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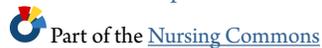
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Development, implementation, evaluation and validation of a haemophilia nurses' education program in South Africa

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Chapter 7

Results and Discussion (Research Question 3): Part Two

7.1 Introduction

In this chapter, the results from Part Two of the study are presented. The findings from the interviews with the RN participants regarding care for PWH in SA are discussed. The interviews with the RNs correlate with Research Question Three, the extent of HNEP transfer of knowledge, skills and perceptions has occurred (see Figure 5.1, study design).

7.2 Research question three: HNEP transfer of learning

What transfer of knowledge, skills and perceptions is likely to occur as a result of training received via a purpose-driven haemophilia curriculum?

Responses to research question three were provided through focus groups and one-on-one interviews with four RNs. Questions asked how effective the HNEP was in allowing them to transfer knowledge, skills and perceptions about haemophilia into the field experiences.

Analysis was conducted using the Kirkpatrick (1975) Four Levels of Evaluation, namely, Satisfaction, Learning, Behaviour and Results. A fifth level Return on Investment (ROI), added by Phillips (2003), focused on intangible characteristics such as competencies, organisational commitment, innovation, and creativity. Being more covert in nature, such characteristics are difficult to evaluate using traditional metric-based procedures. Results in terms of the Kirkpatrick levels + ROI are discussed in what follows.

7.2.1 Kirkpatrick model level 1: Satisfaction.

Of the total number of participants (n=20), nine used the word ‘satisfaction’ to describe the potential of the HNEP to meet their prospective needs. Six mentioned feeling empowered, five stated an increase in confidence and five stated an increase in knowledge about haemophilia. Further information is presented in Table 7.1.

Table 7.2 Kirkpatrick Level 1: Satisfaction with HNEP to Meet Prospective Needs.

<i>Level 1</i>			
<i>Satisfaction</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Satisfaction with teaching content</i>	9	45	<i>When I did the course I have to say it was excellent. (F/G3, N1)</i> <i>[I 2] enjoyed the training, I think it was excellent. They covered everything. (F/G3, N2)</i>
<i>Empowerment</i>	6	30	<i>I felt empowered. (F/G4, N2)</i> <i>Yes, in other ways it also empowers because I think the course itself can help you to have a positive attitude. (F/G4, N5)</i>
<i>Increase in knowledge</i>	5	25	<i>The course developed our understanding and our skills. (F/G2, N2)</i> <i>Since I attended the course, it was an eye opener. (F/G2, N1)</i>

n = 20 interviewed in focus groups and one-on-one interviews.

Identifiers: [I] = Interview data; F/G[x] = Focus Group [x = number]; N = nurse participant.

7.2.2 Kirkpatrick model level 2: Learning.

Eight of the participants confirmed that they felt more knowledgeable about haemophilia following completion of the program. Four nurses commented that prior to completing the HNEP they had no understanding of haemophilia or the urgency of care required by a PWH. Four stated that they had used the HRF and pamphlets provided at the

course in a clinical setting. Six nurses stated that they were more aware (meaning having a better perception) of the intricacies of haemophilia and had a better understanding of the impact of haemophilia on the PWH. Of the n = 20 participants who were interviewed in either the focus groups or one-on-one interview situation, all agreed that the transfer of new knowledge to clinical practice was potentially invaluable. These statistics, together with examples of statements, are presented in Table 7.2.

Table 7.3 Kirkpatrick Level 2: Learning as a Result of Having Attended the HNEP.

