

“I fear no evil for you are with me”: Presence of God as a Source of Strength to Palliative Care Patients

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Human beings in general are in constant need of divine support to sustain their lives. Every child born develops a particular understanding of God depending on his or her religious, psychosocial, and traditional understandings. But sometimes an unexpected life threatening flood, like an incurable disease, shakes the foundation of one’s spiritual strength and sweeps away all their hope and strength. All they have learned about God from childhood seems to be unreal. It seems there is no God. Although this happens, other times we can see during times of trial, especially sickness and suffering, human thirst towards the supreme power or God increases. They are affected in their physical, psychological, social, and spiritual selves. People struggle with their understanding of God. They question God, get angry at God, and get exhausted with life. They need help to regain their inner strength and to find meaning in life.

This struggle to understand God and to find meaning in life happens with people from all religious backgrounds. When it comes to the question of life and death, the search for the presence of God at times goes beyond the boundaries of religion for a common man or woman. They see God, not as a Hindu god or a Christian god, but as the Almighty who can cure them because now all they want is cure from sickness.

Being a chaplain for Palliative care² in a multi- cultural³ and multi-religious⁴ set up in the southern part of India,⁵ I want to share the hopes and challenges that patients with terminal illnesses experience in the spiritual realm. As patients come to palliative care, their understanding of God takes a big turn. The God who gave many blessings, who showed power and might, has now become the source of strength to accompany them through darkness and uncertainty. “*Even though I walk through the darkest valley I fear no evil; for you are with me your rod and your staff - they comfort me*”. Psalm 23:4 NRSV They take a big turn and internalize the grace of God to be sufficient in their life. “*My grace is sufficient for you for power is made perfect in weakness*” II Cor

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² “Palliative care is an active total care of patients and their families with life limiting illness by a multi disciplinary team”. Robert Twycross, *Introducing Palliative Care*, Calicut: Institute of Palliative Medicine, 2003. In Christian Medical College and Hospital, Vellore, where I work as a chaplain, palliative care is especially for advanced stage cancer patients. We provide end of life care, most of our patients live for few months.

³ Christian Medical College, Vellore has patients from all states of India that has a state language, own culture and diverse customs. The local language at Vellore is *Tamil* and the national language of India is *Hindi*. Majority of our patients come from the north due to lack of medical facility in their respective places.

⁴ Our patients in general come from *Hindu*, *Muslim* and *Christian* religious background. We do get people from other religious background like Sikhs occasionally.

⁵ CMC Vellore is a 2409 bedded, multi speciality, tertiary hospital founded by a woman called Ida Scudder. It was her response to three women’s death on the same night due to lack of women doctors. The hospital was started in 1900 as a one room clinic. (Annual Book, Christian Medical College 2007-2008. P 4f), pl. also see www.home.cmcvellore.ac.in. Today people from all over India and few neighbouring countries like Bangladesh and Nepal come here for treatment.

12:9 NRSV. This is not an easy task. They wrestle with God or with the understanding of God as the Almighty, one who has power over nature, one who raised Lazarus.

Pastoral care is vital to such deeply distressed people. A good number of patients also suffer from many other problems like social isolation, poverty, lack of awareness due to illiteracy, and psychological distress. Women, in particular, do suffer a lot. Some of our women patients are ignored by their husbands and are left to themselves without any treatment or care.

Each human being is unique. When it comes to palliative care patients, though they all suffer from the similar diseases, their problems are different and the way they react to their diseases and find ways to come out of it are also different. Here I am attempting to discuss a few cases to help understand and analyze how different each patient's experience can be and what a pastor or a spiritual care giver could do to make their lives more comfortable and meaningful, even at the verge of death.

Case studies

Case 1: Mrs. K, a 29-year-old Hindu woman, was referred to palliative care from the Medical Oncology department. She was suffering from cancer in her breast and the disease had spread to her brain, hence she needed palliative care. Mrs. K hails from a village near Vellore town, her husband is a *coolli*,⁶ and they have two daughters - 12 years and 5 years. The husband was not very responsible and did not come home regularly. When she came to us she was aware of her disease but did not know the prognosis (how serious the disease was and that her life span might be very short). She had not told any of her neighbors or relatives about her disease for fear of being isolated by the villagers as there is a common misunderstanding, even among the educated, that cancer is a communicable disease. The palliative care team worked on this case,⁷ made the husband come to the out patient unit through the help of our social worker,⁸ and spoke with the couple about their current situation. They were shocked and depressed. She was followed up regularly in the out patient unit and was seen by the palliative care team. Her main concern was her two daughters. We spoke to her about sending the children to boarding school but she wanted to keep them with her.

