

**EXPERIENCES OF CRITICAL CARE UNIT NURSES
CONCERNING THE WITHDRAWAL OF LIFE –
SUSTAINING TREATMENT**

BY

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DECLARATION

I, Peliswa Prudence Kupa-Mesa Noroña, declare that this thesis and the work presented in it are my own and have been generated by me as the result of my own original research:

The lived experiences of nurses concerning the withdrawal of life -sustaining treatment from a critical ill patient in a Critical Care unit (CCU): An explorative research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given and, with the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

Either none of this work has been published before submission, or parts of this work have been published.

Signed: 

Date: 03/03/2016

DEDICATION

I dedicate my study to my late parents Mr and Mrs T. V.N Kupa. They had always seen and admired the progress their children were making. I also dedicate it to my late husband, Mr L. Kwatsha, who inspired me to continue despite all odds. May their souls rest in peace.

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ABSTRACT

The purpose of the study was to identify, describe and explore the experiences of nurses in a critical care unit (CCU) on the withdrawal of life - sustaining treatment to patients in Buffalo City Metropolitan, South Africa. A qualitative study was conducted in the critical care units from two institutions in the Eastern Cape. A non-probability purposively sampled seven critical care unit nurses was used. Ethics in the study were considered and the pilot study done in one participant which was not part of the study. Few highlights in the interview guide were noted and taken care of. Unstructured in-depth interviews were used as an instrument for data collection. Five main themes emerged from data analysis:

- Decision making by doctors concerning withdrawal of treatment from a critically ill patient in a CCU;
- Doctor-nurse relationship regarding withdrawal of treatment from to critical ill patients in CCU;
- Nurses' experiences regarding the process of withdrawal of life-support treatment from a critically ill patient in CCU;
- Nurses' responsibilities as health professionals towards the patients regarding their profession; and
- Coping strategies regarding the withdrawal of life- support treatment from a critically ill patient. Recommendations were put forward to try and reduce the moral distress suffered by nurses in CCUs.

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KEYWORDS

Nurse

Critical care environment

Life - sustaining treatment

Chapter 1: INTRODUCTION AND BACKGROUND

1.1 Introduction and background

Patients with acute life threatening health problems such as pulmonary and cardiovascular diseases, cardiac arrests and sepsis are mostly admitted in critical care units (CCU). Often some of these patients suffer from multiple organ dysfunctions and subsequently require all forms of life -sustaining treatment such as mechanical ventilation, hemodynamic support or both (Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman & Gagnon, 2011:32). In such an environment, one nurse is allocated to nurse one patient throughout the shift as the condition of the patient could change suddenly (Vanderspank-Wright et al., 2011:32).

There is also a tendency that nurses in such an environment prefer to look after the same patient until the condition improves and that patient is transferred to the general wards. This form of nursing care advances the attachment between the nurse, the patient and the patient's family. The fact that nurses are the key providers of care further enhances the greater contact with the patient and reinforces the attachment. Trusting relationships are developed between nurses themselves, patients and their relatives (Pattison, 2011:113). The trust that developed is viewed as a crucial element especially when it comes to the end of life care (Wiegand 2008:1116). The nurse therefore is a mediator between the patient and the patient's family in a form of explaining the procedures (withdraw or life- sustaining treatment) in CCU environment and the signing of the consent form when necessary.

The decisions to withdraw life- sustaining treatment are sometimes taken as a result of the ever increasing cost of the health care system as stated in the findings of Van Rooyen, Elfic and Strumpher (2005:43). It is further explained in the same study that, once the patient has died the family can be left responsible for paying large medical bills, which would be lessened if the treatment was withdrawn earlier.

One may be concerned and ask if it is justifiable to withhold or withdraw treatment because of costs. The studies conducted highlight that it is rarely justifiable to discontinue life-sustaining treatment for cost reasons alone. While we should always try to avoid costly treatments that offer little or no benefit, our obligation to the patient outweighs our obligation to save money for health care institutions. There are rare

situations in which costs expended on one terminally ill patient could be clearly better used on another, more viable patient.

The researcher, as once a critical care nurse, observed that it had been a common practice to take out of critical care unit a patient identified as one who no longer will benefit from the aggressive treatment for a patient who is acutely ill. In such cases, to withdraw life-sustaining treatment from the terminally ill patient in favour of the more viable one would be justifiable. However, such decisions need to be taken without taking into consideration the feelings of the patient's family. Reports on previous studies highlight the process of treatment withdrawal as being complex and should incorporate end of life care (Lind, Lorem, Nortvedt & Harvey, 2008: 667).

Several other factors have been found to influence family members' decisions related to withdrawal of life -sustaining treatment which include poor expected quality of life, poor prognosis, the patient's current level of suffering and previously discussed advanced directives (if any) (Wiegand, 2008:1116). Elderly people's attitudes may be influenced by cultural and religious beliefs and background to hold on to life support systems even though they have been advised on their prognosis. This situation may be more pronounced with illiterate family.

Pattison (2011:113) viewed the planning of the process as important because most patients die within one to two hours after withdrawal of treatment. This means that there is a small window for nurses to be involved in shaping the end of life trajectory for patients who have reached the point of futility. The decisions taken have to be those that favour the patient's desires (Lind *et al.*, 2008:667).

The critically ill patients are usually unable to take part in decisions on whether they should be resuscitated or their treatment withdrawn. This is due to the fact that they are intubated and mechanically ventilated or the disease process affects their cognition (Lind *et al.*, 2008:667). The medical professionals and family/significant others become compelled to take the decision (Lind *et al.*, 2008:667). Nurses are not at all involved in such decision making processes (Lind *et al.*, 2008:674). However, Adams, Donald, Bailey, Anderson and Docherty (2011:3) are convinced that other health care professionals, such as nurses, social workers, and chaplains, have legitimate roles to play in the end of life decision making process.

Since the development of life-sustaining treatment, some patients remained dependent on these life support systems until death. However, curative care is rarely the best option for these patients. The disadvantage of the prolonged non beneficial treatment robs the patient of dignity and the family of the opportunity to prepare for bereavement (Azoulay, Metnitz, Sparing, Timsit, Lemaire, Bauer, Schlemmer, Moreno & Metnitz, 2009: 624). Also, it is possible that a patient is kept alive through use of the life-sustaining treatment because of possible legal implications from relatives. Anecdotal non researched information indicated that this is a practice often seen in the private sector as long as patient funds are available, but this needs to be researched.

The primary goal of medical treatment is to maximize benefit by restoring or maintaining the patient's health, as far as possible and minimizing harm (Truog, Campbell, Curtis, Curtis, Luce, Rubenfeld, Rushton, & Kaufman, 2008:953). However, if treatment fails, or ceases to give a net benefit to the patient, the primary goal of medical treatment cannot be realized and the justification for providing the treatment is removed. Unless some other justification can be demonstrated, treatment that does not provide net benefit to the patient may, ethically and legally, be withheld or withdrawn (Truog, et al, 2008:956)

Withholding and withdrawing life-sustaining treatments are legally justified based on the principle of informed consent and informed refusal (Pawlik, 2006:990). An adult patient with decision making capacity may, in advance, formulate and provide a valid consent to the withholding or withdrawal of life-support systems in the event that injury or illness renders that individual unable to make such a decision. A patient may also appoint a surrogate decision maker in accordance with state law (Pawlik, 2006:990). This is not a common practice with some communities. Death and dying are not welcome by many people. Gedge, Giacomini and Cook (2007:216) state that, control over our body has been taken to be central to the interpretation of autonomy. In the context of end-of-life care, the right to refuse treatment places a recognized limit on interventions by doctors, who must respect refusals even against their best clinical judgement and even if a patient's life is at risk as a result. Patients may thus insist that treatment not be given or be withdrawn. This may be any medical intervention, including artificial nutrition/hydration and cardiopulmonary resuscitation

and doctors may be expected to comply. However the patient must be in a capacity for decision making.

Stacy (2012:18) argues that, treatments should not be withheld because of the mistaken fear that if they are started, they cannot be withdrawn. This practice would deny patients of potentially beneficial therapies. Instead, a time-limited trial of therapy could be used to clarify the patient's prognosis. At the end of the trial, a conference to review and revise the treatment plan should be held. Some health care workers or family members may be reluctant to withdraw treatment even when they believe that the patient would not have wanted them continued. Most guiding documents declared that doctors are under no obligation to offer treatment they consider futile (Gedge, Giacomini, & Cook, 2007:216).

Although life -sustaining treatment refers to a number of activities, some people may ask if it is justified to withhold or withdraw food and fluids. This question underscores the importance of clarifying the goals of medical treatment (Adams, et al, 2011:10). Any medical intervention can be withheld or withdrawn, including nutrition and intravenous infusion (IV) fluids. At all times patients must be given basic humane, compassionate care. They should be given a comfortable bed, human contact, warmth, and be kept as free from pain and suffering as possible (Stacy, 2012:18). While some believe that food and fluids are part of the bare minimum of humane treatment, both are still considered medical treatments. Several court cases have established that it is justifiable to withhold or withdraw food and fluids, especially when the gastro-intestinal tract system has proven beyond doubt that it is not functional. This would be confirmed by a distended abdomen with copious gastric contents pouring out through the patient's nose and mouth (Adams, et al, 2011).

Two important principles of treatment withdrawal are cited which are to remove treatment that is no longer desired or does not provide comfort to the patient and that it is a medical procedure (Rubinfeld, 2004:436). The nurse's responsibility is that of carrying out the doctor's prescriptions. Hansen, Goodell, De Haven & Smith (2009:264) state that nurses working in intensive care units have traditionally received little education and training in the care of dying patients and patient's families. In daily practice, the experience in this regard is mostly learnt from daily

encounters. However, other factors that exist, for example strong communication, good work relations, can improve the knowledge gap as a teaching curve (Hansen *et al.*, 2008:264).

Another area of importance is lack of knowledge about the withdrawal of life - sustaining treatment and its role, and does not take into consideration the ethnic background of the patient and his/her cultural influences in the care of a dying patient. The improved communication between nurses and family members therefore concentrates on interaction that enlightens all parties involved to a heightened awareness of the patients' and families' beliefs, culturally, spiritually and social standing (Browning, 2009:20). When accurate and thorough communication between healthcare professionals and the patient's family is facilitated in the critical care setting, the ground for appropriate end of life decision making is somewhat levelled. Cook and Rucker (2014:2513) state that, the power of effective communication also includes the power of silence. This implies to the behaviour of the physicians during the family meetings at the end of life care where by the physicians would be expected to talk less and listen more from family members. Such a behaviour is said to greater improve the family satisfaction for they would have time to express how they feel (Browning, 2009:20). Hence the family should not be coaxed into decisions regarding end of life care.

In essence, critical care nurses are designated to care for acutely ill patients and not for dying patients and their families. A systematic understanding of what roles nurses enact and what strategies they use in end of life decision making is necessary to ensure that decisions made are consistent with the patient's and family's goals of care (Pattison 2011:113). The highly technological and curative focus in the CCU may make fostering quality end of life care more difficult, Nurses in CCU derive pleasure from seeing their patients walking out of the unit being healthy individuals. They may fail to realize that the critical care environment is strenuous and demanding, as long as the mission has been accomplished, that is, the acute illness has been relieved and the patient is healthy and discharged.

1.2 Problem statement

Nurses who are always at the bedside during life-sustaining treatment spend the entire shift with the patient and family. This perspective places nurses in a position to facilitate decision making but they are not involved in any decision making for the withdrawal of life-sustaining treatment related to the patients they nurse and whom they completely understand in all aspects. (Adams, *et al.*, 2011:2)

Bloomer, Lee and O'Connor (2010:18) state that nurses are not well presented in decision making pertaining to patient care. This is interpreted as undermining the importance of the nurse's role in direct patient care that extends to the family in ICU. Also, it has been observed that the meetings for decision making are occurring at the patient's bedside which suggests that either the nurses' presence at these meetings are not recognized or the nurses are not included in those family meetings with the physician. This echoes the fact that the nurses are not taking part in decision making regarding the withdrawal of life- sustaining treatment.

Nurses are defined as knowledgeable on how to take care of critically ill patients in a critical care environment but institutional constraints make it nearly impossible to pursue the right course of action (Epstein, 2008:771). For an example, as nurses are always at the patient's bedside, they could be the one to inform the doctors of deterioration in patient's condition and initiate the family meetings. But that they have to wait to hear from the doctors who probable come once a day to see the patient.

1.3 Purpose of the study

The purpose of the study is to explore, identify and describe the experiences of nurses working in a critical care unit on withdrawal of treatment and its impact. The broad question put to the participants was as follows: what are your experiences concerning withdrawal of life-staining treatment from a critically ill patient?

1.4 Objectives of the study

- To identify the experiences of nurses in a critical care unit on withdrawal of life sustaining treatment to patients.

- To describe the experiences of nurses in a critical care unit on withdrawal of life - sustaining treatment to patients.
- To recommend strategies for the involvement of nurses in decision making.

1.5 Research questions

- What are the experiences of the nurses working in critical care units on the withdrawal of treatment from their patients?
- What strategies are needed to assist critical care nurses to cope in the withdrawal of life-sustaining treatment in a more positive manner?

1.6 Significance of the study

The researcher was a critical care nurse for fifteen years. She has an experience of not being involved in decisions taken towards patient management. The researcher had accompanied students to critical care unit thus been able to observe nurses at work. However, she will not allow her personal experience to influence the findings of the study. The patient's relatives would not understand when the nurse responds in a way they would view as inadequate. The researcher will make recommendations that will increase the involvement of nurses in decisions, especially those related to withdrawal of treatment to patients in a critical care unit. The patients and the patients' families will be well represented by the nurses because nurses are taking care of patients for 24 hours a day. The results may assist the managers to review the current role played by nurses on treatment withdrawal.

The manager may look at the support structures (if there are any in place) and measure their effectiveness against the information received. The Department of Health might benefit from losing the nurses from probable burnout syndrome and the exodus of nurses looking for greener pastures caused by their conditions of service. The government will also benefit in terms of costs, because, life-sustaining treatment is costly if at the end the patient will have brain damage. Nurses will be enriched with knowledge from their medical counterparts.

1.7 Definition of terms

1.7.1 A nurse

A nurse (general, psychiatric and community) and midwife shall be registered in terms of section 16 if:

- (a) he/she received education and training at an approved nursing school;
- (b) he/she was registered as a student in terms of the regulations relating to registers for students published under Government Notice R.3735 of 14 November 1969, as amended by Government Notices R.171 of 12 February 1971, R.1204 of 7 July 1972, R.1647 of 20 September 1974 and R.2207 of 31 October 1980;
- (c) he/she has successfully completed the course of study, has complied with the programme objectives referred to in regulation 6(2), and the other requirements for the award of the qualification concerned.

In this study the researcher refers to all the nurses trained in critical care nursing who have more than two years' work experience in the critical care unit1.7.2 the critical care environment

1.7.2 The critical care environment

This is the specialized care of patients whose conditions are life threatening and who require comprehensive care and constant monitoring (Hirshon, Risko, Calvellode Remireh, Narayan Theodosios & O'Neill, 2013:386). In this study this refers to the specialized environment where some patients' lives depend on machines that sustain them.

1.7.3 Life – sustaining treatment

Life-sustaining treatment may include, but is not limited to, mechanical ventilation, cardiopulmonary resuscitation (CPR), renal dialysis, surgery chemotherapy, antibiotics, and artificial nutrition and hydration.

1.8 Theoretical framework

Humanistic nursing practice theory

The study is based on Paterson and Zderad's humanistic nursing practice theory. It is a practice theory because they believe that the theory of a science of nursing develops from the lived experiences of the nurse and the person receiving care as explained by George (1995:301). The experience in the world of health care is the foundation for understanding the nature of nursing and what it means to be a nurse.

Humanistic nursing is concerned with the phenomenological experiences of individuals, the exploration of human experiences (George, 1995:302). The researcher has found this theory appropriate as the study undertaken was based on the experiences of nurses she explored and interpreted to get the meaning. These two scholars state that individuals need to know what values, biases, myths, and expectations they bring to the nursing experience. Also, they need to appreciate what values biases, myths and expectations others bring to the nursing experience.

The combination of these perspectives brings uniqueness to nursing. George, (1995:302) further suggested that the practice of humanistic nursing is rooted in existential thought. Existentialism is a philosophical approach to understanding life. The individuals are faced with possibilities when making choices. These choices determine the direction and meaning of one's life. Humanistic practice theory's concepts provide the basis of nursing: dialogue, community and phenomenological nursing. The researcher therefore adapts the phenomenological nursing concept with its five phases because of its relevancy to the phenomenon under study. Phases are discussed as follows:

Preparation of the nurse knower for coming to know: nurse always prepared and striving to be open and caring. This means being open to experiences, to one's own view of the world and to other perceptions. In this study the nurse is exposed to wide range of experiences of patients in the critical care unit where they expressed their experiences. The wider the experience the nurse has, the wider the possibility for knowing (George, 1995:302).

Nurse knowing the other intuitively: this phase emphasis on the self of the other, the other refers to the patient experience. Therefore it presumes the phenomenological approach of being open to the meaning of the experience of the other. In this study the nurse is understand each individual situation of the patient and avoid labeling and judging patients (George, 1995:303).

Nurse knowing the other scientifically: the phase is concerned about the analyzing, sorting, comparing, contrasting, relating, interpreting, naming and categorizing the phenomenon under study. In this study the nurse the nurse is carefully selecting words that will seek to clarify and verify the meaning of the patient's experience (George, 1995:302 please check the real page).

Nurse complimentary synthesizing known others: this phase is interested in relating, comparing and contrasting what occurs in nursing situations to broaden one's understanding. In this study the nurse compares and synthesizes multiple realities (similarities and differences) and use the rich theoretical foundation of education and practice in order to put the clinical situation in perspective that will yield informed decision (George, 1995:308 please check the real page).

Succession within the nurse from the many to the paradoxical one: this phase is more of descriptive process of a lived experience of the phenomenon understudy. It emphasize on the refinement of the general idea, intuitive grasp, known realities, studied, compared, contrast and synthesize it in order to arrive at a truth that is uniquely personal but has meaning (George, 1995:309). In this study the researcher adopts all the Paterson & Zderad the key elements of the theory in order to understand better the meaning of the experience of the phenomenon under study.

The researcher concurs with the philosophers because in practice the patients make choices on whether or not to receive or refuse treatment. However those in intensive care unit do not make such choices. George (1995:303) conclude by stating that, though people are alone in choosing the path their lives will take, they can find meaning in sharing their experiences with others who are facing the choices of daily living. This is the time when individuals are able to reflect on their experiences and find meaning and understanding of why things happen the way they do. This means that we as nurses must acknowledge the importance of our own struggle and needs as part of the process of living.

1.9 Humanistic Nursing Practice Theory of Paterson and Zderad

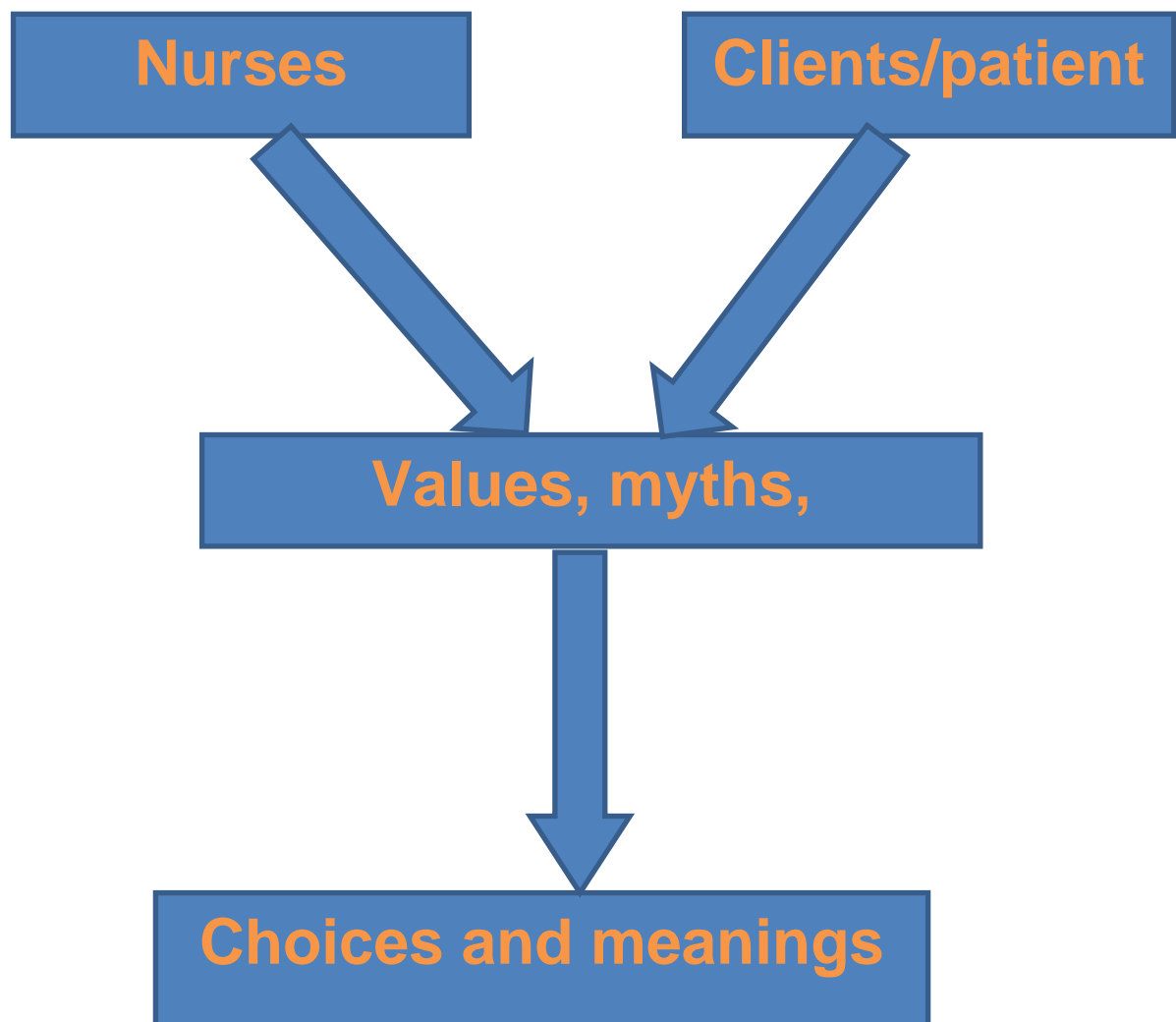


Figure1.1 Adapted theory of Humanistic Nursing Practice by Paterson and Zderad

1.10 Summary

In this chapter the scientific foundation of the study was introduced. The introduction and background, problem statement, the objectives of study, the significance of the study, the research question, the definition of terms and the theoretical framework were discussed.