<i>Level 2</i>			
<i>Learning</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Joy in Learning</i>	8	40	<i>It's actually such an easy condition to learning (sic) so yeah no I enjoyed it, I think it was excellent. (F/G3, N2)</i> <i>So lots of information was given, I think it was almost like a doctors course but squashed into one week. (F/G4, N2)</i>
<i>Knowledge pre course</i>	4	20	<i>I went to the course with nothing, no knowledge at all (F/G3, N3).</i> <i>I didn't have any contact with patients with haemophilia prior to the course. (F/G3, N5)</i>
<i>Transfer of knowledge to practice</i>	20	100	<i>It feel very nice to come back in a set up where you can work with a patient and that you can practice what you have first learnt in the course. (F/G4, N2)</i>

n = 20 interviewed in focus groups and one-on-one interviews.

Identifiers: [I] = Interview data; F/G[x] = Focus Group [x = number]; N = nurse participant.

The following verbatim responses further show that the nurses valued and used the HRF for themselves and others, including doctors, when they returned to the clinical area:

I keep my haemophilia folder with me.... if there's something the doctor will come to me then we'll look up something, it helps a lot (F/G3, N3).

And

All the leaflets & brochures are useful....I constantly refer to that (F/G4, N5). I still use the haemophilia training [book] which were [sic] given to us at the HNEP because sometimes you will do something, you just want to read (F/G4, N4).

Six nurses (30%) articulated that they had a greater awareness of the needs of the PWH after they had completed the HNEP. Examples of this awareness are shown in the following statements:

....made me more aware of the patient's physical and social needs (F/G4, N5).

I gained such a lot especially when I was there and that made me when I came back I could identify the patients with haemophilia, even in our community (F/G3, N3).

I'd heard about haemophilia before, before I did the course but afterwards because I didn't know there were people [PWH] in our area having the condition 'cause I'd never heard about the people (F/G3, N5).

When asked whether the new knowledge they had received from attending the HNEP had helped when they returned to clinical practice to care for PWH, two participants contributed the following experiences, demonstrating how informed they had become:

Working at the gynae [gynaecology] clinic just really opened my eyes - when a woman comes in and say she's got menorrhagia, [heavy bleeding at menstruation] I become very concerned [because this is common symptom of a bleeding disorder] [I 4].

...the most horrific incident that could make you realise what could happen to a haemophilia patient (F/G3, N1).

Participants were also asked if, and how, this new knowledge had made a difference to their practice and how they were perceived by their work colleagues. Two participants volunteered:

[before the training] we didn't have the background [but now] the doctors even listen to you, they don't call the haematologist on call, they ask you (F/G3, N2).

I'd never [given factor] with prophylactic because our doctors didn't know much about haemophilia [so it was not prescribed] (F/G4, N2).

7.2.3 Kirkpatrick model level 3: Behaviour.

Level three relates to if and how the information gained from the HNEP had made a difference to the nurses' competence when managing a PWH. Of the total number of participants (n = 20), there were 39 responses commenting on the increase in competence the nurses felt caring for a PWH. Eighteen participants related how better awareness of the needs of a PWH created changes in perception for the PWH, with many moving from being a demanding and querulous patient to one who was grateful for the prompt and effective treatment received. Moreover, four nurses related how they had, through an exchange of knowledge, influenced a change in the perception of their colleagues towards these patients. Seven of nurses indicated that there had been an improvement in their scope of practice. A summary of these changes in behaviour is presented in Table 7.3 and discussed in what follows.

Table 7.4 Kirkpatrick Level 3: Evidence of a Change in Behaviour as a Result of Attending the HNEP.

<i>Level 3</i>			
<i>Behaviour</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Changed perception of the PWH</i>	18	90	<i>Because we're working such a long time in the clinic they like family to us (F/G4, N2). After the training you just have that little bit of soft spot with them (F/G4, N5).</i>
<i>Scope of practice</i>	7	35	<i>So now after I have done this course I'm able to explain to them [PWH] what is going on then I refer them and they go to hospital (F/G3, N2).</i>

n = 20 interviewed in focus groups.

Identifiers: F/G[x] = Focus Group [x = number]; N = nurse participant.

