

A Model for Pain Self-Management of Patients with Haemophilia: Peer Education

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Abstract—Hemophilia is a lifelong bleeding disorder with no cure. The pain, discomfort and risks that accompany hemophilia can be physically and emotionally stressful. Effective pain management is extremely important for improvement quality of life among patients with haemophilia. While some observational studies show a lack of readiness to change and a low adherence to recommended treatments in patients with haemophilia. The study found that a positive attitude and adherence can be enhanced if people have the opportunity to interact with peers who model and reinforce adherent behaviors. This paper reviewed current pain management strategies for patients with hemophilia and focus on peer education practical examples which have been used in many areas of health, and to find peer education models are well established as a means of self-management education to encourage the patients enhance the learning of pain self-management skills and improve emotional development. Future research in pain self-management of patients with haemophilia using peer education as a strategy should properly designed RCTs to demonstrate the efficacy of this intervention.

Key Words: *haemophilia, chronic pain, pain self-management, peer education model*

I. HAEMOPHILIA AND CHRONIC PAIN

Haemophilia is an X-linked congenital bleeding disorder caused by a deficiency of coagulation factor VIII (FVIII) (in haemophilia A) or factor IX (FIX) (in haemophilia B). A bleed into a joint can cause acute, severe pain whereas the long-term effects of recurrent bleeds can lead to chronic and disabling symptoms [1-3]. Quality of life assessments identified pain occurs in 71% of patients with haemophilia and about 4% of patients with severe pain, and about 50% of haemophilia patients have more than one type of pain, in addition to joint pain. The older person with haemophilia who did not benefit from primary prophylaxis are particularly at risk for persistent pain in multiple target joints as a result of repeated joint bleeding with delayed treatment receive [4-9]. Besides being the leading cause of disability, chronic pain affects patients' overall quality of life including their ability to function and socialize, as well as impacting their family life [10]. Patients who are

in chronic pain experience both physical and emotional distress. With these feelings comes decreased activity, low self-esteem, anxiety, irritability, and even increased pain, leading to serious dysfunction with the family and social life and other non-haemophilia-related health issues [11,12].

II. MANAGEMENT OF PAIN IN HAEMOPHILIA PATIENTS

Now, there are no agreed-upon guidelines for pain management in haemophilia patients, and treatment is largely empirical. Treatment options of chronic pain vary widely, ranging from a number of pharmacologic *therapies* and non-pharmacologic treatments. Pharmacologic *therapies* may be part of a stepped-care progression from topical anaesthetics to mild analgesics to opioids. But another individuals who suffer from chronic pain may be reluctant to use analgesics. In one study, only 36% of haemophilia patients with pain were taking analgesics [13], and more patients expressed concerns about becoming dependent on and drug-related liver damage [14]. Non-pharmacologic therapy for pain management in haemophilia patients has been a mainstay of conservative treatment, include acupuncture, exercise, components of RICE, heat or cold treatments, hydrotherapy, massage and physical therapy. But great deal has been written both for and against these complementary therapies [15-21]. In fact, chronic pain in patients with haemophilia may be a lifetime, the reduced quality of life are the long-term effects burdening to patients and their families. So, effective pain management is extremely important for improvement quality of life among patients with haemophilia. However, current numbers of healthcare providers are not sufficient to provide access to the increasing demand for primary care and many primary care practices have no one available to provide the time-consuming counseling and teaching of management skills to relieve the clinical signs [22,23]. Therefore several models are developed to promote pain self-management for *haemophilics* in chronic pain may be especially needed. While some observational studies show a lack of readiness to change and a typically low adherence to recommended treatments in patients with chronic pain [24-26]. Researchers believe that beliefs, attitudes, subjective norms, self-efficacy, and intentions in the manage-

ment of pain to be the main reasons for lack of adherence [27-28]. This finding suggests that determining methods to improve adherence to recommended treatments is a necessary step to improving pain and functioning in this population.

