1. INTRODUCTION

Viktor Frankl, the well known neurologist and psychiatrist as well as a Holocaust survivor, in his *The Unheard Cry for Meaning* narrates how he helped Anastasia Kotek (suffering from incurable cancer and depression at the thought of her transitoriness of her existence) to shift herself from the state where “all meaning is lost” to where “all meaning is preserved”: “One week later she died. During the last week of her life she was no longer depressed but on the contrary proud and full of belief. Before that, she had lots of difficulties because she thought she was useless. Our talk made her aware that her life was meaningful and even her suffering made sense. The last words she spoke were: My life was not meaningless. My life is a monument.”

Not only the professionals like Viktor Frankl, but even a family caregiver or a community volunteer can touch the lives of people, especially the elderly, when they face with life threatening situations like terminal illness. This may be the sum and substance of the present discussion on the role of the family — caregivers within the family as well as the voluntary caregiver within one’s community — in providing pastoral care with a “whole person” approach in palliative care with compassion, prayer/rituals and morphine, i.e., a combination of empathy and facilitation of medical interventions, with a common goal of promotion of the overall well-being and giving meaning to patient’s lives, along with the reduction of suffering.

The present discussion focuses on the pastoral care in the context of family-based palliative / hospice care of the terminally ill, especially the elderly, from the perspective of ‘whole person’ approach—with its physical, psychological, social, cultural and existential/spiritual dimensions—where pastoral care is not merely providing spiritual and psychological/emotional support and the palliative care is not merely providing clinical support of relieving pain. As part of Community Home-Based Care (CHBC), involving all within and around the family in a community, the present discussion explicates the importance and relevance of applying the principle of ‘task shifting’ in providing pastoral care by capacitating family caregivers and the community of lay volunteers based in parish communities as pastoral caregivers, a realm hitherto mostly confined to the clergy and religious. Task-shifting is thus a means to inculcate, under the guidance of a pastoral care professional, a culture of empathetic understanding among the family caregivers, to mould young people, including local volunteers, into a caring...
community for “the elderly who are increasingly isolated and abandoned … who have been forgotten by everyone else”,\(^5\) especially when suffering from a life-threatening illness.

The message of Pope Francis on the occasion of the XXI Plenary Assembly of the Pontifical Council for the Family, is significant in this context. “Children and the elderly are the two poles of life and the most vulnerable as well, often the most forgotten. … A society that neglects children and marginalizes the elderly severs its roots and darkens its future. … Every time a child is abandoned and an elderly person cast out, not only is it an act of injustice, but it also ensures the failure of that society. Caring for our little ones and for our elders is a choice for civilization.”\(^6\)

2. THE ELDERLY IN NEED OF PALLIATIVE CARE - THE INDIAN CONTEXT

Non-communicable Diseases (NCDs) account for more than half of all deaths in India. In terms of the number of lives lost due to ill-health, disability, and early death (DALYs), NCDs (inclusive of injuries) account for 63% of the total disease burden. Patients needing palliative care usually require care in physical, psycho-social and spiritual dimensions until the end of their lives and for caregivers and family, this extends beyond death to the bereavement period. With respect to cancer, for example, it has been noted that, despite improvements in survival rates, the majority of cancer patients will need palliative care sooner or later.\(^7\) A health ministry’s study showed that 80% people dying from cancer and 50-80% dying from AIDS will need relief from moderate to severe pain during the course of their illness, for an average of 90 days.\(^8\)

NCDs largely affect middle-aged and older populations, the groups growing the fastest due to demographic transition, resulting from technological advancement in health care and improved social conditions. In absolute terms, by 2025, India’s elderly population is projected to reach 158.7 million.\(^9\) The increasing number of the sick elderly suffering from psycho–physical deteriorations (cancer, progressive pulmonary disorders, renal disease, chronic heart failure, neurodegenerative illnesses like dementia and other mental disorders like depression, etc.) comes with it. As per HelpAge India, 52% of India’s Oldest Old (80 +) are in either poor or very poor health, and 80% were without community support.\(^10\) About 64 per thousand elderly persons in rural areas and 55 per thousand in urban areas suffer from one or more long term disabilities.\(^11\) Among the elderly, women suffer most, especially the widows, mostly due financial constraints. The predicament of elderly women is aggravated by a lifetime of gender-based discrimination.

