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Sogn og Fjordane University College. Faculty of Health studies.

Topic: SK108 Medical and Surgical Nursing in a Norwegian Context

Title: Family involvement in the Care of the Dying cancer patient

Delivery date: 16.12.2010

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Number of pages: 12



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INTRODUCTION

When the family member is faced with a terminal illness, the impending death presents a crisis and a challenge to the entire family as they take up roles as caregivers and have to deal with crises like symptom management and hospitalisation (Mehta et al, 2008).

The dying patient with cancer in their terminal phase of disease presents with a lot of distressing symptoms that the health care providers need to address in order to promote quality of life at the end of life. I have chosen to write on nursing care of the dying cancer patient in the hospital setting and see how quality of life can be attained with the support of the patient's family.

This essay will look at the nursing care given to the dying cancer patients in terms of family involvement in Norway, and compare with how it is being done in Zambia where I have worked as a nurse for over 15 years. I also hope to learn the areas of improvement in Zambia by making recommendations. I had six weeks nursing practice in the oncology ward at the Forde Central Hospital in Norway, where I nursed patients in their terminal phase of disease with the symptoms that eventually died while under Palliative Care. I want to know how the family can contribute to the wellbeing of the dying in the final phase of life. What barriers hinder the family involvement in the care of the dying patient? What are the nurse's roles in the care of the dying with support from the family? How can we improve on the care of the dying patients with family involvement in terms of symptom management in Zambia?

STATEMENT OF THE PROBLEM

The World Health Organisation as quoted by Gronemeyer et al, 2005 states that cancer accounts for about one fifth of deaths in Europe. There are approximately 90% of cancer patients receiving palliative care. Parkin et al in the Global Cancer Statistics of 2002 revealed that there were 10.9 million new cancer cases annually with an estimate of 6.7 million deaths while 24.6 million people were living with cancer globally. In Norway, the Cancer Register statistics of 2008 revealed that 10, 667 deaths occurred in 2007. The commonest cause of death was lung cancer having the highest incidence in both sexes at 1,224 deaths in males and 876 in females. Although the place of death has not been indicated, there are a number of patients who preferred to die in their homes with support from the palliative care team, the community nurses and the primary

doctor (General Practitioner). This is made possible with the strong health care system that is in place in this country. In the African setting however, a study showed that out of all the deaths in the period 2005-2006 in Botswana, 36% died at home and 64% were hospital deaths of which 6.6% were from cancer (Lanzenby et al, 2010). There was no data on Zambia but it could be similar.

DESCRIPTION

Palliative care management is aimed at improving the quality of life in a dying patient and their family by prevention and relieving the suffering through early identification, assessment and treatment of distressing symptoms as well as meeting their physical, spiritual and psychosocial needs (Ellershaw, 2003, Sublett and Heidrich, 2009).

Palliative care recognises the importance of the family in the care of the dying patient as it is believed that they play a major role in the dying phase of the patient a thought that is supported by Andershed (2006) who stated that ‘relatives make a large contribution in the care of the dying patient’, this is true as will be seen in the essay concerning the family involvement of the dying cancer patient.

Statistics show that Norway is one of the countries in Europe that is doing well in the provision of palliative care. They have well educated and trained personnel available in hospitals and there is a wide provision of palliative care to inpatients in hospitals and hospices (Gronemeyer et al, 2004). In Zambia palliative care is actively being provided in the hospice and home based care programmes in the community by nurses and trained staff in home based care services. There are no palliative care nurses in hospitals because there is no formal training in the nursing curriculum. The Palliative Care Association of Zambia (PCAZ) is currently spearheading training of health care providers in order to take care of the HIV infected patients (PCAZ, 2005). There are 12 Hospices in the country, with one in Livingstone (where the author resides), St. Joseph’s Hospice with a bed capacity of 33 beds. The hospice admits patients with HIV/AIDS and also terminally ill cancer patients who cannot remain at the hospital or at home due to lack of financial resources (PCAZ, 2008).

