

ESSAY

Advancing Racial Health Equity Through Family-Focused Interventions for Chronic Disease Management

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PEER REVIEWED

The family context has long been regarded as a key setting for health and a target for efforts to strengthen social support for health goals. While improving racial health equity in chronic disease among children and adolescents may more instinctively point toward parent-child experiences, it is not surprising when efforts to improve equity in adults also recognize the role of the family. Broadly speaking, theories and frameworks often bring attention to the family context within considerations of the social environment and social network influences on disease outcomes. In clinic settings, health professionals may speak with adults about their family health history, availability of caregiving, and disease prevention and management within the home environment. Despite these efforts, calls for advancing chronic disease research with families abound. For example, the 2001 Institute of Medicine (IOM) report *Health and Behavior: The Interplay of Biological, Behavioral, and Societal Influences* described family intervention research for chronic disease management among adults as “in its infancy” (1). Deeper attention to the family relationship context, it was argued, was needed to improve chronic disease outcomes for adults. A decade later, the IOM’s 2011 report *Living Well with Chronic Illness: A Call for Public Health Action*, detailed psychosocial, economic, and health-related consequences of chronic illness for families and advocated for greater public health action (2). Moving forward, it is vital that we center racial health equity in our work with adults and their families, including efforts *inside*, *outside*, and *alongside* families.

Centering Equity: *Inside* Families

The collection and discussion of health history with individuals is where many health professionals regularly engage *inside* families. Indeed, a comprehensive family health history is a valuable tool for assessing risk and determining actions that may enhance health and well-being (eg, start, frequency, and types of cancer screenings; lifestyle changes). Gaps in family history information, particularly by race, hamper these efforts. Innovative tools and creative programs have led to success in improving the completeness of family history collection (eg, collecting information at family reunions) (3). As family history data become more complete, we should ask the question, Is there more we can do with this information? Indeed, there is. Despite its reference to the past, an individual’s family health history can also provide an entree into the extent of family multimorbidity (ie, family members’ co-occurring health issues) and opportunities for family disease management support (4). A family’s experiences with disease management over time have likely led them to develop significant skills and strengths that can be leveraged in intervention efforts. The identification of family-level factors, resources (eg, cooperation, role flexibility), and constraints (eg, conflict, rigid roles) likely associated with disease management are integral to these efforts.

Centering Equity: *Outside* Families

Interrogating broader sociocultural and contextual factors *outside* of families that shape members’ lives and livelihoods is crucial for equitable intervention design. These factors, and the relationships between them, contribute to family health historically and contemporarily. Over time, families can benefit in some ways and be disadvantaged in other ways by exposure to these inequitable conditions. For example, structural racism influences the community and the built and social environment of families, their ability to access and receive quality preventive and curative care, and their educational and economic opportunities. The distant and recent past is replete with examples of how racism affects the overall health of families. Families often serve as a buffer to racism and



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discrimination among its members, including providing resources to fortify instabilities resulting from broken, inequitable systems. Families from racially marginalized groups may also take on a greater responsibility to support the health of their members for several reasons, including past experiences with health systems that make accessing services more difficult (eg, poor and/or discriminatory interactions), inadequate treatment when services are provided, and greater disease burden. These caregiving and supportive efforts by families, even when successful, may come at a cost to families' individual and collective well-being (eg, caregiver burden, network stress).

Care systems in the US are organized such that families are expected to take on varying levels of *responsibility* for the chronic disease welfare of their members. Often lacking with this orientation is attention to variations in the *response-ability* of families (5). What we observe as the ability of families to help their members with the myriad aspects of chronic disease prevention and management is reflective of lifelong and multigenerational embeddedness in inequitable social contexts (6). Thus, our work has to be responsive to the accumulation of advantages and disadvantages across the family life course (7,8) through differential exposures to risk and protective factors in various domains of life. This approach also requires considering the varying levels of health and functioning and the interconnectedness of health and well-being among members of a family unit.