Chapter 2: LITERATURE REVIEW

2.1 Introduction

For this research study, a cursory literature review before data collection was carried out to ensure the necessity of the study and the appropriateness of method selection. An in-depth literature review was conducted after data analysis to place the findings within the context of what is already known about the topic (Speziale, Streubert & Carpenter, 2007: 97).

A literature review involves finding, reading and forming conclusions about the published research and theory as well as presenting it in an organized manner (Brink, Van der Walt & van Rensburg, 2010:71). A literature review is conducted to enhance an understanding of what is known about a particular situation or phenomenon and the knowledge gaps that exist. A literature search is a systematic and explicit approach to the identification, retrieval and bibliographical management of independent studies (usually drawn from published sources) for the purpose of locating information on a topic, synthesizing conclusions, identifying areas for future study and developing guidelines for clinical practice (Burns & Groove 2009: 38 & 707).

The researcher performed a literature search on the experiences of nurses working in critical care units on the withdrawal of life-sustaining treatment from critically ill patients in their units. The impact of the treatment withdrawal was looked into from the patient, nursing, and the family perspective. The researcher explored strategies that can be utilized to involve nurses in decisions pertaining to withdrawal of life-sustaining treatment and the availability of support system for nurses and the

application of the humanistic nursing practise in exploring human experiences (nurse, patient and family of the patient).

After the decision to admit a patient to the CCU, life-sustaining interventions are begun. For example, if a patient is experiencing severe respiratory distress, interventions could possibly include the use of high amounts of inspired oxygen or the consequences of implementing life-sustaining treatment in order to stabilize and treat a patient can be continued dependence on technology such as mechanical ventilation for prolonged periods and perhaps continued deterioration of the patient's condition (Wiegand (2008:1115)

2.2 Impact on the patient

Patients in a critical care unit are normally put on life support systems which would be, among others, respiratory support, haemodialysis, cardiac pace makers, artificial feeding, etc. These mechanisms are used to keep the patient alive whilst the body is recovering from illnesses, trauma or surgery.

During the process of treatment withdrawal if a patient has capacity and makes a voluntary and appropriately informed decision to refuse a treatment, the patient's decision must be respected. The right to refuse treatment places a recognised limit on interventions by doctors, who must respect refusals even against their best clinical judgement and even if a patient's life is at risk as a result ((Gedge, Giacomini & Cook, 2007: 215). Often these rights may not be exercised in the critical care environment when doctors are caring for critically ill patient who are comatose (Gedge, Giacomini & Cook, 2007:218).

Park (February 2, 2007) shared views of patients regarding life support systems as follows; one patient asked him/herself if he/she should spend the last months of life undergoing difficult treatment and spending every penny to pay for it. For this patient there was a choice which would just be to forgo treatment. Patients are aware that they can accept what the medical science has to offer or refuse the treatment. Morrow (2014:8) highlighted that patients have rights to accept or refuse the treatment except for pain control and management.

In the article about 'pulling the plug' it is highlighted how some patients show understanding concerning the withdrawal of treatment (Park February 2, 2007). These patients verbalize that the doctor can tell how long they can expect to live when the treatment assisting the vital functions of the body has been withdrawn. Furthermore, they felt that, when they are being supported by a heart-lung machine that is keeping the blood circulating and oxygenated, they know that the situation cannot continue indefinitely. In such situations, they verbalize that when people are ready for their lives to end they can simply refuse to take any kind of treatment that is keeping them alive. However, the patients in CCU are most often unable to engage in the decision.

Halcomb, Daly and Davidson (2004:214) presented a paper highlighting the use of technology and the moral, ethical dilemmas concerning the end-of-life care in the critical care unit. Her study also aimed to explore the lived experiences of critical care nurses caring for clients having treatment withdrawn or withheld. Halcomb et al, (2004:214) stated that, whilst the competent individual has the right to refuse or embrace treatment, those in the ICU are rarely able to exercise this right. This could be due to the disease processes that affect their ability to engage in discussions. Therefore the theory that guide this research study is centered on the experiences of nurses and interpretation of patient's beliefs, values and experiences regarding the process of withdrawal of treatment from a critically ill patient.

The views of Stacy (2012:16) are, that once the decision to withdraw the life-sustaining treatment has been made, all the curative interventions should be discontinued, including dialysis, enteral and parenteral feeding, blood transfusion and antibiotics. Routine monitoring, for example blood pressure, pulse rate and laboratory studies, should all be stopped. The goal is to remove the treatment that no longer is desired by the patient.

2.3 Impact on families

End-of-life care planning is often a long process of negotiation, whereby patient and family needs are addressed, met, and renegotiated based on changing needs. Daily ongoing discourse is necessary to identify these changing needs. Decision making is often an arduous and time-consuming process that involves not only informing the

patient and family but also gaining insight from the family regarding family dynamics and their identities, both individually and in a group, so as to guide them through the necessary decisions (Browning, 2009:22). Family members are the ones who normally take decisions when they are approached by doctors to do so.

Families of patients from whom the treatment is withdrawn are highly stressed following the decision making but the amount of stress tappers down as time goes (Tilden, Tolle, Nelson, 2001:105). Even though the stress level decreases, it will be triggered by the family's subsequent contact with the relevant care givers.

In a qualitative study that explored how the relatives of critical care unit patients experienced the nurses' role and relationship with them in the end-of-life decision-making processes, the findings reveal that despite bedside experiences of care, compassion and comfort, the nurses were perceived as vague and evasive in their communication, and the relatives missed a long-term perspective in the dialogue, (Morgan, 2008:153). However, as the results further unfold, few experienced that nurses participated in meetings with doctors and relatives. The ethical consequences of such limited number of nurses' participation implied increased loneliness and uncertainty on the part of family members. The relatives realized that they had the responsibility for obtaining information from the doctors themselves and understanding their role in the decision making process. The relatives therefore felt that the nurses could have been more involved in the process.

On a positive outlook, the withdrawal of treatment curtails distressing interventions and therapy when there is no hope of recovery. Morgan (2008:153) states that withdrawal of treatment enables families to prepare for death. The ethical principle of justice is facilitated and the reallocation of resources to those who will benefit

However the practice of humanistic nursing theory emphasize on understanding life. In this study the patients and their families are encountered with options of making choices. These choices determine the direction and meaning of one's life. The researcher concurs with the philosophers because in practice the patients make choices on whether or not to receive or refuse treatment. However those patients and their families in critical care unit do not make such choices.

2.4 Family support

Stacy (2012:314) states that families require emotional support as a coping mechanism as well as ensuring that everyone understands the process and is provided an opportunity to gather information regarding the withdrawal of life-support treatment. The family therefore has to be educated on what life -support treatment is and how the patient benefits from the life-support he/she is put on. By so doing, the chances of family having a hard time understanding the withdrawal of treatment which is deemed non beneficial are reduced. Adequate time is given to family members to assimilate the given information. Families respond to pressure in a number of ways including arguing to becoming unavailable after the meeting with doctors so that the decisions could not be made (Luce & White, 2007:1106).

According to Wiegand (2008:1117), the family/significant others welcome the presence of nurses at the bedside for the comfort and support it brings. At the time of grief, the nurse makes the family realize that they are not alone by merely being there, holding hand and talking to them. Also when the family is constantly informed of the patient's progress. Some family members may request to offer the last bath to their loved one, nurses would be there to give permission and assistance, also showing understanding when they feel they cannot continue even though they were so adamant at the beginning. Several scholars have posted videos and DVDs which equip families on coping with the end of life decisions.

2.5 Impact on nurses

Kim, Yates, Graham and Brown (2011:259), state that critical care nurses have to work with families during the end-of-life care of a loved one. These scholars move from the premise that there is, often indecisiveness in family members of critically ill patients when faced with making the decisions described as difficult. Origins of indecisiveness related to decision making by family members may be due to, families' not fully understanding information related to life support, having inadequate information related to patient's prognosis, and not accepting poor prognoses. The situation is worsened by family members who misunderstand or have difficulty in accepting the diagnosis or prognosis of the loved one. The same scholars highlight that dealing with these end-of-life issues can have a tremendous negative impact on

staff. It is cited that the staff become stressful when the family is usually unable to let go of their loved one and demand aggressive therapy that may result in pain and suffering for the patient (Kim, et al, 2011:257). A similar view is brought by Browning (2009:23) stating that there is significant importance in the healthcare team's responsibility to gather adequate and detailed information from the patient and family related to their moral convictions, values, cultural background, and spiritual belief systems.

Studies done in the United States and locally showed that the experiences of nurses at the end of life are moral distress. The findings of the study conducted in the Mandela Metropolitan area highlighted that during the process of treatment withdrawal, nurse experience a variety of emotions and the stress involved can have a significant impact on the mental health of the nurse executing the order (van Rooyen *et al.*, 2005:50).

Little is known about the consequences of moral distress. Hence the researcher conducted this study to identify clinical situations that caused nurses to experience moral distress, to understand the consequences of those situations, and to determine whether nurses would change their practice based on their experiences. Jensen, Ammentorp, Erlandsen, Ording (2011:197) concur with the notion of stress among nurses stating that, most studies conducted on the experiences of critical care nurses on withdrawal of treatment have highlighted that, whilst nurses sought to provide comfort and care to the dying client, they are faced with tension and conflict with medical colleagues and within themselves to provide care that does no harm. The close relationships that develop between the nurse and the family are both a source of comfort and stress. Nurses and physicians express fear of removing all hopes, making the wrong decision or giving up too soon. It is difficult emotionally for both family members and health care professionals to give up on curative care (Adam *et al.*, 2011:1).

As Halcomb, et al., (2004:214) states, improvements in communication between health professionals, debriefing and education about the process of treatment withdrawal would be beneficial and have the potential to improve patient care and reduce the current burden. Apparently, Halcomb, et al., (2004:214) deduces from the rising prevalence of chronic disease that nurses will likely be increasingly confronted

by dilemmas in end-of-life care. The emphasis is put on the nursing research agenda that should include issues such as advanced directives, and palliative care options for chronic disease.

2.6 The support nurses need

Hanna and Romana (2007:38) conducted a study on nursing management after crisis. These scholars identified the need for debriefing sessions for nurses and how the nurses would benefit from such sessions. Debriefing is an information-sharing and event-processing session conducted as a conversation between peers. Group members become informants to each other about a situation or event that occurred to them as a group. The listener can be a therapist, counsellor, or professional peer who helps the group process the information being shared. The person who conducts the session should have the professional skills to guide the established process that will help staff members recover from their distress (Hanna & Romana 2007:38).

An important aspect of debriefing is that, the leader will assess the need for individuals who might benefit from further individual counselling and will make recommendations for individual follow up. Whenever a critical incident has occurred, debriefing should follow as soon as possible (Hanna & Romana, 2007:38). Other scholars for example, Stacy (2012:24) also refers to this method of support as a crucial occurrence, which should be done several days after the event. The purpose of the session is to have focus on the emotional response of the health care team and to allow them to reflect the experience and discuss the grief.

2.7 Summary

This chapter explored the experiences of nurses on withdrawal of life-sustaining treatment from a critically ill patient in CCU. The implications of treatment withdrawal to patients, families and nurses were discussed in relation to the previously conducted studies. The coping strategies used by the relevant stakeholders were also looked into.

Chapter 3: RESEARCH METHODOLOGY

3.1 Introduction

This chapter focus on the scientific discussion of the research methods, sample and sampling method, population, data collection were discussed.

3.2 Research methodology

Research methodology is a guide that provides, clearly structured and easily understood ways on how to design, conduct and report an empirical study in various disciplines in social science (Jin, 2012:1).

3.3 Research approach and design

The qualitative research approach is used because of its participative nature (Buns & Grove, 2009:51). It is a way of gaining insight through discovering meaning. As Brink et al, (2010:10) explains, qualitative research is complex and broad, and tends to explain a phenomenon in its entirety. In this study a qualitative phenomenological design is used to describe and explore the lived experiences of nurses in a critical care unit in relation to withdrawal of life - sustaining treatment.

Speziale et al, (2007:62) concur with the above definition of qualitative research and state that the researcher attempts to understand the entirety of some phenomenon rather than focus on specific concepts, has few pre-conceived hunches, and stresses the importance of people's interpretation of events and circumstances rather than the researcher's interpretation. Moreover, the researcher also collects information without formal structured instruments, attempts to capitalize on the participants as a means for understanding and interpreting human experiences, and analyses narrative information in an organized but intuitive fashion.

The design chosen is phenomenology which is both a philosophy and a research method (Brink et al, 2010:119). The focus of the phenomenology is on the mind which is expressed as an experience rather than on the participants. This approach is relevant for this study and chosen because the researcher undertook to explore the lived experiences of the nurses in a critical care unit. The purpose of phenomenological design is to describe and explore what people experience in regard to certain phenomena and how they interpret the experience or what meaning

the experiences hold for them, (Brink et al, 2010:113). In this study the lived experiences of withdrawal of life- sustaining treatment which are described by the nurses working in the critical care unit.

3.4 Population

The population is a particular group of individuals who are the focus of the research study or the entire group of persons or objects that is of interest to the researcher (Brink, et al, 2010:123, Burns & Grove, 2009: 343). In this study the population is the nurses working in the intensive care units of the public sector. The target population in this study is the entire set of individuals or elements who meet the criteria as the trained nurses working in two intensive care units (Burns & Grove, 2009:344). The operational managers are considered since they are part of the team in the intensive care unit in the East London area.

3.5 Research setting

The setting of this study is Buffalo City Metropolitan. The researcher in this study used the Cecilia Makiwane District Hospital and the Frere Regional Hospital critical care units. These two institutions have a geographical distance of twenty five kilometres apart. Cecilia Makiwane district hospital admits patients from the township where the hospital is located, the surrounding rural areas and the patients referred from small peripheral hospitals, whereas the Frere Regional Hospital admits patients from the larger urban East London metropolitan area. Both institutions cater for general critical care patient management. This refers to all the conditions that warrant critical care observation and management.

3.6 Sample and sampling

A sample is subset of the population that is selected for a particular study. Sampling, however, is the process of selecting a group of people, events, behaviours or other elements with which to conduct a study (Burns & Grove, 2009:344). The researcher's target population is selected from the nurses who have been working in two critical care units for two years and more. The sample of this study comes from the Frere Regional Hospital and Cecilia Makiwane District Hospital.

The researcher used the purposive sampling method. According to Brink (2010:133) purposive sample is the type of non-probability sampling. Furthermore it is a method that is based on the judgment of the researcher regarding participants who are typical or are especially knowledgeable about the participants (Brink, 2010:133). The participants who were chosen are nurses who have worked in the critical care unit for a period of two years and above. They have the experience of nursing patients and have witnessed the withdrawal of treatment in the critical care units. Typical of this method of sampling, the researcher does not know in advance how many participants are needed. The determinant factor is data saturation, that is, when there is no other new information forthcoming. The advantage of purposeful sampling is to allow the researcher to hand-pick the sample, based on knowledge of the phenomena under study (Brink, 2010:134).

3.7 Inclusion criteria

Inclusion criteria are those characteristics that a participant must possess to be part of the target population (Burns & Grove, 2009:345). Participants that were included in the study were critical care trained nurses who were full time employees in the adult critical care units of the two institutions and had worked in the units for two years and more. The operational managers were considered since they are part of the team in intensive care units in the East London area.

3.8 Exclusion criteria

The criteria for exclusion are those characteristics that can cause a participant to be excluded from a target population (Burns & Grove, 2009:345). In this study nurses who are trained in critical care nursing and have two years' experience but suffer from depression were excluded, as were nurses who had been in critical care unit but perform under the supervision because these nurses are not well versed with the critical care language. They perform their duties under the direct supervision of the trained nurses in critical care units or those having vast experience in this field of nursing.

3.9 Pilot study

Pilot study refers to a miniature run of the methodology planned for the major project. It is used to test the design and enables the researcher to determine unanticipated effects. In essence, the pilot study sharpens the researcher's skills for the proposed study before the actual data is collected. Burns and Grove (2009:33) state that the environment for a pilot study should be similar to the one for the actual study in terms of participants and the setting. One participant was interviewed from one institution. The data was analyzed; thereafter the researcher proceeded to collect the data. The participant used for the pilot study was not included in the actual study.

3.10 Data collection

In-depth interviews were done to collect the data. An appointment was secured with the participants. Interviews are methods of verbal communication between the researcher and participants during which information is provided (Burns & Grove 2009:403). The interview guide was designed with open-ended questions. The researcher allowed the participants to control the situation by allowing them to do most of the talking without interruption. The interviews were conducted in the interview room of each institution. Each session scheduled for thirty to forty five minutes. Some went beyond the scheduled time when the participants became emotional and the researcher had to pause. Seven participants were interviewed with questions posed in English. Participants were expected to respond in English however one was allowed to say a word or two in one's own language when one felt the need to put emphasis on a concept. Hence some responses displayed the participant's own language.

3.10.1 Interview guide

Data was collected from participants using unstructured in-depth interviews. According to Brink, van der Walt and van Rensburg (2012:158) unstructured interviews are free flowing more like a conversation but focusing on the research topic and are more suitable for qualitative phenomenological exploratory studies.

An interview guide was used by the interviewer with a broad question and probing questions. The probing questions were guided by how the participants responded.

This was used to ensure that all issues were covered in the in-depth interview (Hennink, Hutter & Bailey, 2011:141).

3.11 Trustworthiness

Polit & Beck (2010:492) prove trustworthiness of any qualitative research based on the following criteria developed by Lincoln and Guba: credibility (true-value), transferability (applicability), dependability (consistency) and confirmability (neutrality).

3.11.1 Credibility

This refers to confidence in the truth of the data and interpretation. The findings have to establish the truth for the participants and the context in the research. Credibility involves carrying out the study in a way that enhances the believability of the findings and the steps to demonstrate credibility to external readers (Polit & Beck, 2010:492). In essence, credibility is the extent to which the findings accurately describe the reality.

In this study the researcher ensured that the questions were not ambiguous. Where a participant did not understand the question, clarity was provided. The participants were encouraged to be frank when expressing themselves. The researcher explained up front that there are no right and wrong answers to the questions asked. The researcher had the flexibility to refer to the previously asked question(s), rephrase and pose it (them) again. If there were contradicting responses, the information was discarded.

The researcher declared her independent status so that the participants knew that she was not working under the instruction of someone else. In conducting the study the researcher did not coerce the participants; only those who felt free to participate were interviewed.

3.11.2 Dependability

Dependability refers to the stability of data over time and over conditions; when the same tool is used at a different time the questions is, will it produce the same findings? Credibility is attained in the presence of dependability (Polit & Beck 2010:

492). The steps taken in data collection were reported in detail to enable a future researcher to repeat the study.

3.11.3 Confirmability

Confirmability is the objectivity that is required for congruency between two or more independent persons about the data accuracy, relevance and meaning (Polit & Beck, 2010:492). The aim is to find out if the data is based on the information that the participants provided and is not the researcher's opinions. In this study the information was verified by an independent coder. This was a colleague of the supervisor. The information was accessed from the audiotape and written notes. Some information was quoted verbatim

3.11.4 Transferability

Transferability refers to the extent to which qualitative findings can be applied in other settings or groups and produces the same results (Polit & Beck, 2010:492). Since the data from the two institutions was not collected at the same time, the same tool was used and the results measured against each other. The researcher had to be mindful of the fact that different results obtained do not mean that the data is not trustworthy. Multiple realities can be reflected that bring a difference to the results.

3.12 Ethical considerations

Ethics are important elements in the formation of moral judgments in professional practice (Muller, 2009:62). They provide guidance for thinking and acting in order to determine what should or should not be done in a particular situation. They may be based on religious traditions, or world view normative ethical theories such as utility and duties or obligations. In research one learns to be more vigilant of the participants' needs and desires.

