



Social Support and Family Resilience Ease the Stress of Parents of Children with Complex Special Health Care Needs

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OVERVIEW

We looked at the effects of three social determinants - community conditions, emotional support, and family resilience on the mental and physical health of mothers of children with complex special health care needs. Mothers across all race and ethnicity groups who reported having formal or informal emotional support, fewer adverse neighborhood conditions, and more family resilience also reported having better mental and physical health. This highlights the importance of social determinants in both physical and mental health. It also highlights the importance of recognizing family context when designing policies and practices for family caregivers.

BACKGROUND

The Maternal and Child Health Bureau conducts the National Survey of Children's Health (Data Resource Center for Child and Adolescent Health, 2019). Starting in 2016, it incorporated the National Survey of Children with Special Health Care Needs. Parents and other family caregivers were asked about physical and mental health, access to quality health care, and family, neighborhood, school, and social context for their child.

For this data brief, we selected caregivers whose children were identified as having "more complex health care needs." Children with more complex health care needs have a "need for more medical care" than usual, and having emotional/behavioral problems, the use of mobility aids/devices, communication aids/devices, medical supplies, durable medical equipment, and/or seeing multiple specialists (Kuo et al, 2014).

We were interested in learning to what extent social determinants affect how mothers rate their mental and physical health. We looked at three factors. The first, community conditions include the lack or presence of neighborhood amenities such as a park, libraries or sidewalks, neighborhood safety, and the extent to which neighborhoods are cohesive. Neighborhood cohesiveness includes neighbors that look out for each other, for example. Neighborhood conditions have been shown to affect both physical and mental health (Diez Roux & Mair, 2010). Exposure to poorer neighborhood conditions may be a contributing factor to the health inequities experienced by people from different race/ethnic groups.

The second factor was whether caregivers reported having emotional support. The support could be formal (therapists or support groups) or informal (family and friends). Prior research has shown that parents of children with disabilities who report having high social support also report having better physical and mental health (Cantwell et al, 2014; Lovell et al, 2012; Peer and Hillman, 2014).

The third factor we considered was family resilience. Four items were included in family resilience. Caregivers were asked how often their families solved problems by:

"talking together about what to do,"

"working together to solve problems,"

knowing "that they had strengths to draw on," and staying "hopeful in difficult times."

Caregivers that used coping strategies that focused on solving problems in a way that attempted prevented them from occurring in the future and who remained optimistic reduced stress levels (Peer and Hillman, 2014). Reduced stress levels lead to better health outcomes.

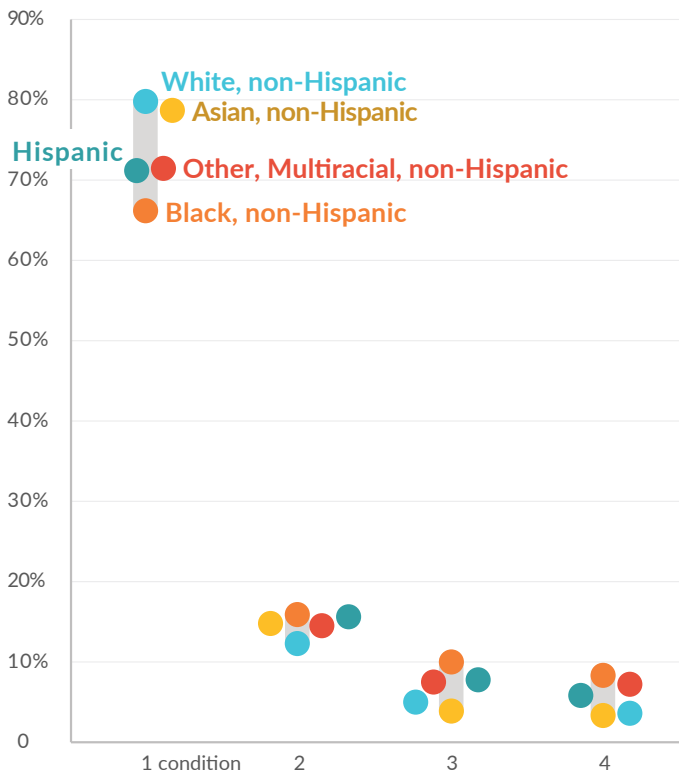
Caregivers reported on their mental and physical health by rating each from poor to excellent. Because most primary caregivers are mothers, we focus on the mental and physical health of 6,686 mothers of children with more complex health care needs. We looked at the similarities and differences in mother's experience by race and ethnicity of the child. While not all caregivers have the same race/ethnic background of their child(ren), this survey does not ask the race or ethnicity of caregivers. 738 mothers identified their child as Hispanic, 4,784 as white, 409 as black, 211 as Asian, and 544 were reported to be some other race or more than one race.

