



Original article

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ABSTRACT

Background: Home therapy for hemophilia reduces pain, deformity and incidence of complication-induced hospitalizations. Therefore, it is an important component of comprehensive hemophilia care. Unfortunately, most hemophilic families in Shanxi province, China do not continue home therapy.

Objective: To analyze the reasons that hemophilic families do not continue home therapy and to provide a foundation for formulating targeted interventions by the Hemophilia Treatment Center (HTC) in Shanxi Province.

Methods: A qualitative phenomenological approach using purposeful sampling of 17 hemophilic families, two physicians, and one nurse from 11 branches across 11 cities in Shanxi Province. Interviews were recorded, transcribed verbatim and analyzed using qualitative content analysis.

Results: Four themes were identified: (1) home therapy was generally positively evaluated; (2) concerns about the safety of home therapy; (3) an imperfect social medical security system; and (4) inadequate continuous nursing of hemophilia.

Conclusions: Home therapy for hemophilia remains in a preliminary stage in Shanxi Province, and inadequate family and social support systems have obstructed the implementation of home therapy. It is necessary to develop a home therapy model suitable for hemophilic families in Shanxi Province as soon as possible. Such a model would improve the community and home care medical systems for hemophilia and guarantee home therapy throughout the entire medical care system, thus enabling more hemophilic families to carry out home therapy. Achieving these goals requires urgent research and attention from medical staff.

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1. Introduction

Hemophilia involves a potentially life-threatening tendency to bleed after trauma to any part of the body, with joints and muscles being common sites. Hemophilia is currently incurable, and patients must depend on infusions of clotting factors throughout their lives.¹ Transient treatment in hospitals cannot

guarantee effectiveness for controlling the disease, thus, home therapy is particularly important for hemophiliacs.²

Home therapy for hemophilia refers to the prevention, evaluation and treatment of bleeding that occurs at home by the hemophiliac and/or their family members. Home therapy is helpful for early treatment of bleeding and reducing pain and the risk of deformity and hospitalizations associated with complications.^{3,4}

The Shanxi Hemophilia Treatment Center (HTC) was established in 2009, and the National Health and Family Planning Commission of China established an information management system for hemophilia cases and 11 branches in Shanxi Province. The hospital-based HTC managed the records of hemophilia patients and a total of 494 patients with hemophilia were registered by the end of 2015.

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The Shanxi Province HTC conducted home therapy training for hemophilia from April 2012 to September 2014 with 165 hemophilia patients and 178 family members. An investigation conducted by the Shanxi Province HTC in October 2015 showed that only 34 hemophiliacs had continued to undergo home therapy. The reasons that others failed to continue with home therapy require urgent exploration to provide a foundation for formulating targeted interventions by the HTC in Shanxi Province.

2. Methods

2.1. Research methods

We adopted purposive sampling for interviewing 17 hemophilic families who did not continue home therapy from 11 branches across 11 cities in Shanxi Province in accordance with the principle of data saturation. There were eight hemophiliacs and nine family members. The inclusion criteria were patients or family members who had received home therapy training for hemophilia at the Shanxi Province HTC, age >18, excellent comprehension and communication, and informed consent. Participants with mental diseases or participants who were unwilling to cooperate were excluded from the interviews. Two physicians and one nurse from the Shanxi Province HTC were also selected for interviews. Data were gathered between December 2014 and December 2015.

We adopted a qualitative phenomenological approach to carry out the semi-structured, in-depth interviews. The researchers developed the interview outline after consulting an expert from the World Federation of Hemophilia (WFH) and conducted preliminary interviews with two interviewees.

