





Common Psychosocial Issues Associated with Disease Specific Camping

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Acknowledgments

- Special thanks to Dr. Courtney Zimmerman, Licensed Psychologist for Texas Children's Hospital Renal Service

Disclosures

- None



Why Camp?

- Play
 - Play is **essential to development** because it contributes to the cognitive, physical, social, and emotional well-being of children and youth. (Zinsburg, KR, 2007)
 - Play assists in developing the skills required for **managing toxic stress**. (Froehner M, Guehr A, Hochstadt J, et al., 2013)
- Opportunities for interaction, observation, and informal assessment outside of medical setting
- Increased Health Related Quality of Life
 - Peer-to-peer support camp for children with ESRD (including some dialysis patients) has been shown to **increase self-confidence and self-efficacy**. Camp participants also reported **feeling more capable of standing up for themselves and being open with their peers** after attending camp. (Silva, JN, Johnson S, van Dijk A, 2012)





Quality of Life

- Definition: Health-related quality of life: "...aspects of overall quality of life that can be clearly shown to affect health—either physical or mental." (CDC)
 - Physical, Emotional, Social, and School domains
- Clearly linked to health outcomes:
 - Lower QOL (KDQOL) associated with increased hospitalizations and mortality among adults on dialysis (Manns et al., 2003)
- Associated with cost burden:
 - Parent-proxy report (PedsQL) predicts pediatric healthcare costs (Said, Varni, Smith & Taylor, 2004)
 - Improvements in HRQOL (PedsQL) resulted in lower Medicaid costs (Wicks & Guo, 2010)



Camp Specifics

- Camp YOLO (You Only Live Once)
 - Bi-annual weekend camp for chronically ill teens and their siblings
 - Texas
- Camp Aranzazu
 - Annual weekend camp for young adult renal patients (18 years and older)
 - Texas
- Camp Okawehna
 - Annual week long camp for school-aged renal patients
 - Tennessee



Psychosocial Issues

- Medication Burden
- Physical Insecurities
- Diet Challenges
- Sleep Challenges
- Social Interactions
- Normalization
- Mood and Behavior Issues
- Caregiver Respite



Medication Burden

- Adherence
 - The daily pill burden in adult dialysis patients is **one of the highest reported to date in any chronic disease state** (Chiu et al., 2009)
 - Rates of nonadherence in pediatric transplantation have been reported to be as low as 3% and as high as 71%, with the **highest incidence of nonadherence reported among adolescent kidney transplant patients** (Shellmer, Dabbs, & Dew, 2011)
- Affects the Patient and Family
 - Staff appreciation for patient and family burden when monitoring medications at camp
- Dose changes
 - Medication reconciliation prior to departure
- Sensory Challenges
 - Taste, Smell, Texture
 - Affects adherence



Diet Challenges

- Normalization and adherence
- Camp food provides renal diet friendly **choices**
- New foods
- Lack of Appetite
- Fluids
 - Dialysis vs. Transplant
 - Staff ability to assist with adherence monitoring



Social Interactions

- Camps "offer children with CKD, ESRD, or a kidney transplant the chance to come together for a typical camp experience while also **enjoying the fellowship of those who know exactly what it means** to be a child living with kidney disease" (Hesselt, 2013)
- Peer support
 - Education - patients learn about various modalities from other patients
 - Normalization
 - Social isolation identified as common issue
- Interactions with Staff
 - Power differential - doctors and nurses may seem more approachable in this setting and this may generalize to when patients return home
 - Provides unique perspective for staff (Woraby et al., 1992)
- Cabins
- Dialysis
- Group Activities



Mood and Behavior Issues

- Presence of chronic diseases during childhood and adolescence considerably **increases the risk of emotional disorders and those of behavior** (Holden, et al., 1997)
- Pediatric dialysis patients (ages 9-15), **nearly half were diagnosed with depression or adjustment disorder with depression** (Bakr et al., 2007)
- 1/4 of pediatric dialysis patients exhibited **clinically significant externalizing problems** (Amr et al., 2009)
- Opportunities to observe mood concerns
 - Withdrawal, sadness, irritability
 - Worry
- Opportunities for behavior management by staff
 - Tantrums
 - Limit Setting



Physical Insecurities

- Changes associated with the medical condition and treatment can **take a toll on children's self-esteem** (Assadi, 2013)
- Self-esteem changes
 - Observe how others manage physical-related aspects of disease
 - Normalization
- Scars
- Size
- Fistula
- Catheter
- G-Button
- Medication Side Effects



Sleep Challenges

- Night Terrors
- Incontinence
- Insomnia



Normalization

- Friendships
- Romantic Relationships
- Arguments
- Nervousness
- Individual Successes
- Winning/Losing
- Homesickness



Caregiver Respite

- Impact of chronic illness **extends to family members** as well as the patient (Gibler, 2008)
- Tong et al. (2010) has posited parents would benefit from regular respite programming to provide relief from the "consuming routine of managing their child's dialysis."
- Very few opportunities for caregivers of patients on dialysis to have a respite, particularly for a full week!
- Time for caregivers to engage in self-care and recharge
- Reconnect with siblings of patients



Summary

- Camp provides unique opportunities for observation, assessment, and growth in areas of psychosocial development



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