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RESEARCH ARTICLE

PALLIATIVE CARE TO PARALYSED PATIENTS: LIVED EXPERIENCES OF REGISTERED NURSES AT THE INTENSIVE CARE UNIT OF A MAJOR CARE CENTRE IN A CARIBBEAN ISLAND

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ABSTRACT

Aim: To explore the lived experiences of registered nurses who give palliative care at intensive care unit of a major medical centre in a Caribbean Island.
Methods: Purposive criterion sample of all nurses at the major hospital was employed to determine their live experiences using a qualitative design based on grounded theory. Questionnaire structured to accommodate their free expression of their experiences was designed for the study. All 12 nurses who work the different shifts volunteered.
Results: The nurses were of three nationalities (Trinidad and Tobago, Philippines, and Cuba). Their experiences included communication issues, the need for spiritual care, and physical stresses, and "mutual positivism", a good feeling the nurses get when the patients and their relatives as well as the nurses derive satisfaction following the nurses' care. This feeling is derived when the care is holistic to include spiritual care.
Conclusion: We found out that regardless of culture and nationality, registered nurses who provide palliative care to paralyzed patients in the ICU experience high levels of stress and negative feelings. The evidence of the study suggests that palliative care nursing of paralyzed patients is a challenge and nurses are aware about these challenges. The most challenging aspect of this type of care is communication with the patients and their relatives. However, when the care is holistic, it benefits the caregivers as well as the patients and their relatives.
Recommendation: The nurses made recommendations that included among others greater involvement of technologies and special training.

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INTRODUCTION

Registered nurses in the intensive care unit who provide palliative care for a particular patient for a long period of time, as in the case of a paralyzed patient, get to the point where they feel they can no longer help this patient to recover even in a small way. As a result they begin to experience a deep sense of sadness, ambivalence and helplessness as they do not know how to cope with the dilemma of providing palliative and curative care. They feel as though they lack the skill and knowledge to effectively provide palliative care (Morgan, 2009, para. 4). Resolutions to these internal barriers must be established in order to ensure job satisfaction and appropriate patient care. Caring, whether it is ones' passion or a requirement, takes time and nurses cannot just walk away from the patient's bedside in the hope that someone else will take over the patient. The nurses are basically the patient's hands and feet and for those patients who are unable to speak, the nurses feel a responsibility towards perceiving what the patient is feeling, thinking and the overall needs of the patients. Davies and Higginson (2004) mentioned that palliative care needs to be a core component of nursing training and continuing professional education (Desbiens, Gangnon, and Fillion, 2012, p. 2014). In 1987 Kim, Fall, and Wang, (2005) offered a definition of palliative care as the study and management of patients with active, progressive, and far-advanced disease for whom the prognosis is limited and the focus of care is quality of life"(Hagelin and Medin, 2012, p. 20). Nurses often have the feeling that they are now the burden bearers of patients and their relatives as it relates to symptom management, communication, culture, ethics, grief and care at the time of death (Malloy, Virani, Kelly, and Munevar, 2010, para. 7). This can mentally and physically drain nurses and in the process devoid them of job satisfaction. Palliative care for paralysed patients is becoming more and more popular, as the statistics for the number of people who are becoming paralyzed are increasing. Nearly 1 in 50 people is living with paralysis. This is 33% more than it was previously thought. It is a serious problem that often needs some degree of care and support for the person for their entire life (Reeve Foundation, 2010, para. 1). Paralysis is medically

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defined as a complete loss of muscle function in one or more muscle groups, depriving the person of muscle movement. In addition, paralyzed persons may have no responses to tactile and painful stimuli as they may lose both sensory and motor function. Macnee and McCabe, (2008), indicated that nursing care was remembered as a positive experience as nurses provided both emotional support and encouragement (p. 364). Further, it indicated that patients' view of the nursing care they received was that the registered nurses vigilant behaviours were characterized by attentiveness, excellent practical skills and the extra "going out of their way" (cited in Macnee and McCabe, 2008, p. 364). The Intensive Care Unit (ICU) at the St. Clair Medical Centre is a specialized department that offers a full spectrum of medical services to critically ill patients.