The permission to conduct the research was obtained from all the relevant stakeholders, including the ethics committee of the University of Fort Hare. Upon the approval of the research by the ethics committee, the proposal was forwarded to the Epidemiology Department of the Eastern Cape in Bhisho. Thereafter, institutions where the study was conducted were written to for their approval. Lastly, permission was obtained from the participants of the study.

3.12.1 Informed consent

According to Speziale et al, (2007:63), there is an expectation that in the clinical setting when a client signs an informed consent they are aware of both the benefits and the potential risks to their health care. Informed consent is a prerequisite for all research involving identifiable participants.

It is crucial that the participants should receive all the information regarding the research study. The researcher therefore discussed and clarified their understanding of the study. The participants were requested to sign a consent form giving the researcher the go ahead to do the interviews. However, the researcher highlighted that they were allowed to withdraw without a reason as signing of the consent form was not binding them to participate in the study.

3.12.2 Respect for person

This principle implies a respect for autonomy, or the right of people who are capable of making their own decisions to make those decisions for themselves. In accordance with this principle they should be provided with all the necessary information to help them make those decisions. In the ethics of research it means that healthy volunteers should only enter studies after they have been provided with all the information (Brink, 2010:32).

In this study the researcher did not manipulate the participants or use any form of coercion. The participants were informed of the objectives and purpose of the study. The researcher echoed that the participants take part in the study on their own free will. If they refused to participate nobody would harm them in anyway.

3.12.3 Beneficence

Participants have a right to be protected from harm and discomfort (Brink, 2010:32). Harm may not necessarily be physical. In qualitative research the participants may experience emotional and/or spiritual harm. The researcher thus observed the participants as they responded to the interview to see if they showed signs of distress. This can be met by giving the participant time to recover his/her composure. In the event of a participant not tolerating an interview, it must be abandoned (Brink, 2010:32). Counseling may be advised.

3.12.4 Confidentiality

The participants were informed that confidentiality would be maintained throughout the study. The information gathered during interviews was not publicized indiscreetly. The names of the participants did not appear in the study and the information provided was not linked to particular individuals as codes were used instead of names.

3.12.5 Justice

This principle includes the participant's rights to fair selection and treatment. In this context it focuses on equal selection of participants, in other words, making sure that the risks and benefits of research are distributed as much as possible, so that no particular individual or group is discriminated against or benefits overwhelmingly from the research. According to Brink (2010:33) justice is the obligation to treat everyone in accordance with what is right and proper and to give each person what is due to them.

In this study the participants were promised a fair chance to be represented in the study. They were provided with all the information regarding the study so that they knew exactly what they got themselves into. The researcher respected the views of the participants in the case of participants withholding information that implicated a second person. Such information cannot be gained by coercion or application of pressure. The researcher also asked for permission from the participants when she found it proper to use an audio-tape.

3.13 Dissemination and implementation of the task

The results were communicated to the Health Care facilities when the study was completed for them to evaluate the findings. The institution policy makers will be spoken to, who may standardize guidelines and policies. In addition, the study will be published in the democratic nurse's journal (Denosa) where it could be accessed by a large population of nurses since it is a well-read journal. The researcher will also present the study at the Critical Care annual congress which is normally attended by delegates from all the provinces and abroad.

3.14 Data analysis

Analysis of data was done as the data was being collected to prevent information overload. The data was descriptive and narrative, gathered in the form of video-tapes and written statements. The interviews were repeatedly listened at, to compare them with the transcriptions. Feelings expressed by the respondents were noted.

The data analysis began with transcribing and later identification of the themes emerging from the raw data, a process sometimes referred to as open coding (Brink, 2003:192). Coding is used to organize data collected in an interview and other types of documents and group similarly coded data into categories of the same characteristics. The aim is to reflect on the possible meanings and relationships of the data collected. This is a cyclical act and is rarely ever perfect the first time.

As the data was gathered, the need to recode becomes evident as influenced by new information. This is a pattern the researcher followed. New emerging themes from the raw data that appeared to be similar was modified or replaced during the subsequent stages of data analysis that followed. Thereafter the researcher re-examined the categories to determine how they were linked. The last step was to translate the conceptual model into the story line that would be read by others. Another person checked the reliability of the coding. The researcher utilized the participants to validate the results. A flow chart was used to represent findings.

3.15 Summary

In this chapter, the scientific foundation of the study was introduced with a brief description of the rationale and background, problem statement, purpose, objectives, research question, significance of the study and definition of terms. The researcher attempted to unpack the questions like the: who, where, by whom and how part of the research study.

Chapter 4: PRESENTATION OF RESULTS

4.1 Data analysis and results

Five main themes emerged from data analysis: (1) Decision making by doctors concerning withdrawal of treatment from a critically ill patient in CCU; (2) doctor-nurse relationship regarding withdrawal of treatment of critically ill patient in CCU; (3) nurses' experiences regarding the process of withdrawal of treatment from a critically ill patient in CCU; (4) nurse's responsibilities as health professionals towards the patients regarding their profession; and (5) coping strategies regarding the withdrawal of treatment from a critically ill patient. The themes were further classified into categories and sub-categories as indicated in the table below.

Table 4.1 Themes, categories and sub categories regarding the lived experiences of nurses concerning the withdrawal of life - sustaining treatment in a critical ill patient in CCU.

NO.	THEME	CATEGORIES	SUB-CATEGORIES
1	Decision making by doctors concerning withdrawal of treatment from a critical ill patient in CCU.	No involvement of nurses in the decision making process	<ul style="list-style-type: none"> Nurses excluded Discussions during ward rounds Next to the patient's bedside Feeling left out Doctors discussing among themselves No formal meeting Nurses as interpreters Information withheld from the nurses Patients nursed 24 hours a day by nurses Nurses have limited authority Not everything is said in front of the patient Never prepared or equipped Never heard of formal sitting with doctor No common understanding Creating conflict No team work

2	Doctor-nurse relationship regarding withdrawal of treatment from a critical ill patient in CCU	Nurses display their unhappiness regarding this practice	<p>Discussion during ward rounds</p> <p>Nurses must still interpret and explain and comfort the relatives</p> <p>Hearing the decision for the first time at the patient's bedside</p> <p>Spending 24hours a day with patients</p> <p>Frustrated</p> <p>Despair</p> <p>No sense of control</p> <p>Poor relations between parties</p> <p>Criteria for dialysis unclear Reasons for not involving nurses are unclear</p> <p>Feeling not important</p> <p>Feeling judged, no authority</p>
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3	Nurses experiences regarding the process of withdrawal of treatment from a critical ill patient in CCU	Emotional impact	<p>Fear of losing a patient</p> <p>Anger</p> <p>Sadness, crying together as a team</p> <p>Helplessness, denial & guilt</p> <p>Blame, rejection & failure</p> <p>Accusation</p> <p>Misunderstanding</p> <p>Loss of control</p> <p>Love for the patient Attachment to the patient</p> <p>Relationship of trust</p> <p>Respiratory support brings relief.</p> <p>Sense of wanting to assist in every possible way</p> <p>Dialysis brings hope</p>
		Social impact	<p>Tired</p> <p>Heaviness</p> <p>Do not want to continue for the day</p> <p>Attachment</p> <p>Bond with relative</p> <p>Depression</p> <p>Desertion</p>

		Impact on the family	Abandoned Loneliness Hysterical, angry at God, racial thoughts, denial, not understanding, wanting nature to take its course, crying, frustration, panicking, hoping for the best, depression, mixed feelings, patient becomes a burden, cultural values, trust and belief In nurses
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4	Nurses' responsibilities as health professionals towards the patients regarding their profession.	The role of the nurse in the withdrawal of treatment from a critical ill patient in CCU	<p>Fairness</p> <p>Nurses have limited authority</p> <p>Patient advocacy</p> <p>Nurse-patient relationship</p> <p>Nurse-family relationship</p> <p>Interpersonal relations</p> <p>Explain and interpret the condition of the patient to the relatives</p> <p>Counselling relatives</p> <p>Intervention strategies</p> <p>Comforting the relatives</p> <p>Maintain patient dignity</p> <p>Providing spiritual support</p> <p>Being a witness that the doctor met and discussed the condition with</p>
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This study was conducted to explore and describe the experiences of nurses concerning the withdrawal of life - sustaining treatment from critically ill patients in CCU.CCU

Theme 1: Decision making by doctors concerning withdrawal of treatment from critically ill patients in CCU

The treatment that was withdrawn from patients in CCU was, at the most, dialysis and respiratory support. The enteral feeding was mentioned to have been withdrawn only to highlight a situation whereby there was poor or no absorption as a result of brain dysfunction.

Category 1: No involvement of nurses in the decision making process

The participants maintained that they render a 24 hour service to the patients in CCU, but when it comes to decision making they are not involved. In this regard some of the participants highlighted instances where they were instructed by the doctors to call the relatives and still interpret the decision of withdrawal of treatment from the patient that was taken by the doctor without informing the nurse practitioners first. Once the family was there the nurses would be there to interpret what the doctor had to say to the relatives. The nurses were allowed time to ask questions when they did not understand a part they had to convey to the relatives; only then the nurses would be aware of the planned withdrawal of treatment.

“You only hear it during ward round but they do give you that time if you got something you don’t understand as a nurse just to explain. And we don’t have a formal meeting.”

Doctors were not even conducting formal meetings with them to discuss the prognosis of the patients they so cared for. From the interviews it appeared that the doctors would discuss among themselves.

“The doctors they were discussing among themselves.”

“I have never had a formal sitting with the doctor unless at times we are discussing with the relatives whereby the doctor explains the condition of the patient then it becomes a formal thing.”

Even though the nurses would be there at the patient's bedside during ward rounds, she would not have an input in the discussion.

This act of supportive treatment withdrawal is a very sensitive issue. It has to be understood by all relevant stakeholders so that at the end of the day each and every individual knows exactly what role he/she has to play in the process.

There were participants who pointed out that the doctors did not tell the family exactly what was going to happen regarding the withdrawal of treatment. The following are responses from the various participants:

“Some information is withheld by doctors when they (doctors) discussed at the patient's bedside with relatives present. They can't explain everything in front of the patient.”

“They will not say to relatives we are going to stop resuscitation. They will tell them we are doing anything we think patient will... will... benefit on but its highly on the side of... there will be no hope for the patient to be treated in that condition.”

“With me with my experience The doctors when discuss with the relatives they do not say no we are going to stop this and that, we are tapering the settings and all that staff, no, they just discuss about the condition that is critical its fatal ends there, they don't go deeper. I've never heard the doctor say we are going to stop a, b, c and d. I have never witnessed that.”

The withheld information also had a negative impact on the nursing teams. It was pointed out that the doctors have a tendency of verbalizing the order of not for active resuscitation. Nurses agreed to have moments of break in communication. They cited that they would sometimes fail to inform the next team that the patient is not for active resuscitation. When the condition starts to deteriorate, the team on duty resuscitates and the doctor when called would be angry that his/her orders were not carried out. Nurses verbalized dissatisfaction and echoed the misunderstandings created by such instances.

“At times more especially when the doctor has not written down do not resuscitate”.

The nurses' opinion regarding the non-involvement in decision making was that they were left out and were neither prepared nor equipped with information to convey to the families of the patients they had nursed for 24 hours.

“They said we gonna do a brain test you call the relatives, the relatives come and they explain to the relatives but they never prepare you or equip you and that bakuxelele uba (tell you that) what are you going to say to the relatives or what you must expect.”

“Some information is withheld by doctors when they (doctors) discussed at the patient's bedside with relatives present. They can't explain everything in front of the patient.”

It was for those reasons that these nurses felt excluded in decision making. The researcher noted that there were some participants who were comfortable in the manner things were run in the unit. Though they admitted that there were no formal meetings held, the doctor would inform them that the patient's supportive treatment will be withdrawn after discussions with the family. To those few individuals the information sufficed.

“Not really to be true, because I feel the doctors are the one who knows better especially when it comes to that point of deciding whether to withdraw the treatment or continue.”

“We believe that is not for us because we feel like we taking the life of the person.”

Seemingly this category of nurses were afraid to get involved probable due to fear of appearing as though they were taking the patient's life as one of them had stated during interviews.

Theme 2: Doctor-Nurse relationship regarding withdrawal of treatment from critically ill patients in CCU

Doctors and nurses are compelled by their work environment to keep a healthy relationship. The nurses take and execute prescriptions from doctors. They (nurses) become responsible, among others, to the quality assuring body for their acts and omissions. It therefore becomes an important factor that they understand each other and keep problems to a minimum.

Category: Nurses display their unhappiness regarding the practice.

From the interviews there was no clear reason why the nurses were not involved in decisions with the doctors. Nurses are the ones to observe a change in the patient's condition and inform the medical team. Some had tried to voice their opinions regarding the management of their patients. To their amazement the doctors did not take them seriously. This is how they commented about that.

“We are the ones that are usually in fact always next to patients with the patient. So at times the doctor orders this and you as a nurse intervene as a just to say no doctor how about this because ever since I've nursed this patient I've noticed this and that, so how about doing this and not that.”

There were unclear practices that the nurses did not understand. To cite but a few, there was a patient on haemodialysis for acute chronic renal failure with pulmonary congestion which according to nurses was relieved by dialysis. The accomplished joy was short lived because the treatment had to be stopped. Worse still, the patient was going to be discharged home to die. Nurses felt that this was an unfair treatment considering that the patient was initially relieved after four days of treatment. They also queried the criterion that was used to come to that conclusion. Nurses felt they had no sense of control over patient management.

“Patient was still in need of dialysis but we could not further dialyze.”

As a result of this practice nurses felt left out and that created frustration and despair. Probably if the doctors had meetings with nurses to discuss everything to be done, they would have understood. It was verbalised as follows:

“To me I think we have to have a formal meeting, discuss this as a multidisciplinary team so that everybody knows why before we take it to the relatives but that never happen. You only hear it during ward round but they do give you that time if you got something you don’t understand as a nurse just to explain.”

Those words were uttered with intense emphasis. The relationship between the doctors and nurses become estranged resulting in nurses feeling unimportant as members of the multidisciplinary health team.

Theme 3: Nurses experiences regarding the process of withdrawal of treatment from a critically ill patient in CCU

According to nurses the process of withdrawal of treatment is an act that brings sadness because there are lives involved. The family looks upon nurses and doctors to provide the best medical assistance possible. When the treatment has to be withdrawn, the nurses experience a variety of emotions and are under pressure to comfort the family, even when their own emotions are not well taken care of.

Category 1: Emotional impact

The participants reported on the emotional hardships of treatment withdrawal which were related to fears, for example, of losing the patient. That became evident when the nurses who were supposed to know the criteria for dialysis (from their training) would display unhappiness when the patient was denied further dialysis because of comorbidities. The following are the responses from participants:

“Sometimes in as much as I know but sometime I may be back ward and look like err...err.. Someone who does not know. I don’t whether... I don’t know what to call it but I become a lay person when it comes to that.”

Having said that, the dialysis did bring hope because the patient came off the acute phase and the pulmonary congestion was resolved. One participant said:

“The patient was dialyzed about 4-5 times. He was off the acute stage because when patient came in, rather than the renal failure he had he was presenting with pulmonary oedema but it was resolved.”

There were some that verbalized accusations by those families who would not really understand and accept the process of treatment withdrawal. The participants explained:

“Sometime you deal with illiterate people who cannot understand, people who would take it as if you are actually saying you do not want to do or to give a help for their loved ones.”

The family may want to do everything possible to assist hence the family member willingly came forward to suggest that she was ready for organ donation.

The participant stating thus:

A member that was willingly, was willing to donate the kidney to the relative

As a result the nurses would feel helpless and see themselves as failures. They admitted carrying a guilt feeling or blame during their daily nursing routine. This is what they said:

“It is when let’s say we were trying to bring the patient’s life, and then all of a sudden the patient died you blame yourself whereby you should have done 1, 2, 3.”

The relationship of trust between nurses, families and patients becomes betrayed.

Category 2: social impact

On the social aspect of treatment withdrawal, the participants verbalized the bond created during their daily encounter with the family and patients.

“The withdrawal of treatment most the time it hurts lots of the people the patient has been in ICU for a long time people tend to bond with that patient and love the patient so much, bond with the family as well which I suppose that makes it very difficult when the treatment is gonna be withdrawn.”

All the participants interviewed voiced that the process of treatment withdrawal was not an easy one. It came up that it is tiring and one would experience a heavy feeling, such that when one was done with counselling of family one would not be in a position to continue the daily tasks for the day, even though there would be other patients to be cared for. The following are the statements from various participants:

“When you come from that counselling you feel like you don’t want to participate in anything you don’t want to do anything whilst there are some other patients that you need to take care of. But emotionally inside you and it goes to physis, you feel like you are tired you will feel heaviness.”

“It’s often is not an easy thing because even me I...I feel like I’m part of that family I become emotional but because of my job I try to contain myself.”

“It is pathetic”.

“I was so emotional then because as she was saying so she was crying”

Nurses felt the strain of treatment withdrawal and its impact on their lives.

Category 3: Impact on family

Nurses commented on racial thoughts verbalised by family during the withdrawal of the treatment process.

“Initially the doctor who was withdrawing the treatment was a white guy. Initially they did not understand, because they thought it may be due to racist. Because he’s white withdrawing treatment to a black guy, we had to explain that it is not that he is racist”.

The family did not understand how the system works. The researcher wanted to know how the doctors responded to the reaction by family on the refusal of their loved one to be taken off the life support system. The participants indicated that the patient is not removed from life - sustaining treatment, instead continued explanation would be given on the condition that has deteriorated.

“If they refuse the patient is not taken off instead you counsel”.

Some families would demonstrate anger even at God asking questions no one can answer. Mixed feelings from families have been reported whereby some would be crying, frustrated, hysterical and hoping for the best while others would be asking from nurses when the treatment would be stopped as it had been a long time and their loved one was not showing signs of improvement.

“That there is no use keeping this patient on a ventilator because even if you keep this patient on a ventilator it is a long time rehabilitation it’s gonna be a burden to the relatives”.

“At times they cry we have to calm them down do whatever you want you can do. So now the relatives are panicking frustrated, hoping for the best, in denial most of the time.”

The withdrawal of life-sustaining treatment had a bearing on family as well. It was not easy for them to let go of their loved-one.

Theme: 4 Nurses responsibilities as health professional towards the patients regarding their profession

The nurses are responsible for rendering a total quality patient care. This obligation is looking at all aspects of nursing irrespective of the conditions that the nurses work under. The fulfilment of that prerogative is nurtured by the relationships built between nurses and their patients in the CCU setting.

Category 1: The role of the nurse in the withdrawal of treatment from a critically ill patient in CCU

Naturally, the nurses are expected to save lives, see to the safety of their patients.

“We are expecting to save life of our people and to make sure that at the end of the day you see the safety of the patient, we do believe that nurses are there to help people psychologically, spiritually”

During interviews the participants verbalized that they would explain and interpret the condition of the patient to the relatives and interpret the doctors' decisions regarding the treatment withdrawal.

“Firstly we explain the condition of the patient to the relatives and explain ways the nursing care, the relative the ways and the treatment that has been used that did not help. We always sympathetic with them, try to talk to them to show them more in our own language.”

They were always there at the patient's bedside providing emotional support to the patient and family. Even though some families would not understand and exhibit anger, at the end nurses would calm them down and eventually the patient-nurse-family relations would be maintained.

“The relation was good because at the end though they were bitter they had to understand. We have to be there for them at first they don't want to listen as if you are saying he is going to die tomorrow. So they don't understand, you explain and explain that he is not going to die tomorrow.”

Other roles include counselling of relatives, a process that the participants described as pathetic, sad and hurting even to them (nurses). It would warrant that the nurses provide comfort to the family. There were instances where the participants had to arrange for spiritual healing for families who were having difficulty in coming to terms with the loss. The participants felt also that they were playing witness to the meetings held by doctors with families in case the families denied ever being informed of the patient's progress and prognosis.

“I don't have much as a nurse to do. it's about helping sometimes in terms of translating making it easy for the other party to understand what is being said in a simpler term but as a nurse I don't have much and be the witness at the same time that the doctor did meet they sat with the family they did discuss because you know the family can turn around sometimes.”

Although nurses had limited authority, they did play an advocacy role. One participant verbalised approaching the doctor in an enquiring manner to determine his plans regarding the further management for a particular patient.

“I do trigger when I see that hey this patient this has been done and this is the situation seemingly we are not weaning in a form of questioning exactly what your plan of action for this patient is. Then we start talking”....they wanted us to switch off the ventilator before even the relatives come as if it just happened, but I couldn’t because I wanted them to have the decision” I am an advocate of the patient I cannot do it myself the doctor is supposed to do it because he is the one...”

From the interviews it was highlighted that the patient’s dignity was maintained. Those few patients who were removed from respiratory support were not allowed to suffocate or drown from their own secretions. The airway was protected by an endotracheal tube. It was mentioned that the patients would be sent out for nursing care, kept clean and provided with physiological needs.

This is how it was done:

“They put the patient sometimes on a T-piece then they transfer patient to the ward.., it’s about seeing to it that the patient is clean and given whatever to be given.”

