

SOCIAL WORKERS IN HEMOPHILIA CARE
STANDARDS OF PRACTICE
May 2017

Canadian Social Workers in
Hemophilia Care



Travailleurs sociaux canadiens
en hémophilie

These standards are based on an original document prepared by Leonarda Szewczyk, MSW CSW, Linda Prentice, MSW CSW Alison Oxalade, MSW, Ron Levin, MSW and Ernie Chase, RSW in May 1996. They were updated for the Canadian Social Workers in Hemophilia Care by Connie Shrubsole, London Health Sciences Centre, London Ontario, and reviewed and approved by the following members of CSWHC in May 2009: Clarke Dale, Yolaine Houle, Lezley Ireland, Ruanna Jones, Denise Labrecque, Jordan Lewis, Linda Mansfield-Smith, Cindy Milne-Wren, Hulda Niv, Patty Phrakonkham-Ali, Michelle Sims, Anne Vaughan, Linda Waterhouse.

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INTRODUCTION:

Background: Across Canada, Bleeding Disorder Health Care Teams (HCT) provide specialized treatment to persons with inherited bleeding disorders. Historically, HCT's were focused on the treatment of hemophilia, an X-linked coagulation disorder affecting primarily males. In acute traumas or as prophylaxis for people with severe hemophilia, treatment consists of intravenous infusion of a synthetic product called 'factor concentrate' to replace the deficient protein needed for coagulation. Hemophilia has both medical and surgical sequelae: head and abdominal bleeds can be life threatening; joint or muscle bleeds may cause long-term disabilities and chronic pain. Many persons with hemophilia require complicated treatments such as joint replacement and synovectomies. Some persons with hemophilia develop inhibitors to treatment which can create additional complications.

Today, HCT's also focus on other inherited/acquired bleeding disorders such as Von Willebrand Disease, and the health issues of people, frequently women, affected by this more common genetic disorder. As well, rare bleeding disorders such as other factor deficiencies and platelet function disorders are being assessed and treated at Bleeding Disorder Programs across the country.

Some members of the hemophilia community were infected with HIV and/or Hepatitis C through the use of tainted blood products, and endure the physical and emotional consequences of this tragedy. The ongoing question of product safety is an underlying fear for many.

Given the complex nature of bleeding disorders, both medical and psychosocial treatment are essential to ensure effective treatment as new treatments and new issues appear on the horizon. As part of the HCT, social workers provide the expertise to address these needs.

Guiding Principles:

Role of the Social Worker

Multidisciplinary health care teams and coordinated comprehensive care is the hallmark of bleeding disorder programs, and is endorsed by the Canadian Hemophilia Society (CHS). Their Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders (2007) states that "effective programs deliver comprehensive care through an integrated, multidisciplinary team" which includes social work as a core team member. These Standards note that effective client care includes "promoting self-fulfillment, self-determination and societal integration", which are key social work values¹.

The multiple social and psychological stressors in persons with a bleeding disorder and their families demand casework that includes both instrumental and supportive services. Social workers have the opportunity to collaborate with other team members to help clients optimize their full potential in the face of a chronic and potentially life-limiting disorder. The social worker must be able to assist clients and families to cope with the chronicity of hemophilia and other bleeding disorders as well as the effects of HIV/HepC. Providing ongoing rather than curative treatment can be challenging for the treatment team, but it is the backdrop against which social workers can form uniquely close relationships with clients and with colleagues on the treatment team. The social worker acts as an advocate on behalf of clients and their families, removing barriers to treatment and empowering them to be effective partners in managing their own care. Social workers bring a strong understanding of the cultural, social and religious values of the client and family in an increasingly culturally diverse society.

Liaison with the Canadian Hemophilia Society

An essential component of social work involvement in the treatment of bleeding disorders includes collaboration and consultation with the Canadian Hemophilia Society and the provincial chapters through participation in committees, advocacy, ongoing education, and research. In the shadow of the tainted blood tragedy, social workers must remain knowledgeable regarding the safety of their clients. Through their specialized knowledge of social issues and community trends in health promotion, social workers can be fruitfully involved in program planning, education, research and policy and resource development.

