Medical complexity and placement outcomes for children in foster care

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Objective: Medical complexity threatens placement stability and permanency outcomes for children in foster care (FC). This study aimed to characterize for US children in FC: 1) medical complexity, using number of diagnosed types of disability as a proxy; 2) demographic and removal characteristics based on level of complexity; and 3) whether increasing levels of complexity were associated with foster care placement outcomes.

Methods: The analysis included children in FC, ages 0–21 whose disability status was clinically assessed and documented (n = 538,695). Using data from the FY 2014 Adoption and Foster Care Analysis and Reporting System, medical complexity was categorized (0–4+) based on 5 disability types: emotional, hearing/vision, intellectual, physical, and other. Bivariate analyses (χ² tests, Kruskall-Wallis) compared the distribution of demographic and removal characteristics among complexity groups. Multiple logistic regression evaluated relationships between medical complexity and placement outcomes, including length of stay in FC, placement stability, and permanency.

Results: Twenty-three percent of the sample had 1 disability type, 7% had 2, 3% had 3, 1% had 4+, and 67% had no disability. Children with increasing complexity were more likely to be older, older on FC entry, male, Black, non-Hispanic, placed in a group home or institution, have abuse, neglect, and/or child disability/behavior as reason for removal, and have poor placement outcomes.

Conclusion: Children in FC with greater medical complexity are at risk for undesirable placement outcomes. By recognizing and addressing the unique needs of this vulnerable population, pediatric providers and child welfare staff may identify strategies to improve placement outcomes.

1. Introduction

On any given day in the United States, nearly 430,000 children are in foster care (Children's Bureau, 2016b) and many have been exposed to social risk factors that influence pediatric health disparities, including poverty, single parent homes, maternal mental health concerns, minority race/ethnicity, and violence (Larson, Russ, Crall, & Halfon, 2008; Stein, Siegel, & Bauman, 2010). Children in foster care utilize a disproportionate amount of health services (Becker, Jordan, & Larsen, 2006; Jee & Simms, 2006; Knight, McDuffie, Gifford, & Zorc, 2016). The American Academy of Pediatrics (AAP) classifies children in foster care as a population of children with special health care needs (CSHCN) based on their high prevalence of health problems and unmet health-care needs (Szilagyi, Rosen, Rubin, et al., 2015).

CSHCN is a broad definition that includes children “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson, Arango, Fox, et al., 1998). Within the broader category of CSHCN is a subgroup of children known as children with medical complexity (CMC), who have the most intensive health care needs and are particularly fragile (Cohen, Kuo, Agrawal, et al., 2011). Cohen et al. defines CMC based on 4 domains—substantial health care service needs, at least 1 chronic condition that is severe and/or associated with medical fragility, functional limitations, and high health care utilization (Cohen et al., 2011). The population of CMC is growing, in part due to advances in neonatal and critical care medicine, technology, and nutrition (Burns et al., 2010). For some CMC, their
biological parents are unable to provide the intensive level of care required and they enter the child welfare system (Seltzer, Henderson, & Boss, 2016).

Child welfare agencies provide services to oversee safe placements, and strive to achieve safety, well-being, stability, and permanency for every child in foster care (Children’s Bureau; Children’s Bureau, 2012a).

Placement stability, defined by the Department of Health and Human Services (DHHS) as 2 or fewer different placements within a foster care removal period (Children’s Bureau, 2016a), is an important outcome in child welfare. Placement stability supports development of attachments with caregivers and reduces child stress and behavioral and academic achievement problems (Carnochan, Moore, & Austin, 2013). In contrast, placement instability is associated with attachment disorders and behavior problems (Carnochan et al., 2013; Rubin, O’Reilly, Luan, & Localio, 2007), creating additional barriers to successful placements. Placement instability can exacerbate existing behavioral problems and lead to new behavior problems (Carnochan et al., 2013; Newton, Litrownik, & Landsverk, 2000; Rubin et al., 2007). One study found that children who failed to achieve placement stability, compared to those who achieved stability in foster care, had a 36–63% increased risk of behavioral problems (Rubin et al., 2007). Former foster youth describe placement moves as experiences of profound loss and resultant challenges with trusting others and managing interpersonal relationships (Unrau, Seita, & Putney, 2008).

To facilitate permanent placements, child welfare teams establish plans for achieving case goals; the preferred and most common goal is reunification with the child’s biological parent(s). When reunification is not feasible, the goal is to place the child in another legally permanent family—with relatives, through adoption, or through guardianship (Children’s Bureau). In 2014, over 20,000 children “aged out” of the foster care system without ever achieving permanency (Children’s Bureau, 2015).