2.2. Data collection and analysis

The interviews occurred in a single room in the Shanxi Province HTC and were recorded after obtaining the interviewees' consent, with brief transcripts taken in the interim. The researchers conducted one-on-one in-depth interviews with each interviewee, who was interviewed 2–3 times across a period of 1–2 weeks. Each interview lasted for 23–60 min. Particular techniques were occasionally used to elicit truthful and comprehensive opinions, attitudes and understanding from the interviewees, while suggestive hints were avoided. The interview records were numbered sequentially within 24 h after the interview, e.g., hemophiliacs: P1–P8; family members: F1–F9; doctors: D1–D2; nurse: N1. The transcripts of both language- and non-language-based information (such as intonation, stress and pause) were analyzed according to Colaizzi's seven steps.⁵ Statements of particular significance were extracted from the transcripts after careful reading, and repeated statements were encoded.

3. Results

3.1. Topic 1. Home therapy was generally approved

The interviews indicated that families of patients with hemophilia generally approved of the benefits of training for hemophilia home therapy. F1 said that his 12-year-old son knew how to handle emergency situations after receiving home therapy training. P2 also thought that he had learned to judge the bleeding after training instead of ignoring the numbness in his legs, which was probably the precursor to bleeding. F5 thought that home therapy facilitated early treatment. He was not experienced enough with bleeding the first time his child grew a permanent tooth, and he had to rush to the hospital for treatment. This time, he injected two shots of drugs to his son at home when faced with the same situation. P1

considered that home nursing allowed him to control his life better. He brought the drugs and previously participated in the patients' association. F8 stated tearfully that her son once thought she was to blame for his disease, but now she feels that he trusts her after treating him twice at home, and their relations have relaxed very much.

3.2. Topic 2. Concerns about the safety of home therapy

3.2.1. Lack of professional knowledge and home therapy skills

Most patients from the Shanxi Province HTC did not have an implantable venous access device. The construction and maintenance of intravenous infusion access had prevented these patients from persisting in home therapy. F1 stated that it was cruel to inject drugs into his son even after being taught by the nurse. P6 thought that professional injection was difficult to master.

Calculating the drug dose also restricted home therapy. F8 said he was not sure when to treat because it may impact the condition. P3 was also uncertain about the drug application dose after bleeding. Safe management of the clotting factor also made families of patients with hemophilia afraid of home therapy. P4 said he was always worried that a drug reaction may occur during home therapy. F2 also said that she was afraid that the poor preservation would affect her husband's treatment.

3.2.2. Lack of confidence in carrying out home therapy

The interviews revealed that long-term hospital treatment resulted in a lack of confidence in home therapy in families of patients with hemophilia. F3 stated that when his child cried from seeing a large hematoma, he wanted to rush to the hospital where he felt at ease. F7 thought that even though home therapy can be carried out immediately, he still felt scared about its effectiveness. In addition, the lack of supervision and guidance by the medical personnel made the families of patients with hemophilia anxious about home therapy. P8 stated that they got into a muddle using home therapy every time. F6 stated honestly that he lacked confidence without the guidance of professional personnel.

3.3. Topic 3. Imperfect social medical security system

3.3.1. Limited access to therapy

Approximately 90% of hemophiliacs had little income due to their disease. Clotting factor products in Shanxi Province mainly comprise imported recombinant clotting factor and domestic plasma-derived clotting factor. Recombinant clotting factor is restricted in Shanxi Province due to its expensive price (it has not been enrolled into the medical insurance system), even though it is common.⁶ P3 said: "The recombinant factor is too expensive to afford." In contrast, plasma-derived clotting factor is cheaper; however, it has been in short supply in China due to a lack of fresh plasma. P2 stated that plasma-derived clotting factor could only be bought from the HTC because they received treatment there. The interviews revealed that hemophiliacs could barely receive timely treatment and that the treatment protocols, dosage and course were also inadequate. P1 admitted that he was reluctant to use the drugs for minor bleeding, so he stopped it by using conservative treatment.

3.3.2. Underinvestment in the social medical security system

The high cost of treatment means that the majority of families of patients with hemophilia in Shanxi Province are experiencing catastrophic medical expenses. Hemophilia was enrolled in the major disease medical coverage in China in 2012. However, recombinant clotting factor has still not been enrolled in medical insurance reimbursement in various cities in Shanxi Province. P4

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