There are three sections in the ICU: Intermediate Critical Unit (IMCU), Main Intensive Care Unit, and Private Intensive Care. There are six beds in the intermediate care unit, four beds in the main intensive care unit and one bed in the private intensive care unit. Patients admitted to the ICU have one or more critically stressful conditions, unstable, and in need of continuous and critical care. Patients may be admitted to the ICU for several reasons including severely injured patients such as those who have suffered from destructive accidents and have become paralyzed, and patients who suffer acute organ failure, such as respiratory failure, heart failure and renal failure. The ICU may also admit patients who are not critically ill but who may develop complications. Patients in the ICU require constant care and because of this there is a team of highly trained and alert professionals with specialized roles which includes: The Intensivist, Registered Nurses, and Physiotherapist. The team members in the ICU strive to provide accurate care. The treatment and management plans for all patients in this unit is planned by multiple specialists and coordinated by the ICU specialist. The ICU is organized for the greatest possible patient security and a central nursing station which allows for personalized observation of each patient. The highly skilled registered nurses in the ICU are required to and responsible for providing one-on-one care for patients 24 -hours per day.

Intensive care nurses are in a critical position to identify and survey a patient and the family's needs by utilizing an all-encompassing methodology including physical, enthusiastic, profound and psychosocial viewpoints (Dawson, 2008). Critical care nursing is "that specialty job in nursing that deals particularly with patient responses to life threatening problems; it is a licensed profession where the nurse responsible must ensure that optimal care was given to a critical ill patient and their family" (American Association of Critical Care Nurses (AACN), 2010). Further, most, if not all of the nurses in the ICU have skills and experiences in dealing with critically ill patients (Hansen, Goodell, Dehaven and Smith, 2009). Patients in the ICU have critically stressful conditions, unstable, and in need of continuous and critical care. As for paralyzed patients in need of palliative care, they need to be made comfortable and relieved of discomfort to enhance a good relationship between the patient and their loved ones (Singer, Martin and Kelner, 1999). This is where the nurse plays a major role by attending to all the needs of the patient even the ones that the patient are not aware of, for example, two hourly turning to prevent skin breakdown. "It is important for nurses to understand the connection between palliative care and the intensive care unit" (Dawson, 2008, p.19). The reason for this is that ethically, ill patients in the ICU and their families may benefit from a palliative care approach, which aims to comfort patients and provide them with good care and alleviate their suffering (Nelson et al. 2004). Further, it is imperative for palliative care to be a part of an ICU as it is appropriate for all critically ill patients who require aggressive treatment to prolong life with good quality of care (Nelson *et al.,* 2004). Given the fact that deaths occur in the ICU and it is inescapable, is one of the main reasons for critical nursing and palliative care needs to be integrated. With particular focus on palliative patients in the Intensive Care Unit at St. Clair Medical Centre, statistics for the past 5 years illustrated that the demands on the registered nurses providing palliative care for paralyzed patients are increasing as illustrated in Table 1.

Table 1. The Number of Paralyzed Patients in the Intensive Care Unit with their Maximum Length of Stay, and Number of Deaths for the Past 4 Years

Year	Number of Paralyzed Patients	Maximum Length of Stay	Number of Deaths
2009	4	22 days	1
2010	6	22 days	1
2011	3	8 days	3
2012	4	67 days	3
2013	10	40 days	6

The statistics illustrates that even though the number of paralyzed patients were the same in 2009 and 2012, the patients stayed longer in the ICU in 2012 than in 2009, hence the reason why the emotional, spiritual and physical demands on the registered nurses are increasing significantly. There are three essential aspects of palliative care nursing namely: symptoms control, support of the family and support of the patient. The role of palliative care nurses is to assess the needs, plan, implement the action and evaluate the outcome. In the ICU department at St. Clair Medical Centre, the registered nurses provide one-to-one care for all patients in the unit and they work up to sixteen hours per day. Spending those long amounts of hours with the patient and the relatives create an attachment to the patients and relatives that can easily encourage nurses to exert more of their physical, emotional, and spiritual energy than they would usually give to other patients in the ICU.

There have been numerous studies concerning families' perspectives of the end-of-life care their relatives received and these studies have constantly emphasized the importance of having adequate support from nursing team 'being there' for both the patient and the family (Linderholm and Friedrichsen, 2010). Supporting the family is considered a central tenet of good end-of-life care (Department of Health, 2008; Linderholm and Friedrichsen, 2010). Therefore, the grounded theory was be used to develop a theoretical analysis that appropriately reflects the experiences of registered nurses working in the Intensive Care Unit in an effort to allow for implementation of innovative strategies. In the preceding discussion it is apparent that there is a physical and emotional strain on registered nurses who provide palliative care for