The nurses also related how their competence in relation to clinical practice had increased following the HNEP. Nineteen stated that they were better able to manage critical incidents in the care of a PWH. The account from one nurse (considered in greater detail in the next chapter) of how she successfully advised doctors about the management of the PWH who was bleeding into his neck, is an example of the competence in the management of a critical incident.

When asked whether they felt competent to manage a PWH, ten nurses replied that the HNEP had encouraged them to advocate for better treatment of the PWH. The following quotations express this level of confidence in practice:

I called the pharmacy and I said to them, this is Christmas Eve you cannot tell me that you don't have factor in the province please get factor [I 3].

So we actually need to format a document to say you know if this treatment doesn't work try that, try that, try that (F/G2, N3). [The patient was] a haemophilia carrier and [had] a HIV issue and we really thought that she must attend our high risk clinic and I even encourage it because this was her tenth pregnancy [I 3].

Eighteen nurses discussed how their attitude towards the PWH had changed once they had completed the HNEP. Two nurses related the profound change in the following way

I really care about haemophilia since I attended the course (F/G2, N1).

.... after the training I just realised you know you must give them also the special care that you give the haematology patient (F/G3, N5).

The participants also discussed how some nurses have a negative attitude to PWH. As the following statements show, this negativity emanated from the nurses not understanding the ramifications of haemophilia:

The course itself can help you to have a positive attitude because there was a very negative approach there [in my workplace] and I felt it did make a difference because I just felt the need to be positive about the whole treatment (F/G4, N4).

Even my Sister [senior nurse] was afraid everybody was like when the patient [with haemophilia] comes, everybody will just have to get a room to go in because we know that if you prick this patient he can bleed and die. So we are afraid of this haemophilia [I 2].

They [the ward nurses] were so mad, why is this woman coming here with the child so often? I said it's not her fault, it's not their fault. Now [I am] explaining

what happened to the child, [with spontaneous] bleeds, about everyday life with the child. Anything can happen and it's not like any normal child (F/G4, N3).

Nevertheless, it was clear that positive changes were occurring, as the experience of one nurse exemplifies:

There are so many patients who are coming in, at least now they're getting help because everybody knows that I'm there and if the patient doesn't get what they're supposed to get then I'll come and then it will not be nice, so everybody is trying their best to do the right thing with haemophilia patient (I 2).

Scope of practice in nursing relates to the extent of the individual nurse's practice and is determined by their education, training and competence to meet the needs of their client group. Seven nurses related how the knowledge obtained from the HNEP had widened their scope of practice. In this instance, the scope of practice of the participants had broadened because by participating in the HNEP, they had received education, training and the opportunity to put the learning into practice. When they returned to the workplace, they became the specialist haemophilia nurse, which in turn increased their competence in the haemophilia client group. They indicated how this increased scope of practice impacted on the care of PWH:

When I came back I could identify the patients with haemophilia even in our community (F/G3, N5).

What personally changed me was my position as a nurse and my impact in the specific clinic where I work (F/G2, N4).

It feels very nice to come back in a set-up where you can work with a patient and that you can practice what you have first learnt in the course (F/G4, N5).

7.2.4 Kirkpatrick model level 4: Results.

Level four of the Kirkpatrick model relates to Results; in this case, how did the completion of the HNEP impact on the institutions, the employees and the available health resources? From n = 20 participants, 21 comments were made about the effect that the HNEP training had had on the service provided to PWH and the subsequent use of resources. Thirty-four comments made by the participants related to the delivery of a more efficient service and nine participants commented on how their delivery of service was influenced by management decisions. Results are reported in Table 7.4.

Table 7.5 Kirkpatrick Level 4: Results Pertaining to Change in Institutions, Employees and Resources.

