

## **Caring for Carers in Palliative Care**

**Dinah Chelagat**

Moi University  
School of Nursing  
P.O Box 4606-30100  
Eldoret, Kenya.

**Elima Kulei**

Moi University  
School of Nursing  
P.O Box 4606-30100  
Eldoret, Kenya.

### ***Introduction***

Palliative care is an approach of care whose aim is to improve the quality of life of patients and their families facing problems associated with life threatening illnesses through prevention, assessment and treatment of pain and other physical, psychological and spiritual problems (Johnson,2005:2; Bennett,2009:13;Coyle,2010:5)

Carers as far as palliative care is concerned are of two categories. They are the health care professionals who take care of those patients/clients with life threatening conditions and the volunteers who are either family members or friends and provide care for these people at home or even stay with them when they are admitted at the hospitals. Volunteers are key partners in the care team in palliative care. (Claxton-Oldfield.2008 on line). The impact of caring for a family member in need of palliative care is well documented where care givers have been prone to negative physical, social and emotional sequelae (Hudson, Aranda, Kristjanson,2004: on line)

Being a carer in most instances is not what people have planned for but individuals find themselves in a situation where they are required to provide the much needed care when a member of the family or a friend has to be on palliative care (Barbara, Charles and Sherwood. 2012 Online)

Taking care of a person with a life threatening condition has been described as one of the toughest undertakings which on the other hand is also most rewarding experience when one knows they have done the best for their loved one. Given the fact that individuals in life are different, caring situations are also expected to be different and no two caring situations are the same even when those requiring care have similar life threatening conditions. Caring for someone with a terminal illness can therefore be confusing, frustrating because each experience is different and is not easy to bank on first experiences (Kemp. 1999: 41-42)

People with a terminal illness have a range of needs that go beyond meeting their medical requirements. A team comprising a number of people such as the health care team to include doctors, nurses and other allied health care workers, Chaplains, family members and other volunteers provide coordinated care addressing the physical, emotional, social cultural and spiritual needs for the patient, family and carers (Kengan City & Labyak. 2010: 35-46). This care may last for weeks, months or years.

### ***Professional Carers***

These are people whose professional expertise is needed in the care of patients/clients on palliative care. They include doctors, nurses, counselors and nutritionists among others ( Wheatley V.J And & Baker J.I. 2007).They are the ones who take care of the patients and also offer advice to non professional care givers on what to do at home once the patients are discharged .

Many health care workers offering palliative care at the hospitals or nursing homes suffer from stress and other challenges related to care provision and the feeling of not being able to cope with the care demands or expectations from the patients, their relatives or friends. (Johnston, 2005: 16-22; Johnston 2005 page 6-7)

The provision of palliative care is time consuming where the health care workers develop therapeutic relationships and are required to walk with patients and their families through prolonged periods of illness. Patients on many instances are deteriorating and often die which puts a lot of emotional stress on the carers who as much as they should sustain hope of the patients, must prepare them to face death.

The carers need to handle their own mortalities, resolve all their past issues, understand their cultural and also the patients cultural diversities so as to adequately handle and provide quality care to patients and families, which can only be provided through training of these carers (Schneider, Mitchell & Murray, 2010: Online; Hudson et al 2004). Some of the health care professionals feel that they have not been adequately trained and prepared to carry/ undertake the new tasks required in the provision of palliative care services (Johnstone. 2005; Dahlin 2010:109). The need to train more palliative care providers with additional skills such as conflict resolution is due to the fact that Palliative care is a journey that continues even after death of the patients where the surviving family members require a lot of support and counseling to enable them continue with their normal and even better quality of life after death (Kemp. 1999) It is also worth noting that the number of people needing palliative care continues to increase as the number of people suffering from cancer and Hiv/Aids increase (Harding R, Karus D, Easterbrook P, Raveis VH, Higginson IJ, Marconi K: 2005. Online). This has created an unmet need of health care professionals requiring training hence the need to integrate palliative care into the existing curricula of the various health professionals.