Slowly, we could see Mrs. K taking courage and organizing herself and preparing her kids for the future. She started teaching the elder some cooking and other household work - giving a bath to the younger sister, etc. She also taught the younger one to manage her basic needs by herself - tie up her hair, etc. She told the elder daughter that "mother is going to die soon and you have to take care of your sister." She told the younger child that she would not be there at home for very long - that she was going to a far away place for work, and that she would not be able to see her. She also spoke with her parents about taking care of the children after her death.

⁶ One who works in the field for daily wages. Approximate one day wage is Rs 50 to Rs. 120 (\$ 1 to 3). They do not get regular work.

⁷ The palliative care team, the doctors would break the bad news to the patient and the chaplain takes over.

⁸ After each new patient being seen in the OPD our social worker visits their family and assesses the financial status etc.

A few months later, her bad symptoms slowly popped up again. In severe pain, she came to get medicine from the out patient unit. This was in November, and *deevali*⁹ was approaching. Her wish was to be with her husband and children on that day and go to their *kula deiva Kovil* (family temple) as they could not go on her wedding anniversary due to her ill health. The daughters wanted new bangles since all their friends had them. Mrs. K said, “I had only a little money, so I did not get them bangles but used it for bus fare to come here to take pain medicines. I want to be pain free for *deevali* to spend time with my family. That is more important for my family and me¹⁰.” She did everything possible for her children, and a few weeks later she died at home.

Case 2: Mrs A, a 28 yrs old, financially well off, well educated Hindu woman, and mother of a two and a half year old daughter, came in with advanced ovarian cancer which had spread to the bone. Her treatment options were very limited. She was offered palliative chemo therapy, but it failed. She was referred to palliative care for further symptom management. When she came to know that she did not have much time, she was terrified. She could not accept that she has such a disease. She said “I can take whatever you say only in my head, but my heart is not able to take it.” She was fighting within herself. Meanwhile she contacted *pujaris*¹¹, pastors, and evangelists, and prayed for a cure. Her only aim was to get a cure no matter which religion it came from. I was regularly visiting her, and she would ask me to pray. I prayed for God’s presence, and for peace and comfort. I always prayed for her child, her husband, and for her larger family. She asked me to visit her regularly, for my visits brought a lot of comfort to her. Her mother mentioned to me that she told her about me sitting by her side and holding and gently rubbing her hand when she was in pain and listening to her – that this gave her comfort.

Within few weeks her conditioned worsened, but she did not want to accept it. She was thinking about more treatment because she wanted more time to be with her child. Nobody in the family was willing to speak to her openly about the seriousness of her situation. During the last week, her younger sister, a medical student, visited her. It was a heart breaking time for the whole family. Yet everybody spent time with the patient, and it was a time of saying good bye. Finally she died in the hospital.

Case 3: Mr. X, is a 38 year old bachelor who came to our out patient unit with many questions about his illness. He was suffering from osteosarcoma, and our doctors spent time with him explaining his condition and encouraging him to continue treatment since he was not ready for palliative care at that point. He continued treatment, but developed lung secondaries.¹²

He is a Catholic Christian living among Hindus. Being the local school headmaster, he was an influential person in the village. He is a sincere Catholic and he used his talents to serve God. He would go to different villages with his music team and have musical performance nights during church festival seasons. His only desire in life was to show Jesus to his Hindu neighbors. He knelt praying for hours in spite of the tumor sitting on his thighs. He always believed that he should be healed - otherwise he is putting off Jesus. He never told the people in his village about

⁹ Festival of lights. (The day when Lord Krishna, a Hindu god killed a giant called Naragasura). It is one of the two major festivals for Hindus celebrated in this part of the country.

¹⁰ We bought bangles for the kids.

¹¹ Hindu priests.

¹² Cancer when spread to other parts of the body becomes extremely difficult for a cure.

his sickness. Even when he lost his hair due to treatment, he told the villagers that he gave his hair as an offering in the Velankanni church.¹³ His conviction was to show his villagers that only when we believe in Jesus everything will be given.