The patients admitted to the ward in Norway were generally elderly aged above 55 years with few exceptions of those below 40 years. The dying patients presented with a variety of cancer diagnoses but the commonest of them were breast, prostate, colon,

pancreas, lymphomas, myelomatose and leukaemia with metastasis to vital organs like stomach, liver, lungs and bones. In Zambian hospitals Kaposi's Sarcoma, prostate and cervical cancers are the commonest cancers nursed in the wards with patients younger than 40 years being affected. More deaths are usually associated with Kaposi's sarcoma which is commonly seen in HIV infected patients.

During my practice in Norway, the dying patients were under the care of the palliative care team that comprised of oncologists, nurses, physiotherapists, social workers, pharmacists and the priest. Other people like the psychiatrists were consulted whenever there was need to review the patient. The team analysed the presenting symptoms and planned the care together with the patient and the family was involved in decision making. The patients were nursed in single rooms and their families were allowed to stay with the patients as long as they wanted. The spouses or significant others were even allowed to spend nights with the patients by putting an extra bed for them to sleep on.

In Zambia however neither doctors who attend to the patients nor nurses are specialised in oncology in other hospitals in the country apart from very few at the only cancer hospital in the capital city. Only patients undergoing investigations and Radiotherapy are admitted there, the rest of the patients are admitted in the general wards close to their homes in line with the health reforms by government. These are normally open wards and only one relative is allowed to be with the patient when the condition is deemed as critical with no provision for sleeping facilities for the family member.

The family has been defined as any group of people related either biologically, emotionally, or legally. That is, the group of people that the patient defines as significant for his or her well-being (McDaniel et al., 2005). But it is important to know that the definition of family differs from one cultural group to another. And this will affect the care given to the patient as an individual and how much the family will be involved in the care.

Understanding family boundaries and the degree to which they are permeable allows health care professionals to gauge their ability to make an impact on the family unit. If the family has extremely rigid boundaries that prevent exchange with other systems, the family members will remain enclosed in their comfort or discomfort of their personal system. And they may not be open to palliative care consultations when an issue such as

symptom management arises. On the other hand a family with a more permeable boundary will allow in more resources and accept contact with other systems openly (Boss et al, 1993). This then means that the nurses and others involved in the care of the dying patient should take time to talk with the patient and find out more on their perception of the family system and incorporate the findings in the care.

In Zambia, like the African Americans have the family system that focuses on the extended family set up and community often includes the non biological family members in their social networks (Pierce and Lutz, 2009). This means that the extended family would like to be consulted when it comes to decision making in the care of the dying patient, and may make decisions that can undermine the patient's decision and care. This has been experienced when the extended family members may decide to take the critically ill patient home against medical advice and against the patients will, hoping to take the patient for traditional medicine without the consent of their spouse. This is not the case in Norway where the family system promotes individual independence and decision making that is respected by the family members as was witnessed during my practice. The traditional nuclear family(Norway) is promoted were the mother, father and children may be solely responsibility for decision making when need arose for them to do so when the patient is not able make decision on their own due to illness.

ANALYSIS

What barriers hinder family involvement in the care of the dying cancer patient? The family may feel helpless and they lose control of the care when their dear one is admitted in hospital and are not able to be the primary care givers, the role they played when the patient was at home. The family may not be adequately informed about the diagnosis and the prognosis of their patients causing them not to actively participate in the care of the dying.

Since end of life is a unique moment for each individual which is likely to stay in the memory of the family members as well as the health care providers, it is therefore necessary to enhance the experience of the dying and promote the dignity and comfort and it is time for the family to prepare for the death of their loved one (Tradman and Roberts, 2007). Studies show that identifying the family members who wish to participate in the care of their dying one and the type of care they wish to provide, will

establish a partnership between nurses and the family thus enabling the family to maintain the much needed control in the patient care Mehta et al, (2009). In Norway the family is informed from the time the diagnosis of dying is made and the patient and their family are informed about the disease progression and the prognosis. They are even involved in the plan of care for the dying patient.