Centering Equity: *Alongside* Families

Another key component of advancing racial health equity in chronic disease is being committed to working *alongside* families. Individuals are often willing to support their family members in managing chronic illnesses, and there are many organizations and groups at the forefront of these issues. Using community-engaged and participatory approaches to this work is critical. In advocating for an *alongside* approach, Anderson (9) expounds on the importance of balance in working with African American families, arguing for the continued promotion of family "resources and cultural strengths" while simultaneously actively dismantling inequitable and unjust social constraints. In the context of chronic disease prevention and management, this requires tackling the upstream and downstream, proximal and distal factors, long identified as important for chronic disease outcomes.

Reflecting on our disciplinary and personal backgrounds can be useful for building effective partnerships with families we aim to serve while working toward this balance. Hardeman and Karbeah (10) provide a valuable framework for engaging in disciplinary self-critiques that can help us examine how racism has hampered our efforts to achieve health equity. They argue for an examina-

tion of our research questions, methodologic approaches, interpretations of our findings, reliance on White-dominant narratives, and what evidence is considered real. These steps toward epistemic justice could also be enhanced by reflecting on additional questions that can help us to identify how personal beliefs, experiences, and biases about family influence our work. For example, how do we define family, personally and professionally, and how might this conceptualization help or hamper our efforts? What do we believe can or should be the role or involvement of families in helping adults manage their health issues? In what ways do we value or promote the needs of the individual over those of the collective (or vice versa)? To what do we attribute the challenges that families such as our own have with managing their health, and how is this similar to or different from the attributions we make about other families? How might our past and ongoing work contribute to narratives about health among the families we serve? Thinking carefully and deeply about these issues can best position us to create meaningful partnerships that can lead to sustainable and practical solutions.

Conclusion

Inequities in chronic disease outcomes by race in the US are distressing, persistent, and unjust. These inequities have exerted an incalculable toll on generations of families and communities. The policies and practices that will increase racial equity in chronic disease will likely need to be multifaceted and intentional about incorporating a familial approach. Working *inside* families intentionally focuses on family-level factors and processes that influence health outcomes, including concurrent health problems, competing demands of family systems, roles, and relational aspects. Working *outside* families includes bolstering institutional and systemic efforts to redress the social inequities that contribute to disproportionate chronic disease morbidity and mortality rates. Lastly, working *alongside* families includes a commitment to engaging with and partnering with families to design, implement, and evaluate policies and practices designed to improve their chronic disease-related health outcomes. Making progress in complementary *inside–outside–alongside* approaches can lead to positive, synergistic effects that can help families thrive.

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Next Steps After Your Diagnosis: Finding Information and Support

Introduction

Your doctor* gave you a diagnosis that could change your life. This booklet can help you take the next steps.

Every person is different, of course, and every person's disease or condition will affect them differently. But research shows that after getting a diagnosis, many people have some of the same reactions and needs.

About this Booklet

Next Steps After Your Diagnosis offers general advice for people with almost any disease or condition. And it has tips to help you learn more about your specific problem and how it can be treated.

The information in this booklet is presented in a simple way to help you scan the material and read only what you need right now. Organizations, publications, and other resources are included if you would like to know more. The on-line version www.ahrq.gov/consumer/diaginfo.htm has many additional resources and their Internet links.

Five Basic Steps

This booklet describes five basic steps to help you cope with your diagnosis, make decisions, and get on with your life.

Step 1: Take the time you need.

Do not rush important decisions about your health. In most cases, you will have time to carefully examine your options and decide what is best for you.

Step 2: Get the support you need.

Look for support from family and friends, people who are going through the same thing you are, and those who have "been there." They can help you cope with your situation and make informed decisions.

* Your medical care might come from a doctor, nurse, physician assistant, or another kind of clinician or health care practitioner. To keep it simple, in this booklet we use the term "doctor" to refer to any of these professionals with whom you might interact.

