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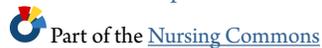
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Development, implementation, evaluation and validation of a haemophilia nurses' education program in South Africa

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## Chapter 6

### Results and Interpretation (Research Questions 1 & 2): Part One

#### 6.1 Introduction

In this chapter, the results from Part One of the study are presented. The findings from the interviews with the three haemophilia coordinators regarding care for PWH in SA are discussed. The interviews with the three haemophilia coordinators correlate with Research Questions One and Two, the creation and implementation of the HNEP respectively (see Figure 5.1, study design).

#### 6.2 Research question one: Creation of the HNEP

*What factors need to be considered when creating a purpose-driven haemophilia curriculum for nurses in South Africa?*

Verbatim comments from the coordinators are presented followed by more interpretive comments based upon further dialogue with each coordinator. Coordinator A described the early ambitions of the haemophilia stakeholders (doctors, nurses and PWH and their families) to provide quality haemophilia care which included education of nurses:

The planning for the HNEP goes back a long way, it goes back beyond the immediate time doing it. The seeds were sown as to how can we have a program for haemophilia care in South Africa? However, because I was working at the Johannesburg hospital at the time, there was no possibility for me to move out of my clinic and go and do any outreach work; there was no such thing. I was actually the only haemophilia trained nurse in the country. So I just concentrated on building up that clinic in the way that the WFH [World Federation of

Hemophilia] program worked and because of being allowed to be dedicated to do that, obviously that did grow up into being proper dedicated [haemophilia] clinic. With these things more people [PWH] are getting treated (Coordinator A).

In some respects it is understandable that the SANDoH were slow to recognise and address the needs of PWH in SA since they had to deal with the horrendous aftermath of HIV (Rispel, 2015). The health system in SA was (and still is) fragile, lacking in both financial and human resources. This situation is reflected in the services provided to PWH which continues to need more recognition. Specialist haematology doctors who care for PWH are included in the scarcity of human resources. However, these specialists cannot provide services to remote areas since they are employed by one hospital. Therefore an RN who is educated about haemophilia management provides a valuable service to PWH. Coordinator L explains the inadequate level of care provided to the PWH:

The doctors that are working with haemophilia, looking after patients, first of all they might not be there forever and second of all, they are usually working in very busy haematology/oncology clinics or paediatric units and only 1% of their work is PWH. When they come and see them [PWH] they just see them, they are not giving them advice, they're not giving them home living tips, they're not giving them any advice on how to make their quality of life better or understand the disease so they [PWH] know what to do. They [the doctors] are not able to do any of that [due to time constraints] (Coordinator L).

Many doctors who do not have expertise in bleeding disorders and other haematology diseases are poorly-informed about the management of a PWH, thus consistent mismanagement of cases is a significant issue. In addition, as Rispel (2015) noted, doctors were spending a disproportionate amount of time having to

attend to those with other conditions such as HIV/AIDS, tuberculosis, non-infectious diseases, violence and mental health issues.

When asked about what they considered the most important elements to be included in the curriculum, each haemophilia coordinator had a different opinion. Coordinator A. believed that an understanding of the genetics, family pedigrees and the construction of genograms (diagrammatic form of a family tree) was most important so the nurse participants could “identify people [PWH] and give them a chance of having care”.

Coordinator L, who serviced the Cape Provinces, believed that an overview of haemophilia, the importance of early treatment, and the psychosocial aspect of haemophilia care were the most important. Coordinator B believed that the practical aspect of the HNEP was essential because it would give the participants an opportunity to apply their new learning. All four lecturers (the three coordinators plus the researcher) agreed that it was essential that a curriculum that supported practical training was essential to learning about haemophilia. Coordinator A was determined that the participants would experience haemophilia in a holistic way, “we wanted to add into the curriculum the more practical training like actually meeting PWH and hearing, feeling and knowing what it was from the horse’s mouth” (Coordinator A).

Regarding HNEP curriculum development, this moved along rapidly and it was only a matter of months before the first program was offered. Once the content of the curriculum was decided, and a list of subjects was agreed upon, specific topics were allocated to three of the four lecturers. Coordinator A explains:

We played around a lot with what should be on the curriculum. In the beginning, you will remember, we had lots of things on the curriculum. In fact our course was [nearly] two weeks’ long and it was far too long. We had to cut it back but

we didn't want to miss anything, we wanted to try and think of everything they might need to know about haemophilia.

