

**AHCDC
Quality of Life Subcommittee
Report 1998-99**

Committee Members:

Dr. D. Barnard (Chairperson)
Dr. M. Pai
Dr. J. Wu (Vancouver)
Dr. P. McCusker

Sub-committee Activities:

Funding:

In 1999, Dr. Barnard and a group of hemophilia traters were awarded funding from the 1999 competitin of the Canadian Hemophila Society to establish a Health Related Quality of Life Instrument for Hemophilia (HRQoL).

Goals:

The goals of the project are:

1. To develop a hemophilia-specific HRQoL instrument
2. To validate the hemophilia-specific HRQoL instrument
3. To make the hemophilia-specific HRQoL instrument available to other researchers.

Background:

The quality of life tools are standard tools, but the approach is novel to the field of hemophilia. There is no currently available instrument to study quality of life in hemophilia, there is currently no method to evaluate quality of life effects of new treatments, nor to follow changes quality of life over time in people with bleeding disorders. This is a very difficult area to work in because of the difficulty determining important factors. In particular, wording of the questionnaires and validation is critical.

The development of the HRQoL instrument has been started with the development of a questionnaire to be distributed to hemophilia patients. In addition, Dr. Barnard is reviewing the literature on hemophilia, and consulting with hemophilia treaters in Canada including physicians, nurse coordinators and others involved in hemophilia care.

Methods:

Generation of Questionnaire: The committee has searched the literature, will sample 50 people with hemophilia and 30 health care professionals for pertinent questions.

Validation of the Instrument: Validation is difficult because of the number of people with hemophilia available for study, so much of the validation will be done in the context of clinical studies in hemophilia. The committee has letters of support from most of the hemophilia clinic directors of Canada.

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