In the recent past ,the Kenyan Government has collaborated with various organizations such as KEHPCA , National and International bodies to scale up palliative care services in the country by training health care providers, establishing palliative care centers and creating as well as intensifying awareness especially on cancer prevention strategies. Currently there are a total of eleven hospitals comprising provincial and level five hospitals providing palliative care services and thirty centers mainly District Hospitals are in the process of being established throughout the country (KEHPCA, 2012: on line). Moreover, KEHPCA has trained lectures from 17 institutions who train Doctors ,Nurses, Pharmacist among others so that they can incorporate palliative care into their curricula. This was done with funds from the Diana Princess of Wales memorial fund.(Kinyanjui, 2012: online) Other challenges faced by the professionals offering palliative care services include: the extreme shortage of staff, emotional distress, inadequate support from employers and coworkers shortage of supplies and materials such as gloves and protective clothing .( David E. Weissman, M.D. and Diane E. Meier, M.D. 2011: on line)

### ***Possible Ways of Addressing the Above Challenges***

1. Have professional carers well trained to offer the required services in palliative care alongside their formal training
2. Offer updates on palliative care from time to time to incorporate new developments in palliative care.
3. Have a large number of staff trained so that rotations are done from time to time and allow them work in shifts in order to prevent burn out
4. Health care institutions to provide the necessary materials and equipment required by the professional carers
5. Provide organized counseling sessions and opportunities to allow carers share personal experiences which serves as a learning forum as well as therapeutic sessions

### ***Volunteers***

Volunteers as earlier stated, are family members or friends and are the major care providers to patients in need of palliative care (Millon Nuzzo , Mc Corkle & Ercolano. 2010: 891-902). Illnesses create a highly charged emotional climate for these carers and there is need for support from the health care professionals as well as other members of the community. Volunteers have various needs which could be physical, emotional and informational during their caring role (Mc Iyntyre & Lugton. 2005 PP 261-267).

### **Possible Ways of Addressing the Challenges of the Volunteers**

1. **Offer physical tangible support** upon discussing and obtaining permission on the best way they would like to be assisted to avoid off ending them in the process of trying to help. Examples of ways in which the physical support could be offered include:
  - Assist in meal preparation or providing readymade meals.
  - Assisting with housework.
  - Assisting in caring for their children or even taking or dropping children from school
  - Advice on engaging assistance required in the caring process to enable the carers get time off for their own self care.
2. **Emotional support** such as:
  - Conveying acceptance
  - Responsiveness
  - Listening to concerns
  - Demonstrating understanding and showing of concern to the welfare of the family.
3. **Informational support** regarding:
  - The cause and course of the illness
  - Management of symptoms
  - How to care for the patient
  - The likely prognosis
  - How to respond to sudden changes in the patient's condition
  - The services available to assist them.

**NB** - Occasionally, the health care providers must deal with carers from a distance especially where a patient on palliative care has adult children who live far from where the patient is being cared for. In such situations, there is need for more flexibility and accommodation because it means there will be increased telephone time between the health care provider and these distant carers so as to give them the required information and attend to their questions and concerns.

-The carer's ability to absorb and retain information may be compromised by memory loss, depression, fear, anxiety and sleep deprivation therefore health care professionals need to ensure that the care givers have heard and understood the content of information provided with sufficient time to have their questions clarified.

### **Conclusion**

Carers are key in the provision of palliative care whether they are health care professionals or volunteers. Carers must therefore be supported so that they can cope in with their caring roles.

