



HHS Public Access

Author manuscript

Cardiol Young. Author manuscript; available in PMC 2019 March 01.

Published in final edited form as:

Cardiol Young. 2018 September ; 28(9): 1142–1150. doi:10.1017/S1047951118000963.

Parental Stress and Resilience in Congenital Heart Disease: A New Frontier for Health Disparities Research

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Abstract

Parental stress is a universal experience for parents who have children diagnosed with congenital heart disease and has been studied within the context of the child's illness but not through a broader health disparity lens. This paper provides a thorough synthesis of the current literature on parental stress addressing disparities in parents of children with CHD. Several theories and models from within this literature are described and a new comprehensive framework, the Parental Stress and Resilience in CHD Model is presented. Future research and clinical implications are discussed.

Keywords

Parent; stress; resilience; congenital heart disease; mental health; health disparities

Introduction

Health disparities research has received much attention in the last two decades¹. Variables of race, ethnicity, gender, sex, and socioeconomic status have emerged as key influencers of environmental resources, relative risk, human capital, and social status². Ethnic, racial, and socioeconomic disparities exist related to the incidence and outcomes for children with Congenital Heart Disease (CHD)^{3–6}. Yet the extent to which these disparities impact the experience of stress for parents of children with CHD is unknown. Parents of children born with CHD experience profound stress, from the time of diagnosis, through the infant's hospitalization for cardiac surgery, and in the months and years that follow^{7–11}. While survival for neonatal cardiac surgery has dramatically improved, children remain at risk for neurodevelopmental delay, including fine and gross motor, speech, cognitive, behavioral, and academic difficulties¹². Many children must return for additional surgeries or interventions throughout childhood, compounding the stress experience for parents⁹. While these procedures are considered either corrective or palliative, the underlying CHD leaves these children with a chronic illness. The stress of parents across the lifespan of the child with CHD will impact overall family functioning and the child's home environment,

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Conflicts of Interest

None

influencing the neurodevelopment of the infant throughout childhood¹³. Parental stress can also affect the parent's own physical health, mental health, overall well-being, and quality of life^{14,15}. Furthermore, studies have shown that parents of children with CHD experience more intense stress than parents of other pediatric populations, and that stress may be of particular concern when the child is less than one year of age^{10,11,16-18}. This finding highlights the imperative for health care providers to pay focused attention to this issue and to address parental stress early and systematically. But the question remains: do additional disparities impact parental stress and ultimately parent and child health outcomes?

Currently, no model exists describing the experience of stress for parents of children with CHD and its full impact on the family across the child's lifespan. Parental stress in CHD has been studied within the context of the child's illness, around the times of diagnosis, surgery, hospitalization, and after discharge home^{7-9,16,18,19}. Most of these studies on parental stress were framed within the context of the child's disease and few had strong theoretical foundations. The disease-specific focus on parental stress research in CHD has not comprehensively elucidated factors related to health disparities. While some studies in CHD acknowledge the influence of specific types of health disparity variables on parent stress, such as parental education or socioeconomic status, the lack of research examining constructs within a broad parental stress framework is apparent. Studies on parental stress for parents of children with CHD have largely reported health disparity variables as incidental or secondary findings, or have included them as a covariate in their analysis and not expanded on their implications²⁰. A comprehensive framework for parental stress in CHD would provide a broader lens with which to understand the full experience of stress for this population of parents.

The lack of theoretical underpinnings in parental stress research in CHD has also resulted in the use of a variety of constructs to study the stress of parents, including but not limited to parental stress, parenting stress, distress, psychological adjustment, trauma, and mental health. The transactional theory of stress originally described by Lazarus and Folkman²¹ has provided a foundation for many stress studies and frameworks for parental stress research. Lazarus and Folkman define stress as an overarching term, encompassing a stressor, or something perceived and appraised by the individual as taxing, which stimulates a stress response. Parental stress refers to any stress that is perceived by an individual while in the role of parent for a child. Parenting stress refers to the specific stressors arising from the parenting role, whereas parental stress is more broad, encompassing all potential stress experienced by a parent. For this review, distress and psychological adjustment will be considered specific types of responses to parental stress. It is of utmost importance that research utilize a theoretical foundation to define these constructs, and that variables be organized within a specific model to guide the research from conception to design and from data analysis to interpretation.