Step 3: Talk with your doctor.

Good communication with your doctor can help you feel more satisfied with the care you receive. Research shows it can even have a positive effect on things such as symptoms and pain. Getting a “second opinion” may help you feel more confident about your care.

Step 4: Seek out information.

When learning about your health problem and its treatment, look for information that is based on a careful review of the latest scientific findings published in medical journals.

Step 5: Decide on a treatment plan.

Work with your doctor to decide on a treatment plan that best meets your needs.

As you take each step, remember this: Research shows that patients who are more involved in their health care tend to get better results and be more satisfied.

Although most of the published research referred to in this publication focuses on cancer, it likely is relevant to people with other diseases and conditions as well.

Step 1: Take the time you need.



*Take time to breathe.
Don't panic, and don't
feel pressured into making
a rush decision.*

Alexis, cancer survivor

A diagnosis can change your life in an instant.

Like so many other people in your situation, you might be feeling one or more of the following emotions after getting your diagnosis:

- Afraid
- Alone
- Angry
- Anxious
- Ashamed
- Confused
- Depressed
- Helpless
- In denial
- Numb
- Overwhelmed
- Panicky
- Powerless
- Relieved (that you finally know what's wrong)
- Sad
- Shocked
- Stressed

It is perfectly normal to have these feelings. It is also normal, and very common, to have trouble taking in and understanding information after you receive the news – especially if the diagnosis was a surprise. And it can be even harder to make decisions about treating or managing your disease or condition.

Take time to make your decisions.

No matter how the news of your diagnosis has affected you, do not rush into a decision. In most cases, you do not need to take action right away. Ask your doctor how much time you can safely take.

Taking the time you need to make decisions can help you:

- Feel less anxious and stressed.
- Avoid depression.
- Cope with your condition.
- Feel more in control of your situation.
- Play a key role in decisions about your treatment.

Step 2: Get the support you need.



I was shocked when I was diagnosed with diabetes. The extra support I got from my friends and support group really helped me adjust to the new lifestyle I had to adopt.

Richard, person with diabetes

You do not have to go through it alone.

Sometimes the emotional side of illness can be just as hard to deal with as the physical side. You may have fears or concerns. You may feel overwhelmed. No matter what your situation, having other people to turn to will help you know you are not alone.

Here are the kinds of support you might want to seek:

■ **Family and friends.**

Talking to family and friends you feel close to can help you cope with your illness or condition. Just knowing that someone is there can be a comfort.

Sometimes it is hard to ask for help. And sometimes your family and friends want to help, but they do not want to intrude, or they do not know how to ask or what to offer. Think about specific ways people can help you. One idea is to ask someone to come with you to a doctor's appointment to help ask questions, take notes, and talk with you afterward.

If you do not have family or friends who can provide support, other people or groups can.

■ Support or self-help groups.

Support groups are made up of people with the same disease or condition who get together to share information and concerns and to help one another. Support groups may or may not be led by experts. Self-help groups are similar to support groups but usually are led by the participants. The names “support group” and “self-help group” sometimes are used to refer to either kind.

Research on support groups shows that participants feel less anxious, experience less depression, have a better quality of life, and have more success coping with their disease or condition. Similar findings have been reported for self-help groups.

■ On-line support or self-help groups.

The Internet has support or self-help groups for people whose concerns and situations may be similar to yours. You can also find “message boards,” where you can post questions and get answers. These on-line communities can help you connect with people who can give you support and provide information.

But be careful. Not every idea or treatment you come across in these groups will be scientifically proven to be safe and effective. If you read about something interesting and new, check it out with your doctor.

■ Counselor or therapist.

A good counselor or therapist can help you cope with sadness, depression, and feelings of being overwhelmed. If you think this kind of help might be right for you, ask your doctor or other health care professional to recommend someone in your area.

■ People like you.

