

# Kinesiophobia in Parents of Children with Haemophilia

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## ABSTRACT

**Objective:** To compare kinesiophobia levels between parents of haemophilic patients and parents of healthy children, and to investigate the factors associated with kinesiophobia in parents of haemophilic patients.

**Study Design:** A cross-sectional descriptive study.

**Place and Duration of the Study:** Department of Physical Medicine and Rehabilitation, Bursa City Hospital, Bursa, Turkiye, between December 2023 and June 2024.

**Methodology:** Thirty mothers of children with haemophilia (MCwH) and thirty mothers of healthy children (MHC) were evaluated using the Visual Analogue Scale for pain, the Short Form-36 for quality of life, the Beck Depression Inventory (BDI) for depression level, and the Tampa Scale for Kinesiophobia (TSK). TSK scores between the two groups were compared using the Mann-Whitney U test. The correlations between TSK scores and the study variables were examined using Spearman's rank correlation coefficient.

**Results:** No significant differences were found between the MCwH and MHC groups in terms of age, BMI, and educational status ( $p > 0.05$ ). The median TSK scores were 44.0 (33.3-46.0) in the MCwH group and 40.5 (36.0-44.0) in the MHC control group. There was no significant difference in TSK scores between the groups ( $p > 0.05$ ).

**Conclusion:** The risk of bleeding in people with haemophilia, the pain secondary to bleeding, and the risk of sustaining an injury contribute to increased levels of kinesiophobia, not only in individuals with haemophilia but also in their parents. Physicians should focus on parents' kinesiophobia when evaluating patients with haemophilia and inform parents about its importance and available treatment strategies.

**Key Words:** Fear of movement, Haemophilia, Kinesiophobia, Emotion regulation.

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## INTRODUCTION

Patients with haemophilia (PwH) typically cope with disease-related suffering in ways that are influenced by both their own coping abilities and those of their parents. Coping approaches refer to cognitive, emotional, and behavioural efforts to manage stressful circumstances or issues, including strategies such as avoidance. Prolonged avoidance may prevent patients from engaging in daily activities, resulting in further avoidance of regular tasks and probably impacting emotional well-being.<sup>1</sup>

According to the Fear-Avoidance hypothesis, people who suffer from acute pain may subsequently become trapped in an endless loop of chronic incapacity and difficulties as a result of their behavioural, emotional, cognitive, and functional reactions to the pain.

Kinesiophobia, or being afraid of movement, is an aspect of this fear model. Kinesiophobic patients tend to believe that movement may cause pain and re-injury. Reduced physical activity, avoidance of daily responsibilities, functional impairment, incapability to use the extremities, and, in more advanced phases, depression and lower quality of life are common consequences of the disease.<sup>2</sup>

To the best of the authors' knowledge, limited data are available regarding kinesiophobia in mothers of children with haemophilia. This study aimed to compare kinesiophobia levels between mothers of children with haemophilia (MCwH) and mothers of healthy children (MHC) and to investigate the factors associated with kinesiophobia in parents of haemophilic patients.

## METHODOLOGY

A cross-sectional descriptive study was conducted at the Department of Physical Medicine and Rehabilitation, Bursa City Hospital, Bursa, Turkiye, between December 2023 and June 2024. Eligible participants were identified among mothers accompanying children attending the Haemophilia outpatient clinic of Bursa City Hospital (MCwH group) and mothers of healthy children attending routine outpatient visits (MHC group) during the study period. A consecutive convenience sampling approach was used.

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Parents who met the eligibility criteria were approached in person at the clinic by the research team, informed about the study, and invited to participate. Questionnaires were completed on site in a quiet area, and incomplete forms were excluded. Written informed consent was obtained from all participants. Ethical approval was granted by the Clinical Research Ethics Committee of the Health Science University Hospital of Bursa City, 2019-KAEK-140 (ID:2023-19/4). The study protocol was recorded in clinicaltrials.gov (NCT04205188).

