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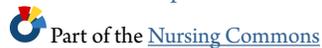
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Development, implementation, evaluation and validation of a haemophilia nurses' education program in South Africa

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## **Chapter 10**

### **Discussion in Relation to the Theoretical Framework**

#### **10.1 Introduction**

This chapter presents a discussion of the findings from Chapters six to nine (Parts One, Two and Three respectively). The discussion is structured around the theoretical framework presented earlier in Chapter four (Figure 4.2), namely, taking into account the models proposed by Leininger, Watson, Knowles and Kirkpatrick.

#### **10.2 Leininger's Culture Care Theory (CCT)**

Leininger's (1997) contention that a culturally competent nurse respects the cultural beliefs of an individual in planning and implementing their chosen health outcomes underpinned the HNEP. MacFarland and Eipperle (2008) highlighted how culturally competent nursing care embraces a holistic approach and is not a separate entity in the care of an individual but an integrated element of the entire care package. Such an approach encompasses the physical, mental, emotional and spiritual care of PWH and their families.

Leininger chose the term "enabler" to depict the diagrammatic form of the CCT (Chapter 4, Figure 4.1). While the researcher acknowledges the holistic approach to the CCT, only those elements that were congruent with the data collected have been referred to in the present study. These elements focus on the influencers that were found to impact on the HNEP and the nurses implementing haemophilia care, of which environment, economics, education and technological factors were the major influences. Each of these is now considered.

### **10.2.1 Environment.**

Leininger (2002) refers to the environmental context as the entirety of events, situations or experiences that influence people's understandings within a geographical, spiritual, socio-political and technological setting. Participants lamented the fact that they could be providing a far more effective service if extra resources were provided. They were however, realistic in recognising that such would take a long time to eventuate. The reality of existing in SA's townships exposes the vulnerable, such as black women (including nurses) and PWH (especially children, the elderly, the disabled), to gang violence, no running water or sanitation to their homes, unreliable power supplies and unpaved, potholed and uneven street surfaces. Furthermore, although health centres are available to many of these townships, the poorly-maintained clinic buildings, overcrowding due to large numbers of patients and broken equipment inhibit the ability of staff to deliver a satisfactory level of healthcare. Nevertheless, nurses do their best they can and HNEP training allows them to operate at an optimum level given the prevailing conditions.

The potency of Leininger's transcultural nursing theory was evidenced by some of the stories related by the PWH during the case study training part of the HNEP. Stories confirmed that PWH possess their own set of shared values such as beliefs, language, ethno-history and behaviours. An example of this culture in action included reference to an active bleeding episode being [termed a "bleed"], where a PWH knew how to manage his condition more effectively than healthcare workers (self-advocacy) because they had learned to look after themselves and attend to their own needs. An example of ethno-history being exhibited was at times when there was no factor replacement available and so PWH avoided culturally mediated behaviours such as refraining from games (that were likely to cause a trauma or damage to a joint) and delaying procedures such as circumcision. Aspects

of the HNEP course covered the need for nurses to be sensitive to cultural mores and to consider these as far as possible when delivering treatment.

### **10.2.2 Economics.**

There was one finding from the study that articulated especially well with Leininger's culture care contentions. This related to "economic factors" in her "Sunrise" model (Figure 4.1, Chapter 4). The study found that socioeconomic factors, especially unemployment, consequent poverty and sub-standard housing, play a huge role in the health provision that is received. In a context of disadvantage, the poor appeared to create their own "culture" and one to which the haemophilia nurse carers had to earn the right to be invited. A culture of suspicion tended to prevail and this made the nurses' job more difficult than it might otherwise have been. Such economically induced inequity is difficult for a government to remedy given the economic fragility of the country itself.

The ability of government to generate sufficient funding to deliver infrastructure and other determinates of health appears to be hampered in developing countries. South Africa is no different in this regard. Added to this are unexpected outbreaks such as HIV and cholera which further deplete available economic resources. Funding restrictions that impacted directly on the HNEP were varied. One example was the difficulty in obtaining payment from the provincial health departments to fund the cost of accommodation and registration for the nurses to be sent to the HNEP. As one coordinator observed, "the course that I had the previous year was quite hard because I think for the provinces to pay was quite an issue" (Coordinator L). A further economic impediment was the inability of PWH to access clinics because they had insufficient funds to pay for public transport.