The palliative care is aimed at symptom relief and the family's involvement in this area is important for them to face grief positively and for quality of patient care at the end of life. In the study conducted in Sweden by Andershed and Ternstedt, (1998), it revealed that those families who were involved in the care of the dying cancer patients expressed as being involved in the light and not in the dark. This was because they followed the patient care from the time the diagnosis of dying was made known to them until the death of the patient. Those on the other hand who reported as being involved in the dark did so because they felt that nurses and other members in the multidiscipline team did not acknowledge the presence of the family structure through communication and involvement in the care provided. They also complained about the inadequate control of symptoms during the dying phase of the patients.

Involvement in the light encompasses a lot of factors that are important as far as the family were concerned such as (Andershed and Ternstedt, 2000):

- **Openness and sincerity:** they appreciate the time that nurses and other health care providers spend with them discussing the progression of the illness and what to expect
- **Support:** the nurses are seen as supportive to the family by just being around and listening. Appreciating their presence helps to make them feel part and parcel of the team of care givers and that they are making meaningful contribution.
- **Connection:** the family felt a connection with the health care providers when they are consulted and their opinions considered in the delivery of care of their dying patient.

In Norway, nurses and the doctors worked together to ensure that the relatives participated in the care through dialogue and consultation sometimes even on phone whenever necessary, they also introduced themselves by name on first contact with the family members, this made them also to open up to the staff and would freely talk to them.

If the patient opts out for death to occur at home, the palliative team will facilitate to ensure that symptoms are controlled through the provision of medication and other

supplies recommended such as adjustable bed and air mattress, diapers etc. In a way this is done in order to promote patient's control in their care and ensure peaceful and quality end of life. In Zambia it is not the policy for the doctor to discharge the dying patient from the hospital in order for them to die at home.

Even though statistics show many people prefer a quick and painless death, ideally while one is asleep, it is different in Africa. An African person prefers a slow and lingering death not through the aid of a machine but a natural prolongation of the dying process so that he or she could make their peace, say farewell to friends and relatives, and give final instructions to immediate relatives. Though it rarely occurs today in our modern cities with its sanitized hospitals, death is preferred in one's home with the family providing comfort to the dying person (Onukwugha, 2008).

The dying phase of the cancer patient with terminal illness is usually precipitated by the following signs that will alert the health care team to make a diagnosis of dying (Ellershaw and Ward 2003):-

- The patient is weak, has fatigue and is confined to bed
- The patient only takes fluids usually sips
- The patient is unable to take oral medications
- The patient is semi-conscious

In a study conducted in the Netherlands on symptoms, treatment and dying peacefully in the terminally ill patients, the study revealed that patients were confronted with an increasing amount of symptoms during the final months of their life. Fatigue, loss of appetite, dependency and feeling unwell were the most prevalent symptoms. Physical symptoms were more often treated than psychosocial symptoms. The number of medical disciplines involved in the patient's care decreased in the period before death, but the number of informal caregivers increased; 73% of patients died peacefully. A peaceful death was impeded by feelings of anxiety and loneliness but promoted by the involvement of children in their patients' care (Georges et al, 2005). This confirms that involvement of significant others in the care of the dying patient does promote quality of end of life, the family play a major role in alleviation of the psychosocial symptoms as was observed in the study. It is therefore important that those people who are

significant to the patient who are seen to promote their wellbeing are encouraged to participate in the care during the terminal phase of illness.

What is the nurses' role in the care of the dying cancer patient and family involvement? The nurse develops a nursing care plan that incorporates the family members and allows them to identify the roles of each family member in the care of the dying patient. Involving the family will enable them identify some of the symptoms that the nurse may miss when the patient does not verbalise, which the significant others detect through interaction with the patient. The nurse should realise this resource and use it by asking the family concerning the patient's wellbeing.

The nurse will provide clear explanations about the procedures prior to doing them; these reduce anxiety levels and help restore the family's equilibrium (Mehta et al, 2008). This was done in the hospital where I had my practical placement, the primary care nurse had time to explain to the patient and the family concerning the planned procedures, where these were planned in advance and they knew exactly when and where these would be done. In Zambia the nursing care plans are not consistently used due to the shortage in human resource being experienced coupled with the increased disease burden due to HIV related admissions in the wards. The planned procedure may not be done at the anticipated time causing both the patient and the family to be anxious as they continue to wait.

