

Your Exclusion, My Inclusion: Reflections on a Career Working With the Most Challenging and Vulnerable in Diabetes

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EDITOR'S NOTE: This article is adapted from the address Dr. Harris delivered as the recipient of the American Diabetes Association's Richard R. Rubin Award for 2017. This award recognizes a behavioral researcher who has made outstanding, innovative contributions to the study and understanding of the behavioral aspects of diabetes in diverse populations. Dr. Harris delivered the address in June 2017 at the Association's 77th Scientific Sessions in San Diego, Calif.

Every professional working in diabetes has a personal story about how he or she got involved in the field of diabetes. Dr. Richard Rubin's story, published in *Diabetes Care* in 2017 and written by Richard's close friend and long-time colleague Dr. Mark Peyrot, highlights his experience with his sister being diagnosed with type 1 diabetes and then, 20 years later, his 7-year-old son being diagnosed with type 1 diabetes (1). These experiences set in motion Dr. Rubin's incredible career in diabetes as a behavioral scientist, clinician, advocate, and leader. My story starts in 1985, when I began my graduate career in psychology at the University of Memphis (formerly, Memphis State University) in Tennessee. As all graduate students, I was assigned to work with a faculty member. Fortunately for me, I was assigned to work with Dr. Cindy Hanson, a junior faculty member who was just beginning her career as a behavioral scientist in diabetes. At that time, I had no idea what would follow for both me and Dr. Hanson.

When I began as a graduate research assistant, I had no knowledge of type 1 diabetes or, for that matter,

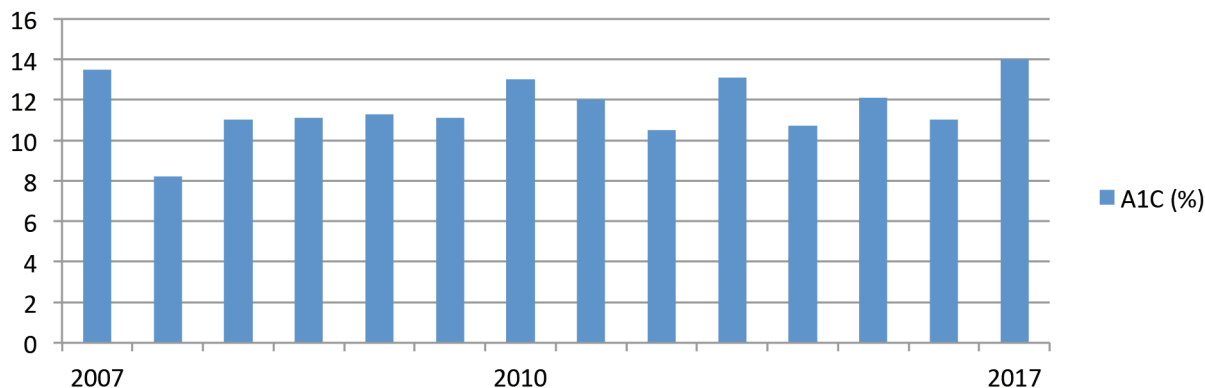
of the psychosocial and behavioral factors in health and illness. At my first meeting with Dr. Hanson, she shared with me several crucial pieces of information. She told me she had type 1 diabetes and had been diagnosed when she was 11 years old. Dr. Hanson shared her personal journey in meeting the day-to-day challenges of diabetes. She highlighted that she was neither "ill" nor "sick;" instead, her pancreas no longer secreted insulin. Second, Dr. Hanson told me that most of the research to date on the psychosocial and behavioral factors in diabetes had been driven by "deficit-model" thinking. In other words, most of the extant research at that time was grounded in the supposition that having a chronic health condition such as type 1 diabetes resulted in poor psychosocial and behavioral outcomes such as lower self-esteem, depression, anxiety, poorer quality of life, and worse family functioning. Finally, she told me that her approach to research in diabetes was both "strength-based" and grounded in the "social ecology" of people's lives (2). Thus, she focused her research on the adaptive and functional psychosocial and behavioral factors in

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■ FIGURE 1. Megan's A1C history.

diabetes and was interested in factors outside of the individual that affected health and health behaviors (e.g., family, school, and peers). Because psychology is more about identifying pathology and deficits as well as looking at problems lying within the individual, Dr. Hanson told me it would be a constant challenge not to view diabetes through that lens.

