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Association of Kinesiophobia with Quality of Life, Hemophilia Joint Health Score and Physical Activity Level in Patients with Hemophilia: A Brief Review

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Abstract: ***Hemophilia is a congenital clotting disorder inherited in an x - linked recessive genetic pattern which leads to lack or failure of a blood clotting factor VIII (Hemophilia A) and factor IX (Hemophilia B). Most common complication of hemophilia is Hemarthrosis (joint bleed) which lead to severe pain, restricted movement, and joint damage over time. One of the growing concern in hemophilia management is kinesiophobia (fear of movement) leads to sedentary lifestyle, worsen joint condition, muscle weakness and decrease all over physical fitness. This emphasizes the importance of addressing kinesiophobia, physical inactivity, joint health deterioration and psychological well being in the overall care of these patients. To determine the association between kinesiophobia, quality of life, the Hemophilia Joint Health Score, and the Physical Activity level in patients with Hemophilia. . This narrative review is conducted on databases from PubMed, Google Scholar, and ResearchGate. This review included 11 studies on association between kinesiophobia, quality of life, the Hemophilia Joint Health Score, and the Physical Activity level in patients with Hemophilia. In conclusion, many studies show us different parameters between joint health physical activity level and quality of life in hemophilic patients but there is no research showing us the association between kinesiophobia, quality of life, the Hemophilia Joint Health Score, and the Physical Activity level in patients with Hemophilia.***

Keywords: Hemophilia, kinesiophobia, joint health, Quality of life, physical activity

1. Introduction

Patient with Hemophilia develop kinesiophobia (fear of movement). This fear stems from the belief that moving might cause pain or lead to another bleeding episode.1 People with Hemophilia are particularly vulnerable to this worry since joint bleeding can aggravate injury and produce severe pain. Avoiding movement may initially appear to be a protective measure, but it eventually results in joint stiffness, muscular weakness, and a reduction in general physical function. Due to restriction in joint movement and physical inactivity can cause joint health towards more worsen side.2 To assess joint health we use Hemophilia Joint Health Score (HJHS) [3]

Even though exercise and adherence to prophylaxis can helps in maintaining joint health and prevent further damage, many Hemophilia patients avoid physical activity due to fear of bleeding. It reduces chronic pain and also reduces bleeding episodes. Poorer adherence was associated with more breakthrough and target joint bleeds.4 Additionally inactivity impairs metabolism, bone strength, and heart health, exacerbating the overall effects of Hemophilia. In addition to their core illness, older people with Hemophilia may have several comorbidities. Hemophilia arthropathy, depression, anxiety, hypertension, diabetes, and viral infections including HIV and hepatitis C (caused by contaminated blood treatments) are common comorbidities. Even with advancements in Hemophilia treatment, older individuals still deal with health issues related to both their condition and age. In order to effectively manage Hemophilia and age - related illnesses, comprehensive healthcare strategies are necessary, as these comorbidities lead to decreased mobility, increased discomfort, and a lower quality of life.5 To fully understand the well - being of people with Hemophilia, it is important to consider their functional capacity, which includes physical strength, endurance, mobility, and cognitive abilities. As joint damage worsens and physical activity decreases, a person's ability to perform daily tasks declines, impacting their independence and overall quality of life.6 Recent research highlights the need to address both physical limitations and psychological fears when managing chronic conditions like Hemophilia. Effective treatment should focus on reducing fear - based avoidance, encouraging safe physical activity, and improving mental well - being. Rehabilitation programs that combine psychological counseling, gradual exposure to movement, and education on safe exercise can help patients regain confidence and stay active.2 This study aims to explore how kinesiophobia affects quality of life, joint health, and physical activity in patient with Hemophilia, as it is becoming a growing public health concern. By understanding the link between kinesiophobia and functional outcomes, healthcare professionals can design targeted interventions to build movement confidence, encourage physical activity, and improve overall joint health and well - being. Managing kinesiophobia in Hemophilia requires a well - rounded approach, including patient education, psychological support, and physical rehabilitation. A comprehensive treatment plan should include psychological counseling, reassurance about

safe exercise, and gradual exposure to movement. By reducing fear - based avoidance and promoting an active lifestyle, individuals with Hemophilia can achieve better physical and mental health, ultimately improving their quality of life.

This study seeks to bridge the gap between the physical and psychological aspects of Hemophilia management, providing deeper insights into how kinesiophobia, joint health, and functional capacity are interconnected.