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\(^{11}\) DIRECTORATE GENERAL OF HEALTH SERVICES. Proposal of Strategies for Palliative Care ..., p. 17.
Aging women are more likely to get excluded from social security schemes due to lower literacy and awareness levels.\(^\text{12}\)

3. THE NEED OF STRENGTHENING FAMILY-BASED PALLIATIVE CARE IN INDIA

73\% of the existing 251 palliative care centres in the country are located in Kerala.\(^\text{13}\) With the exception of Kerala with its own model palliative-care policy and systems in place, most of the other states in the country do not adequately recognize palliative care as a discipline and hence it is not included in the public or private health delivery systems. It is estimated that the total number who need palliative care is likely to be 6 million people a year, mostly the elderly. These figures are likely to grow because of the increasing life span and a shift from acute to chronic illnesses.\(^\text{14}\) Only less than 2\% of these people have access to palliative care that can relieve suffering at the end of life. Therefore, for the vast majority of Indians, the coverage of services in terms of availability, accessibility and affordability of palliative care are grossly inadequate.

Hence, due to inadequate public palliative care facilities, families have to shoulder the sole responsibility of the care of the elderly and others with life-threatening illnesses and in need of palliative care. It involves all the more, strains and stresses for the close caregivers within families. As 83\% of healthcare expenses are out-of-pocket expenditures,\(^\text{15}\) the deprivation is severe and crushing for the elderly whose need for health care increases with age. Even where care is physically accessible, costs of accessing this care become beyond their reach. For the willing caregivers, especially those struggling to make both ends meet, the sick elderly become a severe economic burden. The growing commercialization of health care and the deficiencies in the public health care system also make the situation more complex.

On the other hand, the joint family system, the traditional support system for the sick and dependent elderly people, is crumbling due to the advent of nuclear families and of the migration of the younger generation to cities in search of better prospects. Women who traditionally took on the role of caregivers are also working and cannot spend as much time caring for the elderly. Nonetheless, more than 80\% of caregivers are female and around 50\% are spouses, who are themselves quite old.\(^\text{16}\) Most of the old-age homes do not admit people with chronic, life-threatening diseases and neurodegenerative illnesses.

In sum, there is a sizeable population of the aged who have several spells of hospitalization interspersed with long periods of being confined to their beds at home. As only a small percentage of their time is spent in the presence of trained medical or paramedical professionals, family members and relatives are the main caregivers. However, they generally lack the knowledge and skills to perform the tasks adequately. When chronic or life-threatening illnesses strike, it is a crippling blow for them and their families. Therefore, there is a crucial need for a

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\(^{13}\) DIRECTORATE GENERAL OF HEALTH SERVICES. Proposal of Strategies for Palliative Care ... p. 22.


system of care at home that can best be built by a community-based palliative care movement. Their empowered participation not only enhances the quality of care provided, but the family caregivers also experience an increased sense of fulfillment and satisfaction. While planning strategy, this important resource for continuity and quality of care has to be taken into account.\textsuperscript{17}

4. PALLIATIVE CARE – THE WHOLE PERSON APPROACH

As per WHO, palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process, intends neither to hasten nor postpone death, offers a support system to help patients live as actively as possible until death and also offers a support system to help the family cope during the patient's illness and in their own bereavement. It also uses a team approach to address the needs of patients and their families, including bereavement counseling.\textsuperscript{18}

Modern medicine puts undue emphasis on a compartmentalized/specialized technical approach. In contrast, without neglecting the need for specific and technical approaches to the symptoms of the terminally ill patients, palliative care takes a holistic/interdisciplinary approach. It approaches the patient as a ‘whole person’ (with his/her physical, psychological, social, and existential/spiritual dimensions) who is suffering, not as a faceless individual with bodily pain or a malfunctioning organism. Palliative patients can suffer terribly, not only from severe physical symptoms. Perhaps, even more, may be struggling to cope with existential suffering at a psychological and spiritual level – the need of inner healing and forgiveness; a ‘crying for meaning’ as Victor Frankl puts it.\textsuperscript{19} In other words, providing palliative care means the promotion of happiness and reduction of suffering - healing of his/her life, not just body.

