Employment, Family Leave, and Parents of Newborns or Seriously Ill Children

Paul J. Chung, MD, MS; Camillia K. Lui, MPH, MA; Burton O. Cowgill, PhD; Geoffrey Hoffman, MPH; Jacinta Elijah, BA; Mark A. Schuster, MD, PhD

From the Department of Pediatrics (Dr. Chung), David Geffen School of Medicine and Mattel Children's Hospital at UCLA, Los Angeles; Departments of Health Services (Dr. Chung and Mr Hoffman) and Community Health Sciences (Ms Lui), and Division of Cancer Prevention and Control Research (Dr. Cowgill and Ms Elijah), UCLA School of Public Health, Los Angeles; RAND Health (Drs. Chung and Schuster), RAND Corporation, Santa Monica, Calif; Division of General Pediatrics, Department of Medicine (Dr. Schuster), Children's Hospital Boston; and Department of Pediatrics (Dr. Schuster), Harvard Medical School, Boston, Mass
Address correspondence to Paul J. Chung, MD, MS, UCLA/RAND Prevention Research Center, 10960 Wilshire Blvd, Suite 1550, Los Angeles, CA 90024 (e-mail: paulchung@mednet.ucla.edu).
Received for publication April 29, 2011; accepted February 18, 2012.

Abstract

Objectives: Parents of newborns and children with special health care needs (CSHCN) often experience conflict between employment and family responsibilities. Family leave benefits such as the federal Family and Medical Leave Act and California's Paid Family Leave Insurance program help employed parents miss work to bond with a newborn or care for an ill child. The use of these benefits, however, is rare among mothers of CSHCN and fathers in general and limited even among mothers of newborns. We explored barriers to and experiences with leave-taking among parents of newborns and CSHCN.

Methods: We conducted semistructured qualitative interviews in 2008 with 10 mothers and 10 fathers of newborns and 10 mothers and 10 fathers of CSHCN in Los Angeles to explore their need for and experiences with family leave. Qualitative analytical techniques were used to identify themes in the transcripts.

Results: All parents reported difficulties in accessing and using benefits, including lack of knowledge by employers, complexity of rules and processes, and inadequacy of the benefits themselves. Parents of CSHCN also described being too overwhelmed to rapidly seek and process information in the setting of urgent and often unexpected health crises. Most parents expressed a clear desire for expert guidance and saw hospitals and clinics as potentially important providers.

Conclusions: Even when parents are aware of family leave options, substantial barriers prevent many, especially parents of CSHCN, from learning about or applying for benefits. Clinics and hospitals might be opportune settings to reach vulnerable parents at times of need.

Keywords: chronic disease; family leave; newborn infant; parents

Academic Pediatrics 2012;12:181–188

What's New

Employed parents of newborns or CSHCN experience both enormous need for leave and enormous barriers to leave-taking related to lack of time, information, benefits, and guidance. Parents view healthcare providers as potentially key sources of support.

Introduction

Family leave programs give employees time off work to provide health-related care for family members. Two especially vulnerable categories of family members are newborns and children with special health care needs (CSHCN). Parents of newborns need to bond with their child and manage fatigue and stress associated with parenting.[1,2] Parents of CSHCN need to participate in their child's health care and provide supervision when the child is ill at home.[3–5] Both groups of parents need to manage financial, social, and personal resources to fulfill these needs.[4,6] Parents of newborns or CSHCN are among the most likely to not only miss work but also drop out of the workforce altogether, which can sometimes have damaging effects on family well-being.[3,7–9] Formal and informal leave options are designed to help them remain employed and still care for their children.

The 1993 federal Family and Medical Leave Act (FMLA) provides up to 12 weeks of family leave with guaranteed benefits and job security, but the leave is unpaid and available only to qualifying employees in large companies and public agencies.[10] In 2004, California became the first state to enact the Paid Family Leave Insurance (PFLI) program, which provides up to 55% of salary for up to 6 weeks during family leave.[11] Five states (including California) also offer temporary disability insurance for mothers unable to work because of pregnancy or delivery.[12] Finally, some parents may have access to employer-provided sick leave/vacation, other benefits, or informal leave arrangements.[7,13]

Studies have demonstrated potential benefits of family leave. Paid sick leave coverage is associated with more parental care for ill children.[14,15] Longer leave coverage is associated with longer duration of breastfeeding among employed mothers[16,17] and more paternal bonding

with infants among employed fathers.[8] Parents with access to paid sick leave/vacation are 5 times as likely to stay home with their sick child as those without.[18] Finally, our own research has found that parents believe leave-taking greatly improves child physical and emotional health and, to a lesser degree, parent emotional health.[19]