The nurse can organise and conduct family meetings thereby allowing the family members to participate, be heard and understood. This has been stated as a valuable tool in palliative care provision (Boyle, 2005; King and Quill, 2006). It provides an opportunity for the nurse to acknowledge the feelings and reactions of other family members while identifying the family strengths that will help the nurse to plan for further interventions in the care of the dying patient. It also allows the individual family members to feel valued as they contribute to the family functions. In Norway these meetings were held by the palliative care team and the significant family members as stated by the patient. In Zambia, the doctor may request for a meeting with the family members who may be available and usually the patient is not involved in the family meeting.

The nurse will undertake teaching of the family members on procedures that they wish to participate in, in the care of the patient while in hospital so as to promote the nurse-

family partnership and foster the control that the family desires when the patient is in hospital. In Zambia the result of staff shortages encourages the family to participate in the day to day care of the dying patient. Strengthening the teaching of procedures that the family should be involved in and providing resources like gloves and disinfectants where necessary to prevent and control infections should be encouraged by nurses.

The nurse's understanding of the patient's family adds a dimension to the care they provide, as their understanding of the patient was more complete because family members provided valuable information as stated in another study by Luker et al, (2000) in England among nurses working with palliative patients in the provision of quality care. They identified that getting to know the patient's families was essential in their care delivery.

The family's insight into the patient's condition should be assessed and issues relating to dying and death explored appropriately and sensitively. The family should be told that the clinical expectation is that the patient is dying and will die. Use of ambiguous language such as "may not get better" can lead to misinterpretation and confusion. A constant source of frustration and anger voiced by bereaved relatives is that no one sat them down and discussed the fact that their loved one was dying. If relatives are told clearly that the patient is dying they have the opportunity to ask questions, stay with the patient, say their goodbyes, contact relevant people, and prepares themselves for the death (Ellershaw and Ward, 2003). It is the duty of the nurses attending to the dying patient to make sure that whatever is discussed concerning the patient is communicated to their family in the language that they would understand and in simplicity and allow them to express their views and concerns. The nurses should spend time with the patient and the family in order for the nurse to identify areas where the family will require help as they care for their dying patient.

In a study conducted by Blatt (1999) in America on the decision making process that the family goes through when faced with end of life decisions, it was discovered that the decisions were made by family consensus and not by individuals. She also noted that it was not enough to speak to the spouse of the patient in order to get insight of their decision but to involve all the significant others.

CONCLUSION

The identification and involvement of the patient's family structure in the plan of care is essential, for the patient's fears of being alone are removed and the family will have control and participate in the care of the dying patient. An effective plan of symptom management is crucial to ensure a peaceful and dignified end of life in order for the family to face their grief positively and with satisfaction. The specialised nurses in oncology and palliative nurses had the skill to detect the symptoms in the patients and were empathetic in their approach to the patients and families. The patient's privacy with the family and explaining to the family on what was happening to the patient helps to allay anxiety. The involvement of the other people on the palliative team allows the patient and family access to the service from the expert in areas where such is needed such as psychologists and social workers. The nurse plays the role of an advocate for the patient and coordinates the care with other team players in the care of the dying patient aimed at promotion of comfort even at their end of life.

RECOMMENDATIONS

- Having nurses specializing in oncology would enable the nurses in Zambia to feel confident to care for the patients as seen in Norway where this speciality has been promoted and schools available.
- Palliative care should be introduced in hospitals and not just the hospices as is currently prevailing in Zambia and in most African countries, so that patients dying in hospitals benefit from this care to promote comfort at the end of life.
- The Zambian health care system should allow the family to spend as much time with the patient as they need without interference to enable them spend quality time before death for the patient to face death positively with the support of the family.
- The Zambian health care system should appreciate and uphold the extended family system and allow them to be available in the terminal phase. The nursing shelters where the family members can lodge while nursing their patients are available and their use should be encouraged for those with critically ill patients.
- In Norway, even if the families are allowed to be with the patient, they can be allowed more by encouraging them to participate in the actual care such as providing hygiene than just being around as this contribute to their feeling of loss of control.

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