

FAMILY HEALTH EQUITY IN CHRONIC DISEASE PREVENTION AND MANAGEMENT

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Introduction/Purpose: Efforts to improve chronic disease outcomes among US adults highlight families, particularly support from families, as a key aspect of disease prevention and management. To date, however, an overwhelming focus on individual-level outcomes and unidirectional support (eg, from a family caregiver to an identified care recipient) belies the existence of co-occurring health concerns and interdependent care. There are increasing calls for more sophisticated and intensive family health interventions that better integrate family-level factors, processes, and outcomes to provide comprehensive family support services in health care and community-based settings.

Methods: This commentary provides key considerations for advancing this work while centering family health equity and families themselves in health initiatives.

Results: Several critical barriers are identified and discussed. For example, a narrow focus on family and inadequate measures of family-level disease burden make it challenging to understand how the disproportionate burden of chronic disease observed among individuals of lower socioeconomic status and certain racial and ethnic groups compounds and complicates family health experiences. In addition, limited attention to the interaction between individuals, families, and broader sociocultural factors that influence family resources and constraints, such as racism, hamper program design, implementation, and evaluation.

Conclusion: To center families in efforts to reduce chronic disease disparities, it is necessary to move beyond superficial attention to the complexity of disease prevention and management within the family context. This commentary serves to enhance understanding of important drivers of family-level chronic disease outcomes, while providing important considerations for advancing research and practice. *Ethn Dis*. 2023;33(4):194–199; doi:10.18865/ed.33.4.194

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INTRODUCTION

Within the next decade, it is expected that nearly half of all individuals in the United States will be diagnosed with a chronic health condition, and a disproportionate number of those individuals will be adults who identify as Black, Indigenous, and people of color (BIPOC). Resources are deservedly being given to improving equity in the prevention and management of these preventable and long-lasting conditions. Because family is an important social system that helps BIPOC thrive despite marginalization and injustice, and a key context for chronic disease prevention and management, many of these efforts will likely include (to varying degrees) family members and/or be substantially influenced by the family context. As such, it is critical that family health equity be front and center in this work.

FAMILY HEALTH EQUITY

Existing definitions of health equity (see Table 1) provide a useful foundation

upon which to construct a working definition of family health equity. Family health equity can be described as both a process and outcome that includes the provision of fair and just resources and opportunities to all families (*process*) so that families can attain the best health possible for the family as a collective and its individual members (*outcome*). A family health equity perspective provides a specific lens through which to view the challenges and opportunities associated with improving equity in chronic disease outcomes. Specifically, achieving family health equity in chronic disease requires a commitment to understanding “family” within family systems; enhancing methods of measuring and monitoring family health outcomes; being intentional about considering families in disease prevention and management efforts; and embracing the complexity of family-centered health equity initiatives.

UNDERSTANDING “FAMILY”

Most scholars would agree that families are important for health; however, some may be unfamiliar with the depth of research in this area. While a comprehensive review is beyond the scope of this article, a substantial body of research across disciplines such as sociology, family studies, anthropology, and social work has demonstrated that families are key social institutions¹ with family units themselves described as