You might want to meet and talk with someone in your own situation. Someone who has “been there” can talk about the real-life outcomes of their treatment choices as well as how they have learned to live with their disease or condition. Some advocacy or support groups can help you make this kind of contact.



If only I had known what it would be like to live with the after-effects of this type of surgery, I might have chosen a different kind.

Susan, who underwent surgery for a digestive disease

Help is available.

Take advantage of the support that is available to you. See “Where to Find More Information” on page lvi for specific places to find support. An expanded list appears in the on-line version of this booklet at www.ahrq.gov/consumer/diaginfo.htm.

	Description
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617 Allergies

Allergy means altered reactivity. Allergies are usually characterized by a hypersensitivity to substances, such as pollens, pet dander, certain foods, some medications and molds. Such substances (allergens) can trigger an allergic response in susceptible individuals. Symptoms of allergies may present in a wide spectrum ranging from the mild sneezing, runny nose and congestion of hay fever to life-threatening reactions, known as anaphylaxis. Additional allergic reactions include itchy, watery eyes, skin rashes and asthma. More severe symptoms may include a tingling sensation in the mouth, swelling of the tongue and throat, difficulty breathing, hives, vomiting abdominal cramps, diarrhea, drop in blood pressure, loss of consciousness, and cardiovascular collapse leading to death. Allergic symptoms typically appear within minutes to two hours after the person has been exposed to the allergen.

Approximately 35 million people suffer from allergies in the United States. The cause of allergies is unclear, although there may be a genetic link in some people. Treatment for allergies depends upon the specific substance, beginning with avoidance. Strict avoidance of the allergy-causing food is the only way to avoid a food allergy reaction. There are no medications that cure food allergies. Most people outgrow their food allergies, although peanuts, nuts, fish and shellfish are often considered life-long allergies.

For non-food allergies, medications such as antihistamines and inhaled bronchodilators and steroids, oral leukotriene receptor antagonists, as well as allergy shots to reduce the allergic response, may be prescribed by health care providers. Epinephrine, also called adrenaline, is the medication of choice for controlling a severe reaction. Individuals at risk of an anaphylactic reaction should have a bracelet or necklace with that information. Those who are allergic to insect stings should carry and use a pre-filled syringe of epinephrine (EpiPen) for prompt self-treatment. For food-based allergies, many younger and older children respond to Oral Immunotherapy (OIT), in which the allergenic food is gradually reintroduced to the child, little-by-little. Some OIT-treated children can eventually reincorporate the formerly-offending food into their diets.

National Agencies & Associations

618 Academy of Nutrition & Dietetics
 120 South Riverside Plaza
 Chicago, IL 60606-6995
 312-899-0040
 media@eatright.org
 www.eatright.org

Offers information and support to allergy sufferers. Serves the public through the promotion of optimal nutrition, health, and well-being. Formerly the American Dietetic Association.
Ellen R. Shanley, President
Patricia M. Babjak, Chief Executive Officer

619 Agency for Healthcare Research and Quality
 5600 Fishers Lane
 Rockville, MD 20857
 301-427-1104
 www.ahrq.gov

The Agency for Healthcare Research and Quality's (AHRQ) mission is to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and to work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used.
Robert Otto Valdez, PhD, MHSA, Acting Director
Howard E. Holland, Director, Communications

620 Agency for Toxic Substances and Disease Registry
 1600 Clifton Rd. NE
 Atlanta, GA 30329
 800-232-4636
 www.atsdr.cdc.gov

The Agency for Toxic Substances and Disease Registry (ATSDR), based in Atlanta, Georgia, is a federal public health agency of the U.S. Department of Health and Human Services. ATSDR serves the public by using the best science, taking responsive public health actions, and providing trusted health information to prevent harmful exposures and diseases related to toxic substances.
Robin M. Ikeda, MD, MPH, Acting Director

621 Allergy & Asthma Network
 10304 Eaton Place
 Fairfax, VA 22030
 800-878-4403
 info@allergyasthmanetwork.org
 www.allergyasthmanetwork.org