Moreover, palliative care is not only patient centered, but also family-centered. It is the effective pastoral/spiritual care, not only of the terminally ill patients and dying, but also of the family caregiver and bereaved. One has to be sensitive to the varied needs of the patients which differ according to their belief systems and values relating to life and death in general. In turn, these are influenced by the position they occupy along various dimensions, such as class, religion, caste, community, language, gender, to name a few.

5. TEAM APPROACH & COMMUNITY HOME-BASED CARE (CHBC) IN PALLIATIVE CARE & THE SIGNIFICANCE OF TASK-SHIFTING

The palliative care is ‘whole person’ and interdisciplinary. As such, it is a team approach. With the shortage of trained personnel and facilities, WHO in its guidelines on Palliative care highlights the need of a strong network of trained doctors, nurses, social workers, community leaders, traditional healers, and family caregivers with specific roles and functions across the different levels of care within the community. Besides, many people suffering from terminal

\textsuperscript{17} DIRECTORATE GENERAL OF HEALTH SERVICES. Proposal of Strategies for Palliative Care …, p. 18.
\textsuperscript{19} BERT BROECKAERT. Spirituality and Palliative Care …, S39–S41.
illness prefer to stay in their own families, among those with whom they share a special relationship. “Home-based palliative care services are becoming increasingly popular with care being taken to the doorstep of the patient. Ideally, this is where people are most comfortable at the end of their lives, surrounded by their loved ones. It is also well suited to conditions in India where a family member is usually available and willing to nurse the sick person.”

Nevertheless, rendering constant nursing care to the ill member of the family or friend can be highly demanding, particularly when the caregivers have no prior experience with chronic illness and the dying process.

In a resource-limited setting such as India, a team approach with special emphasis on CHBC is the only means to make palliative care more accessible to a vast majority of the population, mostly marginalized, in an equitable manner across all levels of care. Taking a cue from the model developed in the context of HIV/AIDS, “CHBC is defined as any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of CHBC is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life.”

Assisted by trained nurses and other health workers of the primary health settings, the patients, family members and active volunteers within the community form an integral part of CHBC.

Community Home-Based palliative care is intrinsically linked to the principle of Task-Shifting, especially in the context of the severe deficiency of trained medical practitioners as well as nurses and adequate palliative care facilities. Task-Shifting involves the rational redistribution of tasks among the team members of palliative care. Specific tasks are moved, where appropriate, from highly qualified health professionals to lesser qualified caregivers. It means primarily the capacity building and mentoring by trained health professionals of caregivers at home and local community volunteers, with the basics of palliative care and care for the elderly, with a patient-centred approach to accompany and enable them to cope with suffering and die with dignity.

The empowerment of family members and community volunteers to be effective palliative caregivers through task-shifting may be the most realistic approach for meaningful coverage, especially in rural areas. Family members and community volunteers can also sensitize relevant local and national governmental organizations to focus effectively on palliative care. Once given proper skills through appropriate hands-on training and supervision, thereafter, the community volunteers can provide direct service to patients and families, such as raising awareness, providing health education and counselling, mobilizing local resources, helping with rehabilitation, or even delivering some types of medical care, etc. The Neighbourhood Network in Palliative Care (NNPC), a joint venture of NGOs and palliative care centers in Kerala/India, may be one of the models in CBHC models and task shifting. The NNPC is designated a WHO Demonstration Project for providing cost-effective community-based home care for late stage cancer patients. The main objective of NNPC is to involve friendly neighbours as community volunteers to provide holistic palliative care. It attempts to develop a sustainable "community

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20 KHOSLA D, PATEL FD AND SHARMA SC. Palliative care in India …, p. 149-54.
led" service capable of offering comprehensive long term care and palliative care. NNPC proved the theory that community ownership can work wonders even in financially poor communities.

Task-shifting also brings down health care costs by reducing human resource costs, thereby making quality geriatric and palliative care more accessible and affordable, especially in the underserved areas, with special focus on the elderly of the socially excluded and economically marginalized sections of society.

