

Fundamentals for Families: Transition to Adult Care

Rebecca Johnson, PhD, ABPP

Associate Division Director – Psychology

Division of Developmental and Behavioral Health

Children's Mercy Kansas City

My role:

- Pediatric psychologist with dedicated time to the dialysis and transplant program
- See primarily youth on dialysis or with kidney transplant, sometimes with CKD stage 3-4
- Function as part of the interdisciplinary team
- Accept referrals to psychology clinic, but also see patients in the Kidney Center, dialysis unit, and on inpatient units
 - Tailor my practice to needs of patients
 - Increase patient access

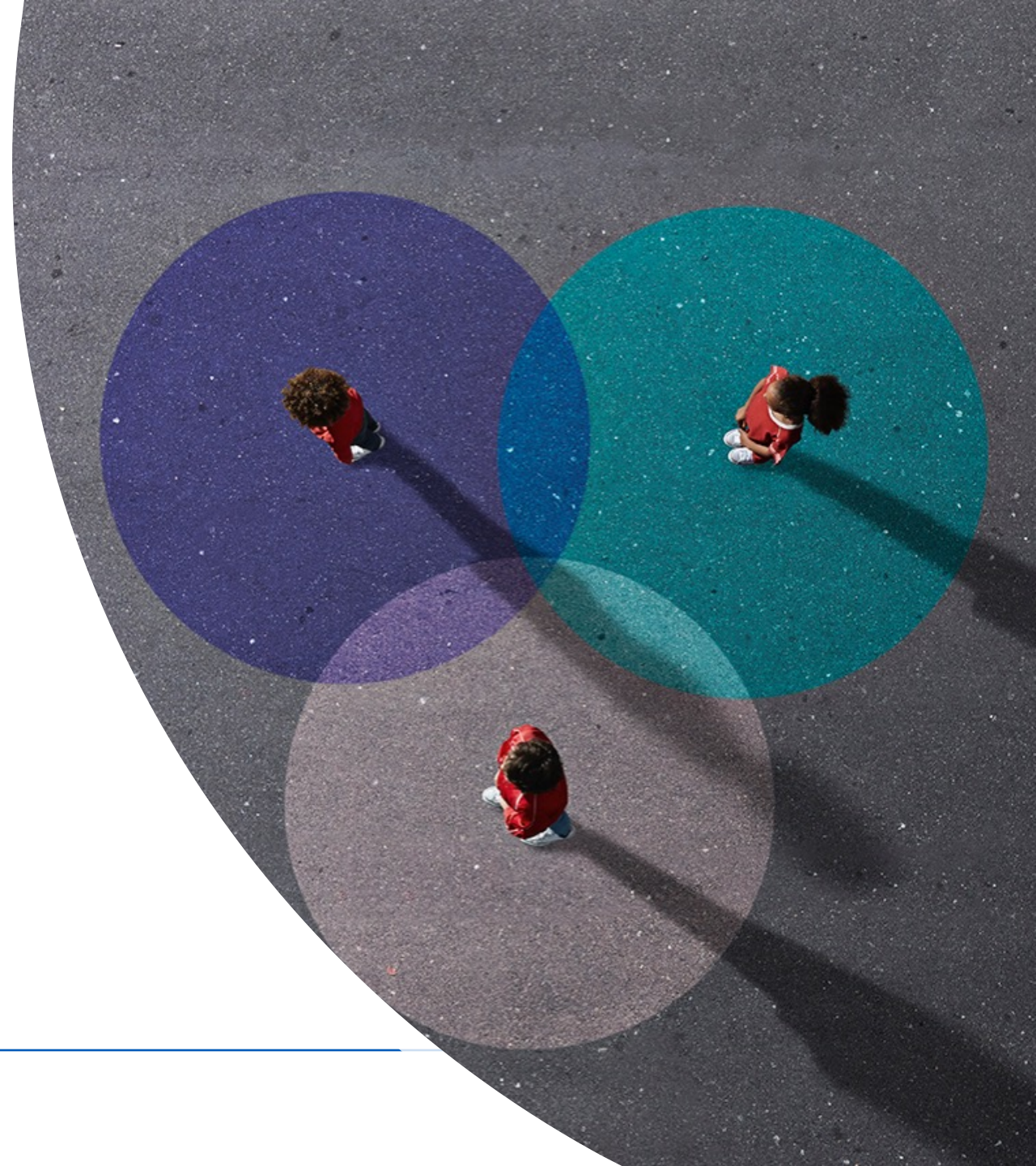
What I treat:

- Nonadherence
- Coping/adjustment
- Depression
- Anxiety
- Suicidal ideation/behavior
- Attention/Learning
- Disruptive behavior
- Behavioral health concerns
- Trauma/medical trauma



Treatment approach in pediatric psychology

- Intersection of patient, caregivers, medical team
- Treatment within the context of development



Unique period of development

- AYA developmental period is socially, physically, and neurologically unique
- Changes are occurring across all domains of life:
 - Establishing autonomy from family of origin
 - Transition to living independently
 - Working toward financial independence
 - Primacy of peer relationships
 - Initiating or advancing romantic relationships

Devine et al., 2017

Risky period of development . . .

- 75% of mental/behavioral health disorders emerge before age 24
- Risk-taking behavior increases
 - Some behaviors have potential for long-term health-related or social consequences
- For AYA with chronic health conditions, transition from pediatric to adult health care
- Transition/transfer of AYA is associated with:
 - Worsening disease/symptoms
 - Decreased adherence
 - Increased healthcare utilization (e.g., hospital admissions, ED utilization)
 - Delays in receiving appropriate medical care
 - Loss to follow-up

Kessler et al., 2005; Devine et al., 2017; Pai et al., 2011; McGrady et al., 2013; Campagna et al., 2020; Annunziato et al., 2011; Garvey et al., 2022



AYA in general . . .

- Frontal lobe fully matures during the 3rd decade of life
- Adolescent and young adult brain is more vulnerable to stress and substances
- Potential for competent decision-making often greater than performance in real-world situations
- Real world presents time-limited, dynamic, and personally stressful cognitive challenges
- While potential is there, sophistication and consistency often are not

7

Feldman & Elliott, 2011; DiClemente et al., 1996

AYA with CKD . . .

- Higher rates of mental/behavioral health disorders
- Developmental differences/delays
- Higher rates of deficits in executive functions
 - Needed for organizing tasks, remembering details, managing time, solving problems
- Depending on disease course, fewer opportunities for cognitive and social development
 - School and social situations are where adolescents learn to navigate relationships and solve problems

Despite all this . . .

- AYA are underrepresented in medical and behavioral health research
- Treated in settings that are tailored to either children or middle/older age adults
 - AYA warrant their own system of care
 - This exists to some extent in cancer care
- Many transition readiness programs or initiatives focus on the individual, not relationships or systems



Psychologist Perspective

- Sheer complexity of adult health care
 - Information
 - Complex social interactions
 - System is difficult to navigate
- Inadequate attention to grief/loss associated with transition
 - Navigating end of relationships
 - Loss of the familiar
 - “I just don’t want to start over”
- Fewer mental/behavioral health resources
- Lack of a developmentally appropriate system of care sets AYA up to fail
- AYA warrant their own unique system of care



Thank you!

