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In 2002, the American Academy of Family Physicians, The American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine issued a joint consensus statement entitled "Health care transitions for young adults with special health care needs". Among the goals set forth were the recommendations to: a) develop a written health care transition plan by age 14; and b) identify core knowledge and skills required to provide developmentally appropriate health care services.

In March 2003, the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation responded by publishing guidelines for the transition of people with bleeding disorders. The guidelines are far reaching and cover the "strategies" of self-advocacy, independent health care behaviors, sexual health, social support, health and lifestyle behaviors, and educational/vocational/financial planning. Although the list provides documentation

## Hemophilia health care adolescent to adult transition assessment

of discussion of each topic with the patient and parent, no measure has been developed to ensure that the goals of the guidelines are achieved. Further, there is concern that uniform implementation of the guidelines by the hemophilia treatment centers is unlikely as the published check list is 13 pages long.

The major goal of this project is to develop an assessment tool which will provide the staff of the treatment center with the information needed to best guide the educational needs of adolescents with bleeding disorders. Development of the assessment tool will proceed through several steps. A draft tool has already been developed which will require review of content validity by a group of experts in hemophilia care. A second patient self-report tool paralleling the main assessment tool will provide concurrent criterion related validity. Reliability of the tool will be assessed by Test/Retest measurement, and by inter-rater measurement comparison.

Although it is accepted that transition is a lifelong process, the target population of this project is adolescent hemophilia patients aged 14-18 years. This age group is chosen since it is assumed that these patients are old enough to clearly understand the nature of their bleeding disorder and able to undertake the majority of self-care responsibilities. The Hemophilia Health Care Transition Assessment Tool will be used to establish a baseline of information regarding what the adolescent already knows about his bleeding disorder. The gaps identified in knowledge and skills will

then provide the starting point for individualized instruction over the subsequent years. Annual re-evaluation will provide a gauge of how the patient is progressing in his understanding and assumption of primary responsibility of his health care with the long-term goal of each patient achieving independence in all categories. The assessment will also provide feedback to the health-care team on how well they are meeting the goals of the MASAC guidelines for each individual patient, and help to identify areas where methods of instruction require improvement.

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