<i>Level 4</i>			
<i>Results</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Change in service</i>	21	105	<i>Now you find that when you, there is a haemophilia you actually like to include their whole family (F/G2, N2).</i>
<i>Efficient use of resources</i>	34	170	<i>When they call me then I liaise with the haemophilia doctor on call and I liaise also with the doctor which is in ward 20 so that the proper treatment can be given (F/G2, N4).</i>
<i>Management</i>	9	45	<i>I've got a problem with our management side (F/G2, N3). Now in the hospital we must train more nurses because T. is by herself now. [Nurse Manager] (F/G1, N1).</i>

n = 20 interviewed in focus groups.

Identifiers: F/G[x] = Focus Group [x = number]; N = nurse participant.

A change in service such as the establishment of a haemophilia clinic or heeding the advice of a nurse who has attended the HNEP, was mentioned twenty-one times by the participants. The following three examples illustrate the impact of the change in service.

Firstly, there were fewer presentations for bleeding episodes because the PWH was better educated in self-care and take precautions to prevent bleeding, as this quote illustrates:

There is a difference because the patients who used to come on a monthly basis, our doctor [converted them] to three monthly [clinic visits] except for those who really are regular bleeders. Most of them don't come often to the clinic [outside of their regular appointments] (F/G2, N4).

Secondly, prompt treatment of PWH as an outpatient reduced the extent of the bleeding and avoided hospital admission:

Gives a challenge to me so that is why I have to work hard in order to like gear up more with the doctor's help so that we can help the patient to attend to their needs quickly (F/G 2, N1).

Thirdly, appropriate management when a PWH was admitted as an inpatient resulted in reduced lengths of stay. Appropriate management was implemented when a PWH was admitted as an inpatient. By supporting the ward staff and reassuring them that the PWH was receiving adequate treatment, the HNEP-trained nurse contributed towards a positive outcome for the PWH:

He spent two weeks there [in another hospital] without the factor. I think it was five days in my hospital [because he had received appropriate treatment] [I 2].

They [the staff in the clinic or hospital] don't really understand haemophilia but they say they [PWH] have to wait their turn and then I just explain to them.

That was in the beginning, now I don't have that problem anymore (F/G3, N2).

All these initiatives are an effective means of reducing the financial cost of treating the PWH thus freeing up in-patient facilities such as the availability of beds. Participants

were mindful that there had been a positive change in the management of PWH in the hospital where they worked and that they played a significant role in this improvement, as is indicated by the following quotes:

There is a huge improvement on the [haemophilia] work in XXX Hospital (F/G4, N3).

I think we are doing a very good job with the patient now and in the hospital also (F/G2, N4).

We also have input in the care of the patient by guiding the doctor, “what about this, what about that” (F/G2, N3).

The quality of treatment as a whole is much better than it was before (F/G3, N5).

In total, participants identified 34 changes which had occurred in haemophilia management resulting in more efficient use of the health resources available. The following statements identify the more significant – with key words being *italicised* – of these changes:

Even the nurses in OPD (Outpatients Department) know that in that cupboard there is factor for this *patient* when he comes. When he says I’m coming for my factor they say ok here’s your factor (F/G1, N2).

[I said to the pharmacist] “the PWH did not receive any *factor* because you [the pharmacist] don’t have factor in stock” and then this woman [the pharmacist] will phone around and she will call me back and tell me “no, phone your patient and tell your patient to come and fetch the factor” [I 3].

I asked Prof before the clinic to go and give some information on women with bleeding disorders to the gynae [gynaecology] *doctors* and ever since then the *management* of women who are bleeding in the hospital has really changed [for the better] [I 1].

I can remember in the past we had haemophiliacs in hospital in the school holidays, the whole *school holidays*. Now we don't see that anymore (F/G4,N5).

Nine of the 20 participants had identified that there has been some resistance from hospital management to provide leave for the HNEP trained nurses to attend meetings to educate or provide outreach care. Outreach is defined as the provision of information or services to a group or individual in society who otherwise may not be able to access the information or services. These participants expressed frustration at management for not considering the importance of outreach care:

When I request a certain date to attend a community meeting or whatever and sometimes like when we need to take another person for the training it's like he [the nurse manager] doesn't understand why (F/G2, N3).