He wanted to get married, and was waiting for word from the doctors. Unfortunately, because of the new progression of disease into the lung, the doctors had to persuade against his marriage wishes. Depressed and dejected, he began to cry. He also felt guilty, and in the next counseling session he expressed this guilt. He used to watch pornographic movies, he used to be angry with Jesus that he could not get married, and he felt that it is a punishment from God that now he can never marry but only suffer. He never wanted to let Jesus down in front of his Hindu neighbors, so he wanted a cure.

His disease progressed rather quickly. He was admitted to the ward for his symptoms. Initially, he was very reluctant to go home and expressed his fear of death. From then on, his concentration changed from the villagers to himself. He never spoke about them, but was asking about going home and managing himself at home. He spoke about God's will for him, though at that point, God's will was not very clear to him. But he said God knows everything and asked for special prayers for him which we did. Finally he went home and died there.

Analysis: As each person is unique, their spirituality is also unique. That is very clear from the above three cases. Each dealt with it in their own way. What is spirituality? It is difficult to define spirituality because of the complexity of the people who carry it, and because of the complexity of the concept itself. It is deeply interconnected with religion¹⁴, culture, and social life. Yet people have attempted to define spirituality. Dossey and Guzzetta define spirituality as a "unifying force of a person; the essence of being that permeates all of life and is manifested in one's being, knowing and doing; the interconnected with self, others, nature, and God/ life force/absolute/transcendent."¹⁵

Spirituality deals with how someone is within himself/ herself. When someone is affected by terminal illness, their spiritual self goes through a lot of change. They go through deep spiritual distress when they have to come in to terms with new understanding of God, relationships, and the world; and most importantly, their own self. Experiencing the hiddenness of God is also a part of human life. People in the Old Testament (Israelites) also went through similar experiences. Herman Gunkel classifies the Psalms into five main types. Only two types celebrate the triumphs of God - the other three deal to various degrees with the fact that God's activity and presence were not always obvious.¹⁶ Each one's spirituality is unique, but a spiritual care giver's presence and support and constant guidance play a vital role. In his book, Victor Frankle says that anybody can find meaning to their life at any given time in life.¹⁷

¹³ It is a practice in this Catholic Church at Vellankanni to shave off hair as an offering to God. This practice is prevalent in many Hindu temples too.

¹⁴ Santosh K. Chaturvedi, "Spiritual Issues at End of Life" in *Indian Journal of Palliative care*. Volume 13. Issue:2, Dec 2007, p 49.

¹⁵ Elizabeth Johnston Taylor, "Spiritual Assessment," in *Textbook of Palliative Nursing*, Betty R. Ferrell and Nessa Coyle eds., New York: Oxford University Press, 2006, Pp 581f.

¹⁶ John Drane, *Introducing the Old Testament*. Oxford: Lion Publishing, 2000. p 247.

¹⁷ Victor Frankle, *Man's Search for Meaning*, New York: Pocket Books, 1985. Pp. 131-136

The woman discussed in the first case was an ordinary woman and had all of life's difficulties. Because she is a poor woman, financial problems and because she is a diseased woman, social problems which also added to her spiritual/emotional pain because she lived in fear and isolation. Her uncertain future stood as a threat to her children. Her family responsibility also increased since her husband was not very responsible. When she understood her situation, she said "I am not worried about my life or death, but I am concerned about my children." She made up her mind to do whatever she could, putting all her trust and confidence in God. In Psalm 23, the psalmist talks about having trust and confidence in God even in the valley of the shadow of death. This proves that God is present with one who trusts and will accompany them to the unknown world.¹⁸ God's unconditional love takes away fear and promises hope and new life - a foretaste of heaven when one holds trust and confidence in God.¹⁹

The way each one finds healing of the inner self, peace and comfort and the degree of it varies from person to person. Sometimes we are not sure of the inner healing as it is seen in the second case.

However, we cannot judge people because they use different ways of coping. The woman discussed in the second case was an educated person and knew what she was going through, but she could not take it to her heart because of her daughter. Knowing everything in her mind and not dealing with it in her heart was the way she could cope with it, since there was nothing much she could do for her child when she was in the hospital. Sources of strength for her were the time she spend with her daughter, the prayers said for her by the family and the special prayers organized by her family, and the chaplain's visits and prayers.

Being available for the patient is itself a great ministry. A care giver who took care of her husband during his terminal stage narrates her experience as follows²⁰ :

[J]ust being there beside him no matter what time of day or night, even if there was nothing I could do to make the pain or discomfort go away. Even if one does not have a medical background there are some simple things one can do to relieve distress and anxiety. The power of touch is almost magical – a gentle massage with warm oil, a soothing hot water bottle, particular comfort foods, music, getting the patient to breath deeply and rhythmically so that he can ride through pain.

