What is Renal Supportive Care? A Nurses Perspective

Renal Supportive Care Symposium
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Outline

- Background to the evolution of supportive care
- Have a basic understanding of our definition of supportive care
- Recognise patients who would benefit from the management of advanced chronic kidney disease (CKD) using supportive care principles
- Identify the role of the nurse

Background

- 1960's dialysis introduced, thus ESKD patients start to survive longer
- 1960-2000: Increasing technical advances and more patients start dialysis
- > 2000: Medicine becoming more aware of QoL of patients with a realisation that not all patients benefit

Background

- 1979 ANZDATA annual report
 - "there has been a continuing trend of treatment to 'older' patients, reflected by the 49.5% of new patients over 49 years of age in the past 12 months compared to 31.5% of new patients in the same age group in 1973" "45% of all dialysis patients were> 45yrs at 31st October 1978"
- 2010: 67% of new patients in Australia were ≥
 55 years. 22% are ≥ 75 years

Primary Renal Disease

1979:

- 7% of new dialysis patients were diabetic and had a 55% 1 year survival
- 18% new patients had analgesic nephropathy

• 2010:

35% of new dialysis patients have diabetic nephropathy

What does conservative management mean for the patient?

- Continue with all CKD measures to:
 - Slow the deterioration of renal function
 - Minimise complications of renal disease
 - Manage symptoms

Also:

- Support for carers and patients (diet, social work, psychological)
- End of life planning (choices, substitute decision maker)

How does dialysis impact the elderly patient?

- Prolong life?
- Increased hospitalisations
- Transport issues
- Some may face a decision to withdraw from dialysis
- Regret

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

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

- People with advanced CKD
 - Are elderly
 - Have co morbidities
 - Choose not to have RRTs
- People on dialysis who have symptoms
- People on dialysis or transplanted who have other terminal diseases
- Patients who are considering withdrawing from dialysis

How is supportive care provided for our patients?

Supportive care - Nursing

- Being aware of patient suffering/being patient centred
- Involving the patient and significant other in all conversations
- Links with allied health
- Being aware of both community and hospital services available to the patients
- Communication and listening skills
- Support for patients withdrawing dialysis
- Forge links to palliative care service
- Meticulous symptom management
- Advanced care planning
- End of life pathways
- Aim for a 'good death'

When do you introduce supportive care?

- Pre dialysis
- During dialysis
- When decision is made to be conservative
- Later along the conservative pathway (ESKD)
- Dialysis withdrawal
- CKD patient burdened with symptoms

Anywhere here is appropriate

Stage	Description	eGFR (ml/min/1.73 m²)
3	Moderate ↓ GFR	30-59
4	Severe ↓ GFR	15-29
5	Kidney Failure	<15 or (or dialysis)

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

- Strong links with palliative care
 - Education
 - Hospice availability
 - Clear pathways
- Nephrologist with a belief in supportive care
- Allied health available
- Clinics available to cater for conservative care or symptom management
- Good communication with other teams

Who can access this program?

All dialysis or CKD patients who have complex symptom management needs

 All conservatively managed patients who belong to a St George nephrologist

 Dialysis nurses can refer – I triage who is appropriate and liaise with nephrologist

When would you commence end of life discussions in dialysis?

- Patients who want to withdraw
- Failing PD, transplant or vascular access when change of treatment not wanted or feasible
- Sentinel event occurs
- QoL unacceptable to the patient

Decision making

- Start conversations early and in collaboration with patient and carer
- Education of health professionals GPs
- Let pt know that the decision can be revoked (within reasonable timeframe)
- Inclusion of supportive care pathway
 - in Pre Dialysis clinic discussions
 - In brochures and information resources for RRT options

• Supportive care included as part of normal renal care.

