Employment and Leave While Parenting Children with Medical Complexity

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Children with medical complexity (CMC) require frequent medical care and are at risk of recurrent hospitalizations. The Family Medical Leave Act (FMLA) allows some workers to take unpaid leave from work to care for family members. This study examines caregiving obligations of parents of CMC, the availability and appropriateness of FMLA in facilitating their roles as caregivers and employees, and how these challenges affect employment and financial security. Parents of CMC were recruited from a primary care pediatric care management program for semistructured interviews. An integrated approach, using both deductive and inductive codes, was used to conduct a thematic analysis. All 16 respondents were female, with half working full-time, five working part-time, and three not employed at the time of participation. On average, their CMC experienced 1.8 hospitalizations in the prior 12 months. Parents described that caring for CMC required ongoing and unpredictable time commitments that conflicted with job duties and schedules. This conflict led to frequent employment changes that negatively impacted parents' eligibility for FMLA, their financial health, and their own well-being. Parents often described not having access to FMLA due to exhausting the allotted time, part-time status, insufficient tenure at their job, or the inability to take unpaid leave. Parents depended on informal workplace policies and relationships with supervisors to maintain employment, as well as personal and formal supports to care for CMC and their families' financial stability. Parents want and need to work in order to support their families and pay for the added expenses related to care for their CMC. Remaining active in the workforce requires that they have flexible schedules that accommodate their unpredictable and ongoing caregiving responsibilities. The eligibility criteria and unpaid nature of FMLA, however, make employment and financial stability elusive for caregivers of CMC.

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