Renal Supportive Care. Nursing Experience and perspectives

Renal Supportive Care Symposium 2013
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Outline

- Supportive care management of the advanced CKD patient
- Recognise patients who would benefit from the management of advanced CKD using supportive care principles
- Nursing role for a conservative patient

What is supportive care?

SUPPORTIVE CARE DEFINITION

- "helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. **It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.** It is given equal priority alongside diagnosis and treatment"

- The National Council for Palliative Care, 2011

Palliative Care Definition

- "The active total care of patients whose disease is not responsive to curative treatment…..the goal of palliative care is to achieve the best quality of life for patients and their families"

WHO definition of palliative care

Which patients do you think would benefit from a supportive care approach

Patients

- People with advanced CKD (usually, eGFR <25)
  - Mainly elderly
  - Have co morbidities (often not renal related)
  - Choose not to have Renal Replacement Therapy
- People on dialysis who have difficult to manage symptoms
- People on dialysis or with transplant who have a 2nd life limiting illness
- Patients who are considering withdrawing from dialysis

How is supportive care provided for our patients from a nursing perspective?

SUPPORTIVE CARE - NURSING

- Being aware of patient suffering/being patient centred
- Involving the patient and significant other in all conversations
  - Communication
- Linking with allied health and palliative care service where required
- Support for patients (and family) when withdrawing dialysis
- Meticulous symptom management
- Manage end of life care with aim for a 'good death'
- Post hospital discharge follow up (clinic/phone/visit)

'Good Death'

- What is this?
  - NFR order in place
  - Planned dialysis discontinuation
  - Palliative care team involved
  - End of life pathway used
  - Patients and family aware that death is approaching
  - Relatives present at death
  - Death judged as 'good' by staff
    - Meticulous end of life drug medications appropriate and used appropriately
    - Implantable defibrillators deactivated
    - There is a choice of place of death

McAdoo, S., Brown, E., Chesser, A., Farrington, K., Salisbury, M., & on behalf of pan-Thomas renal audit group. (2011). Measuring the quality of end of life management in patients with advanced kidney disease: results from the pan-Thomas renal audit group. *Nephrol Dial Transplant,* (0), 1-7.

What resources would you need to provide a supportive care service?

- Strong links with palliative care
  - Education
  - Hospice availability (rural areas may not have this)
  - Clear pathways
- Allied health available
- Clinics available to cater for conservative care or symptom management.
- Rural centres operate different to metropolitan centres (distance, lack of hospice, lack of palliative care physician, outreach services)

WHO CAN ACCESS THIS PROGRAM?

- All dialysis patients who have complex symptom management needs that require expert management
- All conservatively managed patients who are known to a St George nephrologist
- Dialysis nurses can refer – (triage who is appropriate and liaise with nephrologist)

The St George Hospital Supportive Care Clinic

NOT for Dialysis	59%
Symptoms on Dialysis	36%
Withdrawal	5%
TOTAL	100%

When would it be appropriate to commence end of life discussions with dialysis patients?

- Patients who want to withdraw treatment
  - Answer their questions – decision with nephrologist
- Failing PD, transplant or vascular access when change of treatment not wanted or feasible
- Sentinel event occurs (dialysis will likely cease for medical reasons)
- QoL unacceptable to the patient
- Significant change if functional status

Case Study – Not for dialysis decision made in pre dialysis clinic

- 85 year old man
- Previous stroke affecting sight and gait, IHD, Type 2 diabetic, HT, Stage 5 CKD, severe prostatism
- Came to pre dialysis clinic with his wife and daughter
- Choices give and quite relieved that conservative was one of them

Case Study

- Decided to have conservative pathway
  - Still see nephrologist and also come to supportive care clinic
- Admissions for prostatism
- Lots of communications with wife and daughter regarding care
- Respite nursing home for a month
- Last admission: large MI, died 3 days later with palliative care support

Supportive Care

- Supportive care works with other disciplines to support the renal patient.
- We don't take over care or work alone.

- How?

Patient Centred Care

- Supports a better patient and family experience through the ESKD continuum
- Improve decision making consultations
- Improve symptoms
- Allows for a proper/dignified and recognised end of life
- Identify the needs of the patient and family
- Patients do not need to fear ‘abandonment’

RSC Nurse Role in Symptom Management

- Most common education for medication:
  - Ketamine (burst regime, a form of rescue, watch for Psychotomimetic and opioid potentiation side effects)
  - Gabapentin
  - Changeover from short acting to long acting pain relief
  - Educating family how to use pain relief at home (breakthrough)
- Identify and act on patient needs when admitted to hospital
  - Pain assessment
  - Other symptom assessment (nausea, oral thrush, constipation…)
  - Carer distress…

RSC Nurse role in end of life care

- Commence end of life pathway *when the patient is identified as dying*
  - Medication adjustments for ESKD
- Facilitate where able to move the patient to their chosen place of death (home, hospice, hospital)
- Talk to the family
  - How they can participate in the care
  - What to expect
  - Visiting hours
  - Main contact person
  - The patient can still hear
  - Discuss medications used to help maintain comfort
  - Family meetings where required

- The family will remember **everything** that happened the day their loved one died.

Special considerations

- Multi-organ failure
- Implantable defibrillators
- Guardianship
- Religious and cultural considerations

Conclusion

- Supportive Care Nurse provides support to the patient and carers anywhere along the CKD continuum
- Symptom management
- Decrease distress at end of life
- Reduce preventable hospital admissions
- Listen and be available to assist
- Links to palliative care teams and others

REFERENCES

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- The National Council for Palliative Care. (2011). Palliative Care Explained. Retrieved 04/07/2011

Useful Resources

- http://stgrenal.med.unsw.edu.au/
- http://hospicefoundation.ie/publications/ethical-framework-on-end-of-life-care/
- http://clinicalethics.info/what-is-clinical-ethics
- http://www.swslhd.nsw.gov.au/services/pepa/