Those three pieces of information have forever informed and influenced my work in diabetes. For example, while interacting with Dr. Hanson for many years, I was constantly exposed to the personal side of diabetes and the associated challenges. Thus, my research and care in diabetes have always been heavily influenced by seeing the incredible day-to-day challenges that diabetes brought to Dr. Hanson. In addition, I have always been mindful of avoiding the trap of deficit-model thinking when crafting and conducting my own research in diabetes or when working clinically with individuals with diabetes. Finally, my career in diabetes has always involved examining the adaptive qualities of children, adolescents, and their families in meeting the challenges of diabetes management and always being mindful of the contextual factors as both facilitators and obstacles to successful diabetes management. As my own career path was paved, I gravitated toward working with and conducting research on the most vulnerable populations with diabetes, such as adolescents (3),

youth whose diabetes is poorly controlled (4), youth transitioning from pediatric to adult diabetes care (5), and, most recently, youth who are repeatedly hospitalized for diabetic ketoacidosis (DKA) (6).

When I think about vulnerable populations in diabetes, I think about individuals with whom I have worked, such as a young woman I'll call "Megan." Megan is 18 years old and had been diagnosed when she was 8 years old. She has had 10 years of elevated A1C levels (Figure 1). In the 12 months before my meeting Megan, she had been hospitalized for six episodes of DKA.

Megan certainly needs the best that the field of diabetes has to offer; however, there's more to Megan's story. Without having knowledge of important contextual factors, we as health care providers (HCPs) are at a loss regarding how best to care for patients like Megan. For example, Megan dropped out of school and reads below a fifth-grade reading level. She has a 2-year-old child who is drug affected and behaviorally challenging. Megan lives with her mother, who also has diabetes. Megan is in and out of a relationship with a known gang member. In addition, she is in the developmental stage of "emerging adulthood" (7) and likely needing to transition from pediatric to adult diabetes care.

Do we have a care model in diabetes that can help to improve Megan's health? If so, how does it adequately

address all of the social vulnerabilities she is experiencing? Are there data from our research efforts to inform our care of Megan or the impact of her psychosocial functioning on her diabetes? Are there studies that Megan could participate in and possibly benefit from? Or does Megan's situation and diabetes management exclude her from our current research efforts in diabetes care?

What about young "Alejandro," a 3-year-old boy with newly diagnosed diabetes? He lives with his mother in a house with six other people, some unrelated. Alejandro's mother speaks very little English. She has unreliable transportation, and the family lives 80 miles away from the diabetes center. Alejandro and his family have food insecurity. His mother has depression and a history of using illicit drugs, and she has been reported to Child Protective Services for neglect. Alejandro's mother works upwards of 10–12 hours per day picking strawberries. When she is working, Alejandro is left in the care of his paternal grandmother who runs a daycare.

Do we have a care model in diabetes for Alejandro? If so, how does it adequately address all the many social vulnerabilities in his life? Are there data from our research efforts to inform our care of Alejandro? Are there studies that Alejandro could participate in and benefit from? Or does Alejandro's social situation fall

within our typical “exclusionary criteria?”

By excluding the most vulnerable patients from our research studies, we are leaving out the very individuals—such as Megan and Alejandro—who have the most to gain from our efforts. For example, individuals with poorly controlled diabetes may be excluded from participating in a research study to improve adherence because their A1C is out of the acceptable range for that particular study. When you look at most diabetes clinical research, very rarely does it include (or focus on) individuals whose A1Cs have most often been in the double digits. Of course, there are limits to how much any one person’s A1C can improve, so this demographic presents an opportunity to improve health, not just at the margin, but to a degree that could potentially be life changing.

Those excluded also frequently demonstrate specific health-related social vulnerabilities. When research fails to include such individuals, a positive feedback loop ensues, further driving health inequities for a population that is already at high risk.