We have asked for an extra one [nurse to work in haemophilia clinic] for almost two years at the hospital but they don't have the money to provide it (F/G2, N1).

7.2.5 Return on investment: [Level 5].

The fifth level, Return on investment (ROI), was added to the Kirkpatrick model by the researcher. This level considers the value of intangible measures when engaging in a cost/benefit analysis of the outcomes of an education program. Examples of intangible components of a program are leadership, advocacy, informal sharing of new information

(Phillips, 2003). In the case of the HNEP, the following intangibles were identified within two specific areas: benefits to the PWH and gains to the individual nurse.

7.2.5.1 ROI benefits to the PWH.

Table 7.5 identifies the eight main intangibles that emerged from focus group dialogue and one-on-one interviews. These are discussed individually with verbatim comments indicating the significant role that intangibles play in having well trained haemophilia nurses in situ. The data identify important factors such as the realisation by the PWH that a nurse with haemophilia education will understand their needs and they can develop a relationship, resulting in a better level of care. The nurse can advocate for the PWH, educate him and his family about self-care and instruct him to become proficient in accessing veins and sterile technique to enable home therapy. For some PWH, with this knowledge, a critical bleeding episode can be averted.

Table 7.6 Return on Investment: Benefits to the PWH.

<i>Level 5: ROI</i>			
<i>Benefits to PWH</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Recognises the nurse can help</i>	13	65	<i>He was excited to know that now there's a nurse who knows his condition (F/G1, N2).</i>
<i>Improvement in care</i>	3	15	<i>The quality of treatment as a whole is much better than it was before (F/G3, N2).</i>
<i>Develop a relationship</i>	6	30	<i>I think they're also used to us (F/G 4, N1).</i>
<i>Advocate for self</i>	3	15	<i>This boy was really instructing the Sister [I 4].</i>
<i>Home therapy</i>	8	40	<i>If the mums observe the child [having the port needed] they can be confident [that they can needle the port] (F/G 4, N1).</i>
<i>PWH who have died</i>	3	15	<i>Many women that we normally lose after delivery through certain bleeding problems [I 3].</i>
<i>Effect of treatment</i>	6	30	<i>The improvement is much, much better and the education also because the bleed is less (F/G3, N4).</i>
<i>Nurse advocacy for PWH</i>	19	95	<i>I did insist that the patient get the factor first; first treat them then get them to get the scan because the bleed could continue in that time (F/G4, N5).</i>

n = 20 interviewed in focus groups and one-on-one interviews.

Identifiers: [I] = Interview data; F/G[x] = Focus Group [x = number]; N = nurse participant.

Thirteen nurses spoke about how the PWH understood that once the nurse had completed the HNEP, they had the skills and ability to help them. The following quotes by the participants indicate how they and the PWH have benefitted from the nurse attending the HNEP:

I get phone calls from (sic) other problems they've got and at least I can refer them to someone else if I can't help them (F/G3, N5).

The patient when they come [to the hospital] they know that there's Sister F.
[who will be able to help] [I 2].

We also had a case where the patient was sent away from the hospital and I
was phoned half past ten in the evening, so I phoned the hospital [to explain
that the PWH needs treatment and to not turn him away] (F/G3, N2).

She had the Caesarean section eventually she came back to me to say the
baby is negative [for HIV] and also the baby does not, is not a (sic)
haemophilia [I 4].

Three nurses recognised that the haemophilia training had made a beneficial impact
on the care of the PWH. One of the significant benefits was professional support, as these
comments indicate:

The fact that after I did the course and [now] they've got someone at least. [For
example] I will phone the ambulance on their behalf and explain.... it's easier for
the patients to get help now than it was before (F/G3, N2).