Non-profit membership organization dedicated to eliminating suffering and death due to asthma, allergies and related conditions through education, advocacy, community outreach, and research.
Lynda Mitchell, MA, CAE, Interim CEO
Charmayne Anderson, MPA, Director, Advocacy

622 American Academy of Allergy, Asthma & Immunology
 555 East Wells Street
 Milwaukee, WI 53202-3823
 414-272-6071
 info@aaaai.org
 www.aaaai.org

Strives to serve the public through information on asthma and allergies, as well as referrals to allergists.
Jonathan A. Bernstein, MD, President
Frank S. Virant, MD, Secretary-Treasurer

623 American Academy of Environmental Medicine
 215 West Bandera Rd.
 Boerne, TX 78006
 316-684-5500
 Fax: 888-411-1206
 www.aeemonline.org

The AAEM Promotes the education of healthcare professionals in the interaction between humans and the environment. Offers names of Clinical Ecologists and Allergy Specialists in the United States.
Diego Saporta, MD, President
Renee Grandi, MD, Secretary

624 American College of Allergy, Asthma & Immunology
 85 West Algonquin Road
 Arlington Heights, IL 60005
 847-427-1200
 Fax: 847-427-9656
 mail@acaai.org
 college.acaai.org

Focuses on research and public awareness of allergies, asthma, and immunology. Distributes informational brochures and pamphlets, offers referrals and counseling services, as well as patient care.
Todd A. Mahr, MD, FAAAAI, Executive Medical Director

625 Asthma Canada
 124 Merton Street
 Toronto, Ontario, M4S-2Z2
 416-787-4050
 866-787-4050
 Fax: 416-787-5807
 info@asthma.ca
 www.asthma.ca

National, volunteer-led organization devoted to enhancing the quality of life for individuals with asthma and respiratory allergies.
Jenna Reynolds, Interim CEO & Dir., Programs & Services
Zhen Liu, Director, Operations & Administration

626 Birth Defect Research for Children, Inc.
 976 Lake Baldwin Lane
 Celebration, FL 32814
 407-895-0802
 staff@birthdefects.org
 www.birthdefects.org/allergies

A non-profit organization providing parents and soon-to-be parents with information resources about birth defects, and support services for their children. Offers fact sheets on allergies.

- 627 Canadian Society of Allergy and Clinical Immunology**
207 Bank St
Ottawa, ON, K2P-2N2
613-265-7571
info@csaci.ca
www.csaci.ca
- Promotes the advancement of the knowledge and practice of allergy, clinical immunology, and asthma for optimal patient care.
Anne Ellis, MD, MSc, FRCPC, President
Jasmin Lidington, Executive Director
- 628 Centers for Disease Control & Prevention: Division of Adolescent & School Health**
1600 Clifton Road
Atlanta, GA 30329
800-232-4636
TTY: 888-232-6348
www.cdc.gov/HealthyYouth
- CDC promotes the health and well-being of children and adolescents to enable them to become healthy and productive adults.
- 629 Centers for Medicare & Medicaid Services**
7500 Security Boulevard
Baltimore, MD 21244
www.cms.gov
- U.S. federal agency which administers Medicare, Medicaid, and the State Children's Health Insurance Program.
Chiquita Brooks-Lasure, Acting Administrator
Jonathan Blum, Principal Deputy Administrator & COO
- 630 Food Allergy Research & Education**
7901 Jones Branch Drive
McLean, VA 22102
703-691-3179
800-929-4040
Fax: 703-691-2713
www.foodallergy.org
- FARE aims to increase public awareness about food allergies and anaphylaxis, advance research, and provide education, emotional support and coping strategies to patients. It also serves as the communication link between the food industry, the government and the airline industry.
Sung Poblete, Chief Executive Officer
Dominique Rodriguez-Sawyer, Chief People Officer
- 631 Food Safety and Inspection Service**
U.S. Department of Agriculture
1400 Independence Avenue SW
Washington, DC 20250
202-720-9113
fsis.webmaster@usda.gov
www.fsis.usda.gov
- The Food Safety and Inspection Service (FSIS) is the public health agency in the U.S. Department of Agriculture responsible for ensuring that the nation's commercial supply of meat, poultry, and egg products is safe, wholesome, and correctly labeled and packaged.
Paul Kiecker, Administrator
Sandra Eskin, Deputy Under Secretary, Food Safety
- 632 National Center for Complementary and Integrative Health**
9000 Rockville Pike
Bethesda, MD 20892
888-644-6226
TTY: 866-464-3615
info@nccih.nih.gov
nccih.nih.gov
- The National Center for Complementary and Integrative Health (NCCIH) is the Federal Government's lead agency for scientific research on the diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine.
Helene M. Langevin, MD, Director
David Shurtleff, PhD, Deputy Director
- 633 National Eczema Association**
505 San Marin Drive
Novato, CA 94945
415-499-3474
800-818-7546
www.nationaleczema.org
- Engages in research, support, and education to better the lives of individuals with eczema, including information on allergies.
Julie Block, President & CEO
Michele Guadalupe, Vice President, Advocacy & Access
- 634 National Human Genome Research Institute**
Building 31, Room 4B09
Bethesda, MD 20892-2152
301-402-0911
Fax: 301-402-2218
www.genome.gov