A study done among cancer patients in Bangalore shows that the coping methods of the patients were resort to religion as karma.²¹ Many of our patients finally say "whatever way God leads me.... for we cannot do anything more".

Another very important way of showing God's presence to such people is journeying with them during time of spiritual distress. The man discussed in the third case was deeply distressed in his spirit. He could not let it go since he believed that he was standing for Jesus. He did his best to live as a faithful child of Jesus. He needed someone to whom he could express his

¹⁸ Peter C. Craigie, ed., Word Biblical Commentary (Nashville: Thomas Nelson Publishers,1983.) p.207.

¹⁹ Robert Twycross, "Spirituality and Terminal Illness" in *Indian Journal of Palliative Care*, volume 11, Issue: 2, Dec 2005, p 99.

²⁰ Usha Jesudasan, "An Experience of being a Care giver" in *Indian Journal of Palliative Care*, ., Volume 9, Issue: 2, 2003, p 85.

²¹ Santosh K. Chaturvedi, Op.cit, p. 49.

anxieties, hopes, and fears. When he was angry with Jesus and when he felt guilty for whatever he had done, he was in need of someone to whom he could express his difficulties. He was relieved after expressing it and receiving a word of assurance and God's grace. Our presence, counseling, and caring can be a way of saying yes, I am coming with you and I am willing to understand what you are saying.

Being present with the patient and offering the assurance that he or she is open to accept and actively listening can itself bring comfort. Added to that, the prayers and caring gestures/ words bring the presence of God in the midst of helplessness. Similarly, silence can be a powerful tool to bring God's presence while trying to help in spiritual healing.

Life cannot be sought after without hope and God's presence. In the above mentioned three cases, the presence of God was felt in three totally different ways. I have observed that many of our non-Christian patients pray to Jesus for cure, but at the end, when they die, they die following their own religious practice and in their own faith.

God reaches out to people in many different ways through many different experiences. Through little prayers, through shared love, through meeting with someone who is of great importance to the person, or through the realization that God accepts this person can bring healing in peoples lives. Healing is something that comes from God, that renews someone. It can happen at any time - even when physical cure is not possible. Usha was the wife of one of our doctors - a very friendly man loved by the whole CMC community loved him. He was dying of a liver disease and she shares her experience with her husband on his death bed²²:

To strengthen ourselves and to find hope, we held a service of anointing and communion in our garden that morning and we asked God to heal Kumar or release him. We believed that God was with us in the garden that morning, sharing our pain and confusion. Each one of us, regardless of our different faiths,(the community people) dipped our hands in sacred oil. As we laid our hands on Kumar with love, with prayer and with faith, peace flowed into him and his soul was healed of all the anger and pain. What happened and the way it happened was almost magical and it was a complete surprise. The lesson to be learned from such an experience is that a care giver should be open to the mystical aspect of faith and healing. we often think of healing as a reversal or halt of the disease or as freedom from pain, yet there is a healing which is much more miraculous and more necessary- both for living and for dying in peace- a healing of a whole being.

The doubly disadvantaged: "Womanhood is part of an asserted and desired, not an actual cultural continuity. Femaleness is not an essential quality. It is constantly made and distributed; one has to be able to see the formation of femaleness in each and every form at a given moment or in later interpretations, and see what it is composed of, what its social correlates are, what its ideological potentials are and what its freedom may be."²³ This construction by the society which starts from the patient's own family, continues to change as the patient proceeds. Breast cancer patients suffer from identity crisis. Along with many other deep psychological adjustments such as accepting their bodies in the new form, they have to force themselves into many other adjustments because of the culture. They live in isolation. They are not welcomed in

²² Usha Jesudasan, Op.cit, p 87.

²³ Evangelin Anderson - Raj kumar, "Significance of the 'Body' in Feminist Theological Discourse" in *Bangalore Theological Forum*, December, 2001, Volume 33, No.2. p. 84.

the community. One of our patients who was a college lecturer found it difficult to attend functions after her treatment because she was not welcomed and accepted as she was before.