paralyzed patients. The strain on nurses as it relates to providing palliative care is increasing as nurses continue to voice that they feel stressed and burnout of nurses. However, there are limited studies that consider the issue of negative experiences of registered nurses who provide palliative care for paralyzed patient in the Intensive Care Unit. Many studies focus on the experiences of the patients who receive palliative care with emphasis on their needs. In palliative care nurses are required to provide holistic care which involves physical, emotional, and spiritual care. Through the use of a grounded theory approach it was possible to discover new findings that contributed significantly to the existing literature and knowledge in the field. This approach allowed for the development of a substantive theory. This study was influenced by the researchers' colleagues who have shared their experience of providing palliative care for paralyzed patients. We note that there is a dearth of knowledge in these areas in Caribbean. The conjecture that despite worldwide improvements in palliative care, Trinidad and Tobago is still far away from providing the level of Palliative Care seen in developed countries (The Palliative Care Society of Trinidad and Tobago, 2014, para. 1) will be put to test as the intension is to document the lived experiences of the Registered Nurses in this well-known specialised hospital in the Island. This will also serve as a case study of this kind in the Island.

MATERIALS AND METHODS

Design: Qualitative method was employed which allows researchers to collect data surrounding the 'emic' or lived experiences of people (Polit and Beck 2010, p. 17). A grounded theory approach was used to provide an in-depth analysis and exploration of the experience of registered nurses in the intensive care unit who provide care for paralyzed patients. In keeping with small-scale grounded theory studies the intention was to explore, and describe the underlying social processes evident during this life event, rather than to generate a theory (cited in Van Brummen and Griffiths, 2013, p. 86). This type of strategy enables the researchers the flexibility to examine the phenomena in an unrestricted manner (Strauss and Corbin 1998; and Cresswell, 1994).

Population: Purposive criterion sample comprising 12 nurses who provide palliative care at the intensive care unit of the hospital were recruited. They number 12 from across all of the age demographics with the greatest percentage of participants being in the over 30-year age group. This small sample of an accessible target population of twelve registered nurses working in the Intensive Care Unit at St. Clair Medical Centre have over ten years of experience caring for paralyzed patients and consist of six males and six females. Their nationalities were Cuban, Philippines, and Trinidad and Tobago. This diversity in gender and nationality provided further variability in perspectives (Polit and Beck, 2004, p. 729).

Instrument: Polit and Beck (2004) highlight the goal of data collection is to generate data that is of exceptional quality. Grounded theory relies on methods that permit researchers into the personal lives of the participants (p. 17). With the purpose of exploring the experiences of nurses when caring for paralyzed patients, the use of a semi-structured questionnaire containing six open-ended items was used as the main instrument for obtaining data. Although, interviews are better suited for a grounded theory research (Woods, 2011), the inflexible times of the participants made this impossible. The use of questionnaire was considered feasible rather than miss out the opportunity of the study entirely. However, during the process of distributing the questionnaires, the researchers encouraged the participants to thoroughly express their thoughts, feelings, and experiences.

Data Analysis: Polit and Beck (2004) advised that with grounded theory, the data collection and analysis should be done simultaneously. After the first four questionnaires were collected, the analysis began by comparing the responses of the participants. Thematic analysis was used for the participant data (Strauss and Corbin, 1998). This allowed the data to be simultaneously analysed to enable exploration of similarities and differences (Charmaz, 2010). The data analysis was done by using the En Vivo software. This was used to code the data, uncover subtle connections and meticulously justify findings by conducting open coding. Open coding was also done for initial analysis of the data and the formulation of notes identifying key areas, with line-by-line examination of the data to identify patterns and themes (Strauss and Corbin, 1998). All of the participants responses were transcribed from the questionnaire form to En Vivo and labels were assigned to the data for the purpose of categorizing identifying categories them (Strauss and Corbin 1998; Charmaz 2005, 2006).