This paper will brief overview of the parental stress literature addressing disparities in parents of children with CHD. Several theories and models will be presented from within the CHD literature as well as from other pediatric populations. Based on the synthesis of the literature, a new comprehensive model for parental stress in CHD will be proposed. Future research and clinical implications will be discussed.

Review of Literature

To date, research on parental stress in CHD has focused on the influence of the child's severity of cardiac disease, caregiving burden, or coping to identify predictors of stress or stress response in parents. Some studies, however, have uncovered disparities that exist. As opposed to providing a systematic literature review on stress and coping of parents with CHD and their mental health outcomes, which has already been recently presented^{20,22,23}, this review will focus on the health disparity outcomes found in the cardiac literature and compare and contrast it with parent stress literature from other populations.

Socioeconomic Status and Social Status

Education status may influence the stress of parents of children with CHD²⁴. Education status has been frequently used in research as a proxy for socioeconomic status and/or social status in family research²⁵. Many studies on parents of children from various populations (CHD, general surgery, pediatric cancer, irritable bowel syndrome, and trauma) have found that education status influences stress for parents, with lower education associated with an increased risk for stress and post-traumatic stress symptoms^{14,26-31}. Mothers with higher education who had infants in neonatal intensive care were shown in one study to experience significantly higher stress response, as measured by state anxiety³². This was also found to be true in one study from the cardiac population that examined mothers of children with CHD³³. More research is needed to determine the influence of education on parental stress.

Other measures of socioeconomic status including income and occupation have been shown to influence parental stress. Parents with low income or financial difficulty experience an increase in both perceived stress, chronic stress, and stress response^{31,34,35}. The financial burden arising from the child's chronic illness has been noted in cardiac and non-cardiac populations^{36,37}. Spijkerboer and colleagues found that low socioeconomic status classified by occupation type influenced greater psychologic distress in parents of children treated for CHD³⁸. Lower scores on mental well-being, as measured by the General Health Questionnaire, were found to be significantly correlated with poverty in parents with a child undergoing cardiac surgery³⁹. Another study examined parental stress levels in a pediatric cardiac ICU and step down unit and found that parental stress scores were negatively correlated with poverty level and that foreign born mothers had significantly higher stress during their child's hospitalization¹⁶. They concluded that poverty, place of birth, and citizenship may all play a role in predicting parental stress levels. Other studies in both cardiac and non-cardiac populations have also proposed that foreign born parents or immigrants experience lower social status than parents living in their place of birth. These studies have shown that parents with this particular vulnerability are at risk for higher stress symptoms^{9,14,27,34,40}.

Sex

Fathers are often overlooked in maternal and child health research³⁴; however, the role of the father for child well-being should not be ignored. Studies from community samples confirm that the mental health of fathers influences the child's behavioral and emotional development, as well as later psychopathology, independent of the mother's mental

health^{41,42}. Unfortunately, much research on parental stress has focused on mothers, yet studies including fathers have found differences. Studies on parental stress in both cardiac and non-cardiac populations have shown that mothers and fathers perceive stress and react to stressors differently^{26,32,37,43-49}. The majority of research has shown that mothers score significantly higher on stress and anxiety measures^{9,17,26,46}. For parents of children with CHD, mothers have been shown to have significantly higher distress, anxiety, depression, and somatization than fathers^{9,18,49-52}. Mothers and fathers have also been shown to use different coping mechanisms to adjust to stressors as parents of children with CHD^{19,23}. Furthermore, the literature is replete with examples of how sex differences exist in the physiology of the stress response between men and women across the life span⁵³⁻⁵⁸. Due to these clear differences, it is important to consider sex as a biomarker in research on parental stress.

