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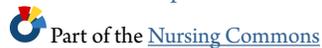
2017

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

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Publication Details

Smith, J. (2017). Development, implementation, evaluation and validation of a haemophilia nurses' education program in South Africa (Doctor of Philosophy (College of Nursing)). University of Notre Dame Australia. <https://researchonline.nd.edu.au/theses/184>

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Chapter 8

Three Critical Incidents in Support of Study Part Two

8.1 Introduction

Three critical incidents were selected from the participants interviewed in the previous chapter. The critical incidents demonstrate different situations when an RN, who had completed the HNEP, was engaged in culturally complicated interventions. Although the cases are different, together they demonstrate the advocacy role of the nurse. In each instance, decisions were taken that could be considered courageous and would probably (on the basis of the information presented in the previous chapter) not have been made without the benefit of the knowledge gained from the HNEP. The three critical incidents emphasise the danger to the PWH if not treated promptly and appropriately.

8.2 Critical incident 1: The need for cultural sensitivity

This critical incident concerns the circumcision of an adult male with haemophilia. The procedure of circumcision is undertaken for cultural reasons and demonstrates the possible associated problems for a PWH. Historically, African societies have been socially organised for millennium into groups who share cultural standards and beliefs about socio-economic, technology, cultural values and governance issues (Konare, 2004). According to Halloran (2004), culture is a system of shared knowledge and practices which are significant to groups within a society and to the individual as a member of that society. Shared knowledge includes beliefs, norms and values while practices encompass language, law and kinship mores. One of these cultural rites is circumcision, a private ritual, performed by certain members of the tribe.

To safeguard confidentiality, the nurse in this critical incident will be called Steven. He completed the HNEP within the past five years and regularly provides a service to haemophilia patients in the hospital where he works, in the Eastern Cape Province of South Africa.

Steven was asked to relate the most memorable event related to a PWH and the part he played in the management of this individual. He told the story of a young Xhosa man who wished to undertake the traditional manhood initiation ceremony common to his tribal customs. The young initiates, all males, are taken into the bush for several days or weeks and instructed in the initiation rituals, including circumcision. This practice is widespread in the Xhosa population and is supervised by traditional practitioners who are bound by the provincial Eastern Cape government legislation known as the Application of Health Standards in Traditional Circumcision Act 2001. The Act promotes the use of hygienic standards and good conduct when the manhood ceremony is undertaken by the traditional practitioners during traditional initiation rituals (Meissner & Buso, 2007). In accordance with this law, traditional practitioners are required to be recognised and registered with the Eastern Cape Department of Health (Peltzer, Nqeketo, Petros & Kanta, 2008). Halloran (2004) writes that culture creates an opportunity for the individual to acquire a sense of personal value by adhering to the cultural values of the social roles, personal values and conduct that the culture stipulates to stave off fears of social isolation.

For a PWH, the risk of bleeding after surgical intervention, even a minor procedure, is high unless factor replacement is administered prior to the intervention and at regular intervals afterwards, until healing of the wound has taken place. Steven was well aware of this risk when he began to plan how best to manage this situation. Risks are increased because the rituals are carried out in secret and attended by the traditional coordinator, the

traditional doctor and the traditional nurse, none of whom had any knowledge or training about haemophilia. To complicate matters, these rituals were carried out in a remote location in the bush on a mountain far from medical help.

It was clear that this traditional ceremony had great significance to the young man, Thabo, and his family. Although he had severe haemophilia B, Thabo was "...adamant he wanted to go to be circumcision in the mountains like his forefathers, his uncles and the rest of his family" (Steven).

Steven was unfamiliar with this young man because he attended the haemophilia clinic in another hospital in the same province. A nurse from this clinic telephoned Steven to inform him that Thabo wished to undergo the initiation process in accordance with the custom of his father's family. Thabo had been reared by his mother and had spent most of his life in Cape Town. However, for traditional reasons he returned to his place of birth so that his foreskin could be buried there.

Steven advised Thabo and his mother to meet him so that a full assessment could be conducted. Baseline blood tests and a general check-up were performed on Thabo to ascertain his health status. The blood tests would determine whether Thabo had inhibitors or sexually transmitted diseases. Steven hoped to use this opportunity to convince Thabo to have the circumcision at the hospital in a clean theatre. However, Thabo was adamant that he would undergo the traditional ceremonies in the bush: he was steadfast that he wanted to follow his culture. He stated, "I want to go and circumcise in the mountains". This emphasises that circumcision is an important ritual and regardless of Thabo having haemophilia, he was determined to adhere to his culture. Steven understood that if they consent to a clinical circumcision performed in a hospital, the young men are "not regarded as real men and are stigmatised and subjected to all sorts of ugly things".