The labelling of data is one and the same with the creation of a code. The creation of code was done by examining and analysing the exact words of the participant for example, positive or negative comments or other words which reflected understanding of the data. As a result, the initial coding of the labels were largely descriptive which included actual words used by the participants and therefater, selective coding was the method that was used to create four categories namely:

- Challenges with communication
- Nurses emotional and physical status with reality of prognosis
- Nurses' other challenges and
- Nurses' recommendations

RESULTS

Communication between the nurse and patient

This category acknowledges that registered nurses do feel that communication is a great challenge in caring for paralyzed patients. Four out of the six female nurses found it challenging. The two female nurses who did not find it as a challenge comprised one Trinidadian nurse and one Filipino nurse. All of the six male participants found commuicating with palliative patients as a challenging experience. The responses that reflected the overall consensus that communication with patients as a challenge were:

"Most quadriplegic patients whom I nurse are usually ventilated with a tracheostomy. Therefore, the patient cannot talk. The nurse has to find some means or ways to

communicate with the patient to find out what they want. "The nurse can get burnout because they have to communicate continuously with the family and patient in order to allow transition for them to accept the condition". (Female Nurse)
"The initial communication is filled with anger, apprehension, and sadness. Both the patient and the relative are not vey accepting of the diagnosis and some are in shock. In order to get through to them it takes a lot of patience and support". (Male Nurse)

On the other hand, the two responses that reflected communication with patients as not being a challenge:*"However they are not always sedated and paralysed. When they are coherent an alphabet chart is used to spell out each word and pointing to the letter, also words used frequently such as 'yes' or 'no' would be written out".* (Female nurse)

"My experience in these regards is that I have kept an adequate communication based on professional ethics, respect and love". (Female nurse)

Communication between the nurse and relatives

The study found that the female nurses found it less challenging to communicate with patients' relatives that male nurses. Only two female nurses, one Cuban and one Filipino, found it as a challenge to communicate with relatives. However, four out of the six male nurses found it as a challenge to communicate with relatives; two Cubans, one Filipino, and one Trinidadian. A relationship is shown between nationality and communication with patient. Overall, the Cuban and Filipino nurse population, found it more difficult to communicate with patients' relatives than the Trinidadian nurses. The responses that reflected the overall consensus that communicating with relatives as challenging were based on the fact that the patient's relatives expect the nurse to give them any and all the information that they want.

"Family members become so demanding in taking care of the patient/loved one. Some family members ask you anything and all types of questions and we as nurses try our best to answer". (Female Nurse)

"With respect to communication with the family, as nurses we cannot freely give all the information to the family that they want. When you do not tell them what they want to hear, they can get very demanding. Also, it is very challenging, if the family are elderly or if their education state is low. This makes communication very hard in terms of explaining medical conditions and also anwering the same questions everyday for those relatives who are in denial". (Female Nurse)

When a patient's condition deteriorates and the physicians inform the relatives of the poor prognosis, the initial reaction is denial and they do not accept the diagnosis. The relatives then ask the nurse countless questions and when the nurse repeats what the physician has said, the relatives belief that the nurse is lying.

"The initial communication is filled with anger, apprehension, and sadness. Both the patient and the relative are not vey accepting of the diagnosis and some are in shock. The relatives even belief that the nurses are lying, even though the nurses repeated the same thing that was said by the doctor. In order to get through to them it takes a lot of patience and support". (Male Nurse)

However, the participants whose experiences in communicating with relatives were not seen as challenge felt that interaction with the relatives on a regular basis was therapeutic for the relatives because they felt including in the care process.

"The family is important as their involvement with patient care makes them feel useful. I try as much as possible to let them know what is happening with the patient". (Female Nurse)

"My experience in these regards is that I have kept an adequate communication based on professional ethics, respect and love. The family is very thankful when they are incorporated into the patient's care by communication". (Male Nurse)

Nurses Emotional Status

The findings highlighted that ten out of the total twelve participants found it as emotionally stressful when providing palliative care for paralyzed patients in the ICU. The two participants who experienced positive emotions consisted of a Cuban male nurse and a Trinidadian female nurse. It is very common for the nurse to become attached to the patient because of the long hours that are spent everyday caring for the patient. As the patient's condition deteriorates and death becomes inevitable, the nurse usually experiences great sadness and even depression.

"The patient's will to live or survive has impacted me the most when providing care for paralyzed patient. The prognosis of the patient is not good at all and yet they make plans for the future. This cause the me to feel sad and often times, depressed". (Female Nurse)

Paralyzed patients who are quadreplegics are unable to do anything for themselves and because they are totally dependant or another to provide total care for them, after a period of time they become bitter and resentful. These feelings are usually vented on the nurse because he/she is the frontline of care. This causes the nurse to experience fustrations and anxiety.

"When the patient learn not to be thankful for the care that they are being given and are aggressive, this is emotionally challenging for the nurse". (Male Nurse)

"At the beginning of the experience I felt sympathetic and driven to provide ultimate care but as time goes by the patient become more demanding as they go through their own emotional turmoil. I try to be patient and understanding but sometimes their demands become unrealistic and unbearable". (Female Nurse)

Another factor that contributes to the emotional burden of the nurse is the great amount of time that is spent on counselling

the patient even for those pateints who have regular visits from the psychiatrist. The nurse spends a lot of time with the patient and because of this the patient feels a freedom in expressing themselves to the nurse.