To avoid a totally didactic approach and to accommodate different learning styles, a variety of teaching strategies were included, such as group work and videos. Preparation of the lectures was undertaken by three coordinators, one of whom was the researcher. The following insight shows how the discussion regarding the need for a variety of presentation modalities remained uppermost in the mind of the coordinators:

We wanted to .... add not just talking and Power Point presentations but other means of communication so that if you weren't a good listener maybe if you watched a video or did group work, you would get it (Coordinator A).

A great deal of attention was given to deciding which subjects to include in the curriculum. Coordinator A explained "we looked at all kinds of things; we looked at training in hospitals .... because we are getting candidates from all over the country". The lectures were based on whatever scant literature was available which addressed the nursing care of a PWH. The four lecturers were especially on the lookout for any education program for haemophilia nurses that might be available, but as explained previously, primarily had to rely on their own experience. However, they were cognisant that care should be research-based as the following statement demonstrates, "actually J. [the researcher] taught us how we have to have it evidence-based.....you have to say, does it work for everyone, what's the evidence for that?" (Coordinator A).

Another consideration was that English was not the first language of many of the participants, so care was taken to ensure that the lectures used appropriate terminology.

Coordinator A observed,

“.... for most of our students, English was not going to be their first language. Even though they had English in school, it still doesn't mean to say they could cognitise (sic) those phrases....”

The level at which to pitch the teaching for the RNs was also discussed. Coordinator A proposed that because all the lecturers were nurses, they could teach at a level that would be comprehended by the RNs using a theoretical base which the participants could apply to clinical practice. As Coordinator A stated:

Most of the nurses we were going to be training had been in the field for as long as us. Most of them had come through the system as diplomas and not university students .... so very practical with a good theoretical base (Coordinator A).

Coordinator L offered the following statement,

“I think that the most important part was trying to make it simple, trying to make it applicable so that .... you will have someone who is able to use the information and use it wisely”.

### **6.3 Research question two: Implementation of the HNEP.**

*What factors need to be considered when implementing a purpose-driven haemophilia curriculum for nurses in SA?*

Coordinator A took responsibility for the overall organising of the program since she possessed a large and diverse network of contacts and was familiar with the SA infrastructure. Frequent emails and telephone conference calls between the researcher and the three SA coordinators ensued. The time difference between SA and Australia meant that the researcher often discussed the HNEP program in the evening to correspond with the time difference between Australia and SA. In later years Skype became the communication medium.

It was decided that the initial HNEP would be held in Johannesburg. However, recruitment of participants would be from further afield, therefore suitable accommodation for the participants and coordinators was required. It was necessary to find a hotel which had a conference room equipped for teaching, could cater for a large group and with accommodation at a price that was reasonable. Land transport was required to collect the participants from the airport, train and bus stations. Additional transport was needed to ferry the participants from the conference centre to the Haemophilia Treatment Centre (HTC) situated at the Johannesburg General Hospital so that the participants could meet with PWH. Coordinator A explained some of the organisational challenges she faced:

But then we had problems with logistics of where do they [the participants] stay, and then how do we get them from A to B and we had to find money for the food. So there was lots of investigation that went on and a lot of time and effort....  
(Coordinator A).

The cost of these arrangements as previously discussed, was met by the WFH grant awarded to Coordinator A. Therefore, although participants were recruited from a variety of provinces, attendance was cost-free to employers. These employers would ultimately

benefit from employees who attended the program and be knowledgeable about haemophilia management.

When recruiting RNs, the coordinators targeted hospitals that treated PWH, but where management of haemophilia care tended to be substandard. As Coordinator A stated; “we wanted the candidates to come from hospitals where there were PWH being treated, so they would have key people there who would know how to manage them”.

Despite the support of the SANDoH, local governments also influenced the implementation of the HNEP. The following quotes from Coordinators A and B explain the situation:

You do need the support of the provincial health department to say that they agree that this is a training that must be done. Then it has to filter down from the leadership to say [approve sending a nurse to training] and then the most important thing is to find a key person who’s going to show leadership in the hospital (Coordinator A).

