COMMENT

"The gender gap in caring for children with medical complexity"

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INTRODUCTION

The following is an unfortunate but common scenario: a baby born extremely premature who needs a tracheostomy for long-term ventilatory support might have no home nursing available in her area, regardless of insurance status, and might wait months for a rehabilitation bed in the closest facility in a neighboring state. If she is able to be discharged home, her mother will quit her job to provide bedside care and her father will work full-time (or more) for the provision of financial support and medical insurance. In the most recent example this writer recalls, the patient's father's work schedule did not permit him to come into the hospital to learn tracheostomy care. The weight of this responsibility is considerable for all parties, but the scale for primary caregiving tends to tilt heavily toward women/gestational parents [1]. On superficial analysis, one might attribute the gender gap in unpaid care work to societal and cultural attitudes about gender norms, femininity, and motherhood. However, newer data have revealed that economic and public policies have a substantial impact on the gender care gap. As medical providers for children with medical complexity (CMC), we must examine the issues facing their families and high-yield areas to advocate for policy change, including home nursing, paid caregiving for CMC by family members, family leave, and increased job flexibility.

CARING FOR CHILDREN WITH MEDICAL COMPLEXITY

Those who provide medical care for CMC recognize that some parents' proficiency in bedside care rivals that of some nurses, and their diagnostic acumen rivals that of some physicians. Through varying degrees of choice, they have devoted their lives to caring for their children, with varying degrees of support from a partner or other caregiver. This level of expertise results from a scarcity of rehabilitation facility beds and home nursing support to give CMC the medical support they need when they leave the hospital. A 2022 study identified seventeen states with no inpatient pediatric rehabilitation services [2]. In a 2018 study, families reported a dearth of 40 h per week in home nursing coverage compared to their allotment, resulting in 23 h per week of missed employment [3]. This often tethers one caregiver to the home, resulting in strained relationships, poor health outcomes, and sacrifice of economic and educational opportunities.

While both parents are impacted by caring for CMC, the literature suggests caregiving at home impacts psychosocial and physical health of the primary caregiver [4]. In a cross-cultural study, Krulik et al. found that mothers of young children with chronic illness experienced more problems with attachment, depression, a lowered sense of competence, social isolation, and problems with their spouses compared to mothers of children without chronic illness [5]. In a study of mothers and fathers of preschool children with developmental disability, mothers reported higher stress and worse health outcomes than fathers [6]. The same observation was noted in a study of parents of children with rare diseases, especially single mothers [7]. Gray found that a child's disability tends to revert families to traditional gender roles [8]. Studies of work-family policies from 38 developed democracies confirm that where the availability of childcare is very limited, very expensive, or of poor quality, women are more likely to be unemployed, hold low-quality jobs, have job turnover, and lower wages [9]. The same is true for those who care for CMC due to lack of home nursing, with 52% dropping to part-time and 21% quitting their jobs [11]. The body of evidence available suggests the following: mothers of CMC likely suffer greater mental and physical hardship than mothers of healthy children and more than fathers of the CMC, and thus suffer from the inequality inherent to unpaid care work. The disproportionate impact on women of color who care for CMC remains to be studied.

CLOSING THE GENDER CARE CAP

Several explanations have been offered for the gender gap in unpaid care work, including attitudes about gender roles in a given country and the nature of the jobs that women hold [1]. However, these microeconomic reasons have failed to explain cross-country variation. In an analysis of thirteen European countries, comparative modeling demonstrated that *the single most important factor in predicting a gender care gap was presence or absence of public care services*, and that gender attitudes and women's position in the labor market played a minor role [10]. This key observation should inform our efforts at the national, state, and local levels.

Most importantly, the dearth of home nursing availability throughout the U.S. negatively affects families. Due to disproportionately low wages, nurses are dis-incentivized from working in homecare agencies [11]. Although every state's Medicaid program allows paid caregiving for adults by their family members, including by adult children and spouses, most states prohibit paid caregiving for CMC by family members [11]. No justification for this differential treatment is apparent. Some private insurances simply do not cover home nursing. Increasing Medicaid reimbursement for pediatric

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home nursing, allowing family caregivers for CMC to be paid by insurance, mandating private insurance coverage, and instituting national standards for waivers to obtain Medicaid coverage would increase availability of home caregiving services, particularly to low-income patients, and decrease healthcare dollar expenditure on intensive care hospital stays.

In addition, job flexibility for part-time and full-time employees would expand a family's ability to share the responsibility of caring for CMC. With respect to family leave policies, the U.S. remains one of a handful of countries in the United Nations that does not guarantee paid family leave. Only twelve states have paid family leave laws [12], which prevents many fathers from being able to share in caregiving as much as they would like. Predictably, the lowest paid workers are least likely to have access to family leave [13]. Analysis of data from 35 Organization for Economic Cooperation and Development (OECD) countries suggests more generous maternity leave decreases the gender gap in employment, and paternity leave is positively correlated with mothers' employment [14]. For families receiving insurance through an employer, one parent often needs to work full time, thereby perpetuating the traditional dynamic of one income-earning parent and one caregiving parent. Pediatricians and sub-specialists who saw outpatients during the COVID-19 pandemic may recall a serendipitous phenomenon: an upsurge in fathers taking their children to appointments, likely due to increased job flexibility for higher-income families. An early study corroborates more egalitarian division of household labor during the pandemic [15]. Another study has shown that increased physical involvement by fathers in their child's cancer care improves marital outcomes and decreases the burden each parent experiences [16]. As such, reform in labor policy to guarantee paid leave, especially for fathers/non-gestational parents, promotes steps toward gender equity and increases well-being for both parents and their children.

CONCLUSION

Of course, most parents derive fulfillment from caring for CMC, but the social dynamic in which one parent must be a full-time, unpaid bedside nurse/nursing assistant/paramedic/care coordinator/physical therapist/teacher denies that parent of educational and employment opportunities, and deprives the other parent of time with their family. Options likely are further narrowed for mothers who are single or have low incomes. In the U.S., the problem is not with lower healthcare or social spending compared to other OECD countries [17], but with misplaced priorities which overlook the needs of children and families [18, 19]. Thus, we as pediatricians and other healthcare providers have an obligation to advocate for expanded home nursing availability, institution of paid caregiving for CMC by family members, universal and egalitarian paid family leave, and increased job flexibility for our patients' families.

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KW contributed all aspects of this manuscript.

COMPETING INTERESTS

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ADDITIONAL INFORMATION

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