Inclusion criteria were being a mother of a child with haemophilia (MCwH group) or a mother of a healthy child (MHC group), ability to read, understand, and complete the psychosocial evaluation questionnaires independently, and provision of written informed consent. Exclusion criteria were incomplete or missing questionnaire data, presence of cognitive or language difficulties that could interfere with understanding or completing the questionnaires, having a child with a chronic disease other than haemophilia, and failure to provide written informed consent.

Data on the psychosocial variables of the participants were collected. The variables evaluated in the study were kinesiophobia, depression, and perception of quality of life. Kinesiophobia was measured with the Turkish version of the Tampa Scale of Kinesiophobia-17 (TSK-17). This self-administered measuring instrument consists of 17 items, with a 4-point Likert scale. The score range was 17-68; a score of 37 or over was considered high, and higher scores indicate greater fear of re-injury from movement.<sup>3</sup> Depression was measured using the Beck Depression Inventory (BDI), a 21-item self-report questionnaire used for evaluating the severity of depression in both normal and psychiatric populations.<sup>4</sup> The perceived quality of life was measured with

the Turkish version of the 36-Item Short Form Health Survey (SF-36).<sup>5</sup>

Data analysis was performed using the SPSS statistical software package, version 25.0 (IBM, Inc., Armonk, NY, USA). The Shapiro-Wilk test was used to assess data normality, while Levene's test was employed to evaluate the homogeneity of variance. The statistical analysis was performed using non-parametric tests. Continuous data were presented as median (IQR). Categorical data were expressed in numbers and frequency. Mann-Whitney U tests were used to compare continuous variables. Spearman's correlation analysis was used to evaluate the relationship between continuous variables. Confidence intervals were set at 95%, and values were considered statistically significant at  $p < 0.05$ .

## RESULTS

A total of 60 participants were included in the study (30 MCwH and 30 MHC). The median age of the parents was 44.5(40.0-48.0) years. In the MCwH group, 20% ( $n = 6$ ) had completed primary school, 10% ( $n = 3$ ) secondary school, 43% ( $n = 13$ ) high school, and 27% ( $n = 8$ ) university education, whereas in the MHC group, 20% ( $n = 6$ ) had completed high school and 80% ( $n = 24$ ) university education. The number of more educated participants was higher in the MHC group. No significant differences were observed between the groups in terms of TSK scores ( $p > 0.05$ , Table I). TSK scores of participants were found to be negatively correlated with some of the SF-36 items, including physical functioning ( $r = -0.277$ ,  $p < 0.05$ ), social functioning ( $r = -0.378$ ,  $p < 0.05$ ), role limitations attributed to physical problems ( $r = -0.631$ ,  $p < 0.05$ ), role limitations attributed to emotional problems ( $r = -0.311$ ,  $p < 0.05$ ), pain perception ( $r = -0.446$ ,  $p < 0.05$ ), and mental health ( $r = -0.275$ ,  $p < 0.05$ , Table II).

**Table I: Differences between the two groups regarding kinesiophobia, depression, and quality of life.**

Variables	MCwH Group (IQR)	MHC Group (IQR)	p-values
TSK	44.0 (33.3-46.0)	40.50 (36.0-44.0)	0.236
BDI	7.5 (5.0-16.3)	3.5 (0.0-10.0)	0.005*
Physical functioning	80.0 (65.0-91.3)	92.5 (70.0-100.0)	0.292
Social functioning	75.0 (63.0-88.0)	63.0 (59.4-75.0)	0.160
Role limitations attributed to physical problems	50.0 (25.0-100.0)	100.0 (25.0-100.0)	0.060
Role limitations attributed to emotional problems	84.0 (34.0-100.0)	100.0 (100.0-100.0)	0.003*
Mental health	66.0 (52.0-76.0)	68.0 (51.0-77.0)	0.795
Energy and fatigue	62.3 (45.0-75.0)	60.0 (50.0-60.0)	0.994
Pain	59.0 (45.0-80.0)	73.0 (45.0-92.5)	0.155
General health perception	65.0 (44.5-71.3)	60.0 (45.0-75.0)	0.694

TSK: Tampa Scale of Kinesiophobia; BDI: Beck Depression Inventory. \* Mann-Whitney U test,  $p < 0.05$ .