When the participants were asked on who switches the respiratory support off, all the interviewed participants stated that it is done by the medical officer except for one participant who said:

“Because there was that order I switched it off after that explanation.”

Participants demonstrated knowledge of cultural values which they saw as important elements in nursing because they form basis of understanding cultural diversity.

“Depending on the level of knowledge because if they are knowledgeable they quickly understand... But if they don’t understand like they will refuse especially when it comes to our people, African people they will say no-no we brought this person here to be cured you can’t tell us when you take him off the machine he is going to die, that means you are killing the patient that is

why you need to constantly talk to them make them see what is going on because.”

Nurses had to consider the needs of their patients and families learn their cultural beliefs and values so that there is nurse-patient-family understanding.

Theme 5: Coping strategies regarding the withdrawal of treatment from a critical ill patient.

Each individual is born with mechanisms that the body utilizes to defend self from harmful situations that would otherwise throw an individual off balance. These are coping strategies in times of physical, emotional and spiritual attacks. The individual genetic makeup will determine one's ability to utilize the intrinsic coping skills. At times one will require external support to enhance the coping strategies.

Category: 1 Self-coping mechanism

The participants verbalised skills they employed to cope in the environment they referred to as being strenuous. There were those who could not explain how they coped.

“In this stressful environment I ...mh I don't know. I don't know what to say really. I don't know maybe because I'm used to this situation. I don't know how I cope.”

The researcher observed as they verbalised that there was sadness but they had to work in the unit. Their self determination to work in the CCU was one of their strongholds for coping. This was enhanced by the outcome of their patient care, that is, when the patient fully recovers and is taken out of the unit.

“but what gives us the drive is because of those who enter this unit even in our eyes we throw towels but, we are doing because we have to do but they go out as healthy people those are the people

All interviewed participants could not see themselves working in any other department except for CCU.

“as a result I feel like I don’t have elsewhere to go and work ar ar I’m I’m... Im just a CCU nurse. That this is the place I want to be. I enjoy being here

The passion and loyalty they had for this department outweighed the tears they cried so often with their patients’ families. However, they saw a need for one to take short leave just to get a break.

“as much as it is stressful but you need at the end of the day maybe after a week or after a month or two months just go out and enjoy yourself that will be part of team building an be away of this environment and talk about something different so that when you come back you are fresh.”

Other coping strategies were quoted as follows:

“I think what makes me to cope here is the relationship we had err... we have a good relationship between err the staff member even with the doctors but if we have err... something they we ...I don’t want to say we are fighting but err... but lastly we just talk and solve that problem.”

There were those participants who believed that professional and chronological maturity pay. They felt a more matured person is able to look at things in a different perspective. For example, to them death in CCU was inevitable so they had to support the new nurse cadres to deal with it, in-service each other on how to deal with situations they encountered. Another important mechanism used was to adopt a positive attitude towards each other and address their work differences promptly so that a conducive environment is created.

“You know it’s very, very, difficult especially initially, but I think as you grow in the department you tend to mature you learn to realize the reality. When you matured you can handle most of the things, you suffer for other people you know! You suffer for other people you feel this thing is not nice for me as well its hurting but this one is worse, so you attend to that one. And another thing that helps is the fact that whilst you are here promote good attitude, good working relationships, communicate in a manner that everybody wants to be here as much as it is hurtful. Then we discuss that and how to deal with these relatives how to handle the situation.”

So having older nurse professionals was of benefit to the younger ones for them to gain experience. It is not everything that is learnt from books.

Category 2: Religion/Christianity

The participants were all Christians and believed that beyond medicinal substances there were supernatural powers. Because they were human beings they realized that they had to steer patients to put their trust in God for them to get comfort when the worst was inevitable. The participants also resorted to prayer when they felt they did not have strength to comfort the family that was consumed with grief.

“My coping mechanisms are when you are speaking to the relatives you always put to instil that you are a nurse you are a human being and you also believe in God ...in the CCU because sometimes miracles are happening. They must also pray as to help curing”.

“We prayed like anything we said no you must have hope from God.”

Critical care nurses were observed to have developed coping strategies though some enhancement is required.

4.2 Conclusion

In this chapter the data was analysed and coded into categories and sub-categories until themes emerged. The findings were interpreted and quoted verbatim to make the meaning clear.

Chapter 5: DISCUSSIONS, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter presents the discussion of the findings with reference to previously conducted studies, conclusions and recommendations. The experiences of nurses working in a critical care unit concerning the withdrawal of life -sustaining treatment from critically ill patients were explored and described.

5.2 Discussion

The participants cited that they are not involved in the decision making concerning the withdrawal of life- sustaining treatment from their critical care patients. They echoed that the doctors were not conducting formal meetings with them to discuss the prognosis and future plans of the patients nurses cared for. Nurses felt like they did not exist even though they were there at the patients' bedsides during ward rounds. As the participants stated, they felt so powerless with very little authority.

Simmonds (2010:33) conducted a study on the experiences of physicians and nurses with dying patients in CCU. In that study, the nurses verbalized powerlessness which emanated from the inability to change what is happening to certain patients because someone else other than nurses themselves was making the decisions. As nurses further explained, the doctors would continue discussing among themselves. Often nurses would be there to interpret what the doctor had to say to the relatives. The participants verbalized being allowed time to ask questions when they did not understand as they were conveying the information to the relatives. It would be only then that they would learn of the planned withdrawal of treatment. The situation would be worsened by the fact that the doctors would give a verbal order of do not resuscitate. Luce (2010:8) concurs with the responses of the participants and states that unfortunately physicians sometimes do not speak in absolutes when discussing the prognosis with family and do not explicitly discuss the chances for short term survival.

Similar studies conducted on withdrawal of treatment have also highlighted the physicians' reluctance for open discussion with nurses. These studies have revealed that the lack of regular meetings between physicians and nurses, or lack of conclusions about withholding or withdrawing of curative treatment also made the nurses feel alone in bearing the responsibility. Even if there were discussions, they usually started accidentally (Hov, Hedelin & Athlin, 2007: 206).

It was the same as in the case of this study. One participant verbalized that, based on the experience she had gathered in the critical care environment, she would in a questioning manner ask the doctor what his/her plans were for a particular patient. Then a kind of discussion would start. Hov *et al.*, (2007:206) in their study on being an intensive care nurse state that sometimes the nurses become assertive in their behaviour towards physicians to make them take the responsibility. This was the case when physicians showed signs of giving up by not showing plans of treatment withdrawal for a patient who over time has shown no progress. This is a common occurrence in CCU.

Much as the nurses were not involved in decision making concerning the withdrawal of life- sustaining treatment, their role in this practice was as well unclear. They all verbalized interpreting the doctor's plans to family, counselling of the families, providing comfort and support to relatives, being there for the patient at the bedside (Kirchhoff & Kowalkowski, 2010:532). Nurses also felt that they were the ones to make the relatives understand the withdrawal of treatment because they were able to come down to the level of relative understanding. This was not an easy task since families would not understand why the supportive treatment would not cure the patient. One participant was instructed to follow a written order to switch the ventilator off. The question one may ask is what the scope of practice is for nurses working in the critical care unit.

The duties of a critical care nurse are explained by Mahon (2011:4) as to: plan, coordinate and implement care with the health care team to meet the physical, psychosocial, cultural and spiritual needs of the patient and family. As Mahon explained, the critical care nurse must balance the need for the highly technological environment with the need for safety, privacy, dignity and comfort (Mahon 2011:4). Apparently, the majority of nurses in this study wanted to be fully engaged in the

initial decision making meeting concerning the withdrawal of life - sustaining treatment. As it was verbalized, this could be obtained by nurses and doctors coming together in a special setting and the nurses' views aired and their voices heard. Baggs, Norton, Schmitt, and Sellers (2004:528) share same views in this regard and state that, there is evidence that CCU nurses and physicians both value and wish for more collaboration in caring and decision making for the dying CCU patient and that they believe a collaborative team approach would lead to better outcomes for patients and the families. However as Baggs, et al, (2004:528) explain, barriers to collaboration need to be overcome. In this study nurses verbalized the need of working in collaboration with the doctors as far as decision making is concerned but there was nothing to suggest the same sentiments from the medical point of view.

Pattison (2011:114) concludes that when nurses engage and involve themselves at all stages of end of life care from decision making to withdrawal of treatment, it could be a profoundly satisfying, albeit sad experience. The researcher noted that there were some participants who were comfortable in the manner things were run in the unit. These were participants who felt they were somewhat involved in decision making. The researcher probed more to find out exactly how they were involved. It came up that they were also doing the same task as others, that is, to interpret for the doctor, counselling the families. They admitted that there were no formal meetings held; the doctor would inform them that the patient's supportive treatment would be withdrawn after discussions with the family. To those few individuals the information sufficed. The researcher did not find this an act of involvement since they were not part of the decision making. In a study conducted by Pattison (2011:114) on end of life care highlighted that not all nurses would wish to be engaged in the process of end of life decision making because of past experiences in their own lives.

Among the duties performed, the participants verbalized taking the patient to a step down unit when there was nothing else that could be done for the patient. This act would be done following the doctor's prescription. The patient would leave the unit with an endotracheal tube in place for adequate respiration and clearing of secretions after the respiratory support has been detached. Nurses did not have a say on that. This was impacting on the patient's dignity since the patient was sent

out to continue basic nursing care not in a state of being moved up and down. The same patient could have been kept in the unit until nature takes its course rather than moving the patient around especially if the ward is far from the critical care unit.

In CCU doctors normally take decisions regarding the withdrawal of treatment without involving the nurse practitioners in the department. This practice affects the doctor-nurse relationships. The participants commented on the relations between nurses themselves and doctors as being strung at times. Nurses were, however, able to work this through using problem solving skills. At another institution the participant saw a promising future outcome since they were starting to work as a multidisciplinary team, which means that the grounds for conflict were reduced. In the critical care unit it is common that there is conflict between the doctors and nurses. As explained by Breen, Abernethy and Tulskey (2004: 289), conflict associated with decisions to limit life-sustaining treatment is more prevalent in the setting of intensive care decision making. While conflict over the treatment decision itself is most common, conflict over other issues, including social issues is also significant. By identifying conflict and by recognizing that the treatment decision may not be the only conflict present, or even the main one, clinicians may address conflict more constructively.

Other cited causes of the conflict would emanate from inaccurate information. The studies in the past have indicated that in the end of life care, overwhelming preference for honest information is essential (Norton, Tilden, Nelson & Eggman, 2003:543). Some scholars highlighted that many physicians feel uncomfortable discussing the patient's prognosis. The belief is that physicians fear the emotional reaction by the patient and the family after the news is given (Morrow, 2014:5).

In this study the participants were concerned about doctors who were not stating directly what the next step of action was. The doctors would not write down a do-not-resuscitate order which would impose conflict on nurses. As the nurses were functioning in teams, one team would institute resuscitation measures when the patient was going into cardiac arrest, whereas the next did not. Health care providers are frequently confronted with conflict on every day practice. Halcomb, et al. (214:222) as cited by Kendall (2008:37) conducted a study on end of life care.

The results highlighted the tension and conflict that occur in the caring of patients who had treatment withdrawn or withheld that, it emanated from medical staff who make decisions without nurses' involvement and then leave the nurses to manage the dying process unsupported. Even without legal action, these conflicts can have serious consequences thus, negatively affecting the quality of decision making and patient care, as well as the satisfaction of both family members and health care providers (Breen, et al, 2004:288).

The withdrawal of life-sustaining treatment is perceived by family members of patients in critical care units as the hardest thing they ever had to take. The family members highlighted the severe stress it brings to families who at times are, often misunderstanding the prognosis of the patient for whom they are making decisions (Wiegand, 2010:1118). The families in end-of-life decision making relate to withholding and withdrawing of life - sustaining treatment as quite a burden. Sentiments from relatives such as "horrific experience" are highlighted. Some families viewed participating in the process of withdrawal of life - sustaining treatment as difficult, intense, painful, overwhelming, devastating, and traumatic (Wiegand, 2008:1117). For them, the presence of the nurse brings comfort and support. The family's strong emotional reactions to an acute life-threatening illness, and deeply held religious or secular beliefs are cause for concern (Wiegand, 2008:1118).

In the CCU, the family will communicate with the nurse each time they visit the patient. Nurses give clarity about the condition of the patient, enabling the family to understand the prognosis. Adams, et al, (2011:3) highlight a trusting relationship that develops which allows the family to feel that they can ask the nurse anything pertaining to their loved ones and trust that she/he will respond truthfully. Nurses provide support by being there for the family and listen to what they (the family) have to say. The participants in this study echoed being there at the patient bedside all the time for their patients and families.

The relations between nurses, families and patients are often good. This could be due to the established trust the parties had developed. Morgan (2008:156) concurs with this understanding and states that families rely on nurses to interpret medical language, sharing and updating them and responding to their needs. In this study

nurses found the relations with the patient family to be healthy even though at one time the relatives were not happy with the suggestion of treatment withdrawal. As the participants narrated, the family members would be very bitter at the suggestion. Nurses showed understanding since the displayed anger was not necessarily directed at them. Families could see that nurses were not the ones giving the orders to withdraw the treatment.

Communication can be especially difficult during stressful or anxiety-provoking situations, such as when a loved one is critically ill. Researchers have described the stress that patients' families experience during the hospitalization of the patients as being normal responses to external or internal threats. As Ryan and Seymour (2013:2) explained, any situation that produces stress can complicate communication. These two scholars aimed to highlight that stress and anxiety can have an impact on thinking, perception, and learning which mainly is; to lower concentration, reduced recall, distorted perceptions, and confusion. The support provided by nurses is therefore very important because the information doctors attempt to deliver to patient's families, such as a prognosis of imminent death has to be correctly perceived.

Workman, McKeever, Harvey, Peter and Singer (2003: 20) state that, many family members may ask the physician to do everything for their loved ones even though they may not be able to state clearly what that means. Aslakson (2011:112) interprets the term everything as; if someone is dying, all measures that might keep vital organs working will be tried, for example, using a machine to help with breathing or starting dialysis for failing kidneys. Aslakson (2011:112) further state that, such life support can sometimes be a temporary measure that allows the body to heal itself and begin to work normally again. It is not intended to be used indefinitely in someone who is dying. There are however, factors driving the family members to make such demands. In particular, is the belief that, doctors are cost oriented and show reluctance to give medication to patients at the end of life care. For the basic premise is probably true, even though it is unusual for physicians to abandon therapy unless they truly believe it to be futile (Workman, et al. 2003: 21).

Another frequent factor which leads to demand of futile therapy is guilt. When family members feel guilty about past relationships with the dying patient or have reason to believe something they have done may have contributed to the death, they are likely to want to continue care to the very end. In such situations, the physician may change his/her approach to the family. Instead of asking what the family expect the doctors to do, involve the family and ask what the family think the loved one would have wanted to see being done. Asked in this way, the person who feels guilty about not doing what the dying person wanted done in the past is likely to honor the patient's wishes ahead of his or her own (Workman, et al. 2003:21).

At least at the beginning, family demands for futile therapy should probably be honored by physicians. An attempt should be made to determine the basis of what appears to be unreasonable demands without specifically trying to change family opinion. Written documentation that therapy is being continued at the family's demand based on certain family beliefs should be provided, along with a statement that the providers do not expect a positive outcome (Workman, et al. 2003:21).

When this is done, as long as the family has not lost trust in the providers and given time to observe that continued therapy fails to reverse the patient's downhill course, the family will invariably recognize the presence of continued suffering without visible improvement and will come to a consensus in favor of forgoing non-comfort care. Legal decisions have repeatedly backed family demands for futile care even when the scientific evidence is overwhelming that, the care will not benefit the patient

Simmonds (2010:34) argues the same concept of doing everything for the loved one, echoing as well that most family members do not actually understand what that involves. In this study, one family wanted the doctors to continue with the life - support treatment and knowing that the patient had renal failure, the family wanted to donate a kidney even though it was explained to them that no further intervention would be done. Patients did not to have insight into what was planned even though the doctors have informed them. Nurses as well had gaps in their knowledge as far as the doctor's plans were concerned regarding the withdrawal of life-sustaining treatment even though they had been there in the unit. As a result, conveying the information to the families was not an easy task. Nurses verbalized experiencing difficult time in making the relatives understand. This could be the result of

inadequate information nurses had, thus they did not succeed in getting the information through that would have satisfied the relatives.

Simmonds (2010:34) highlighted as well in the study conducted on experiences of physicians and nurses on the withdrawal of treatment in the intensive care unit that, the relatives have difficulty deciding to discontinue treatment or to wait until nature responds. However, nurses and doctors do not blame families entirely for their unrealistic expectations because they believe that health-care providers are not always realistic and do not make further treatment or resuscitation clear. Ryan and Seymour (2013:2) share the same sentiments and stated that nurses have to develop trusting relations with the loved-ones (patient's relatives) and support them to accept the inevitability of death.

It was noted that the nurses would form a special bond with their patients and their families. This bond would be transferred to love and attachment. The term attachment has been defined by Haya (2012:103) as an emotional bond between two individuals based on the expectation that one or both members of the pair will provide care and protection in times of need. This is what is happening between nurses and their patients in their everyday encounter. Horstman (September 13, 2013) refer to this bond as an invisible boundary that nurses should not cross. This would make things difficult for all the stakeholders when the treatment was withdrawn whereby nurses would be aware that the condition has deteriorated and there was nothing else to be done, but letting the patient go would be so difficult because they had come to love the patient so much as one participant cited in this study. Horstman, is quoted in the New Times (September13, 2013) stating thus:

As nurses, we are taught that we are professionals and we must maintain a certain emotional distance with our patients. It's a boundary that encompasses the therapeutic relationship: nurses as caregivers, patients as the recipients of the care. But now, working as a nurse, I have found that while most of my professional boundaries are well defined, sometimes the line between a professional and personal relationship with a patient can become blurred.

Ryan and Seymour (2013:4) are also of the opinion that, critical care nurses who regularly care for dying patient and their relatives can experience actual grief reactions such as fear, guilt anger and sorrow. Horstmann (New York Times,

September 13, 2013) is citing an important factor in the relationship between nurses themselves, families and patients that patients move in and out of nurses' lives so quickly, for example two to three days in CCU, but every encounter does make a change. The behaviour of a relative or patient in CCU teaches the nurse something. This scholar is moving from the premise that it is better sometimes that nurses and patients should allow themselves to feel more than a professional bond, like one participant was saying she would feel as a part of the family. The nurse is helping the patient/relative to heal while at the same time some behaviours exhibited by the patient or family members help the nurses to heal as well from their own past experiences.

As Horstmann (New York Times, September 13, 2013) further explained, nurses are blessed to have the depth of human encounters. It is stated in that article that there is no other profession that could be compared to nursing that allows humans to connect in the way nurses can. Being touched is all part of the richness of the profession. Nurses are aware that patients are most vulnerable when they first come to the hospital environment. Hence, if they feel the connection between themselves and nurses they respond better to all the care they receive. This therefore is evident that the condition may deteriorate despite the care given.

After all, as participants verbalized that, a patient is a human being who needs to feel just like that. It is good for people to have a connection with their care givers. This notion is supported by Adams *et al.* (2011:2) who stated that nurses gain a unique perspective that allows them to become aware when a patient is not responding to treatment. This is made possible by the fact that nurses are at the patient's bedside from admission, and during a dying process. It could therefore, in the context of this study be of help for the doctors to discuss treatment withdrawal with the nurses.

Nurses experience such an emotional turmoil which they narrated as being hurtful, traumatic, draining physically and emotionally. As they were verbalizing the experiences some re-lived the moments. One participant narrated with tears streaming down her face pointing at the empty chair where the grieved family member was sitting when the news of the proposed withdrawal of treatment was received. As the nurse reported, the emotions were uncontrolled and the researcher had to pause. As narrated by Horstmann (September 13, 2013), nurses would feel so

emotional as if someone they loved was going to leave them forever. A study conducted on end of life emphasis on care, the results showed that critical care nurses are at greater risk of post-traumatic stress symptoms than general nurses. The various reasons cited are said to be either in isolation or in combination of one-in-one nursing, high technology equipment, repeated exposure to stressful events (Pattison 2011:112).

In another study conducted on experiences of physicians and nurses with dying patients in CCU, Simmonds (2010:36) stated that nurses feel they are taught they can do a lot for people and the more they study the more knowledgeable they become and their skills are enhanced. So if a patient dies they take it as their fault, thinking that they should have read and done more, hence the feeling of blame. The studies that were done internationally including South Africa pertaining to the lived experience of nurses participating in the process of withdrawal of life -sustaining treatment highlighted a knowledge gap. Hence the researcher decided to conduct this study to focus on the experiences of nurses in a critical care unit during the recent years since the training of nurses is dynamic and advancing.

The participants also experience accusations from relatives who were so angry at the announcement of treatment withdrawal that they blamed nurses stating that they did not want to help their loved ones. Nurses would blame themselves and felt that they had failed the family. Hamric and Blackhall (2007:227) also highlighted that nurses expressed moral distress in caring for these patients, a sentiment shared by other scholars, stating that, moral distress among nurses occurs when the nurse knows what is best for the patient but that course of action conflicts with what is best for the organization (Epstein & Delgado, Sept 30, 2010). The families did not understand that nurses have limited authority. They demanded care that was out of nurse's hands as they were not well versed of the process of health care service. Hence the family would at times refuse to consent to treatment withdrawal from their loved ones. In the event of a family refusing to consent to their loved one being taken off the life – support system, the family decision would be respected. Nurses would be tasked by doctors to continue counselling the family, making them understand that all the efforts to rescue the patient have been tried but to no avail.

