

Sexual activity and the adolescent with haemophilia

Atanas Banchov^{1,2}

¹Expert Center for Haemophilia, Thalassemia and Other Rare Benign Haematological Disorders, Department of Paediatric Haematology and Oncology, University hospital “Tzaritza Giovanna – ISUL”, Sofia, Bulgaria; ²Department of paediatrics, Medical University - Sofia, Bulgaria

Abstract. Haemophilia A and B are congenital bleeding disorders, associated with joint and soft tissue bleeding episodes. Adolescence is an important period of the individual development, associated with tendency to risky behavior in those, who suffer chronic conditions. The current review focuses on sexual health in the adolescents with haemophilia and related to sexual activity complications in the course of the disease such as iliopsoas hemorrhage and joint bleedings, models and strategies for sexual health promotion and education in this specific age group and disorder. (www.actabiomedica.it)

Key words: haemophilia, adolescents, sexual activity, promotion, iliopsoas bleed

Introduction

The rare X-linked disorders haemophilia (H) A and B (inherited deficiencies of coagulation factor VIII and IX) represent the most common coagulopathies with occurrence rate of 17.1 per 100,000 newborn boys for haemophilia A (HA) and 3.8 per 100,000 for haemophilia B (HB) (1). By nature, the coagulation factor VIII serves as cofactor for the function of coagulation factor IX, thus the deficiency of any of the two leads to similar clinical symptoms. The severity of the disease is inversely correlated to the residual activity of the missing factor (2). About 40% of the patients, included in haemophilia registries are patients with the severe form of the disease, 10% - with the moderate form of the disease. The remaining half of the patients form the group of patients with mild form of haemophilia (3). Major hallmark of haemophilia are the recurrent spontaneous or traumatic bleedings in the soft tissues – muscles and large index joints (ankles, knees and elbows). The bleed in the articular capsule might cause synovitis, cartilage damage and bone destruction, thus placing the people with haemophilia (PwH) at risk for disabling hemophilic arthropathy with severe impact on mobility and quality of life (QoL) (4). Historically, before the invention of replacement treatment

haemophilia was often associated with fatal bleedings and life expectancy confined to childhood (5). With the advances of transfusion medicine which commenced in the mid XX century and the introduction of efficacious and safe clotting factor concentrates that can be given as long-term prophylaxis from early childhood in the more severe cases, from crippling diseases haemophilia A and B gradually transformed into chronic conditions, defined by life expectancy relatively comparable to the one of the general male population in the western world. (6). The latter transition towards chronic state necessitates a shift in the focus of the medical care from the conventional need to properly diagnose and treat the damaging and often life-threatening bleeding complications into understanding and modifying the factors which influence the quality of life of PwH (7).

Sexual life - a major player for the QoL

Sexual activity is observed as major biological human function and consists of activities done alone (e.g., masturbation) or with another person (intercourse, oral sex, etc.) or people (group sex). Sexual life is deemed as paramount for the social functioning

(also referred to as social health), which is distinct from mental and physical health and seen as an important dimension of quality of life (8). The World Health Organization (WHO) defines sexual health as a “state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity” (9). Furthermore, different studies indicate that sexual health and sexual satisfaction are highly important to QoL in chronic disease (10). Therefore, sexuality and sexual health in PwH has to be assessed and understood by medical doctors and medical professional who are working at comprehensive haemophilia treatment centers in order for them to effectively deal and improve the overall outcomes concerning QoL of their patients (11). Yet, an international survey assessing sexual health in PwH demonstrates that the proportion of patients with haemophilia who had discussed the topic about sexual life with their haemophilia treater varies from country to country between 6% and 52%. However, in 9 out of the 10 countries included in the study the majority of patients had never had such a discussion during any visit to the haemophilia treatment center (12).

Adolescence with chronic condition and sexual behavior

Adolescence is defined by the WHO as a phase of life between childhood and adulthood, from ages 10 to 19 – a decade of unique stage of human development and an important time for laying the foundations of good health. Adolescents experience rapid physical, cognitive and psychosocial growth (13). In general, adolescence could be divided into three periods (14): (a) early adolescence (10 – 13 years of age) in which increased interest in sexual health is noted; (b) (14 – 16 years of age) – a phase of the first sexual experiences and risk-taking behavior; (c) late adolescence (17 – 21 years of age) – a period of time spent in relationships based on mutual enjoyment. The latter phase usually overlaps with the young adulthood continuing until the mid-20s. Despite their diseases or disabilities, adolescents with chronic health conditions, like all adolescents, are sexual beings (15). Conditions, such as haemophilia which are present ever since birth of the