6. THE RELEVANCE OF PASTORAL CARE IN PALLIATIVE CARE

Palliative care is much broader than just technical palliative medicine. Especially when confronted with its own limits, when all curative or life-lengthening attempts have been in vain, highly compartmentalized and technical modern medicine demonstrates its inadequacies and limitations. It then paves the way for a holistic and interdisciplinary palliative care, accepting that a terminal illness and the pain and symptoms it entails, affect the whole person, shake the foundations of his or her existence. Indeed, the existential or spiritual domain is an important determinant of the quality of life for many patients. Palliative care, as noted, thus is the ‘active total care’ of those with advanced, incurable life-limiting illness that requires a multidisciplinary team approach – integrating physical, emotional, spiritual and social aspects of care.

The research studies reveal that the spiritual beliefs and religious rituals can help patients cope with disease and face death. They may be then yearning for companionship and spiritual comfort, perhaps more than concerned with advance health care directives, financial and social concerns. The most common spiritual reassurances cited were beliefs that they would be in the loving presence of God or a higher power, that death was not the end but a passage, and that they would live on through their children and descendants.

Complementing medical care meant to stabilize the physical symptoms and reduce pain, the role of pastoral care addresses the spiritual and psychosocial aspects of ‘whole person’ palliative care. The Church through pastoral care, provides conscious compassionate care, empathetic listening, facilitation of emotional expression, use of meditation, prayers and rituals, respecting and being sensitive to one’s faith. It involves praying with patients and their families, performing rituals along with counseling, including listening and responding to the existential questions of the patients and their close family members, reconstructing their life stories, assisting them in solving life-long interpersonal problems, etc.

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23 KHOSLA D, PATEL FD AND SHARMA SC. Palliative care in India …, p. 149-54. See also WHO. Palliative Care …, p. 33: “The Neighbourhood Network in Palliative Care (NNPC) in Kerala, India, is a successful programme that involves volunteers at various levels. Under the programme, people who can spare at least 2 hours per week to care for the sick in their area are enrolled in structured training (16 hours of interactive theory plus 4 days of clinical practice under supervision, with an evaluation at the end). On successful completion of this ‘entry point’ training, the volunteers are encouraged to form themselves into groups of 10–15 people per community. Each group then works to identify the problems of the chronically ill in their area and to organize appropriate interventions. These NNPC groups are supported by trained doctors and nurses. The NNPC groups work closely with existing palliative care facilities in their area or, if necessary, create such facilities themselves. Volunteers from these groups make regular home visits to follow up the patients seen by the palliative care team. Volunteers also identify patients in need of care, and address a variety of non-medical concerns, including financial problems, organizing programmes to create awareness in the community and raising funds for palliative care activities. (Source: Kumar S (2007) Kerala, India: a regional community-based palliative care model. Journal of Pain and Symptom Management, 33:623–627.)”

24 BERT BROECKAERT. Spirituality and Palliative Care …, S39–S41.


Pastoral care helps terminally ill patients and the dying and their families to cope with existential suffering at the psychological and spiritual level – the need of inner healing and forgiveness. Extending Christ’s healing ministry to the terminally ill patients, the dying and their family members, pastoral care restores in them strength and hope; prepares the patient for the inevitable - to die with dignity and peace, and the family members to accept the eventuality.

In a nut-shell, Pastoral care is a ministry of the physical and emotional presence of the ‘shepherd’ with caring acceptance and a non-judgmental attitude, facilitating the inherent human resilience to cope with life-threatening situations like terminal illness. A comprehensive definition of pastoral care in this context may be that of Rumbold Bruce, “Pastoral Care is a person-centered, holistic approach to care that complements the care offered by other helping disciplines while paying particular attention to spiritual care. The focus of Pastoral Care is upon the healing, guiding, supporting, reconciling, nurturing, liberating and empowering of people in whatever situation they find themselves.”27

7. THE RELEVANCE OF COMMUNITY HOME-BASED PASTORAL CARE IN PALLIATIVE CARE & TASK SHIFTING

To fulfil psychological and spiritual tasks as the Pastoral Constitution Gaudium et Spes states, “in pastoral care, sufficient use must be made not only of theological principles, but also of the findings of the secular sciences, especially of psychology and sociology, so that the faithful may be brought to a more adequate and mature life of faith.”28