And

If the local doctor of the hospital is not supporting the program then it won’t be implemented. If you can get the interest then the local doctor is the most important person because the local doctor can open up a clinic, can prescribe ..... then it’s easy to get the local hospital and provincial government to support them (Coordinator B).

Recruitment proved to be difficult. Firstly, the Directors of Nursing of targeted hospitals were contacted by letter, providing details about where and when the HNEP would occur and asking them to send a nurse who would benefit from the course and then be able

to bring the knowledge back to the hospital. If there was no response, follow-up telephone calls were instigated. Sometimes a direct approach was required. A coordinator would visit the hospital and ask the Director of Nursing to allocate a RN to attend the program.

Coordinator L.'s perceptions of the recruitment process are representative of the experiences of the other two coordinators:

I think we've always battled. I don't think it's been easy to get the nurses, actually to attend. I would go to every unit, every single manager, it can be sent out from the directorate, from the Department of Health and you still get no response. When bad things happen in the area, I say, 'you have the training why don't you come?' and they don't respond (Coordinator L.).

The hospitals had difficulty releasing a nurse to attend the HNEP because of the lack of human resources to free a nurse from clinical responsibilities. Since the hospitals could not confirm that the nurses could be released, it made the planning and pre-payment of accommodation and catering costs difficult and made relations with the hotel more complicated. Difficulty with recruitment continued for subsequent HNEP intakes, as Coordinator L observed, "the biggest challenge every single time was to get the nurses to the program".

Funding to support subsequent HNEPs was sourced from government health departments in the various provinces. Coordinator A related the difficulties about these departments and allocation of funds.

We demanded that the Health Department .... pay for their trainees to come themselves because then they [the nurses] would be accountable, they would know that they'd sent them for training and they expected them to work. They

[the various Health Departments] do have money for training – it's to get them to part with it and agree on the costing of it.

Pertinent cultural aspects of care needed to be accommodated and were included in the curriculum. Considered were the use of English as the language of instruction, the variety of ethnic groups represented and the customs of some of these groups. As all the participants spoke English and had received basic nursing training in English, the lecturers expected that the participants would be fluent in English and therefore understand the content of the lectures. However, the use of English for instruction in the classroom was not explored with the RNs in the evaluation process after they had completed the HNEP. Therefore it was not fully appreciated until the researcher conducted the interview with Coordinator B, the BSA, who explained how the use of English affected learning in black South Africans:

....[something] that might be [a] barrier is people not understanding based on the language.... you know English is different and you find for us being black people if you are going to speak English.... you would like someone to speak slowly so you can read their lips...it's not something we grow up talking at home.....

Another issue that emerged from the interview with Coordinator B was that for the BSA, the culture of learning is dissimilar to a western perspective, as she explained:

.... even if it is written, you have to be told again and again and again. I'm not saying that people are not understanding because they take things easy, but you have to tell people again and again.

Some of the traditions within ethnic communities needed to be considered. One of these traditions was witchcraft. Haemophilia Coordinator B related a story of a young boy

with haemophilia whose parents no longer lived together. The mother would bring the boy to the haemophilia clinic but his attendance was sporadic. The coordinator arranged to visit the mother at her home to determine why the boy did not attend the haemophilia clinic. The mother explained that when the boy went to stay with his father, he did not attend the clinic. It transpired that the father and his family were sangomas (traditional healers) and the mother believed that the paternal family had bewitched the boy. The mother related that when the boy stays with her family he is much better and because the father's family did not want the boy to be with his mother, they put a spell on the child. Consequently, the mother was afraid to have another child because she believed that her ex-husband's family had put a spell on her too. The haemophilia coordinator gave her some education about haemophilia but the mother was unconvinced about the origins of her son's condition until she eventually brought him to a haemophilia clinic. At the clinic she found other parents with children, some of whom were white, and as the quote reveals, she began to question the role of witchcraft on her son's disorder. "[She said to me] if this is witchcraft, who has bewitched white people because I saw white people [at the clinic] as well?" (Coordinator B).