"Emotionally, the patient often develops depression and is concerned about change of image. The patient also becomes fearful for his future and social independence. The nurse then has to spend a great amount of time counselling the patient". (Female Nurse)

On the other hand, the two participants who verbalised that they experience positive emotions when providing palliative care for paralyzed patients emphasized that it gives them great satisfaction in being able to provide total care for the patient.*"My experience has been of a great satisfaction since I have achieved a better quality of life in these patients through nursing cares related to their hygiene, nutrition, physiotherapy, I have provided adequate psychological support for them".* (Female Nurse)

Providing support for the family is seen by nurses as emotionally satsifying. Support can be in the form of teaching the relatives in providing supportive care for the patient.

"This is a good experience because I enjoy teaching the relatives care for the patient by teaching them how to suction, turn, and fee the patient". (Male Nurse)

One of the paricipants stated that the positive emotion stems from those patients and relatives who have accepted the diagnosis and have a positive outlook. Patients and relatives who are accepting of the diagnosis help to create an environment that is conducive for satsifying healthcare.

"My experience in providing support for the family is that once the patient and family accepts the diagnosis, the emotional and physical experience is more positive and everyone moves forward together. I am seen as a member of the support team that works together with the patient and relative. The family and patient are more positive when they are involved in daily care". (Female Nurse).

Nurses' Physical status

Similarly to the category of emotional experience, out of the twelve participants in the study, only two of the participants stated that their physical experiences in providing palliative care for paralyzed patient in the ICU is stressful; five males and five females. The two paricipants who found their physcial experience as effortless comprised a Cuban male nurse and a Trinidadian female nurse. Likewise to the emotional category, the relationship between gender and physical attributes of care was non-existent. For the quadreplegic patient, the nurse is the hands and feet of the patient. This involves attending to every need and care for all the activities of daily living for the patient and as a result the nurse can feel burnout and void of energy at the end of a shift.*"It is physically stressful because you have to do all the physical activities of the of the patient; bathe them, turn to avoid pressure sore, help with physiotherapy, nutrition, excretion. These stresses are double if you have an obese patient".* (Male Nurse).*"As the nurse you become the patient's device for them to touch themselves from their head to their toe. This makes the job physically stressful".* (Female Nurse).

The study also revealed that the lack of human resources, in particular nursing staff, accounted largely for the stressful physical experiences of the nurses as they provided palliative care for paralyzed patients in the ICU. The nurses stated that because the policy of the ICU is to have a ratio of one nurse to one patient, this prevented nurses from being allowed to go on a break.

"Yes, it is physically stressful because of the low nurse to patient ration. The nurse is always overworked physically and mentally". (Male Nurse)*"There are many challenges namely a lack of physical human resource"* (Male Nurse)

On the other hand, the two participants who verbalsied that physical care of paralyzed patients in the ICU was effortless, highlighted that the acceptance of diagnosis by the patient and relatives not only makes the emotional experience for the nurse as satisfactory but also the physical experience.

"My experience in providing support for the family is that once the patient and family accepts the diagnosis, the emotional and physical experience is more positive and everyone moves forward together. I am seen as a member of the support team that works together with the patient and relative". (Male Nurse)

Challenges faced by the nurses

In this category, the findings showed that all of the participants found that providing palliative care for paralyzed patients in the ICU to be challenging in one way or the other. Holistic care is given to the patients: physical, emotional, mental, and spiritual. For the patients' relatives, they usually seek constant communication, comfort, and empathy from the nurse. One nurse said: *"As nurses the experience is very challenging because we try to understand the feelings of patients and their families and give them sympathy because of what they are going through".* (Male Nurse). High importance is placed on including spiritual care as part of the nursing care, for patients whose illness score is high with a low survivial rate. Although this is seen as important both for the nurse and the patient , overtime it is seen as a challenge. Nurses feel exhausted because the totality of care elicits not just spiritual responses from the nurse but also physical and emotional. *"My experience for providing palliative care for paralyzed patient is that it is very important to pray before starting your shift. Usually, paralyzed patients require a vast amount of emotional, physical, spiritual, and mental support. This literally cause severe fatigue for the nurse over prolong period".* (Male Nurse).On the other hand, the results showed that while all twelve of the participants verbalised that palliative care for paralyzed patients in the ICU is challenging, four of these participants also stated that palliative care is a rewarding experience. These four participants comprised three Trinidadian nurses, two male nurses and one female, and one Filipino male nurse.*"Caring for these patients really brings out what a nurse is and how beautiful it feels caring for*

