Children and Families Living With Diabetes

Preface

Paul B. Madden, MEd, Guest Editor

"It takes a village to raise a child."

This East African proverb continues to be supported both in research and through the life experiences of many. In my role as guest editor, I would like to point out some of the areas in which this figurative village (support community) has changed, especially over the past generation.

These changes have important implications for mental health specialists and all health care providers working with young people and families who are learning to handle diabetes in the most balanced manner possible. Providers must use well-honed counseling skills to connect well with their young patients and families as they try to deliver the most relevant, life-enhancing diabetes education and treatment programs. They must further draw on these skills to ensure that such programs make a significant, positive difference in the lives of their patients and families.

The experts who have contributed to this From Research to Practice section—Barbara J. Anderson, PhD; Deborah A Butler, MSW, LICSW; Margaret T. Lawlor, MS, CDE; and Joe Solowiejczyk, RN, MSW—have all discussed important studies and shared their experiences to demonstrate clearly the importance of a nurturing environment for young people with diabetes. Such an environment includes caring, warmth, support, understanding, and healthy limit setting from parents and other significant adults; positive peer experiences with others who are living with diabetes; and strong positive connections with knowledgeable and skilled professionals. The components of this village work together to help develop a dynamic diabetes management program that empowers young people to make healthy decisions related to their diabetes and their lives. I am indebted to the wise words shared by these superb professionals who bring an abundance of experience and understanding to the challenges faced by families living with diabetes.

"There is no disease in which an understanding by the patient of the methods of treatment avails as much. Brains count. But knowledge alone will not save the diabetic. This is a disease which tests the character of the patient, and for success in withstanding it, in addition to wisdom, he must possess honesty, self-control and courage. These qualities are as essential with as without insulin."[1]

Diabetes is a disease that must be understood not only by the individuals who develop it, but also by their family members and other significant people in their lives. Families and significant others of young people with diabetes must support their positive decisions to help ensure more balanced health now and throughout their adult lives to come. How family members and significant others assist with children's diabetes management changes as children mature, understand more, become more manually dexterous, and gain the confidence to implement more of their treatment program for themselves. Support from loved ones and others regarding the diabetes management program are vital throughout the life of people with diabetes.

"I hear and I forget, I see and I remember, I do and I understand."[2]

Today's village for young people and their families living with diabetes is often very different from what it was just a generation ago. Today, the village can be viewed as a neighborhood, or even a city block, and may include, among others, such disparate members as immediate and extended family, neighbors, abusive adults and peers, Internet connections, friends, health care providers, drug dealers, teachers, coaches, and religious leaders.

We have all read or heard sobering and alarming statistics that indicate less stability in today's families. Fifty-two percent of all marriages within the past 10 years will end in divorce. Twenty million, or 28%, of children in the United States under 18 years of age live with only one parent.[3] Eighty-four percent of the children who live with one parent live with their mother.[3] The percentage of children who live with two parents has been declining among all religious and ethnic groups.[3] Fifty-six percent of single-parent households have no other adults living in the house.[3] These and similar statistics clearly show us that Margaret Mead's concept of village has been redefined for many young people.

Coupled with this dramatic increase in single-parent families, we have also seen a significant rise in the number of parents who are working outside the home while raising their families. In addition to so many single parents having to work, in 71.2% of two-parent families, both parents work outside the home.[4] We all understand that it takes a considerable amount of emotional and physical energy and commitment to raise children successfully. The energy level of working adults is often compromised so that when they return home at the end of the day, their ability to focus life-enhancing emotional, intellectual, and physical energy and time on their children is diminished.

Add to this lack of parental energy and availability additional factors such as dwindling school and town recreation budgets, larger and more television sets in homes, increases in home movies and video and computer games, and increased availability of poor nutrition choices, and you wind up with an environment in which today's children have even fewer opportunities for positive interaction with and mentoring by adults, including through adult-supervised recreational activities. This lack of involvement and support by adults will make it harder for today's generation of children to master the many challenges of diabetes. These changes also dramatically encourage the continued rapid rise in new cases of type 2 diabetes among children.

These challenges are exacerbated by the reality that more and more families and neighborhoods are breaking down as a result of adult job demands, more frequent job transfers, and increasing distances between children's homes and their schools, among other factors. These changes have resulted in an adult world around children that is more variable and often less available than just a generation ago.

These societal changes require us all to work harder to connect our young patients with positive programs and positive adults, including positive, stable adults who also have diabetes. In this endeavor, well-run diabetes specialty camps,[5] family camps that specialize in diabetes,[6] and recreation, education,[7] and support groups for young people and their parents can be very helpful.

Erik H. Erikson, a leading figure in psychoanalysis and human development during the 20th century, frequently spoke and wrote about the ongoing development of a person's identity.[8] This development of identity occurs over a lifetime, and some of the most vital parts of the search for and development of identity evolve during our first 21 years. For our patients, the challenges of diabetes have been added to the development of identity, for the young people themselves and for their immediate and extended families.

The advent of diabetes in a family does bring about changes. Dr. Priscilla White[9] noted that when the challenges of diabetes appear to be overwhelming to a young person, we often see that normal growth and coping skills are inhibited and that the diabetes regimen becomes a battleground that stalls the healthy development of families. White wrote that when young people learn to work well with their diabetes, we often see that they mature at an earlier age.

Every generation of young people appears to be in a rush. As early as the 8th century B.C., Hesiod noted, "I see no hope for the future of our people if they are dependent on the frivolous youth of today, for certainly all their thoughts are reckless beyond words . . . . When I was a boy, we were taught to be discreet and respectful of elders, but the present youths are exceedingly wise and inpatient of restraint."[10] Most of us have heard or made a similar statement.