Table 1. Example definitions and descriptions of health equity

Source	Definitions and descriptions	Key elements
Robert Wood Johnson Foundation Braveman P, Arkin E, Orleans T, Proctor D, Plough A. <i>What Is Health Equity? And What Difference Does a Definition Make?</i> Princeton, NJ: Robert Wood Johnson Foundation; 2017.	"Health equity means that everyone has a fair and just opportunity to be as healthy as possible. Achieving this requires removing obstacles to health—such as poverty and discrimination and their consequences, which include powerlessness and lack of access to good jobs with fair pay; quality education, housing, and health care; and safe environments. For the purposes of measurement, <i>health equity</i> means reducing and ultimately eliminating disparities in health and in the determinants of health that adversely affect excluded or marginalized groups." ^{p2}	Health equity viewed as both an outcome and a process
World Health Organization World Health Organization. Health equity. World Health Organization. June 6, 2023. Last accessed July 13, 2023 from https://www.who.int/health-topics/health-equity	"Equity is the absence of unfair, avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequality (e.g. sex, gender, ethnicity, disability, or sexual orientation). Health is a fundamental human right. Health equity is achieved when everyone can attain their full potential for health and well-being." ^{para1}	All differences are not inevitable; health equity is a human right
Health Equity Framework Peterson A, Charles V, Yeung D, Coyle K. The health equity framework: a science-and justice-based model for public health researchers and practitioners. <i>Health Promot Pract.</i> 2021;22(6):741-746.	"... having the <i>personal agency</i> and <i>fair access to resources and opportunities</i> needed to achieve the best possible physical, emotional, and social well-being." ^{p742}	Human agency is necessary; health has many dimensions
National Institute of Minority Health and Health Disparities (NIMHD) NIMHD. <i>Health Equity</i> [fact sheet]. National Institutes of Health. Last accessed June 7, 2023 from https://www.nimhd.nih.gov/docs/uhd_healthEquity_factsheet.pdf	"Health equity is the principle underlying the continual process of assuring that all individuals or populations have optimal opportunities to attain the best health possible. Applying the principle of health equity requires that barriers to promoting good health are removed and resources are allocated among populations and/or communities proportional to their need(s). . . Health equity is not a specific outcome or end point but includes measurements across factors that influence health . . ." ^{p1}	Recognizes the importance of measurement

individual and collective own social systems. A family systems perspective recognizes that the interactions between individuals within a family—and interactions with that system and the broader environment—are key to understanding individual and collective health and well-being. Family systems have norms, values, and beliefs that shape individuals' behaviors and interactions with each other (ie, at individual and family levels) and those outside the systems (eg, community and clinical contexts). Family systems vary over time in size, roles, and functions in relation to internal (eg, life transitions, values) and external factors (eg, social and economic policies). Definitions of family that consider the diversity of family structures and attention to

family functioning (eg, mutuality and interdependence) are central to the current discussion.

Defining Family

Greater attention to the structural diversity of families—and the individuals and relationships represented within them—is critical for responding to the upstream, midstream, and downstream social conditions that foster health inequities.² There is broad usage of narrow definitions of family in policy and practice, which consider only nuclear families consisting of parents and dependent child(ren) younger than 18 years living in the same household. The CHIEF framework—capturing Chosen, Household, Immediate, Extended, and Fictive

kin—is one such effort to help scholars and practitioners systematically consider and make intentional choices regarding this structural diversity in research and practice.³ This mnemonic device is useful for prompting discussions of who is included and excluded in work with families, highlights the role of important and family-like nonbiological relationships known to influence health outcomes (ie, chosen family, fictive kin), rationale for these decisions, and potential implications of the work.

Family Functioning

In addition to considering families structurally, it is also important to think about families functionally, that is, consideration of what families do with and

for each other, including provision and receipt of social support, perceptions of reciprocity, and family stress and coping. When we look closer at interventions in community and clinic settings that work directly with families affected by chronic disease, however, we often see limitations in attention to family functioning (eg, communication, cohesion, capacity, adaptability). For example, there is an overwhelming focus on individual-level processes and unidirectional support (eg, support from a family caregiver to an identified care recipient) in chronic disease prevention and management interventions. This approach belies the existence of important family-level care functions such as mutual, interdependent care. Prudent incorporation of factors that more readily attend to family involvement and collaboration⁴ in chronic disease prevention and management programs, models, and policies is a critical step toward improving family health equity.⁵

ENHANCING METHODS AND MEASUREMENT

There is considerable variation in the manifestation of chronic disease, types of chronic conditions, and disease severity. This variation, and disease-specific factors (eg, management needs), has implications for the measurement and analysis of family-centered research. At the most basic level, reporting the chronic conditions presently affecting a family system at a specific point in time (eg, by type, number, combination, and degree to which these health conditions are managed) remains a complicated and elusive endeavor. In addition, inadequate measures of family-level disease burden make it especially challenging to understand how the disproportionate burden of chronic disease observed among individuals from marginalized groups can compound and complicate family health experiences.

