada by native volunteers who were acquainted with the field of hemophilia. Participation in the survey was voluntary and prior consent of the respondents was obtained. If the respondent was found uncomfortable answering the questionnaire, he was allowed to quit at any moment.

Table 2: Factors and Corresponding Variance

Factors	*% of Variance*	*Cumulative %*
1	31.016	31.016
2	14.588	45.605
3	11.303	56.908
	Kaiser-Meyer-Olkin Measure of Sampling Adequacy.	800
	Bartlett's test of sphericity	
	Chi-Square	817.689*

p <.001

Results and Findings

KMO of 0.80 indicate that the sample is adequate for analysis.

Total variance explained by the three factors was 56.9% (Table 2). Rotated component matrix showed that all items loaded significantly on each factor (Table 3) (Hair & Anderson, 2010; Clark & Watson, 2016).

Three factors which clearly emerged were Family, Self-Esteem and Disease Management (Tables 4 and 5).

Table 3: Rotated component matrix[a]

	Component		
	1	*2*	*3*
I am placing too much burden on my family by making them adjust their expectations and lifestyle			.611
I feel tensed that my parents will live with the guilt of giving me this disorder			.669
I feel my family members are smothering me too much			.849
I feel my family members are invading my privacy too much by telling me what to do			.779
I am apprehensive about my career options as I feel my capabilities are restricted due to my disease	.627		
I feel I might not be promoted / succeed like my colleagues / my peers	.752		
I feel I don't have equal opportunities because of haemophilia	.819		
I feel I don't have enough to be the best version of myself	.698		
I feel I am not perfect for marriage/to have a family of my own	.656		
I take utmost physical care of my body since I have bleeding disorder		.679	
I stay away from sharp objects and wires to keep myself safe from bleeding episodes		.626	
I do not play contact sports such as cricket, football etc.	.524	.413	
I prefer playing indoor sports like table tennis or badminton since they have less chances of resulting in bleeding episodes / I refrain from playing sports	.452	.553	
I think Government and other related organizations are providing enough treatment facilities for Haemophiliacs		.713	
I feel the doctors and nurses provide immediate care during emergency		.811	

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

Table 4: Domain/Factor-wise reliability

	Cronbach's alpha	*rho_A*	*Composite reliability*	*Average variance extracted (AVE)*
Attitude towards haemophilia	0.828	0.846	0.862	0.304
Family	0.759	0.759	0.847	0.582
Self-esteem	0.825	0.834	0.878	0.592
Disease management	0.748	0.771	0.824	0.443

Table 5: Discriminant validity

	Attitude towards haemophilia	*Attitude towards family*	*Attitude towards self*	*Disease management*
Attitude towards haemophilia	0.551			
Family	0.697	0.763		
Self esteem	0.873	0.461	0.770	
Disease management	0.671	0.190	0.386	0.666

Family

Four items loaded, namely, invasion of privacy by family, over protective tendency of family, unable to meet family expectations, parents are living with guilt.

Self Esteem

Five items namelyapprehension about career, insecurity related to equal opportunities, insecurity about promotion, apprehension about future family, inability to be the best version of self-were put together and identified under the dimension 'Self Esteem'

Disease Management

Six items namely, I take utmost care of myself, refrain from sharp objects and outdoor sports, prefer indoor sports to prevent bleeding, Role of Government in treating haemophilia, role of doctors and nurses in provision of emergency services loaded on single dimension and we named the dimension as 'disease management'

Scale internal consistency reliability, as expressed by Cronbach's alpha , was very high in all dimensions, ranging between 0.748 and 0.828.The hypothesized structure of the scale was confirmed with internal consistency and discriminant validity (Hair & Anderson, 2010; Malhotra & Dash, 2010)

Analysis and Discussion

Out of the 82 indicators which were culled with the help of previous research and stakeholder interactions, our data reflected that our respondents were least affected by knowledge of the disease. The study identified subjective or psychological indicators that are relevant for young as well as adult patients in developing countries.