Most research on parental stress tends to only include mothers or have increased participation by mothers, creating a bias in the sample^{7,20,59}. This may create an unfortunate disparity in the literature and potential bias of interpretation on the experience of parental stress for fathers. In addition, no research has been published that specifically addresses parental stress in CHD for same sex couples, adoptive parents, or single parents. It has been shown in community samples that single parents living alone are at higher risk, bearing a greater burden of stress^{29,60}, and that love between partners, regardless of sexual orientation, can mediate parental stress^{14,61}. Furthermore, cohabitation seems particularly important³⁴. One study concluded that cohabitation with a partner was “a major determinant of stress during pregnancy and the year following birth for parents, especially for mothers. What mattered most in this sample was living together at the time of birth, not whether the couple was legally married at that time”³⁴ (p. 623).

Additional Health Disparity Variables

Several variables were not identified in the cardiac literature, but should be considered when examining health disparities, including race, language barriers, physical health, stigma, and social capital. General population studies on parenting stress have found an increased risk of high stress in parents who are Black, Hispanic, or non-English speaking^{14,34}. Unfortunately, most research on parental stress in CHD has been conducted with mainly White samples or have not reported race as a demographic variable^{7,16,24,37,47,51,62-69}. Additionally, study design for parental stress in CHD research in the United States, United Kingdom, Canada, and Australia often limits inclusion criteria to subjects who have the ability to read or write English, or the authors do not mention translation of research instruments^{7,24,37,47,51,62-65,67,68,70}. Furthermore, a parent’s own health or special needs status can exacerbate the parental stress experience for parents¹⁴. Mothers of infants with CHD are especially vulnerable after giving birth and recovering from a vaginal delivery or cesarean section³⁷. Stress arises when parents are not well, in pain, or limited in their ability to care for their child. Additional consideration can be given to the stress occurring from stigma associated with certain health issues like obesity, diabetes, and even stress and mental health itself⁷¹⁻⁷³. Stigma can also be experienced by parents for a variety of reasons based on race, gender, and sexual identity, among others, and has been shown to greatly contribute to stress and impact health^{72,74,75}. Finally, social capital, defined as social cohesion and

community networks, is emerging as a variable contributing to health and mental health outcomes in disparities research^{76,77}. While few studies have examined its influence on parent stress, one study in Vietnam has demonstrated the influence of social capital on the distress of mothers who have children with disabilities⁷⁸.

Review of Theoretical Frameworks on Parental Stress

In 2006, Mussato provided a review of literature in *Cardiology in the Young* on theoretical frameworks on child and family adaptation and illness⁷⁹. In her review, she highlighted constructs integral to the adjustment of families with a child who has a chronic illness and proposed an adapted framework (Figure 1). Mussato posited that prior experience with stress, the child's illness-related factors, anxiety, and family developmental stage would all influence the parents' perception of the initial stress of the child's diagnosis with a chronic illness. In addition, she proposed that the ability of the parents to cope with the stress of the child's chronic illness is impacted by their social support and resources, hardiness, problem solving, and communication skills.

Mussato's model includes essential components influencing the stress experience for parents of children with CHD, such as stress appraisal, coping, and adaptation, mirroring similar frameworks cited in the literature including Thompson's Transactional Stress and Coping model of adjustment to chronic illness⁸⁰ and McCubbin and Patterson's Double ABCX Model of Adjustment and Adaptation⁸¹. She also highlighted the importance of social support on parent and child well-being, which has been proposed and validated by other frameworks, such as the Family Stress Model³⁰. From a broader perspective, however, none of the constructs directly address issues regarding health disparities. Some, however, can be inferred. Prior experience with stress, for example, is important when considering how individuals perceive stress, cope, and react to stress, which in turn can influence long-term physical and mental health outcomes. Prior stress, when chronic, has been referred to in the literature as allostatic load, which occurs when physiologic systems adapting to stress are overworked, do not shut off after a stressful event, or under-respond to stress causing other systems to overwork⁸². Like Lazarus and Folkman's definition of stress in which a stressor elicits a stress response²¹, the allostatic load model proposes that:

“the perception of threat and mobilization of these allostatic mechanisms are fundamentally shaped by individual differences in constitutional (genetics, development, experience), behavioral (coping and health habits), and historical (trauma/abuse, major life events, stressful environments) factors that ultimately determine one's resiliency to stress”⁸³(p.3).

