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Challenges facing community-dwelling adults with hemophilia: Implications for community-based adult education and nursing

Charity Chinelo Okide[1], Chiedu Eseadi[2], Uzoamaka Lucynda Koledoye[1], Felicia Mbagwu[1], Nwakaego Ebele Ekwealor[1], Nkechi Mercy Okeke[1], Chioma Osilike[1] and Polycarp M.D. Okeke[1]

Abstract

Community-dwelling adults are members of society residing in community settings. Community-based adult education is designed for local residents and groups, to enable them to improve their quality of life within their community. Hemophilia is a bleeding disorder that can be inherited or acquired. World Hemophilia Day 2018 helped to raise awareness about the importance of sharing knowledge and the experience of hemophilia, as well as to improve access to care and treatment among people with this bleeding disorder. We used the documentary method of research, which has been adopted in recent review articles, to collect and analyze the findings of published literature on hemophilia. Our results showed that community-dwelling adults with hemophilia have concerns that merit the attention of government and non-governmental agencies. Some challenges faced by many community-dwelling adults with hemophilia include the cost of treatment and employment challenges. Herein, we discuss the implications for community-based health education and nursing with respect to patient care, adult education, nursing education, management, research, and policy. Finally, the authors note that sustainable efforts are needed in the provision of local, national and international leadership and educational resources to improve and sustain health care for community-dwelling adults with hemophilia.

[1]Department of Adult Education and Extra-Mural Studies, University of Nigeria, Nsukka, Enugu State, Nigeria
[2]Department of Educational Foundations, University of Nigeria, Nsukka, Enugu State, Nigeria

Corresponding author:
Felicia Mbagwu, Department of Adult Education and Extra-Mural Studies, University of Nigeria, Nsukka, P.M.B. 410001, Enugu State, Nigeria.
Email: mbagwu.felicia@gmail.com

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Introduction

Hemophilia is a health impairment that has been described as a sex-linked, genetic disorder typified by the shortage or lack of one of the clotting proteins in plasma.[1] This genetic disorder prevents the normal clotting of blood, causing the individual to bleed for a longer time than normal.[2,3] At present, there is no definitive cure for hemophilia.[1] Health care goals related to this disorder include the prevention of bleeding, recognition of bleeding episodes, provision of timely treatment, and intervention to avert complications.[1] Hemophilia affects all people, irrespective of socioeconomic class, race, or ethnicity. To raise awareness about this condition, World Hemophilia Day is held as an annual event on 17 April, with the aim of raising public awareness about this life-threatening disorder that is a serious public health concern; awareness about the importance of access to treatment and care is another goal of this event. The theme of World Hemophilia Day in 2018 was "Sharing Knowledge Makes Us Stronger."[4] The 2018 event was organized by the World Federation of Hemophilia (WFH) and focused on the importance of sharing first-hand knowledge and experience to help increase awareness and improve accessibility to care and treatment among people with this bleeding disorder.[4]

As educators, we aim to contribute to attainment of this knowledge-sharing goal from a cross-disciplinary standpoint. According to Connor,[5] no single professional group can provide all of the fundamental elements needed for a comprehensive health education program for individuals with hemophilia. Therefore, using a cross-disciplinary approach, we sought to add to the academic literature and resources required for patient education in relation to treatment and care of people with hemophilia. This is necessary at this time because according to the World Federation of Hemophilia,[3] approximately 1 in 10,000 individuals are born with hemophilia. In the United States alone, hemophilia affects 1 in 5,000 male newborns, and about 400 babies each year are born with this disorder.[6,7]

At present, about 400,000 individuals globally are living with hemophilia, and up to 20,000 of these individuals are in the United States.[6,7] Scholars and health organizations have identified at least four types of hemophilia. Hemophilia A is the most common type of hemophilia; it is a condition in which the individual has insufficient clotting factor VIII. Hemophilia B is a condition in which the individual has inadequate clotting factor IX.[3,6–8] In hemophilia C, the affected person does not have sufficient clotting factor XI. Acquired hemophilia is an uncommon condition in which a person can develop hemophilia owing to illness, medications, or pregnancy.[6] Acquired hemophilia typically resolves itself with accurate diagnosis and proper treatment.[6] Regardless of the type of hemophilia involved, individuals with the disorder bleed for a longer time than normal.