Given today’s complexities of life, pastoral care too has to be a team work as part of ‘whole person’ approach in palliative care. As is the case with the severe deficiency of trained practitioners and facilities to provide medical care, the deficiency of trained priests and religious to fulfill psycho-social and spiritual needs of patients in palliative care and their families, necessitates Community Home-Based Pastoral Care – a network of the priests and the religious trained in pastoral care, family members of the patients, active volunteers as extended caregivers, and above all, the patients themselves.

Such a Community Home-Based Pastoral Care network has to originate and be anchored within the parish community which is the “family of families”. It is the principal centre of renewed pastoral care which receives and guides people and is animated by sentiments of mercy and tenderness. In this regard, parish organizations have a significant role in sustaining the family, especially when one of its members is suffering from a terminal illness and in the process of dying. Times such as these, marked by illness and bereavement, are a particularly opportune occasion to rediscover the sustaining and consoling nature of faith.29

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To provide quality pastoral care effectively and extensively, the Church in India has to adapt the aforementioned CHBC model of the Neighbourhood Network in Palliative Care (NNPC) in Kerala/India with the concept of task-shifting. While initiatives like NNPC are more oriented towards clinical and physical rehabilitation services, the Community Home-Based Pastoral Care network within a parish should address the psycho-social and spiritual needs. Such initiatives may/need not be altogether a new initiative for a parish community. What may be required is only to facilitate the existing organizations of youth, mothers, elderly, etc. to focus on Community Home-Based Pastoral Care, forming a network of active volunteers who are willing to spend time to accompany terminally ill patients and their families. They thus assist and complement the pastor in pastoral care (except the administration of sacraments) while providing all other services such as praying together with family members, raising awareness, health education/counselling, mobilizing local resources, helping with rehabilitation, or even delivering some types of medical care, etc. “In our time, spiritual movements make a special contribution to promoting an authentic, effective pastoral programme for the family. Christian communities are characterized by a variety of ecclesial situations and approaches aimed at specific individuals. Clearly, local Churches should be able to find that this richness is a real resource for not only promoting various initiatives … but devising ways to provide suitable pastoral care for families today.”

Elaborating on the parish and a pastor’s vision, in Evangelii Gaudium, Pope Francis reminds us, “The parish is not an outdated institution; precisely because it possesses great flexibility, it can assume quite different contours depending on the openness and missionary creativity of the pastor and the community. … if the parish proves capable of self-renewal and constant adaptivity, it continues to be “the Church living in the midst of the homes of her sons and daughters”.”

The charism of Jesus’ healing is also noticeably holistic, focusing not only curing illnesses (bodily) but above all healing the whole person (spiritually) as one created in the image of God (Gen 1:27). Having received the mandate from Christ, the Divine Healer of soul and body, to heal and care for the sick, to render unconditional love and service to the needy and the afflicted (Mark 6:13; Matt 10:1, 7-8; Luke 9:1-6; 10:1-12; Matt 25:36, read with James 5:14-15, etc.) and given the Church context, Community Home-Based Pastoral Care should be inclusive and comprehensive. It should involve all within and around the parish community - the priests and the religious trained in pastoral care, family members of the patients, active volunteers from the community as extended caregivers, and above all, the patients themselves. It should be inclusive to take care of not only Catholics/Christians but also those of other faiths. It should be comprehensive that, while emphatically addressing psychological and spiritual needs, it should also be involved in other services to terminally ill patients and their family members.

It is this context that brings in the importance and relevance of applying the concept of ‘task shifting’ in providing pastoral care by capacitating family caregivers and the community of lay volunteers based in parish communities as pastoral caregivers, the spiritual realm hitherto confined to the clergy and the religious. Task-shifting is thus a means to inculcate, under the

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31 FRANCIS. Apostolic Exhortation Evangelii Gaudium … , 28.
guidance of pastoral care professionals, a culture of empathetic understanding among the family caregivers, and to mould young people, including local volunteers, into a caring community to accompany the terminally ill patients, especially “the elderly who are increasingly isolated and abandoned.”

