

Medical Complexity and Healthcare Experiences Among Mothers of Children With Special Healthcare Needs: The Roles of Sociodemographic Factors

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ABSTRACT

- The goal of this study was to examine the association between the medical complexity of children with special healthcare needs (CSHCN) and the healthcare experiences of their mothers, while exploring the influence of sociodemographic factors on these associations. Findings showed that socioeconomic factors (e.g., race, community, insurance) were significantly related to the association between medical complexity and healthcare experiences. This emphasizes the need for targeted interventions to address healthcare inequities within the underserved population.

INTRODUCTION

- The prevalence of special healthcare needs among children under 18 has increased by 6% since 2001 (HRSA, 2020), largely due to advancements in medical technology and enhanced management of developmental disorders (Durkin, 2019). The growing population of CSHCN highlights an expanding disparity between the need for specialized healthcare providers and the access to services that meet the recommended standard of care (Singh et al., 2009). A health equity framework highlights critical factors driving disparities in care between CSHCN and children without such needs.
- As healthcare systems expand, barriers to accessing recommended treatments often require parents of CSHCN to take on greater responsibilities in navigating and advocating for necessary healthcare services (i.e., care coordination, family-centered care, and shared decision-making). In particular, mothers frequently assume primary roles in healthcare decision-making, including coordinating medical appointments and administering treatment.
- This study aimed to understand the relationship between medical complexity and the healthcare experiences of mothers of CSHCN (**Aim #1**). It also investigated how sociodemographic factors (i.e., race, community, and insurance) impact CHSCH complexity and healthcare experiences (**Aim #2**).

SAMPLE

- The merged 2016-2020 National Survey of Children's Health (NSCH) data included 25,909 mothers of children aged 0-17 with special healthcare needs. After further removing cases with missing information (e.g., insurance and community type), 17,434 were retained in the final sample.

METHOD AND RESULTS

Measures

- Medical Complexity (MC):** Mothers reported whether the child had chronic health conditions and complexity levels were determined by the number of health consequences, such as prescription or specialized therapies, with higher scores indicating greater complexity.
- Care Coordination (CC):** The NSCH incorporated six items on parental experiences with referrals and communication from healthcare providers. Higher scores indicated more effective coordination of the child's healthcare services.
- Family-Centered Care (FCC):** Five items measured the collaborative relationship between healthcare providers and family members. Higher scores indicated greater levels of FCC.
- Shared Decision-Making (SDM):** Three questions were used to assess the frequency of collaborative decision-making between doctors and patients. A higher score reflected a greater degree of SDM.
- Sociodemographic Variables:** Child race, community setting, and insurance type were dummy-coded as binary variables. Children ages, sex, and federal poverty level were added as covariates.

Statistical Analysis

- Multiple regression analyses were conducted in SPSS 28.0 to examine the association between medical complexity of CSHCN and mothers' healthcare experiences (**H1**). To test the moderating effects of sociodemographic factors, interaction terms between medical complexity (centered) and each sociodemographic factor were created to assess their impact on healthcare experiences (**H2**).

Table 1. Descriptive Statistics and Correlations of Model Variables

	1	2	3	4	5	6	7	8	9	10
1. MC	-									
2. CC	-0.21**	-								
3. FCC	-0.13**	0.50**	-							
4. SDM	-0.11**	0.47**	0.72**	-						
5. Race (1=Minority)	0.02**	-0.02**	-0.05**	-0.04**	-					
6. Community (1=Rural)	-0.01	0.02**	-0.02**	-0.01	-0.08**	-				
7. Insurance (1=Public)	0.12**	-0.03**	-0.07**	-0.08**	0.22**	0.12**	-			
8. Child Sex (1=Female)	-0.08**	0.01	0.01	-0.01	0.01	0.01	-0.01	-		
9. Child Age	-0.01	0.02*	0.02*	0.02*	-0.05**	0.02*	-0.06**	0.09**	-	
10. Federal Poverty Level	-0.11**	0.03**	0.10**	0.09**	-0.22**	-0.14**	-0.60**	0.01	0.06**	-

Note. * $p < 0.05$. ** $p < 0.01$.

RESULTS (Cont.)

Table 2. Healthcare Experiences Moderating Effects of Sociodemographic Factors in the Association between Medical Complexity and Healthcare Experiences.

	CC		FCC		SDM	
	B	SE	β	SE	β	SE
MC	-0.23**	0.01	-0.13**	0.02	-0.10**	0.02
RACE (1=Minority)	-0.05**	0.02	-0.06**	0.09	-0.02	0.09
Race x MC	0.05*	0.01	0.03*	0.04	-0.01	0.01
Child Sex (Female)	-0.01	0.01	-0.01	0.04	-0.03	0.06
Child Age	0.02*	0.00	0.01	0.01	0.02	0.01
Federal Poverty Level	-0.00	0.01	0.07**	0.02	0.07**	0.14**
Medical Complexity	-0.22**	0.01	-0.12**	0.02	-0.11**	0.02
Community (1=Rural)	-0.01	0.02	-0.03*	0.11	-0.02	0.11
Community x MC	0.03	0.01	0.04	0.04	0.03	0.04
Child Sex (Female)	-0.01	0.01	-0.00	0.04	-0.02	0.04
Child Age	0.02*	0.00	0.02	0.01	0.02	0.01
Federal Poverty Level	0.01	0.01	0.08**	0.02	0.08**	0.02
Medical Complexity	-0.24**	0.02	-0.14**	0.02	-0.11**	0.02
Insurance (1=Public)	-0.08**	0.01	-0.06**	0.10	-0.06*	0.11
Insurance x MC	0.08**	0.02	0.06**	0.04	0.04	0.03
Child Sex (Female)	-0.01	0.01	-0.00	0.04	-0.02	0.04
Child Age	0.02*	0.01	0.01	0.01	0.02	0.01
Federal Poverty Level	-0.00	0.01	0.07**	0.03	0.07	0.02

Note. * $p < 0.05$. ** $p < 0.01$.

- Results from multiple regressions showed that greater medical complexity was associated with more negative healthcare experiences, including CC, FCC, and SDM.
- Minoritized mothers, those in rural areas, and families with lower income reported lower levels of FCC, indicating significant disparities.
- There were a few significant interactions, but some findings were contrary to H2. The negative association between medical complexity and healthcare experiences was pronounced for White families and those with private insurance compared to minoritized families and those with public insurance.

PRACTICAL IMPLICATIONS

- This study highlights the necessity for targeted interventions to improve CC, FCC, and SDM, emphasizing the need for a comprehensive approach to address healthcare disparities and promote health equity for CSHCN and their families.
- Healthcare providers can leverage these findings to tailor their services effectively, addressing the unique challenges faced by CSHCN families.
- Policy makers can advocate for policies that promote health equity and ensure equitable access to healthcare services for all children, irrespective of their background or geographic location.