PSYCHOSOCIAL ASPECTS OF RENAL DISEASE

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They’ll be fine...

Don’t worry, she’s new. She’ll get the hang of it soon.
What we will cover…

- Grief and loss
- Emotional Reactions
- Sex/sexuality
- Non-Compliance
- CALD
- Quality of Life
- Working with Aboriginal communities
- Transplant
- Carers
- Mental Illness
- Advance care planning
- Therapeutic and Psychosocial Interventions
Grief and Loss - Defined

- Not just about death and dying
- Change, loss and grief
- Chronic illness and grief and loss
- Understanding grief and loss issues – Movement of theory to current approaches – e.g. continuing bonds, dual process model, beyond affect
Experiences of Grief

Disbelief, Shock

Sobbing, Crying

Physical Symptoms

Why?

Denial

Repetition

Reality of Death

Confusion

Idealization

Identification

Anxiety/Panic

(Fear of Losing Control)

Bargaining

Relief (Laughter)

Depression

Expectations

Lowered Self-Esteem

Guilt

Preoccupation

Sadness

Despair

Anger

Loneliness

Helplessness

Life is Worth Living

Struggle with New Life Patterns

Missing

Hope Emerges

Limbo

Bitterness

Resentment

Envy

Hatred

Frustration
Grief and Loss

Chronic illness can incur grief reactions
Bio - Psychosocial Effects of Renal Disease

Chronic Kidney Disease

End Stage Renal Disease

No Treatment

Initiation of Treatment

Expected Death

Delayed Expectation of Death

Bio-Psychosocial Effects

Biological Effects
* Loss of normal body function
* Physical Impairment
* Complications associated with long term dialysis therapy
* Unstable health status

Psychological Effects
* Anger
* Grief
* Anxiety
* Depression
* Fear
* Loss of self image
* Positive coping
* Perception of illness

Social Effects
* Changes in role as family member/member of society
* Others perception of illness
* Loss of dreams/aspirations/lifestyle
* Loss of choice and options
* Social isolation
* Effects on Family/work relationships
* Time commitments to dialysis

White and Brin (1999:1314)
In the later stages of the illness – focus shifts to Palliative

- Existential issues - meaning of life
- Family issues - unfinished business
- Dying process - fear of pain, loss of control/independence/integrity
Issues of Change

- Family Roles
  - Routine
  - Roles may change

- Social Roles
• Physical and lifestyle changes – diet
Some emotional reactions may be caused by kidney failure itself. Build up of waste products can cause changes in behaviour including irritability, edginess, moodiness, memory loss, depression and anger. This can be temporary.

N.B.
- Cannot assume people will emotionally react the same
- People may experience different emotions at any time
Living with ESRD

- **Main fears**
  - fear of: being a burden/separation/welfare of loved ones/painful death

- **Predictors of emotional adjustment**
Sex/Sexuality

- Men and women on dialysis may undergo changes in their sexual functioning
- Diminished sexual functioning and sexual interest is common in both sexes
- This can impact on current or future relationships
- With emphasis on sexuality this can be devastating to one’s self esteem
Sex/Sexuality cont...

- **Causes**
  - Physical and Psychological.

  - **1. Physical**
Sex/Sexuality cont...

- 2. Psychological

- Relationships/ Sexual functioning
  - Can affect interpersonal relationships due to emotional changes
  - Change in sexual functioning due to dialysis – diminished interest in sexual activities.
Kidney failure brings about a lot of change and adjustments into the person's life. This not only affects the person but also their family and friends.
Older Adults
Life stages have been said to have a significant bearing on adjustment to renal disease:

- This may apply to some, but cannot be generalised to all the older adult with renal disease.
Non - Compliance
CALD

- Other Stressors
- Culture
- Religious/spiritual beliefs
Culture

- Culture affects the ways we look at dying, death, loss and grief
- Every culture approaches loss differently
- ‘What do I need to know about your culture to understand you more effectively?’
Quality of Life

- It is mediated by one’s personal and cultural values and beliefs, self concept, goals and life experiences.
- Predictors include symptom management, pain, attention to psychosocial and spiritual needs.
- It includes:
  a) Health and physical functioning
  b) Psychological and spiritual functioning
  c) Socio-economic function
  d) Family relationships
Transplants

- The hope of a transplant:

Connie was so proud of her new kidney that she invited everybody to watch her newfound function.

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Transplants cont...

- Cadaver Donations
  - Stress of long waiting lists
  - Frustrations of waiting

- Living Related Donor
  - Psychological difficulties for both the donor and the recipient
Family relationships

- Role re-reversals

- A psychological process of accepting the transplanted kidney as part of self
Carers

- Experience a range of emotions
- Change of role
- Guilt is not uncommon.
- Expectation to remain the strong supportive role.
Recent studies (Pereira, Kimmel, Watnick 2004)

Watnick et al (2003) 44% of pts in the early stages off dialysis met the criteria for depression

Prescott (2006) states that dialysis pts prefer to seek and receive treatment for depression for some mental illnesses (depression) from their dialysis social worker.

“The trust and relationship established with their nephrology social worker appears to improve the odds they will seek needed treatment when compared to services available from a mental health provider in the community” (Prescott, 2006, p.33)
Guzman (2003) reports that although ‘distress’ is a universal experience in patients with ESRD from time to time, depression occurs in up to 40% of ESRD patients.

Depression is not a “normal” condition for dialysis patients. It is a serious co-morbid illness that calls for treatment. If treated effectively is likely to improve treatment outcomes.
Therapeutic Interventions

- Cognitive Behaviour Therapy
- Solutions focused
- Systems
- Crisis Intervention
- Client focused
- Grief and Loss
Systems

Physical

Spiritual

Social

Intellectual

Psychological
Grief therapeutic approaches

- Grief is unique to all

- A diverse approach
Working with Aboriginal communities

- Be aware and respectful of relevant extended family and kinship structures when working with Aboriginal people. Ensure that extended family is included in important meetings and in making important decisions.

- Think about the language used (written, verbal and non-verbal) when communicating with Aboriginal people. Respect the use of silence and don’t mistake it for misunderstanding a topic or issue.

- Always consult with Aboriginal staff/people if unsure.
Advance care planning

- Facilitates patient autonomy
- Consideration of patient preferences in different contexts throughout illness
- Appointment of substitute decision maker and defining person responsible
- Ongoing open dialogue with all health professionals in patient care facilitated by nephrologists.
Psychosocial Interventions

- Goals
  - Decrease isolation, helplessness and hopelessness
  - Reduce anxiety about treatments
  - Assist in clarifying misperceptions and misinformation
  - Increased sense of control over well-being
Psychosocial Interventions

- **Components**
  - Information and education
  - Coping skills (e.g., relaxation, problem-solving)
  - Emotional support + supportive counseling
  - Psychological therapy
  - Risk assessments and liaison with psychiatry as appropriate
What can we all do?

- Education about common reactions
- Normalize and validate feelings
- Encourage expression of feelings
- Encourage self-care behaviours
- Encourage pt to enlist social support
- Provide information to pt and family
- Make appropriate and timely referral
Web resources

- Human Services network - www.hsnet.nsw.gov.au
- Palliative care - www.caresearch.com.au
- www.kidney.org.au
“The greatest mistake in the treatment of diseases is that there are physicians for the body and physicians for the soul, although the two cannot be separated.”

~Plato

…and then renal palliative care came along.