Community-dwelling adults with hemophilia experience considerable challenges, which merit the attention of several government and non-governmental agencies. Based on the reviewed literature and resources on hemophilia,[1–8] the challenges faced by community-dwelling adults with hemophilia include but are not limited to meeting the financial costs of treatment, remaining in unsuitable jobs, vulnerability to distress, concerns about loss of independence, concerns about self-disclosure, poor interpersonal relationships, job loss, and impaired work functioning. These concerns of community-dwelling adults merit the attention of government and non-governmental agencies, who have an interest in achieving the sustainable development goal number three by 2030, which is to ensure healthy lives and promote well-being for all at all ages.[9]

Community-dwelling adults are members of society who reside in community settings. Some authors use the term community-residing adults to describe individuals living in the community.[10] An analysis of previous research indicates that community-based adult education is a form of adult learning within a community that draws from and strengthens existing community structures, creates a sense of community among and for its beneficiaries, and offers a number of positive benefits for individuals, families, communities and society at large. In turn, community-based adult education helps to create social capital, community cohesion, and social inclusion.[11] One study revealed that participation in community-based adult education classes enables participants to gain improved mental health, increased self-identity, and educational progress.[11] Community-based adult education can contribute to attaining the goal of easing the global burden of human suffering, which negatively affects individual and community mental health and limits the potential for human development on a global level.[12] Community-based adult education can facilitate learning, which supports mobility and growth toward complete actualization of human nature. Further details regarding the goals, principles, and practices of community-based adult education can be found in the literature.[12] Community-based adult education is designed for local individuals and groups, to enable them improve their life quality within their community.[13] Many experts support the notion that community-based adult education can provide the basis for improving health and well-being.[14] In the following sections, we discuss the challenges faced by community-dwelling adults with hemophilia. The final section of this paper discusses the implications for community-based adult education and nursing with respect to patient care, adult education, nursing education, management, research, and policy.

Methods

The documentary method of research,[15] which has been used in recent review articles,[16,17] was adopted to collect and analyze the findings of previous studies on hemophilia. Documentary research is a method that involves the use of primary, secondary and virtual documents such as government papers, newspapers, and diaries to derive information for conducting a document-based study.[15]

We conducted a literature search between March and July, 2018. Grey literature and peer-reviewed journal articles on hemophilia were identified in a search, using Google, Google Scholar, and PubMed Central as the main sources of information. Search terms included hemophilia, hemophilia policy guidelines, hemophilia in adults, hemophilia treatment, out-of-pocket expenses for hemophilia treatment, and interventions for hemophilia. The methods followed for selecting and

analyzing studies in this review are in line with recently published reviews on community health.[16,17]

Results and discussion

Challenges facing community-dwelling adults with hemophilia

Challenges in meeting the financial costs of treatment. Owing to the dynamic nature of health insurance coverage, there is a continuous increase in the cost of treating hemophilia and its associated complications.[1–4] As a result, community-dwelling adults living with hemophilia often have substantial concerns about financial stability and the cost of caring for their health. This concern in particular merits the attention of government and non-governmental agencies that are interested in achieving sustainable development goal number three by 2030, which is to ensure healthy lives and promote well-being for all at all ages.[17] Providing funds to cover the cost of health care for treating individuals with hemophilia could be one of numerous ways to contribute to realizing the development goal of good health and well-being for all.[4]

Unsuitable jobs and vulnerability to distress. Many community-dwelling adults with hemophilia may choose to work in jobs that are unsuitable for them, so as to obtain or maintain insurance coverage. At the same time, many with insurance coverage face rising costs of co-payments and lifetime restrictions. In addition to uncertainty about their ability to keep working, health insurance concerns can be distressing to people with hemophilia and their families.[2–6]

Concerns about loss of independence. Making feasible plans for health care with regard to hemophilia is a critical task for an adult living with this disorder. As a result, concerns about independence are often present. Although some health care responsibilities can be handled by a partner or family member, it is imperative for community-dwelling adults with any form of hemophilia to continue to maintain control or be in charge of some aspects of the decision-making process related their health care.[1–8] Many patients with hemophilia have jobs and sufficient resources to take care of themselves and their families. However, increasing physical disability can lead to major lifestyle modifications and role reversal within the household.[1,2,7,8] These alterations to their abilities, roles, and functions represent considerable losses for adult patients, who have prevailed over numerous barriers to attain their independence. When such lifestyle changes occur, many people feel concern over loss of the ability to control of certain aspects of their lives and care and about being impacted by poor decisions made by caregivers or partners.[3–8]