Bongard, Sue and Vintch (2012:218) concur with the participants' responses stating that there may be situations in which the physician recommend that a do not resuscitate order be written, but the family disagrees and wishes cardio-pulmonary resuscitation to be initiated when the need arises. The physician and family engage in discussions to get clarity but the treatment will not be stopped until a common understanding has been reached. Luce (2010:10) is of the opinion that, when families and physicians disagree over continuing treatment, physicians sometimes choose to withdraw life-support unilaterally, although they run the risk of being sued for malpractice. However, in this study, that never happened because as one participant recalled, the nurses insisted on letting the family come to see the patient and agree on the treatment withdrawal proposal.

In a study conducted on the role of the interdisciplinary team in caring for dying patients in CCU, it was found out that nurses were described as information brokers (Adams, et al, 2011:2). This refers to empowering others by giving information, mediating, and clarifying information given. Nurses may also request the presence of other disciplines, including chaplains or social workers, to mediate end of life decision discussions. Furthermore, nurses may request that a physician speak to a family or prompt a family member in what questions to ask the physician (Adams *et al.*, 2011:11). This is the role that nurses enact, that is, the role of bringing people together to exchange information directly and facilitating communication among family members as well as between the family and the team. Dracup and Brian-Brown (2005:457) as well echoed that, communication among the healthcare team, the patient, and family is essential to devising an appropriate plan, especially when the patient fails to improve with heroic measures. Care plans must contain clear criteria for success or failure so that patient response can be reviewed and communicated each day. Dracup and Brian-Brown (2005:457) further stated that in one study, an intensive communication intervention between healthcare providers and family members in the CCU led to the continuation of advanced supportive technology for patients with the potential to survive and allowed for the early withdrawal of advanced supportive technology when it was deemed ineffective, leading to a reduced length of stay and lower CCU mortality.

Gathered from the interviews it was quite clear that the participants had done exactly the same tasks as had been discovered in other studies. As it has been previously cited, the nurses played a role in the process of treatment withdrawal, that is, they interpreted the information conveyed by the doctor to the patient (if awake) and informed the family of the patient's condition. When the family members had difficult times to accept the decision of withdrawal of treatment, nurses would resort to calling professionally matured nurses to manage and comfort those emotionally distressed individuals. The support from physicians was very limited.

Some scholars have cited that the critical care nurses have an essential role in the provision of effective end of life care however; this dimension of their role needs further exploration. Efstathiou and Clifford (2011:123) stated that it is noted that educational opportunities need to be provided for critical care nurses to increase the knowledge on planning and delivering end of life care. To inform this evaluation of current end of life care provision in critical care, it is necessary to address a knowledge deficit of the needs of nurses who seek to support patients and their families at a critical time. In this study the deficit was mostly caused by information inadequacy and communication that was limited from the doctors. The participants verbalized that some information would be withheld by the doctors both to patients and nurses.

The practice of withheld information is echoed by Norton et al, (2003:543) in the study on communication and conflict when life-support treatment is withdrawn. The results of that study reported on family members who felt that clinicians lied to them because they thought the family was not able to handle the truth. Another thought that clinicians might not have told the truth because they would not admit to themselves that the patient was going to die. Norton, et al., (2003:5430) suggested that, families generally do not view withholding prognostic information as a way to maintain hope. Whether they agree with the prognosis or not, discussions about it help families prepare for the possibility that the patient will die. Nurses, however, continued to play advocacy and support roles, which meant that nurses had to assess what the family and patient understood and provide education about the disease process and possible outcome, which would be honestly communicated

(Adams *et al.*, 2011:7). This is an individual function that the nurses have to perform irrespective of the hindrances they encounter.

It was also observed in this study that often the doctors would be in a hurry to perform a specific procedure or even withdraw the treatment. The nurses would insist on doctors waiting for the family to come. One participant mentioned that the doctor wanted everything to be removed before the relatives came and act as though everything happened spontaneously, but the nurses pleaded with the doctor because they wanted the family to be the ones to make that decision. This action suggested that nurses do not entirely give up but are aware of the advocacy role as one of their independent functions they have to perform

The South African Nursing Council scope of practice (2014) under the domain of critical practice care and management states that the critical care nurse will safely and confidently operate various types of technology used in the critical care setting, for example mechanical ventilation cardiac monitors and infusion pumps, among others. She will be able to interpret the information on the cardiac monitor to diagnose and initiate resuscitation using the advanced airway management techniques, cardioversion, etc. The critical care nurse according to the scope of practice will execute appropriate critical care nursing to a special patient population when confronted with such in the critical care practice/setting, among others, end of life care.

Some families had high expectations of the supportive treatment. Supportive treatment is used in a critical care unit during the acute phase of sickness. For example, the respiratory support would be used to relieve respiratory distress or to rest the affected lung or the heart stimulated by pacing wires for the purpose of healing; it is an unfortunate situation that a patient cannot continue to live on a life support system. Gedge, Giacomini and Cook (2007: 215) support this notion stating, people will have unrealistic expectations about technology and medical advancements, thus see death as a failure of the health care system rather than a natural and inevitable event. These scholars are highlighting that death cannot be prolonged indefinitely. Patients and their families are assisted to accept the

inevitability of death which is perceived as one of the most difficult challenges for health care professionals,

The participants commented on dialysis that had to be withdrawn. This is a renal replacement therapy for patients with renal function impairment. It is commonly provided in a special renal unit. With advancing technology the machine is brought to the critical care unit where the patient warranting the dialysis is. The participants highlighted the benefits of this treatment to the patient which was to give relief in terms of removing excess fluid in the body which would normally be removed by the kidneys. Because the patient did not meet the criterion for continued dialysis as he had other comorbidities, the treatment had to be stopped. The family was disturbed by the decision taken and displayed bitterness. Nurses as well did not welcome the decision. They felt that there was no fairness in the criteria. The incident occurred in a government-run institution. The question of financial implications becomes evident, which is availability of funds. Now the non-researched anecdotal use of the private sector becomes an option where the patient will receive the treatment as long as there are funds available. The question is what happens to patients who cannot afford the treatment.

Adams *et al.* (2011:4) stated that nurses provide support to families by taking time to develop trusting relationships. Family members reported that they trusted nurses who introduced themselves to the family, explained equipment, and were willing to talk. Nurses also identified the importance of establishing rapport with families. This is echoed by Ryan and Seymour (2013:2) stating that nurses provide one –on- one care and therefore have the potential to develop close and supportive relationship with patients and their significant others. Nurses reported taking time to introduce the family to the oncoming shift nurse, to show confidence in that nurse and to facilitate the shift change. In this same study, nurses reported allowing family members to take part in daily care and important rituals as a way of supporting the family. Other ways that nurses supported family members included finding out what was important to them, storytelling, assessing readiness, helping with practical needs, etc.

The participants echoed how they would blame themselves when patients died. They constantly would ask themselves if they could not have done things differently. Nurses also acknowledged that the experience they have is putting them in position

to identify a patient who can pull through from the one who cannot. However, the knowledge nurses in CCU have is not applied when it comes to withdrawal of life - sustaining treatment. Pawlik (2006:990) referred to the same sense of blame and stated that, care givers 'discomfort about withdrawing life -sustaining treatment may reflect the view that such action rendered them more responsible and therefore more culpable for the patient's death. This view made the researcher understand to some extent why the few participants would accept the status quo and not verbalize none involvement in decision making.

The participants referred to the critical care unit as a stressful environment. Many factors were cited to attribute to that, namely, the high technology used with its ever beeping alarms and the nature of patients admitted, some with respiratory distress syndrome who needed immediate endotracheal intubation, to head trauma patients some with diffused axonal injury. It was also highlighted that the unit requires people who are able to think and act fast. That meant, nurses are bound to be highly strung. The fact that nurses had to do counselling on patients when the withdrawal of treatment was proposed, added to the stress nurses experienced. Another element was the use of life - sustaining treatment. The treatment would be withdrawn because of certain criterion followed. Going back to the example of patient with respiratory distress following renal impairment, the patient was denied further dialysis as he had multiple organ dysfunctions. Ill feelings would emerge especially when relief has been observed. Simmonds' view of this environment is that, while it plays an important part in the management of patients who will eventually recover from their illnesses, the same environment has the ability to delay death by monitoring and intervening in all bodily system with aggressive medical care Simmonds (2010:36). Having perceived the critical care environment as stressful and strenuous, the amazing part was the fact that all the participants could not be comfortable working in any other department than the CCU. They felt loyal to their profession and were passionate about their work and patient.

The participants cited few coping strategies they used to keep them working in the unit. One coping strategy was to break away after two or three months. By so doing participants gave themselves time to refresh their minds. When one takes time off, one meets other people and talk about something else. Whatever was troubling

one's mind is forgotten. They also utilize peer influence by allowing the professionally matured nurses to guide the neophytes. The participants also believed in older nurses because they are able to tolerate anything, tend to be subservient, and eager to assist others.

Another means of coping was to attend to challenges they had against each other immediately, using problem solving skills so that they do not bear grudges. The two institutions had prayer sessions in the morning after taking report. During that time those patients who are not critical would be involved either in taking the prayer or reading the scripture. All these strategies seemed to ease the load. Nurses believed that a prayer is assisting them in preparing themselves spiritually and emotionally to start the day. The scripture is meant to soften the soul. The participants as Christians would eventually accept the impending death attributing the state of affairs to God, with the belief that everything happens because of God's will. That the nurses believed in supernatural powers helped them when they comforted their patients and families. Participants would make the families look upon God quoting from the Holy Bible (Acts, 14:22) encouraging them to continue in faith, reminding them that we have to go through severe hardship to enter the kingdom of God. For Christians it is a reality.

They also believed that miracles could happen and silently asking themselves questions like, what if a miracle happens while they are on life - support and they are cured? The same question is asked by Morrow (2014:4) in a study on deciding to withdraw life - sustaining treatment. Often such questions trigger a thought and nurses find themselves faced with fear that they might be removing all hopes and giving up too soon. As Adam, et al, state, (2011:1) it is difficult emotionally for both family members and health care professionals to give up on curative care.

With the increasing anecdotes of miraculous healings performed by church pastors from all walks of life, nurses are human beings too who cannot say to relatives it does not happen as long as nurses do not give false hopes and that perception remains an individual thought and feeling. Wiegand (2008:111) in the study on withholding and withdrawal of treatment, highlight the hopes some families had for miracles to happen to their loved one. It is stated in the same study that families though they had come to accept the proposed withdrawal of treatment; they continued to wish for a miracle up until the very end.

There were a few individuals who could not really identify what strategy worked for them. They were bitter and frustrated and verbalized that they do not know how they coped. They even felt that it could be the fact that they are used to the environment; as such they had to continue doing their job. The behaviour of these participants got the researcher thinking that something has to be done. The researcher had to find out if there were any structures for support; unfortunately there were none in place.

Wilson (2014:38) is citing few coping mechanism that nurses can utilize in a critical care environment which are: task allocation to prevent prolonged contact with individual patients. Though this coping mechanism is useful in reducing moral attachment, it however reduces the chances of nurses knowing more about their patients and disease progression. The second one also cited by Wilson(2014:38) was, avoidance of change so that nurses felt comfortable doing tasks that were familiar to them rather than feeling stressed by trying new ways of working. All participants in this study were comfortable with this strategy as they all verbalized pleasure working in the critical care unit.

The participants verbalized one outstanding coping mechanism which was seeing a patient said to have a poor prognosis fully recover and leave the unit. This was a big comfort to nurses. Even if there was no one coming to pat them on their backs, to them it was a big job done. Despite the existence of recognized care planning frameworks that may help nurses in providing end of life care, these are not used by all units and many nurses rely on experience to inform practice.

All participants had a vast number of experiences in the unit ranging from 13 to 27 years. This experience provided them with coping mechanism to tone down what Hart (2009:54) referred to as the hurtful experiences of treatment withdrawal. Despite their frustrations from not being involved in decision making and losing the patients they so loved, they continued to provide quality nursing care. Even though nurses in CCU have a high level of performance, on the whole they are not perceived as friendly people. Often the unit is quiet with constantly beeping alarms and the social interaction is limited. The state of affairs brings uneasiness to patients and families. As Kelly, Kutng-Lee, Lake & Aiken (2013:483) explain, the work environment is characterized by facilitating or constraining the professional nursing

practice. So the environment plays a part in the experiences of nurses in the critical care unit.

5.3 Limitations of the study

One limitation of this study was the limited number of participant sample who were interviewed. Because it is an emotional study, the researcher limited the study to the number interviewed. The interviewed participants were all female nurses. This is caused by the fact that nursing is predominantly a female profession. There was no male participant interviewed from both institutions as male nurses in the CCUs did not meet the criteria of two years of placement in the unit.

5.4 Conclusion

The non-involvement of nurses in decision making on withdrawal of treatment was a cause for concern as these nurses remain with their patients for 24 hours but did not have input in the patient management.

The withdrawal of life- support treatment is a difficult process that impacts on spiritual, emotional and physical aspects of all the people involved. For that reason, the process has to be planned. In the management of this process all relevant stakeholders have to communicate openly and intensely to gain understanding. The patient in the process is given first consideration because he/she is the core of the process. What and how he/she feels is given attention and this will enable nurses to release the patient and find closure with less grief.

The impact of treatment withdrawal was an emotional experience. The participants admitted these critically ill patients and for several reasons they became close and formed ties. Due to disease progress the treatment is withdrawn from patients. Nurses feel that these patients are taken away. The loss becomes unbearable and they feel so helpless.

Nurses have to develop coping strategies to cope with the loss and continue to provide quality patient care. There are families as well who are looking up to nurses for support as they find themselves having to decide whether they should consent to withdrawal of treatment from their loved ones or not.

5.5 Recommendations

The findings of the research study recommend that:

Recommendations for Department of Health

- Since nurses are trained and experienced in the critical care nursing, the department has to consider policies that will act as directives to enhance discussions between the medical and nursing personnel. As Epstein (2008:771) had cited, that, nurses are defined as knowledgeable on how to take care of critically ill patients in a critical care environment but institutional constraints make it nearly impossible to pursue the right course of action. If nurses could feel as members of the team they are likely to participate as such.
- The institution needs to make provision for all those who would like to go out of CCU for some time to relieve stress.
- Theory therefore is based on the experiences of nurses and interpretation of their beliefs, values and experience regarding the process of withdrawal of treatment from a critically ill patient. However aspects like decision made by doctors concerning withdrawal of treatment from a critically ill patient in CCU, nurse's responsibilities as health professionals towards the patients in CCU and coping strategies regarding the withdrawal of treatment from a critically ill patient must be considered in order to apply the theory. Policies should also accommodate the nurse's input during decision making as they are qualified critical care nurses and they are with the patient all the time.

Recommendations for Practice

1. There has to be a psychologist designated for critical care nurses who will see them:
 - After an emotional family counselling
 - Sudden/ unexpected death
2. The manager of the department has to design team building activities for nurses. These can be done within or outside the institution. This was highlighted by participants during interviews as a means of distressing.

3. The doctors must involve the nurses in decisions concerning the withdrawal of treatment by:

- formal meetings as a multidisciplinary health care team to discuss the prognosis of the CCU patient;
- during ward visits nurses to take a leading role by asking questions on the patient management;
- the nurse allocated to nurse a patient be given time to present her views during ward rounds; and
- Debriefing sessions for both doctors and nurses.

However the practice of humanistic nursing theory emphasize on understanding life. In this study the patients are faced with possibilities of making choices. These choices determine the direction and meaning of one's life. The researcher concurs with the philosophers because in practice the patients make choices on whether or not to receive or refuse treatment. However those in intensive care unit are usually unable to make such choices.

Recommendations for research

As it was cited before, this study was qualitative in nature focusing at the lived experiences of nurses; the results therefore cannot be generalized to all nurses in CCUs because the focus was on experiences which are perceived by nurses as individuals. Perhaps in a quantitative study where big numbers of participants with specific experiences can be studied, then the results can be generalized. Further intense study needs to be undertaken to evaluate the outcome of the current study.

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Vanderspank-Wright, B.B.; Fothergill-Bourbonnais, F.; Braitman S.; Gagnon, P. 2011. Caring for Patients and Families at End of Life: The Experiences of Nurses during Withdrawal of Life-Sustaining Treatment. *Dynamics Winter*; 22(4):31-5. PubMed PMID: 22282952.University of Ottawa. Canada.

Van Rooyen, D.; Elfick, M. & Strümpher, J. 2005. Registered Nurses' Experience of The Withdrawal of Treatment from The Critically ill Patient In An Intensive Care Unit. *Curationis*, 28(1), 42-51.

Wiegand, D.L.; Funk, M. 2008. In Their Own Time: The Family Experience during the Process of Withdrawal of Life-Sustaining Therapy. *Journal of Palliative Medicine* 11(8), 1115–1121.

Wiegand, D.L.; Funk, M. 2012. Consequences of clinical situations that causes critical care nurses to experience moral distress. *Nurse Ethics*, 19(4) *Journal of Pallative Medicine*

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ANNEXURE A: Application letter to the University of Fort Hare Ethics Committee to conduct research.

14Elm Street

Beacon Bay

East London

Fort Hare Institution Ethics Committee

Fort Hare

East London

Request to conduct a research study

I hereby request permission to conduct a study on the lived experiences of nurses concerning the withdrawal of life-sustaining treatment from patients in a critical care unit.

The study will be conducted at Cecilia Makiwane district and Frere Regional hospitals. The following are the objectives of the study

- To explore the experiences of nurses in critical care unit on withdrawal of life-sustaining treatment from their patients
- To recommend strategies to improve the involvement in decision making

The researcher wishes to interview nurses who have been working in these two institutions over a period of 2 years.

Thank you

P. P. Kupa-Mesa Noroña

ANNEXURE B Ethics clearance letter from University of Fort Hare



University of Fort Hare
Together in Excellence

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: VEL011SNOR01

Project title: **The lived experiences of nurses concerning the withdrawal of life sustaining treatment in critical care unit: an explorative research Amatole District, Eastern Cape.**

Nature of Project: Masters

Principal Researcher: Peliswa Prudence Kupa – Mesa Norona

Supervisor: Ms. N Vellem

Co-supervisor:

On behalf of the University of Fort Hare's Research Ethics Committee (UREC) I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instrument(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the UREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

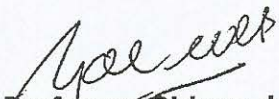
The Principal Researcher must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

The UREC retains the right to

- Withdraw or amend this Ethical Clearance Certificate if
 - Any unethical principal or practices are revealed or suspected
 - Relevant information has been withheld or misrepresented
 - Regulatory changes of whatsoever nature so require
 - The conditions contained in the Certificate have not been adhered to
 - Request access to any information or data at any time during the course or after completion of the project.
 - In addition to the need to comply with the highest level of ethical conduct principle investigators must report back annually as an evaluation and monitoring mechanism on the progress being made by the research. Such a report must be sent to the Dean of Research's office
-

The Ethics Committee wished you well in your research.

Yours sincerely


Professor Gideon de Wet
Dean of Research

21 November 2013

ANNEXURE C: Application letter to the department of Health for permission to collect data.

14Elm Street
Beacon Bay
East London

Epidemiology Research Surveillance Unit
Bisho

CONSENT TO CARRY OUT A RESEARCH STUDY

Title of the Research

The lived experiences of nurses concerning the withdrawal of life – sustaining treatment in a critical care unit: an explorative research.

Researcher: Mrs P.P. Kupa Mesa Norořa

The study will be conducted at Cecilia Makiwane district and Frere Regional hospitals.

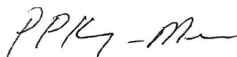
Purpose of the study:

The purpose of the study is to explore, identify and describe the lived experiences of nurses working in the critical care unit on withdrawal of Life- sustaining treatment and its impact.

Objectives of the study:

- To explore the experiences of nurses in critical care unit on withdrawal of life-sustaining treatment from their patients
- To recommend strategies to improve the involvement in decision making

Thank you



P. P. Kupa-Mesa Norořa

ANNEXURE D: Ethical clearance letter to collect data from the Department of Health.



Eastern Cape Department of Health

Enquiries: Zonwabele Merile
Date: 07th March 2014
e-mail address: zonwabele.merile@impilo.ecprov.gov.za

Tel No: 040 608 0830
Fax No: 043 642 1409

Dear Ms P.P. Kupa-Mesa Noroña

Re: The lived experiences of nurses concerning the withdrawal of life sustaining treatment in a critical care unit: an explorative research

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.


DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT



Ikamva eliqoqambileyo!

ANNEXURE E: Application letters to Frere and Cecilia Makiwane hospitals to collect data.

14 Elm Street
Beacon Bay
East London

The Nursing Service Manager
Frere Hospital
East London
5201

Dear Madam

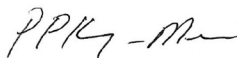
Request to conduct a research study

I hereby request permission to conduct a study on the lived experiences of nurses concerning the withdrawal of life-sustaining from patients in a critical care unit.