Exclusion affects our care models and the designs of our interventions by not allowing us to appreciate the demonstrated impact of context on behavior and health. One example of not considering context on behavior and health is the iatrogenic problem of increasing the frequency of office visits for individuals with diabetes who also have a number of social vulnerabilities. Most HCPs would react to a deterioration in glycemic control by requesting that the patient schedule more frequent checkups. However, the potential for “increased burden” is rarely a factor in such decisions. For an individual with transportation or financial insecurities, who lives in a high-risk area not proximal to a hospital, more office visits can mean having to spend more money on gasoline, hire a babysitter, or miss more work hours. These contextual factors could negate any

positive effect that could accrue from more face-to-face time with a physician. Furthermore, increasing that individual’s laundry list of expected medical adherence behaviors could create an additional barrier to obtaining the initially desired higher level of care.

Interestingly, when we do include those who are typically excluded from our research efforts, our inherent biases often are only confirmed through our study designs. In 1963, Robert Rosenthal conducted a landmark study on expectancy effects (8). Unbeknownst to his research assistants, he labeled half of the rats in his performance trials as “smart” and the other half as “dull.” He did this randomly and arbitrarily. Rosenthal then told his research assistants that half of rats had been tested and determined to be dull, while the other half were found to be exceedingly smart. In a blind experiment (in which the labels of smart and dull were not known), he then instructed his research assistants to run the rats through the mazes and found that the rats labeled smart outperformed those labeled dull. He hypothesized that this finding was a result of the manner in which the research assistants had handled, fed, spoken to, or otherwise interacted with the smart rats compared to the dull ones.

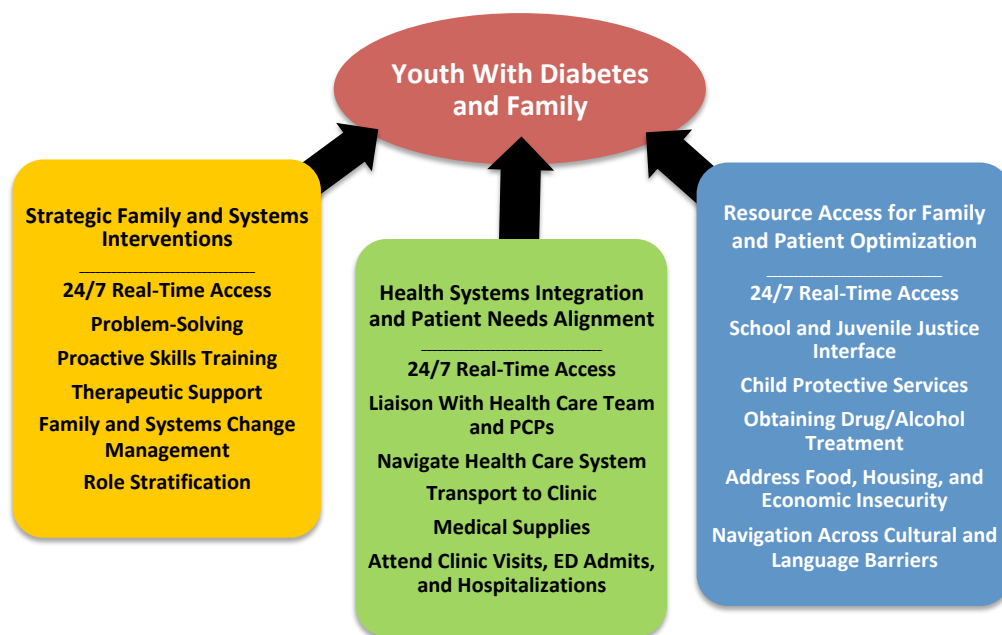
This line of research emphasizes the astounding degree to which outcomes can be affected by our expectation biases. When we expect individuals with diabetes to adhere poorly, we should not be surprised when they do. When including typically excluded populations in our research, the ways in which we set up our protocols are often riddled with confirmation bias.

When we actively attempt to battle with this type of bias (or, as Dr. Hanson put it, employ deficit-model thinking), we find results that frequently challenge conventional wisdom. In my own work with Dr. Hanson, we compared the self-esteem of youth with diabetes with

the self-esteem of their otherwise healthy peers (9). For years, it was assumed that there was a one-directional, causal relationship between having diabetes and having lower self-esteem. However, in our research, we found the opposite in that the youth with diabetes in our study scored higher on the same measure of self-esteem as their otherwise healthy peers. This not only emphasizes the importance of conducting research on marginalized and at-risk populations, but also demonstrates the necessity of applying our research uniformly, regardless of our preconceived notions and personal prejudices.