them. A tender loving care really comes out". (Male Nurse). *My experience has been of a great satisfaction since I have achieved a better quality of life in these patients through nursing cares related to their hygiene, nutrition, physiotherapy, I have provided adequate psychological of support".* (Female Nurse).The patient's relatives can be very cooperative and supportive of nursing care when they are accepting of the patient's diagnosis. In these instances, the nurses experience of palliative care as rewarding and it surpasses the challenges. *My experience when providing support for the patient's family has been gratifying because they have been very cooperative and eager to learn about providing palliative care".* (Female Nurse)

Nurses Recommendations

The participants made several recommendations to improve the palliative care experience of paralyzed patients. The three suggestions made were: communication in training, support groups and increase human resources. Communication in training was the most frequently mentioned recommendation; it was proposed by six of the participants. *"Have electronic technology that will improve the communication between the nurse and patient so that it will be less stressful on the nurse to determine what the patient needs or want. Also, the workplace should send nurses on courses which teaches how to read lips".* (Male Nurse).*"Communication can be improved if we can find ways/means on how to communicate/understand patient's wants"* (Male Nurse).

Increase human resources were mentioned by four of the participants as a way of improving palliative care of paralyzed patients. The lack of human resources where one nurse has to work for sometimes 12 hours straight without getting a break causes the nurses to feel void of energy at the end of the shift.

"I recommend/suggest to have a proper nurse to patient ratio because this will help the nurse to provide proper care for the patient and improve the nursing experience". (Male Nurse).*"Thirdly, provide adequate supportive staff, example, physiotherapy. And support workers to help turn the patient".* (Male Nurse).Support groups for the nurses, patients, and patients' relatives were also recommended by four of the participants.*"Firstly, to have a support group for nurses, patients, and relatives because if they are emotionally stable, this improves the nursing experience*" (Male Nurse). *"I recommend more supportive nursing staff. Training for relative in post hospitalization care. Stress leave or rotation out of the intensive care unit".* (Female Nurse) .

DISCUSSION CONCLUSIONS AND IMPLICATIONS FOR NURSING

The theoretical analysis that was developed from the data is that regardless of culture and nationality, registered nurses who provide palliative care for paralyzed patients in the Intensive Care Unit experience high levels of stress and negative experiences. The findings illustrate that the physical and emotional stresses of registered nurses in the intensive care unit who provide palliative care for paralyzed patients are essential and there is a need for supportive system in Trinidad and Tobago for these nurses. Very often the nurses feel as if they have all the burden in caring for these paralyzed patients and the responsibility of supporting patients' families. These experiences and emotions may stem from some ICU beliefs that do not support nurses in facilitating discussions about code status, end-of-life issues, or patients' preferences. With palliative care of paralyzed patients, nurses in this situation have been termed "the responsible powerless" (Palliative Care Society of Trinidad and Tobago, 2014) when they are asked to care for patients and implement prescribed orders but are not allowed or encouraged to discuss such important and serious topics with the patients, the patients' families, or colleagues. The data shows that the relatives ask the nurses many questions which prove as a challenge because the nurses have to try their best to answer the questions in a way that does not break protocols and policies. The concept of "moral distress" in ICU nurses is directly correlated to feeling pressure to continue aggressive treatment when the nurses did not think the treatment was beneficial.

Moral distress has even led to nurses' leaving their bedside positions (Martin and Koesel, 2010). According to the Patients' Rights Act, when a patient is assumed incompetent to consent to treatment, the relatives should be included in the decision-making processes to provide information on the patient presumed preferences. (Lind, Lorem, Nortvedt, and Hevrøy, 2012, p. 667, 672). The participants reported that they feel burnout because they have to provide physical, emotional and spiritual care for the patients and extends to the relatives. Stressors such as theses can result in decrease in wellness, burnout and lack of quality care. It was stated that "stress may be a reason for nurses leaving their jobs" (as cited by Edwards. 2003, p. 170). A recent review found that key nursing roles are information broker, supporter and advocate. Further, the key roles nurses play is being present at the bedside, providing comfort, a caring touch and a listening ear (Lind, Lorem, Nortvedt, and Hevrøy, 2012, pp. 667, 672). It is hoped that an understanding of the nurses' experiences when providing palliative care for paralyzed patients will positively influence the development of new interventions and adequate recognition for palliative nursing care in Trinidad and Tobago.