### **10.2.3 Education.**

Through the HNEP education program, the RNs reported an increase in their skills and knowledge about haemophilia, which in due course changed their perceptions and opinions of PWH. This is perhaps the most pleasing aspect of the course – that information provided had transferability, longevity and the ability to create a change in consciousness. Participants not only became culturally aware of the living habits imposed upon PWH but actively sought to advocate on their behalf. One nurse participant applauded that fact that the HNEP had made a great deal of difference to how she approached her task of providing care for a PWH:

Mine [nursing colleagues] are very bad, some of the nurses, even myself before I did the course, there was this attitude of “who are these [PWH] coming in and ask them [nurses] why did they have to come for this time”, unaware they need immediate treatment when they come (GS1/N3).

Concern about nursing education was expressed by one expert educator who had personal experience of teaching RNs in SA. The concern related to the level of understanding by RNs of science topics. This was a justified consideration given that the HNEP included aspects such as the physiology of coagulation and genetics. Another expert expressed the opinion that the level of academic competency could be ascertained by perusing the regulation and accreditation standards in nursing education in SA. Unfortunately, although a strategic plan for nursing education in planning and practice in SA was mooted in 2013/4, with the aim of implementation in 2015, it has still not been instigated (Armstrong & Rispel, 2015), so up-to-date requirements for nursing standards are not available at the time of writing.

Armstrong and Rispel (2015) also found that there is a shortage of nurse educators, further adding to the burden of providing training. Additionally, they found that nurse educators lacked modern teaching skills and grappled with resource limitations similar to health facilities, such as access to technology. Further challenges reported by the researchers included weak leadership, poor teamwork, lack of emphasis on PHCs and competencies that did not align with patient needs. Such a perspective resonates with one coordinator's experience:

Without haemophilia education they will always tell you it's too expensive .... they were trying to save by giving him factor then he would be sent back home. The hospital manager was very angry saying No! No! No! This is too much for a knee bleed and this child's not even getting better (Coordinator B)

When surveyed about who they believed was responsible for nursing not being prioritised by health entities, nurses blamed the SANC who seemed disinclined to liaise with other government bodies, and the SANDoH for lack of planning, coordination and implementation. The provincial health departments who are responsible for "grassroots" health facilities such as PHC clinics were considered fragmented and low in morale (Armstrong & Rispel, 2015). It is in this environment of poor nursing governance and lack of health resources that the RNs practice what they learnt from the HNEP. Despite some of the participants not having a preferred level of education, Coordinator B indicated that the HNEP lecturers "try to make sure everyone understands. That person will leave with so much confidence and they will learn more when they get to their [clinical] area".

Already discussed are the education levels of the four haemophilia coordinators of which two had no university-based education. This deficit resulted in an incomplete understanding of the importance of evidence-based practice supported by research,

references, teaching and learning strategies and evaluation of teaching programs. However, the HNEP was created originally by four haemophilia nurses with extensive clinical skills in haemophilia care. It was encouraging to see theory and practice were beginning to synergise in the minds of the coordinators. This process also meant that as time progressed, the learning pattern that had now been established would likely be embellished into the future. This would eventually enable them to perhaps offer a train-the-trainer type of course to help address the lack of haemophilia nurse educators. It was heartening to hear Coordinator B, who had joined as a HNEP lecturer after completing the HNEP course, saying “I am telling you the people who are giving the education are really good”. In time, she may become just as good herself.

