Understanding suicidal behavior and ideation in patients with hypermobile Ehlers-Danlos syndrome: a qualitative study

Jelena Forget[1,2]; Naëlle Bourdon[1]; Cécile Flahault[1]; David Attali[1]; Roland Jaussaud[3]; François Jedryka[4]; Philippe Courtet[5,6] & Carolina Baeza-Velasco[1,5,6]

Abstract

Aims: Suicide is a major public health problem. More than 700,000 people die by suicide every year [1]. Thus, it is important to identify vulnerable populations and the risk factors associated with suicidal behaviour (SB). In this sense, physical and chronic pain, physical disability, psychological distress, and female gender are well-known risk factors of SB [2]. These characteristics are overrepresented in people with hypermobile Ehlers-Danlos syndrome (hEDS) [3,4]. Various studies have explored suicidality in people affected by this syndrome, but no qualitative studies have been carried out so far. The present study explored how patients suffering from hEDS understand and explain their SB and suicidal ideation.

Method: Twelve participants with a diagnosis of hEDS and antecedent of SB or SI were included in this study. Narrative data collected through semi-structured interviews were analyzed by thematic content analysis.

Results: The analysis is articulated around three main axes: the consequences of hEDS, misunderstanding, and suicide as an escape strategy.

Conclusion: This study highlights the severity of symptoms affecting daily life and the fragility of the emotional state. It therefore contributes to sensitizing the medical community to the need to integrate psychosocial aspects into the global assessment of patients with hEDS.

Recent Publications (minimum 5)

[1] World Health Organization. (17 juin 2021). Suicide. https://www.who.int/news-room/fact-sheets/detail/suicide

[2] Calati, R., Laglaoui Bakhiyi, C., Artero, S., Ilgen, M., & Courtet, P. (2015). The impact of physical pain on suicidal thoughts and behaviors: Meta-analyses. Journal of Psychiatric Research, 71, 16–32. https://doi.org/10.1016/j.jpsychires.2015.09.004

[3] Chopra, P., Tinkle, B., Hamonet, C., Brock, I., Gompel, A., Bulbena, A., & Francomano, C. (2017). Pain management in the Ehlers-Danlos syndromes. American Journal of Medical Genetics Part C: Seminars in Medical Genetics, 175(1), 212-219. https://doi.org/10.1002/ajmg.c.31554

[4] Baeza-Velasco, C., Bourdon, C., Montalescot, L., de Cazotte, C., Pailhez, G., Bulbena, A., & Hamonet, C. (2018). Low- and high-anxious hypermobile Ehlers–Danlos syndrome patients: comparison of psychosocial and health variables. Rheumatology International. 38 (5), 871–878. https://doi.org/10.1007/s00296-018-4003-7



Jelena Forget

PhD student at the Laboratory of Psychopathology and Health Processes at Université Paris Cité. The title of her thesis project is “The link between pain and suicidal behaviors in people diagnosed with hypermobile Ehlers-Danlos syndrome”. She is also a clinical psychologist in palliative care and oncology sector.

Email: jelena.forget@etu.u-paris.fr

Notes/Comments:

[1] Université Paris Cité, Laboratoire de psychopathologie et processus de santé (LPPS, EA 4057), Boulogne-Billancourt, France.
[2] Fondation Œuvre de la Croix Saint-Simon, home care service, 35, rue du Plateau, 75019 Paris, France.
[3] Department of Internal Medicine and Clinical Immunology, School of Medicine, University of Lorraine, CHRU Nancy, France.
[4] Pain Assessment and Treatment Center, CHU Nîmes, Montpellier-Nîmes Faculty of Medicine, Nîmes, France.
[5] Département d'Urgences et Post-urgences Psychiatriques, CHU de Montpellier, France.
[6] Institute of Functional Genomics, University of Montpellier, CNRS, INSERM, Montpellier, France.