CMC in foster care are a particularly vulnerable population due to their concurrent medical risks and social risks, a combination shown to result in higher healthcare utilization and poorer health outcomes than either risk alone (Stein et al., 2010). Yet, very little is known about this population. Thirty percent of children in foster care have at least 1 chronic condition (Jee et al., 2006; Szilagyi et al., 2015), but existing child welfare databases do not typically collect the level of health information needed to categorize children in foster care by level of medical complexity. As such, systematic data about child welfare and health outcomes for CMC in foster care are lacking because this group of children is not readily identifiable (Williams, Seltzer, & Boss, 2017).

Existing databases do report disability status and prior studies have shown that having a disability is a barrier to permanency and associated with other poor outcomes (Children’s Bureau, 2016a; Hill, 2012; Lockwood, Friedman, & Christian, 2015; Slayter, 2016a; Slayter, 2016b). Children with disabilities experience higher rates of maltreatment and are disproportionately represented in the child welfare system (Lightfoot, 2014). Studies have shown that foster youth with disabilities, compared to those without disabilities, have longer lengths of stay in foster care, are less likely to be reunified with their parents or achieve permanency, have higher rates of placement and adoption disruptions, perform worse academically, and receive lesser quality services (Geenen & Powers, 2006; Hill, 2012; Lightfoot, 2014; Romney, Litrownik, Newton, & Lau, 2006; Slayter, 2016a; Steen & Harlow, 2012). In 2013, only 79% of children with a diagnosed disability achieved permanency when exiting foster care, compared to 89% of all children exiting foster care (Children’s Bureau, 2016a). Yet, simply reporting presence or absence of disability does not provide meaningful information regarding the severity or complexity of a child’s health problems, which may differentially impact placement and permanency.

Better understanding how medical complexity relates to child welfare outcomes could allow health care providers and other professionals working with children in foster care to identify a population at risk for poor outcomes and target resources and strategies to better address their unique needs. The objectives of this study were to characterize for US children in foster care: 1) medical complexity, using number of diagnosed types of disability as a proxy; 2) demographic and removal characteristics based on level of complexity; and 3) whether increasing levels of complexity were associated with foster care placement outcomes, including length of stay (LOS) in foster care, placement stability, and permanency.

2. Methods

2.1. Study design and data source

A secondary analysis of data from the Fiscal Year 2014 Adoption and Foster Care Analysis and Reporting System (AFCARS) Foster Care File was conducted (Children’s Bureau, 2014). AFCARS, a federally mandated reporting system, collects case-level information on every child served by state or tribal Title IV-E agencies that provide adoption or foster care services (Children’s Bureau, 2017). The Children’s Bureau, DHHS, oversees AFCARS. Data were de-identified and publically available through the National Data Archive on Child Abuse and Neglect (Children’s Bureau, 2014). The Johns Hopkins Institutional Review Board approved this study. Individuals in the AFCARS database were included if they were 21 years of age or younger, and their disability status was clinically assessed and documented.

2.2. Measures

2.2.1. Primary independent variable: Medical complexity score

AFCARS codes for 5 different disability types but does not have specific variables for medical complexity. The primary independent variable, medical complexity score, was derived from the disability coding. Medical complexity was categorized from 0 to 4 + (no diagnosed disability to most complex) based on the number of 5 disability types coded in the database: emotional, visual/hearing, intellectual, physical, and other (Table 1).

While disability and medical complexity are not equivalent terms, they have many overlapping features; disability is the closest proxy to medical complexity available in AFCARS. The Americans with Disabilities Act states that an individual with a disability “is a person who has a physical or mental impairment that substantially limits one or more major life activities” (US Department of Justice, 2009). The terminology used to define disabilities in AFCARS (Table 1) includes functional limitations, chronicity, and severity, which overlaps with Cohen’s domains of medical complexity (Cohen et al., 2011). While not specifically included in the definitions, the two other domains for medical complexity—higher healthcare utilization and service needs—relate to children in foster care in general (Becker et al., 2006; Jee & Simms, 2006; Knight et al., 2016), but likely are even more pronounced for children with disabilities.

State welfare agencies report whether a qualified professional has clinically assessed the child and diagnosed a disability. Agencies are instructed to code all diagnosed disability types for each child in their care. “Not yet determined” for clinical disability indicates that a clinical assessment has not yet been conducted. Only children who were clinically assessed were included in this analysis.

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2.2.2. Dependent variables: Placement outcomes

Placement outcomes included LOS in foster care, placement stability, and permanency case goal. DHHS outcome measure definitions for extended length of stay (> 24 months) and placement stability (2 or fewer placement settings within a single foster care removal period) were used for this analysis (Children’s Bureau, 2016a). LOS in foster care (in days) was converted to a binary outcome with a cut-point of 24 months (730 days). For this analysis, number of placement settings was dichotomized to 2 or fewer vs. > 2 placements (instability). Based on AFCARS guidelines, trial home visits are not counted towards
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