A Family Perspective on Population Health: The Case of Child Health and the Family

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ABSTRACT
Context: This paper makes the case for a family perspective on population health and specifically focuses on how children’s health can impact family health and well-being.

Objective: To review and synthesize the diverse set of papers that has examined the associations and linkages between children’s health and family health.

Results: Based on the synthesis of the existing literature, additional research is needed that focuses on (1) the longitudinal impact of childhood chronic illness on the family using national samples, (2) the application of interdisciplinary methodologies to studying childhood chronic illness in the family, and (3) understanding the psychobiology of caring for a child with a chronic illness and the concordance of such measures with self-reported stress and burden.

Conclusions: We propose a new integrated conceptual framework for better understanding the mechanisms that influence children’s health and health care.

INTRODUCTION
The field of population health includes studies of “health outcomes, patterns of health determinants, and policies and interventions that link these two.” Population health research focuses on the multiple determinants of health (including medical care and public health, the social and physical environment, genetics, and individual behavior). A crucial, and often overlooked, link between health outcomes and health determinants is the family. In particular, our view is that the family plays a particularly important role in mediating and moderating the effects of determinants on health outcomes. An individual’s health can affect family members’ health and the family environment can also impact individual health outcomes. While previous studies have incorporated the family into a health determinants framework, future work should expand the examination of health as a family phenomenon.

This article is based on the specific case of how children with chronic health problems can impact family health and well being. We review and synthesize the diverse set of papers that has examined the associations and linkages between children’s health and family health. We also propose a new integrated conceptual framework for better understanding the mechanisms that influence children’s health and health care.

IMPACT OF DISABILITIES AND CHRONIC ILLNESSES
Chronic illness and disability among adults and children affect more than 20.3 million families in the United States, representing about 30% of all households. Moreover, nearly 4 million families, about 5.5%, have at least 1 disabled child. Chronic illness or disability in a child can place tremendous physical, financial, time, and psychological burdens on the rest of the family. These burdens may present substantial additional risk for family dysfunction, continued adverse health outcomes for the child, and adverse health outcomes for family members. Despite the potential scope of these burdens, little is known about the long-term impacts of chronic illness among children on families across the United States. Understanding these relationships is essential to improving pediatric health outcomes, reducing health disparities among children with chronic illness, and addressing the health of caregivers and families of chronically ill children.
Impact on the Child
Children with disabilities or chronic illnesses are at increased risk for psychological morbidity. In particular, psychological maladjustment is 10%-15% higher in children with chronic conditions, as compared to healthy controls. Finally, the Ontario Child Health Study reported that children with chronic conditions and major disability were 3 times more likely to have a psychiatric disorder than their healthy counterparts, controlling for age- and sex-specific risks for psychiatric problems. Potential interactions between the burdens on the family that result from a child’s chronic illness and family members’ psychological morbidity are hypothesized to explain the associations with the child’s psychological morbidity.

Impact of Child Health on Other Family Members
Clinical studies show a higher prevalence of psychological distress among parents of chronically ill children. A possible mechanism for this effect is the negative influence of children’s health on maternal role functioning, which in turn affects maternal psychological problems. Finally, siblings of a child with a disabling medical condition are likely to have higher than normal levels of psychopathology and distress, indicating that effects of childhood disability are experienced throughout the family.

Living with an individual with a chronic illness is often associated with an increased probability of incurring personal medical expenditures. Psychological distress is a major factor in the decision to seek health care for adults and children, even when controlling for their physical health status. This implication underscores the need for focused care, and for understanding how addressing caregiver needs may improve their mental health status and reduce costs.

Most existing national and convenience sample studies do not include physiological measures of stress. The physiological response to such stressors, and the relationship to perceived stress, has not been examined adequately among pediatric caregivers; such research might further help to understand the increased risk for and development of parental physical and mental health problems.

Impact of Chronic Illness on the Psychobiology of Caregivers
Although data do not exist for caregivers of children, studies in the aging literature report that caregiving, often a source of psychological stress, is associated with long-term endocrine and immune dysregulation among spouses of elderly patients. In particular, 1 study found that Epstein-Barr virus (EBV) antibodies were significantly higher among caregivers as compared to non-caregivers, indicating poor cellular immunity. This immune dysregulation, a response to chronic stress, can persist for years even after the caregiving ends and may be related to the acceleration of the aging process, as shown from the increase in the production of proinflammatory cytokines among caregivers.

Parental Caregivers and Stress Biomarkers
Parental caregivers often experience anxiety and fear about managing care for their chronically ill child; however, it is largely unknown how this distress relates to their physiology and health. To date, no studies have simultaneously examined biological and self-perceived measures of caregiver stress among caregivers of children with chronic conditions, and how well these measures correlate with subsequent health outcomes for these children. However, 1 study of parents of pediatric cancer patients examined chronic psychological stress and immune function reporting that caregiving stress impaired the parents’ immune response to anti-inflammatory signals.