**Table II: Correlation analysis of kinesiophobia with other dependent variables.**

Variables	r-values	p-values
BDI	0.259	0.046*
Physical functioning	-0.277	0.032*
Social functioning	-0.378	0.003*
Role limitations attributed to physical problems	-0.631	0.001**
Role limitations attributed to emotional problems	-0.311	0.016*
Mental health	-0.275	0.034*
Energy and fatigue	-0.131	0.317
Pain	-0.446	0.001**
General health perception	-0.071	0.192

BDI: Beck Depression Inventory; \*: Spearman's rank correlation,  $p < 0.05$ ; \*\*:  $p < 0.001$ .

## DISCUSSION

Parents of chronically ill children, such as PwH, should manage their child's condition and emotional well-being, while also addressing their own response to this new condition. Campo *et al.* reported that depression and anxiety are more prevalent in mothers of children with chronic pain (CwCP), compared to MHC.<sup>6</sup> According to Eccleston *et al.*, parents of CwCP often experience social restrictions, as well as high levels of stress and anger.<sup>7</sup> To the best of the authors' knowledge, this is the first research examining the emotional status of the parents of PwH. Parents with higher kinesiophobia presented worse quality of life and increased incidence of depression; their perceived quality of life regarding physical health was also poorer. In addition, the severity of haemophilia was related to kinesiophobia. All MCwH with arthropathy exhibited greater kinesiophobia scores.

In contrast to the present study's findings, lower TSK scores were observed in the MCwH group by Santavirta *et al.* The low TSK scores they observed may be attributable to the patients' pain experiences. The experience of pain may contribute to reduced or negative emotional and cognitive reactions.<sup>8</sup> Given the IASP definition, which states that pain is an experience learned throughout life, this idea seems reasonable. Akbari *et al.* pointed out that caregivers' emotional communication with patients with chronic pain (PwCP) plays a role in patients' pain experience. A potentially more emotionally distant caregiver may be the health-care provider of a PwCP.<sup>9</sup>

The Social Communication Model highlights the significance of biopsychosocial, interpersonal, and intrapersonal factors in both the PwCP and the caregiver, which interact to shape the PwCP's experience of pain.<sup>10</sup> Indeed, Romano *et al.* noted that bidirectional relationships exist between caregivers' emotional responses and a patient's chronic pain and associated suffering.<sup>11</sup>

According to the Pain Empathy Model, effective care for PwCP requires caregivers to accurately perceive the patients' pain and affective distress and then manage their own emotional response to it.<sup>12</sup> Botvinick *et al.* showed, using fMRI, that observing someone in pain activates the same affective neurons as when the observer themselves experiences pain.<sup>13</sup>

Caregivers' overestimation of pain may prompt patients to reappraise their pain as more intense and may lead to over-protective behaviours to the point that they deter the patient's independence. For example, Goubert *et al.* found, in a sample of 107 adolescents with chronic pain and their caregivers, that parental pain catastrophising significantly explained children's disability and school attendance beyond their pain intensity.<sup>14</sup> Parents who observe pain in patients need to manage their own emotions. Emotion regulation

(ER), as defined by Gross, is a process model that involves several steps leading up to the generation of an emotion and, consequently, a behaviour.<sup>15</sup>

In contrast to the findings of Calatayud *et al.*,<sup>16</sup> the present study observed high mean TSK scores in the parents of PwH. Nevertheless, when compared to the averages observed in individuals with chronic musculoskeletal pain, these findings were only slightly higher than those observed in osteoarthritis patients. A significant correlation between TSK levels and pain intensity was observed in the present study. The fear of getting another haemarthrosis, which could exacerbate joint disease, represents a considerable nociceptive source that may be linked to the high degree of kinesiophobia. Additionally, previous traumas and their arthropathic effects may be associated with this high level of kinesiophobia observed in adult PwH.