Concerns about self-disclosure. In the past, many community-dwelling adults openly discussed their hemophilia diagnosis; however, following increasing awareness about coinfection with other viruses, many people have begun to re-evaluate the issue of self-disclosure.[1–3] Most community-dwelling adults with hemophilia will discuss their diagnosis and related complications with friends, family members, employers, and colleagues. But when it comes to disclosure to employers and colleagues, this is usually dependent on the patient's inclination, concerns about privacy, treatment needs, extent of physical disability, and previous experience of sharing information about their health condition in the workplace.[2,3]

Poor interpersonal relationships. Hemophilia can have a negative impact an individual's interpersonal relationships in that their

mobility, outlook, and mood are affected at times. In light of coinfection with viruses like HIV, safe sex practices and sexual transmission are considered primary issues that can affect family planning. For such individuals and their partners, support in adopting alternative approaches to family planning can be helpful.[1–4]

Job loss and impaired work functioning. For community-dwelling adults living with hemophilia, loss of employment can raise concerns about financial security, insurance coverage, and the potential need for additional education or training. For some community-dwelling adults with hemophilia, progressive joint disease or complications of HIV or hepatitis can negatively affect their ability to continue doing some types of jobs that were previously easy for them to handle.[3–7]

Implications

This section discusses the implications of caring for community-dwelling adults who have hemophilia with respect to patient care, adult and nursing education, management, research, and policy.

Patient care

It has been acknowledged that greater efforts are required to completely eliminate a broad array of diseases and to tackle persistent and emerging health concerns.[17] As with the diagnosis of other chronic diseases, a diagnosis of hemophilia requires that support be provided to individuals with this disorder and their families, to assist them in overcoming their feelings of distress. Families might need support in recognizing that people with hemophilia must cope in different ways. Continuing adult education-related health information and patient advocacy can help to close gaps in awareness about hemophilia.

Participants in community-based adult education can play important roles in disseminating health information to their families and communities.[18] These individuals can offer assistance with regard to sharing information about hemophilia to other adults living in their community. Health counseling and guidance from nurses can also help spouses and families in this regard. Nurses provide health care services to young, middle, and older community-dwelling adults, as well as family members of these individuals. Several interventions by nurses and other health care providers have been shown to be effective for the management of hemophilia.[19–24] In addition, clinical practice guidelines on drug interventions for hemophilia management and cost-effectiveness of such interventions have been identified; these details can be found in a 2016 report.[23] Several behavioral and exercise interventions have also been demonstrated to be helpful in hemophilia management.[24–28]

Community-based adult education, nursing education, and management

Psychosocial support from adult educators and nurses can assist adult patients and their families to move through the grieving process and to adjust and cope with living with hemophilia. Community-based adult education and nursing interventions rooted in psychosocial counseling and support services can be helpful in this regard. In addition, nurses can learn to initiate comprehensive hemophilia therapy and home treatment programs, to enable them to assist adults with hemophilia in the community to choose an appropriate career and pursue the education or training required to achieve their life goals.

Through training, students of community-based adult education as well as nurses can learn to adapt the HemoAction Games[20] to teach adult patients, spouses, and other

family members about hemophilia. These games educate players on how to prevent bleeds and manage hemophilia, and provides information about the clotting process, types of bleeds, factor infusions, and appropriate physical activities. The HemoAction Games were developed following introduction of the popular HemoAction playing cards, which were developed by Frederica Cassis in 2003.[29] Via visual communication, these games can be used to teach individuals about hemophilia in an entertaining, comprehensible, and interactive mode. Community education specialists, nurses, and other health care providers would benefit from learning how to apply the games in explaining relevant concepts about hemophilia and its management to patients and caregivers.

