

Is sexual health education in men with hemophilia needed? The University of California, at San Francisco experience.

Anjee Mahajan MD^{1,2}, Dana Francis, MSW², Andrew Leavitt, MD^{1,2}, Adam Giermasz MD, PhD^{2,3}, Patricia Tobase PT, DPT, OCS^{2,4}

¹UCSF Division of Hematology and Oncology, ²UCSF Hemophilia Treatment Center, ³Present Affiliation: UC Davis Hemophilia Treatment Center, ⁴UCSF Department of Physical Therapy and Rehab Science

Introduction and Objective

Sexual health is defined by the World Health Organization 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”. At the University of California, San Francisco (UCSF) Adult Hemophilia Treatment Center (HTC), we do not regularly assess the need for sexual health education. The authors suspect from discussions with other hemophilia providers that sexual health is not routinely discussed with men with hemophilia (MWH) during HTC visits.

The purpose of this study was to identify the need for sexual health education in MWH seen at the UCSF HTC.

Methods

- A 54-item patient-reported questionnaire was generated based on anecdotal information from our patients, existing sexual health surveys for people with arthropathy, and other intimacy surveys.
- Questionnaires were mailed to English-speaking UCSF Adult HTC patients over age 18 with a diagnosis of hemophilia.
- Data were entered into a secure, web-based server.
- Descriptive analysis was performed on collected data that included demographics, sexual beliefs, sexual confidence, bleeding rate related to sexual activity, and sexual health education preference.

Results

- 97 questionnaires were mailed; 23 were returned (23.7%).
- 3 of the 23 men who returned questionnaires declined to participate.

Table 1. Demographics of Participants

	No. (%)
Total number of participants	20
Mean age (years)	48.8
Severity of Hemophilia	
Severe	13 (65%)
Moderate	2 (10%)
Mild	5 (25%)
Type of Hemophilia	
Hemophilia A	13 (65%)
Hemophilia B	6 (30%)
Not sure	1 (5%)
Factor administration schedule	
Prophylactic	12 (63.2%)
On-demand	7 (36.8%)
Declined to respond	1 (5%)
Co-Morbidities	
HIV	9 (45%)
Hepatitis C	5 (25%)

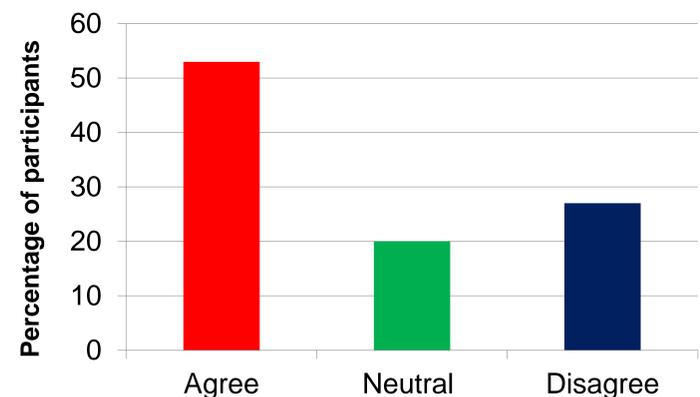


Figure 1. “Throughout my life I have noticed that having a bleeding disorder has negatively affected my sexual relationship with my partner”

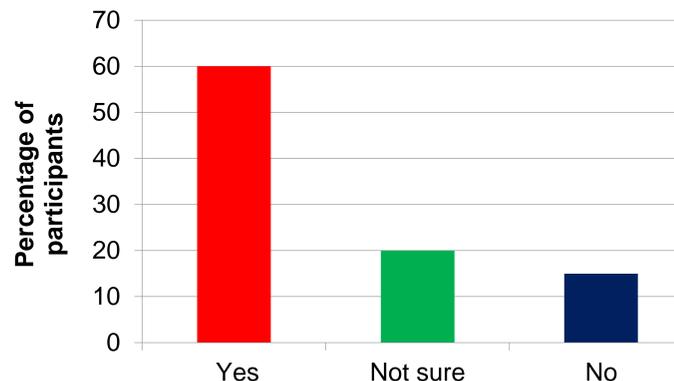


Figure 2. “Would you like sexual health to be discussed during your clinic visit?”