Regular exercise considerably lowers kinesiophobia levels. Daily physical activity can help patients to overcome their anxiety and fear of movement, as well as to improve body awareness and confidence. Cserep *et al.* reported that ER strategies in adolescents with various chronic illnesses predicted their own quality of life, while parental ER predicted the quality of life of both the parents and adolescents.<sup>17</sup> Maladaptive ER strategies have been associated with pain and psychological comorbidity and have therefore been identified as a risk factor for the maintenance of pain. According to Social Learning Theory, parents' distress in response to their child's pain may influence how they respond, linking parents' emotional and behavioural experiences (e.g., parental behaviours such as allowing the child to stay home from school).<sup>18</sup>

Despite the median TSK score of MCwH being slightly higher than that of the control group, no significant differences were observed between the groups in this study. Nowadays, a growing number of parents are expected to serve as nutritional advisers, emotional coaches, academic strategists, or sports managers for their children. High TSK scores observed in the healthy group may warrant future research, focusing on the concept of good parenting and modern parental expectations, such as constant engagement, optimisation, and protection of their children.<sup>19,20</sup>

This study examined psychological and functional outcomes together in the MCwH group, providing a broader understanding of caregiver well-being. The use of different tools for kinesiophobia, depression, and quality of life supports the validity of the results. The study also has several limitations. The sample size was relatively small, which may limit the generalisability of the results. The cross-sectional design limited the examination of causal relationships between kinesiophobia and psychological or functional outcomes. Several factors, including socioeconomic status, disease severity, caregiving duration, and social support, were not examined and could have influenced the results.

This study points out that kinesiophobia concerns not only individuals with haemophilia but also their parents. Parents' emotional distress can shape daily caregiving behaviours and influence how children approach activity and rehabilitation. Simple psychological screening and clear information may help parents respond more stably during the care process.

Future studies should follow families over time to better understand how these relationships develop. Research focusing on reducing kinesiophobia through psychoeducation or exercise-based approaches could benefit both parents and patients. Additionally, qualitative studies may also provide a clearer picture of how parents experience fear, responsibility, and uncertainty in daily life.

## CONCLUSION

In this study, kinesiophobia was found to be related to lower quality of life and higher depressive symptoms among parents of children with haemophilia. Even though kinesiophobia levels did not differ significantly between the groups, parental kinesiophobia appeared to play a significant role in how parents experience and manage their child's condition. These findings highlighted the importance of a biopsychosocial approach to haemophilia care, which considered not only patients but also the emotional well-being of their parents.

### ETHICAL APPROVAL:

The study protocol was approved by the Clinical Research Ethics Committee of Bursa City Hospital, University of Health Sciences, Bursa, Turkiye (Approval No. 2019-KAEK-140, Decision No. 2023-19/4, date: 20 December 2023).

### PATIENTS' CONSENT:

Written informed consent was obtained from all participants prior to enrolment.

### COMPETING INTEREST:

The authors declared no conflict of interest.

### AUTHORS' CONTRIBUTION:

EK, TD: Conception and design of the study, data analysis and interpretation, and critical revision of the manuscript.

EK, EGK, RGA: Data collection.

All authors approved the final version of the manuscript to be published.