Research and policy

Given that hemophilia is an X-chromosome-linked condition, males are typically more affected and are thus more frequently diagnosed than females.[7] Therefore, empirical research is needed to substantiate how psychosocial interventions can help ameliorate the distress experienced by most adult males with hemophilia and their families. Multidisciplinary interventions and evaluation research among individuals with hemophilia are needed. Studies are required to further increase our understanding of the emerging symptoms of hemophilia among female patients. This is particularly important because a number of women live with their symptoms for years with no diagnosis or even a suspicion of having the disorder.[30] As research has indicated, linkage-based prenatal diagnosis of hemophilia A using an intragenic short tandem repeat marker has been shown to be feasible among families in Pakistan. However, the long-term response of the families of people with hemophilia to improved accessibility of prenatal diagnosis is yet to be clarified.[23] However, a short tandem repeat marker can be used for carrier detection among female members of families affected by hemophilia.[31]

Transition is considered an individualized age- and development-appropriate process by means of which individual patients can be empowered to self-manage their disease with the assistance of their family and multidisciplinary teams.[32] Therefore, further research on nurse-led interventions are required to assist young people with hemophilia achieve a smooth transition to adult services for hemophilia. Therapeutic care programs for people with hemophilia should not be assessed only in terms of the monetary cost of achieving adequate musculoskeletal outcomes.[33] Community-based adult education specialists should expose their trainees to a broad range of theories that view humans as whole persons with inherent and universal potential for growth and development, and that view psychological well-being as more than the absence of disease, by incorporating such approaches in their school curriculum and research focus.

Researchers have noted evidence-based guidelines that offer practical recommendations on hemophilia diagnosis, general management, and management of complications like transfusion-transmitted infections, musculoskeletal issues, and inhibitors.[19] For instance, the widely referenced policy guidelines for hemophilia by the WFH[20] highlights the principles of patient care; the components of and need for comprehensive hemophilia care programs and multidisciplinary care teams; the importance of and strategies for encouraging fitness and physical activity among patients; why regular monitoring of health status and outcome in individuals with hemophilia is needed; and the importance and components of several kinds of therapies and interventions for people with hemophilia such as adjunctive therapies, prophylactic factor replacement

therapy, home-based therapy, pain management procedures, surgery and invasive procedures, and dental care and management procedures.[20]

The WFH policy guidelines are aimed at assisting health care teams and providers who are seeking to begin or sustain hemophilia care programs, supporting practice harmonization globally, and encouraging suitable research in cases where recommendations have insufficient evidence.[19] The WFH policy guidelines for management of hemophilia are being reviewed by clinical experts from different health care organizations for adaptation and use. An example is a review and adaptation of these guidelines being jointly conducted by the Australian Hemophilia Centre Directors' Organisation and National Blood Authority of Australia; this process will lead to revised guidelines for hemophilia management in Australia.[21] Other regions worldwide without existing policy guidelines for managing this health condition are encouraged to make further efforts to review and adapt the WFH policy guidelines for the management of hemophilia.

The need across nations for the establishment of hemophilia care centers cannot be overemphasized, to foster the translation of health care policies into practice. Substantial changes in the care of patients with hemophilia can be achieved through the reorganization of resources and provision of education and training at all levels.[22,23] It is indispensable to ensure that people with hemophilia and their families are participating in a comprehensive health care program, and to endeavor to gain legislative and financial support of the government so as to have a national comprehensive care program covering all aspects of care required for improving the quality of life of community-dwelling adults with hemophilia.[23]

Further research in hemophilia is imperative, particularly multicenter studies in countries like India where researchers have shown that little public health attention is being paid to hemophilia.[34] The low priority given to this bleeding disorder by public health authorities in developing regions hinders patient care and management, resulting in poor health outcomes.[34] This could be because many national public health authorities in developing countries are unaware of the number of patients with hemophilia in their region, which is in turn owing to a lack of national surveillance registers.[35] This emphasizes the need for and initiation of national surveillance registers by public health authorities in developing countries for uncommon genetic disorders, such as hemophilia. Given that out-of-pocket expenses for hemophilia treatment are catastrophic for patients and their families in the developing world,[36–38] future research aimed at increasing advocacy for subsidized treatment costs and initiating government interventions for patients in these regions is very relevant. Additional research in the form of case reports, clinical studies, reviews, and economic evaluation studies are required to provide additional substantiation of promising evidence regarding complications related to this congenital disorder,[39,40] case management and treatment options,[41–43] and cost-effectiveness of treatment[22,44–49] for various types of hemophilia. Finally, when providing educational information about hemophilia to community-dwelling adults, it is crucial to understand that these individuals are often confident, pragmatic, and goal-oriented learners and that in general, adults are affective learners, learners-in-transition, integrated learners, and risk takers whose culture is often reflected in their stories, activities, characteristics, and beliefs.[50]

