

'A day in the life of nurses caring for terminally ill patients with AIDS'

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by

Sr. Nokwanda Bam CPS

Member Congregation of Missionary Sisters of the Precious Blood. Age 42. Registered Nurse 18 years. Registered Midwife. Master of Nursing, University KwaZulu Natal. Bachelor of Nursing & Health Care Management, University of Applied Sciences, Bremen, Germany. Nurse Educator Diploma, Community Health Nursing Diploma, UKZN. Pastoral Counselling Certificate, Redemptorist Communications, Marianella, Dublin, Ireland.

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Introduction

The paper is based on my Master of Nursing degree thesis *'The lived experiences of nurses caring for the terminally ill patients with AIDS in selected wards in a level one district hospital in KwaZulu-Natal.'* The study was approved by the Ethics Committee of the University of KZN

The study involved probed insights into the day-to-day experiences of nurses whose patients are facing imminent certain death. The patients had moved irreversibly beyond the HIV/AIDS status and were in the condition of full-blown AIDS.

Interviews were held individually with a sample of nurses who had worked for a minimum of a year in palliative care wards for people dying with AIDS.

The location of the study was a level one district hospital - St Mary Hospital, Mariannhill KZN.

All interviews were conducted and recorded personally by myself. At the time of the fieldwork I was a lecturer at a Nursing College and had no contact with the hospital nurses.

Background to the study

Caring for people terminally ill with AIDS for 24 hours a day is the responsibility almost entirely of nurses.

Very little study has been made of the experiences of nurses caring for AIDS patients; of the effect on nurses of caring for people facing imminent certain death; of how nurses cope with patients deaths every day, day after day.

There is virtually no researched information on the needs of nurses to sustain their commitment to provide the best possible care for their dying patients; of the impact of their fears and of being infected by accident with AIDS and TB; of their attitudes to their professional development as nurses in AIDS wards.

All text *'in italics'* are verbatim statements of the nurses who participated in the study.

Nursing services for patients terminally ill with AIDS

Basic services:

Providing nutrition, hygiene and comfort care - supervising application of antiretroviral medications - making home visits - teaching the families basic nursing skills and emergency measures- maintaining patients records.

Psychological & spiritual support services:

Involves - listening - counseling - spiritual support to accept their AIDS status - making home visits - teaching the families basic nursing skills and emergency measures - assisting them in planning the future of the family after their death - particularly placement of their children.

Social welfare services:

Arranging for welfare services to provide legal support - information on care networks - poverty alleviation services - pastoral and bereavement care - facilitating peer support groups.

Nurses perception of 'caring'

Nurses described caring as a personal value system; stemming from a nurse's background; transforming; requiring sacrifice; holistic in practice.

'Caring' as a personal value system

Nurses conceptualize caring as an essential trait in the nursing profession. Caring and the desire to help others is the catalyst enabling the nurse to continue working within the context of palliative care.

"Nursing is really a calling. This is what I have come to believe, so when nurses care basically they are fulfilling their calling."

Caring is transforming

Nurses regard their role in caring as a way of changing the lives of their patients as they helped them to manage their illnesses. Caring is seen as a transforming process of renewing hope and enriching the lives of the patients.

"For me I get joy when I help or care for someone, and I notice improvement, that the patients manage to do something for themselves"

Caring requires sacrifice

The nurses characterized caring with sacrifices of time and money. Caring for AIDS patients is challenging which means that nurses are compelled to make sacrifices. Nurses often work extra shifts and longer hours; some sacrifice more lucrative positions in other wards.

"Caring for me, in essence, means to be everything for the patient in need, to be the mind and think for the patient, to be the feet to walk for the patient, and the mouth, the voice of the patient."

"We are nurses 24 hours around the clock. We sacrifice a lot, our meal times, our family times in order to bring relief to the lives of our patients."

Caring is holistic

Nurses embrace a holistic care for their patients as human beings with body, mind, soul and spirit.

"Caring includes the whole person, meaning to give love to the unloved; to bath and feed them, to maintain communication freely so that patients are not afraid to approach you, psychologically to respect them as individual human beings."

"Due to HIV/AIDS caring now is more holistic than ever."

"The multi-disciplinary team needs to be involved, the social worker for those with social or financial problems; counselors to support Counseling and Testing."

Terminal illness requires long-term care

The nurses affirmed that with antiretroviral drugs people with AIDS can live relatively normal lives provided they receive the care that ensures they take the medications properly.

