

MARGARET GREY'S INTELLECTUAL TRAJECTORY

Margaret Grey

I wanted to be a nurse from the time I was six years old living in eastern Pennsylvania. What nursing meant to me at that age was what many in this room probably think nursing is, which is the bedside role that nurses just do what the doctor tells them to do. But my parents had the good sense not to send me to Easton Hospital School of Nursing, which was a diploma program and would have been a lot cheaper for them than college. But they did send me to college at the University of Pittsburgh. I was then introduced to the idea that there was an intellectual discipline that went along with the practice. After graduating, I moved to New Haven to take a nursing job at Yale New Haven Hospital. I met my husband there, who was a Yale PhD-prepared particle physicist.

I was well aware of what his career trajectory was. As nurses, our trajectory is different because we usually start nursing at the undergraduate level and then work for a while. In my case, I then went back and got a master's degree, and it was in the master's program that I fell in love with research. I didn't even think about research until I went to Yale for my master's degree. In those days we were required to do empirical research for our master's thesis. And I thought, this is so cool.

Unlike most people who become nurses, I moved fairly quickly from being a bedside nurse to being a nurse practitioner and learning to do research. Eventually my husband did a postdoctoral fellowship in high energy particle physics in New York City, so I went to Columbia and got a doctorate there.

I ended up at Yale and eventually became dean of the School of Nursing – a job that almost killed me, but I survived. I focused much more on clinical research over the course of my career than on traditional clinical nursing practice.

Margaret Grey, the Annie W. Goodrich Professor Emerita of Nursing, was the ninth dean of the Yale School of Nursing. She earned her BSN from the University of Pittsburgh, MSN in pediatric nursing from Yale University, and DrPH from Columbia University. A pediatric nurse practitioner, Dr. Grey has focused her research on improving self-management in youth with diabetes and the study of psychoeducational interventions that improve metabolic control of diabetes and quality of life. She has published more than 410 journal articles, chapters, and abstracts and has received numerous regional, national, and international honors. She was elected to the American Academy of Nursing and National Academy of Medicine. She received the Rubin Award for Outstanding Contributions to Behavioral Medicine from the American Diabetes Association, Pathfinder Award from the Friends of the National Institute of Nursing Research, Outstanding Nurse Scientist Award from the Council for the Advancement of Nursing Science, among many other distinctions.

One of the things that attracted me to the Yale School of Nursing was that they viewed nursing as an intellectual discipline. The Yale School of Nursing was one of the first schools in the country to require master's students to do a thesis. I just happened to be in New Haven working as a staff nurse. But it was the perfect fit for me because it is what I really wanted to do.

When I was dean, the School of Nursing moved to the Yale West Campus, where we further developed our identity and had room to grow our research programs. We had room to do what we needed to do.

Historically, what made the Yale School of Nursing unique was the place of research in the master's program. Students had two semesters of research, and everybody did a thesis. If I had not had that experience when I was a student there in the 1970s, I never would have become the researcher I became. I have always been grateful that I had the common sense to focus on the research.

Mine was not a rapid trajectory through undergraduate, graduate, academic position, and the like. My career was built on my clinical expertise. My clinical work focused on children with diabetes. Most people think of diabetes as type 2 diabetes, which is different than what kids get, as kids get type 1 diabetes – they all require insulin. The focus of my work has been first on helping kids and their families *adapt* to managing a complex chronic condition. It has also been focused on the ramifications for the family of having a child who requires two or three injections of insulin every day. And that's what I built my research career on. It grew out of the work I was doing clinically.

My focus as a researcher was on not just the physical but also the psychological and the social issues. One of the things you learn very quickly is if you don't pay attention to those things, you're going to get nowhere. Most people think that it is all about insulin. Insulin is the easy part. It's managing all the psychosocial things – the family issues, the food issues – that are difficult for families. The problem is that kids must be willing to take the insulin and do what they need to do to manage their diabetes.

People were so busy trying to figure out how to take care of these kids medically. We came up with all these fancy insulin regimens of two or three insulin injections a day. But nobody was paying attention to what was going on in the family and what it takes to manage diabetes for a child, particularly a teenager. Often the last thing teenagers want to do is what their parents want them to do. I worked with some great pediatricians, and they would throw up their hands and say, "Margaret, you've got to do something because we don't know what to do with them." I became by default an expert in how to get teenagers to do what they needed to do so they didn't get sick.

Families – particularly the parents – are important because they are the ones who feel responsible if the kid isn't doing what they are supposed to do. The key is to help the kid and the family to work as a team. When they don't work as a team, you're in deep trouble.

The best approach is not to tell them what to do. Instead, you have conversations, such as asking "What do you hate the most about this? How can we make this better?"