The evidence of the study revealed that communication with the patients proved to be very challenging and stressful. In fact the population revealed that most of the quadriplegic patients that required palliative care had some type of mechanical ventilation, mainly tracheostomy. As a result, this presented a great barrier for communication between the patient and the nurse (Jui-Hsia, Shin-Ling, Wan-Ju Cheng, and Jui-Chu, 2012, p. 95). The participants in the study also emphasized that paralyzed patients with little chances of survival who were dependent upon mechanical ventilation were very angry and irritated because of their inability to tell the nurse exactly how they were feeling and what they needed. The frustrations of the patient inevitably were transferred to the nurse because of the long hours that were spent caring for the patient (Happ, Tuite, Dobbin, DiVirgilio-Thomas, and Kitutu, p. 211). With reference to communication between the nurse and the patient's relatives, although the findings showed that it was mostly the male nurses who experienced communication challenges with the patient's relatives as a challenge, the

problem still needs to be addressed. In a qualitative study addressing the factors affecting the nurse-patients' family communication in the Intensive Care Unit of Kerman, the authors disclosed that optimal quality communication with the patient's relatives is the foundation for the art and science of effective nursing care and the well-being of the patient. The authors stated that in their findings, the participants revealed that one of the difficulties in communicating with families is that if there is no hope for survival of the patient, the family members still wants to be given hope and when they are told otherwise they have the belief that the nurse is not being truthful (Loghman, Borhani, and Abbaszadeh, 2014, p. 71). Similarly, in this present study the participants stated that it is difficult having to explain the patient's condition to the relatives especially when they are in denial stage. Further sthis communication between the nurse and patient's relatives is expected to detoriarate but can be improved by presenting the educational plans and programs for the nurses (Abedi, Alavi, Aseman rafat, and Yazdani, 2005).

On the positive side, the research showed that the participants found that giving comfort to the patient's relatives improves the attitude and feelings of the relatives and hence, enhances the communication between the nurse and the patient's relatives. Evidence in a study done by McAdam and Puntillo (2009); and Norman, Rutledge, Keefer-Lynch, and Albeg (2008), confirmed that the patient's relatives who were the recipient of empathy, sympathy, and kindness from the nursing staff, expressed a high degree of gratification and fulfilment during their time of grief (cited in Loghman, Borhani, and Abbaszadeh, 2014, p. 73). In this present study, the participants stated that because of the environment and the culture of the ICU which requires a high degree of isolation as opposed to other units in the hospital, the family members of the patient are more sensitive and vulnerable because of the restrictions that are placed on them, for example, visiting schedules. Therefore, the family members expect constant communication from the nurses concerning the status of the patient as this acts as a therapeutic coping mechanism.

The study revealed that there are physical, emotional, and spiritual challenges involved in providing palliative care for paralyzed patients in the ICU which confirms Strand, Kamdar, and Carey (2013) Loghmani, Borhani, and Abbaszadeh (2014) The participants of this present research stated that the work overload caused them to feel drained of their energy and at times they did not look forward to return to work the next day. Caring, whether it is ones' passion or a requirement, takes time and nurses cannot just walk away from the patient's bedside in the hope that someone else will take over the patient. The nurses are basically the patient's hands and feet and for those patients who are unable to speak, the nurses feel a responsibility towards perceiving what the patient is feeling, thinking and the overall needs of the patients. According to Hollins, (2009), "Hospitals are places where people struggle to hold on to their individuality amid the clinical procedures set in place to help restore their mental and/or physical health (p. 2). Therefore, it is seen as high importance that care of paralyzed patients in the ICU should be given based on the culturally, religiously, and spiritually specific knowledge of the members of the healthcare team. One of the purposes of spiritual care, whether at the point in time of calamity or over a much longer period of time, is to enable the individual's response and to support them (Hollis, 2009, p. 17). In the end, all patients should be given individualised care based on their diverse culture, religion and spiritual views with the goal of providing optimal quality of care. The nurses at St. Clair Medical Centre strongly believes in incorporating spirituality in palliative care of paralyzed patients because of the it immensely enhances the quality and effectiveness of care that are given to patients and by extension, the patients' relatives. However, the spiritual aspect of nursing care can be very challenging for the nurses because it is not independent of all the other aspects of care. In palliative care, spirituality does not stand on its own but has to be integrated with physical and emotional care (Hollis, 2009).