The study will be conducted at your institution in the critical care department. The following are the objectives of the study:

- To explore the experiences of nursing in a critical care unit on withdrawal of life-sustaining treatment to patients.
- To recommend strategies to improve the involvement in decision making. The researcher wishes to interview nurses who have been working in these two institutions over a period of 2 years.

Thank you



P. P. Kupa-Mesa Norořa
Student No.9808027

14 Elm Street
Beacon Bay
East London

The Nursing Service Manager
Cecilia Makiwane Hospital
Private Bag x 13003
Cambridge
5201

Dear Madam

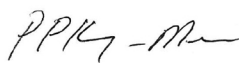
Request to conduct a research study

I hereby request permission to conduct a study on the lived experiences of nurses concerning the withdrawal of life-sustaining from patients in a critical care unit.

The study will be conducted at your institution in the critical care department. The following are the objectives of the study:

- To explore the experiences of nursing in a critical care unit on withdrawal of life-sustaining treatment to patients.
- To recommend strategies to improve the involvement in decision making. The researcher wishes to interview nurses who have been working in these two institutions over a period of 2 years.

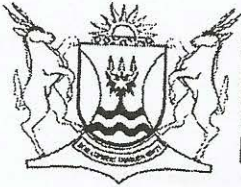
Thank you



P. P. Kupa-Mesa Noroña

Student No.9808027

ANNEXURE F: Permission from institutions



Province of the
EASTERN CAPE
HEALTH

Cecilia Makiwane Hospital • East London Hospital Complex • East London
Private Bag X 9047 • East London • 5200 • South Africa
Tel: 043 708 2135 • Fax: 043 760 2252 • e-Mail: siphokazi.peter@impilo.ecprov.gov.za

TO: EASTERN CAPE DISABILITY ECONOMIC EMPOWERMENT TRUST
FROM: DR L. GALO – MANAGER: MEDICAL SERVICES
SUBJECT: RE: Mrs Kupa-Mesa Norona Approval to conduct research at CMH
DATE: 30 JUNE 2014

Dear Mrs Kupa-Mesa Norona

I am pleased to inform you that your request to conduct research at Cecilia Makiwane Hospital has been approved.

Please contact the Nursing Service Manager Mrs Sixishe to make an appointment to plan your study as you are one of three other candidates approved to conduct studies amongst our nursing personnel. It would be therefore prudent to ensure a flexible timetable. Please carry this letter when you are at the institution and interviewing staff so as to be able to produce it when necessary.

Again thank you for considering our institution, wishing you well in your studies.

Regards,

DR. L. GALO
DATE 30/06/14
MANAGER: MEDICAL SERVICES

MEDICAL SUPERINTENDENT
CECILIA MAKIWANE HOSPITAL
PRIVATE BAG X 9047 EAST LONDON 5200

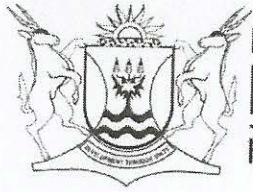
DR LUNTU GALO



United in achieving quality health care for all

24 hour call centre: 0800 0323 64
Website: www.ecdoh.gov.za





Province of the
EASTERN CAPE
HEALTH

EAST LONDON HOSPITAL COMPLEX

Frere Hospital, Amalinda, Private Bag/Ingxowa Eyodwa X 9047, East London, 5200
South Africa • Tel: (043) 709 2135 • Fax: (043) 709 2443 • Website: www.ecdoh.gov.za

INTERNAL MEMORANDUM

To:	Mrs. P. P. Kupa-Mesa Norona, Student, University of Fort Hare, Nursing Sciences
From:	Dr. J. Thomas; Acting Director Clinical Governance, Frere Hospital
CC:	Mrs J. Scholl; Acting Hospital Manager, Frere Hospital Mrs T. Mguli; Deputy Director Nursing services, Frere Prof D. Morrell; HOD Anaesthetics, ELHC Mrs Gwele; Area Manager Theatre, Frere
Subject:	Research Request: "The lived experiences of nurses concerning the withdrawal of life sustaining treatment in critical care unit: an explorative research in East London".
Date:	30 July 2014

Your correspondence for the above Research Request refers. Your request to access Frere Hospital has been approved.

It is requested that a copy of the completed analysis be submitted to this office for record purposes.

You can liaise with the following persons to coordinate the research:

1. Mrs T. Mguli, Tel: (043) 709 2781
2. Prof D. Morrell, Tel: (043) 709 2529
3. Mrs Gwele, Tel: (043) 709 2067

Regards,


Dr. J. Thomas
Acting Clinical Governance Director: ELHC

United in achieving quality health care for all

24 hour call centre: 0800 0323 64
Website: www.ecdoh.gov.za



Ikamva eliqaqambileyo!

ANNEXURE G: Participant information sheet.

CONSENT TO PARTICIPE IN A RESEARCH STUDY

Title of the Research:

The lived experience of nurses concerning the withdrawal of life-sustaining treatment in a critical care unit: an explorative research.

Researcher: Mrs P. P. Kupa-Mesa Noroña

Purpose of the study:

The purpose of the study is to explore, identify and describe the experiences of nurses working in the critical care unit on withdrawal of treatment and its impact.

You are requested to participate in the research study. You will be interviewed in safe environment. Apparatus like tape recorder will be used. You will be provided with all the necessary information.

Acceptance or refusal of the request will have no impact on you in anyway as you will not be penalized reward. Answering the questions will take you approximately forty five (45) minutes.

Potential risks and discomfort

There are no known risks or discomfort associated with your participation in this research.

Potential benefits

As it has been highlighted earlier. You will not benefit directly from your participation in this study. However, the recommendations resulting from this study may influence the future development of policies, procedures and protocols on the provision of the role of nurses in the process of withdrawal of life-sustaining treatment.

Privacy and Confidentiality

Your privacy will be respected and confidentiality will be maintained. Unless required by law, no information that might directly or indirectly reveal your identity will be released or published without your specific consent to the disclosure.

Participation or withdrawal from the study:

There will be no penalty if you decide to withdraw. You are free to withdraw from this research study at any time and your choice will not affect your relationship with your institution.


Contact details

If you have any questions, concerns or complaints about this research you may contact my supervisor, Mrs N. Vellem at nvellem@ufh.ac.za

Rights of the research respondent

For questions about your rights while participating in this study, you may contact the Institutional Review Board at University of Fort Hare, The Research Ethics Committee at 043 704 7588.

My signature below indicates that I have agreed to participate in this study. You will be given a copy of this consent form to keep with your records.



13/02/2014

Signature of Respondent

Date

C.H. Mavuso

Printed Name of Respondent



13/02/2014

Investigator's Signature

Date

Your privacy will be respected and confidentiality will be maintained. Unless required by law, no information that might directly or indirectly reveal your identity will be released or published without your specific consent to the disclosure.

Participation or withdrawal from the study:

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My signature below indicates that I have agreed to participate in this study. You will be given a copy of this consent form to keep with your records.

Damsanga

31. 07. 2014

Signature of Respondent

Date

DAMLA TAMSANGA

31. 07. 2014

Printed Name of Respondent

Investigator's Signature

Date

PPH-Me

31. 07. 2014

Your privacy will be respected and confidentiality will be maintained. Unless required by law, no information that might directly or indirectly reveal your identity will be released or published without your specific consent to the disclosure.

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My signature below indicates that I have agreed to participate in this study. You will be given a copy of this consent form to keep with your records.

Signature of Respondent

Nwabila Jude M.

Date

14-07-14

Printed Name of Respondent

NWABILA JUDE M.

Investigator's Signature

PPM

Date

14/07/14

Your privacy will be respected and confidentiality will be maintained. Unless required by law, no information that might directly or indirectly reveal your identity will be released or published without your specific consent to the disclosure.

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My signature below indicates that I have agreed to participate in this study. You will be given a copy of this consent form to keep with your records.

Signature of Respondent



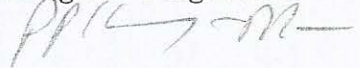
Date

10.01.2015

Printed Name of Respondent

Naxow Siso

Investigator's Signature



Date

2015/01/10

Your privacy will be respected and confidentiality will be maintained. Unless required by law, no information that might directly or indirectly reveal your identity will be released or published without your specific consent to the disclosure.

Participation or withdrawal from the study:

There will be no penalty if you decide to withdraw. You are free to withdraw from this research study at any time and your choice will not affect your relationship with your institution.

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My signature below indicates that I have agreed to participate in this study. You will be given a copy of this consent form to keep with your records.

NBuo

Signature of Respondent

Date

NOMABANI PATIENCE SIKO

14.07.14

Printed Name of Respondent

Investigator's Signature

Date

PAU-M

14/07/2014

Your privacy will be respected and confidentiality will be maintained. Unless required by law, no information that might directly or indirectly reveal your identity will be released or published without your specific consent to the disclosure.

Participation or withdrawal from the study:

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Rights of the research respondent

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My signature below indicates that I have agreed to participate in this study. You will be given a copy of this consent form to keep with your records.

Signature of Respondent

Date



15.01.15

Printed Name of Respondent

N.Y. Rani.

Investigator's Signature

Date



15.01.15

Privacy and Confidentiality

Your privacy will be respected and confidentiality will be maintained. Unless required by law, no information that might directly or indirectly reveal your identity will be released or published without your specific consent to the disclosure.

Participation or withdrawal from the study:

There will be no penalty if you decide to withdraw. You are free to withdraw from this research study at any time and your choice will not affect your relationship with your institution.

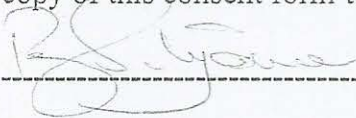
Contact details

If you have any questions, concerns or complaints about this research you may contact my supervisor, Mrs N. Vellem at nvellem@ufh.ac.za

Rights of the research respondent

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My signature below indicates that I have agreed to participate in this study. You will be given a copy of this consent form to keep with your records.





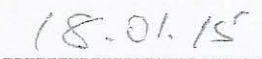
Signature of Respondent

Date



Printed Name of Respondent





Investigator's Signature

Date

ANNEXURE H: interview guide

An interview guide on: The lived experiences of nurses concerning the withdrawal of life – sustaining treatment from a critically ill patient in a critical care unit.

You are requested to assist in the study mentioned above. This interview will take up to 45 minutes of your time.

Broad question: Please tell us about your experiences concerning the withdrawal of life-sustaining treatment from a critically ill patient in your unit.

A. EXPLORING THE EXPERIENCES OF NURSES:

1. For how long have you been working in the critical care unit?
.....
.....
2. How was the decision to withdraw the treatment reached?
.....
.....
3. For how long did you nurse that particular patient on whom the withdrawal of treatment was proposed?
.....
.....
4. Were the relatives around?
.....
.....
5. Did they understand what the plan of action was?
.....
.....
6. Who communicated the decision to the relatives?
.....
.....
7. How was the status of the patient?
.....
.....
8. How did the family perceive the order perceive the order?
.....
.....
9. Tell us about the relations between you as a nurse and the patient
.....
.....
10. Tell us the relations between yourself and the patient's relatives
.....
.....

11. Did this action bring a change in the relation between the patient's relatives and yourself?.....
.....
.....
12. If yes, how?
13. What can you say about the process of withdrawal?
.....
.....
14. How soon after withdrawal of treatment did the outcome become evident?
.....
.....
15. What was the outcome?
.....
.....
16. How did that make you feel

B, NURSE'S INVOLVEMENT

1. How often have you been involved in the process of withdrawal of treatment?
.....
.....
2. Would you say you are involved in the process?
.....
.....
- 3, Were you given opportunity to voice out your thoughts regarding the order and the patient's condition?
.....
.....
4. What role did you play in the process of treatment withdrawal?
.....
.....
5. When the order was made to withdraw the life- sustaining therapy, did you know exactly what you were expected to do?
.....
.....
6. Are the processes concerning the withdrawal of life- sustaining treatment running according to your expectations?
.....
.....
7. If no what would you like to see happening?
.....
.....

C. SUPPORT

1. Do you have a time when you would feel the need to talk to someone?

.....
.....

2. Who do you turn to?

.....
.....

3. Do you have support structure /system in your institution?

.....
.....

4. What are your coping mechanisms?

.....

Thank you for your valuable information and your time.

ANNEXURE I: Letter from the editor.

8 Nahoon Valley Place

Nahoon Valley

East London

5241

1 June 2015

TO WHOM IT MAY CONCERN

I hereby confirm that I have proofread and edited the following master's thesis using the Windows "Tracking" system to reflect my comments and suggested corrections for the author to action:

The live experiences of nurses concerning the withdrawal of life sustaining treatment in a critical care unit: an explorative research by Peliswa Norona, a thesis submitted in fulfillment of the requirements for the degree of Masters of Nursing in the Department of Nursing in the Faculty of Science and Agriculture at the University of Fort Hare.

Brian Carlson (B.A., M.Ed.)
Professional Editor

Email: bcarlson521@gmail.com

Cell: 0834596647

Disclaimer: Although I have made comments and suggested corrections, the responsibility for the quality of the final document lies with the author in the first instance and not with myself as the editor.

BK & AJ Carlson Professional Editing Services

ANNEXUREJ: letter from independent co-coder

DEPARTMENT OF NURSING SCIENCES

P.O. Box 1054
East London 5200
Tel: +27 (043) 7047574 Fax: +27 (0866282021)



REGARDING: Co-coding of analyzed data.

This is to confirm that I co-coded and analyzed data for MCur Student Peliswa Norona Kupa-Mesa. Student No: 9808027.

The processes that I embarked on are as follows:

I read her proposal and methodology chapter to understand the approach and the design of choice for the study so as to understand the objectives and the questions the participants had to answer.

I thereafter read how she delineated the meaning units from the data transcripts.

I examined the analyzed data to understand how segments of meaning units were clustered. I then made suggestions with regard to how she and her supervisors could modify categorization of some information so as to come up with the final themes, categories and sub-categories where applicable.

I do have experience in qualitative data analysis and have been utilized by Nursing Science Department to co-code analyzed qualitative data for several studies.

D.Murray

D.Murray

Signature

29/4/2015

Date

Annexure K: Interview transcript

TRANSCRIPT

Dolly NO1

Q: May I ask, How long have you been working in a critical care unit?

D: Its 25year

Q: Would you like to share with me your experiences pertaining the withdrawal of life sustaining treatment from a critically ill patient? Anything you that you would like to say?

D; It was when..? There was a patient with renal failure. He was older than 65 and when he was diagnosed it was the first time that he was diagnosed but on this first time the patient was diagnosed as acute on chronic renal failure. Then he was started on dialysis since he was on acute stage. After some days the dialysis had to be stopped stating that the patient other than renal failure he had diabetes mellitus, he had hypertension and they said they can't go further with dialysis because they will never transplant this patient with those diagnoses that he is having. So we had to withdraw the treatment and the patient was going to be discharged home to die because there was nothing else that is going to be done.

Q: For how long was it? - the period you had nurse the patient, how long was it t?

D: I think the patient was dialyzed about 4-5 times. He was off the acute stage the acute stage because when patient came in, rather than the renal failure he had he was presenting with pulmonary edema then was diagnosed to relieve that pulmonary edema but it was resolved the pulmonary edema ,now the renal failure was still there but we couldn't further dialyze the patient . Patent was still in need of dialysis but we could not further dialyze.

Q; Then the decision to withdraw the treatment was taken based on...?

D: The decision was taken based on the diagnosis that the patient had, the age because the patient was over 60

Q: Did the relatives come to visit the patient?

D: They did.

Q; On the day the decision was taken were they there?

D: They were there and the condition was explained and everything that is going to happen from then, was explained to them

Q: Did they understand>

D: They didn't, they were so bitter

Q: What role did you play as a nurse/

D: We had to explain because; initially the doctor who was withdrawing the treatment was a white guy. Initially they did not understand, because they thought it may be due to racist. Because he's white withdrawing treatment to a black guy, we had to explain that it is not that he is racist it's something that has to happen we had to explain why because they did not even understand that if I've got diabetes, I have got hypertension I cannot be transplanted because there was a member that was willingly, was willing to donate the kidney to the relative if the bloods are ok but that was not necessary then. So we had to explain even if they do have a donor but they can't give a kidney to those patients with those diagnoses, because the transplant won't last. The kidney will reject. That was the condition. So we had to explain to immediate family member they will call another one, because they don't understand they will call another one we had to explain so that they come to terms. It was a sad, sad thing

Q: May I ask again a question, at the time the decision was taken to withdraw the treatment was there a formal meeting between the staff that is, the nurses and the doctors/?

D: No there was not a meeting with doctor but it was during the rounds. During the ward rounds nurses are there. The doctors they were discussing among themselves and the nurse looking after the patient. Because I was the team leader then I had to be there for the nurses and because I had to explain and interpret to the relatives.

Q: Would you say you do have a say in the management, do you have a contribution a part of the decision of some sort that is being taken?

D: No I don't think we do have because they discuss among themselves. And we don't have a formal meeting.

To me I think we have to have a formal meeting, discuss this as a multidisciplinary team so that everybody knows why before we take it to the relatives but that never happen. You only hear it during ward round but they do give you that time if you got something you don't understand as a nurse just to explain. But sometimes they can't explain everything because we do rounds in front of the patient so they can't talk everything in front of these patients sometimes. The meeting I'm sure It would be better if we had a meeting as a multidisciplinary team to discuss this before we tell the relatives.

Q; May I ask, the relations between you, the family and relatives how would you go about explaining them?

D: The relations was good because at the end though they were bitter they had to understand. We have to be there for them at first they don't want to listen as if you are saying he is going to die tomorrow. So they don't understand, you explain and explain that he is not going to die tomorrow

And if it happens that he has acute phase he can come to hospital, we will treat that but as long as it is chronic we can't go further.

Q; how often were you involved? Was that the only incident or other related incidents?

D: There are. The other one was when we had to switch the ventilator off because the patient was brain dead. When the relatives come and the patient on a ventilator. They saw the patient as if he is breathing, because the machine was breathing. When you explain that the patient is no longer breathing, you show them practically by removing the ventilator from the patient. Sometimes they think that he is just holding the breath

They don't understand that the brain test because they saw the patient the kidneys are working the heart is still beating the blood pressure is there so we had to switch the ventilator off because the patient was brain dead but the relatives did not understand. But the doctors did explain that we are doing this because no further management can be done

Q; You are saying something here, you are saying you had to switch off the ventilator , on whose orders was that?

D:No, I as a nurse I don't switch off the ventilator but the doctor do switch the ventilator off but before you have to explain and with the explanation and interpretation the nurse is there. Is going to tell them what is going to happen

Q: that patient, for how was the patient in the unit?

D: Mh....it was plus minus a week but the patient was badly injured he had a brain injury post MVA

Q: And the patient was not conscious on admission?

D: Was not conscious on admission.

Q; How long after the ventilator was switched off did you see the results/?

D:: In less than 30 minutes everything went down

Q: And how do you feel about that?

D:: I don't feel good but at the same time it's the right decision.

Because to prolong the life that is not going to be better its nothing but its not good when you are told that one of your patient is not going to improve. Because of the experience I have, I know a patient that can be given a chance; I know a patient that can't be given a chance. I can differentiate.

Q Do you mind if I go back to this question? You are saying you don't feel good, what is it that makes you not feel good, exactly how do you feel?

D: You feel sore in losing someone

Sometimes in as much as I know but sometime I may be back ward and look like err...err.. someone who does not know. I don't whether... I don't know what to call it but I become a lay person when it comes to that because when you explain this to the relatives it hurts,(scribbling something down)

Ok. When Xana mhlawumbi ngamanye amaxesha kusenzeka le nto uzizthatha uzibeke ezinyaweni zaba bantu. Awufeel (ishi) good sengaske bayi understand(e) nagamanye amaxesha bangabi belila

Xana belila bayakukhathaza nawe. Sometimes you end up crying which is funeka ube stronger. its not a feeling e right

Sometimes they brought up everything their problems saying this was a bread winner and everything so uyazithatha uzibeke kula ndawo.

Q: with the last incidence you quoted was there any difference between the way it was treated the decision to withdraw, in terms of getting all the nurses coming together?

D; No. There was no difference because err... they did a brain test but we never had a meeting or we never set as nurses and doctors to discuss it. But the doctors did a test. They said we gonna do a brain test you call the relatives, the relatives come and they explain to the relatives but they never prepare you or equip you and that bakuxelele uba what are you going to say to the relatives or what you must expect.

They did a brain test but we never had a meeting to discuss. After examination the during rounds this patient after examination and it's the end

Dolly NO 2

Q May I ask for how long have you been working in an ICU environment?

D: from 1996 till now

Q Would you like to share with me your experiences pertaining the withdrawal of life sustaining treatment anything you would like to share?

D: Mh.. mh...can you ask again the question

Q you share with me your personal experience regarding the withdrawal of a life sustaining treatment?

D: I'm just thinking of starting this to answer.

Q There is no correct answer; anyway you want to approach it? Your experiences?