Exclusion limits our understanding of the most challenged and vulnerable, thus rendering interventions impotent outside of highly controlled conditions with largely homogeneous samples. By relaxing our inclusion criteria and limiting our exclusionary criteria, we have the opportunity to include in our efforts a more heterogeneous sample, thus increasing the value of our findings to a broader range of people. Likewise, by including the most challenged and vulnerable individuals in our research, we have the opportunity to better understand how interventions actually work or do not work in the real world, with a real-world population. Something as simple as including people regardless of their A1C level would offer opportunities to better understand the value of our interventions to broader populations.

Our failure to include those most challenged by diabetes and most socially vulnerable means that our ability to generalize is very limited, and we deny groups who are both in great need and at high risk the potential benefits of participating in research (10). In addition, failing to include challenged and vulnerable populations does not allow for ensuring that the interventions we are testing are safe for use with these populations (e.g., insulin pump and continuous glucose monitoring tri-



■ **FIGURE 2.** The NICH intervention model. ©Michael A. Harris, PhD. ED, emergency department; PCPs, primary care providers.

als) (10). As previously discussed, our exclusion of the most challenged and vulnerable people with diabetes prevents us from learning about those with diabetes who experience the greatest burden of disease and thus are most likely to benefit from our work (10).

Exclusion of the most challenged and vulnerable patients also results in our failure to make the economic case for behavioral health as a component of diabetes care. There is a disconnect between wanting to provide the highest-quality and most effective diabetes care and being willing to pay for that care as a society. Dr. Barbara Anderson has said that “behavior is the most important drug in diabetes care.” I think many scientists and clinicians working in diabetes would agree with her, but behavioral interventions are not financed as well as pharmacological interventions in diabetes care. Most diabetes clinics do not have embedded behavioral health professionals or even access to outside behavioral health professionals who

are trained in diabetes. The missed opportunity in excluding the most challenged and vulnerable diabetes patients from our research is that these individuals cost the health care system a disproportionate amount of money, and unfortunately, money talks. Showing a significant cost savings by including those with diabetes who cost our health care system the most allows for more resources and funding for the care of people with diabetes.

For example, previously published data indicate that the average cost of an episode of DKA is somewhere between \$7,000 and \$13,000 (11,12). However, those data were published many years ago, and more recent data indicate that just 24 hours in the intensive care unit costs ~\$10,000 (13). If someone were in the intensive care unit for DKA for 2 days (48 hours), then the cost of just one episode of DKA would be closer to \$20,000. Testing interventions to reduce the number of DKA episodes and consequently to reduce the avoid-

able related health care expenditures gets people’s attention (14).

Let’s look back at Megan, who I spoke about earlier. She had six DKA episodes in 12 months. The cost of care for Megan in just a 12-month period ranged from \$42,000 to \$78,000. If we could establish effective clinical care models for someone like Megan, we could save the health care system significant money by reducing avoidable medical care. Likewise, if we had data from research involving individuals like Megan, we could better understand what the drivers of poor diabetes management are and craft interventions that target those drivers.

My current scholarly efforts in diabetes involve examining the implementation of an innovative intervention known as NICH (Novel Interventions in Children’s Healthcare) for youth who have repeated DKA episodes (Figure 2) (6). I developed NICH to align with the “triple aim” of health care reform: improving care, improving

health, and reducing costs, targeting the most vulnerable (e.g., those who are on public assistance, do not speak English, or are single parents) (15). Because a growing body of research indicates that social vulnerability and social risk factors are significant drivers of both poor adherence and deterioration in health, the NICH team works within the social context in which patients and their families live. The NICH team is dispatched into the community, families' homes, schools, and the health care system to address obstacles to health care and improved health. The NICH intervention is intensive, community-based, and family-focused, providing 24/7 real-time access, with NICH interventionists maintaining contact with families via face-to-face meetings, texts, phone calls, email messages, and teleconferences.

NICH interventions are crafted to remediate many of the problems and challenges that result from having a child with medical complexity. Many of these families are on the edge, frequently feeling marginalized by the system, and feeling an incredible sense of hopelessness as they find themselves drowning in a broken health care system. Thus, NICH represents a life preserver for those youth who are most challenged by their diabetes due to many social vulnerabilities.