III. A MODEL FOR PAIN MANAGEMENT: PEER EDUCATION

The study found that a positive attitude and adherence can be enhanced if people have the opportunity to interact with peers who model and reinforce adherent behaviors [17-29]. Dictionary defines peer as one that is of equal standing with another: one belonging to the same societal group especially based on age, grade, or status. Peer education is "the process whereby well-trained and motivated people undertake informal or organized educational activities with their peers" [30-32]. Peer education as a behavioural change strategy draws on several well-known behavioural theories. Such as in social learning theory, people change behavior by their individual values and self-esteem, while they have significant impacts on others [33]. The theory of reasoned action states that one of the influential elements for behavioural change is an individual's perception of social norms or beliefs about what people who are important to the individual do or think about a particular behavior [34]. To the diffusion of innovation theory, social influence plays an important role in behavior change, and the opinion leaders in a community or their society act as agents for behavior change, their influence on group norms or customs affect new behavior development [35]. However, the theory of participatory education interprets empowerment and participation of the people affected by a given problem. Peers talk among themselves and determine a course of action, leading to the behavior change [36]. According to historical records peer education can be traced back to Aristotle. There have been many peer education initiatives throughout history, working in a variety of contexts [37]. Soon after peer education was begun to prevent Asian influenza epidemic at Nebraska University in 1957 [38], it has been utilized in health projects seeking to reduce the incidence of smoking [39-43], substance misuse [44-49], violence and promotion sexual health and prevention HIV among different age groups, especially in young men [50-57]. Today, as an important and effective method, peer education is implemented in protecting from cancer and early detection of it [58-65], providing adequate and balanced nutrition, controlling blood glucose of diabetics to effect change at the individual level by modifying a person's knowledge, attitudes, beliefs, or behaviours [66-71]. Besides, it is used as well in the immigrant women to increase the level of physical activity [72]. Current the power of peer education and social supports in control chronic pain has been confirmed [73,74]. Peer education which will provide sharing feelings and experiences by peers to other patients with chronic pain to make living with chronic pain easier. Furthermore, the strategies help to promote pain self-management in patients with chronic pain. Sandra and colleagues reported two randomized clinical trials in a Chronic Pain Self-Management Program (CPSMP), the research studies found that, on average, people who have participated in the peer support have more vitality or energy, less pain, less dependence on others, improved mental health, are more involved in everyday activities, and are more satisfied with their lives compared to those who have not taken the program.

Hemophilia is a lifelong bleeding disorder with no cure. The pain, discomfort and risks that accompany hemophilia can be physically and emotionally stressful. Education about safe pain management will help prevent undertreatment of pain and the resulting harmful effects. Many patients and doctors feel the best 'cure' is powerful medication, however it is important to realise that in many cases of chronic pain, medication alone may cause more problems than it solves. And while nondrug techniques pose minimal safety issues, the efficacy and safety of many of the non-pharmacologic approaches to pain management have not been demonstrated in randomized, controlled clinical trials. Peer education is to provide an environment to encourage the peer participants enhance the learning of pain self-management skills and promote growth of self-esteem, self reliance, emotional development, and creativity. Healthcare providers should recognize and understand the importance of peer-based behavioural strategies to improve patients with haemophilia effective pain self-management for these patients [75,76]. Now a longer-term (four months) study will determine whether use of peer mentorship to promote effective pain management in adolescent. The protocol for this new study has been approved by an independent ethics committee and is published in BioMed Central Public Health [77]. A trial of a peer education intervention will be carried out in Shanxi haemophilia treatment center, through using trained haemophilics who have successfully learned pain management skills as peer educators, the educators will help all participants feel understood and cope with problems, enhance engagement in and adherence to chronic pain treatment programs. We hypothesize that haemophilics receiving the peer education intervention will report better to understand and cope with pain and improve overcome the harmful effects of stress skills, as compared to patients with haemophilia who do not receive the intervention.

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