Studies have demonstrated the physical and biopsychosocial impact of allostatic load across the lifespan⁸³. The accumulation of allostatic load can overexpose the body to pro-inflammatory mediators of stress, resulting in adverse effects on body organs and systems, ultimately leading to disease onset and/or progression⁸⁴. Both acute stress and chronic stress can contribute to allostatic load. What is wholly unknown is the impact of past chronic stress on parental stress and on parent and child health outcomes in CHD. Furthermore, parental stress in CHD could perhaps be considered its own form of chronic stress, contributing to the allostatic load on parents. Consideration for both acute and chronic stress is paramount

in the examination of allostatic load, the overall stress experience, and its impact on parent health and well-being.

Examining both chronic and acute stress for parents of children with CHD will also elucidate important health disparity variables impacting overall stress and allostatic load³⁴. Chronic stress is a wide category of stressors defined as the “ongoing demands that threaten to exceed the resources of an individual in areas of life such as family, marriage, parenting, work, health, housing, and finances”³⁴(p. 616). Chronic stressors are more prevalent for parents of racial/ethnic minorities, who tend to live in more impoverished settings with crime, pollution, and fewer resources³⁴. Acute stressors are those conditions or events that occur with a clear beginning and ending, such as the death of a loved one, divorce, injury, or catastrophic event. Within the context of CHD, the child’s diagnosis and day of surgery could be considered acute stressors for parents, but parents are not isolated from exposure to other acute stressors as well. The examination of different forms of stress can more fully describe the influences of stress on parent health disparities³⁴. These forms include financial stress, pregnancy stress, life events, chronic life stress, perceived stress, interpersonal violence, perceived racism, and parenting stress. A more accurate conceptualization of parental stress in CHD must include all of these forms of stress that individuals can experience while in the role of a parent for a child born with CHD.

Another model worth review is The Preconception Stress and Resiliency Pathways Model, which was developed through an interdisciplinary initiative of the National Institutes of Health and the National Institute of Child Health and Human Development to address health disparities in pregnancy and child developmental outcomes⁸⁵. Major elements within the model include the

“centrality of the preconception/inter-conception period, role of fathers and the parental relationship, maternal allostatic load (a composite biomarker index of cumulative wear-and-tear of stress), resilience resources of parents, and local neighborhood and community level influences (e.g., employment, housing, education, health care, and stability of basic necessities)”⁸⁵(p. 707).

The model also highlights the inextricable link between parent stress and parent mental health with child neurodevelopment, health, and behavior outcomes. For parents of children with CHD, this link cannot be understated, yet remains under researched. However there is growing recognition to explore parental stress and its influence on child development in CHD¹³.

Finally, The Preconception Stress and Resiliency Pathways Model addresses an important concept related to stress: resilience. Historically, resilience has been defined in varying ways, as a response to stress, a final outcome, a protective factor, or as a return to baseline after a stress-inducing experience⁸⁶. Scholars who seek to apply resilience to chronic stress have criticized these definitions of resilience and argue that a more broad conceptualization is needed. More recently, resilience has been defined as “a state of adaptation to a lifetime of stress and strain”(p.13)⁸³. The Preconception Stress and Resiliency Pathways Model defines the concept as an overarching process and capacity of an individual, not an isolated factor or outcome, using resilience resources such as perceived social support, spirituality and

religious practices, cognitive and coping skills, and tangible resources to resist the effects of long term stress⁸⁶. Resilience is then a “process involving an ability to withstand and cope with ongoing or repeated demands and maintain healthy functioning in different domains of life such as work and family”⁸⁶(p.637). Within the context of parental stress in CHD, resilience can be defined similarly as the process and capacity of individuals to positively adapt and cope to stressors while in the role of parent for a child with CHD. This process of resilience will influence the stress response of the parent and the overall health and wellbeing of parent and child.

Revised Conceptual Model

Using the themes and constructs from the theoretical models reviewed above as well as synthesis of literature from the pediatric cardiac population, community samples, other pediatric populations, and vulnerable populations, a new conceptual model, the Parental Stress and Resilience in Congenital Heart Disease Model, was created to provide a comprehensive perspective on parental stress (Figure 2). This new model will provide a broader lens through which researchers and clinicians can examine and support parental stress in CHD. A more comprehensive understanding of parental stress through this model will help to identify health disparity variables influencing parental stress and inform the development of interventions to support all parents and their children with CHD.