Early Attention to Measurement

One of the earliest examples of a family-level measure of chronic disease in published academic literature is found in a sparsely cited study of the “chronic disease family.”^{6(p589)} The study was conducted in the Eastern Health District of Baltimore and consisted of approximately 15,000 White or “Colored” families or households. The dated terminology of *Colored* to describe Black Americans reflects the racial climate of the day. Their further exclusion from this study does as well: the remainder of the article and analysis focuses solely on chronic illnesses among White families in the district.

In the mid-1970s, the World Health Organization reported on the work of the Study Group on Statistical Indices of Family Health.⁷ The group outlined several approaches to the study of family health. For example, the demographic approach included a recommendation to collect and consider data about family members, including who is ill and how many members are affected by a specific illness or condition. In their discussion of the epidemiologic approach, they called for new indices that could help to identify families at higher risk of mental or physical health problems, reductions in family functioning, and to inform the implementation of health and social service resources. The social approach, which recognizes the family as an important unit of health with its own “patterns of morbidity, responses to symptoms, and utilization of medical facilities,”^{7(p20)} was hampered by lack of routine data collection about patterns of health in families. Many of the recommendations and limitations discussed 50 years ago remain relevant today.

Family Comorbidity and Family Multimorbidity

In 2003, Burton and Whitfield⁸ introduced the term *family comorbidity* based on the findings from the *Welfare, Children, and Families: A Three-City*

Study conducted in San Antonio, Boston, and Chicago between 1999 and 2003. One of the key objectives of this study was to understand the prevalence of physical and mental illness within low-income families. All the families had at least 1 child aged 2 to 4 years and household incomes below 200% of the federal poverty line. Most of the sample participants (82%) were BIPOC, with Hispanic or Latino respondents and African American respondents comprising most of the sample. The term *family comorbidity* was used in reference to the observation that in 4 of 10 families, the primary caregiver and at least 1 of the children reported poor physical and mental health. More recently,⁹ the term *family multimorbidity* was also introduced, defined as the co-occurrence of multiple chronic conditions within a family system without the identification of an index person or illness. While the terms *family comorbidity* and *family multimorbidity* readily parallel measurement at the individual level, the implications for interventions should not be overlooked. Framing research studies and discussions with families themselves about the rationale or need for a family intervention because one of the members has a specific condition (eg, cancer, diabetes) requires different considerations than work with families that is tied to collective illness risk or burden.

FAMILY HEALTH EQUITY AND INTERVENTION CONSIDERATIONS

The family unit is often considered the cornerstone of stability and resilience for BIPOC communities and therefore is a natural place for family-focused health intervention to be embedded.

Family Prevention and Management

Denham,¹⁰ creator of the Family Health model, notes that ambiguity

Table 2. Examples of family-involved and family-focused chronic disease interventions