Conclusion

In this review, we primarily discussed the challenges facing community-dwelling

adults with hemophilia and the implications for community-based adult education and nursing. Hemophilia can impact anyone, regardless of socioeconomic class, race, and ethnicity. World Hemophilia Day serves as a reminder of the importance of sharing knowledge and experience, to help increase awareness as well as improve access to care and treatment for people with this genetic disorder. From this perspective, we noted some of the challenges facing many community-dwelling adults living with hemophilia, including costs of treatment and employment challenges. Given the issues facing many of these adults with hemophilia, greater attention from relevant government and non-governmental agencies is needed to help combat this public health problem. The implications of caring for community-dwelling adults with hemophilia via community-based adult education and nursing should not be overlooked with respect to patient care, adult education, nursing education, management, research, and policy. Sustainable efforts are needed to provide local, national, and international leadership and resources for patient education and to improve and sustain health care for all people living with hemophilia. There is a need for further research to examine patient needs and the development of interventions that can be used by nurses and educators on health care teams to help patients and families cope with the manifestations of this illness. In future research, it would also be helpful to analyze the literature, including reports of nursing and other interventions and policies that have been applied and have been effective in this area of health care and adult patient education. Advocating for subsidized costs of treatment for these patients is also needed. It is suggested that participants in community-based adult education as well as nurses can learn to adapt tools like the HemoAction Games to improve knowledge and awareness, as well as to teach other adults in the community about hemophilia.

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ORCID iD

Charity Chinelo Okide https://orcid.org/0000-0002-3912-9165
Chiedu Eseadi https://orcid.org/0000-0003-1711-7558

References

1. Centers for Disease Control and Prevention. Training & Education on Hemophilia. Last updated on September 6, 2018. Introduction to hemophilia care. Atlanta, GA: CDC; [cited on April 2nd, 2018]. Available at: https://www.cdc.gov/ncbddd/hemophilia/training.html
2. National Hemophilia Foundation. NHF's Fast Facts. [cited on April 2nd, 2018]. Available at: https: //www.hemophilia.org/About-Us/Fast-Facts
3. World Foundation of Hemophilia. What is hemophilia? Last updated on May 2012. [cited on April 1st 2018]. Available at: https: //www.wfh.org/en/page.aspx?pid=646
4. World Federation of Hemophilia. World Hemophilia Day 2018. Sharing Knowledge Makes Us Stronger. [cited on April 1st 2018]. Available at: https: //www.wfh.org/en/whd
5. Connor FP. The hemophiliac child in school. *Ann N Y Acad Sci* 1975; 240: 238–245.
6. Hemophilia Association of the Capital Area. Hemophilia. [cited on April 1st 2018]. Available at: https: //www.hacacares.org/bleeding-disorders/hemophilia
7. Hemophilia Federation of America. Hemophilia A. [cited on April 1st 2018].

