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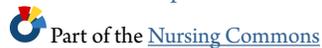
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Development, implementation, evaluation and validation of a haemophilia nurses' education program in South Africa

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# Chapter 1

## Background to the Study

### 1.1 Introduction

This study evaluated a purpose-designed program to educate Registered Nurses (RN) in South Africa (SA) about the care and management of people with haemophilia. Since South Africa is a developing country, factors such as poverty, illiteracy, inequality and poor infrastructure were considered in designing a program for RNs concerned with haemophilia care. In a context where appropriate care is often difficult to find, this congenital bleeding disorder has the potential to be fatal and to have effects well beyond the immediate sufferer.

In this chapter the nature of the disease known as haemophilia was considered. The study aims were then presented and the theoretical underpinnings introduced. The significance of the study was also explored.

### 1.2 Haemophilia

Haemophilia is a rare, genetically linked lifelong bleeding disorder for which there is no cure. Globally, haemophilia occurs in 1 in 10,000 live births (World Federation of Hemophilia, 2012). Essentially, proficient management of the disorder is the only means to avoid severe morbidity and ultimately death. The disorder is characterised by prolonged bleeding due to a missing clotting protein which prevents the formation of a solid robust clot. Predominantly affecting males, haemophilia is an inherited genetic disorder carried on the X chromosome (World Federation of Hemophilia, 2012). In approximately 30 percent of haemophilia births, for reasons which are unclear, a spontaneous mutation occurs and a child is born with haemophilia (World Federation of Hemophilia, 2012). Haemophilia can

be classified as severe, moderate or mild. In the most severe form, bleeding can occur unexpectedly without reason or trauma. An untreated bleed, which can progress for days or weeks, can have catastrophic results with significant morbidity and mortality and inflicting severe pain (World Federation of Hemophilia, 2012).

The most common sites for bleeding are into joints and less commonly in muscles and organs such as the brain or kidneys. Uncontrolled and repeated bleeding into joints causes acute pain and results in severe osteoarthritis and crippling. Untreated bleeding into muscles can result in nerve damage and permanent loss of function and bleeding into organs such as the brain can be fatal. Without treatment most individuals with severe haemophilia will not survive past adolescence (World Federation of Hemophilia, 2012).

Haemophilia and its consequences have been known to physicians for hundreds of years. The first documented episodes of excessive bleeding were described by the Jewish community in the second century when deaths occurred from severe bleeds following male circumcision (Ingram, 1976). An Egyptian physician, Albucasis, in the tenth century also observed that this bleeding tendency was linked to familial tendencies. Furthermore, an Arabic physician in the twelfth century suggested that cautery was the best method to treat excessive bleeding, thus providing the first record of effective treatment (Ingram, 1976). At the end of the eighteenth century, a New York physician Dr John Otto published his observations of haemophilia, hence provided a sounder understanding of the phenomenon. Otto wrote of a woman with no symptoms of bleeding who had birthed several sons all of whom had excessive bleeding tendencies. From this observation he concluded that the disorder was sex-linked and related to premature death (Lee, 2010). These discoveries paved the way to improved management and care.

### **1.2.1 Treatment of haemophilia.**

Haemophilia is a deficiency or absence of clotting proteins called factors. The clotting mechanism relies upon there being sufficient properly functioning factors to form a clot. Principally, the treatment for haemophilia is to replace the missing clotting factor (World Federation of Hemophilia, 2012). Factor is separated from donated blood plasma in a complex manufacturing process and is therefore expensive to purchase (Muller, 2004). Many developing countries cannot afford to purchase factor replacement so people with haemophilia (PWH) in these nations are denied optimum management and treatment. In contrast, PWH who are citizens of developed economies have access to recombinant factor replacement; a synthetic product (World Federation of Hemophilia, 2012). This differentiation is important as in previous years the plasma-derived product was manufactured using plasma that was infected with blood-borne viruses such as the Human Immunodeficiency Virus (HIV) and hepatitis. These viruses contaminated the blood supply and therefore infected the factor replacement. In South Africa (SA), there is sufficient factor replacement available for all PWH, however the factor is plasma-derived, and it therefore poses the risk of transmitting blood-borne viruses.

Since haemophilia is a rare disorder, there is scant information in relation to care and management available in medical or nursing textbooks. As a consequence, nurses' and doctors' knowledge of haemophilia is limited. Additionally, there is a paucity of information in relation to the existence of haemophilia nursing education programs in the public domain. There is, however, a small, albeit slowly-growing, body of literature about various aspects of haemophilia nursing care written by nurses, for example the WFH Nurses' Committee produced a Power Point program outlining the basics of haemophilia

nursing (WFH Training module for nurses, 2007). Nevertheless, the paucity of literature makes the task of seeking information about haemophilia and its management difficult.