The dimension 'Self-esteem' was found important by our respondents that defines their quality of life. The condition of haemophilia results in the feeling of being inadequate, the feeling of being not equal, lack of confidence to compete with their peers or to present themselves to their prospective partners, the insecurity associated with having a spouse and family, insecurities related to having a good career and associated joy. Self-efficacy had a significant impact on HRQoL of haemophilia patients (Shah, 2016). In such cases, counselling of affected persons and families can prove to reduce anxiety and stress. Sports activities can improve not only physical well-being, but also the emotional and social well-being of persons with haemophilia (Von Mackensen, 2007). Disease-specific social networking could benefit adolescents with severe hemophilia as they get peer support and experi-

ential learning gained online (Khair *et al*., 2012). It is important to understand that irrespective of the severity of the disease, having a career or building a family which are important to build self-esteem,have helped the patients in leading a life of quality.

By using new QoL questionnaire, QoL of young people can be determined from family support. While family support has two dimensions, one is the suffering caused to family due to emotional and financial burden, second is intangible aspect of family support available to the patients that helps them live with dignity. While most of our respondents felt lack of personal space due to over protection or binding conditions imposed by their family,they were also highly affected by the burden this disease is causing to their family. In many cases, family or caregivers also suffered in terms of their quality of life, while the burden was more in case of children suffering from hemophilia than in adults (Lindvall, 2013).In Austria, due to better family bonding, the quality of life of affected persons was found to be better as they were better able to cope with the disease (Hartl *et al*., 2013). However, a contrasting finding was introduced that social support did not have any direct impact on their HRQoL (Shah, 2016). Most adults reported that haemophilia affected their ability to form close relationships with partners or prospective partners(Cutter *et al*., 2019). Opportunities exist to more proactively counsel individuals with mild to moderate haemophilia B and their families to better navigate interpersonal relationships and disclosure and improve quality of life when they choose to engage with the HTC and community (Cutter *et al*., 2019).It is needless to mention that families of affected individuals need to be counselled and given practical tips to not only overcome insecurity themselves but also support the affected individuals in every possible manner to allow them to manage/control the severity of the disease. Family support has been found to be directly proportional to containing the severity of the disease in earlier researches.

An important issue is disease management which has been incorporated in the new QoL scale development. Disease management is understood as responsiveness of the system to offer preventive and curative support to the affected persons. The respondents in our study were found to be responsibly taking care of themselves, staying away from outdoor sports or physical activities which would put them to risk of bleeding. Such persons need to be guided appropriately to take up physical activity with caution. Research has shown that physical activity, physiotherapy and other rehabilitation measures should be encouraged to reduce Haemophilia induced morbidities and to improve HRQoL of affected persons (Ferreira *et al*., 2013). Two important preventive measures against joint damage associated with haemophilia are physical activity/exercise and treatment timing, either early treatment of a bleeding episode (i.e., within 1 hour) or treatment with prophylaxis (a regimen of regular infusions) (Nazzaro, 2006).The mobility aspect of disease management is important to understand as it holds the key to manage the severity of the disease only if done adequately and appropriately. While due to lack of awareness and knowledge in Indian settings, most persons with disability think that they are not allowed to undertake physical stress, they need to be educated about the quality and quantity of physical exercise which is imminent to keep the condition under control.

While our respondents reported that they take adequate measures to keep their condition in check in order to lead a good quality of life, they also solicit adequate support from Government and healthcare infrastructure.

It should be noted that the factors such as self-esteem and family support emerged relevant not only for the young Haemophilic population but also for the adult respondents interviewed. While disease management was found more prominent among adult respondents than young respondents.

Policy and Managerial Implications

The dimensions are relevant to the Indian context as access to treatment, financial burden, knowledge to manage the disease and emotional turmoil are some characteristic burdens of Haemophilia disease (Mohan *et al*., 2021).

