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Disparities and Factors Associated With Unmet Needs in Families of Children With Special Healthcare Needs

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Purpose:

The Maternal and Child Health Bureau defines children with special healthcare needs (CSHCN) as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (The Child & Adolescent Health Measurement Initiative, n.d.). One in five United States households has a child with a special healthcare need, according to the 2010/2011 National Survey of Children with Special Healthcare Needs (Bramlett, Blumberg, Ormson, et al., 2014). The families of CSHCN face multiple challenges related to the management of their child's condition, including: stress, fatigue, marital distress, difficulty maintaining employment, and family financial problems. Quality medical and supportive services that meet the needs of the families can help facilitate family self-management. Effective family self-management can result in improved individual and family health outcomes, enhanced family quality of life, and lower direct and indirect costs of healthcare for both families and society. However, previous research indicates that needs are largely unmet (Lindly, Chavez, & Zuckerman, 2016). Additionally, there is evidence that disparities in unmet needs exist (Benedict, 2006). Whitmore (n.d.) found that families of CSHCN with Autism Spectrum Disorder (ASD) had seven times the prevalence of unmet respite care needs compared to families of CSHCN without ASD. Evidence from several studies with small sample sizes also suggests that racial disparities in unmet needs exist.

Therefore, the purpose of this study is to examine racial disparities and individual, family, and environmental factors associated with different levels of unmet medical and supportive service needs in families of children with special healthcare needs (CSHCN). The Individual and Family Self-Management Theory (IFSMT) will guide the study. This theory proposes that self-management is a process by which individuals and families use knowledge and beliefs, self-regulation skills and abilities, and social facilitation to achieve health-related outcomes (Ryan & Sawin, 2009). Self-management takes place in the context of risk and protective factors specific to the condition, physical and social environment, and individual and family.

Methods:

An exploratory secondary analysis of the 2016 National Survey of Children's Health (NSCH) will be conducted using a non-experimental, descriptive, correlational design. The NSCH is a national cross-sectional telephone survey of 50,212 US households. The final analytic sample will include the subgroup of families of children aged 2–18 years with one or more self-identified special healthcare need(s). In the NSCH, participants are asked a series of questions related to their need for a variety of medical and supportive services (e.g., medical care, specialized therapies, counseling, special education, and respite care), and if those needs have been met. Latent class analysis (LCA) will be used to assign the heterogeneous families into homogeneous sub-groups based on the level of unmet needs in order to analyze and explore the possible differences between these family classes and various individual, family and environmental factors, aligned with the Individual and Family Self-Management Theory.

Results:

Knowledge gained from this study will fill a gap in the literature and inform the development of future externally funded studies to design and test interventions to improve the ability of healthcare professionals to identify and support families with unmet needs. The results will also inform the

development of an unmet needs screening tool and pilot study in partnership with public health, the healthcare system and other community partners that work with families of CSHCN.

Conclusion:

To better identify and ultimately support families of CSHCN, it is important to understand what factors are associated with unmet medical and supportive service needs, how those factors vary by the level of unmet need, and examine possible racial disparities. The proposed study will be the first known to examine racial disparities and factors associated with unmet medical and supportive service needs in families of CSHCN using data from the 2016 National Survey of Children's Health. As a result, findings from this study will help expand knowledge of racial disparities and identify risk factors for unmet medical and supportive service needs in families of CSHCN at the population level.

Title:

Disparities and Factors Associated With Unmet Needs in Families of Children With Special Healthcare Needs

Keywords:

children with special healthcare needs, disparities and unmet needs

References:

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Abstract Summary:

One in five US households has a child with a special healthcare need. Quality medical and supportive services can help facilitate family self-management, yet little is known about why these needs are often unmet. This study examines racial disparities and factors associated with different levels of unmet needs.

Content Outline:

Significance:

The Maternal and Child Health Bureau defines children with special healthcare needs (CSHCN) as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”. One in five United States households has a child with a special healthcare need, according to the 2010/2011 National Survey of Children with Special Healthcare Needs. The families of CSHCN face multiple challenges related to the management of their child’s condition, including: stress, fatigue, marital distress, difficulty maintaining employment, and family financial problems. Quality medical and supportive services that meet the needs of the families can help facilitate family self-management. Effective family self-management can result in improved individual and family health outcomes, enhanced family quality of life, and lower direct and indirect costs of healthcare for both families and society. However, previous research indicates that needs are largely unmet (Whitmore, n.d.). Additionally, there is evidence that disparities in unmet needs exist. Whitmore (n.d.) found that families of CSHCN with Autism Spectrum Disorder (ASD) had seven times the prevalence of unmet respite care needs compared to families of CSHCN without ASD. Evidence from several studies with small sample sizes also suggests that racial disparities in unmet needs exist. To better identify and ultimately support families of CSHCN, it is important to understand what factors are associated with unmet medical and supportive service needs, how those factors vary by the level of unmet need, and examine possible racial disparities. The proposed study will be the first known to examine racial disparities and factors associated with unmet medical and supportive service needs in families of CSHCN using data from the 2016 National Survey of Children’s Health. As a result, findings from this study will help expand knowledge of racial disparities and identify risk factors for unmet medical and supportive service needs in families of CSHCN at the population level.

Approach:

An exploratory secondary analysis of the 2016 National Survey of Children’s Health (NSCH) will be conducted using a non-experimental, descriptive, correlational design. The NSCH is a national cross-sectional telephone survey of 50,212 US households. The final analytic sample will include the subgroup of families of children aged 2–18 years with one or more self-identified special healthcare need(s). In the NSCH, participants are asked a series of questions related to their need for a variety of medical and supportive services (e.g., medical care, specialized therapies, counseling, special education, and respite care), and if those needs have been met. Latent class analysis (LCA) will be used to assign the heterogeneous families into homogeneous sub-groups based on the level of unmet needs in order to analyze and explore the possible differences between these family classes and various individual, family and environmental factors, aligned with the Individual and Family Self-Management Theory.

Expected Results:

This knowledge will fill a gap in the literature and inform the development of future externally funded studies to design and test interventions to improve the ability of healthcare professionals to identify and support families with unmet needs. The results will also inform the development of an unmet needs screening tool and pilot study in partnership with public health, the healthcare system and other community partners that work with families of CSHCN.

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Author Summary: Kim Whitmore has had more than 15 years of experience working with individuals and families with special healthcare needs as a nurse, public health leader, educator, and researcher. Currently, Dr. Whitmore is an Assistant Professor in the School of Nursing at UW-Madison. She received a Master of Science Degree in Nursing with a specialization in Healthcare Systems Leadership from Marquette University and a Doctor of Philosophy in Nursing Research from the University of Wisconsin-Milwaukee.