

Living Well with Diabetes:

How researchers at YSN are helping families develop better coping strategies that improve their quality of life.

HOMework AND HOME RUNS, theater, piano and trumpet, musicals and science: the breadth of Andrew Nappo's talents as he entered 6th grade in Madison, Connecticut would make any parent proud. Andrew's mom and dad, Patricia and Greg Nappo, were no exception. "Andrew's academic and after-school schedule was grueling," recalled Patricia, "but this is how he is; he loves to challenge himself and he has so many interests."



Andrew Nappo (left) with brother Greg, Sister Jackie, and mom Patricia.

As the school year began, Andrew's parents spoke to him about easing his workload, but Andrew was resolute in giving his all to every one of the activities he had committed to. "We were very proud of him and supported his decision," his mom said.

Most days, Andrew's schedule left him feeling exhilarated, but exhausted. "I thought that with all his activities—sports, music and theater—plus the normal 6th grade load, well, no wonder he was tired," recalled Patricia. However, Andrew's fatigue became more severe just before his eleventh birthday in September of 2002. "In those days just before and after his birthday he had lost weight and really looked worn out," recalled Patricia. She became further concerned when Andrew experienced nausea after having two bites of birthday cake. Patricia noticed that Andrew was not improving and kept him home from school a couple of days later. She noticed that her son seemed irritated, overly thirsty and was urinating often. As Andrew's fatigue persisted, Patricia became certain that the problem was more serious than she had first suspected and called his doctor.

As a result of that doctor's visit three days after his eleventh birthday, Andrew was diagnosed with type 1 diabetes mellitus, a chronic disease that affects approximately one in every 400 to 500 children and adolescents in the United States. Type 1 diabetes develops when the body's immune system destroys pancreatic beta cells, the only cells in the body that make the hormone insulin that regulates blood glucose. The news of Andrew's condition came as a shock to the Nappo family.

"For the first several months after Andrew's diagnosis I could not sleep at night," recalled Patricia. What made those first few months more manageable for Andrew's parents, however, was that diabetes was "not unknown" in their community. Several families in the area had children who had been diagnosed with the disease and following Andrew's diagnosis the Nappos immediately sought their counsel. "We were fortunate because there were others in our community who knew what we were going through because they had gone through it themselves and were managing well," said Patricia. "They were our first source of information and support, and their help to us during that most difficult time was invaluable."

In talking to other parents of children with type 1 diabetes and reading extensively about the disease in the first months after Andrew's diagnosis, Patricia and Greg Nappo learned that diabetes self-management education is an integral component of care. They sought to further their family's education about how to better manage their son's condition. From Andrew's doctor they learned that significant research was being conducted in self and family management of Type 1 diabetes at Yale University, and this soon brought the Nappo family in contact with researchers at the Yale School of Nursing (YSN).

Working Inside the School System: Helping Children at Risk to Avoid Weight Gain



Margaret Grey's work with children who are at risk for type 2 diabetes grew out of her coping skills training (CST) study of adolescents with type 1 diabetes. In analyzing the results of that study, researchers found something unexpected: while they believed that CST would help some of the study participants avoid gaining weight, what they found was that CST helped girls, but not boys, to avoid weight gain. Dr. Grey explained: "A lot of boys came into our study thin and really wanted to gain weight, whereas girls came into the study thin, and wanted to remain thin. The girls were able to avoid weight gain by using skills we taught in CST." These findings came at a time when the rates of childhood obesity were rising at epidemic levels, and type 2 diabetes in childhood, unheard of until five years earlier, according to Dr. Grey, was now being diagnosed in 40% of new cases of childhood diabetes. The investigators sought to develop an intervention to help children at risk for type 2 diabetes avoid weight gain and prevent type 2 diabetes.

They applied for and received NIH funding for a pilot study that tested CST in the school system. The findings of the study were remarkable, according to Dr. Grey. Working in two schools with a group of children who were insulin resistant and "practically guaranteed" to develop type 2 diabetes within 3-5 years, the investigators were able to curb their weight gain significantly and minimize their risk of developing the disease. In 2004, the investigators applied for and received NIH funds for a larger study that will train seventh grade science and physical education teachers to deliver an intervention that combines CST and physical activity and nutrition education to children in five area middle schools. While the investigators will be working specifically with children who are at high risk for developing type 2 diabetes, the information will be shared with everyone in the schools. "In helping to make a positive difference in what these kids eat and drink, how much they exercise and how they approach problem solving, we are doing as much as we can in the schools so that the information gets to those who need it most and the intervention model remains in the (school) system after the study is complete," said Dr. Grey.