Steven acknowledged that the culture and traditions were important to this young man, however, it was imperative that Thabo realised that there was an element of danger associated with circumcision in the bush, requiring untested procedures with no precedent to use as guidelines. Steven decided to call in a local circumcision coordinator to help explain the position to Thabo and his mother. Steven commented, “my own background coming from a predominantly coloured population and my patient coming from a predominantly Xhosa culture, I had to respect his [Thabo’s] wishes.”

A precise plan needed to be devised to accommodate Thabo’s requests. After much discussion with Thabo and his mother, managers of the hospital and the CEO, it was agreed to offer assistance to enable Thabo to undertake a cultural circumcision. Permission was granted for Steven to travel to the bush near the town of Cofamvaba to administer factor IX to Thabo at the time of the circumcision. The traditional circumcision coordinator, the registered traditional doctor and the registered traditional nurse would be present for the circumcision but since Steven is coloured (of mixed race heritage) and would be bringing western medicine into a traditional setting, permission from the tribal elders was required. Steven was aware that he would be a guest at the ceremony; saying “me not being African coming from [XXX] my forefathers, I am welcome there as a [XXX] and they are happy that western medicine can be brought into the circumcision camp”. Steven's recognition of the importance of maintaining tradition is clearly evident from this comment.

A further setback to the ceremony plans was due to a delay in the return of blood results which caused more anxiety. Thabo’s mother was anxious about whether her son had HIV or other infections. The tests results were negative and she was relieved. Apart from anxiety about her son's health, Thabo’s mother had made a substantial financial investment in this traditional ceremony for her son. She had bought new clothes for Thabo and for the

ceremony. Liquor and food must be provided so she purchased a sheep and a cow, to be slaughtered to honour the forefathers. Steven's expertise and knowledge of haemophilia care helped to allay her fears and validate her spending.

Steven made every endeavour to ensure that Thabo could be initiated in the cultural tradition, despite misgivings about the safety of undertaking such a procedure on a PWH. He successfully negotiated with the health authorities to release him from his hospital duties so he could accompany Thabo. He worked diligently to support Thabo's mother and her anxiety about her son's health and that the money she had spent on the traditional manhood ceremony was not wasted. He effectively negotiated with the Xhosa traditional circumcision personnel to allow him to attend to Thabo during the ceremony even though he understood the taboos surrounding the presence of non-Xhosa individuals at these ceremonies.

Finally, with the preparations in place, the traditional coordinator and Steven drove to the hospital close to where the initiation rituals were to take place. At the hospital, Steven was introduced to Thabo's father and to the local traditional coordinator, the traditional doctor and the traditional nurse who would be conducting the ceremony. Steven gave Thabo the prescribed first dose of factor replacement intravenously. Following this, the initiates and their mentors departed on foot for the mountains. Left behind, Steven became very apprehensive about the well-being of his patient. The following words exemplified that Steven was taking a huge risk which he worried may not pay off, "this was my first outreach so far from my own hospital". Then, the enormity of the situation was realised:

....something went through my head and I started to cry. I thought, what is going to happen to this young man. It's such an urgent mission, it's not just an

outreach, this is a first circumcision that we are treating with no clinical trials we know and this young man led away into the mountain and he's standing on the other side of the river.

He continued to worry. His haemophilia education and experience caring for PWH, alerted him to the potential for excessive bleeding after circumcision and there was no immediate support should anything go wrong. The circumcision is performed in the traditional way with a spear and Steven knew that this crude instrument could increase the likelihood of excessive bleeding. His anxiety was justified. Peltzer, Nqeketo, Petros, and Kanta, (2008) described how circumcision in non-clinical settings carry a risk of complications such as haemorrhage, infection, mutilation and death, thus supporting Steven's concern about the welfare of Thabo.

As Thabo and the other young men were led up the mountain, Steven described how "cold shivers" went down his spine. He phoned his wife and then his mother, asking them to pray because he was so apprehensive that something would go wrong. As they drove back to town from the river, Steven asked the coordinator, his guide, several times about the amount of blood loss with traditional circumcision. The circumcision coordinator assured him that the blood loss was normal; "no my friend, don't worry, the blood loss was like any other one, nothing, there was no excessive blood loss."