FINDINGS

Social Determinants

Community conditions. Most caregivers (77%) across all groups reported no adverse neighborhood conditions. There were differences across the groups, however. Mothers of black children (66%) were the least likely to report no adverse community conditions and the most likely to have all 3 (8%). 71% of mothers of Hispanic and other/multi-race children, 79% of mothers of Asian children, and 80%

Number of Community Conditions

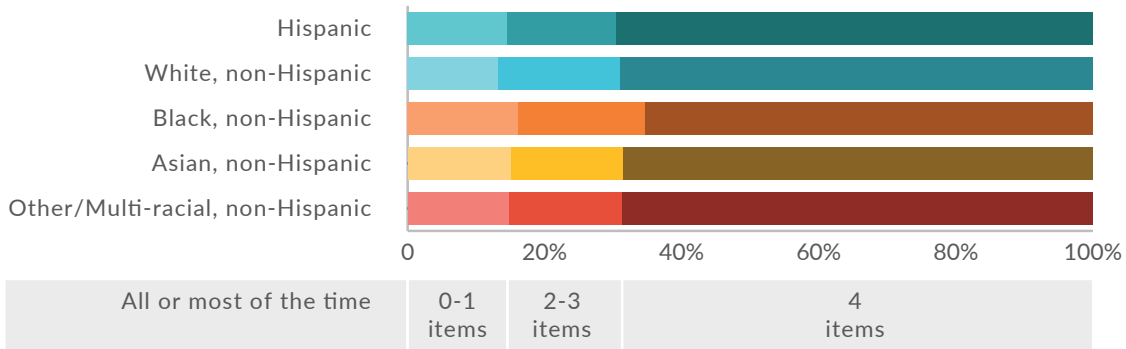


of mothers of white children reported no adverse community conditions. All of these groups were also less likely to report having three neighborhood conditions than mothers of black children (Other/multi-race, 7%; Hispanic, 5%; white and Asian (3%). (Note: We recognize that mothers can have a different race or ethnic identity than the child they care for. For reading ease, we will refer to the reported race/ethnicity of the child in the rest of the report.)

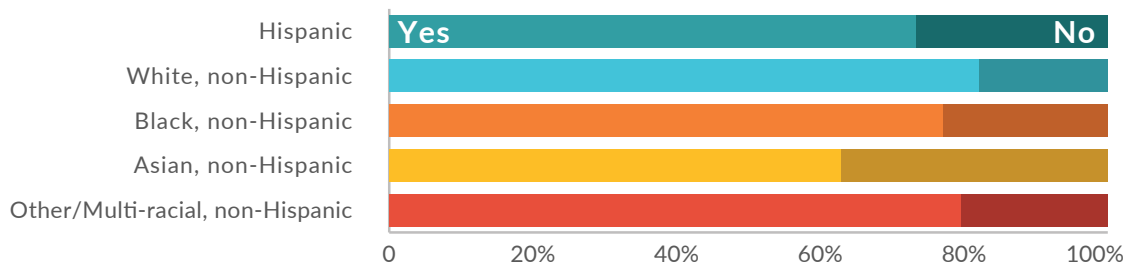
Caregiver emotional support. The number of mothers reporting having formal or informal emotional support ranged from 63% (Asian) to 82% (white). Other mothers also reported higher levels of emotional support than Asian mothers (Hispanic, 73%; black, 77%; other/multi-race, 80%).

Family resilience. More than 2/3 of mothers reported that their family does four indicators of family resilience all or most of the time (black, 66%; white, Asian, other/multi-race, 69%; Hispanic, 70%). Between 16% and 18% of families said they do 0-1 of the indicators all or most of the time (Hispanic, Asian,

Family Flourishing



Parents have Emotional Support



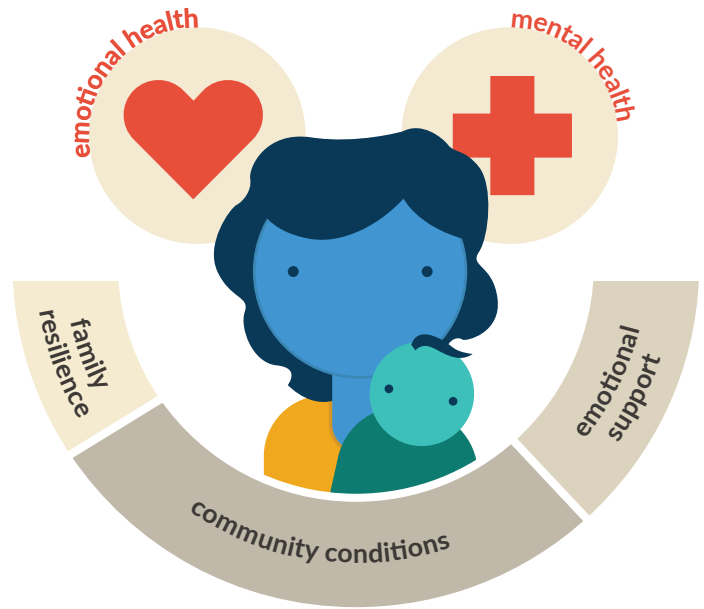
16%; Other/multi-race, 17%; white, black; 18%).