individual or early childhood can change one’s psychosocial development by altering long-term expectations that the preadolescent has of himself. Many of these children grow up feeling different, stigmatized, or trying to hide visible differences (15). According to current paradigms, chronic illness does not always protect young people from risk behaviors, which are typical for the period of the adolescence (16). Early sexual debut, having multiple sex partners and low contraception use are considered risky sexual behaviors (14). Studies suggest that adolescents with different chronic disease tend to report higher rates of risky sexual behavior. (17,18). However, in a recent publication Ibrahim et al. (19) postulate, that a chronic condition is associated with more risky sexual behavior in univariate analysis among adolescent boys versus girls. As haemophilia is predominantly occurring in males, one could speculate that risky sexual practices might be prevalent among adolescents with haemophilia. Nevertheless, due to the nature of the condition associated with life-threatening and non-predictable bleeds, adolescents with haemophilia are more often subjected to hyper protectivity and greater parental safeguarding. This paradoxically might cause less anticipatory guidance and less preventive counseling towards adolescents with chronic illness, especially with regards to sexual health (14). In fact, although several research groups focus on sexual health in adults with haemophilia (12, 20-23) information about sexual health, practices and prevention in adolescents with haemophilia remain sparse. Therefore, the need for proper promotion of sexual education in adolescents with haemophilia remains unmet. If those needs are not met in childhood, they would present an even greater challenge during adolescence. A large study, assessing haemophilia and sexual health (12) reports that haemophilia impacts sexual life of adults with haemophilia in the physical aspect mostly by causing limitation in the movements of the person, by the fear that the individual has previously bled in conjunction to sexual activity, or because sexual activity interferes with the haemophilic arthropathy and causes actual pain. Another questionnaire (23), evaluating sexual health in PwH over 18 years of age, outlines that joint stiffness and joint pain from sexual activity affects sexual life, bleeding episodes as result of sexual intercourse are major concern. Thus, sexual education

and promotion of sexual health for adolescents with haemophilia needs to be focused on musculoskeletal challenges related to sexual activities

Sexual activity from the sporty point of view

There seems to be an equivocal consensus on the relationship between physical activity and bleed occurrence in PwH. Various studies define higher rate of experienced sport- or exercise-related bleeds in heterogeneous samples of PwH (24,25) a higher prevalence of sport-induced bleeding (26), as well as a significant association between bleeds and strenuous physical activity (27) in pediatric patients with haemophilia (28). On the other hand, 30–60 min of physical activity per day is required to maintain adequate muscle strength and reduce the rate of injury in PwH (29), combined with the positive effects of physical activity on obesity, hypertension and diabetes mellitus type II (28) physical activity and exercise of low impact and risk are now recommended for PwH. From that standpoint comparing sexual activity to physical exercise could elucidate the reasons for reporting disease related problems during or after intercourse and navigate the dos and don'ts of sexual habits for youngsters with haemophilia.

For comparison of sexual activity to various activities one of the most commonly used clinical measure is the metabolic equivalent of energy expenditure (MET). According to Thorson et al. (30) walking at 2 mph on ground level would be equivalent to 2 METs; walking at 3 mph to 3 METs. Pre-orgasmic sexual activity averages 2–3 METs, while orgasm during sexual activity - 3–4 METs. Compared to higher-intensity physical exertion, such as cycling at 10 mph (6–7 METs) or walking on the treadmill (13 METs), the exertion of sexual activity is relatively modest (31). Of note is a study (32) conducted among young heterosexual couples (median age of 22 years) during sexual activity, which was defined as the onset of foreplay, intercourse and at least one orgasm by either the man or woman and ended at the couple's discretion. The research concluded, that despite that on average the mean sexual intensity equals 6.0 METS in men, which corresponds to a moderate intensity (range 3–6 METS), in certain moments the sexual activity may

potentially be considered as a significant exercise. In the context of severe haemophilia the latter would suggest that significant bleeding events could be caused by the high intensity exerted during sexual practices.

Muscle injuries and sexual activity

Muscle bleedings are the second most common bleeding types besides joint bleedings in PwH.

According to different sources, between 10% and 25% of bleeding complications in haemophilia occur within the muscles (33). To understand why muscle bleeds occur after sexual activity in PwH attention shall be paid to the naturally occurring resistance exercise-induced muscle damage (34). In the healthy individual skeletal muscle damage is a potential consequence of unaccustomed or eccentrically biased muscle contractions. The cellular damage alters the structural components of the sarcomeres and to the sarcolemma, causing leakage of intramuscular proteins into the systemic circulation. Resistance exercise-induced muscle damage (EIMD) may cause muscle soreness, limb swelling, reduced flexibility, and most notably, decreased muscle force-generating capacity (34). The severity of EIMD is dependent on several extrinsic variables – the muscle group exercised, total number of eccentric contractions, velocity of movement, muscle length at which the contraction is initiated, and maximum force is generated, as well as the maximum force produced. The analysis of intercourse positions postulates that most of the sex positions involve overloading of force-producing muscles in a state of substantial lengthening or shortening (35). This is especially the case of the iliopsoas muscle.