YNSN research staff Evie Lindemann, MA, MFT (left) and Glenda Insabella, PhD lead the coping skills training sessions in which Patricia, Gregg and Andrew Nappo took part

For the past decade, researchers at YNSN have led the field in examining the efficacy and effectiveness of coping skills training for children and families with Type 1 diabetes. The impetus for advancing this area of study at YNSN came in 1994, with the release of findings from the Diabetes Control and Complications Trial (DCCT), a large multi-site clinical trial that demonstrated for the first time that intensive insulin treatment with the goal of getting the blood sugar to normal levels and keeping it as close to normal levels as possible could prevent or delay the devastating long term complications of the disease. "One of the important questions raised after the DCCT findings were released was whether these findings could be translated to a general population of teenagers with type 1 diabetes," said Dr. Margaret Grey, director of research affairs at YNSN and lead investigator on a series of studies at Yale that looked at ways to help children and families better manage type 1 diabetes and live quality lives. In 1995, researchers under Dr. Grey's direction launched a study to test the intervention in adolescents who were beginning intensive insulin treatment. The researchers hypothesized that the addition of coping skills training to an intensified insulin regimen recommended as a result of the DCCT and standard diabetes education would help teenagers better control their blood sugar levels. According to Dr. Grey, what they discovered was quite profound: in addition to the improvement of metabolic control, improvement in quality of life in the experimental group was also highly significant both statistically and clinically.

At the time, conventional treatment of type 1 diabetes involved two injections of insulin per day, 2-4 blood glucose tests daily, and careful dietary control. Intensive treatment recommended as a result of the DCCT findings meant teenagers had to increase their insulin injections to 3 or more, and their blood glucose tests to 4-6 daily. Prior to, and for some time after the DCCT findings were released, there was concern in the health care community that the intensive treatment regimen would be so onerous for teens that, while achieving good metabolic outcomes, their quality of life would suffer as a result. "This is why we were especially gratified by the results of our study," Dr. Grey said. "Our findings demonstrated that, contrary to common belief in the health care community at the time, metabolic control and improved quality of life were complementary. Good metabolic control did not have to be a trade off against better quality of life."

The YNSN study was the first full scale clinical trial of a behavioral intervention in type 1 diabetes ever attempted. Aspects of the study were published in *Diabetes Care*, the *Journal of Pediatrics* and numerous other publications. It changed common perceptions about self management of type 1 diabetes, and helped to pave the way for further research that would help families better manage chronic health problems.

The next study involved two areas of interest. First, YNSN researchers looked at what happened to the cohort of 120 adolescents involved in the previous study as they transitioned to young adulthood. This question was important, according to Dr. Grey, because literature released

prior to the DCCT suggested that the teens who strove for good metabolic control during adolescence were likely to have poor outcomes as adults. "Given that the DCCT changed everybody's philosophy of treatment, we thought that we could demonstrate that teens could have better quality of life as adults if they maintained good metabolic control during their adolescent years," Dr. Grey said. In 1999, YSN researchers received funding to follow a cohort of 120 teens for a period of five years to see if their quality of life would indeed improve as adults. "These kids were very committed to us and wanted to remain in the study," said Dr. Grey, "which made the pursuit of this question especially important." What the researchers found was that the worsening of metabolic control one would expect in the transition to adulthood was nowhere near the level previously reported. Researchers also found that quality of life, in terms of functional outcomes such as gainful employment, meaningful relationships and self image, were all much more positive in this group of young adults than had been reported in the pre-DCCT studies. "This was good news for parents who were concerned that their children who acted out a bit as teens would not do well as young adults," explained Dr. Grey. "Our findings demonstrated that, for the most part, these kids still do well as adults psychologically while maintaining good metabolic control." Dr. Grey lead a team of researchers who presented these findings at an American Diabetes Association conference in 2002.