Resources required for Supportive Care

- Shared Care arrangements for Supportive care:
 - Nephrologists
 - Aged care team
 - Palliative Care team
- Supportive Care Clinic outpatients
- Supportive Care in-patient rounds
- Community Resources

Resources required for Supportive Care

- Allied health team
- Follow up dialysis patients regularly
- Ability to manage admission of patients coming directly from home or clinic
- Resource book so that other staff can cover staff holidays
- Forms on hand for everything
- Pastoral care
- Phone follow up for patients unable to visit

Supportive Care

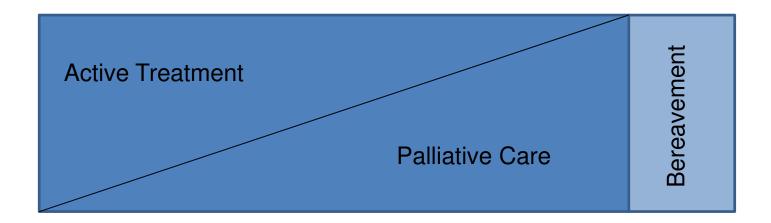
- Supportive care works with other disciplines to support the renal patient.
- We don't take over care or work alone.

How?

Patient Centred Care

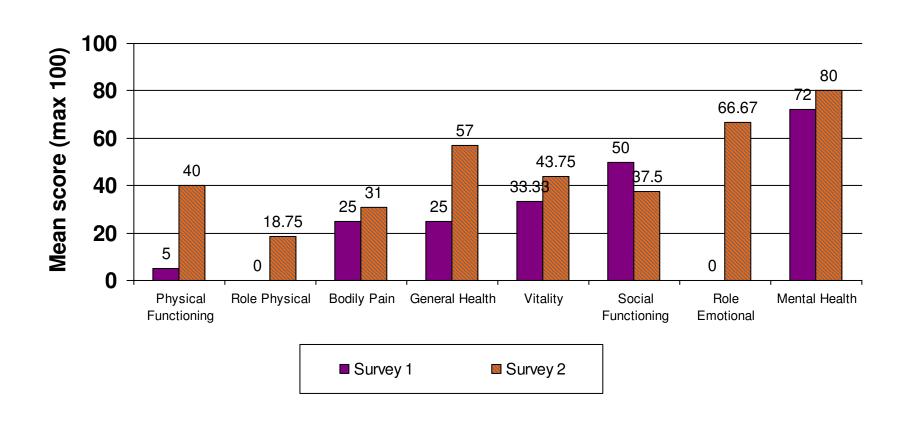
- Supports a better patient and family experience through the ESKD continuum
- Improve decision making consultations
- Improve symptoms
- Allows for a proper/dignified and recognised end of life
- Identify the needs of the patient and family
- Patients do not need to fear 'abandonment'
- Contactable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