The National Human Genome Research Institute began as the National Center for Human Genome Research (NCHGR), which was established in 1989 to carry out the role of the National Institutes of Health (NIH) in the International Human Genome Project (HGP).

Eric D. Green, MD, PhD, Director
Nicole C. Lockhart, PhD, Program Director

- 635 National Institute for Occupational Safety and Health**
Patriots Plaza 1
395 E Street SW
Washington, DC 20201
800-232-4636
www.cdc.gov/niosh
- The National Institute for Occupational Safety and Health (NIOSH) is the U.S. federal agency that conducts research and makes recommendations to prevent worker injury and illness.
John Howard, MD, Director
Leah Ford, Chief of Staff
- 636 National Institute of Allergy and Infectious Diseases**
NIAID Office of Communications & Govt Relations
5601 Fishers Lane
Bethesda, MD 20892-9806
301-496-5717
866-284-4107
Fax: 301-402-3573
TDD: 800-877-8339
ocpostoffice@niaid.nih.gov
www.niaid.nih.gov
- Conducts and supports research on allergies; focused on understanding what happens to the body during the allergic process. Educates patients and health care workers in controlling allergic disease; offers various research centers that conduct and evaluate educational programs focused on methods to control allergic diseases.
Hugh Auchincloss, MD, Acting Director
- 637 National Institute of Biomedical Imaging and Bioengineering**
9000 Rockville Pike
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www.nibib.nih.gov
- The mission of the National Institute of Biomedical Imaging and Bioengineering (NIBIB) is to improve health by leading the development and accelerating the application of biomedical technologies.
Bruce J. Tromberg, PhD, Director
Jill Heemskerck, PhD, Deputy Director
- 638 National Institute of Environmental Health Sciences**
111 T.W. Alexander Drive
Durham, NC 27709
919-541-3201
Fax: 919-541-5136
webcenter@niehs.nih.gov
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- The mission of the NIEHS is to discover how the environment affects people in order to promote healthier lives.
Rick Woychik, PhD, Director
Trevor K. Archer, PhD, Deputy Director
- 639 National Institute of Food and Agriculture**
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- National Institute of Food and Agriculture (NIFA) provides leadership and funding for programs that advance agriculture-related sciences.
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- The National Institute of General Medical Sciences (NIGMS) supports basic research that increases understanding of biological processes and lays the foundation for advances in disease diagnosis, treatment and prevention.
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- 641 U.S. Food and Drug Administration**
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