Enabling caregivers within and around the family of a parish community through task-shifting to take care of the elderly and the terminally ill echoes the Church’s vision of healthcare inspired by His compassionate love, ensuring life in its fullness (Jn. 10:10).

Task-shifting instills solidarity and empowers the young ‘Community Home-Based Pastoral Care-Givers’ to witness the compassionate care of Christ for the suffering, the persistently unconscious and the dying. And as Christians, opposing the culture of death before time in today’s utilitarian socio-cultural milieu, and defending the inherent dignity and inalienable rights of human beings, to declare that “the old age is not the disappearance of life but its completion.”

In sum, in contrast to the growing commercialization of geriatric and palliative care, task-shifting in a Christian context encourages caregivers and local volunteers, especially the young, to be unique, to enable themselves to practice being the ‘Good Samaritan’ in caring for the elderly and the terminally ill, demonstrating the compassionate care of Jesus for the marginalized and vulnerable, irrespective of caste, creed, and sex (Mt. 25:40; Lk. 9:2; Lk. 10:25-37; Acts 10:38). In contrast to the growing culture of consumerism, individualism, and the abandonment of the most vulnerable, task-shifting enables one to experience that “it is more blessed to give than receive” (Acts 20:35), to bear witness that all of life is a gift from God, especially in its final stage.

8. GUIDING PRINCIPLES & ACTIVITIES IN RENDERING COMMUNITY HOME-BASED PASTORAL CARE

In line with the concept of task shifting in providing pastoral care and complementing the tasks carried out by the priests and the religious, the family members and active volunteers as extended caregivers are to be trained and mentored in palliative and geriatric care. The following discussion focuses on some of the guiding principles intertwined with corresponding activities pertaining to Community Home-Based Pastoral Care:

a. Nurturing of trusting relationships and profound hope: The pastoral caregiver can help the patient to find self acceptance and grace in the midst of the struggle and search for meaning. For this, foremost, the family caregiver or a community volunteer has to build rapport and a trusting relationship with the care receiver. One has to understand the spiritual needs of a patient and help him/her to reach out in faith for a relationship with God in whose hands they experience trust and peace. Often the patient experiences feelings of fear, anxiety, anger, isolation, loneliness,

35 For the points from 1 to 6 in this section, unless otherwise specified, I am mainly indebted to LAPSLEY JAMES N. Pastoral Care and Counselling of the Aging. In WICKS ROBERT J, PARSONS RICHARD D AND CAFPS DONALD E (eds.). Clinical Handbook of Pastoral Counselling, Paulist Press: New York; 1985: pp. 250, 257-258, 261-262.
despair, or other such feelings in varying degrees. While caring for those in palliative care and dying, especially the elderly, the caregiver should be able to nurture, through spiritual and religious resources, in the patient a profound hope in the faith that death is not the end. In this regard, the care-giver is to be enabled to facilitate the care-receiver to find such meaningfulness. Palliative pastoral care has to be the intense witnessing of Christ’s compassionate care and healing touch assisting one to eternity.

b. Inclusivity:

Pastoral care is to be all inclusive. As noted, pastoral care in its main function offers spiritual support, especially for the terminally ill and their families, mainly based on one’s religious traditions, along with addressing psycho-social needs. Pastoral care through spiritual support and respective religious resources helps people to relate to their own inner self and their quest for meaning especially when faced with life-threatening illness. Nonetheless, while rendering pastoral care, one may meet with persons who are not affiliated to any conventional religion (beliefs and practices) but tend to seek spiritual experiences of inner healing.

It is a fundamental requirement of pastoral care that the caregiver, especially in the pluralistic context of India, has to be sensitive to the spiritual beliefs and customs and the ethical positions thereof of the patients and their families/close caregivers. The caregiver has to take utmost care not to force patients and their families into spiritual, religious and cultural practices.