It's always nice to have someone specific you can contact. Because today
that one's on duty, tomorrow it's another one on duty and if you've phoned the
hospital if you've got someone specifically to phone then I definitely think it's,
the quality of treatment as a whole is much better than it was before (F/G3, N5).

It's definitely better if you have someone specifically that you know I can phone
this person and she will be able to know what to do. Be able to phone someone
else or ask (F/G3, N1).

Six nurses described how they developed a relationship with the PWH and their family and how this relationship resulted in the PWH having more confidence and trust in the health system. These participants related how this relationship improved care:

I built a relationship with the family because of the fact that our paediatrician has explained to them the product that we're using here in South Africa [is similar to the one they are used to using in the UK] (F/G3, N2).

Now she's one of the mothers who is always coming to me when she goes to the clinic because the baby is, the boy is now 3 years old and he is on prophylaxis and it's really nice to work with such a mother [I 3].

Education from the haemophilia nurse has informed the PWH and his family of the importance of self-care when a bleeding episode occurs. If the haemophilia nurse is not present at the time of admission to hospital, the PWH has been taught to self-advocate, which gives them the confidence to insist that they receive the correct treatment. Six nurses related how the patients (PWH) demonstrated this self-advocacy when placed in a situation when they were not satisfied with the treatment given. Examples of comments include:

This one lady said to me, "I want to know what is haemophilia because when we got to the accident scene we wanted to put on a drip but this boy said to us 'please don't touch me just take me to XXX Hospital' " [PWH to ambulance officer] [I 3].

This boy was really instructing the Sister and telling her how to draw the factor telling her "I don't want bubbles in my body so you must be very careful" [I 3].

Eight nurses described the advantages of home therapy for the PWH and their family. Home therapy allows the PWH, or their parent/guardian, to manage a bleeding

episode when in the home environment. Treatment can be given promptly at home, thus reducing the incidence of a critical or prolonged and damaging bleed. Such a strategy also serves to minimise disruption to the family and the individual and to ensure safety, as the following quotes show:

Our people really love it, [the preparation for home therapy] the washing of the hands ... (F/G4, N4).

This mum.... she came in she demonstrated to a group of [haemophilia] people how to prime the port and give the factor through the port (F/G3, N3).

Unfortunately, due to mismanagement of the PWH experiencing a bleed, death could be the outcome for the PWH. Nurses with haemophilia training find such a situation extremely difficult because they know that a death was probably avoidable. These three nurses (15 percent) express their sadness when patients die unnecessarily.

When we are releasing the balloons [to celebrate Haemophilia Awareness Day] we'll be thinking of the patients that we've lost through some haemophilia event [I 4].

The many women that we normally lose after delivery through bleeding. [I 4].

[There are] patients that are undiagnosed because we've got many bleeding disorders [I 3].

Competent management improves quality of life for the PWH. Six nurses discussed how good treatment has made a difference to some PWH. The PWH is better informed about how to recognise a bleeding episode and can seek treatment early, thus preventing complications. Home therapy allows the PWH more autonomy and reduces the need to attend the hospital or health centre for treatment, causing less interruption to school or work.

Haemophilia education can allow the nurse to advocate on behalf of the PWH when an intervention is necessary, thus ensuring that bleeding episodes are treated adequately and appropriately:

If it's someone say with haemophilia, that is as I say rather easy to treat, and that the treatment can make such a huge difference in the patient's life and in the quality of life that they have if you treat immediately (F/G3, N5).

Of the 20 nurses who participated in focus groups, 19 described how learning about haemophilia had invested them with the confidence to advocate for the PWH in a crisis situation. All 20 participants recognised that a PWH requires assistance 24 hours a day, seven days a week. To accommodate this, all the nurses interviewed carried their own personal mobile telephone. This allowed the PWH or hospital staff members to contact them when the PWH needed urgent treatment. The nurses admitted that they paid their own phone bills and were not recompensed for the use of their phones, thus indicating their commitment to the welfare of the PWH.