	Family-involved chronic disease intervention	Family-focused chronic disease intervention
Focus of primary outcomes	Individual with a specific health concern	Health outcomes of multiple family members
Participants	Individual with a specific health concern of interest and family member(s); the person with the specific health concern of interest is the primary focus of attention (index person)	Multiple family members (2 or more); could include family members with similar or different health concerns of interest (eg, cancer, diabetes, hypertension, lupus)
Key distinction	Index person included in an intervention to improve their chronic disease–related outcomes; family members are included in the intervention to provide support to the identified index person	Multiple members of a family system are included in an intervention to improve their chronic disease–related outcomes; family members as providers and receivers of support to each other in an intervention
Direction of support	Unidirectional: from family member(s) to the index person with specific health condition	Bidirectional: between family members
Types of support	Various, eg, emotional, instrumental, informational, appraisal	Various, eg, emotional, instrumental, informational, appraisal; of note, type, timing, and intensity of support between members will likely vary
Potential guiding theories or frameworks (not exhaustive)	Theory of Planned Behavior; Health Belief Model; Social Cognitive Theory	Revised Self-Management and Family Management Model; Interdependence Model of Communal Coping and Behavior Change; Social Cognitive Theory
Example mechanism(s) of change - social cognitive theory	Self-efficacy for chronic disease management, ie, belief in one's ability to take necessary steps to manage one's chronic disease	Self-efficacy and <i>collective efficacy</i> , ie, belief in the family's collective power to work together to manage chronic diseases affecting members of the family system (a family-level concept that is <i>not</i> the sum of individual self-efficacy beliefs)
Vignette	Tammy is a 42-year-old Black woman who has stage 2 hypertension who is also overweight. Her primary care physician suggested that she attend an 8-week hypertension management program hosted by her health system. Tammy's husband Shawn attends the program with her. Shawn has managed his own hypertension for almost 2 decades but struggles quite a bit with clinically diagnosed major depression. Shawn attends the hospital program with Tammy so he can learn how to better help Tammy with dietary changes (eg, DASH eating plan). Success in this program is primarily based on Tammy's dietary changes, weight loss, and hypertension management.	Jalen is a 38-year-old Black man with type 2 diabetes. He is married to Sonia, who recently completed treatment for breast cancer and is managing cardiac side effects from treatment. He lives near his parents and an aunt, all of whom have had increasing chronic health challenges in recent years, and with whom he maintains close personal relationships. He helps them in many ways, including with housework and accompanying them to doctor visits; they all support him as well, including emotionally (eg, coping with wife's cancer diagnosis) and informationally (eg, diabetes-friendly recipes). Despite this closeness and support, talking with each other about their health and finding effective ways to give/receive help can still be a challenge at times. Jalen, his father, and his aunt agree to participate in family-focused intervention to help them each better manage their individual health concerns and learn ways to enhance the support they are already providing to each other for disease management. Success in this program is based on improvement in individual-specific health outcomes (eg, better blood sugar control for Jalen) and family-level drivers of change (eg, communication).

DASH, Dietary Approaches to Stop Hypertension

about family health as a concept has hampered efforts to provide care for multiple members of a household, continuity of care across the life course, and care that attends to the intergenerational influences on health behaviors and outcomes. At the family-level, *family-involved chronic disease management*

and *family-focused chronic disease management* could mean very different things (see examples in Table 2). The former suggests outcomes may be specific to a target individual or family member(s), whereas the latter suggests the family unit, and its associated outcomes, is the target of intervention

efforts. This work also needs to examine interactions between individual and family-level constructs (eg, self-efficacy and collective efficacy) more closely.¹¹ Prior research examining health care utilization and morbidity via health insurance records uncovered patterns that suggested strong interactions between the behavior

of family members and greater benefits from intervening at the family (vs individual) level.¹²

Social Determinants of Health

Recent efforts have sought to incorporate knowledge of social determinants of health more explicitly to better respond to the lived experiences and needs of our most vulnerable family systems.¹³ For example, social policies that influence where families live and play, the ability of families to obtain a quality education and obtain gainful employment, and opportunities for families to build and maintain wealth have far-reaching implications for the health of immediate and future generations.¹³ Few initiatives and goals to improve the impact of social determinants of health on well-being and quality of life, broadly, or chronic disease prevention and management, specifically, are designed to consider multigenerational family systems or work that moves beyond family dyads (eg, mother/child, spouses, and nuclear families). Broadening this work to include multigenerational family systems can enhance our ability to identify and address factors that place families at increased risk of poorer chronic disease outcomes in successive generations and increase the sustainability of positive changes.¹⁴

Implementation Science

Implementation science (IS) may be particularly helpful for refining approaches to achieve family health equity because it guides researchers to conduct multilevel, nuanced dissections of context¹⁵—where many assaults to health equity occur—and provides insight into what components of an intervention may need to be adapted to reach health equity. IS frameworks do not innately address specific aspects of health equity.¹⁵ However, the Health Equity Implementation Framework¹⁶ and the updated Consolidated Framework for Implementation Science¹⁷ are recent examples of IS frameworks that have been developed or

amended to include health equity concepts. Many of the uncertainties and questions about family intervention facilitators and barriers, such as relational connections, communication, and culture, are key domains of the Consolidated Framework for Implementation Science¹⁷ and can be parsed out, studied, and adapted in future interventions. Partnering with families and other key stakeholders in this work is critical.

