

The challenges, adaptations, and areas of need that confront adult men with hemophilia: A community-based qualitative study

Rolstad, Erik Bruce

The University of Utah, ProQuest Dissertations Publishing, 2014. 3643759.

Hemophilia is a rare genetic bleeding disorder that primarily affects men. Treatment is extremely expensive and places a tremendous financial burden on individuals with hemophilia and their family members. This study was conducted in response to Utah service provider concerns that men with hemophilia may be disengaged from their local community-based support network. The goal of the study was to gain a better understanding of the (a) unique challenges, (b) adaptations, and (c) physical, financial, psychological, and social needs of adult men with moderate to severe hemophilia. Three independent, but interrelated, studies were conducted with each of the aforementioned groups. The first study consisted of verbal qualitative interviews with 11 men with moderate severe hemophilia and written interviews that were provided by 3 additional affected men. The second study involved face-to-face interviews with Utah's two active HTC social workers and the collection of written interview data from 14 HTC social workers from surrounding regions. The third study included the following: six face-to-face interviews, two written interviews, three field interviews, ten one-on-one meetings, five field observations, and content analysis of 20 internet articles or online postings. I used a qualitative, grounded theory approach to analyze the data. Resilience theory provided a lens for interpreting the results. Findings indicate that men value the array of educational, social, and medical services that are available to them in the community but choose to manage their hemophilia independently. They often appear to feel ambivalent toward the services that are offered for reasons related to their age, current work and/or insurance status, prior personal history with the bleeding disorders community, strength of relationship with local service providers, and the degree to which their local HTC customizes services to meet their needs as adult men. Understanding this dynamic may be helpful in developing services that are more specifically tailored to the needs of adult men with hemophilia in addition to potentially providing stronger community-based support to men with other genetic disorders. A model of men's process of living with hemophilia is presented with specific recommendations for providing support.