It is the responsibility of the social worker to keep abreast of new medical and psychosocial developments in the treatment of persons with bleeding disorders and their families.

Social Workers and Other Responsibilities

In most instances, social workers work on teams that are attached to a hospital or bleeding disorders treatment centre. Consequently, they are governed by the policies and procedures of these organizations. Social workers are also governed by the standards and ethics of their provincial regulatory bodies.

STANDARDS:

Standard 1: Relationship to Clients:

The social work services provided to persons with a bleeding disorder and their systems are considered a mutual endeavor between participants. Arising from the belief that clients have the right and capacity to determine and achieve their goals and objectives, workers and clients jointly identify psychosocial issues requiring attention and devise a treatment plan.

Standard 2: Qualifications

Social workers are university graduates at the Bachelor of Social Work and/or Master of Social Work levels. They are registered members of the regulatory bodies governing social work practice in accordance with the institution and province in which they are employed. The individual is required to develop an appropriate level of knowledge regarding bleeding disorders, its usual course of treatment, its psychosocial implications for clients and family and relevant resources. The individual will be able to intervene utilizing individual, family or group skills.

Standard 3: Ethics and Values

Social workers providing social work services to those with a bleeding disorder adhere to the code of ethics of their governing body/college.

Standard 4: Responsibility to Clients:

All clients with a bleeding disorder and their families have access to social work services as part of their overall treatment program in accordance with the CHS Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders. The social worker's intervention is to be timely, appropriate to the situation and documented according to standards set by their employer and their professional regulatory body. The development of a treatment plan is based on the belief that clients have the right and capacity to determine and achieve their goals and objectives. In some instances this may require the social worker to advocate for the client and family's wishes with the bleeding disorders team and mediate conflicts between the client and team members.

Standard 5: Client and Community Education

Social workers advocate for the needs/rights of clients and families within the context of the treatment centre and with related community agencies and services. Social workers will have the ability to access resources at a municipal, provincial and federal level for the benefit of client and families. Social workers may contribute to the education of relevant community groups.

Standard 6: Documentation

Social workers shall provide documentation of all social work services, which reflect the client and client systems' pertinent information for assessment and treatment. Social work entries in the client's health record shall be timely, clearly and concisely written so as to facilitate communication with other professionals involved in the client's care. Documentation should conform to the standards of the treatment centre and the governing college, which insures accountability and confidentiality.

Standard 7: Confidentiality

In accordance with the social workers governing body and treatment centre, all interactions with clients and families will remain in strictest confidence. Disclosure of client information will occur only with client consent or as required/allowed by law. Client records will be stored in a secure facility by the bleeding disorder treatment centre and/or host institution and any records maintained by the social worker (where permitted) will be kept in a secure and protected environment.

Standard 8: Research

Social workers in bleeding disorders care provide education and information to health care professionals regarding psychosocial functioning. In addition social workers pursue opportunities for involvement in discipline specific and/or interdisciplinary /program research where possible. Social workers may participate in and integrate outcome based research into their practice.

Standard 9: Professional Development

Social workers will review appropriate literature involving health care and psychosocial issues related to those with a bleeding disorder. In addition, social workers will present at or attend seminars, conferences and workshops towards the goal of continually enhancing their clinical skill set and theoretical knowledge base. It is expected that the social worker maintains and updates knowledge of relevant community resources to keep current with best practices.

Standard 10: Teamwork and Collaboration

In accordance with the CHS Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders, social workers in bleeding disorders care are active members of an interdisciplinary team whose approach to care is client and family centered, and organized towards care specific to those with a bleeding disorder. Social workers will work closely with other health care team members and will show leadership in contributing a psychosocial perspective to the client and family centered care process.

Standard 11: Involvement with Canadian Hemophilia Society

Social workers involved in treating clients with bleeding disorders will be considered as members of the Canadian Social Workers in Hemophilia Care. They will be affiliated with the Canadian Hemophilia Society, and will be governed by the Standards of Care endorsed by these groups. Social workers will attend the annual general meetings of the CSWHC sponsored by the Canadian Hemophilia Society.

References:

Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders (2007) available at www.hemophilia.ca