Despite the existence of various leave options, access to and use of family leave is limited.[13] A U.S. Department of Labor 2000 survey of employees found that only 47% of private-sector employees were covered by FMLA.[20] Even use of California's PFLI, which provides most employees access to family leave, has since its inception been limited mostly to parents with newborns.[11] Private employers typically do not fill in the gaps; although 83% of U.S. private-industry workers reported access to employer-provided benefits such as paid sick leave/vacation in 2008, only 8% report access to employer-provided paid family leave.[21] Our 2007 study of employed parents of CSHCN found that 40% reported an unmet need for leave in the past year.[22]

What factors restrict access to and use of leave are unclear. Possible factors include limitations of leave benefits (eg, eligibility, duration, pay), lack of information about options, and concerns about job security, career advancement, or workplace acceptance. In a study of FMLA, 64% of employees who reported needing leave did not take it because it was unpaid, and among those taking leave, approximately one-half returned to work early because they could not afford additional time off.[23] Our earlier study of employed parents of CSHCN found that only 18% had heard of PFLI and only 5% had used it.[24] In a survey of California adults, just 28% knew about PFLI compared with 55% and 69% who knew about FMLA and temporary disability insurance, respectively.[25] Finally, 26% of women and 18% of low-income workers who took leave reported feeling pressure from their employers to return to work.[26] How these barriers affect leave-taking decisions of vulnerable parents must be understood before effective interventions can be devised.

In this study, we examined the experiences of parents of newborns or recently hospitalized CSHCN in identifying and using family leave benefits. We compared employed parents of newborns and recently hospitalized CSHCN because both groups involve a vulnerable child requiring continuous care or supervision from an adult. In both cases, short-term work−family decisions may have long-term impacts on both their child's overall health and their employment. Examining both expected (birth) and unexpected (hospitalization for illness) events allows us to investigate access and use of family leave programs through distinct pathways. Moreover, family leave policies (other than maternity and paternity leave) have historically been catchall policies that do not distinguish between the 2 events. Examining the distinctions, therefore, may have direct policy relevance. Finally, the authors of previous studies have surveyed parents about knowledge of leave programs and health benefits for children when taking family leave. However, few have inductively explored parents' experiences of how they respond to work−family conflict in regards to the health of their child.[27,28] Using semistructured qualitative interviews, we captured detailed experiences with leave-taking and work-family decisions surrounding the care of a child after a birth or hospitalization.

METHODS

PARTICIPANTS AND STUDY DESIGN

In 2008, we conducted qualitative interviews with a convenience sample of parents of newborns and CSHCN. Potential participants were recruited from UCLA or UCLA-affiliated pediatric outpatient waiting rooms, clinical referrals, and online postings. The primary inclusion criteria were having a first child born or having a CSHCN (ages 0−17) hospitalized in the last 3 to 9 months, receiving health care for their child in Los Angeles County, living with the child, and being employed full-time (which we defined as at least 25 hours/week, in alignment with FMLA eligibility criteria) at anytime in the past year (Fig. 1). CSHCN was defined as having or being at risk for having "a physical, developmental, behavioral, or emotional condition" requiring "health or related services of a type or amount beyond that required by children generally."[29] A validated 5-item CSHCN screener was used to identify children who met this definition.[29] Two parents whose child qualified as both newborn and CSHCN were placed in the CSHCN parent sample.

We aimed to interview at least 40 parents (10 mothers of newborns, 10 fathers of newborns, 10 mothers of CSHCN, and 10 fathers of CSHCN), with more if needed to improve the likelihood of valid comparisons between parents of newborns and CSHCN.[30] We screened 101 potential participants (58 parents of newborns and 43 parents of CSHCN) to reach our initial sample of 40. Concurrent iterative analyses of notes and transcripts suggested no major new themes emerging, which allowed us to halt recruitment. Each parent was selected from a different family unit. Interviews were conducted in English and Spanish (only one parent requested a Spanish interview). The study received institutional review board approval from RAND and UCLA.

MEASURES

Interview Protocol

A semistructured protocol was developed to guide the interview in 2 parts: 1) descriptions of typical days prior to, during, and after the birth or hospitalization of their child; and 2) factors in decision-making regarding whether to take leave from work. For each time point, participants were asked to describe a typical day spent around work, family, and leisure activities. Participants were then asked whether they or their spouse took leave from work. Open-ended follow-up questions were used to explore their experience with identifying and understanding leave options and the factors that influenced their decision whether to take leave from work. We also asked parents to express perceived strengths and shortcomings of family leave benefits