#### **10.2.4 Technology.**

In Leininger’s sunrise “enabler” model, technological factors encompass sophisticated machinery such as imaging technology, computers, mobile telephones and computers for databases. Sadly, the RNs in SA did not have access to much of the technology that is associated with health care in developed countries. Almost without exception though, they did have mobile phones and used them extensively in their work with PWH. After-hours phone calls from a PWH and communication of problems involving these patients from work colleagues came up regularly in focus group discussions. One RN articulated the need for her mobile phone, “so the doctors know I am the link, the link to other communications” (F/G 3, N2). The national haemophilia database is electronically managed and updated regularly with new information about PWH. But the use of computer technology is not always available to nurses caring for PWH, especially in the more remote areas without internet coverage. When computers were available, they required required servicing and help-desk assistance. Resolution may take weeks or longer in rural areas.

Consequently, the nurses often have to work around the technology in offering the required service to the PWH.

Governance is the term used to describe the culture and institutional environment in which the norms and values of public affairs are administered in a transparent, inclusive and responsive manner (UNESCO, 2016). Findings from this present study have added further detail to Leininger's sunrise "enabler". Leininger's model does not specify governance and management as influencers and her culture care theory and the sunrise enabler does not refer to the impact of poor governance on health. It could be argued that politics and legal factors encompassed in the sunrise enabler are more closely related to the making of policies rather than the oversight of operational aspects of policies. Sound governance is considered a necessary condition of an environment in which poverty reduction and sustainable human development can thrive. Good governance was deemed one of the United Nations Millennium Development Goals aimed at promoting participation, transparency, accountability, effectiveness, equity and lawfulness (United Nations Educational, Scientific and Cultural Organisation – UNESCO, 2016). Management is a component of governance, principally in place to operationalise the planning, implementation and monitoring of organisations within the guidelines set by the governance bodies. In developed countries this is usually undertaken with the assistance of sophisticated technological software with accountability structures being built into any governance protocol. In SA, creating a comparable mechanism of due diligence still has some way to go. Consequently, the trickle-down effect of potential benefits to grassroots level, such as haemophilia nurses, often does not occur.

It was evident from the present study that broader cultural context is an extremely important factor when preparing to support a PWH. As such, the decision to give it strong

emphasis in the HNEP was warranted. In fact, given the insights of several of the RNs and expert evaluators, it is clear that in further iterations of the HNEP, culture per se will need to be further differentiated. It is a mistake to define culture by country, especially in the SA context where a variety of cultural nuances exist.

### **10.3 Watson's theory of human caring.**

Watson's theory encompasses components of nursing in its broadest sense and is applicable to all roles and specialties. Patient advocacy, a guide for ethical practice, recognition of the importance of patient safety and providing a framework for nurses to self-care so they can care for others such as patients, are all part of the application of this theory. Each of these factors was a topic of discussion for HNEP participants.

The application of the *caritas* processes in teaching and learning is evident in the HNEP. As the lecturers were cognisant of the constraints under which many of the participants worked, they understood the difficulties these nurses encountered in relation to the work environment, which often prevented them from engaging with patients and colleagues in a positive manner. In this regard, it is opportune for the researcher to acknowledge her lack of personal experience of working in the SA health environment, and to express her gratitude to the three coordinators who, in compensating for this deficit, added a tremendous amount to the creation and delivery of the HNEP. Although involved in numerous short-term visits to developing countries to lecture, and living in a developing country for some years, this was insufficient for the researcher to develop an in-depth understanding of the precise nature of "caring" as found within the SA cultural context. The lesson to be learned here is the need for engaging in collaborative projects if optimal success is to be achieved. There is little value in an overseas researcher simply coming into a

country and telling the Indigenous population what needs to be done and how to do it. Such an approach is not only culturally offensive but smacks of patriarchal arrogance.

The second and third of Watson's key concepts, namely, transpersonal caring-healing relationships and the caring moment, which describes the one-on-one nature of the nurse-patient occasion, were demonstrated to the participants by the Indigenous haemophilia coordinators who related scenarios about PWH; and by participants directly observing the relationship that had been built between the haemophilia coordinators and PWH.