2. Methods

Studies are searched from the following search engines PubMed, Google scholar, and ResearchGate to review the literature. Studies include kinesiophobia, quality of life, joint heath and physical activity level. Keywords used to search studies are Tampa scale of kinesiophobia, WHOQol - BREF, HJHS, physical activity and hemophilia.

Authors	Objective	Design	Characteristics of participant and sample size	Material and Method	Outcomes measures	Results
Tat et al[1] (2020)	The effect of manual therapy on musculoskeletal system, functional level, joint health and kinesiophobia in young adults with severe hemophilia	Pilot study	Total =17 patients Control group =9 Manual therapy group=8	17 patients were included in the study. ROM, Strength and pain intensity, joint health, kinesophobia, functional independence were evaluated. myofascial release techniques and mobilization were applied to MTG. Interventions were applied 3D/weekly for 5 weeks. Assessmets were performed at baseline and after treatment.	ROM, (goniometer), strength (digital dyanometer), pain (visual analogue scale), joint health (HJHS) kinesiophobia (Tampa scale of kinesiophobia.)	ROM, strength, activity pain, HJHS and FISH improved in MTG but kinesiophobia were not significant. MT have greater effects on all functional variables.
Hilberg et al[7]	To investigate proprioceptive performance and isometric muscular strength before and after a specialized training in hemophilic subjects compared with two groups of control subjects	Experimental study	9 subjects with severe hemophilia A (H) 8 subjects without hemophilia take part in physical training programme over a 6 - month period (AC). 11 subjects without hemophilia with no additional training during 6 month (PC).	A 6 - month physical training program was implemented for the H and AC groups. Proprioceptive performance and isometric strength were assessed before and after the training period.	Proprioceptive performance was evaluated using one - leg - stand tests, angle reproduction tests, and quantitative sensory testing with a tuning fork.	specific sports therapy focused on proprioceptive function and accompanied by gentle strength training with low resistance and 20–25 repetitions is able to increase proprioceptive performance and muscular strength with a minimal stress to the joints
Deniz et al[8]	To assess the effect of an 8 week supervised therapeutic exercise program on musculoskeletal health, gait kinematic parameters (GKP), functional capacity, and QoL in adult PwH.	Pilot study	Total =19 patient with hemophilia Exercise group =10 Control group =9	Total 19 patients were included. exercise group followed an 8 week supervised therapeutic program. Program includes aerobic, proprioceptive, strenghtening and stretching exercise performed for 3 days a week. HJH, a two dimensional video based gait kinematic analysis, the 6 min walking test and Haem - A - Qol were measures at baseline, after exercise program (at the 8th week) and at the 6 month follow up.	The hemophilia joint health score (HJHS), a two - dimensional video - based gait kinematic analysis (2D - GKA)	The 8 week supervised therapeutic exercise program was successful in achieving improvement in jaoint health, GKP, functional capacity, and QoL in PwH.
Zanon et al[4]	To collect prosepctive data on adherence to prophylaxis for over	Shape study	Total= 42 Patients with Hemophilia	Italian patients with severe hemophilia A on prophylaxis with octocog alfa were included in the	Physical finding (hemophilia and exercise project (HEP) test - Q and the early	PWH with better orthopedic scores reported better physical performance.