"I like to give my patients love: physically by bathing or feeding them etc; socially by maintaining communication freely so that patients are not afraid to approach us: psychologically by respecting them as human beings. Of fundamental importance is providing on-going counseling to keep them motivated to comply with their ARV treatment regimen."

The dying process has to be regarded as a normal process and it is their role to help the patients to die peacefully with dignity.

"For the patient who is terminally ill nothing much can be done really. It means I should help them to die with dignity and provide pain control so they die peacefully."

Terminal illness raises consciousness on HIV/AIDS

Responding to the reality of death faced by terminal patients with AIDS, nurses are awakened to the reality of their own mortality. This motivates them to be more thoughtful about their actions and to provide real quality care.

"Caring for terminal patient helps because it gives me the awareness that one day I will be dying, so this helps me to care for others more."

The overwhelming effects of AIDS

Because of the overwhelming nature of AIDS the nurses do not always cope effectively in their roles as carers. They experience periods of intense emotions which can affect their spiritual, emotional and physical well-being.

They often feel frustrated being the recipients of problems from patients and their relatives while they have no one to confide in. At times they feel unable to cope due to exhaustion.

"We deal continuously with dying patients. There are at least two or three deaths a day – no exceptions."

"The patients and relatives off-load on us to relieve their pain. At times we feel helpless and angry with no one to share the pain with. As a result some simply absent themselves, and who is to blame them?"

"It's painful and mind-blowing for me. Sometimes, especially if someone of my age dies, with a sense of guilt I ask God 'Why? Why are there so many deaths?'"

Fear of infection

Whenever the nurses are at work they have the fear of infection of HIV and AIDS through accidental needle stick. They take reasonable precautions by wearing gloves when handling the terminal patients under their care to minimize the risks of contracting HIV or masks for other diseases like TB.

"If a nurse gets infected with AIDS she will be victimized by being suspected to loose irresponsible sexual activities."

They report aggravating circumstances that expose them to the risk of infection. These mainly relate to the patients' attitudes, particularly those who are in denial of the diseases become offended when precautionary measures are taken.

In some situations the nurses ask the patients to take protective measures when coughing and if the patient refuses to comply the nurses become reluctant to care for them.

Imbalances in the health care

The nurses were concerned that the professional standards had dropped as a result of staff shortages and lack of equipment.

“At times, I ask myself about the standards of nursing, “What’s going on? Are the standards dropping when there are so many deaths in increasing numbers? Are we doing something wrong?”

“We cannot give the best quality care we could with shortage of staff; we can only manage the basics. But our patients need more than just basics, they need individualized care.”

“We need to have more permanent staff. We need to improve doctors too, to have one doctor for the floor with 44 patients is difficult.”

“It is not good to depend on locums; they come and mess up your ward and systems and go away. We need permanent staff to maintain our systems.”

“We have lost patients unnecessarily through faulty equipment. If the family knew this it could be very dangerous for us as they would blame us.”

HIV/ AIDS as “just another common condition”

The nurses felt that caring for terminal patients with AIDS is “self-limiting and monotonous” as they do not have opportunities to learn about new diseases. They feel their professional progress and growth is restricted.

“As nurses in training, it is really, a challenge. The cases you care for are all categorized under the same conditions HIV/AIDS”

“You do not get to see other conditions, as they have HIV/AIDS as the underlying cause for TB and pneumonia. You want to see different conditions, to learn, to practice what you learn.”

Antecedents that can affect a nurse’s level of caring

The personal circumstances and history of nurses needs to be taken into account to provide appropriate support to enable them to function at the best possible level.

“We need to remember the background from which some of the nurses come from, before we judge them.

Some came from a past of violence such as apartheid, others have lost both parents, so this is the work force we have and may thus not care much about the pain of a patient. They grew up without a background of feeling loved and cared for,”

“We need to support them. We all need support when the going is tough”

Caring conflicting with the need for money

The nurses generally express that nursing is more a vocation than a job, with more important issues than money. They need a salary to live, but the care they provide is more important than receiving a bigger wage. They disapprove of nurses who work solely for a salary.

“It is not about working for money. Yes, a nurse needs it for living, but it’s about giving your whole heart to the patients.”

“Money is important, but it is not everything. I value caring for my patients above everything; if they are happy, I am happy too.”

“If you take nursing as a job, you have lost it as you are not going to be happy because whatever you do you do not get satisfied. If you just need money, money, money, you have lost the concept of caring.”

Effect of death on some nurses

The nurses observed that sometimes the daily deaths have negative effects on caring, particularly among some younger nurses. One of the nurses who has over 20 years of experience in terminal care wards observes that among some younger nurses they “*seem to get used to deaths.*” That they could end up being hard and lose respect for their patients. It is evident that the attitude of “*getting used to death*” has potential serious consequences for such nurses as even their colleagues perceive them as failing to have any sadness over the death of patients.