The Parent Stress and Resilience in CHD Model acknowledges that prenatal factors occurring in the preconception period will have lifelong impact on the parent as well as the child with CHD⁸⁵. Evidence is growing suggesting that the biologic stress response of mothers, specifically that of the hypothalamic-pituitary-adrenal axis dysregulation, before and during pregnancy, can have profound impact on the future mental and physical health of the mother’s offspring^{34,85,87}. Past chronic stress from poverty, racism, residential segregation, community violence, and stigma will also contribute to the biologic impact of stress on the mother and child in utero^{34,74,85,88}. In addition, this model posits that both acute and chronic stressors³⁴ arise from three categories^{7,37}: infant/child with CHD, environment, and parent^{7,37}. Child related factors include the child’s gestational age at birth⁸⁹, current age^{16,29}, illness related factors^{9,11,60,66,68,89–91} (severity of illness, length of hospitalization, developmental delay, other genetic issues), length of hospitalization after cardiac surgery⁶⁰, child temperament and behavior^{10,64,66}, and caregiving burden^{18,92–94}. Environmental stressors can occur from the home environment⁸⁵ (such as family functioning²³ and number of children⁷) as well as the parent partner/marital relationship⁸⁵. Neighborhoods or communities with violence, crime, poor resources, and pollution generate an added challenge for parents⁸⁸. Parents living in neighborhoods located a far distance from a children’s hospital or who have poor access to care may also experience greater stress³⁷. In addition, social stigma experienced by parents in their environment as well as social capital will influence parent stress and overall health^{74,77,78}. Stressors arising from the parent include a myriad of personal factors including age⁹⁵, sex^{50,52,96}, race and ethnicity^{14,34}, trait anxiety^{7,96}, personality³⁷, worry⁶⁶ and uncertainty of illness^{60,97}. The parent’s socioeconomic status and social status^{18,24,30,96,98}, any past or current life stress or life events⁹⁵, as well as the parent’s own health²⁹ contribute to the stress faced by parents. In addition, the perception of the child’s severity of illness^{37,69} as well as the parent’s

knowledge or lack of knowledge about the child's health and CHD^{99,100} influence parental stress. Finally, parental role⁷, parenting¹⁰, and attachment/bonding¹⁰¹ impact the stress experience for parents.

Coping^{46,60,97}, social support^{18,26,30,44,46,63,96,102,103}, caregiving self-efficacy¹⁰⁴, locus of control²⁶, and other resilience resources^{85,86} (spiritual and religious practices and beliefs^{70,99}, financial and tangible resources, and support from health professionals^{70,97}) mediate between the perception of stressors and stress response for the parent of a child with CHD. Both psychologic and physiologic forms of stress response can occur^{7,37}. Psychologic forms of stress response manifest as feelings of anxiety⁷, depression⁹³, and/or hopelessness⁹⁸, as well as clinical symptoms of acute stress disorder^{46,51}, post-traumatic stress symptoms⁶⁰, or post-traumatic stress disorder⁴⁰ in some. Physiologic stress responses include parent biomarkers⁸⁵, somatization¹⁸, and allostatic load^{34,82,85}.

Over time, the cumulative impact of the stress/coping/response cycle in parents and the process of resilience will influence parental mental and physical health⁸⁵, behavior⁸⁵, parenting²⁴, well-being¹⁰⁵, health care utilization¹⁴, quality of life^{15,69,89}, and adjustment^{15,24}. Parents may also experience Post-Traumatic Growth, a positive change through the process of resilience that includes improved self-perception, self-esteem, confidence, and personal power, increased compassion and authenticity with others, and an enhanced philosophy of life that brings meaning and maturity from past difficult circumstances¹⁰⁶. These parental outcomes will ultimately influence the child's mental and physical health¹⁰⁷, behavior and neurodevelopment^{11,108}, and quality of life¹⁵.