Mother's Health

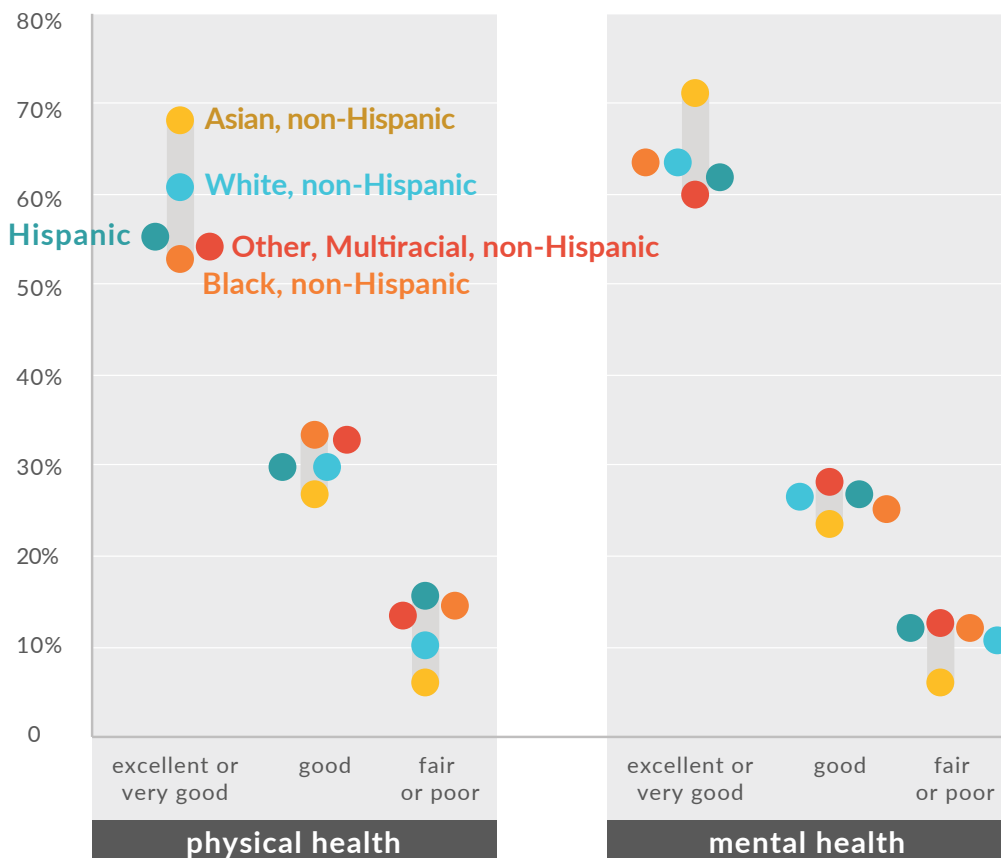
More than half of all mothers reported that their physical health was very good or excellent (black, 53%; other/multi-racial, 54%; Hispanic, 55%; white, 61%; Asian, 68%). Asian mothers (71%) were also more likely to report that their mental health was very good or excellent than other mothers (other/multi-race, 60%; Hispanic, 62%; white, black, 63%).

Effects of Social Determinants on Mothers' Health

We found that across all race/ethnicity groups mothers who reported fewer adverse neighborhood conditions, having social support, and who reported more factors of family resilience were also more likely to report



Physical and Mental Health of Mother



better mental or physical health. For example, mothers with very good or excellent mental and physical health were 4 times more likely to report no adverse conditions than mothers reporting poor or fair health. Having emotional support and family resilience also was associated with better mental and physical health in mothers.

SUMMARY

Social determinants such as community conditions, family resilience, and emotional support affect the emotional and physical health of mothers of children with more-complex health care needs regardless of race/ethnic background. However, the exposure to social determinants that may have a negative effect on caregivers does differ by race and ethnicity. Considering social determinants and the context in which families live are important considerations when developing policies and practices aimed at supporting family caregivers.

REFERENCES

- Cantwell, J., Muldoon, O. T., & Gallagher, S. (2014). Social support and mastery influence the association between stress and poor physical health in parents caring for children with developmental disabilities. *Research in developmental disabilities, 35*(9), 2215-2223.
- Data Resource Center for Child & Adolescent Health (2019). The National Survey of Children's Health. Retrieved from <https://www.childhealthdata.org/learn-about-the-nsch/NSCH>.
- Diez Roux, A. V., & Mair, C. (2010). Neighborhoods and health. *Annals of the New York Academy of Sciences, 1186*(1), 125-145.
- Kuo, D. Z., Cohen, E., Agrawal, R., Berry, J. G., & Casey, P. H. (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. *Archives of pediatrics & adolescent medicine, 165*(11), 1020-1026.
- Lovell, B., Moss, M., & Wetherell, M. A. (2012). With a little help from my friends: Psychological, endocrine and health correlates of social support in parental caregivers of children with autism or ADHD. *Research in developmental disabilities, 33*(2), 682-687.
- Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92-98.

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