That afternoon, Steven and the coordinator drove back to the village close to where Thabo was staying to administer the second dose of factor to Thabo to significantly reduce the risk of excessive bleeding. As they drove, it began to rain. Closer to the village they found that the rain had been heavy in that area. Creeks were in flood, bridges were under water and roads damaged. Eventually they had to leave the vehicle and walk. Upon reaching the rendezvous site, they found that:

...the little stream was turned into a river. The village was situated in a valley and all the water was running down the mountain and the little stream which we crossed very easily in the morningwe couldn't even cross it.

At this point Steven's anxiety increased. He called the haemophilia coordinator in Cape Town for help and advice as he could not contact the haemophilia doctor by telephone. The doctor returned Steven's call after receiving the haemophilia coordinator's call: "Dr M said 'no, it's not worth it, risking your life going across that river'." Steven and the coordinator decided to return to the town but when they reached the vehicle, Steven's fears for Thabo intensified. Thabo needed to have the second dose of factor to ensure that he did not bleed post-circumcision: "I started to cry and this is the first time I mention it now to anybody".

Despite the advice he received from Cape Town to abandon the project, Steven was convinced that it was necessary for Thabo to receive his second dose of factor. He informed his companion of his decision to return to the river and try to cross it. His companion cautioned Steven to be very careful and tried to discourage him. However, Steven was convinced that he needed to find a way to Thabo. He carefully packed the factor and implements to administer the injection in a carry bag and strapped it around his waist. He and the coordinator then headed back to the river bank to find a way across. The next paragraph describes the difficulties Steven faced to cross the river:

I said to Mr [XXX] you go to your left I go to my right. About one kilometre upstream I saw these big rocks, boulders. I didn't see it in the morning when we was [sic] there because I was just looking, it was not necessary to look up and then I saw them myself. I can see that rock but how deep it is down there and there's the same, never tested the water with both feet but as I was putting my left

foot I could feel another boulder and Mr [XXX] was screaming to me “Steven please don’t slip, if you slip there you are gone”. I managed to cross the dam.

The two men found the crossing treacherous and were exhausted from the effort. Eventually, they proceeded up the mountain to find Thabo. It was still raining, there was thick cloud on the mountain and sometimes they lost sight of each other. They were relieved to smell smoke and then finally found the hut where Thabo was staying. Steven questioned the traditional nurse about Thabo’s welfare. The nurse was perplexed about why they had returned: He had applied the traditional dressing made of leaves and said there had been no bleeding. Steven explained why another dose of factor was important and subsequently the second dose was administered. Steven and his companion decided to wait until the rain had stopped and the river water had receded before attempting to return to their vehicle. There was no mobile phone reception at this place and Steven began thinking about what could have happened:

What went through my mind is that if the PWH get a huge bleed because of not receiving this dose. Number one how would the ambulances reach the place now and number two we’ve got a shortage of almost everything in [this province]. It was a do or die situation.

Steven stayed in the area for several days until Thabo had completed his initiation with no complications and was invited to the initiates’ home-coming ceremony, a privilege which is afforded to very few outsiders. Unfortunately he had to decline because he knew he needed to return to his workplace.

Steven described an incident that occurred a little later as the most embarrassing part of the story. He was approached by a local magazine who wanted to write his story. He was not in favour of this because he was concerned about violating Thabo and his family’s

confidentiality. However, the newspaper were more interested in why Steven found the courage to cross the swollen river to ensure the welfare of a young man in the mountains in such conditions. He replied that it was because there was a young man who had his future in front of him and that he (Steven) was very fortunate to be privy to this ceremony. He stated:

God was looking after me and people praying for me to reach that man.if I never had the insight or the interest in haemophilia I could have stopped this thing in my clinic already and say listen, I am doing haemophilia in the clinic.....not outside the hospital. But in respecting the culture of another person and going beyond the call of duty, going to the authorities and saying you must put pen to paper and say yes or no you cannot go, and assist this young man.

The following quote emphasises the humility of this nurse. When asked about his feelings in relation to the incident, Steven said, “the incident itself I don’t really talk about, it means nothing to me as long as this young man’s life has been saved”. And, “this could have been done by anyone who had the courage and to really consider haemophilia as an important part of nursing throughout the world.”

Also,

As a haemophilia nurse you must always put your patient before yourself and really the training I received from [HNEP coordinator] and [HNEP coordinator] and the other [HNEP coordinator]... I think is one of the best and I’d do it again.