Family support emerged as a significant factor which decide the quality of life of young people. In countries like India and other South Asian cultures, young and adolescent children mostly continue to

reside with their families and remain financially and emotionally dependent on parents even after they attain the age of 18 years. Hence, their happiness factor is linked to the resilience of the families to face and wholeheartedly support their suffering children, without feeling guilty.

Disease management or Governance factor is equally significant in Indian context. Being a developing nation, healthcare facilities are not sufficient for the size of its population. For a condition like Haemophilia which is affecting a relatively smaller proportion of the total population, focus needs to be brought to managing this condition by creating adequate infrastructure and provision of counselling facilities.

Conclusion

The burden of haemophilia is increasing in India and so is the financial and emotional burden associated with the disease. Most researches in the past have associated haemophilia with the physical ailment. No doubt, the condition is more of physical, however, it is important to note the other psychology related externalities associated with the disease.We developed and refined a scale consisting of the three dimensions which were found to be most significant in defining the quality of life of our respondent group. The dimensions are family support, self-esteem of the affected person and disease management This scale can be a starting point for researchers and policy makers to identify areas of concern for young people suffering from haemophilia(McDowell, 2006).

Limitations of the Study

- The data in the study is currently taken from two large states of the country. However, same dimensions can be tested and further explored in other parts of the country.
- Though we have taken responses from two different age groups to include all significant concerns, the scale can be tested and verified over a period of time to assess how factors affecting the quality of life change.
- The sample size used for developing and validating the tool was limited to 169. This is because of the limitation of availability of persons with haemophilia and their willingness to participate in the survey. Low participation rate has been consistent with the experience of other authors working with this patient population (Dunkley *et al*., 2018).

Acknowledgments

We would like to thank the contributions Ms. PratigyaKwatra, Researcher at MART Global Management Solutions LLP for her assistance in Analysis.

Conflict of Interest

The authors stated that they had no interests which might be perceived as posing a conflict or bias

References

Aledort, L., Bullinger, M., Von Mackensen, S., Wasserman, J., Young, N. L., Globe, D., & Health Related Quality of Life Expert Working Group of the International Prophylaxis Study Group. (2012). Why should we care about quality of life in persons with haemophilia?. *Haemophilia*, *18*(3), e154-e157.

Buckner, T. W., Witkop, M., Guelcher, C., Frey, M. J., Hunter, S., Peltier, S., ... &Sidonio Jr, R. (2017). Management of US men, women, and children with hemophilia and methods and demographics of the Bridging Hemophilia B Experiences, Results and Opportunities into Solutions (B-HERO-S) study. *European Journal of Haematology*, *98*, 5-17.

Carpenter, S. (2018). Ten steps in scale development and reporting: A guide for researchers. *Communication methods and measures*, *12*(1), 25-44.

Clark, L. A., & Watson, D. (2016). Constructing validity: Basic issues in objective scale development.

Cohen, J. S., &Biesecker, B. B. (2010). Quality of life in rare genetic conditions: a systematic review of the literature. *American Journal of Medical Genetics Part A*, *152*(5), 1136-1156.

Cutter, S., Guelcher, C., Hunter, S., Rotellini, D., Dunn, S., & Cooper, D. L. (2019). Mild-severe hemophilia B impacts relationships of US adults and children with hemophilia B and their families: results from the B-HERO-S study. *Patient related outcome measures*, 257-266.

de Vries, M., Ouwendijk, R., Kessels, A. G., de Haan, M. W., Flobbe, K., Hunink, M. G., ... & Nelemans, P. J. (2005). Comparison of generic and disease-specific questionnaires for the assessment of quality of life in patients with peripheral arterial disease. *Journal of Vascular Surgery*, *41*(2), 261-268.

Dunkley, S., Lam, J. C. M., John, M. J., Wong, R. S. M., Tran, H., Yang, R., & Srivastava, A. (2018). Principles of haemophilia care: The asia pacific perspective. Response. *Haemophilia: the Official Journal of the World Federation of Hemophilia*, *24*(4), e243-e244.

Ferrans, C. E., Zerwic, J. J., Wilbur, J. E., & Larson, J. L. (2005). Conceptual model of health-related quality of life. *Journal of nursing scholarship*, *37*(4), 336-342.