	36 months. To verify whether adherence correlates with physical activity.			study. Physical finding were assessed by the hemophilia and exercise project (HEP) test - Q and the early prophylaxis immune; ogic challenge (EPIC) Norfilok physical activity Quesstionnaire; orthopedic status was assessed by hemophilia joint health score (HJHS). Adherence was measured as percentage of empty vials returned with respect to the prescribed amount.	prophylaxis immunologic challenge (EPIC) Norfilok physical activity Quesstionnaire); orthopedic status (hemophilia joint health score (HJHS). Adherence (percentage of empty vials returned with respect to the prescribed amount).	Adherence to long - term prophylaxis proved to be high and correlated with reduction in bleeds, target joints, school/work days lost, and with a performance improvement in endurance sports activities over time
Curtis et al[5]	To compare the impact of hemophilia on comorbidities Joint problems, HR QoL and health care utilization.	Observational study	PwH of two age groups: 40 49 years and>50 years.	HUGSVI study recruited PwH AorB age>40 years. sample included 69 males. Data collected on joint pain, HRQoL, depression, anxiety, comorbidities.	Individuals >50 years had mild and moderate hemophilia than 40 - 49 years. >50 year old had more joint pain, limited ROM than younger group.	Older group experienced lower QoL, more comorbidities both of aging and hemophilic arthropathy and lower rates of health care utilization.
Poonnoose et al[6]	To assess the functional independence in patients with hemophilia	Experimental study	63 patients with hemophilia	FISH was assessed in 63 hemophilic patients to measure the patient's independence in performing activities of daily living (grooming and eating, bathing and dressing), transfers (chair and floor), and mobility (walking, step climbing and running)	FISH assessed 8 activities and the score ranged from 1 - 4 for each activity on the basis of his ability to perform the activity.	FISH was found to be a reliable and valid tool with good internal consistency and responsiveness to therapy, for the assessment of functional independence in persons with hemophilia.
Trindade et al[9]	To evaluate the QoL of patients with hemophilia using the WHOQOL bref and the Haem - A - QoL instruments.	Cross - Sectional Study	17 patients aged 18 year or older with hemophilia registered at hemocenter.	Data collected using a specific questionnaire Haem - A - QoL comprised of 46 items on physical health, feelings, sports and leisure, future, family planning, relationship/ sexu ality and a generic questionnaire WHOQOL bref comprising 26 questionnaires on general QOL, physical, psychological, social relations.	WHOQOL - bref questionnaire had highest score in the domain of social relation and Haem - A QoL had highest score in family plannning	Hemophilia had high negative impact on physical, sports and leisure in sample subjects. Haem - A QoL is more specific to evaluate QoL.
Ucero - Lozano et al.1[0]	To evaluate the efficacy of extended half - life (EHL) prophylaxis in improving perceived quality of life, adherence to treatment, and kinesiophobia in patients with Hemophilia	prospective cohort study	Total=46	46 patients from different regions, who had started EHL FVIII concentrate prophylactic treatment, were evaluated at baseline and at 12 - month follow - up.	Perceived quality of life (36 item Short Form Health Survey) adherence to treatment (validated hemophilia regimen treatment adherence scale - prophylaxis) and kinesiophobia (tampa scale of kinesiophobia)	EHL prophylaxis can improve the perceived quality of life of people with hemophilia. The prophylactic regimen, which requires fewer infusions, may improve adherence to treatment in adult patients with hemophilia over a 12 - month period. The administration of extended half - life factor VIII concentrates can reduce kinesiophobia in adult patients with hemophilia arthropathy.

Deniz et. al[12]	To investigate the effects of therapeutic exercise on kinesiophobia and health related quality of life in adult Hemophilia patients.	Experimental study	Total =24 patients with hemophilia Exercise group=12 Control group=12	Total 24 patients between the age of 18 to 42 were included. exercise group received 2 phase exercise program including resistant exercise, stretching exercises and balance exercises. Control group received only verbal information about positive effects of ecercise on hemophilic arthropathy.	Quality of life (36 item Short Form Health Survey and hemophilia adult quality of life) Kinesiophobia (Tampa scale of kinesiophobia)	Decrease in kinesiophobia and increase in HR - QoL in adult hemophilic individual were observed. Therapeutic exercises are simple and safe treatment modalities that can be used to improve kinesiophobia and health - related quality of life in adult Hemophilia patients.
Aykar et. al[13]	To research the relationship between kinesiophobia and physical activity levels in adult Hemophilia individuals.	Retrospective study	Total=44 patients with hemophilia 33 with hemophilia A 11 with hemophilia B.	Total 44 male patients were included and between the ages of 18 - 60. Tampa scale of kinesiophobia and international physical activity questionnaire was used.	Tampa Scale for Kinesiophobia (TSK) was used to determine fear of movement. To determine the physical activity levels of individuals, the "International Physical Activity Questionnaire - Short Form" was used.	These results showed no correlation between physical activity level and kinesiophobia, but high kinesiophobia rates in adult Hemophilia individuals. Hemophilia patients should be educated and encouraged about safe and fearless physical activity.17
Lozano et. al[11]	To analyse the perceived Quality of life of adult patients with hemophilia arthropathy and its relationship with pain, joint condition, kinesiophobia and catastrophism.	Observational study.	Total=83 adult patients with hemophilia	83 adult patients with hemophilia were included. Perceived quality of life (SF 36) perceived usual and maximum pain (visual analogue scale), joint condition by Hemophilia joint health score (HJHS) Catastrophism (pain catastrophizing scale), Kinesiophobia (Tampa scale of kinesiophobia) were assessed.	Perceived quality of life (36 item Short Form Health Survey) Joint condition by Hemophilia joint health score (HJHS). Perceived pain measured with a visual analogue scale. Catastrophism assessed by pain catastrophizing scale. Kinesiophobia assessed by Tampa scale of kinesiophobia	. The quality of life perceived by patients with hemophilia is lower than that reported by spainsh population and by patients in other European countries, Pain, kinesiophobia and catastrophism are the main psychosocial variables that are related to worse quality of life. Clinical variables, such as hemophilia severity and the use of drugs for pain control, are also related to worse quality of life.

