PALLIATIVE CARE FOR PATIENTS WITH END STAGE RENAL FAILURE

This is the eighth in the series of on-line educational initiatives from the Education Board. You are invited to review the following websites and/or articles from the internet. Sections 1-2 are to update your general knowledge on palliative care, and sections 3-6 contain a selection of the latest publications on the topic. After reviewing the references, evaluate your knowledge and reflect on possible improvements to patient care by answering the questions in section 7.

If you are updating your knowledge and wish to include the number of learning hours that you have spent on this work, complete section 7 below and then include your answers in the EDTNA/ERCA Professional Portfolio that is available free to members from EDTNA/ERCA Head Office (translated into nine languages). See the following EDTNA/ERCA journal for further details:


Palliative care is a direct outgrowth of the hospice movement, and hospice has its earliest roots in fourth century Byzantium, in the Christian institutions that were established to welcome travellers. The 1970s through to the 1990s we saw a rapid proliferation of supportive care units. By the year of 1994, only 27 years after St. Christopher's Hospice opened its doors, there were at least five journals being published in the field of palliative care, such as: Palliative Medicine, Journal of Palliative Care and Journal of Pain and Symptom Management. Furthermore, a comprehensive textbook – Oxford Textbook of Palliative Medicine – is now in its second edition (1998).

Nearly two millennia after the establishment of the first hospices of Byzantium, hospices are once again flourishing throughout the world and providing comfort to travellers on their last journey. We have more sophisticated measures today for relieving the symptoms of terminal illness, but the concept of caring unites twentieth century palliative care with its fourth century predecessors (Waller & Caroline, 2000).

1) Definitions for Palliative Care

There are several definitions for palliative care, most of them have the same component. In most cases the WHO definition is cited as the agreed definition.
Palliative Nursing Care for the Patient Experiencing End-Stage Renal Failure. Kim K. Kuebler; full article: http://www.suna.org/contedu/06167178.htm

World Health Organization Definition of Palliative Care
http://64.85.16.230/educate/content/elements/whodefinition.html

The traditionally definition and relation of palliative care to terminally ill patients, is now changes and adapted to the care of people suffering from chronic diseases, such as CRF.


2) The Philosophy of Palliative Care

As mentioned, palliative care has its roots from the hospice movement, "hospice is not a building and not a model but a supportive approach. The methods and models for palliative care can change from place, but certain basic characteristics are common to every hospice program everywhere. In every hospice, there is: ...ongoing efforts to control the patient's symptoms, helping the patient to cope with fear of death, loneliness, and many losses that attend advanced illness", etc. (Waller & Caroline, 2000).

American Board of Hospice and Palliative Medicine Definition of Palliative Medicine:

In 2000, the American Board of Hospice and Palliative Medicine said Palliative Medicine is:

"the medical discipline of the broad therapeutic model known as palliative care. This discipline and model of care are devoted to achieve the best possible quality of life of the patient and family throughout the course of a life-threatening illness through the relief of suffering and the control of symptoms. Such relief requires the comprehensive assessment and interdisciplinary team management of the physical, psychological, social, and spiritual needs of patients and their families. Palliative medicine helps the patient and family face the prospect of death assured that comfort will be a priority, values and decisions will be respected, spiritual and psychosocial needs will be addressed, practical support will be available, and opportunities will exist for growth and resolution."

A definition of Hospice was developed by The National Hospice and Palliative Care Organization.

Ref: The American Board of Hospice and Palliative Medicine

Palliative Care Provision in End-Stage Renal Failure. J. Casey and S. Hodson; EDTNA/ERCA Journal 2003-1: 4-6. Summary:


3) Symptom management in ESRD patients

ESRD patient might experience a variety of disturbing symptoms that are in correlation with a deterioration in their Quality of Life. Sometimes pain is considered to be the most disturbing symptom, but patients may suffer from fatigue, insomnia, pruritus, depression etc. Assessing the symptoms by using the relevant assessment tools and managing the care, are the major roles of the multidisciplinary renal team.
The Renal Palliative Care Initiative. Lewis M. Cohen, MD:  
http://www.mywhatever.com/cifwriter/content/41/pe1240.html

PRESENTER -- Alvin H. Moss, Incorporating Palliative Care into Your Dialysis Unit  
MD  Power Point slide presentation. OVERVIEW -- This module describes how to implement  
the six components of a palliative care program into dialysis patient care: 1) palliative care  
inclusion in regular conferences, Quality Improvement activities, and in-services; 2) pain and  
symptom assessment and management protocols; 3) systematized advance care planning; 4)  
psychosocial and spiritual support for patients and families; 5) terminal care protocols  
including use of hospice as appropriate; and 6) bereavement support including a memorial  
service for deceased patients.

