

MASAC Recommendation #81
March 1998
Medical Advisory #315

NATIONAL HEMOPHILIA FOUNDATION
MEDICAL AND SCIENTIFIC ADVISORY COUNCIL (MASAC)

CONSIDERATIONS FOR DEVELOPING PSYCHOSOCIAL INTERVENTIONS FOR
WOMEN WITH BLEEDING DISORDERS
(MARCH 1998)

The following recommendations were approved by the Medical and Scientific Advisory Council (MASAC) on March 6, 1998, and adopted by the NHF Board of Directors on March 11, 1998. By affirming this recommendation, NHF recognizes the importance of improving the quality of life for persons with hemophilia and other related bleeding disorders.

This material is provided for your general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

PHYSICIANS: Please distribute this information to all providers in your area who treat patients with hemophilia.

CHAPTERS: Please distribute to your membership.

CONSIDERATIONS FOR DEVELOPING PSYCHOSOCIAL INTERVENTIONS FOR
WOMEN WITH BLEEDING DISORDERS
(MARCH 1998)

Women with bleeding disorders have many psychosocial and medical issues that are without parallel in their male counterparts. The uniqueness of their circumstances warrants special attention. The lack of awareness that women can have a bleeding disorder contributes to a sense of isolation. Women with bleeding disorders often find that their own experiences of menstruation, pregnancy, postpartum wellness, and menopause do not mirror those of their healthy peers, reinforcing their isolation. These women are commonly faced with inadequate support from all aspects of their lives including their immediate family, the health care system, and the employment arena. Without appropriate and sensitive intervention by professional providers, the problems experienced by these women can lead to undesirable emotional and physical outcomes.

It is recommended that psychosocial providers include the following components in the development of interventions for women with bleeding disorders:

1. Psychosocial providers should consider the emotional impact of physical limitations, menstrual bleeding, and chronic pain when providing services to women with bleeding disorders. Interventions should be designed to address these issues when appropriate.
2. Psychosocial providers should consider employment status and financial resources and their impact on the emotional well-being of women with bleeding disorders.
3. Psychosocial providers should assess the degree of social support in the lives of women with bleeding disorders, with the objective of maintaining an adequate level of support.
4. Psychosocial providers should consider the issues of adolescent sexual identity and maturation, family planning, pregnancy, postpartum wellness, sexuality, intimacy, and menopause when providing services to women with bleeding disorders. Issues of grief and loss should be addressed as needed.
5. When providing services to women with bleeding disorders, providers should display the following characteristics:
 - a. Demonstrate a willingness to learn and to listen.
 - b. Be forthcoming with patient education.
 - c. Take a personal approach to your service delivery.
 - d. Emphasize patient choice and autonomy.

Psychosocial services that include these components should be available at all comprehensive centers for the treatment of bleeding disorders.