In the second part of the study, researchers looked at pre-adolescent children to see if some of the challenges kids with type 1 diabetes experience as teens due to hormonal changes during this time period could be minimized or prevented. The researchers adopted coping skills training to work not only with the children in this age group, but also with their parents. The 6-week training program involved group sessions that addressed kids needs and concerns, separate sessions with parents, and then, joint sessions designed for kids and parents to work together to create systems for managing the disease that each family would customize to fit their unique situation and needs.

Patricia and Greg Nappo, and Andrew, then age 11 and recently diagnosed, took part in this study. Two other families also participated in their



Coping Skills Training group. Parents and children met with their peers in one-hour sessions weekly. The children's session was lead by Glenda Insabella, and the parents' session by Evie Lindemann "Through our discussions we developed real tools to help us manage diabetes better," said Patricia Nappo. For Andrew's parents, the interaction with other parents proved especially helpful. As Andrew was diagnosed most recently out of all the children, Patricia and Greg had the additional benefit of learning from the experiences of others in the group. "The other parents were wonderful and very generous with information regarding what they had learned in the years since their children were diagnosed," said Patricia. "I think that was my saving grace; I was able to voice my feelings in this group and to develop an understanding of how other parents coped. As a result of those sessions, I learned a lot about myself and what I had to do to help my son better manage diabetes. My husband and I also learned to handle this disease and learned to avoid the stress that it brought to our family life."

Andrew and the other children in his group also benefited from learning about one another's experiences. "Since I was newly diagnosed, I did not know how other kids lived with diabetes or felt about it, and they had a lot to tell me," said Andrew. "I think I had a lot to tell them too," he added. Andrew, and the other two kids in the group, David and Katryn, did not limit their conversations to diabetes. "We talked about all sorts of things, like school, sports, and all the other things we liked to do," said Andrew. David, as old as Andrew but

Silent Heart Disease and Type 2 Diabetes



Deborah Chyun, Associate Professor and Director of the Adult Advanced Practice Nursing Specialty at YSN, is conducting research that focuses on the physiological and psychosocial aspects of type 2 diabetes and coronary heart disease. She is co-Principal Investigator with colleagues at Yale School of Medicine (YSM) on the industry-sponsored multicenter screening trial, Detection of Ischemia in Asymptomatic Diabetics (DIAD), that examines silent heart disease in patients with type 2 diabetes. Baseline results have recently been published in *Diabetes Care*, August 2004.

In conjunction with the DIAD study, Dr. Chyun and Dr. Gail Melkus have completed an ancillary study focused on the psychosocial factors involved with management of diabetes and cardiac risk factors. They examined data on anxiety, depression and quality of life in the studied population. Dr. Chyun found that these patients were in need of psycho-social intervention and diabetes management. Dr. Chyun explains "So we now have two pilot intervention studies going forward to address the patient needs of this population."

She explains further that in the original DIAD study a randomized group of patients received a specialized screening for heart disease, a test known as myocardial perfusion imaging, which detects the presence of otherwise asymptomatic heart disease. According to Dr. Chyun, "The remarkable finding of the study was that one out of five patients was diagnosed with perfusion abnormalities or silent heart disease." She continues, "So on top of diabetes, the patient now finds out they have heart disease they didn't know they had, and they don't have any symptoms." Patients are likely to be confronted with, "How can you tell if you are doing too much or too little in relation to your health? How can you begin to get your bearings once this new information is revealed to you?"

Dr. Chyun's current pilot work, with colleagues at YSN (Dr. Melkus, Dr. Sandra Talley and Jessica Coviello) and YSM, will serve as the basis for a larger, randomized trial that will assist individuals with type 2 diabetes who undergo screening for silent heart disease to manage both their diabetes and heart disease. Dr. Chyun concludes, "The challenge will be to offer a multidisciplinary intervention to help patients prepare psychologically for the possible outcome of the screening, as well as to better manage their diabetes and cardiac risk factors."

Using technology to support family management of type 1 diabetes



Kathleen Knafl, professor and Director of the Doctoral Program at YSN, as well as Acting Dean for Academic Affairs, focuses her research on family management of childhood chronic conditions and normalization of family life in the context of chronic illness.