Implications

The newly created Parental Stress and Resilience in CHD Model will provide a helpful foundation for clinicians and researchers to create interventions to reduce stress and the subsequent impact of stress for parents of children with CHD and improve overall family well-being, quality of life, and child development. The model reveals that a one-size-fits-all approach will not be successful in adequately addressing the many facets influencing the stress experience to support the process of resilience for parents of children with CHD. However, there are interventions that all centers caring for children with CHD and their parents should implement as a standard of care.

First, substantial evidence exists that the support of parental and child mental health should become a priority for the care of patients with CHD and their families. Interdisciplinary teams should address this priority in all centers caring for patients with CHD and should include mental health professionals such as psychologists. Mental health screening for issues of stress, anxiety and depression need to be initiated for parents at diagnosis⁴⁹ and during the child's hospital stay for cardiac surgery^{24,109}. Early and regular screening for mental health problems should continue at outpatient clinic visits throughout the child's first year of life²². Routine screening for mental health problems will assist health care providers in identifying parents who need early psychological support by social work or psychology. In addition, routine screening should include assessment of social risk, prior trauma, and other risk factors for parental stress and negative mental health outcomes identified by the Parental

Stress and Resilience in CHD Model. Until routine screening becomes the standard of care for all centers, it will be difficult for centers to systematically address the specific needs regarding health disparities of parents and their children with CHD.

Psychological support interventions have been proposed and studied in parents of children with CHD. Prenatal counseling and support can reduce anxiety, especially for fathers⁴⁹. In-hospital preoperative education also reduces anxiety for parents whose child is undergoing cardiac surgery¹¹⁰. Psychoeducation tailored to parents of infants with CHD that includes coaching for improved coping abilities, caregiving self-efficacy, and parenting skills (such as reading the infant cues and activities to promote development) has also shown promise¹¹¹. Most recently, mindful meditation has been proposed as a potential strategy for coping while the child is in the hospital for cardiac surgery¹¹². Future research should determine whether these interventions mitigate parental stress for parents who are experiencing disparities as well as ensure that the interventions do not widen any disparities by disproportionately benefiting parents at lower risk¹¹³. Integrating routine mental health screening by mental health professionals coupled with standard educational and psychoeducational interdisciplinary programs at targeted, at-risk periods (prenatal diagnosis, infant birth and hospitalization for cardiac surgery, at discharge and in the early months following) only represent the first set of interventions we must provide to all parents. Community-based participatory research including parents who may be at risk for disparities would be a useful methodological approach in designing future interventions that target at-risk populations.

Additional attention should also be given to family-centered care and family-based interventions as an essential strategy to reduce the mutual influences of stress between parent and child¹¹. Some studies have specifically suggested ways to enhance parental role beginning in the pediatric cardiac ICU by providing opportunities to increase bonding and attachment between parent and child^{7,22}, which is uniquely threatened when a child is diagnosed with CHD^{65,114–117}. It is well established that early attachment behaviors between parent and child independently influences parent mental health and child physical, behavioral, and emotional development^{107,118,119}, and this relationship has been confirmed in one study of mothers and children with CHD¹²⁰. More attention must be given to this area of research and intervention. Other family-based interventions such as a family liaison nurse or a home visiting nurse would provide an added layer of support to families in parenting and caring for their child. These types of home visits have also been successful to support particularly vulnerable populations such as mothers with low SES¹²¹.

Social support has already shown to be effective in reducing some of the psychological and family outcomes of stress for parents of children with CHD^{18,44,90,100}, in parents of critically ill children¹⁰², and in parents of children with other chronic illnesses³⁶. More attention is needed, however, by both researchers and health care providers to assess parents' current social support systems and provide ways to enhance their social network. One study by Lawoko and Soares found that significant predictors existed that placed parents at particular risk for limited social support: increased caregiving time, foreign-born parents, unemployment, financial burden of CHD, and increased levels of distress and hopelessness⁹⁴. While social support is needed by all parents and is critical for parent-child health and well-being³⁰, a sobering reality exists: the very parents who are the most