So often, young people live for the moment. Children do not typically plan for a future that is more than a day or two away. Such a short time reference can be detrimental to children more fully understanding and, more importantly, integrating positive diabetes treatment methods into their daily lives. What's more, diabetes is a chronic condition, and most people have difficulty maintaining the energy and momentum required to face a long-term condition.

Health care providers must keep this in mind when trying to help young people work toward positive diabetes management goals. Short-term goals often will be attainable. Multiple successes with short-term goals will help build positive habits that, when woven together over weeks, months, and years, will help ensure long-term health.

This generation of children has an increasing number of helpful tools and a wealth of information sources related to diabetes. Lawlor and Laffel[11] have discussed many of the newer technologies and therapeutic approaches that might now be used for diabetes management in children and young adults. It is both exciting and challenging to note that, at the end of their 2001 article, they anticipated that it would soon be outdated, as technologies and therapeutic approaches to diabetes management continue to change rapidly.

Still, without proper education, training, mentoring, and support from adults, some of these advances that can be so helpful could also put our children in harm's way. The challenge and responsibility of health care professionals to stay current with the latest technologies will increase as these advances continue at a rapid rate. With more children having less stability in the adult world around them, health care professionals will need to devote even more time to ensuring that young people have adequate support from important, positive adults in their lives so that they can safely integrate treatment advances into their lives.

"Never doubt that a small group of thoughtful, committed people can

change the world. Indeed, it is the only thing that ever has."[12]

Pediatric diabetes health care professionals are in short supply. At the time of this writing, there were more than 100 vacant positions for pediatric endocrinologists in the Untied States. Many diabetes specialty clinics and hospitals do not have mental health professionals as members of their teams. There are shortages of pediatric diabetes health care providers at all levels in many parts of the United States.

Add to this shortage of diabetes specialists the fact that many of us have also seen an increase in the number of cases that we follow. This increase in patient load magnifies our challenge to help young people and families living with diabetes learn the necessary skills and make the necessary decisions to better balance their lives with diabetes.

Another challenge has been presented to our patients, their families, and to us in more recent times by insurance carriers and by our sour economy. During the 1990s, individuals and families living with diabetes, health care providers, volunteers, and the staff of the American Diabetes Association worked together to realize substantial gains related to more comprehensive insurance coverage for people with diabetes.[13] However, over the past few years, we have seen more insurers limit benefits for diabetes education and diabetes supplies and equipment. Over the past year, we have also seen some serious Medicaid cuts that are eliminating coverage for many people with diabetes. Reductions in coverage for diabetes education, support, equipment, and supplies for people with diabetes will significantly reduce both the quality and the number of years of life of our patients. These cuts threaten the lives of our patients.[14] Diabetes health care providers must now also serve as dynamic, political advocates for our patients and their families.

Children and families living with diabetes have made some wonderful gains in civil rights. Today, many children with diabetes play on athletic teams, participate in school field trips, and are allowed to check their blood glucose and take insulin as needed either in their classrooms or in their school nurse's office. The gains made for children with diabetes in schools over the past 30 years have been refreshing and substantial and have helped allow children with diabetes to be more fully integrated into normal childhood activities.

At the same time, however, there has been an increase in risk management concerns fueled by newer infectious diseases such as HIV, hepatitis B, and hepatitis C and by the growing number of frivolous lawsuits regarding decisions and policies related to children and young people's activities. Our children with diabetes are at times more discriminated against now than even a generation ago, when at least some children and young adults with diabetes were quietly allowed to participate and do what they needed to do to keep themselves balanced. When a problem with diabetes occurred 30 years ago, it was often viewed as unfortunate but unavoidable. Now, it sometimes seems that more energy is spent on assigning blame than on preventing and correcting the problem.

We are now also seeing some newer, powerful, life-threatening challenges, which all too often pull this generation of young people away from better health. Alcohol has been a challenge for adolescents for centuries and continues as such. We know that drugs are far more available today, even in our elementary schools. Mind-altering drugs used by young people who are still intellectually and emotionally fragile can lead to a life of heartache and ill health and to early death. Young people in my practice tell me that these drugs are often easier to get than alcohol. Use and abuse of these drugs can dangerously distract young people from developing more positive, life-enriching health habits. Coupled with other rash decisions, it can rob a young person of life.

"Life does what it can: health and illness are but two forms of this effort to live … which is life itself."[15]

Young people and their families need positive role models who can help them realize that honestly addressing the challenges of diabetes, with a solid understanding of their management program and ever-present support, does help ensure that they will have a full and healthy life. This generation of young people with diabetes needs to be inspired as much as previous generations to know that *living a life with balanced diabetes is truly living your life.*

Diabetes is now the single most expensive disease in the United States, according to the Centers for Disease Control and Prevention. But it still falls far short of the necessary funding required to more rapidly enhance the lives of people with diabetes today and help us discover the cures and preventions tomorrow.

To gain more appropriate levels of support for people with diabetes, health care providers must also be advocates for increased funding for diabetes treatment, cure, and prevention research initiatives and programs. Just as we must encourage our young patients to be appropriately assertive when ordering restaurant foods to fit with their meal plans, so too must we be appropriately assertive in the political world to ensure funding for programs that will enhance our patients' lives.

"Just keep banging until someone opens the door."[16]

The challenges in front of us to help ensure healthy lives for young people and their families living with the multiple daily challenges of diabetes are formidable. With humility and respect, I understand that the challenges faced by my patients—my friends—and their families who have to balance their lives with diabetes are far more significant than the challenges I face as a professional trying to listen, inspire, nudge, and suggest ideas that I hope and believe will help in their quest for enhanced health.

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