Steven wrote a report to the authorities which he considers helped to raise awareness of haemophilia among management at his hospital and the importance of having nurses

educated in haemophilia care. He believes they are now working together as a team for the betterment of PWH. An example of this is the case of twin brothers, one of whom had traditional circumcision last year and his brother, who is factor VIII deficient and will undertake the initiation program later this year. This young man is better prepared than Thabo. His parents are well-educated and he attends the haemophilia clinic regularly, understanding his condition well. When he becomes an initiate, the ceremony will take place locally and if the hospital management agree and sign the indemnity, Steven is willing to attend and assist if required.

8.3 Critical incident 2: Advocacy in the face of a haemophilia emergency

This critical incident demonstrates how a RN who had completed the HNEP was able to challenge the management of a PWH in a crisis situation. In essence, the case demonstrates the confidence of the RN to advocate for the patient. To maintain confidentiality the nurse is given the pseudonym Amanda.

Advocacy is defined by Macquarie Dictionary (2013) as “pleading for, supporting or recommending” (p. 15). Within the nursing profession, advocacy for a patient is an accepted part of the role of the nurse and is incorporated into the International Council of Nurses (ICN) Code of Ethics which states: “The nurse shares with society the responsibility for initiating and supporting action to meet the health and social needs of the public, in particular those of vulnerable populations” (2012, p.2).

Amanda lives and works in SA, and currently facilitates clinics for PWH. Amanda completed the HNEP in 2009, and is currently employed as a haemophilia coordinator based in Johannesburg, supervising and mentoring nurses in haemophilia care in several provinces. Amanda stated that since completing the HNEP, her capacity to advocate for the patient has improved greatly, stating, “being haemophilia trained nurse has helped me a lot

with advocacy". To demonstrate how the HNEP has influenced her practice, she related two situations where, without her advocacy, the PWH almost certainly would have died.

The first case concerns Tom (a pseudonym), a four year old boy who has severe haemophilia A. Tom was the first child in his family to be diagnosed with this disorder. Once the diagnosis was established, the nursing staff educated Tom's mother about haemophilia care. She was informed about how to recognise a bleed, how the disorder is inherited, how to administer first aid when a bleed occurs at home, when to contact the haemophilia treatment centre staff and what situations will almost certainly provoke a bleed. The mother was very compliant and brought her son to the HTC when necessary. Unfortunately, Tom had veins that were difficult to cannulate and only one doctor at the HTC was able to regularly accomplish venous access. After some months, Tom's mother married and moved to another province with her husband. There was a small hospital but no staff, doctors or nurses, skilled in haemophilia care. This situation for Tom became more critical because of the difficulty in venous access, which caused some concern for the staff.

A short while after the relocation Tom's mother contacted Amanda to inform her that her son had an elbow bleed and she had taken him to the local hospital. The doctors admitted Tom as an inpatient but were not prepared to accept the parents' word that Tom had haemophilia, so due to Tom's inaccessible veins, the doctor decided to take blood from his neck. The site where the needle was inserted continued to bleed and the child's neck was increasing in size. The parents tried to inform the doctors and nurses that the bleeding was due to haemophilia and emphasised that the bleeding would not stop without the correct treatment, that is, factor replacement. The medical staff refused to listen. In desperation, the mother called Amanda and asked her to speak to the doctors at the hospital. Amanda tried to do this but a member of the nursing staff assured her that Tom was improving and

there was no need for Amanda to speak to the doctors. The next day Tom's father visited the boy and was so concerned that he also phoned Amanda. The father said; "his neck (Tom's) is as big as his head" and Amanda realised there was a very large haematoma on his neck.

Recognising that Tom was in imminent danger of an obstructed airway due to a haematoma, and as the nursing staff continued to prevent her from speaking to the doctors, in desperation, Amanda phoned the doctor at the nearest HTC. The response to Amanda's concern was immediate. Arrangements were made for a helicopter to transfer Tom to the HTC facility as soon as possible. Here the boy was appropriately treated and recovered within days. As Amanda stated, "I don't think if I was not haemophilia trained I could have managed to follow up and make sure that the boy gets the right treatment."

Following this terrifying incident the parents and the medical staff at the local hospital began cooperating and working together to ensure that Tom received the correct treatment should he have another bleed. For Amanda this collaboration was a positive outcome. She stated:

.... being able to help the boy survive, it makes me feel very good, and it was not only the process of helping the boy survive but we managed to teach the medical staff, the parents and everybody who was involved so that makes me feel good that at least I've helped someone.

According to Beyea (2005) nursing advocacy is critical to maintaining patient safety while they are in the care of the health system. Mallik (1997), a British nurse who conducted a review of the literature of nurse advocacy agrees, suggesting that if a nurse should be in a similar situation and believed their professional knowledge was central to the decision-making process, then patient advocacy was appropriate. However, Mallik (1997)

cautions that the nurse would be required to have “knowledge of ethical decision-making” (p. 135) in order to apply the advocacy role.