Furthermore, the evidence of this study revealed that emotional experiences of the nurses who provide palliative care for paralyzed patients are very significant because it has a negative impact on the nurses as they begin to experience a deep sense of sadness, ambivalence and helplessness as they do not know how to cope with the dilemma of providing palliative and curative care. Moreover, when a patient is first diagnosed with a life-threatening diagnosis, the nurses, who work alongside with the doctors, are usually second in line to provide information to the patient and family, actively listen to the fears, concerns and responses of the patient and relatives relating to the illness and treatment, and clarify medical information. Nurses often have the feeling that they are now the burden bearers of patients and their relatives as it relates to symptom management, communication, culture, ethics, grief and care at the time of death (Malloy, Virani, Kelly, and Munevar, 2010, para. 7). This can mentally and physically drain nurses and in the process which would affect their level of job satisfaction. Morgan (2009, para 4) summed it up thus that the nurses would feel as though they lack the skill and knowledge to effectively provide palliative care (Morgan, 2009, para. 4).

Additionally, the expectancy of patients paralyzed patients from registered nurse are so great that nurses at times feel pressured and negative feelings about going to work. Resolutions to these internal barriers must be established in order to ensure job satisfaction and appropriate patient care. The most frequent recommendation that was made by the participants is that there should be more training in communication with patients, for example, learning how to read lips, and knowledge on certain words or suitable lines that can be used to convey messages to the patients. Efficient and effective communication is the core of palliative nursing care. The holistic care of the patient as it relates to physical symptoms and psychosocial concerns, responses to suffering, listening to expressions of loss and grief, and recognition of ethical or spiritual concerns are all reliant upon effective communication. Therefore, in order to provide quality care in response to these patients' needs, it is imperative for nurses providing palliative care across a variety of populations and settings to be trained in skillful communication (Kelly, Malloy, Munévar and Virani, 2010).

It was suggested by one of the Trinidadian male nurses that training should be given in modern technology that assists in

communication of mechanically ventilated patients. However, in Trinidad and Tobago, there is no automated technology that is being used to communicate with paralyzed patients who are unable to speak either due to a tracheostomy or due to their nature of their illness. Grossbach, Stranberg, and Chlan (2011) indicated several strategies for enhancing communication between the patient, nurse, and relatives. Some of the strategies were: (1) Create an environment that is promotes pleasant and approachable communication, (2) Assess patient's ability to communicate, (3) Predict and foresee if possible the needs of the patient, (4) Practice reading of lips, (5) Employ substitute communication tools, and (6) Educate the patient along with their relatives, and the healthcare providers about the various communication strategies. Additionally, Jui-Hsia, Shin-Ling, Wan-Ju, Jui-Chu (2012) found that the main reasons that communication was not satisfactory between the nurse and patient were because of the lack of a standardized nursing guidebooks for communication with intubated patients and also because of insufficient communication assisted devices. These recommendations will be presented to the healthcare at the St. Clair Medical Centre.

Conclusion

In conclusion, the study explored the lived experiences of nurses providing palliative care to patienst in the ICU at a local medical Centre. We have been able to document the lived experiences of these nurses. We found out that regardless of culture and nationality, registered nurses who provide palliative care for paralyzed patients in the ICU experience high levels of stress and negative feelings. The evidence of the study suggests that palliative care nursing of paralyzed patients is a challenge and nurses are aware about these challenges. The most challenging aspect of this type of care is communication with the patients and their relatives. Even the Trinidadian nurses found that communicating patients and relatives are very distressing because most times the patients have a tracheostomy and hence, the needs and wants of the patients are not easily articulated. As it relates to the relatives, the participants indicated that they asked very difficult questions concerning the prognosis of the patients and the nurses are not always able to give the exact information that the relative desire. Further, physical and emotional care from nurses are also important aspects in palliative care, yet insufficient support are given to the nurses in the ICU in order to motivate them and build their confidence. Hence, several recommendations were made to improve the experience of registered nurses who provide palliative care for paralyzed patients in the ICU including training in communicating with paralyzed patients, increase human resources, support groups, innovative equipment, recreational activities, and a palliative care society. Of note is that the lived experiences provided what we termed "Mutual of positivism", a term that denotes the rewarding feelings for the nurses, the patients and their relatives that surpasses the burdens of the challenges in the caring relationships.

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