EMBRACING COMPLEXITY IN FAMILY-FOCUSED WORK

It is useful to acknowledge common critiques of family-related research and practice and embrace the complexity therein. One critique is that only families doing well relationally will enroll in family-centered programs or initiatives. However, while relational well-being is likely beneficial, it does not preclude disease management challenges. This argument also places failures of recruitment, messaging, and accessibility on the families themselves. Another critique is that this work is too difficult to tackle given the degree of heterogeneity of families and intricate layers of family life; however, we would be hard-pressed to identify aspects of health and equity-focused work that does not require consideration of within- and between-group differences and the complicated interactions between individuals and their social environment. Lastly, the importance of this work may be called into question given that families may not play a role or be present in the lives of everyone we seek to serve. Yet, we make many decisions as health professionals to target one population, setting or health condition in certain initiatives; doing so does not mean that the individuals, families, and communities that do not fit that set of priorities are less important. Thus, while it is important to examine the limitations of any approach, it is critical

that this practice does not impede meaningful progress.

Systemic and Structural Racism

The role of systemic and structural racism is, unequivocally, relevant for every aspect of the current discussion.¹⁸ Addressing the diversity of families, issues of measurement, and intervention pathways will continue to fall short if these efforts are not tied to redressing the ways in which racism systemically and destructively perpetuates racial inequities in chronic disease and other health outcomes and permeates the culture and context of family life.¹⁹ Letiecq and colleagues²⁰ call for increased recognition of “structural racism at the root of racialized family disparities and inequality” and the adoption of antiracist structural solutions instead of Black family interventions, the latter of which may, implicitly or explicitly, promote deficit perspectives. They contend that structural racism and oppression, not family deficits, warrant much more attention. Furthermore, in their analysis of white supremacy and race science, Chatters and colleagues²¹ call for challenges to traditional, whiteness-dominated approaches that do not explicitly consider the role of racism and racialized experiences across the life course that have oppressed, destabilized, and harmed BIPOC families. It is also important to pursue multilevel solutions that address the consequences of structural racism. That is, how do we fortify the pieces of family life, intergenerational connections, and resources that racism has worked to chisel away? How can we reify and avoid further damage to the aspects of family that have helped to protect its members and communities against the negative consequences of structural racism on health?

Moving Toward Solutions

In summary, these issues matter greatly for research (eg, concepts, design, measurement, analysis), practice, policy, and overall efforts seeking to find effective,

equitable solutions that support family health equity in chronic disease. These solutions must recognize the urgent need to provide support and resources directly to families while also addressing the structural and systemic issues that lead to poorer health outcomes among marginalized and racially minoritized families. We have at times (rightly) championed how family resiliency can promote and maintain the health of its members in the midst of overwhelming challenges, without also acknowledging our role as health professionals, researchers, policy-makers and practitioners in the systems that create these often insurmountable conditions.²² In charting a path forward to promote racial equity in chronic disease among families, we should aim to harness the synergy that comes from building and maintaining strong family systems and supportive health-promoting interventions while also attending to critical structural and systemic change.

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CONFLICT OF INTEREST

No conflicts of interest reported by authors.

AUTHOR CONTRIBUTIONS

Research concept and design: Ellis, Young, Langford; Acquisition of data: Ellis; Data analysis and interpretation: Ellis; Manuscript draft: Ellis, Young, Langford; Administrative: Ellis; Supervision: Ellis, Langford

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