Dialysis and the Family: The role of the Psychologist

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Objectives

• Objective #1: Understand what psychologists can do and how they can help.

• Objective #2: Explain why psychology is important and what outcomes may be impacted.

• Objective #3: Identify common presenting concerns that psychologists can address and recommendations for management.
Psychologist: What does that mean?

• Psychology:
  – Scientific study of the mind and behavior

• *Pediatric Health Psychology*:
  – “An interdisciplinary field addressing physical, cognitive, social, and emotional functioning and development as related to health and illness issues in children, adolescents, and families”  
    (APA, 1999)
Psychologists: What can they do?

• Role on a medical team:
  – Consultation and referrals
  – Education
  – Clinical

• Role with families:
  – Liaison with medical team
  – Evidence-based Assessment
  – Evidence-based Therapy
  – Education
Why does psychology matter?
Link between Psychology and Medical Outcomes

• Depression
  – Half of patients (ages 9-15) diagnosed with depression or adjustment with depressed mood (Bakr et al., 2007)
  – Poorer adherence for patients who are depressed

• Anxiety
  – Increased worry and separation anxiety, avoidance of being alone (Park et al., 2012; Fukunishi et al., 1995; Brownbridge et al., 1991)
  – Anxiety, not depression, higher for those on dialysis compared to kidney transplant (Park et al., 2012; Fukunishi et al., 1995; Brownbridge et al., 1991)
  – Indirect associations with medical outcomes
Why does psychology matter?
Link between Psychology and Medical Outcomes

• Adherence
  – Non-adherence is a primary cause of kidney, heart, and liver transplant failure in adolescents (Schwartz & Axelrad, 2015)
  – Nonadherence to fluid and dietary restrictions associated with complications

• Quality of Life
  – Pediatric patients with ESRD- decreased HRQOL
  – Poorer QOL associated with poorer health outcomes
Helping the Patient
Common Psychosocial Issues

• Common concerns:
  – Adjustment and coping
  – Mood (Depression, Anxiety)
  – Behavior
  – Adherence
  – Academic performance
  – Disclosure of health info
  – Bullying
  – Self-image, self-esteem

• Other concerns:
  – Needle phobia
  – Social skills
  – Substance use
  – Communication skills training
  – Romantic relationships
  – Palliative care
Adjustment

• Adjustment Disorder:
  – is an abnormal and excessive reaction to an identifiable life stressor…more severe than would normally be expected … significant impairment in…functioning. (DSM-5)

• Up to three-fold increase in adjustment problems
• ~30% adjustment disorder at diagnosis of some illnesses (e.g., diabetes, cancer)
  • Typically resolves (Kazak, 2006)
• 1/3 hemodialysis patients dx with Adjustment d/o (Bakr et al., 2007)

• TO DO: Screening/Intakes with newly diagnosed families
Adherence

• What is adherence?
  – The extent to which a person’s behavior—taking medication, following a diet, or making healthy lifestyle changes—corresponds with agreed-upon recommendations from a health-care provider (World Health Organization, 2003)

  • Behaviors – targets to improve adherence

  • “Extent”- a continuum; adherence is not dichotomous
    – Adherence to certain parts of the regimen and not others
    – Usually a patient is at least “partially adherent”

  • Coincide with medical advice…what is the “standard?”
    – 80% or more has been frequently quoted standard
Nonadherence

• Largest single cause of treatment failure (Schwartz & Axelrad, 2015)

• Renal patients:
  – 32.5% transplant patients were nonadherent to regimen (Shaw et al., 2003)
  – APD adherence is 55% (Chua & Warady, 2011)

• Associated with significant morbidity/mortality
  – Graft failure, ED visits, Hospitalizations

• Estimated Cost: >$300 billion/year (DiMatteo, 2004)

• TO DO: Minimize regimen, referrals to team members
Quality of Life

• Health-related quality of life: “..aspects of overall quality of life that can be clearly shown to affect health—either physical or mental.” (CDC)

• PedsQL – measurement of HRQOL
  - Generic Core survey, ESRD specific, Transplant specific
  - Parent proxy and child self-report
  - Dialysis QOL typically lower than Transplant QOL
  - Parent and Child report were significantly lower than Healthy controls, often lower than other illness groups

• TO DO: Ongoing assessment and refer to team
Behavior Problems

• 1/4 of pediatric dialysis patients exhibited clinically significant externalizing problems compared to only 5% of the pre-dialysis group (Amr et al., 2009).

• Higher rates of behavior problems among children receiving hospital-based dialysis compared to dialysis in the home (Brownbridge & Fielding, 1991).

• Also some mixed evidence- some studies don’t show differences between those on dialysis and healthy controls.

• TO DO: Ongoing monitoring, rewards, referrals to team
Internalizing Problems

- Greater depression and anxiety symptoms in pediatric dialysis patients compared to healthy controls
- High rates of depressive and anxious symptomatology have been reported in children undergoing dialysis (Bakr et al., 2007).
- Pediatric dialysis patients (ages 9-15) - nearly half were diagnosed with depression or adjustment disorder with depression (Bakr et al., 2007).
- Increased worry and depressive sx$s in pts undergoing in-hospital dialysis compared to home

TO DO: Ongoing screening, referrals to Psychology
Neurocognitive Effects of CKD/ESRD

• Pediatric dialysis patients lose up to 60% of their school contact time (Watson, 2014; Fukunishi et al., 1993)

• All dialysis pts performed below grade level, while all transplant pts performed at or above grade level. Groups did NOT differ in school absences (Lawry, Brouhard, & Cunningham, 1994).

• Cognitive functioning did not differ based on modality; may be the ESRD that is associated with risk (Brouhard et al., 2000)

• Cognitive impairment for patients on dialysis (Neu et al., 2012) and patients with CKD compared to healthy controls (Bawden et al., 2004)

• TO DO: Referral for Neuropsychological evaluation
Considerations for Parents/Guardians

• Additional **roles** for parents:
  – Health-care provider, problem-solving, information seeking, and financial and practical skills (Tong et. al, 2008)

• Themes from research on Caregiver Experience (Wightman et al., 2019)
  – Caregiver medicalization (diagnosis, disease management)
  – Emotional adjustment (acute phase, acceptance, growth)
  – Pragmatic adaptation (disruption, adapt life goals)
  – Social adjustment (relationship opportunity and risk, family functioning)

• **TO DO:** Refer families to mental health providers and facilitate family connections
Considerations for Siblings

• Wide range of typical emotional responses:
  – Worry
  – Fear
  – Sadness
  – Confusion or lack of understanding
  – Jealousy

• Behavioral outbursts or changes

• TO DO: Check in with parents and offer referrals
Recommendations
Recommendations

• Ideal:
  – Initial screening/assessment of baseline functioning via Diagnostic Intake and Neuropsychological evaluation
  – Triage families based on screening
  – Annual screening of QOL, depression, and anxiety
  – Include various multidisciplinary team members
  – Ongoing inquiry about family functioning

• Realistic:
  – Refer for Intake or Neuropsych when indicated
  – Annual screening of QOL and depression
  – Utilize multidisciplinary team for treatment
Summary
Summary

- Pediatric Health Psychology focuses on health and illness issues in youth.
- Psychologists can help with coping, adjustment, adherence, etc.
- There is a link between psychosocial concerns and medical outcomes.
- Children on dialysis can struggle with internalizing, externalizing, academic, and social functioning.
- Families are also impacted and need consideration.
- Utilize the multidisciplinary team.
Thank You!