As stated, some doctors did not know about the treatment or management of PWH. If this is the case, the nurse must advocate on behalf of PWH to ensure they receive the correct management. To confront a doctor requires considerable courage and tenacity, as nurses do not usually instruct doctors about patients' treatment regimens. An account of this advocacy has been related by a nurse and is presented as a case history in Chapter 8.

7.2.5.2 ROI benefits to the individual nurse.

Six nurses expressed how they had developed skills such as outreach work (where the nurse leaves the hospital and takes healthcare to people in the community) and teaching about haemophilia. They also described how being able to help the PWH provided them

with satisfaction in the work they were doing. From the data, Table 7.6 outlines the variety of ways that the nurses believed they had gained from completing the HNEP, which are then described in detail. These gains are differentiated from Kirkpatrick's Level 1, Satisfaction, which describes the participant's satisfaction with the HNEP program.

Table 7.7 Return on Investment: Benefits to the Individual Nurse.

<i>Level 5: ROI</i>			
<i>Gains to the nurse</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Teaching other professionals</i>	32	160	<i>we share information....during the ward round. (F/G3, N 2).</i> <i>I'm able to educate the nurses in my hospital about haemophilia. [I 2].</i> <i>what to tell the doctor... (F/G3, N2).</i>
<i>Know PWH better</i>	4	20	<i>They can relate to you (F/G3, N3).</i>
<i>Improvement in the health of PWH</i>	17	85	<i>Even the family will come to you and thank you because they can see there's a difference now [I 2].</i>
<i>Skills: outreach</i>	6	30	<i>This was my first outreach, so far from my hospital [I 4].</i>
<i>Job satisfaction</i>	8	40	<i>I was also happy because if I didn't intervene that patient would have stayed in that hospital without the factor and then we don't know what would happen to that patient [I 2].</i>
<i>Influence of nurse</i>	7	35	<i>You know your presence there in that room at that moment made the difference in the child's life (F/G3, N2).</i>

n = 20 interviewed in focus groups and one-on-one interviews.

Identifiers: [I] = Interview data; F/G[x] = Focus Group [x = number]; N = nurse participant.

The nurses interviewed indicated how important the role of teaching was for those with knowledge about haemophilia. Four of the 20 nurses spoke about educating doctors.

Although doctors are considered better educated than other health care workers such as nurses, when a nurse who has received education about haemophilia management from the HNEP attempts to inform doctors, this action possibly will not be well-received by some doctors. Nevertheless, the nurses understand that they must attempt to educate other healthcare professionals about haemophilia management as illustrated by these examples.

We managed to teach the medical staff [I 1].

At the emergency unit we were helping the newer doctors, so we do a lot of training (F/G4, N2).

Since PWH came into contact with nurses and a range of other allied health professionals such as pharmacists, dentists and physiotherapists, who were involved in the management and care of PWH, it was important that the health professionals understood the significance of symptoms and the management of haemophilia. Six of the nurses realised that they were responsible for educating these staff members who would be part of the team caring for the PWH, as these statements indicate:

After I finished the course I did some training in XXX Hospital with most of the staff (F/G3, N1).

After I finished the course I did some training at the hospital (F/G3, N5).

Regarding home therapy instruction, it is essential to teach the PWH or parent about sterile techniques in order to reduce the risk of infection. Haemophilia nurses are usually the front line personnel who provide instruction in appropriate technique. The nurses also ensure that the PWH or parent understands the need for correct dose of factor replacement, how to prepare the solution, when to administer factor and what to do in the event of a bleeding episode that is not improving. To learn venous access is not an easy task and the

PWH or parents require on-going support and encouragement from the haemophilia nurse both during the learning process and when the technique has been mastered. The same applies to other nurses who may not be familiar with the correct technique. Three nurses described their involvement in this process:

Patients...have also been teached (sic)...how to do home therapy (F/G3, N5).