When teaching the management of a PWH, the custom of ritual circumcision practices required attention. In the Eastern Cape Province, for example, young men are expected to undertake "manhood ceremonies". This involves a ceremony carried out over several days at a secret location in the bush, conducted by the men from their ethnic group. During that time these young men learn about the traditions and mores of their society, thus honouring their ancestors. One important part of this tradition is the ritual of circumcision. For a PWH, circumcision is a high-risk procedure; and ideally should be performed in a hospital setting. However, many young men believe that by not following the traditional form of initiation in the bush, they are diminished as men, so they choose tradition over safety. This risk factor was recognised by the traditional circumcision coordinators who are

male nurses. The traditional coordinators approached the haemophilia coordinators about education in relation to the management of the PWH who elects to have a traditional circumcision. A modified version of the HNEP was offered to the circumcision coordinators, omitting topics about women with bleeding disorders as they were deemed irrelevant by the haemophilia nurses. However, the circumcision coordinators objected, because they believed a holistic approach to haemophilia care could benefit all members of their ethnic group, not just the males. The following quote from Coordinator L emphasises this belief, “The .... men in the Eastern Cape said ‘no Sister, this is important, you really must include this as well’ and it’s true, they are going to come across women” [who have bleeding disorders].

Violence in the society was also a topic of discussion during implementation the HNEP. One nurse described how she advocated for a child with haemophilia at his school. This nurse gave information to the teachers about haemophilia and indicated that the child should not be beaten as it could be catastrophic for the child. She stated:

The mothers will even report to me that the child is being beaten at school by the teachers. Then I visited one school to tell the principal that this child is haemophilia (sic) and that the beating is just not allowed. (F/G1, N1)

[Note: F/G = the focus group identifier; N = nurse identifier]

Inadequate infrastructure, particularly in rural and regional areas in SA, undeniably impacts on haemophilia care. This inadequacy emphasised how important it is to educate health care providers. Coordinator B explained the importance of education in this regard:

The [haemophilia] treatment cannot reach certain areas especially if they are far from the hospital setting. I think most important is education. If the nurses and

doctors are not well-educated with haemophilia it really hinders the implementation of treatment in rural areas (Coordinator B).

In SA, especially in regional and remote areas, poor infrastructure impacts on health services and many patients living in these areas travel long distances to access health services. Roads are an important part of infrastructure and it was difficult bringing PWH to the training centre as guest speakers and to ensure their safety and wellbeing. The poor quality of some roads directly impacts on the ability of the PWH to access assistance, as Coordinator B explained: “for haemophilia patients you find that the ambulance system is not reaching those areas and it takes time for them to get assistance with the ambulance.” (Coordinator B). And further:

....when the PWH gets treatment [for a bleed], they go home then they play like a normal person would play. Where they live and play, [for example in the street] the ground is uneven and they twist and they get bleeds often (Coordinator B).

The condition of the roads also affects the ability of participants to reach the HNEP venue. For this reason, the participants needed to arrive the day before, incurring extra financial costs, as Coordinator A identified:

....people might live too far or the roads are bumpy and they have to get up at three o'clock in the morning to get there in time to start the course..... they are just too exhausted to actually listen, too anxious, everything's new and the first day is very important (Coordinator A).

Long distances, poor road systems and poor infrastructure were major issues to consider in implementing the HNEP. The three haemophilia coordinators spoke about how long distances made it difficult to treat the patients who resided in outlying areas. These

distances can be extreme, for example from Johannesburg to Nelspruit it is 326 kilometres by road. This particular part of the country is serviced by a good highway but there are many regional areas with road systems in poor condition. Two coordinators mentioned distance as an issue preventing adequate quality of care to PWH. The frustration of attempting to reach a remote area was expressed by Coordinator B:

Sometimes....when I am going to do outreach I will look at the map before I go and see where I am going. But when you arrive you don't know whether it's this village because there are no signs and you try to phone them, no network. The roads are so bad .... (Coordinator B).

Poor infrastructure, which includes interrupted electrical supply resulting in power failures are commonplace in SA and can impact on the provision of the HNEP. As mentioned earlier, the lectures are accompanied by Power Point presentations and interruptions in the power supply can disrupt teaching sessions. The following quote shows that the lecturers were aware that there may be interruptions to power supplies and that versatility was essential to overcome this. "Now we've had so much experience a power failure is much easier to deal with. In the beginning we would have been fraught but now I think it probably wouldn't play such a role." (Coordinator L.)

