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

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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

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

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?”

<table>
<thead>
<tr>
<th>Percentage of participants</th>
<th>No</th>
<th>Not sure</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pamphlet/Book</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hemophilia related website</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion with Primary Care Provider</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion with HTA social worker</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion with HTC provider</td>
<td>60</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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