#### **10.4 Knowles' adult education theory**

Knowles' (1975, 1980, 1990; Bastable, 2008) six assumptions (Chapter 4, Section 4.3.3) were integrated into the HNEP in a variety of ways. Based on the assumption that most of the learners were unfamiliar with haemophilia and its management, it was seen as essential that the initial days of the HNEP were conducted using a didactic approach supported by Power Point presentations and the lecturers' anecdotal vignettes. Thus, by allowing "interruptions" to help the learners clarify new knowledge, the lecturers encouraged the learning process. Each participant was encouraged to comprehensively introduce themselves at the beginning of the HNEP. This allowed the individual to become known to the rest of the group and have their experiences acknowledged, further enhanced by the implementation of group work in the later part of the program encouraging participation and collaboration. When the adult learner is exposed to new information, they are keen to see how this new information can be applied to their own situation, or what it would look like when viewed through the new lens. The HNEP provided the opportunity for the nurses to see how the new information about haemophilia can be applied through interviews with a PWH about the lived experience of haemophilia.

Further, when conducting the HNEP, the lecturers allocated case studies to each group, providing the participants with real-life scenarios which were linked to personal and client goals. Student groups were asked to “diagnose” a specific problem and to prepare a response. Each group then presented their opinion of the problem and their solution to the rest of the class. This setting accepted that mistakes may take place – considered by Knowles as part of the learning experience – which were corrected in a non-confrontational manner. Also, interaction with patients and their lived experience provided opportunities to apply theoretical knowledge to practice, helping to consolidate the new learning and gain confidence. Throughout, the lecturers showed respect by acknowledging the experience that the adult learner brought to the training and taking an interest in the individual student which reinforced student participation. Nurse feedback revealed an appreciation for the respect shown to them as experienced nurses and adult learners. The nurses stated they had learned a great deal about haemophilia and its management, with one nurse stating “now I’m sure what I’m talking about” (F/G4, N2). Such respect translated into empowerment when the nurses volunteered that post-HNEP, they felt secure in their knowledge about haemophilia treatment, were certain of treatment options they would now endorse, and were prepared to advocate more vigorously for the PWH. One nurse volunteered to the researcher that “after the training we become so effective...to say things you know to other people [coordinators]...and they appreciate them” (F/G3, N2).

### **10.5 Kirkpatrick’s four levels of evaluation + ROI**

The five levels of the Kirkpatrick (1975; Yardley & Dornan, 2012) model of evaluation are now discussed in relation to the data obtained from the focus groups and interviews.

### **10.5.1 Level 1: Satisfaction.**

The RNs were asked whether, immediately upon the conclusion of the HNEP, they were satisfied that the program had delivered sufficient information for them to believe that haemophilia had been well explained during the training. Without exception, all the participants agreed that the HNEP had provided the content of the curriculum and consequently had increased their knowledge about haemophilia and its management, with one participant's comments representing a conglomerate of views, "it made me more aware of the patient's physical and emotional needs" (F/G4, N4). Furthermore, one-third of the RNs stated they felt empowered by the knowledge they had gained. Such findings bode well not only for the continuation of the HNEP but for haemophilia practice and training in SA. It is once people feel competent and see that they are being supported that effective change becomes a real possibility.

On conclusion of the HNEP the RNs were asked to complete a feedback form which evaluated the program (Appendix C). This evaluation enabled the organisers to make changes so that subsequent programs were more efficient and would meet the needs of future participants. Being followed up several years after the RNs had completed the HNEP allowed them to examine their HNEP training with the benefit of hindsight. Not one of the RNs expressed any doubt about the value of the curriculum and its usefulness, with one stating "the haemophilia course was a very good thing because the doctors still come to me and the unit manager, [saying] we have a child bleeding". Such positive affirmation indicates that the HNEP curriculum is meeting the real needs of RNs, namely, enabling them to provide effective haemophilia management.

### **10.5.2 Level 2: Learning.**

One-quarter of the nurses expressed that prior to the program, that they had no knowledge of or pre-training in haemophilia care. There were 26 comments about how the acquired knowledge had been transferred to clinical practice. The HRF was mentioned frequently by the participants as a useful reference tool, with one nurse stating “the course was well-structured and all the info I was given there, I use it daily with my patients” (F/G2, N1). This file was also a valuable resource for fellow colleagues, including doctors. Although an obvious comment, one might propose that the RNs would be unable, or lack in confidence, to implement haemophilia management and treatment to PWH had they had not learnt sufficiently well about haemophilia. Their comments and anecdotes about PWH demonstrate that they had a comprehensive understanding of the needs of PWH and their families: “Now you find that when there is a haemophilia you actually like to include their whole family because if the haemophilia patient wife is pregnant then you must know .... What if the child bleeds?” (F/G 4, N4). Post the course, nurses appeared to be asking all the right questions and showed an awareness of the intricacies of providing haemophilia care.