Paradigm

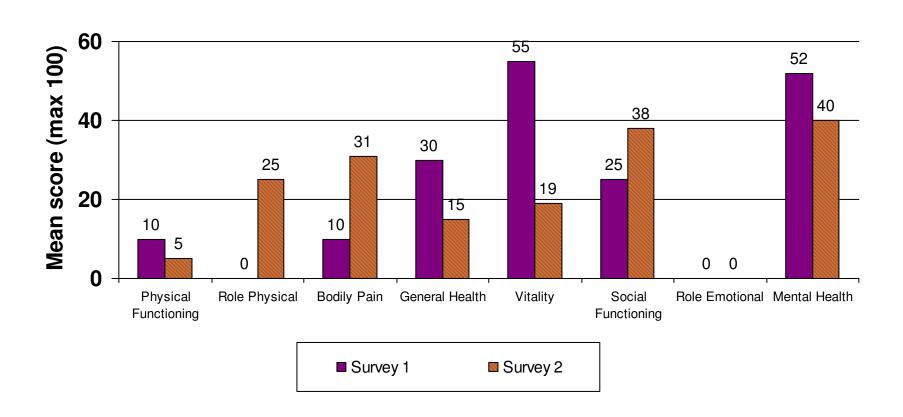


Quality of Life Case Studies

Case: 76yrs Conservative Patient – Multiple admissions. Diabetic Nephropathy



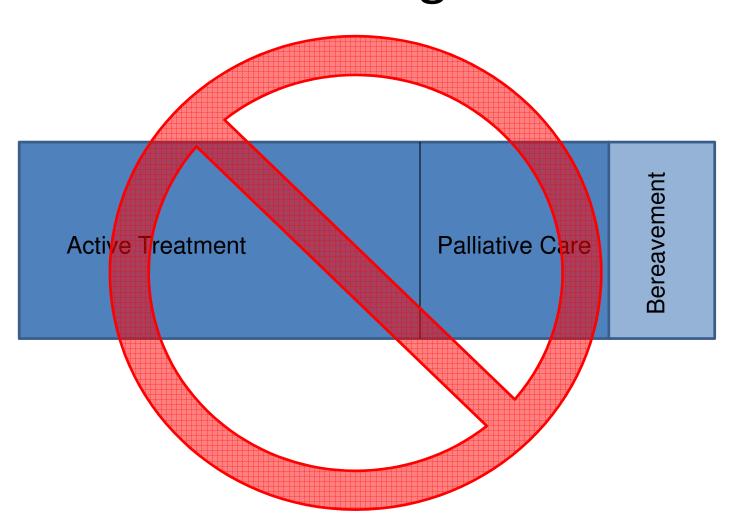
Case: 74yrs Dialysis Patient. Difficult to control OA pain



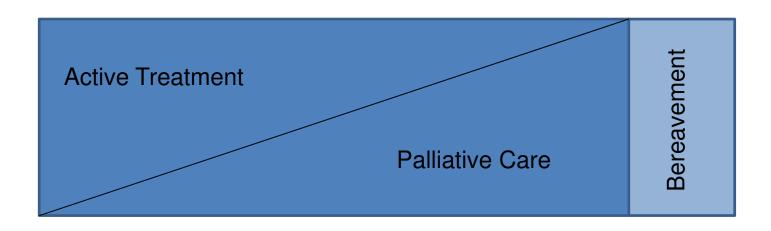
What non-dialysis patients require when presenting to hospitals unwell

- All the normal appropriate assessments
- Depending on the results of the assessments
 - Discussion with the patient and family on possible investigations/treatments and how appropriate they may be
 - Discussion with renal team whether potentially renal impairing investigations/treatments are necessary i.e. use of contrast, angiogram
 - Uphold the patient and family dignity at all times

Non-Dialysis Pathway is <u>NOT</u> this Paradigm

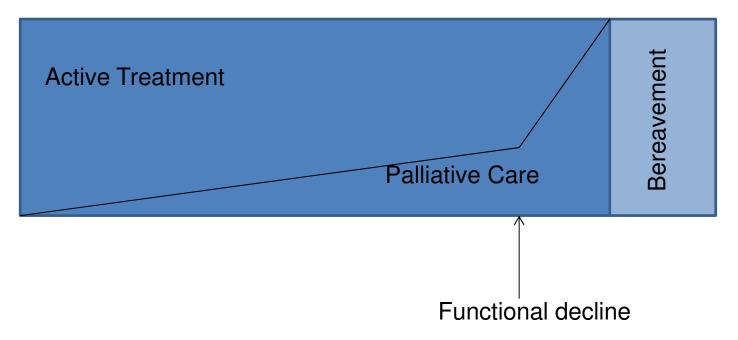


The correct non-dialysis pathway Paradigm



It may even be more like this

 As the patient deteriorates functionally, the palliative care needs increase



Conclusion

- Supportive Care Nurse provides support to the patient and carers anywhere along the CKD continuum
- Decrease distress at end of life
- Decrease symptom distress
- Listen and be available to assist/advocate
- Links to palliative care teams and others
- Educational opportunities to many interested facilities around Australia

References

- Australian Institute of Health and Welfare 2011. End Stage kidney disease in Australia: total incidence, 2003-2007. Cat. No. PHE 143. Canberra; AIHW
- ANZDATA 2011 <u>www.anzdata.org.au</u>
- Kidney Health Australia
- Chambers, J. Brown, E. Germain, M. 2010. Supportive Care for the Renal Patient. Second Edition
- Wilson IB, Cleary PD. JAMA 1995;273:59-65
- Chandna S, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood R, Farrington K. Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. Nephrology Dialysis Transplantation. 2011;26(5):1608-14.
- Brown E et al. *End of Life Care in Nephrology from Advanced Disease to Bereavement,* 2007, Oxford Specialist Handbooks, p. 280.
- The National Council for Palliative Care. (2011). Palliative Care Explained. Retrieved 04/07/2011