My colleagues that work with me obviously I inform them and give a little bit of training with them (sic) (F/G3, N5).

[If] the nursing staff they don't know how to mix the factor they will always phone [me] and ask over the phone (F/G4, N1).

An important role for the nurse with haemophilia training is to be able to educate the PWH and their family about the disorder. If the child is very young when diagnosed, the parents are supported in their learning to understand haemophilia. Ten nurses described the experience involving teaching the parents of the PWH about how to manage the disease. The following insights are illuminating:

Teach (sic) the mother about haemophilia care and the disease and she was compliant [I 1].

My two patients are trained, they know what they will tell the doctor, even if they need an ambulance they will tell the ambulance that 'I must go to XXX [hospital], don't take me there' [to another hospital] (F/G3, N4).

[I explain to the PWH] the Sisters won't know if you don't tell them that you are from a family where there's boys with haemophilia [I 1].

After they had completed the HNEP, the participants had a better understanding of how the experience of haemophilia impacted on the lives of PWH. They were able to empathise which helped them to gain the trust and confidence of the PWH. In addition, the nurses could manage the situation during a bleeding episode or a crisis, engendering in the PWH confidence that the nurse would know how to help them. Four nurses related how their interactions with PWH improved as a result of them having participated in the course:

I came to know my patients better (F/G1, N1).

There's a better relationship between me and the patients (F/G3, N2).

They [PWH] can relate to you (F/G3, N4).

Seventeen of the nurses believed that their expertise had improved the health and well-being of the PWH. The following quotes are indicative of this belief.

The patients will come straight to you and say, "Sister I want you to treat me" (F/G3, N1).

Acknowledgement that you can accept as a haemophilia nurse to know that you had thought right (sic) in a specific patient treatment to make him feel better (F/G3, N2).

So I was also so happy because there are so many patients who are coming in, at least now they're getting help because everybody knows I'm there [I 2].

Outreach is considered an acceptable means of reaching the wider community who may not otherwise have access to health information. World Hemophilia Day raises awareness in the community about the disease of haemophilia. This awareness is especially important when factor supplies are plasma-derived as the supply is dependent upon blood

donations from the community. Celebrating World Hemophilia Day, one nurse was able to educate pupils at the school of a PWH and then raise awareness by organising a street parade highlighting haemophilia. As she indicated:

In 2009 for our World Hemophilia Day celebrations we went out on an outreach to Kimberley [I 3].

[Kimberley is a city located in a remote region of Northern Cape in SA]

This is one example of a nurse using outreach to broaden the services of haemophilia. Six other nurses also spoke about increasing their outreach skills.

It was evident that some nurses working with PWH found utilising their new skills very satisfying. Eight nurses expressed job satisfaction, with the following quote regarding professional fulfilment being fairly representative of the group:

The fact that you know that someone can call you.... I can just tell whoever is on the other side “just send them in immediately to XXX [hospital] or XXX” [hospital] (F/G3, N4).

Of the 20 nurses interviewed or in focus groups, one nurse held a senior management position, with seven of the other nurses believing that nursing management had an influence in haemophilia care. One nurse indicated how she worked directly with management to help with the organisation of a significant haemophilia event:

When we’re preparing for World Hemophilia Day I request[ed] that she [another nurse] has support (F/G1, N1).

7.3 Chapter summary

Research question three asked about whether there was a change in knowledge, skills and perceptions of RNs since undertaking the HNEP. Focus groups and one-on-one interviews were utilised to gather data from the RNs who had completed the HNEP and were working with PWH. Responses were organised around Kirkpatrick's Four Levels of Evaluation (1975) + Phillips (2003) Return on Investment (ROI) concept.

The next chapter presents three critical incidents which elaborate on how a nurse who had completed the HNEP was able to intervene at critical times for a PWH. The critical incidents are also included to provide the reader with a more comprehensive understanding of the conditions under which the haemophilia nurses work and the challenges that they encounter.