Sensitivity to these factors is essential to providing end-of-life care to the patients and their family members/close caregivers. “In India, patients come from varied backgrounds. Their end-of-life needs differ according to their belief systems and values relating to life and death in general. In turn, these are influenced by the position they occupy along various dimensions, such as class, religion, caste, community, language, gender, to name a few. Moreover, cultural variations in attitudes and values have important practical implications for individuals making crucial medical decisions.”36

c. Reflective listening towards an empathetic understanding: The pastoral caregiver, especially the close relative in the family, needs to be a non-judgmental listener to inculcate a feeling with the other, with an unconditional openness of heart and mind. Empathetic understanding awakens or reiterates one’s sense of self worth. The caregiver has to treat the care receiver as subjects and not objects of compassionate care.

d. Importance of memories and responding to them: Memories affirm one’s present identity as a person, who she/he has been, providing participatory links through the past to the present. While providing pastoral care and counseling for the elderly, especially those suffering from the terminally ill, the caregiver has to sensitively respond to these memories.

e. Engagement of the care receivers in household activities: As much as they can, engage the elderly and those in palliative care in providing loving care for others, especially the care of

children. This will enhance their sense of dignity and self-worth as they feel that they are contributing in the present to the life of those in and around the family. Also, they may eventually relate to the theological perspective/spirituality in which she was nurtured and brought up.

f. Facilitation of new pattern of relationships: The pastoral caregiver within the family or the community volunteer has to motivate the elderly to enter into new patterns of relationships with their peers (for instance, Senior Citizens Association) and with the younger generations, by making use of common programmes within the community.

g. Facilitation of interpersonal relationships within the family: The pastoral caregiver should be able to bridge communication gaps that may occur between the elderly and their children and other family members. One has to facilitate a reconciliation process when required; to help the elderly to express their own needs and wishes as clearly as possible. In the context of a patient at the dying stage, the pastoral caregiver is to enable the family to face the looming separation in the context of faith. The period of terminal illness can be a time of family bonding, when family members can express their love and appreciation of one another. It may be also turned into a time of reconciliation, experiencing the mercy and grace of God and of looking forward together to heaven. The dying person should be encouraged to be a help to their relatives in the grieving process. It is also an effective means of removing possible causes of guilt after the death of the patient.37

h. Identification of mental health problems: The pastoral caregiver should be enabled to recognize mental health problems among the elderly especially those faced with life-limiting and progressive neurodegenerative illnesses, and facilitate proper care. Many of the elderly suffer from problems properly associated with mental, rather than physical illness, especially depression, and need to be treated with a full range of medical remedies, as well as with appropriate pastoral care. These problems may occur due to an intensive loss like that of a long beloved spouse. In such instances, counselling by a pastoral caregiver within the family or community may be useful as a supportive relationship, allowing the grief to be ventilated, along with religious and non-religious resources. Anchoring on the rapport and trust that the pastoral caregiver provides, the person is to be reassured that experiences such as imagining that the lost relative is still alive, or searching for him/her is normal; encourage him/her to share the feelings with friends and relatives and participate in rituals associated with death; listen quietly and allow the sadness to be expressed and encourage gradual return to daily life.38

i. Pastoral caregiver as a social worker: Many a time, the pastoral caregiver, especially the community volunteers, as social workers, are to help the family and patient to deal with the social problems of illness and disability. They have to be capable to assess the patient’s and family’s needs from a social perspective, and help anticipating problems within the family that may result from dysfunction and financial difficulties, particularly as the family begins planning for the future. They have to do facilitate support during the progression of the disease and the bereavement process, if the patient is at the end of life.39

39 Cfr. WHO. Palliative Care .... p. 28.
9. CARE OF THE CAREGIVER

A caregiver in a family has to face a variety of consequences in caring for the sick person, such as, physical burden/exertion, emotional burden and difficulty in dealing with symptoms of mental disorders even to the extent of physical harm or abuse, and the guilt because of negative thoughts about the patient. Often the caregiver herself may fall with nobody around to relieve her especially in the case of old couples or where both suffering from terminal illness like AIDS. The caregiver may have only limited access to good food as expenses rise when the sickness gets chronic or loss of livelihood due to full time care. She also may have only limited social contact, less time for unwinding activities and eventually suffer grief due to the death of the beloved person.  