Need for support services for nurses

The nurses state they often experience emotional and stressful situations which make them feel vulnerable which affects their emotional, spiritual and professional well-being.

Through their prolonged exposure to the care of terminally ill patients with AIDS, they learn through internal and external processes to cope with the stresses they encounter daily in caring for dying patients. These included compassion, love, religion and the application of the principle of reciprocity - to treat others as one would like to be treated. They emphasize the need for professional support services.

“Love keeps me going on to give the care I can to the best of my ability and keeps me passionate about my job, to actually want get up and go to my work. This is sustained with prayer. When I wake up I always ask God “Give me strength to carry through this day.”

“As a way of coping with the challenges of caring, I do what I would like done to me. So I care for my patients so they can feel cared for and loved. If I do good, somebody will do good for me”

“It would be very helpful if there could be a service to support us, so that we could cope with the situation because we have experiences that drain us. Sharing experiences of the day would provide psychological healing.”

Accepting death as a reality of life

The nurses express that a good nurse-patient relationship poses difficulties for them as they develop these relationships in the full knowledge that their patients will die.

The nurses state that the clinical conditions of terminally ill patients ultimately worsen and the awareness of death becomes a prominent feature in their lives, forcing them to change their goals and focus on specific end-of-life needs. This places a huge emotional burden on the nurses who have become the confidants of their dying patients.

It is an imperative the nurses have an established service to help them cope and relieve the emotional burdens.

“We have to adapt to the reality of the disease itself and that nothing can be changed. It’s me who has to change and accept that my patients with HIV/AIDS will die.”

“We need to accept the reality of death as a daily thing which I cannot change, especially patients who become gasping. Acceptance of the situation, and just conform to the reality of our time, it’s the only way that helps me out.”

Some nurses feel that exposure to death and dying provides them with opportunities to discover meaning in life through the lessons they learn from their patients, which helps them to become more spiritual and come to terms with their own mortality.

Validity of the study in relation to other hospitals

The location of the study was St Mary's Hospital Mariannhill – a level one district hospital - which has its particular ethos. The general nursing environment however is similar to that of any hospital.

The palliative care wards for patients terminally ill with AIDS are similar to such wards in any hospital. The patients themselves are representative of patients dying with AIDS in any hospital.

The nurses who accepted the invitation to participate in the study have worked full time in the palliative care wards and had done so continuously for a minimum of one year. The nurses responses and expression of their needs, wants and desires are self-evidently responses which would be expected in any hospital. The nurses identified that not all nurses at St Mary's had the same level of commitment to caring that is required to provide the best possible care for the patients. This would be the case with some nurses in any hospital.

Accordingly, the outcomes of the qualitative study provide for any hospital a sound basis on which to develop strategies to meet the expressed needs of nurses and, thereby, ensure high quality care of AIDS patients into the long term future.

Significance of the Study

Statistics SA Report P0302 July 2011 (pages 5,7,8)

- 5.4 million South Africans living with HIV - 10.6% of total population
- over 381000 new HIV infections in the year
- of which 63000 are children under fourteen
- over 258000 AIDS related deaths -32% of all deaths
- Median term from HIV infection to death around 11 years

While the incidence of AIDS in South Africa is slowing, until there is a cure for AIDS and radical change in sexual behaviour the disease will continue to grow. While early ARV treatment changes AIDS from a terminal condition to a chronic condition it will take many years to eliminate HIV/AIDS. Accordingly, the huge need for palliative care of AIDS patients will continue long into the indefinite future.

Going forward: to ensure high quality care of AIDS patients strategies are needed to deal with the fears - stresses - frustrations - needs - wants - desires of the nurses. The process for selection to become a nurse needs to be addressed. The selection criteria should include assessment of the applicant's '*caring for others*' attitude as an inherent personal value.

Transfer of a nurse from curative care wards to palliative care of AIDS patients needs assessment of the capacity of the nurse to work in the environment of certain death every day. Training programs need to have major focus on issues specific to nursing AIDS patients and on how nurses interact with patients families during their illness and when the death occurs.

Dissemination of the Study findings

The Study findings will be disseminated by

- presentations to hospital management
- provision of papers to professional media
- publication on the internet
- presentations at conferences and symposia
- Issuing of précis papers to national, provincial and local hospital authorities.

Sr. Nokwanda Bam CPS. St Mary's Hospital Mariannhill KZN

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