## References

- Barbara A, Charles W and Sherwood P R. 2012. Family and Care giver Needs over the course of Cancer Trajectory. Available [Online] from:  
[http://www.skinandallergynews.com/fileadmin/content\\_images/jso/PDF/v10\\_i02%20Family%20and%20Caregiver.pdf](http://www.skinandallergynews.com/fileadmin/content_images/jso/PDF/v10_i02%20Family%20and%20Caregiver.pdf)
- Bennet, MI .2009.principles of designing clinical trials in palliative care. In Addington-Hall JM, Bruera,E, Higginson IJ,and Payne S.(ed).Research Methods in Palliative Care. London: Oxford University Press.pp.13.
- Claxton-Oldfield S, Claxton-Oldfield J. Keeping hospice palliative care volunteers on board: Dealing with issues of volunteer attrition, stress and retention. *Indian J Palliat Care*. 2008; 14(1):30-7 on line at <http://www.caresearch.com.au/caresearch/tabid/216/Default.aspx>
- Coyle N.2010.Introduction to Palliative care Nursing Care. In Ferrell Br and Coyle N.(ed).Palliative Care Nursing 3<sup>rd</sup> Edition.london:Oxford University Press.pp 5.
- Dahlin C M. 2010.Communication in Palliative Care; An Essential Competency For Nurses. In Ferrell Br and Coyle N.(ed).Palliative Care Nursing 3<sup>rd</sup> Edition.london:Oxford University Press.pp 109.
- David E. Weissman, M.D. and Diane E. Meier, M.D. Identifying Patients in Need of a Palliative Care Assessment in the Hospital Setting. A Consensus Report from the Center to Advance Palliative Care[on line] available from: <http://www.capc.org/tools-for-palliative-care-programs/national-guidelines/primary-palliative-care-trigger-criteria-capc-consensus.pdf>
- Egen City K.A & Labyak M J. 2010.Hospice Palliative Care For The 21<sup>ST</sup> Century: A model For Quality End – of- Life Care in Ferrell, BR & Coyle N in *Palliative Care Nursing* . pp 35-46. Oxford University Press
- Harding R, Karus D, Easterbrook P, Raveis VH, Higginson IJ, Marconi K:2005.Does Palliative Care Improve outcomes for Patients With HIV/AIDS? A Systematic Review of Evidence.[ on line] Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15681714>
- Hudson P.L, Aranda and KristJanson L.J. 2004: Meeting the Supportive Needs of Family Caregivers in Palliative Care: Challenges for Health Professionals [on line].Available from:  
[http://www.hawaii.edu/hivandaids/Meeting\\_the\\_Supportive\\_Needs\\_of\\_Family\\_Caregivers\\_in\\_Palliative\\_Care\\_Challenges.pdf](http://www.hawaii.edu/hivandaids/Meeting_the_Supportive_Needs_of_Family_Caregivers_in_Palliative_Care_Challenges.pdf)
- Johnson, BI.2005. Introduction to Palliative Care: Overview of Nursing Development. In Lugton J and McIntyre. Ed). *Palliative Care, the Nursing Role*.2<sup>nd</sup> Edition. London, Churchill Livingstone. Pp5.
- Johnson, BI.2005. Introduction to Palliative Care: Overview of Nursing Development. In Lugton J and McIntyre. Ed). *Palliative Care, the Nursing Role*.2<sup>nd</sup> Edition. London, Churchill Livingstone. Pp 7
- Johnston B M .2005. The Role of The Nurse In Palliative Care in Lugton J & McIntyre. *Palliative Care. The Nursing Role*. 2<sup>nd</sup> Edition. London. Churchill Livingstone. Pp 16-22.
- KEHPCA.2012. Celebrating Community Leadership and Action On AIDS.[on line] from [http://www.redribbonaward.org/index.php?option=com\\_content&view=article&id=416&Itemid=286&language=ru#.UJoOnYHIJdg](http://www.redribbonaward.org/index.php?option=com_content&view=article&id=416&Itemid=286&language=ru#.UJoOnYHIJdg)
- Kemp C. 1999.Psychological needs problems and Interventions: The Family in Kemp C. (ed). *Terminal Illness: A Guide to Nursing Care*.2<sup>nd</sup> Edition. Philadelphia. Lippincott Pp 34-42.
- Kemp.C 1999. Grief and Bereavement Care. Family in Kemp C (ed). *Terminal Illness: A Guide to Nursing Care*. 2<sup>nd</sup> Edition. Philadelphia. Lippincott Pp 78-80
- Kinyanjui A .2012.Need for Education In Palliative [on line] available from <http://kehpc.org/conference/wp-content/uploads/2012/09/p-71.pdf>
- McIntyre R &Lugton J. 2005. Supporting The Family And Carers in Lugton J & McIntyre. *Palliative Care the Nursing Role*. 2<sup>nd</sup> Edition. London. Churchill Livingstone. Pp 261-267.
- Millon Nuzzo P, Mc Corkle R and Ercolano E. 2010.Homwe Care in Ferrell Br and Coyle N.(ed).Palliative Care Nursing 3<sup>rd</sup> Edition.london:Oxford University Press. Pp 891-902
- Schneider N, Mitchell G K, and Murray S A. 2010. Palliative care in urgent need of recognition and development in general practice: the example of Germany.[Online].Available from:  
<http://www.biomedcentral.com/1471-2296/11/66>
- Wheatley V J and Baker J I. 2007. “Please, I want to go home”: ethical issues raised when considering choice of place of care in palliative care. [online].Available from:  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2600129/>