(A long pause)

D: It is not easy to answer as human beings that is the first thing, because we are dealing with people and err... we are dealing with our people where in ICU, we are expecting to save life of our people and to make sure that at the end of the day you see the safety of the patient, that is you want to see the patient walking out of ICU in a good condition and working well with all the systems doing very well, and you feel so good about it

Otherwise when it comes to those grounds firstly you take it personal err... to approach the relatives. To approach. ..When I'm saying the relatives it's a closest people to this patient and then because you have to do it so you have to be realistic and err ..You have to err... check on the avenues where you can try to convince the relatives because most of the time the patient is unconscious, you are dealing with the relatives that are the ones that are conscious. So convincing the relative you go psychological first you go spiritual and because the nurse must have all those avenues to gain the relative so but at the end of the day because it's gonna be done eer... you will end up being praised by relatives for that competence

Q: You are saying you have to do it. Tell us exactly how is it done and your involvement?

D; Firstly we. explain the condition of the patient to the relatives and explain ways the nursing care, the relative the ways and the treatment that has been used that did not help or eill not help you try to do it by showing also the pictures showing X-ray,

all the things to have done the investigations bloods and so on that has to be done
try to convince the relative that it has to be done

Q: have been directly involved whereby the treatment was going to be withdrawn?

D:: Yes not once.

Q How was the process?

D: I will make an example of a patient that is always most of the time motor vehicle accident whereby The patient is head injury some of the areas totally out totally failing to be in use like the condition is diffused axonal injury to those whereby the GCS will remain 3/15 patient unresponsive the patient scan will show that there is no improvement instead the condition is deteriorating, you count also the days the patient has come all the investigations done are showing no progress try to show the relatives this and that has been done.

Q: I'm sure Im going to go back to this question from that particular incident coming to your mind how was the process of that particular patient?

D: The process.. You mean that one of explaining. It was not a good one because the one that I had it was the latest I have. It was a son. So the parents don't have the in sight. I had to try and use my language first , happening at the end of the day patient is gonna the patient promising according to them and the relatives were not happy I put it like that with the God will do miracles to the son anyway. But then with the involvement of the scan and blood results and the progress that, the treatment we had given to the patient it showed that there was nothing we could do

Q: So the information that you conveyed to the family was it from your own understanding of the situation or were you getting the information from the doctor?

D:: Firstly it was from my own experience and understanding and then because all this things that we are doing for the family to understand the doctors must also be involved so that , it is not coming from as a professional nurse. The doctors is the one who saw and has done all the investigation and the treatment and I'm just helping or conveying the information to the family, and it was also from my understanding because I've been dealing with these conditions for a long time and have never seen a patient surviving from that condition.

Q Did the doctor have a kind of like, a meeting with the family to explain /

D: Yes the doctor from initially err...the investigation that are done and from initial admission of the patient. The doctor was involved and then it was a continuous meeting with them until the last

Q: you sighted that the family was not happy initially, did they show the same response to the doctor as well?

D: They did show the same response. But most of the time mh..I will say, the people who are close to the family is us nurses the doctors err... they have got a minimal period err... with the family so at the end of the day I've got to be there for the family and try to convince and make the patient understand

Q: What kind of treatment was going to be withdrawn from this patient?

D: To stop the ventilators err because he was just supported with the ventilator and the medications that were given like err... the injections, and the feeds because was not even retaining the feeds and because all the organs were almost not doing well do they were failing so we were stopping all that because it was showing from the renal functioning it was also on the abnormal side

Q: For how long this patient, this patient you talking about , how long was the patient in ICU?

D: Oh I. .. will say we kept the patient for about 2 weeks because it was not an easy one.

It was a son a young guy, of 23years.

Q: And how were the relations between you and the relatives?

D: It was very good, very good because I was the one in my shift who was always with them even though sometimes I was not nursing the patient err initially it was me who was with them for a longer time but because of the change of duties so I had rotate and nurse another patient .

But at the end of the day On the last day I decided to go back because I saw that even though the patient was nursed by other people they still coming to me. ... may be they formed that relationship with me

Q; Then the treatment was withdrawn and what happened?

D; The treatment was withdrawn err...errr.. we had to explain but initially they did not want us to switch off the machine. The father did understand, the mother couldn't Until the mother the following day came with sister and I had to re-explain because the doctor then was not there. it was me now waiting for them to finalize because they said as a family they are going to discuss again and then they came in, I re-explained, the doctor is not there the and the mother...

Q: And in you explanation you saying we did, they allowed us, I want to ascertain something, here who switched off the ventilator was it the doctor or you nurses?

Because the order was there from the doctor er...mh.. the doctors, they wanted us to switch off the ventilator before even the relatives come as if it just happened, but I couldn't. because I wanted them to have the decision, because there was that order I switched it off after that explanation

Q I assume the patient died?

D: He died within 5 minutes.

Q: if you were to go back looking back at the whole situation how do you feel about that or how did it make you feel?

D: Initially it was not good. For me to go and explain whilst the doctor was breaking the news that now he had to withdraw I couldn't go in to that counselling I took it personally; if it was me what was I going to do because we do believe that God can do miracles. But I couldn't prove to them they must put it to the doctors not to withdraw but I took it to if it was ... so I allowed them to discuss because the doctor was able to explain even to their understanding of the language. So I got in when I saw that they were about to finish to see their expression

Q You are saying this was not the first time, it has happened several times?

D: We do believe that nurses are there to help people psychologically, spiritually and it also help us believe that when you touching the soul of the patient you touching the soul of the patient. So when you are dealing with the patient before you deal with the patient you pray first. That will lead to the patient to be treated with help if it can happen,,, come again with the question?

Q. I'm trying to get your coping mechanisms. ?

D:My coping mechanisms is when you are speaking to the relatives you always put to instill that you are a nurse you are a human being and you also believe in God. They must also pray as to help curing mechanism that we are dealing in the ICU because sometimes miracles are happening but in this situation it makes me to define when the relatives understand and don't put the blame to me.

So when I'm explaining to the relatives of the patient I tried to gain them so that they can trust me that I will never do something that will err.. cause as if I did purposely the patient was fine so as long as I gain the relative, then I feel so good about that and then I always believe in prayer.

Q; Is there a situation in all these instances whereby you carry a blame, you feel that you blame yourself?

D: In this situation I will say I never have to carry the blame. I never had that problem. I almost try to be able to talk to the relatives at all times as a result where I come from, they used to say call her she is a social worker she will be able to convince them. At least they will be fine with her. I think God has given me a way of convincing them when it comes to that.

Q I want to go back. You are saying in this instance you don't carry the blame, was there any other instance where felt you blame yourself?

D:: It is not withdrawal. It is when let's say we were trying to bring the patient's life, and then all of a sudden the patient died you blame yourself whereby you should have done 1,2,3, or you were so slow to do this instead of starting that where it could happen in my presence I could feel I got a blame.

Q: if I may ask do you as a nurse working in that environment feel at some stage you need like an external support to keep you going?

D: You mean external support mhlawumbi by going to the psychologist or whatever? Sometimes we do need that one because when it happens sometimes you could feel because it was not supposed to happen like that.

Dolly 3

Q: For how long have ou been working in the critical care unit?

D: From 1992

Q when were you trained as an ICU nurse

D: Mh ... 2008

Q Can you share with me your experiences in an ICU setting concerning the withdrawal of life sustaining treatment?

D: Ok the decision is being made by doctors yes and they usually say it verbally that the patient is not for active resuscitation but some of them they do have a guts to write it down But most of the doctors they say don't jump on the chest because the patient won't make it there is no point of sustaining life unnecessarily

Q you are saying the decision is made by doctors. How about the nurse/ or How do they reach that decision

D: Depends on the condition of the patient sometimes most of the time in fact the patient is usually the brain dead, declared brain dead ja so that when they decide not resuscitate otherwise generally its very very rare to decide not to resuscitate They do give the patient that chance to survive... if necessary

Q where would the nurse be when the doctors are taking that decision?

D: They are always next to the patient there next to the patient always in ICU. it's Always the nurse and the doctor

Q As a nurse are you given a chance to say something pertaining the management the treatment of that particular patient?

D Yes

Q Just give me one example?

D: at times since we are nurses mos. We are the ones that are usually in fact always next to patients with the patient. So at times the doctor orders this and you as a nurse intervene as a.. just to say no doctor how about this because ever since I've nursed this patient I've noticed this and that so how about doing this and not that. And most of the doctors they listen to you even if he is not going to do what you are saying and try to convince you why he decides like this and sometimes does agree with you

Q Cannot be always it's a normal situation?

D: Yes

Q I m going back to this question again do you have a situation whereby you are coming to sit down formally and discuss the patient and then come to that decision?

D: I.. I.. Not formally per se because its always there by the patient with the doctor. It is not a formal thingper se it's always there by the patient with the doctor. it's not a formal thing thereby you sit aside and discuss.I have never had a formal sitting with the doctor unless at times we are discussing with the relatives whereby the doctor explains the condition of the patient then it becomes a formal thing

Q In your nursing experience in this environment could you remember rather a situation where the treatment was going to be withdrawn where you were nursing that particular patient?

D: Yes .Not once

Q Could you tell me more about that particular situation?

D: As I said... it's when the patient is declared brain dead when they decide to withdraw. Many a times in ICU we've got a patient who is in that situation it is not a rare thing

Q When that decision is taken ok ,you were saying you would be discussing with the doctor next to the patient, at the patient's bedside and now would that be the first time you as a nurse hearing of the action the doctors are planning to do?

D: I don't understand

Q At the time you are discussing the next step the decision to withdraw the treatment you are there next to the patient bedside and the doctor is explaining, would that be the first time you hear it, there is no other time where the doctor has mentioned ?

D: At times maybe it is about report giving since we are teams I don't know if I'm hearing you quite nice whereby the doctor has told this nurse in a particular team. They fail to report to the next team and when the patient is having cardiopulmonary arrest and this particular team resuscitate and when the doctor come will ask didn't I say to you don't resuscitate.

Q Are you sighting that now breakdown in communication at times?

D: At times more especially when the doctor has not written down do not resuscitate

Q you are saying you have nursed a patient whereby the treatment was going to be withdrawn, how was the process done. The process of withdrawing the treatment

D: ok Most of the time the doctor stops the like antibiotics sedation .cocktail because at that time the patient is deeply unconscious but at times he leaves out IV fluids and feeding neh and he tappers down ventilator stings he does fiddle on the ventilation but usually the feeding and IV fluids are left out, things like antibiotic's sedation, At times he leaves out analgesia so that the patient may die peacefully no pain.

Q And how do you as a nurse perceive that. How do you feel about the process of treatment withdrawal?

D: It's always not nice... always pathetic you just feel for the patient and relatives kaloku we are dealing with human beings we are human also.

Q And How would the relatives perceive the treatment withdrawal?

D: With me with my experience The doctors when discussing with the relatives they do not say no we are going to stop this and that, we are tapering the settings and all that staff, no they just discuss about the condition that is critical its fatal and it ends there, they don't go deeper. I think the legality or legal implications of this withdrawal of treatment in my mind. I've never heard the doctor say we are going to stop a, b, c in front of me and d I have never witnessed that Always err mmh being

sympathetic with the relatives per se because the patient he is almost dead I can say.

Q after the doctor has explained the withdrawal how would the relations be between you and the patient and you and nurse?

We always be sympathetic with them, try to talk to them to show them more in our own language. Because the doctor speaks with the relative in a higher level. So now the relatives are panicking frustrated, hoping for the best, in denial most of the time. So we do try to talk to them try to calm them down to talk sense with them I can say.

Q That is quite a heavy load on you!

D: Very. At time they cry we have to calm them down do whatever you want you can do.

Q: What is that doing to you as a nurse?

D: It's pathetic as I said you put yourself in their shoes. What if it was me who lost a brother or mother or father just being traumatic also .I can say

Q: The ventilator settings have been tapered and I suppose the oxygen, ?

D:yeah as I said It's part of ventilation.

Q: how long would it be between the treatment is withdrawn and the patient responding to that?

D: How does it take for a patient to respond to this tapering down of everything? (participant) You know what,... this withdrawal of treatment is not always one day decision it takes a day or two when they decide , ok this patient, they give in fact the patient time to recover or to ... or anything to happen . and then when they see that the medication there is no response whatsoever and clinically the patient there is no response and then they do the brain test so this tapering down it does not take long maybe few hours always few hours in my experience because the patient by that time was in a ventilator or this treatment for quite some days yabona so at that time the treatment is being withdrawn the patient at that time... I don't know what to say but it does not take long.

Q; I would like to find out, you have a vast experience. what makes you to be able continue , what are your coping strategies?

D: In this stressful environment? I ...mh I don't know. I don't know what to say really. I don't know maybe because I'm used to this situation. I don't know how I cope.

Q Is it out of loyalty perhaps, duty bound or anything like that?

D I can say it's out of loyalty not duty bound, out of loyalty really and loving your profession. ja

Dolly N0 4

Q; If i may ask for how long have you been working in icu?

D; From 1997

Q: For how long are trained as critical care nurse?

D: Mhm From 1998

(corrected and laughing at the correction) 2007 then 2008

Q;I would like you to share your experiences concerning the withdrawal of life sustaining treatment in a critically ill patient in ICU. For me in fact the two of us it will be easier if you can recall a particular incident whereby you were nursing a patient and we move from that and you mention anything that comes to mind as your experience.?

D: OK .With the withdrawal of treatment as we are next to the patient here in ICU. When the patient changes condition or needs resuscitation we did resuscitation and call the doctor. Then the doctor will come If err... fortunately we are still doing with resuscitation he will join us with the resuscitation.

If maybe resuscitation done more than 15 minutes then there is no improvement and we did give the drugs as ordered for example adrenalin atropine we did chest compressions and ambu bag the patient and there is no improvement then the doctor will doctor will order to stop resuscitation Sometimes if the patient is terminally ill there is no hope even if we can do resuscitation there will be no improvement according to the doctors assessment with the type of condition of the patient the doctor will say no don't start resuscitation

Q is that order normally written down?

D: Which one

Q In the case of terminally ill patient?

D: Some doctors do write, some they don't they just order verbally

Q If I may ask for how long would you have nursed that particular patient?

D: which one the one not for active resuscitation? Sometimes for a long time plus minus 5 days maybe then according their investigations and the condition of the

patient then they will say even if we can do this and that there will be no improvement will just elongate the time of patient in ICU.

Q how involved are you as a nurse in the process rather in the decision of withdrawal of treatment?

D: We are involved in such that the doctors explain, because we do have a concern why are we not resuscitating the patient. Then they will explain to us why and with that ke ngoku we agree with that decision..

Q: Do you have like formal meetings whereby you sit discuss a particular patient and come to a decision?

D: Yes

Q So you would meet before?

D: Yes

Q: Is it all the nurses or one particular nurse one nursing the patient?

D: Sometimes, sometimes some nurses not all nurses. it's either the one nursing the patient or sometimes others who are interested in this condition

Q: Are you given a chance to input on the decision taken by the orders?

D: Yes we do have a chance they will explain we ask and they will explain

Q: Was there a situation whereby you would not agree with the decision taken and advocate ?

D:Yes there are some patients that sometimes for example if the patient is young you think they may have a chance to improve but the doctors will tell you, they will give that chance and said ok let's not terminate, you will resuscitate
But at the end of the day we end up losing the patient

Q: In a situation now you are getting ahead to withdraw the treatment, how would it be done?

D:..How would it be done? Come again with the question

Q: in that particular patient the doctors have come to a decision, how would it be executed?

D: Firstly the doctors will ask the relatives to come and explain the condition and the relatives they explain fully when the relatives come. They will explain fully to relatives the patient is critical ill and there is no hope. They will do whatever .They ..they are not saying to relatives we are going to stop resuscitation. They will tell

them we are doing anything we think patient will... will... benefit on but its highly on the side of there will be no hope for the patient to be treated in that condition.. So they prepare in fact the relatives for anything that may happen. Thereafter the relatives will ask questions is the doctor the nurse nursing the patient .and the relatives they will ask the questions and they will be explained to them. When they are satisfied with the explanation then the doctors will do whatever

Q You are saying they do not say they are stopping the treatment why do you think is the reason for that?

D:Uh... for the relatives...it... I think the relatives will not be happy because they want life to take its course.so they won't be happy if... Some who are educated even themselves will ask how about switching off the ventilator because it's a long time now?

Q: Now you are saying the relatives will probably not be happy, was there a situation whereby the doctors were explaining that the condition is critical and then maybe suggest that that particular treatment will be going to be stopped and the patient is going to die

D::No not at the moment

Q: How do you feel about the treatment withdrawal as a person ?

D:: Me as a person its eh... 50/50 .Sometimes when the patient is critically ill and he/she is old and the condition has been explained and you can see that the patient is suffering a lot and with the explanation and with the consultation even with the books this condition is fatal there is nothing that can be done that one really we agree with the doctors . But when it comes to the young people you don't agree easily you always have that hope that this one can fight can have the ability to fight against the condition even if this condition is fatal.

Q: Often you have seen the doctors withdrawing treatment, and then how long would it between the treatment withdrawal and final outcome. ?

D: Even that one it depends with the particular patient because everybody is individual some they take time, some immediately when the treatment stopped they just within 30 minutes then everything stops. But sometimes even 24 hours they go far as 24hours. It depends with that particular patient..

Q You as a nurse how do you feel about that? How do you feel/now the outcome is there you have seen the outcome?

D Mh...You don't feel good but as you already explained err... and ,,you don't want the patient to suffer too long but you don't feel good because is a human being you become a human being even yourself not a nurse at some stage.

Q: Your role as a nurse that you playing during the treatment withdrawal, what is your actual role?

D: The actual role, first you play a role with the relatives when they come to the patient, try to comfort them try to explain the condition to a certain level of a nurse not far to the doctors level try to explain to them that this patient is critically ill but the doctors are doing their best and we are doing our best and we have to pray for the patient to get better. That is the role with the relatives. Then with the patient you always comfort the patient treat the patient as if he/she is alive give that dignity talking to him or her if they need the relatives need to bring their priest then allow them to come and for their prayer if the relatives want to bring a priest let them.

Q: I've noticed you have spent a long period of time in ICU, since 2007 you are working in this environment you say there is anger sadness ,You have a long time in this environment.? How do you cope ??

D: We do have sometimes in-services whereby we discuss about coping skills from each and every nurse s. and also with the doctors sometimes we ask from them how to deal with this situation and just pray by as a person on our own

Q if I may ask you say you do have in-service and discussing coping skills. What examples you can give that you have touched as a group?

D:Like if the relatives are very angry? Sometimes the relatives. .the patient. for example the patient was not ill it was an injury.. so an injury is a sudden thing ,that particular person was alive and healthy then the relatives will come and then the patient is just unconscious and Glasgow coma scale 3/15 and the doctor say there is no hope even us mos we become attached. Have that feeling that this person was fine before. Then we discuss that and how to deal with these relatives how to handle the situation.

Q: Would you continue to work in ICU?

D: Yes

Dolly N0 5

Q: Tell me for how long have you been working in ICU?

D; almost 30 years

Q: Tell me, can you share with me your experiences pertaining the life withdrawal system, those patients who have been on life support system and it had to be withdrawn for whatever reason?

D: Mh;;;The patients with Organophosphate poisoning neh and also gynae patients nehlike oo.. Eclampsia they have a problem they need to be ventilated sometimes. So sometimes the condition change then they had to just to continue with ventilation until such time where no more resuscitation measures to be done

Q; Can you tell me more how is withdrawal done?

D; Ok eh.... the doctor will look at the patient and err...he will do or she will test from the patient but he/she will say we must continue with the management neh until the pulse go down so there will be no resuscitation to be done. neh So there will be bradycardia then asystole. Although the patient was on inotropes neh, so he said there is nothing can be done

Q I am, probably thinking you are talking just in general. Is there just a particular instance where you were directly involved maybe you were nursing that particular patient . is there none of the incident coming to mind?

D: When the patient is on mechanical ventilation neh? A; I'm not sure This question is not clear to me.

Q: Why I'm asking that I want to come to a situation whereby I would like you to narrate if you recall that particular instance that the relatives were there, how the information was conveyed to the relatives and by whom that is, decision to withdraw the treatment?

D; Interrupted by telephone) I'm just thinking now neh there was a patient neh it was transferred from St Dominic's neh the relatives were here with the patient neh Err This patient was on mechanical ventilation right through and she was edematous the whole body and also,, she was on inotropes right through from St Dominic's and we continued with inotropes. And she was not responding at anything and fortunately the relatives of the patient they understood the condition because the doctor told them that the patient is very sick everything has been done to her so they did understand of that but they remained in the unit until such time. And when we saw that the condition is changing because the doctor was not here at that time neh we phoned the doctor and the doctor came

And she had I bradycardia and then we call the relatives because they were in the lounge and came next to the patient and she was very, very edematous even the lips everything , the arms everything neh

But one of them said err... err... so and so we can see we are losing you and there is nothing can be done the doctor has told us everything so we are releasing you then she was so was released by family and also we were all around the patient then the bradycardia goes down and then there was asystole. And one of the family was also a nurse so she understood so she understood everything all that all about that. The doctor told them that she was gone, so they did a prayer for her then everything was signed as ...the doctor certified dead the patient that time

Q; For how long was in ICU?

Mh... At CMH he had 2 days and from that hospital plus minus 10days

Q for how long did you as a person nurse the patient?

for 2days

Q How were the relations between you, the patient and family the three of you?