Education of nurses serves multiple purposes. Education is essential to equip nurses to provide appropriate and competent care to the patient and family. Regardless of geographical location, every human being has the right to safe and quality health care. Supporting better understanding and knowledge of this concept is the notion of patient reported outcome measures (PROMS). The Australian Commission on Safety and Quality in Healthcare takes the PROMs patient opinions seriously. Williams, Sansoni, Morris, Grootemaat and Thompson (2016) were commissioned to provide a literature review to learn how PROMs are utilised in health systems similar to Australia's. This aspect of learning from the experiences of others will help to ensure that the best care is available to Australian patients.

Education by nurses is expected and presents in different scenarios: Mentoring and clinical instruction of student nurses by experienced nurses in the practice setting is important to help bridge the theory-practice gap. The nurse also plays a large part in the education of the patient and family to help them understand their disease condition and the steps needed to provide self-care. Additionally, nurses play a significant role in health education by promotion and education about health interventions and disease prevention (Wills, 2014).

It is vital that nurses comprehend the significance of patient education. However, according to Aghakhani, Nia, Ranjbar, Rahbar, Beheshti, et al., (2012), ineffective education provided by the health care system is the most common complaint made by patients. Education is essential to assist patients to accept and adapt to the physical and psychological changes related to health. Despite having received information in relation to their condition,

patients demonstrate low levels of knowledge and therefore understanding about their health issues and relevant self-care behaviour (Aghakhani et al., 2012). Miller (2016) undertook a meta-analysis of studies that explored the correlation between patient health literacy and adherence to medication and non-medication interventions. Findings from this study showed that a health literacy intervention, that is education, is more effective in improving patient's health knowledge (literacy) and adherence to treatment. Thus, an educated patient is more able to problem solve, improve their health status, and practice preventative measures (Beta, 2014).

This aspect is a factor when considering chronic diseases, such as haemophilia, as the transition from paediatric healthcare to adult care is an important step for adolescents and young adults. Empowerment of this group to enable a successful transition to self-care is central to augment chronic healthcare management. According to Coyne, Prizeman, Sheehan, Malone and While (2016), successful transition seems to assist with observance of appointments, patient satisfaction, parent satisfaction, autonomy, and balanced disease control. These are precisely the factors likely to contribute to PROMs.

In view of the lack of nurse education about haemophilia, the role of the haemophilia nurse plays a vital part in the management of these patients. In countries where haemophilia treatment is not well-funded, such as developing countries, conservative measures can be employed to assist reduce the severe consequences of bleeding episodes. Simple interventions such as rest, application of ice packs, compression bandages and elevation of the bleeding limb will assist to slow the bleeding and promote clot formation at the site of the bleed. These measures can be implemented in the hospital setting but can also be taught to the PWH and his family so they can be applied at home immediately when bleeding occurs.

### **1.2.2 Education of the nurse to manage the care of the PWH and family.**

In developed countries such as Australia, education of the PWH and family is a major priority. In Australia, care of the PWH is implemented using a team approach and referred to as comprehensive care. This approach involves a multidisciplinary team of health professionals and is considered the optimum choice of care for PWH (World Federation of Hemophilia, 2012). The team is located at a Haemophilia Treatment Centre (HTC) which is usually based at a major teaching hospital. The core team members consist of a haematologist with expertise in bleeding disorders, a haemophilia nurse, a physiotherapist and a laboratory scientist with expertise in diagnosing bleeding disorders in the laboratory. By concentrating services within one area, any staff members who are new to managing PWH have immediate access to appropriate expertise in the diagnosis and management. Staff members employed in haemophilia care are encouraged to attend conferences and scientific meetings to stay abreast of new research. Experienced staff at other HTCs such as nurses and physiotherapists, provide mentoring and backup.

As outlined above, education of the PWH and their family plays a vital role in the health of the PWH. Therefore, the role of the haemophilia nurse is central. In the absence of factor replacement, conservative measures are taught to the PWH and his family. Furthermore, education can include preventative measures to avert a bleeding episode, such as avoidance of common medications such as salicylates. Advice is given in relation to physical activities which facilitate physical fitness without the danger of inflicting serious injury. Advice about when to contact the haemophilia centre if the bleeding progresses or an emergency occurs, for example after trauma, is provided. Invasive medical procedures such as surgery should never be attempted without adequate factor replacement and the PWH and his family need detailed education about self-advocacy to prevent cataclysmic

bleeding in these circumstances (Australian Haemophilia Centres' Directors' Organisation, 2016). The transition to adult care and therefore self-management, is an important step, guided by the haemophilia nurse. Although haemophilia is a significant health issue, if properly managed, with factor replacement, the individual can lead a predominantly normal life. Prior to factor replacement being available, most people with severe haemophilia were unlikely to live beyond adolescence.