NICH is the product and culmination of all of the knowledge I gained from the diabetes professionals and behavioral scientists who have influenced me throughout my career, including Drs. Barbara Anderson, Tim Wysocki, Korey Hood, Jill Weissberg-Benchell, Mark Peyrot, David Marrero, Neil White, and the late Julio Santiago, in addition to Drs. Rubin and Hanson. Equally important, NICH came about because of my interest in those excluded from extant research efforts and clinical care. NICH, I believe, is truly a translational research effort in diabetes, taking an evidence-informed intervention and implementing it

with a real-world, highly vulnerable clinical population.

Interestingly, NICH is largely a one-of-a-kind intervention, despite a 2005 plea from the director of the National Institutes of Health (NIH), who said “[NIH] asked ourselves: What novel approaches can be developed that have the potential to be truly transforming for human health? . . . Medical and public health practices in this nation will have to undergo a profound transformation in the coming decades if we are to succeed in access to care for all Americans at reasonable costs” (16). Twelve years have passed since Dr. Zerhouni issued this call to action, but very few in the research and clinical care communities have responded with more novel approaches that are truly transformative and succeed in facilitating access to care for all.

I have faced many challenges in my work with “excluded” people with diabetes. For example, few researchers or clinicians are focused on the most challenging and most vulnerable patients. In addition, there has been little research on interventions such as NICH that target social factors that affect diabetes and health, despite a considerable amount of data demonstrating how social factors directly affect health. On the clinical side, care continues to be delivered in silos. Few venture out of their comfort zones and disciplines to meet the needs of those most challenged by diabetes. Our current health care environment is still focused on seeing more patients and bringing in more revenue, while the value of the care provided is less of a focus. Our current interventions continue to be medically focused and fail to include contextual factors and social factors that drive health outcomes. Instead, we continue to assume that patients who are struggling are in need of more education and support for better diabetes management. When we do identify a problem and intervene in the social lives of our patients, our default tends to be to use the least

intensive interventions, such as care coordination, community health workers, and telephonic behavioral health support. Interestingly, when someone's diabetes is poorly controlled, we offer the highest level of care, but when someone has an equally challenging social situation, we offer the lowest level of care, and most often to no avail. Finally, there is considerable instability in health care right now and a great deal of uncertainty with regard to health care reform and the health care environment. Regardless of how vulnerable the social setting is, the challenges faced by HCPs, researchers, and patients are ever-present and unrelenting.

So, where do we go from here? How do we move from exclusion to inclusion with regard to our research and our diabetes care models? Going back to the work of Rosenthal, all of us in diabetes care could make an effort to change our expectation biases and believe that anyone can be a “smart rat.” In addition, despite all of the current challenges in the U.S. health care environment, we are at a tipping point. Payors and health care institutions are looking for a bigger bang for their buck. Everyone is starting to focus on the “big spenders” in health care, which also happen to be those with the greatest social vulnerabilities (17). The language and dialogue are changing around health care, with terms such as “value” starting to replace “volume” (18) and concepts such as “integrated care” and “medical home” starting to become realities. Even payment models are changing to offer HCPs more freedom to provide patients with what they need to manage and improve their health (19). For example, the Department of Health and Human Services has a goal that 50% of all Medicaid and Medicare payments will be delivered and contracted through bundled payments or alternative payment methods by the end of 2018 (20). Under bundled payments or alternative payment

methods, HCPs can make decisions about the care they provide, but they also assume financial risk. There will always be a strong need for taking care of our most vulnerable and challenging, and there is no better time than now to implement and test care models in diabetes with our most vulnerable patients.

In summary, my efforts as a behavioral scientist in diabetes have been heavily informed by my clinical care of youth with diabetes, my close personal connection to someone with diabetes, and the incredible work of my behavioral scientist colleagues. I am both honored and humbled to be recognized for my work with an award named after Dr. Richard R. Rubin, as his seminal work paved the way for individuals like myself.

I am also forever indebted to my mentor and good friend, Dr. Cindy Hanson, who is now unable to work because of the impact that diabetes has had on her body. In her honor, I have never forgotten those three pieces of information she shared with me some 30 years ago: keep it personal, avoid deficit-model thinking, and understand the strength and adaptive qualities of individuals with diabetes. To the larger diabetes community, I remain committed to focusing on those most challenged by diabetes and those most socially vulnerable, who too often have been forgotten and excluded from the battle we have all been waging against diabetes.

Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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