Palliative Nursing Care for the Patient Experiencing End-Stage Renal Failure. Kim K.  
Kuebler; full article:  
http://www.suna.org/contedu/06167178.htm

Cancer patient pain is a subject of care and research for the last decades. What can we  
learn from this field and implement for the benefit of renal patients?  
cancer pain relief definition, you can find this at:  
http://www.whocancerpain.wisc.edu/eng/12_4/research.html

Chronic Fatigue Syndrome which is sometimes also present in renal patients. For example  
http://www.cdc.gov/ncidod/diseases/cfs/defined/defined5.htm see:

On Chronic Fatigue Syndrome Treatment:  
http://www.excel.net/~jaguar/cfids-cure.html

Exercise benefits patients with chronic fatigue syndrome:  
http://www.pslgroup.com/dg/1F2892.htm

Psychological Burden Of Chronic Pain Tied To Chronic Fatigue Syndrome  
http://www.docguide.com/news/content.nsf/news/8525697700573E1885256C7D005CDC0D  
?OpenDocument&c=&count=10&id=48DDE4A73E09A969852568880078C249

4) Withholding / Withdrawal of treatment  
Is the renal team is prepared to deal with this difficult issue? What is the role  
of the renal specialist in supporting the patient and family decisions  
concerning this issue?  
In USA, "more than 50,000 long-term dialysis patients die per year, with  
roughly 20% of these deaths after decision to stop dialysis. After dialysis  
discontinuation, the average dialysis patients lives for only 8 to 12 days. The  
renal care community recognizes and recommends a role for palliative care in  
the end —of- life treatment of these patients" (Moss, 2000).

Withholding dialysis:

- Patient's Right In Receiving or Rejecting Dialysis Care. James B Riley Esq. and  
  Robert J Pristave Esq. full article:  
  http://www.ikidney.com/iKidney/Community/Pro2Pro/Dietitians/PatientsRightInReceiv  
ingorRejectingDialysisCare.htm

- No dialysis and stopping dialysis:  
  http://renux.dmed.ed.ac.uk/EdREN/EdRenINFObits/NoRRT.html

- Withholding dialysis? Withdrawing dialysis? Power Point slide presentation:  
  http://www.wramc.amedd.army.mil/departments/medicine/Nephrology/education/Lect


Conservative Management of ESRF, Palliative Care and Withdrawal from Dialysis: http://www.kidneyalliance.org.uk/docs/foursix.htm

5) The rights and the choice of patients in end of life decision

- Patient's Right In Receiving or Rejecting Dialysis Care. James B Riley Esq. and Robert J Pristave Esq. full article: http://www.ikidney.com/iKidney/Community/Pro2Pro/Dietitians/PatientsRightInReceivingorRejectingDialysisCare.htm

6) Models for implementing Palliative Care in renal care.

The Renal Palliative Care Initiative. Lewis M. Cohen, MD: http://www.mywhatever.com/cifwriter/content/41/pe1240.html


How to establish a palliative care program
Square of Care, Square of Organization, Square of Care and Organization http://64.85.16.230/educate/content/elements/whodefinition.html see:

Books:


Journal Articles:


Web Sites:

International Association for hospice and palliative care:
http://www.hospicecare.com

hospice web:
http://www.hospiceweb.com

hospice and palliative nursing association
http://www.hpna.org

American pain society
http://ampainsoc.org

7) Evaluation and reflection

Review questions

1) What are the main domains of palliative care that should be implemented and integrated in renal care?
2) Discuss the available methods of managing pain in renal patients
3) Define what the rights of the patient and family who are willing to withdraw from dialysis
4) How should the renal team address the relief of symptoms of patients that withdraw from dialysis?

5) Estimate with your team their thoughts about the importance of palliative care, and try to outline a tentative model for providing palliative care in renal care.

**Reflection**

- How many learning hours have you spent on reading and reviewing the websites/articles/abstracts?
- Which was the most useful article/abstract that you reviewed, and why?
- How does this most useful article/abstract relate to your work and how has it or will it inform and influence your practice?
- Is there any further learning that you have identified that you may do related to this topic?

We hope that you have enjoyed the eighth of our on-line educational programmes. Please address any queries or questions to Head Office. I would like to thank André Stragier, the EDTNA/ERCA Communication and Publication Relations Officer for his invaluable help and support in searching the internet for appropriate websites and articles. The next topic will be published on the Homepage in August 2003.

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*July 2003*