While not impacting directly on the implementation of the HNEP, other insufficiencies can affect the delivery of adequate care for the PWH. For example, participants had been informed about the importance of sanitation but encountered practices that were contrary to what they had learned. The following quote emphasises the despair expressed by Coordinator B, "I went to one village and I asked myself, is this happening in SA? People were drinking water with cows and donkeys."

## 6.4 Compensations

It would be remiss to leave the reader with the impression that planning for and implementing the HNEP was no more than a matter of grind in overcoming obstacles. Despite the difficulties, all three coordinators related positive experiences in their roles and their involvement with the HNEP. They were fully engaged with their work with Coordinator B describing how she “enjoyed her work enormously”. The haemophilia coordinators related stories which illustrated that education is vital. As previously mentioned, education of PWH and their families is an integral part of managing a PWH. When family members are illiterate and cannot read pamphlets and other educational material, oral teaching is fundamental to health. The following reports the experience of Coordinator B when she visited a remote province:

We had this mother, she is illiterate. She didn't seem to understand anything. In my mind I thought let me teach all the mothers and then we talked to the mothers, every time we talked about haemophilia. When you get to your local hospital tell them that your child is bleeding, when you touch its hot tell the doctor he's bleeding, you have to give his treatment and transfer him to the hospital, you know all those things. The other day we had a World Hemophilia Awareness Day in their hospital and we met her at the gate and she came with us. She said what are you doing here and she hadn't been for some time. She had a baby, a new baby [she said] “I have a baby and I want to take the baby to the clinic but I'm not going to take the baby today I am coming to join you”. That's how she came, she was not prepared. In the hall where we had the Awareness we had the heads of the hospital, we had the matron, we had the student nurses, everybody was there to hear about haemophilia and they didn't have a patient. But S. [the

manager] said as we have this mother of a patient here, we would like this mother to tell you about her child. I got goose-bumps because she spoke exactly how we spoke about haemophilia to her. When she gets to Emergency she says “no, no, no, this is not how you mix it you don’t shake it” [the factor]. You know I nearly cried because you cannot measure what you are doing but with that you can see that something is happening (Coordinator B.).

From its original conception, the HNEP underwent refinements over the years. The importance of having an understanding of teaching strategies is exemplified for Coordinator L. in the following:

The good thing about the course and the way it’s done now.... is the repetition. Repetition from different angles so that at the end all fits together like a jigsaw puzzle. All the pieces fall into place because that one links to that one, links to that one....because you repeat stuff (Coordinator L).

When Coordinator B was asked to provide an opinion in the context of being involved in teaching in the HNEP after it had been well-established, she remarked, “for now I think the program is absolutely perfect.” This response conveys that coordinator B who had been a previous participant in the HNEP, believed the program had provided the necessary information to deliver effective haemophilia care and management.

The three coordinators were asked about their personal gains from their involvement with the HNEP. Responses were:

Firstly, knowledge: I didn’t know haemophilia. Most of all what I got was from the fulfilment after treating them [PWH].... it’s something you can’t explain. Patients come back [and you find] they understand themselves (Coordinator B).

And

It's an extremely rewarding job, I enjoy my job tremendously. Obviously there are hiccups and battles but as you get more experienced you manage them [PWH] better so the job gets better. I think being passionate about it makes it so much better for the patient (Coordinator L).

Also

I've had an enormous amount of self-education through being involved with it [HNEP]. I've learned such a lot because I've had to learn more through my research getting ready for all my talks. I've had an enormous amount of satisfaction in empowering people with knowledge, not only knowledge about haemophilia care, with knowledge about life, knowledge about caring for someone else, knowledge about being ethical, being moral and .... to be given that platform, I have been absolutely blessed (Coordinator A).

## **6.5 Chapter summary**

This chapter presented haemophilia coordinator insights that illuminated answering Research Questions One and Two. Some of the positive effects of having participated in the HNEP were also relayed. The following chapter addresses the experiences of the RN HNEP participants.