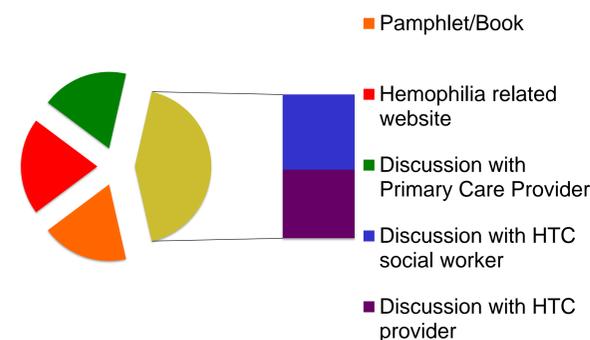


Figure 3. “What would be the most helpful way for you to get information on bleeding disorders and sexual health?”

Conclusion

This study indicates that MWH have experienced bleeds related to sexual activity and would like to receive information on the topic of sexual health. MWH identified the HTC provider and social worker as the preferred HTC member with whom they would like to receive information on sexual health and bleeding disorders.

References

1. World Health Organization, Defining sexual health: report of a technical consultation on sexual health, 28–31 January 2002, Geneva. 2006
2. Baker JR, Crudder SO, Riske B, Bias V, Forsberg A. A model for a regional system of care to promote the health and well-being of people with rare chronic genetic disorders. *American journal of public health* 2005; 95: 1910-6.
3. Soucie JM, Nuss R, Evatt B, Abdelhak A, Cowan L, Hill H, et al. Mortality among males with hemophilia: relations with source of medical care. The Hemophilia Surveillance System Project Investigators. *Blood* 2000; 96: 437-42.
4. Levine PH, McVerry BA, Segelman AE, Cranford CM, Zimble S. Comprehensive health care clinic for hemophiliacs. *Archives of internal medicine* 1976; 136: 792-4.
5. Smith PS, Levine PH. The benefits of comprehensive care of hemophilia: a five-year study of outcomes. *American journal of public health* 1984; 74: 616-7.
6. Butler RB, Cheadle A, Aschman DJ, Riske B, Senter S, McLaughlin KM, et al. National needs assessment of patients treated at the United States Federally-Funded Hemophilia Treatment Centers. *Haemophilia : the official journal of the World Federation of Hemophilia* 2016; 22: e11-7.
7. Angelini D, Konkle BA, Sood SL. Aging among persons with hemophilia: contemporary concerns. *Seminars in hematology* 2016; 53: 35-9.
8. Plug I, Van Der Bom JG, Peters M, Mauser-Bunschoten EP, De Goede-Bolder A, Heijnen L, et al. Mortality and causes of death in patients with hemophilia, 1992-2001: a prospective cohort study. *Journal of thrombosis and haemostasis* : JTH 2006; 4: 510-6.
9. Philipp C. The aging patient with hemophilia: complications, comorbidities, and management issues. *Hematology / the Education Program of the American Society of Hematology American Society of Hematology Education Program* 2010; 2010: 191-6.
10. Bar-Chama N, Snyder S, Aledort L. Sexual evaluation and treatment of ageing males with haemophilia. *Haemophilia : the official journal of the World Federation of Hemophilia* 2011; 17: 875-83.
11. Parish KL. Sexuality and haemophilia: connections across the life-span. *Haemophilia : the official journal of the World Federation of Hemophilia* 2002; 8: 353-9.
12. Areskoug-Josefsson K, Oberg U. A literature review of the sexual health of women with rheumatoid arthritis. *Musculoskeletal care* 2009; 7: 219-26.
13. Hill J, Bird H, Thorpe R. Effects of rheumatoid arthritis on sexual activity and relationships. *Rheumatology* 2003; 42: 280-6.
14. Josefsson KA, Gard G. Sexual health in patients with rheumatoid arthritis: experiences, needs and communication with health care professionals. *Musculoskeletal care* 2012; 10: 76-89.
15. Abraham L, Symonds T, May K, Althof SE, Hallam-Jones R, Rosen RC. Psychometric validation of gender nonspecific sexual confidence and sexual relationship scales in men and women. *The journal of sexual medicine* 2009; 6: 2244-54.
16. Symonds T, Abraham L, Bushmakina AG, Williams K, Martin M, Cappelleri JC. Sexual function questionnaire: further refinement and validation. *The journal of sexual medicine* 2012; 9: 2609-16.
17. Tristano AG. Impact of rheumatoid arthritis on sexual function. *World journal of orthopedics* 2014; 5: 107-11.