## REFERENCES

- Gerdle B, Dragioti E, Rivano Fischer M, Ringqvist A. Acceptance and fear-avoidance mediate outcomes of interdisciplinary pain rehabilitation programs at 12-month follow-up: A clinical registry-based longitudinal cohort study from the Swedish Quality Registry for Pain Rehabilitation (SQRP). *J Pain Res* 2024; **17**:83-105. doi: 10.2147/JPR.S438260.
- Stromer W, Pabinger I, Ay C, Crevenna R, Donnerer J, Feistritzer C, et al. Pain management in hemophilia: Expert recommendations. *Wien Klin Wochenschr* 2021; **133** (19-20):1042-56. doi: 10.1007/s00508-020-01798-4.
- Roelofs J, Sluiter JK, Frings-Dresen MHW, Goossens M, Thibault P, Boersma K, et al. Fear of movement and (re)injury in chronic musculoskeletal pain: Evidence for an invariant two-factor model of the Tampa Scale for Kinesiophobia. *Eur J Pain* 2004; **8**(5):495-502. doi: 10.1016/j.ejpain.2003.11.016
- Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatry* 1961; **4**:561-71. doi: 10.1001/archpsyc.1961.01710120031004.
- Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care* 1992; **30**(6):473-83.
- Campo JV, Bridge J, Lucas A, Savorelli S, Walker L, Di Lorenzo C, et al. Physical and emotional health of mothers of youth with functional abdominal pain. *Arch Pediatr Adolesc Med* 2007; **161**(2):131-7. doi: 10.1001/archpedi.161.2.131.
- Eccleston C, Crombez G, Scotford A, Clinch J, Connell H. Adolescent chronic pain: patterns and predictors of emotional distress in adolescents with chronic pain and their parents. *Pain* 2004; **108**(3):221-9. doi: 10.1016/j.pain.2003.11.008.
- Santavirta N, Bjorvell H, Solovieva S, Alaranta H, Hurskainen K, Konttinen YT. Coping strategies, pain, and disability in patients with haemophilia and related disorders. *Arthritis Rheumatism* 2001; **45**(1):48-55. doi: 10.1002/1529-0131(200102)45:1<48::AID-ANR83>3.0.CO;2-1
- Akbari F, Dehghani M, Mohammadi S, Goubert L, Sanderman R, Hagedoorn M. Why do patients engage in pain behaviors? A qualitative study examining the perspective of patients and partners. *Clin J Pain* 2020; **36**(10):750-6. doi: 10.1097/AJP.0000000000000868.
- Craig KD. Social communication model of pain. *Pain* 2015; **156**(7):1198-9. doi: 10.1097/j.pain.0000000000000185.
- Romano JM, Jensen MP, Turner JA, Good AB, Hops H. Chronic pain patient-partner interactions: further support for a behavioral model of chronic pain. *Behav Ther* 2000; **31**(3):415-40. doi: 10.1016/S0005-7894(00)80023-4.
- Goubert L, Craig KD, Vervoort T, Morley S, Sullivan MJL, Williams CAC, et al. Facing others in pain: The effects of empathy. *Pain* 2005; **118**(3):285-8. doi: 10.1016/j.pain.2005.10.025.
- Botvinick M, Jha AP, Bylsma LM, Fabian SA, Solomon PE, Prkachin KM, et al. Viewing facial expressions of pain engages cortical areas involved in the direct experience of pain. *Neuroimage* 2005; **25**(1):312-9. doi: 10.1016/j.neuroimage.2004.11.043.
- Goubert L, Eccleston C, Vervoort T, Jordan A, Crombez G. Parental catastrophizing about their child's pain. *Pain* 2006; **123**(3):254-63. doi: 10.1016/j.pain.2006.02.035.
- Gross JJ. Emotion regulation: Current status and future prospects. *Psychol Inquiry* 2015; **26**(1):1-26. doi: 10.1080/1047840X.2014.940781.
- Calatayud J, Perez-Alenda S, Carrasco JJ, Cruz-Montecinos C, Andersen LL, Bonanad S, et al. Safety and effectiveness of progressive moderate-to-vigorous intensity elastic resistance training on physical function and pain in people with haemophilia. *Phys Ther* 2020; **100**(9):1632-44. doi: 10.1093/ptj/pzaa106.

17. Cserep M, Szabo B, Toth-Heyn P, Szabo AJ, Szumska I. The predictive role of cognitive emotion regulation of adolescents with chronic disease and their parents in adolescents' quality of life: A pilot study. *Int J Environ Res Public Health* 2022; **19(23)**:16077. doi: 10.3390/ijerph192316077.
18. Connelly M, Bromberg MH, Anthony KK, Gil KM, Schanberg LE. Emotion regulation predicts pain and functioning in children with juvenile idiopathic arthritis: An electronic diary study. *J Pediatr Psychol* 2012; **37(1)**:43-52. doi: 10.1093/jpepsy/jsr088.
19. Nomaguchi KM, Milkie MA. Costs and rewards of children: The effects of becoming a parent on adults' lives. *J Marriage Fam* 2004; **65(2)**:356-74. doi: 10.1111/j.1741-3737.2003.00356.x.
20. Segrin C, Wosidlo A, Givertz M, Bauer A, Murphy MT. Overparenting is associated with child problems and a critical family environment. *J Child Fam Stud* 2015; **24**:470-79. doi: 10.1007/s10826-013-9858-3.