Ferreira, A. A., Leite, I. C. G., Bustamante-Teixeira, M. T., Corrêa, C. S. L., Cruz, D. T. D., Rodrigues, D. D. O. W., & Ferreira, M. C. B. (2013). Health-related quality of life in hemophilia: results of the Hemophilia-Specific Quality of Life Index (Haem-a-Qol) at a Brazilian blood center. *Revistabrasileira de hematologia e hemoterapia*, *35*, 314-318.

Ghosh, K., & Shukla, R. (2017). Future of haemophilia research in India. *Indian Journal of Hematology and Blood Transfusion*, *33*(4), 451-452.

Gringery A., & Von Mackenson, S (2008). Quality of life in haemophilia, Haemophilia. (14Suppl. 3), 19–25

Hair, J. F. J., W. C. Black, B. J. Babin, and R. E. Anderson. (2010). *Multivariate Data Analysis*. 7th ed. Prentice Hall, NJ: Pearson.

Hartl, H. K., Reitter, S., Eidher, U., Ramschak, H., Ay, C., & Pabinger, I. (2008). The impact of severe haemophilia on the social status and quality of life among Austrian haemophiliacs. *Haemophilia*, *14*(4), 703-708.

HERO-S(2020). Available at: http://www.herostudy.org/hero-insights.html. accessed on June 20, 2020

Hinkin, T. R. (1995). "A Review of Scale Development Practices in the Study of Organizations." *Journal of Management* 21 (5): 967–988.

Kar, A., Phadnis, S., Dharmarajan, S., & Nakade, J. (2014). Epidemiology & social costs of haemophilia in India. *Indian Journal of Medical Research*, *140*(1), 19-31.

Khair, K., Holland, M., & Carrington, S. (2012). Social networking for adolescents with severe haemophilia. *Haemophilia*, *18*(3), e290-e296.

Lindvall, K. (2013). Health-related quality of life and adherence in haemophilia.

Mackensen, S. (2015). Interpreting important health-related quality of life change using the Haem-A-QoL. *Haemophilia*, *21*(5), 578-584.

Malhotra, N. K., and S. Dash. (2010). *Marketing Research: An Applied Approach*. New Delhi: Dorling Kindersley.

McDowell, I. (2006). *Measuring health: a guide to rating scales and questionnaires*. Oxford university press.

Mohan, R., Radhakrishnan, N., Varadarajan, M., & Anand, S. (2021). Assessing the current knowledge, attitude and behaviour of adolescents and young adults living with haemophilia. *Haemophilia*, *27*(2), e180-e186.

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

Raja, M. W., Anand, S., & Kumar, I. (2020). Multi-item scale construction to measure consumers' attitude toward advertising music. *Journal of Marketing Communications*, *26*(3), 314-327.

Remor, E. (2011). Quality of life in hemophilia. *Current and future issues in hemophilia care*, 49-52.

Schreiber, J. B., Nora, A., Stage, F. K., Barlow, E. A., & King, J. (2006). Reporting structural equation modeling and confirmatory factor analysis results: A review. *The Journal of educational research*, *99*(6), 323-338.

Shah, R. M. (2016). Measuring and understanding health-related quality of life among adult patients with Hemophilia.

Von Mackensen, S. (2007). Quality of life and sports activities in patients with haemophilia. *Haemophilia*, *13*, 38-43.

Von Mackensen, S., Czepa, D., Herbsleb, M., &Hilberg, T. (2010). Development and validation of a new questionnaire for the assessment of subjective physical performance in adult patients with haemophilia–the HEP-Test-Q. *Haemophilia*, *16*(1), 170-178.

World Health Organization (2020). Genes and Human Diseases, https://www.who.int/genomics/public/geneticdiseases/en/index2.html#:~:text=Thalassaemia%20Screening%20Programme,Haemophilia,%2C%20very%20often%20%2C%20is%20internal. Accessed on July 1, 2020