

THE HEMOPHILIAC AND KNOWLEDGE OF THEIR CONDITION. M.J.Inwood, J.D.Barr and R.George. Canadian Hemophilia Society, Hamilton, Ontario, Canada.

The Canadian Hemophilia Society (CHS) emphasizes education of the hemophilia and his family. A questionnaire was designed to answer the following. Was the level of knowledge a sample of Canadian hemophiliacs and their parents had of their condition related to the educational objectives of the CHS? Was the standard of treatment they received directly related to this level of knowledge, and in turn did it affect the degree of compliance to physician's orders? 220 hemophiliacs and parents across Canada were interviewed and 203 (91%) responded. The following results were verified using suitable statistical analysis. Individuals who attended CHS meetings, received CHS literature and Handbook had superior knowledge of their condition compared to those hemophiliacs and parents not receiving these services. Although physicians knew more about hemophilia than the average parent or hemophiliac, if a parent had post secondary education, or if the hemophiliac was severely effected, their knowledge was equal to that of non actively treating physicians. Hemophiliacs had increased knowledge if they were enrolled in a home infusion program and had regular inhibitor and factor assays performed. Only 5 of 167 hemophiliacs and parents were non compliers, and had a lower level of knowledge compared to the compliant group. This suggests that the hemophiliac with superior knowledge is severely affected and enrolled in a home infusion program. He is cared for by a physician actively treating hemophilia, who arranges regular inhibitor and factor level assays. Furthermore he is a member of the CHS, possesses a CHS Handbook and attending regular CHS meetings.

PSYCHO-SOCIAL STATUS OF PATIENTS ON HOME CARE-6 YEAR FOLLOW UP. B. Granich and M.W. Hilgartner. Fordham University School of Social Work, New York, New York, U.S.A. and Department of Pediatrics, New York Hospital-Cornell Medical Center, New York, New York, U.S.A.

Hemophiliacs on home care are more concerned with the daily management of their illness than with the more global considerations of longer life and better health. In a study of the total population of patients on home care at the New York Hospital, and of their families, the obvious advantages of greater personal freedom, better management of pain and stress, great saving of time, and control of and responsibility for their own lives was affirmed by the respondents. This has led the patients to seek to and largely succeed in giving up the sick role, which requires close dependence on medical supervision. Patients now tend to see themselves as partners in the management of their illness rather than as passive recipients of medical care. However, they recognize a continuing need for information and psychological support and for involvement in organizations which will supply these services. They recognize that they are receiving excellent care. In general, it seems that for this group of patients, hemophilia has become less a disaster and more a problem to be managed. The study was done in July-September, 1976, under the auspices of the New York Hospital and the Metropolitan Chapter of the Hemophilia Foundation. The information was gathered in 146 face to face interviews with patients, parents and spouses, by trained social workers from Fordham University. The study population was largely middle class, white, suburban and 50% Catholic. By contrast, a study of a similar population from the same hospital, done before the advent of home care, revealed a principal concern to be complete dependence on hospital care and the physical and emotional burden that is imposed.

MENTAL HEALTH COLLABORATION IN A COMPREHENSIVE CARE TEAM. D.L. Jonas and E. Wincott. Mount Sinai School of Medicine of the City University of New York, New York, USA.

Effective multidisciplinary mental health participation in a comprehensive care center is discussed. Routinely, areas of input include initial evaluation, periodic clinic follow-up, home care screening, and pre-surgical evaluation. Methods evolved by a psychiatrist and a social worker working separately and together will be reviewed, as well as techniques of communication and decision making among the whole team to develop effective treatment plans. Specific areas of activity in clinics, in-patient hospital, and office will be reviewed using case examples. The role of the mental health worker in educating health care professionals and community groups is discussed, as well as responsibilities to the National Hemophilia Foundation and its local chapters.