71,000 women are estimated to die of cervical cancer in India in a year.²⁴ Studies show that these women could not have a good quality of life and that all aspects of their lives were affected, including their sexual life²⁵. They suffer from severe pain and they are not properly looked after by their own family members because they are foul smelling. What is the reason? Lack of medical facilities, lack of awareness about cancer screening, and people's ignorance.²⁶ Many of our cervical cancer patients come to hospital only when they feel that they cannot handle it anymore. The reasons are that the problem is very delicate, the women are poor, there is a lack of health awareness, many are illiterate, there is a great deal of ignorance about the problem, and these women give much more importance to their family members but not to their own self. Gender problems continue to be deep rooted in India. A study shows that women are the main care givers of cancer patients while men are the main decision makers. "90% men were cared for by their wives but only 10% of women had their husbands as their primary care givers."²⁷

One of our patients with cervical cancer had nobody in the family to look after her. She had a foul smell and suffered from severe burning pain. She was a widow and had two daughters. The elder one was married, living with her husband's family and she could not come home often to look after her mother. The younger daughter was studying with help from the church. The patient was worried about her second daughter's future. She was admitted in our hospice and was being managed symptomatically. She was very happy in the hospice and was visited by her second daughter. When she became very sick, she wanted to go home. She did get home and she died there. Awareness about such patients and their needs is not sufficiently brought out. There is no facility for screening although some efforts are being made. But more than all these things, we should also see the problem of women from a wider point of view. The gender discrimination and patriarchy (the diseased mind of people) contributes to the oppression, exploitation and submission of these poor women.

Conclusion: Palliative care pastoral care aims at helping people to die healed. "To die healed is to be able to say 'I love you', 'forgive me', 'I forgive you', 'Thank you'," ²⁸ to God and to other people. We start with actively listening to stories. Listening eyes welcome the fainting heart, listening ears relax the heavy heart, and a listening mind provides room for the broken heart to relax and settle (Helen Grace, "Counseling in Palliative Care" Care Beyond Cure – a quarterly newsletter on palliative Care issues by Christian Medical Association of India, no :15, 2007.) Pastoral care and counseling play important roles for palliative care patients. Providing compassionate care and building hope of finding meaning in life are important to palliative care

²⁴ Reena George, "Doubly Disadvantaged- Dying of Cervical Cancer" in *Indian Journal of Palliative Care*, December, 2005, Volume 11, Issue: 2, p 62.

²⁵ Mary Ann Muckadan, et.al., "Psychosocial issues faced by women with incurable cervical cancer in India-how can we help?" in *Indian Journal of Palliative Care*. December, 2005. Volume 11, Issue 2. Pp 94 -96.

²⁶ Ibid. Pp 62,63.

²⁷ Ramu Kandasamy, et al., "A Survey of the Domiciliary Situation of Urban and Rural Patients of Palliative Care Unit in South India" in *Indian Journal of Palliative Care*, December 2008, Volume 14, Issue 2. p 85. <http://www.jpalliativecare.com>

²⁸ Robert Twycross, Op.cit., *Spirituality and Terminal Illness*. p. 99

patients. They need someone to listen to their questions, to wipe their tears, to be by their side so that they can experience the presence of God in and through those around and feel the warmth of God's love and care for them. Ralph L Underwood suggests that praying and holding hope for people is of much greater value to educe hope, when he talks about the question of hope among people with chronic pain including cancer patients.²⁹ The prayers lifted up in the presence of patients bring a great source of strength in times of hopelessness.

The psalmist says "your rod and your staff they comfort me". This staff reminds the sheep of shepherd's presence, especially in the night when the sheep cannot see the shepherd, they can still hear the tapping sound he makes with the staff and know that the shepherd is there. Similarly when people go through death's dark vale, God shows His presence through people, prayer, things, activities, or anything from which the patient can see and derive strength. The chaplain plays a role of a staff in making the presence of God visible through his / her presence and availability, and in journeying with the patient through prayer, counseling, and all other activities like helping the patient meet important people in their lives to express love, to forgive, and to receive forgiveness .

The church world wide needs to wake up and respond to the needs of palliative care patients. We need to be increasingly aware of their need for our presence and love. We need to know what to tell and what not to tell, when to speak and when to be silent. Lutheran pastors need to be trained to provide pastoral care to such needy souls. Our own congregations might be in need of such understanding and caring pastors.

Questions for discussion:

Discuss different means through which we can bring awareness to our Lutheran pastors about such needy people.

Discuss different ways the Lutheran church world wide can create awareness and support Palliative Care world wide.

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²⁹ Ralph L, Underwood. *Enlarging Hope for Wholeness: Ministry with Persons in Pain*. The Journal of Pastoral Care & Counselling, Spring-Summer 2006, Vol.60, Nos.1-2. p 9.

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