Available at: http: //www.hemophiliafed.org/understanding-bleeding-disorders/what-is-hemophilia/hemophilia-a/
8. National Hemophilia Foundation. Types of Bleeding Disorders. [cited on April 2nd 2018]. Available at: https: //www.hemophilia.org/Bleeding-Disorders/Types-of-Bleeding-Disorders
9. United Nations. Sustainable Development Goals. [cited on April 2nd 2018]. Available at: http: //www.un.org/sustainabledevelopment/health/
10. Brock K, Clemson L, Cant R, et al. Worry in older community-residing adults. *Int J Aging Hum Dev* 2011; 72: 289–301.
11. Power MJ, Neville P and O' Dwyer M. The social value of community-based adult education in Limerick City. *Limerick Ireland*; 2012. Available at: http: //www.limerickcityaes.ie/Publications.aspx
12. Ayvazian AS. Goals, principles, and practices for community-based adult education through the lens of a Hatcher-Assagioli synthesis. *Open Access Dissertations* 2012; 628. Available at: https://scholarworks.umass.edu/open_access_dissertations/628/
13. East Lothian Council. Community based adult learning. [cited on June 5, 2019]. Available at: https: //www.eastlothian.gov.uk/info/210595/east_lothian_works/11967/services_for_adults/5
14. South Ayrshire Council. Community based adult learning. [cited on June 5, 2019]. Available at: https: //www.south-ayrshire.gov.uk/community-learning-development/community-based-adult-learning.aspx
15. McCulloch G. Documentary research: In Education, history and the social sciences. New York: Routledge, 2004.
16. Wogu JO, Chukwu CO, Nwafor KA, et al. Assessing the role of the media in the prevention and control of meningitis in Nigeria. *J Int Med Res* 2019: 300060519841168. doi: 10.1177/0300060519841168
17. Wogu JO, Chukwu CO, Nwafor KA, et al. Mass media reportage of Lassa fever in Nigeria: a viewpoint. *J Int Med Res* 2019: 300060518821552. doi: 10.1177/0300060518821552
18. Nwobi U, Ogbonnaya KA, Agboeze MU et al. Health information needs of rural women in Sub Sahara Africa: a case study of Nigeria. *Eur J Sci Res* 2017; 145: 129–138.
19. Srivastava A, Brewer AK, Mauser-Bunschoten EP, et al. Guidelines for the management of hemophilia. *Haemophilia* 2013; 19: e1–e47. doi: 10.1111/j.1365-2516.2012.02909.x
20. Srivastava A, Brewer AK, Mauser-Bunschoten EP, et al. Guidelines for the management of hemophilia. *Haemophilia* 2013;19:e1–e47.
21. Australian Haemophilia Centre Directors' Organisation. *Guidelines for the management of haemophilia in Australia Malvern East VIC*. Australia: Australian Haemophilia Centre Directors' Organisation, 2016. [cited on July 24th, 2018]. Available at: https: //www.blood.gov.au/system/files/HaemophiliaGuidelines-interactive-updated-260317v2.pdf
22. Ruiz-Sáez A. Comprehensive care in hemophilia. *Hematology* 2012; 17: s141–s143.
23. Center for Evidence-based Policy Medicaid Evidence-based Decisions Project (MED) Oregon Health & Science University. Interventions for Hemophilia A and B: Clinical Practice Guidelines and Cost-effectiveness. A Report for the Washington State Bleeding Disorder Collaborative for Care. Portland, OR: OHSU MED; June 2016. [cited on July 24th, 2018]. Available at: https: //www.hca.wa.gov/assets/program/bdc_med_report_draft.pdf
24. Goto M, Takedani H, Yokota K, et al. Strategies to encourage physical activity in patients with hemophilia to improve quality of life. *J Blood Med* 2016; 7: 85–98. doi: 10.2147/JBM.S84848
25. Cassis F. *Psychosocial care for people with hemophilia. Treatment of Hemophilia, Monograph no 44*. Montreal: World Federation of Hemophilia, 2007.
26. Goto M, Takedani H, Kubota M, et al. The effect of a home exercise program for patients with hemophilia. *J Jap Prim Care Assoc* 2014; 37: 22–26.
27. Miller R. Counselling about diagnosis and inheritance of genetic bleeding disorders: haemophilia A and B. *Haemophilia* 1999; 5: 77–83.