### **10.5.3 Level 3: Changed behaviour.**

Advocating on behalf of PWH was acknowledged by 18 nurses, with 19 stating they felt competent to manage PWH. One third of the nurses recognised that their scope of practice had broadened after they had completed the HNEP. This is valuable information which substantiated that the RNs felt competent and confident in the management of PWH. Many participants exhibited a realisation that something cannot just be done for a PWH, but that they needed to ensure that it did in fact happen. One nurse indicated that when she had spoken with a patient recently she closed the session with the comment, “so I’ll do a follow-up, on Monday” (F/G2, N2). This is immensely encouraging, knowing that many nurses

realised that care extends well beyond merely the initial encounter. A further example of a nurses' change in behaviour was her realisation that in certain cases she needed to refer the patient. She indicated that rather than dealing only with the immediate symptom, she was able to explain to the PWH how the bleeding was impacting on their health and why they needed to attend the hospital: "so now, after I have done this course I can explain to them [PWH] what is going on and I refer them and they go to hospital" (F/G3, N4).

#### **10.5.4 Level 4: Results.**

The RNs stated that attending the HNEP had facilitated a better service for PWH in the clinical setting. Indicators such as decreased lengths of stay for inpatients, and new haemophilia clinics being established, were given as quantifiable examples of results. Proactive action was also being taken to obtain better results: "I phone the casualty department to inform them that a PWH is on their way, so then they usually get treated quickly" (F/G 4, N2). Unfortunately, some nurses expressed the view that management at their workplace was uncooperative; for example, not releasing the nurse to make an outreach visits to PWH. In an environment where nurses are attempting to provide the best possible care under already compromised conditions, such an attitude may preclude more positive results from being realised. It needs to be remembered though, that administrators and managers are also under pressure. As mentioned previously, their budgets simply may not allow them to offer the sort of nurse support that would be ideal and that might be their preference.

#### **10.5.5 Level 5: ROI.**

The fifth Level, ROI, is related to the cost of the training against the benefit to the workplace. Intangible benefits, which consisted of results which cannot easily be easily quantified, are part of the assessment of ROI. For example, the RNs feeling that they were

valued by PWH and their colleagues; bringing new knowledge and practice to their workplace; and having greater enthusiasm for their job, are extremely important and desirable employment characteristics. Eight nurses reported an increase in job satisfaction and that they felt they were an influential nurse in their workplace. There were thirty-two responses about their teaching role, with RNs educating nurses, doctors, PWH and their families and the community about haemophilia and as a result, witnessing an improvement in the care of the PWH.

The comments by the RNs pertaining to the HNEP were highly favourable, which was heartening, particularly in view of the context of nursing in public health establishments. Although there are no figures about a decrease in morbidity and mortality, one nurse, a midwife, explained that she was well aware that a pregnant woman who gave a history of heavy bleeding at menstruation may have a bleeding disorder. As such, she knew that when such a woman goes into labour, there is a chance she may be carrying a child with haemophilia and was also at risk of post-partum haemorrhage. This scenario shows how post-HNEP nurses have developed a greater awareness of haemophilia as a possible cause for symptoms with which they were being confronted. In short, haemophilia is on their radar in a way that it probably would not have been prior to participation in the HNEP. Unfortunately, potential prevention of disaster cannot be claimed as a quantifiable result, but it can as a ROI.

## **10.6 Chapter summary**

This chapter has showed how the theoretical framework proposed at the outset of the work has been used to better understand and interpret the data. Data were considered using the models proposed by Leininger, Watson, Knowles and Kirkpatrick. The final chapter presents the conclusions and recommendations that stem from the research.