vulnerable also have the highest risk for being the most isolated. Innovative strategies are needed to foster social support networks for these vulnerable groups. Furthermore, social networks differ based on culture and race. One example is that Black/African American parents often rely on grandparents or other family members to help care for their children, whereas White/Caucasian parents use non-family networks, such as friends or neighbors¹²². Social support interventions must be tailored based on individual need, resources, and cultural considerations. In addition, disparities have been identified in low-income families with respect to positive parenting practices that support child development. Parents from low-income households are less likely to participate in frequent, high quality positive parenting practices, including reading, singing, and interactive play, which are associated with increased risk of child developmental delay¹²³. Higher perceived social support has been correlated with increased positive interactions between parent and child³⁰. Social support is a promising target for intervention to reduce parent stress while also promoting child development. The development of social support beyond the neighborhood and community context should also be considered. In the last decade, social networks have been created through organizations and social media¹²⁴. Parents of children with CHD are interested in joining organizations to meet other parents¹⁰³ or using social media sites to enhance their support network¹²⁵. Research has begun to emerge revealing how social media sites such as Facebook can be used to provide social support to individuals during health-related events¹²⁶. Much more research is needed to understand the extent to which social media communities and other organizations support parents of children with CHD and how social risk may impact access to and utilization of these supports.

Many more interventions could be created to address issues proposed by the Parent Stress and Resilience in CHD Model and a comprehensive listing of potential innovations is beyond the scope of this review. However, the model elucidates certain vulnerabilities for parents that can be targeted in future research or clinical projects. Efforts must be given to support parents with low social status, directing particular attention to parents who are foreign born, non-English-speaking, single parent, low-income, of a minority race or ethnicity, or from an at-risk community with fewer resources.

Conclusion

This comprehensive review of literature on parent stress synthesized with research from other pediatric populations, uniquely conceptualized parent stress through the lens of health disparities. A new conceptual framework, the Parental Stress and Resilience in CHD Model, describes a broad view of parent stress with health, well-being, and quality of life implications for both parents and their children with CHD. Health care providers and researchers alike can utilize this model to design clinical projects, research studies, and innovative interventions to mitigate stress and promote resilience for all families, regardless of their risk for health disparities. The reality of allostatic load, arising from acute and chronic stress, and its biopsychosocial impact on families with a child diagnosed with CHD must be a focus of future study. Furthermore, the link between parental stress and child emotional, behavioral, and neurodevelopmental outcomes should become a priority for research in the next decade.

Acknowledgments

The author would like to thank several colleagues for their review and thoughtful feedback on this manuscript: Dr. Barbara Medoff-Cooper, Dr. José A. Bauermeister, Dr. Lisa M. Lewis, Dr. Kaitlin M. Best, and Dr. Abigail C. Demianczyk.

Financial Support

This work was supported by the National Institute of Nursing Research (NINR T32NR007100).

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Figure 1.

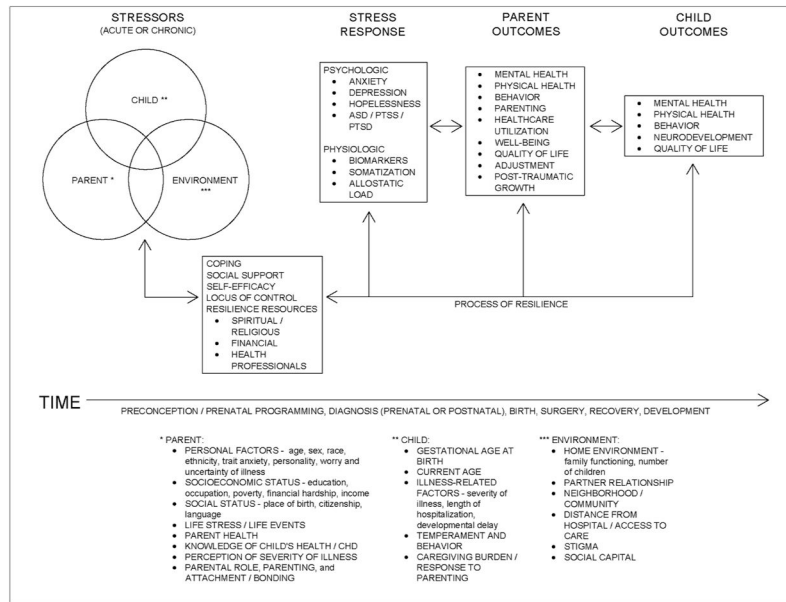


Figure 2.