### **1.2.3 Management of PWH in SA: The education imperative.**

In SA there are situations which prevent all PWH accessing appropriate treatment. Although SA has sufficient factor replacement to treat the haemophilia population, approximately one-third of affected individuals have not been diagnosed, so remain untreated (verbal communication with Professor Karabus, the administrator of SA's haemophilia database). Despite being diagnosed and being provided with a treatment plan, however, good outcomes are not always guaranteed for PWH. The treatment plan may be either ignored by staff when the PWH presents at hospitals and clinics, or PWH are not treated appropriately. Substandard management of episodes of bleeding can have catastrophic outcomes such as amputation of limbs, brain damage and death.

The SA haemophilia coordinators, considered expert nurses commonly refer patients to the HTC's for diagnosis, genetic counselling and education (of PWH, caregivers and health professionals); and lobby for treatment facilities and programs. In addition, these nurse coordinators are part of an outreach program which was developed to provide support to RNs who participated in the HNEP. It was these coordinators who suggested that by educating nurses in haemophilia management, outcomes for PWH could possibly improve. It was further indicated that education would be of particular benefit to nurses who work in

health facilities in regional and rural areas geographically distant from HTCs. Education is therefore fundamental to furthering competent and confident nursing care of the PWH.

Unfortunately, there are many issues that conspire against adequate provision of healthcare in developing countries. Munyewende, Rispel and Chirwa (2014) conducted a study to investigate barriers to health provision in SA. They found purchasing of material resources such as pharmaceuticals, medical equipment, refrigerators to correctly store the drugs and maintenance of buildings was inadequate. Frequently there were insufficient financial resources to ensure adequate staffing levels of doctors and nurses in wards and clinics, clerical and maintenance personnel.

Additional significant socio-economic issues also exist in the population, such as poverty, unemployment, and illiteracy. The social determinates of health such as adequate housing, sanitation, clean water supplies and malnutrition impact on the health of the socially disadvantaged of SA. The ability to achieve adequate medical support is also hampered by the long travel distances, inefficient public transport, poorly maintained roads, unreliable or absent power supplies and inadequate telecommunications. These problems pose barriers to the provision of health services, especially in remote and regional locations and provinces.

Finally, many developing countries have a history of various degrees of colonisation and government which were not designed for the well-being of the indigenous population. In SA, colonialism followed by apartheid discriminated against groups and communities on racial grounds, thus preventing marginalised groups from acquiring education in relation to decision-making and governance issues. Once the old regimes were dismantled, many of the government employees who came from these disadvantaged groups were expected to assume management roles. Consequently, these employees were inadequately prepared

which resulted in policies and projects either not implemented or poorly managed. Indeed the knowledge of how to govern and implement health policy was not available, which lead to inadequate service across many areas of health provision.

#### **1.2.4 Resources to treat haemophilia.**

Clearly the gap between developed countries and developing economies in their ability to provide haemophilia care is wide, and varies from nation to nation. Some governments do not attempt to address chronic disorders such as haemophilia because they perceive it to be too costly and too difficult. In more recent times, Tagny, Moudourou, Ndoumba, Mbanya (2014) published an article about haemophilia diagnosis and care in Cameroon describing the infancy of haemophilia management and the limitations due to lack of resources. However, this does not mean that the PWH in these countries need to feel abandoned. The importance of educating the individual with haemophilia, their family and health care providers about how to manage haemophilia with limited resources, that is, factor replacement, is espoused by clinicians in many developing countries. Chandy (2005); Chuansumit (2003) and Shamsi and Chughtai (2001), clinicians working with PWH in developing countries, agree that education of clinical staff is the key to delivering better haemophilia care and thus reducing morbidity.

#### **1.2.5 Development of the Haemophilia Nurse Education Program in SA.**

In 2000, the SA National Department of Health (SANDoH), conducted a survey which revealed that it would be advantageous to establish a haemophilia care program in SA. One of the terms of this proposed program was that the key to provide a high standard of care for PWH could be achieved by training nurses to manage PWH and their families.