8.4 Critical incident 3: Advocacy in the face of doctor’s resistance

Amanda related another incident that had a similar level of seriousness in terms of patient morbidity. The event occurred during the Easter break when there were reduced staffing levels. In this situation, Amanda had to deal with a challenging doctor. Amanda was well aware of the difficulties that may arise, stating, “since this boy [pseudonym, Jim] has been diagnosed we have dealt with this doctor who he [PWH] has been taken to and he’s not an easy person”.

Jim suffers from severe haemophilia and inhibitors. His mother contacted Amanda to say that he had injured his neck and that it was swelling. The family understood the urgency of the situation and rushed him to the nearest hospital. However, the treatment for inhibitors was not available. Amanda spoke to the doctor and asked him to send Jim to a hospital where treatment for this condition was available. She was aware that the doctor was obstinate, and that a difficult situation could occur. According to Mallik (1997), the need for advocacy arises when there is an unequal balance in power relationships between the vulnerable patient and the professional in control in the particular context. This situation reflected such an unequal balance but Amanda was cognisant that she must be an advocate for Jim and his family.

After some uneasy dialogue between the nurse and the doctor, the doctor agreed to send the boy to the hospital which had a supply of factor for inhibitors but would not acknowledge there was any urgency and admitted Jim to the ward at his hospital overnight. Throughout the night Jim’s neck continued to increase in size. Clearly, this was a crisis situation and as the hours passed, the bleeding continued. Amanda felt that there was a

problem with the doctor acknowledging that Amanda, as a nurse, knew the risks involved in delaying appropriate treatment better than he did, so chose not to treat the case with any sense of urgency.

When Jim was finally transferred to a hospital with available factor, the doctors were horrified at the severity of the boy's condition because according to Amanda, "he was already drooling saliva and the neck was big and they wanted to take him to ICU." The doctors telephoned Amanda to check that it was safe to transfer the boy to ICU. Amanda indicated that it was, on the proviso that they continued to give Jim the factor. Two hours later, they again contacted Amanda to inform her that they wanted to transfer the boy to a large metropolitan hospital, where there was a dedicated HTC, as they were concerned that the treatment was not working quickly enough. Amanda strongly advised the doctors to keep the boy at their hospital and to continue to give him factor. If the transfer took place this would cause an interruption in the treatment which could increase the risk of further bleeding and a real danger of airway obstruction. Convinced by Amanda's assessment of the situation, the doctors kept the boy at their hospital and continued to administer factor. This action is in stark contrast to the first doctor who saw Jim and continued to keep him under his care even though he did not have the necessary treatment that the child so desperately needed. Amanda knew that she may well be faced with opposition from the doctors or that they may simply ignore her advice but that she had to be insistent in order to do all that she could to save Jim's life. Her experience in the second hospital renewed her faith in the fact that there are doctors who do respect the expertise of haemophilia nurses.

The next day, when Amanda phoned and enquired after the boy's well-being, she was informed there was no change in his condition. By the time Amanda phoned again in the evening, Jim had made a slight improvement. The next morning, Amanda was informed

that he was out of bed and playing. She was relieved that his condition had greatly improved and there was a plan to discharge him the next day. On hearing this news Amanda stated:

That made me realise that my training is very important, being a haemophilia trained nurse is very important because I wouldn't be able to ask them about the symptoms of this boy. When they told me that he's drooling saliva I knew that it was serious.

Kohnke (1980) advised that the nurse needs a mix of "personal qualities and specific education for the role" of patient advocate and that they need to be "innovators and risk-takers" (p. 135). Mahlin (2010) supported this view by stating that nurses face challenges when advocating for patients, as the institutionalised system that prevents patients from accessing appropriate health care, also impacts nurses, as was the case in this incident. In the following statement, Amanda concurs with the above viewpoint, stating, "I feel very happy to realise that at least I can help the patient and also by just giving advice, the patients are able to be saved."

8.5 Chapter summary

The incidents related in this chapter serve to demonstrate the actions two nurses, who had completed the HNEP, took to mitigate a crisis situation in three separate incidences involving PWH. The physical bravery of one nurse to provide treatment in a dangerous geographical location, and the strong sense of advocacy in the other nurse, almost certainly saved their lives.

The next chapter details the data collected from the expert nurse educators in the service of evaluating the HNEP. Data were collected in Australia as this is where the researcher resides and locating herself in SA for this phase of the study was not necessary.