D: Err.. the family when they were here they wanted to know how is the condition now and you had to explain for them but I could not go deep neh and I told them that I'm going to call the doctor so that he or she can explain the condition now to them neh, fortunately doctor... our doctor ICU doctor was present neh

So I had to call him and he went there and explained the condition to them they understand, they understood but most of the time they were here, they were around here neh. And also they were just brushing their...their sister err talking to her and they told her that they loved her all of that neh..so I had to talk again to the patient err. Mrs so and so here is your sister they said they love you so they want you to be up my dear but they are still talking to you.

Q: So this particular patient the condition went down and patient died , the doctor did not stop the resuscitation if I get you correctly?

D: Yes because he was already on inotropes . no they did not stop until there was asystole

Q They did not stop that and the ventilator either?

D; No they didn't until asystole

Q Is there a situation whereby you were nursing the patient and for some reasons maybe the patient was declared not for active resuscitation and the treatment had to be stopped?

D: Mh...yes they will say that is not for active resuscitation but they don't stop all the ventilation and the treatment until the cardiac monitor will shows asystole

Q What do you think of the process of withdrawal. The whole process , what do you think of it?

D: I think there will delay there will be a delay to the family and also to the... it will not be nice to the family to see the suffering of their relative I think

Q : In the instance of the patient you nursed so the relatives were there .and you were sighting that they were understanding and accepted. Was there a situation in your nursing experience whereby the doctors are explaining to the relatives and the relatives are not accepting the situation?

D: Yees... because I am thinking of err.. there was err a little lady she was about 13 to 14. They said its guillain barre syndrome they were querying guillain barre syndrome neh . but this child err... she was on ventilation and also they said no they don't think she will make up . then but the family continued

And the doctor did go to the family and explained the condition to them the way they were so worried we said no you must have hope from God because we don't know what will happen. But they continue err coming to see their child but it was on and off, we find out sometimes err she will go to bradycardia but we had to resuscitate the patient neh but fortunately enough she was alright

Q: Normally in an ICU setting you are experiencing a lot. I'm picking up all this you have a lot of experience, What makes you cope working here all these years?

D: I think what makes me to cope here is the relationship we had err... we have a good relationship between err the staff member even with the doctors but if we have err... something they we ...I don't want to say we are fighting but err.. but lastly we just talk and solve that problem

NO 6

Q: May I know for how long have you worked in an ICU setting?

D: From 2002 up to date

Q looking at this period, you have gathered a lot of experience in this environment. Will you share with me your experiences especially concerning the withdrawal of life

sustaining treatment from a critically ill patient? Anything that you would like to share concerning that.

D: Where do I start you know mh I would say I 'd. first start saying it err... it drains emotionally because there is family involved you need to be part of the counseling when you counsel and you deal with different people with different understanding so that's the most part with me that is quite draining and at some stage. I even said we actually need counselling ourselves . When people are crying saying all kind of things some others they understand and err ...sometime you deal with illiterate people who cannot understand people who would take it as if you are actually saying you do not want to do or to give a help for their loved ones. But in essence there isn't anything more medically that you can do to help this person

Q: Tell me since you highlighted that, may I ask, how is it done? How is the process of treatment withdrawal done?

D The process when everything is been done in my experience since Ive been here and the doctors could see that there isn't anything more that they can do, first thing is to call the family. They most of the time since I've been here they let the decision be taken by the family sometimes. Sometimes they do tell the family that fine this is the situation this is what we did and we are not achieving anything positive and now we sought of keeping this patient on this bed knowing very well that there isn't anything more that we can do and now is occupying the space there is somebody else there who can utilize this bed and be well.

Then the doctors normally ask now that the patient is err... ventilatory dependent they ask from the family after the full explanation of what has been done and what is the state now. They put the patient sometimes on a T-piece then they transfer patient to the ward. We normally transfer the patients to the ward those that are fully recovered from ICU then recuperating in the ward. But this is a different, even in the ward there isn't anything more they can do, it's about seeing to it that the patient is clean and given whatever to be given. Those are the kind of staff.

But there are cases whereby they do take a decision that we can't even take this patient to the ward, especially with the cases whereby the brain stem has been confirmed, the brain stem death has been confirmed by those doctors who are senior. . its then that they switch off , they actually tell the family first they just do it. They first talk to the family

They explain they let the family verbalize whatever the family wanted to verbalize, they let the family ask questions to let them be in par with the understanding that its not about killing the patient sought of killing the patient it's about letting the patient free and ease the family too, because that we let the patient on this ventilator thinking that the patient is ok its not it's not ok its only the ventilator. Then they switch off the ventilator then everything follows

Q: May I ask, I've picked up you are saying the doctors let the relatives take the decision sometimes. There are those instances where the doctors are going to take the decision. I would like to know your role as a nurse? Where are you in this decision making?

Err.. in this part most of the time its... I don't have much as a nurse to do. it's about helping sometimes in terms of translating making it easy for the other party to understand what is being said in a simpler term but as a nurse I don't have much and be the witness at the same time that the doctor did meet they met they sat with the family they did discuss because you know the family can turn around sometimes.

Q: How comfortable are you that you are not really part of the decision making? Does it bother you that you not part of decision making?

A: Not really to be true, because I feel the doctors are the one who knows better especially when it comes to that point of deciding whether to withdraw the treatment or continue but sometimes according to my experience and experience in terms of the time I've been in ICU and my understanding, I do trigger when I see that hey this patient this has been done and this is the situation seemingly we are not weaning in a form of questioning exactly what is your plan of action for this patient. Then we start talking. But I don't feel much uncomfortable about not being involved because the participation that Im actually having now is enough for me

Q: I would like to go back to where you are saying you explain to the family. How would the family receive the news?

A; It's often is not an easy thing because even me I..I feel like Im part of that family I become emotional but because of my job I try to contain myself. But you will get...Most of the time mna ever since I started this thing counselling pertaining the withdrawal of treatment they become hysterical they cry they do everything. I still remember one other time we had a very young girl who had her sister admitted on the other side in high care. Then they were involved in an accident the brothers died instantly. In fact the first died instantly the other on the way to hospital. This one

when she arrived she was already 3/15 she was nonresponsive but we couldn't rule out that time that it could be the end even the age because that's exactly the other thing that the doctor consider the age and they give a person a chance. They do everything that's exactly what happen with that one. Then it was this all these years that I have been involved in the counseling of patients whereby this lady said:, she was not talking to us she was talking to God but through us like she was saying why do you want us to decide now God because You did your own decision You took my two brothers you took my other sister but now why do You want us to decide on this particular somebody. I was so emotional then because as she was saying so she was crying and I felt like... O my God! She even said we are leaving it up to you but I'm giving an ultimatum because I want to bury these people all of them on Saturday it was on a Monday, tomorrow, she was actually saying tomorrow you must decide God.

We were in this room, I was... I didn't... I was crying tears were just flowing and I become emotional as I'm talking even now.(participant cried). This lady was sitting here, oh my God! You know! After that I said to the doctor whom were conducting the counseling lets pray, I did not know that young lady can pray that much.

We prayed like anything, everybody was crying the doctor crying everybody was crying it was such an emotional state. The patient was not even mine. I even said but she wanted to have this counseling with me. I even said oh my God why did you chose me because this patient Im not even looking after this patient it was such an emotional day but to a surprise because the God we talking to is the listening one, the following day that child died without any withdrawal everything full ventilation everything but the child died and they were all buried on the same day...

They even had a the..the..the.. sought of government sought of state funeral I will say because the government was involved throughout it was... in my life... that lady was not talking to us she was talking to God. She was asking because the doctor told her that there isn't anything more it's about switching off the ventilator then this lady started saying no its not easy for us to say because even with the three we did not decide He decided why does He let us decide now. You can imagine that question why do you let us decide now you continue you finish up your job.

So I've been even yesterday I had another emotional one a very emotional but it was not withdrawal per se because the patient died. Then I was dealing with the parents just the mother and father they were just coming because the child was admitted

here had surgery has been sick after we had a lot of conversation I found out she has been sick for quite some time she has been going to the doctors but up until this time this doctor said no maan you go to the hospital then she came to hospital was admitted and found out she's got a chronic hematoma and abdomen they did that, did some drainage and that young girl did not make it I think she had septic shock I did not even see that young girl because I was off I just came in the part that I participated in is when I was checking, I heard that the family does not know because when they were called the phone went to voice mail ring ring. I said mhxm maybe because it's this private number others do not answer this let me call them with my own cell phone.

I called these two numbers but had the same problem. the first one was answered by a Zulu lady, said no I don't know that person but by the time they arrived I found out this numbers they are theirs but they didn't understand what was happening now, now that it was being answered by a Zulu girl this one. only to find the other one was the deceased phone ,and the other one was the mother's phone and they were staying in Quigney and th is lady is working here then the father asked some short leave from to come and assist the wife in taking care of this onr . she had the kids that she was staying with at Kwikwini (Quigney) and it was that kind of situation. Now they don't even know East London and the body by that time was in in Woodbook

I phoned Woodbrook I found out no the body mh...this thing the post mortem will only be done on Monday because yesterday mh...this ... the district surgeon was sick. I wanted the assurance that they can move from Transkei with the parlour to fetch the body by Woodbrook and this warrant officer said no Im certain sister they can come but must not come very early at least by eleven o'clock and they then can come I don't want them to stay here They wanted to stay ... oh.. I had another day, they wanted to stay now in Quigney waiting for Monday and I said no there is no body in Quigney who has died there is no family in Quigney that has this nto, its only back home there are other kids there. You can't relay the message to the kids. Who is going to support those kids? You must go up nina back home

If you want to come with that parlour then you tata you can come with the parlour to... to... Woodbrook then you take your child. you just let the.. the... this person the Mastandi(Landlord) to know that you are leaving and there won't be anybody at the flat . then you will come and collect... and this old man said you know when you are

stuck in a problem you become like you don't think well because what you are saying is what we should be doing because it's the whole weekend you will be looking at each other with this kind of a problem whilst when you are home there will be people coming in and out making prayers and comforting you making you to get to understand that this is the reality. It was just another day and I said Oh my God! I don't know what is happening here, but it was better because I found out I was dealing with people who know God. Because after all that conversation and whatever he is the one who actually comforted me now with the words from the bible. And this and this ... So it's that kind.... It's not an easy thing.

Q: Now tell me you are mentioning something here that you often engage in counselling of these people who have lost the loved ones. Are you guys getting any counselling?

A Im that's exactly.. but I....I'm hoping it will...but we never had any. Err we've got this doctor now who is running the unit now of which she is such an easy young lady. We sit down we, we we sorry(belching) we have short meetings we discuss certain issues.. this one this issue of having people to counsel us because its actually draining us because I ...i...remember I was not part of that I wasn't even on duty I was off I heard of counselling that was being done in that other room whereby the doctors themselves didn't even know what to do with family you know.so now guys I think we also need counselling because this thing tearing us its draining . When you come from that counselling you feel like you don't want to participate in anything you don't want to do anything whilst there are some other patients that you need to take care of. But emotionally inside you and it goes to physis, you feel like you are tired you will feel heaviness. ...but.. when... I think it's still happening because I still remember when I was at St Dominic's at St Domininics you know because it's a private institution they do....they do those kind of things I'm not so sure whether they are doing it for ICU where

these things are more often so they...they organize there will be a day that they organize especially when they found out for a month yoooh! in ICU?...ICU is not a place a place whereby in a month you can have when you can have four death it's a big number a big number. Then when you got twenty something Im I mean i don't even know how to call it we really need that because this is the last place of health I would say ICU and even a family member outside there she or he has that one of their loved ones is admitted become worried because they know uba is the

last place hence I would say even with the young ones that are coming in listen guys the attitude of somebody in ICU it must be different to others because this place we are looking after critically ill people and the most critically ill people are ones who are walking coming to visit these. You would think they are the ones who are sick we need to have a way of talking to them when we talking we must be giving them hope that even the one that is lying in bed is gonna get help because the way we talk to them is the one that whose gonna oh there isn't anything even this thing because yena he is helpless when they do this to me how about this one who is helpless but...uuu this young lady u Doctor arr we are working with at least she promised she said no we are going to attend. We need to do things step by step because we have to escalate this because maybe its gonna involve money so we need to escalate to the higher people so that, but we need to make them understand that there is dire need for this,

Q That makes me ask this question. From this interview I'm asking myself how do these people cope, how do these people continue? Where do these people get the drive to come back tomorrow?

D: but what gives us the drive is because of those who enter this unit even in our eyes we throw towels but, we are doing because we have to do but they go out as healthy people those are the people who are actually giving us...I as a person even when I'm home... wena...and mm I did something good. I feel like a today I've done something .Even when I am having a tea in my house I feel like Oh God I did something for umtu wakho. You know I think I'm not so sure about other people but with me they are the ones that actually keep us going because we had we had a young, young, young lady even the mother the family still praising us.. badly injured and the injuries were here on the head which I regard as most vital part.She spent so much time here but she is walking. I met her and then I didn't realize her and so and she said you don't realize me because now I'm walking. You only know me when I am a patient. Heeee! then there comes I wasn't a mother came then I quickly realize the mother then we started charting walking those kind of people they are the ones because its not everybody who gets in to this room and live out you know. So those are the kind of things that I as the person they, they keep me going and I feel like coming as a result I feel like I don't have elsewhere to go and work ar ar I'm I'm im just an ICU nurse

Q; I was just about to ask that question, Would you work in any other area?

D: I don't see myself you know I started in the interest in ICU I was doing bridging course then. During that time of clinical exposure I went to ICU and I felt like wow! this is the right place for me. Everybody, everybody is doing his or her own job. When the patient arrive its started when the patient is arriving I would say one other time Yhooo! If I were a patient Id actually jump and actually run because everybody come the other one is fixing the drip and other one connecting this everybody is on top of you the doctors this side and I felt ha ah I think this is the place. I must go and work in this place. I started (clapping hands) and I felt like I'm not turning back. I'm here to stay

DOLLY NO 7

Q: How long have you been working in ICU?

D: Ah... plus minus 15 years

Q: For how long are trained in this environment?

D: 13years

Q Will you share with me your experiences that are concerning the withdrawal of life sustaining treatment?

D: Ok ehh... withdrawal of treatment most the time it hurts lots of the people the patient has been in ICU for a long time people tend to bond with that patient and love the patient so much, bond with the family as well which I suppose that makes it very difficult when the treatment is gonna be withdrawn because now you must talk to the relatives who trusted and believed that you going to help them. For instance we had one case down stairs in ICU2 of a guy that was involved in an accident in P.E and then waas not admitted there

Was seen and discharged only to find out that he had complicated during that period. By the time he came here to FRERE he was already bad. He had lung contusion which was not detected earlier. He had to be ventilated for a long time Develop SIRS developed MODS then that was a big problem. He was swelling up could not be weaned from ventilator at all. Now the family had to be counseled at a later stage that that now there's nothing we could do. Is not improving instead ne becomes worse. That was the worse thing for us because we were so close to the family in such a way that it hurt me a bit because after the guy has passed on... (pause)...

And you know at that case you even avoid to call them when there is a change because I was the one who had to call them to come in so that the doctor can

explain to them the patient is not here anymore only the machine that is working, the patient is brain dead. When they come they see the chest moving they believe he is still alive because he is breathing, now the doctor must come and demonstrate to them that you see if I take him off the machine then look at the chest there is no movement meaning it is air that is going from the machine and still cannot not accept that because they see that no ,no the chest was moving now –now even when you remove it to them it is still moving because it was moving when they saw it.

Ok finally the guy was taken off the machine he passed on. I think a month later I went to (FNB) his sister was working at FNB. As soon as she saw me she started crying the i told I won't come here anymore if whenever you see me you gonna cry. Then she said whenever I see people that were nursing him they remind me of him. I know that he is gone but because you were so close to you guys its like I'm gonna see him again. You know such thing Because now It's a funny experience for you as a nurse as well because you remain with eish if I go to FNB no no I must not go to this FNB until sometime sothat when you see them again you see that they are fine but fortunately because we counsel them for a long time. We continue with counselling even whenever we call them every time there is a change even though they will cry because its their loved one after some time they accept and . they are grateful that at least they did not miss anything we were updated with all the information

Q What is your role is the actual withdrawal of treatment?. (There is a knock at the door)

D; Somebody interrupting)In the actual treatment my role is to talk to the relatives , I am an advocate of the patient I cannot do it myself the doctor is suppose to do it because he is the one.... Ok he is gonna make me understand and Im gonna make the relatives understand but at the end of the day its his duty to check properly do everything see that the patient is really brain dead involve other doctors the seniors to confirm that its like that then is the one who is taking the patient off not the nurse

Q: how do you come to the decision of treatment withdrawal? My question is looking at your involvement as a nurse in the decision making of the withdrawal of treatment.?

D: You know with us nurses it is not an easy thing to do if I can remember one case when there was a patient that was for a long time on a ventilator. You know still very new in ICU at that time I did not know the nitty gritty because at some point in ICU if

you are in ICU for a long time you realize that there is no use keeping this patient on a ventilator because even if you keep this patient on a ventilator it is a long time rehabilitation its gonna be a burden to the relatives. Because they have to do everything for the patient.

So when I was still new the doctor came, she said we must take the patient off the ventilator and we all knew what was going to happen then we said no no we are not going to do that, if you want to do it do it. He said but the prognosis of the patient. We said ok we understand you but we believe that is not for us because we feel like we taking the life of the person. So you as a doctor take the patient off.

Q: Do you have like session you know before they tell to remove the patient? Do you sit down and discuss the plan ahead?

D:: A lot. We do a lot of it considering how long the patient has been in ICU Was there any improvement is the patient deteriorating? Its worse when all the organs are failing ther is nothing you can do. You cant withhold somebody who has gone into renal failure, kidney are not working, the lungs are bad, respiratory wise is not doing well, patient unwinnable from the ventilator and the GCS is down to 3. Then you cannot say I'm gonna keep this patient on the ventilator.

But before anything is done the family is called several times. its worse here we've got a proper place for talking to the relatives, we've got a counsel room , that we call them in. everything is explained to them . After that they are allowed to go back home, discuss among themselves as family how do they feel about it so that they can decide agree and understand what is going on. Its a lot its several sessions, several sessions.

Q S o you can say you are playing part?

D: :We play part, we play part because even if they were here when the doctors feel they want to do something then we said you cannot do it now you must call in the relatives first so that we talk to them and make them understand what is going on.

Q The relatives, how do they normally perceive this idea that is brought up by the doctors?

D: Depending on the level of knowledge because if they are knowledgeable they quickly understand. But if they don't understand like they will refuse especially when it comes to our people, African people they will say no-no we brought this person here to be cured you cannot tell us when you take him off the machine he is going to die. that means you are killing the patient that is why you need to constantly

talk to them make them see what is going on because fortunately now at the present moment we have anesthetists they are always available they show them the scans even the neuro doctor Dr Harrison will come and show them on the scan that this is what is happening, normally if this is what is happening you are going to behave like this but when you are normal... you show them normal and abnormality so that they can really understand and you find that if it is done constantly when the patient is taken off the machine they already accepted. In that way you are even preparing them for the worst. You don't just say to them the patient is gone. So they must know exactly what is happening

Q so in other words you telling them exactly what is going to happen?

D: Exactly what is going to happen and if they are around you ask them to be here because if they feel they want to be here and see all the process then they are allowed, the patient is taken off the machine then they sit they can sit there and wait until asystole.

They have been prepared. They have been prepared

What happen when the relatives voice out that they would

Q: Is there a situation...You are talking about literate people and those who do not understand and when they voice (interruption from someone at the door someone) out that they would not love the patient to be taken off the ventilator. What do you do in that instance?

D: Yes? I was disturbed I did not get the question

Q: Those who are illiterate what do you when they voice out that they do not want their relative to be taken off.

D::If they refuse the patient s not taken them off instead you counsel and show them especially when the patient is in renal failure you call them and you show them then you cant go over what that say because at the end they can go because at the end and sue you

Q We are towards the end of our interview but I would love to know how do you cope in this environment with all these things you are sighting because you just said initially this is a very hurting environment and you bond with those people. How do you continue all those years? What are your coping strategies?

D:: You know it's very, very, difficult especially initially, but I think as you grow in the department you tend to nature you learn to realize the reality. That this is the place I want to be. I enjoy being here. as much as it is stressful but you need at the end of

the day maybe after a week or after a month or two months just go out and enjoy yourself that will be part of team building and be away of this environment and talk about something different so that when you come back you are fresh.

And another thing that helps is the fact that whilst you are here promote good attitude, good working relationships, communicate in a manner that everybody wants to be here as much as it is hurtful and we are ...all...because it does help sometimes. It's worse sometimes. We still have young ones who still cry when they see somebody passing away but you sit down and talk to them they also need counselling.

The only thing we were planning to do as much as we don't have it at the moment we said we would like to have a psychologist. Somebody who can counsel the staff now and again, now and again. We need that.

Q; that was my next question I was going to ask if you don't feel you need counselling?

A: We do need a psychologist somebody who can come now and again and do that to you. But so far we have got matured people. When you matured you can handle most of the things, you suffer for other people you know! You suffer for other people you feel this thing is not nice for me as well it's hurting but this one is worse, so you attend to that one. You tend to nurse the staff as well. You nursing the patients and then end up nursing the staff as well. You want everybody to be happy on duty. People must enjoy where they are.