3. Discussion

Hemophilia patients' general health, mobility, and quality of life are greatly affected by kinesiophobia, an important but frequently overlooked concern. Muscle weakness, joint deterioration, and inactivity are all caused by the fear of movement, which is supported by prior experiences with joint bleeding and pain. According to this study, there is an obvious connection between kinesiophobia, joint health, physical activity levels, and quality of life. To break this loop, specific treatments are necessary. The negative impact of kinesiophobia on joint health is among the most important findings. Patients with greater kinesiophobia scores had more severe joint injury, according to objective data on joint function provided by the Hemophilia Joint Health Score (HJHS). This happens as a result of prolonged inactivity, which increases risk to more bleeding episodes by causing muscular atrophy and joint stiffness. Although clotting factor replacement therapy has greatly enhanced the management of hemophilia, it ignores psychological barriers that prevent patients from exercising regularly. For Hemophiliacs, physical activity is essential for preserving their general cardiovascular health, muscle strength, and joint stability. But the fear of bleeding prevents people from doing even simple workouts, which results in physical degenerative conditions and weight increase, which makes joint issues worse. The findings of the International Physical Activity Questionnaire (IPAQ) confirm that Hemophiliacs who have greater levels of kinesiophobia are much less active, which raises their risk of developing comorbid conditions including obesity and metabolic diseases. Promoting safe, supervised exercise programs can enhance patients' general wellbeing and help them regain their confidence in their ability to move. Chronic pain, limited mobility, and social limitations all have a major impact on hemophilia patients' quality of life. Patients with severe kinesiophobia had worse physical, emotional, and social well - being, according to their WHOQOL - BREF assessments. Fear of movement causes psychological distress, social disinterest, and loss of independence, all of which increase anxiety and depression. Since ignoring the

psychological effects of hemophilia can result in long - term disability and inadequate therapy, effective care of kinesiophobia requires dealing with both physical and mental health elements. Several studies suggest that multidisciplinary interventions, including cognitive - behavioral therapy (CBT), physiotherapy, and structured exercise programs, can help reduce kinesiophobia. CBT can assist in modifying fear - avoidance behaviors, allowing patients to gradually engage in movement without excessive anxiety. Physiotherapy, particularly progressive resistance exercises, balance training, and proprioceptive exercises, can improve joint function and muscle strength, reducing the risk of injury. Research also highlights the role of telemedicine and wearable technology in encouraging physical activity and tracking movement patterns, helping patients stay active while minimizing risks. Despite these promising approaches, certain challenges remain in managing kinesiophobia in hemophilia patients. Limited awareness, lack of specialized rehabilitation programs, and inadequate psychological support contribute to ongoing movement avoidance. Future research should focus on developing individualized rehabilitation programs that integrate both physical and psychological interventions to ensure long - term benefits.

4. Conclusion

For people with Hemophilia, kinesiophobia is a major factor in limiting their mobility, level of physical activity, and overall quality of life. A vicious cycle of inactivity and worsened health outcomes is created when people fear movement, which results in joint destruction, muscle weakness, and an increased risk of comorbidities. A multidisciplinary approach is needed to address kinesiophobia, which includes telemedicine interventions, supervised exercise programs, physiotherapy, and cognitive - behavioral therapy (CBT). Promoting safe exercise can improve psychological well - being, functional ability, and joint health. In order to help patients overcome their movement anxieties, increase their mobility, and enhance their quality of life, future research should concentrate on creating specific rehabilitation plans that incorporate both psychological and physical interventions. Hemophilia treatment can become more comprehensive by managing kinesiophobia, which will have long - term health advantages.

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