28. Von Mackensen S. Quality of life and sports activities in patients with haemophilia. *Haemophilia* 2007; 13: 38–43.
29. World Federation of Hemophilia. HemoAction Games available online – play, share, learn! [cited on April 1st 2018]. Available at: https: //www.wfh.org/en/page.aspx?pid=889
30. World Federation of Hemophilia. Carriers and women with hemophilia. [cited on April 1st 2018]. Available at: https: //www.wfh.org/en/abd/carriers/carriers-and-women-with-hemophilia-en
31. Ahmed S, Ali W, Anwar M, et al. Prenatal diagnosis of haemophilia-A: a basis for the Pakistani families. *J Pak Med Assoc* 1999; 49: 230–233.
32. Chaplin S. Transition from adolescent to adult services in haemophilia. *J Haem Pract* 2016; 3: 71–93. doi: 10.17225/jhp00059
33. Shapiro AD, Donfield SM, Lynn HS, et al. Defining the impact of hemophilia: the Academic Achievement in Children with Hemophilia Study. *Pediatrics* 2001; 108: E105.
34. Jadhav U and Mukherjee K. Assessment of healthcare measures, healthcare resource use, and cost of care among severe hemophilia A patients in Mumbai region of India. *J Postgrad Med* 2018; 64: 138–144. doi: 10.4103/jpgm.JPGM_701_16
35. Kar A. Making haemophilia a global priority. *Lancet* 2012; 380: 216–217. doi: 10.1016/S0140-6736(12)61214-8
36. Dharmarajan S, Phadnis S, Gund P, et al. Out-of-pocket and catastrophic expenditure on treatment of haemophilia by Indian families. *Haemophilia* 2014; 20: 382–387.
37. O'Hara J, Hughes D, Camp C, et al. The cost of severe haemophilia in Europe: the CHESS study. *Orphanet J Rare Dis* 2017; 12: 106. doi: 10.1186/s13023-017-0660-y
38. Singh P and Mukherjee K. Cost-benefit analysis and assessment of quality of care in patients with hemophilia undergoing treatment at National Rural Health Mission in Maharashtra, India. *Value Health Reg Issues* 2017; 12: 101–106. doi: 10.1016/j.vhri.2016.11.00
39. Olivier M, Madruga M, Carlan SJ, et al. Hemophilia a complicated by ulcerative colitis. *Case Rep Gastrointest Med* 2018; 2018: Article ID 2342618. doi: 10.1155/2018/2342618
40. von Drygalski A, Rappazzo KC, Barnes RF, et al. Knee fat pad volumes in patients with hemophilia and their relationship with osteoarthritis. *Arthritis* 2017; 2017: Article ID 1578623. doi: 10.1155/2017/1578623
41. Binet Q, Lambert C, Sacré L, et al. Successful management of acquired hemophilia a associated with bullous pemphigoid: a case report and review of the literature. *Case Rep Hematol* 2017; 2017: Article ID 2057019. doi: 10.1155/2017/2057019
42. Murray NP, Muñoz L, Minzer S, et al. Management of thrombosis risk in a carrier of hemophilia a with low factor VIII levels with atrial fibrillation: a clinical case and literature review. *Case Rep Hematol* 2018; 2018: Article ID 2615838. doi: 10.1155/2018/2615838
43. Fernández RM, Peciña A, Sánchez B, et al. Experience of preimplantation genetic diagnosis for hemophilia at the University Hospital Virgen Del Rocio in Spain: technical and clinical overview. *Biomed Res Int* 2015; 2015: Article ID 406096. doi: 10.1155/2015/406096
44. Unim B, Veneziano MA, Boccia A, et al. Haemophilia A: pharmacoeconomic review of prophylaxis treatment versus on-demand. *ScientificWorldJournal* 2015; 2015: Article ID 596164. doi: 10.1155/2015/596164
45. Miners AH, Sabin CA, Tolley KH, et al. Cost-utility analysis of primary prophylaxis versus treatment on-demand for individuals with severe haemophilia. *Pharmacoeconomics* 2002; 20: 759–774.
46. Lippert B, Berger K, Berntorp E, et al. Cost effectiveness of haemophilia treatment: a cross-national assessment. *Blood Coagul Fibrinolysis* 2005; 16: 477–485. doi: 10.1097/01.mbc.0000178830.39526.ff
47. Risebrough N, Oh P, Blanchette V, et al. Cost-utility analysis of Canadian tailored prophylaxis, primary prophylaxis and on-demand therapy in young children with severe haemophilia A. *Haemophilia* 2008; 14: 743–752. doi: 10.1111/j.1365-2516.2008.01664.x

48. Colombo GL, Di Matteo S, Mancuso ME, et al. Cost-utility analysis of prophylaxis versus treatment on demand in severe hemophilia A. *Clinicoecon Outcomes Res* 2011; 3: 55–61. doi: 10.2147/CEOR.S16670
49. Miners AH. Economic evaluations of prophylaxis with clotting factor for people with severe haemophilia: why do the results vary so much?" *Haemophilia* 2013; 19: 174–180.
50. Endorf M and McNeff M. The adult learner: five types. *Adult Learning* 1991; 2: 20–25. doi: 10.1177/104515959100200708