As part of Community Home-Based Pastoral Care, the parish priest and the pastoral care volunteers within the parish community have the task of reaching out to the direct caregivers within the family. In the holistic palliative care system, the care of the caregiver in the family has a prominent place without which the system will not be effective. A patient’s illness can affect the entire family, especially when the illness is relentlessly progressive and causes changes in the patterns of life for all the family. As noted, although caring for the patient at home is rewarding, it may also be physically strenuous and emotionally draining.

In caring for the caregiver, the pastoral care volunteer within the parish community can resort, under the guidance of the pastor, to the guiding principles and activities enumerated in the above section. The pastoral care volunteers have to be able to facilitate the caregiver in the family to receive practical help from other family members and the volunteers, create occasions to open up her feelings to her and a professional counsellor if needed and to attend spiritual/religious exercise in the parish or any other outside location. The pastoral care volunteers may get involved in providing day-care services at patient’s own home or taking patients to the nearby day-care centres if the condition permits, providing respite for the caregiver. They may also as noted elsewhere facilitate the caregiver with basic health skills required, mobilizing resources, even delivering some types of medical care, etc.

In the eventuality of the death of the beloved person, the parish priest and the pastoral care volunteers, as a natural follow on to the pastoral care of the sick, have to engage her in rituals associated with death; encourage her to share her feelings with friends and relatives; listen her quietly and allow the sadness to be expressed and encourage gradual return to daily life.

10. CONCLUSION: WAY FORWARD

In the context of very limited awareness and resources concerning palliative care, the Church in India has to promote behavioral change among the laity at parish level communities in particular and the peoples of other faiths/communities in general, through appropriate awareness creation measures. This may be the first step towards inculcating community responsibility on ‘whole
person’ palliative care and the initiation of Community Home-Based Pastoral Care networks, to be originated and anchored within the local parish community.

As is the case with the public health sector, the Church too has hitherto neglected its human potential, especially the laity, in communitizing health care and building caring communities of active pastoral care volunteers to accompany the needy and the marginalized in their hour of struggle, including holistic palliative care.

Perhaps more than the religious world, of late, the secular milieu begins to understand the need of communitizing health care and building caring communities. Down the centuries of human existence, it is a proven fact, in the midst of suffering, calamites and violence, that human beings are capable of working together for common causes or for other people in or outside the community. The Expert Group Report on the Strategies of Palliative Care in India highlights the point that crises like life-threatening illness and dying are valuable opportunities of empowerment in the community, “building/enhancing social relationships as the problem is universal and visible. Community participation in the care of the incurably ill, elderly, bed ridden and dying people can bring solace to millions of people. Until recently, people were neglected as a health resource; they were viewed merely as sources of pathology and as target for preventive/therapeutic services.42

In this context, the Church is placed in a better position, with such a vast and committed human resource, to adapt or innovate into such initiatives like Community Home-Based Pastoral Care networks where parish-based active volunteers are trained. As pointed out, spiritual movements are there today within the Church, many of them being led by lay leaders, contributing towards authentic, effective pastoral programme for the family. Taking this as a vantage point, the Church has to direct the focus of these movements and associations in Community Home-Based Pastoral Care, forming networks of active volunteers. The Catholic Health Association of India (CHAI) with the Health Commission of the Catholic Bishops Conference of India and others, with their pan Indian presence and expertise, have to inculcate and strengthen such efforts. This includes awareness creation to training the lay volunteers at the parish community level to undertake Community Home-Based Pastoral Care and to spend time to accompany the terminally ill patients and their families, thereby assisting and complementing the pastor in pastoral care. As Bishop Anthony Fisher puts it, it is a call for investing in “hard-loving” in the midst of the existential awareness that even with the best of care, pain and death cannot be eliminated from this life.43 The hard-loving of a caregiver in the family or a parish community volunteer, committed to be with the terminally/chronically ill and the elderly, to be with them when they “pass through the waters” (Isaiah 43:2).

Such task-shifting may strengthen further the empowerment process of the laity, the decentralization and democratization of pastoral care, the renaissance of diakonia of the early Church and renewal of life in the laity and the religious to be co-pastors with Christ, the Divine Healer.

42 DIRECTORATE GENERAL OF HEALTH SERVICES. Proposal of Strategies for Palliative Care ..., p. 5.