Iliopsoas muscle and sexual activity

An Iliopsoas bleed could be a consequence of sexual act as the muscle function allows the typical thrusting movements of male penetrative intercourse in lumbar lordosis. The rhythmic iliopsoas contractions are also considered to have a role in the excitement in masturbation (36). Despite the growing evidences (12) for the association between intercourse

and iliopsoas bleeding, haemophilia treaters, understandably due to the delicacy of the matter, often do not tend to try to verify this relation in direct history taking and do not make the patients aware of that risk (36). Proper education about this probable complication has to focus on the signs and symptoms in case of intramuscular iliopsoas bleeding, including pain in thigh, hip, groin, abdomen or lower back, inability to stand straight, lie flat, or presence of flexion contraction in the hip joint, as well as inability to walk, to sit up without pain, or numbness and/or tingling sensation along the thigh (37). Early recognition of the bleed in the iliopsoas muscle, followed by proper replacement therapy and resting regimen might prevent the patient to experience the possible devastating and often life-threatening and long-term complications of this specific bleeding, such as hypovolemic shock due to blood loss (38) in the muscle or within the peritoneal cavity (39), development of pseudotumor and development of fistulae (40), femoral nerve compression, acute renal failure (38).

Joint bleeding and sexual activity

The largest study (12), assessing sexual life and activity in PwH report either significant proportion of patients who have experienced joint bleeds as a direct result of intercourse or have reported an association between joint disease and sexual difficulties. Much alike muscle functioning in different sexual positions, in the majority of cases during intercourse, joints are put at extremes of their range of motion for extended periods of time (35) and in the same moment the extremities carry the load of the body itself. If the intercourse coincides with a period of low hemostatic coverage of the replacement factor (below 1%) (41) this might trigger a bleed even in a pristine joint. In case of preexistence of joints which are showing signs of acute synovitis or chronic synovial proliferation (target joints) (42), putting them into extreme extension or flexion for untypical duration could lead to new bleeding and worsening of the symptoms. Furthermore, painful joints or stiffness due to arthropathic changes in the joint cartilage or the subchondral bone can hinder some traditional sex practices such as intercourse in the missionary

position in case of flexion contraction in the elbows for example (36). Recently, some authors have developed patient booklets (35, 43) in which most of the sexual positions are discussed from the standpoint of a physiotherapist, emphasizing the tissues and body structures which are most likely to be injured by exerting each specific sexual position. Using this guidance, the youngster and his partner could choose the most suitable position, striving to prevent any joint or muscle bleed which might cause inconvenience during or after intimacy.

Prophylactic replacement therapy in case of sexual activity

As discussed above, sexual activity needs to be considered as either moderate or high intensity physical exercise. Current guidelines, which are openly promoting active life to children, adolescents and young adults with haemophilia in conjunction with modern prophylactic regimen and individualized therapies (44), recommend a hemostatic coverage in case of moderate to high intensity activity corresponding to factor VIII or factor IX activity level between 5-30%. Consecutively, the strategy for bleed prevention by application of factor concentrate before sport activity (45), shall be adopted as suitable in case of sexual activity. Such circumstances have to be assumed and the preventive manner needs to be communicated between the young patient and the haemophilia treater ones the boy reaches sexual maturity.

Talking about sexual life and haemophilia

Promotion of sexual health among adolescents with haemophilia suggests fine relationship with the treating physician or haemophilia treatment team. Most of the research performed in the field of sexual life and chronic conditions demonstrates that although medical professionals understand the significance of sexual life and wellbeing (46), they usually do not open the issue in a conversation unless challenged by the patient himself (47). This approach to the matter is understandable due to cultural, gender, age and

individual barriers. Nevertheless, in the case of haemophilia and the possible long term and life-threatening complications, which may evolve when the patient is not properly educated on the topic, raise the need for development of models (11) and strategies for overcoming the communication barriers related to sexual activity (21). It is expected that such interventions would improve the comprehensive approach to the patients with haemophilia managed in the haemophilia treatment centers.

Conclusion

Sexual activity, sexual life and sexual health are major determinants and factors for the adolescence as a crucial period of the individual development. They are equally important to PwH, yet in them further complications may arise due to additional physical factors associated with this chronic condition. In order to minimize the possible complications associated to sexual activity, haemophilia treaters have to be aware of the specifics referring to musculoskeletal challenges of exerting random sexual activity in patients with haemophilia, to find proper strategies for promotion and prevention of false sexual practices and spread the information among adolescents with haemophilia.

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Correspondence:

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Atanas Banchev, MD, PhD

Expert center for haemophilia,

Thalassemia and Other Rare Benign

Haematological Disorders,

Department of Paediatric Haematology and Oncology,

University hospital "Tzaritza Giovanna – ISUL",

Sofia, Bulgaria

Ul. Byalo More 8, 1527 Sofia Bulgaria

E-mail: bantschev@gmail.com