After some delays, in 2002 planning for the Haemophilia Nurse Education Program (HNEP) began in earnest. As no ready-made curriculum was available, the four haemophilia coordinators, three based in SA and the author of the present work from Australia, set about writing the curriculum, utilising their extensive clinical knowledge. The first HNEP was implemented in the same year. Since its initial creation and development, it was realised that the program needed to undergo a formal evaluation. Evaluation is an essential component of any teaching program (Worral, 2008) since it is imperative that the nurse educator determines whether learning has occurred and to what level. A robust evaluation process to determine whether the HNEP has been effective in improving the knowledge of haemophilia management needed to be undertaken.

### **1.3 Aims and significance of the study**

Since its inception in 2002 and to the point of this research, the HNEP had been offered for 15 years. Within that time no comprehensive evaluation process had been completed. Formative evaluations had been conducted at the completion of each program however, the appraisal was simplistic and did not gather the sort of data required to facilitate a deeper analysis of content and delivery. It was recognised that a robust evaluation would be beneficial to the programme in terms of its on-going credibility and funding requirements.

The aim of the study is to firstly, determine if the introduction of the HNEP in SA has improved the care of a PWH and their family. Secondly, to determine whether the education program changed the participants behaviour and attitude toward the PWH and finally, whether attendance at the HNEP had increased the confidence of the nurses to manage a PWH and advocate for the PWH and family. The aim of this present study therefore is to explore whether a transfer of knowledge, skills and attitudes occurred and

whether it has increased the confidence and competence of Registered Nurses (RNs) in SA to manage the care of a PWH.

The study is significant in both its theoretical and applied endeavours. The significant theoretical aspects include firstly, the use of Leininger's (1998) Cultural Care Model to help the creators and organisers of the HNEP to take into account the multiple cultures in SA. Secondly, the utilisation of the Kirkpatrick (2006) Four Levels of Evaluation, which guided evaluation of the responses from the RN interviews to be presented as meaningful data. The significant applied aspect takes account of the fact that cultural differences amongst PWH in SA are varied. Teaching nurses about generalised haemophilia care, while taking account of cultural aspects of the individual, would likely ensure that there was improved compliance by the PWH and his family. The RNs were instructed that to be mindful of the particular cultural mores among the patients they manage and the context of the situation facilitated the ability of the PWH to be compliant.

A further significant aspect of the program was to educate nurses about basic haemophilia care. This was important, especially in regional and remote areas, as it assisted to overcome the lack of medical personnel in these areas. The haemophilia-trained nurse can assess the risk to the PWH and has the capacity to refer on to, or seek advice from, a Haemophilia Treatment Centre (HTC) at the same time ensuring that appropriate treatment is initiated promptly.

#### **1.4 Study research questions**

Based on the foregoing discussion, the following questions will be answered by the researcher as a result of having completed the study:

- a) What factors need to be considered when developing a purpose-driven haemophilia curriculum for nurses in South Africa?
- b) What factors need to be considered when implementing a purpose-driven haemophilia curriculum for nurses in SA?
- c) What transfer of knowledge, skills and perceptions is likely to occur as a result of training received via a purpose-driven haemophilia curriculum?
- d) How robust is a purpose-driven haemophilia curriculum when subjected to expert evaluation?
- e) On the basis of feedback received for research question four, what are the implications for a future iteration of the HNEP?

### **1.5 Chapter summary**

In summary, this introductory chapter presented a brief overview of haemophilia. It acknowledged that education of nurses is an important aspect of efficient and effective management of haemophilia but contested that such is received by many nurses. In developing countries such as SA, PWH are not proficiently managed due to lack of recognition and understanding of the disorder by healthcare professionals. To address this problem, a decision was made by health authorities to approve a nurses' education program. This program, the Haemophilia Nurses' Education Program (HNEP), was developed and implemented by four haemophilia nurse coordinators in 2002. Although the HNEP had been in operation for fifteen years, a formal evaluation had not been undertaken. The aim of the study was to address this omission.

In Chapter two, the term haemophilia is defined. Also considered is the literature in relation to the history of haemophilia, its inheritance patterns, clotting mechanisms, diagnosis, potential complications, treatment regimens, and the nurses' role in caring for the PWH in the SA context. In Chapter three the creation, development and implementation of the HNEP is explained within the context of culturally sensitive care approaches. Aspects of epistemology, theory, conceptual design and method are elaborated in chapter four.

Chapter five describes the method of the research in detail. Chapters six and seven contain the results of the interviews from the haemophilia coordinators and the RN participants respectively. Chapter eight presents three critical incidents in support of the RN's perspectives. Chapter nine relates the data from the expert nurse educators who examined the haemophilia resource package and Chapter ten refers back to the theoretical framework in discussing the work of the four theorists to whose work reference has been made. The final chapter, Chapter eleven, presents the study conclusions and recommendations for further research.