The Impact of Chronic Illness on Family Functioning
Childhood chronic illness can have a considerable impact on family functioning. In turn, the manner in which the family adjusts to and copes with a child’s illness can substantially influence the psychosocial adjustment of the child and the family as a whole. For example, mothers of children with spina bifida and more supportive families and marriages reported lower levels of psychological symptoms. Thus, positive family functioning may moderate the relationship between caregiving and poor mental health and increased levels of stress. Family functioning also moderates the association of children’s externalizing behavioral problems to caregivers’ symptoms of hostility among caregivers of children and adolescents with sickle cell syndromes. Indeed, family factors may be more predictive of psychopathology among children than the type and severity of a childhood chronic condition. In particular, poor family functioning, low income, parental distress, and an increased burden of illness on the family are all associated with the child’s psychological maladjustment. Moreover, positive family-based characteristics such as parental self-esteem, family social support, the child’s coping mechanisms, and health care beliefs all contribute to adaptation among children with chronic conditions.
Economic Impact
Caring for a chronically ill child often requires much time and effort of parents. A child’s condition can have an impact on the parents’ ability to work, their work attendance, and the availability of financial resources in the family. For example, nearly 20% of US families with children with a health condition reported that the illness had affected the parents’ ability to work, as many employed parents lack sick benefits. Indeed, mothers of children with health limitations are at particularly high risk of losing their jobs. Finally, the decreased employment among parents has an added impact on the economic resources available to the child through reduced access to employer-sponsored insurance.

Bidirectional Nature of Family Spillovers
Child and family adjustments are often inter-related and can impact future levels of distress and quality of life among children. For example, research on pediatric cancer survivors has shown that survivor behavior is correlated with parental caregiver stress and coping.

SUMMARY
Chronic illness and disability among children are potential stressors that may present a substantial additional risk for family dysfunction, continued adverse child health outcomes, and adverse health outcomes for other family members. Protective mechanisms, such as individual and familial resources, may help moderate the relationship between family stressors and children’s health status. One potential resource is the health and mental health care systems, which are well positioned to assist families in coping with stressors, so as to meet the psychosocial needs of children and their parents and reduce over-utilization of health care. Economic Impact
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LIMITATIONS OF EXISTING RESEARCH
There are 3 main limitations to the current research on the impact of childhood illness on the family. First, nearly all existing studies have been conducted on convenience samples or in families that are receiving health care services. The majority of these studies have taken place at single clinics. The referral patterns that help these families obtain care potentially bias such studies and call into question the generalizability of the research findings. Most national studies that examine childhood chronic illness are cross-sectional. Therefore longitudinal, population-based studies are needed to clarify the clinical studies that have identified these issues. Second, current methods in health services research do not account for the direct, indirect, and interactive effects of childhood chronic illness on the family. The application of existing econometric and sociological research methods to health services research could greatly enhance our understanding of the dynamic and interdependent nature of family health. Third, little is known about the relationship between caregiver-reported stress and its physiological manifestation and how caregiver perception and biology interact over time. A paucity of research exists on the physiological, behavioral, and social pathways by which health perceptions affect the health of caregivers and children with chronic illness.

In summary, additional research is needed that focuses on the:
- Longitudinal impact of childhood chronic illness on the family using national samples.
- Application of interdisciplinary methodologies to studying childhood chronic illness in the family.
- Understanding the psychobiology of caring for a child with a chronic illness and the concordance of such measures with self-reported stress and burden.

Addressing these substantive and methodological gaps will significantly improve our understanding of the mechanisms that lead to health disparities among these children and their families. As such, we propose a new integrated conceptual framework to help guide future research about the pathways that influence children’s health and health care.

CONCEPTUAL FRAMEWORK
Substantial theoretical and empirical work supports the concept that chronic health conditions and functional impairments are major life stressors. A social-ecological systems framework posits that stress on any person in the family system is a major influence on the health of all family members. Such models are helpful in conceptualizing the bidirectional pathways of chronic illness and child and family functioning. However they do not explicitly incorporate the role of health care needs and/or utilization.

To conceptualize and examine child and family use of health care, researchers often employ the Aday and Anderson model, or “behavioral model,” which characterizes the determinants of use as need, enabling, and predisposing factors. Need factors include medically evaluated and self-perceived health problems and symptomatology; enabling factors refer to resources available to the individual or community, such as a regular source of care; and predisposing factors include an individual’s demographic characteristics and health beliefs. Recent
studies, however, have suggested that incorporating psychosocial and social ecological components into access-to-care models may better explain patterns of physical and mental health care utilization.69-70

Therefore, we propose an integrated theoretical framework that draws from a hybrid of several frameworks. As seen in Figure 1, the conceptual framework for this evolving field incorporates aspects of the Aday and Anderson model but also incorporates systems theory,71-74 social-ecological systems theory,63,75 role theory,76 and stress theory into the framework.77-78 This integration highlights that stress on any person in the family system has a major influence on the health of all family members. Moreover, this program of research hypothesizes that the biopsychosocial burden on the family as a result of the child’s chronic illness may mediate, in part, the relationship between sociodemographic characteristics and health disparities among these children and their families.

**Funding/Support:** This project was supported with grants from the National Institute of Child Health and Human Development (grant numbers HD049533 and P30HD03352 [Witt]) and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (grant number 3 U01 PE000003-06 [DeLeire]). The opinions and conclusions expressed herein are solely those of the author(s) and should not be construed as representing the opinions or policy of any agency of the federal government.

**Financial Disclosures:** None declared.

**REFERENCES**

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