Dr. Knafl's current diabetes research, entitled *Use of a Handheld Personal Computer to Support Family Management of Type 1 Diabetes*, examines the use of technology to enhance family-management of type 1 diabetes in children. Based on the findings of an initial pilot study, this project proposes to test the feasibility of using handheld personal computer (HHPC) technology for monitoring children's blood glucose levels. According to Dr. Knafl, "HHPCs are portable, affordable, fully integrate with many computer software applications, and have the advantage of being easy to use." Their use will provide the opportunity to test the potential of an incentive, in the form of password-based access to computer games, for sustaining children's motivation to report blood glucose levels on a daily basis.

Although HHPCs have the potential to provide children, parents, and practitioners with timely feedback on children's blood glucose levels, their effectiveness as an adjunct to care has not been studied. So the specific aims of Dr. Knafl's proposed study are to first test the feasibility of using a HHPC to record and monitor blood glucose levels in children with type 1 diabetes, and then to evaluate the effects of a computer game incentive on children's use of the HHPC. Finally, the study will yield important data describing exactly how families incorporate the HHPC into their daily management of their child's diabetes.

"This research sets the stage for developing and testing nursing interventions that meet the unique needs of diverse families and support optimal family and child functioning. Nurses are ideally positioned to support families and help them take advantage of the opportunities provided by new technologies," says Dr. Knafl.



diagnosed a few years earlier, taught him some "neat baseball and basketball tricks," and Katrin, who was older than Andrew, told him what to expect as he entered 7th and 8th grade. "The children in this group were a particularly good match," said Patricia. "They formed a bond that was very helpful to each child's understanding of their situation."

"By sharing our experiences we learned that we were not alone in this, and that, if we managed diabetes effectively, we could continue to do the things we have always enjoyed and to live a quality life," said Andrew.

Andrew speaks openly about his life and his diabetes with others, including his older brother Greg and his younger sister Jackie. He also talks about diabetes with his friends at school. In fact, on the day he returned to school after being diagnosed, Andrew felt it was important to talk to the other students in his home-room about what the diagnosis meant to him and his family. "I told them about how I felt, and what I had to do to manage diabetes," said Andrew. "I don't think the other kids treated me differently as a result," he added, "but I think they respected me because I was trying to be honest with myself and with them about what had happened to me."

Researchers at YSN are just now wrapping up analysis for the study in which Andrew and his parents participated. The preliminary findings, according to Dr. Grey, reveal important effects of coping skills training on quality of life, particularly in depressive symptoms in both parents and kids. "Between 25 and 40 percent of parents and kids with type 1 diabetes nationwide report very high levels of depressive symptoms," said Dr. Grey. "The fact that we've had

some positive impact on these symptoms is a very good sign for families." The investigators hope that what they learn from this study will assist parents to prevent the onset of depression and to parent more effectively. Dr. Grey discussed the preliminary findings of the study at the State of the Science Conference in Washington, DC, in October of 2004.

In 2003, YSN researchers received additional funding to extend their work in this area, and to look at what happens to the group of pre-teens in Andrew's study as they transition to adolescence. "The issues these kids now face as teens are different from those they faced as pre-adolescents," explained Dr. Grey. "We are looking at whether they will need a booster in their coping skills training to help them to maintain high quality of life as teens."

Andrew has much to say about the quality of his life these days. His schedule in 8th grade is just as demanding as when he was diagnosed with type 1 diabetes two years ago. Still an honor student, Andrew continues to play the piano and trumpet, he acts and sings in a church theater group, is a member of the Connecticut Youth Jazz Workshop, and, of course, he plays baseball. "Pitcher, shortstop, and sometimes catcher," his mom adds proudly. Andrew's baseball team, the Madison Mad Dogs, is doing well this season. In the eighth inning of a recent game, Andrew's hit scored the deciding run, helping the Mad Dogs triumph over the rival team from Hamden, Connecticut with a final score of 7-6.

Andrew's demeanor is humble, his attitude proud and determined. He credits his mom and dad, brother and sister, his grandparents and his friends, his school nurse, Karen Owen-Buckley, and the researchers at YSN for helping him to remain focused and keep a positive attitude. And he has a message for other kids who may be diagnosed with type 1 diabetes: "You don't have to be scared," he would tell them. "It won't be as hard as you think if you just take care of yourself."

And he would tell them: "Don't ever give up and don't let anything hold you back."