The general rule was you do what the doctor tells you to do. Well, that is the absolute worst approach. When you start telling a teenager what to do and go through long-winded explanations about why they should do it, such as you can get complications, it's the last thing they want to do. They just want to be kids. The focus should be negotiation: helping parents to understand how to negotiate with their kids. Telling kids to do something isn't going to make it happen. How can you work as a team – the clinical team and the parents – to help kids be well? The more you tell them what to do, the more they rebel. I am trained in social science as well as in nursing. My early research involved descriptive studies trying to understand what the dynamics were. Later I did multiple clinical trials of interventions trying to help families and kids do better. It is traditional clinical research, but with a focus on these types of problems as opposed to figuring out a better way to give insulin.

Most of my clinical trials did not have a no-contact control. Ethically, given the problems that these kids and families are dealing with, you can't just say we are putting you in the experimental group and say to the control group that "you get nothing." Some of the first studies we did had sham control groups, meaning that the interventions that were meant to be therapeutic were carefully designed and the control conditions were carefully defined to exclude those behaviors. Most of my controlled trials had an intervention for the control group, but it was not the therapeutic intervention that we were studying.

When we first started doing these clinical trials, few people were doing those kinds of studies, particularly with teenagers. One of the reasons that we did it was that parents wanted their kids to be in studies because they thought that was state-of-the-science. If we did nothing for the control group, except waitlist them, then nobody would enroll in the study.

The studies that made me famous were studies of an intervention I developed called Coping Skills Training. The idea was that kids focused on taking their insulin, doing their shots, all of that. But their adjustment to having diabetes got in the way. So, we focused on teaching them how to cope with all the stressors that were going on in their lives.

The idea was that you can teach them how to give insulin. You can teach them how to prick their finger and test their blood sugar, but if they didn't learn how to cope with what they had to deal with and if their parents didn't understand, then you had a battle that went on in the home all the time. Mom is yelling at the kid, "Did you take your insulin?" And the kid says, "No. Leave me alone." Although I was a pediatric nurse, we also had to understand what was going on in the family. The coping skills interventions came from helping families and kids understand what they were going through and then finding positive ways of managing.

We had to help families cope. Everybody was stressed. The kid has a serious disease. The parents are very concerned that if the kid doesn't take care of himself and doesn't do what he's supposed to do, then he's going to have complications. I had

done a series of descriptive studies that looked at factors that predict better outcomes. Realizing the importance of coping behaviors – being positive about what had to be done but still having to do it – led to a series of studies with different-age kids, teenagers, whole families, etc. studying Coping Skills Training.

We looked at the coping literature. There are different ways that people cope: pathological and positive. We focused on helping people eliminate the pathological coping behaviors and develop positive coping behaviors. It involved the parents and the kids. With the teenagers, we did it with the kids alone. But with the younger ones, we did it with the parents and kids together.

As a clinician, I had the kids' trust. I often was in a position where I could say, "You're not telling me something." We have a measure called hemoglobin A1c. A kid comes in and says, "I've taken all my shots. I'm doing all this." But his A1c is very high. Having worked with teenagers for many, many, many years, I was never afraid to say, "This doesn't make any sense. You're telling me you're taking all your shots. You're testing your urine, and blood tests at home are all close to normal. This pattern doesn't fit." It's usually one of those things where the kid is sitting there thinking "Oh – she knows this." My medical colleagues – this is not a criticism, it's just the fact – view the world through a medical lens. When they see that your A1c is very high, they want to give you more insulin. That doesn't solve the problem. The problem is: "I hate this disease. I don't want to do this. I feel crappy all the time." And I would sit in a room with them and say, "Let me tell you what I think." They sit back in their chair and say, "How do you know?" I replied, "Because I've been in this field for twenty years, picking up the pieces of these teenagers." Parents think that if I just tell him to do it, he'll do it. Well, no, he won't, or she won't. The parents, kids, and clinicians need to work as a team. It's always funny, because the kids would say to me, "How do you know so much about this?" because I don't have diabetes. But I grew up with a grandfather who had type 1 diabetes. I watched him decline because he didn't take care of himself. It is empathy more than knowledge.

In all my studies, in addition to assessing diabetic control with hemoglobin A1c, we also measured coping skills using questionnaires and other approaches. We found that once they got the coping part, they then translated that into taking care of their diabetes.

To accomplish this, the family must be involved. Some parents get frustrated and just want us take care of it. One of the most difficult conversations was helping people understand that this is a family problem. Parents can't just throw up their hands and say he's going to deal with it because a twelve-year-old can't do it alone – from both an intellectual and a psychological standpoint. Establishing coping skills is an approach that psychologists have used for years to help people understand what they were doing to solve a problem. I had a responsibility as a nurse to do the clinical work, but my clinical work also included teaching coping skills to families so that they could have better outcomes. I had six NIH-funded clinical trials to test various approaches to do that.

The idea was to help the parents understand that just telling a teenager to do something was not going to make it happen. The key is to give people tools, and coping skills is one of those tools. The use of coping skills helps families manage better.

The coping skills intervention that we developed focused on diabetes because that was the problem the kids in my clinical practice had. But one of the things that the families figured out quickly was that once they acquired these skills, they could use them for many different things. I had a lot of parents who said, “Why didn’t somebody teach me this when I became a parent?”

The coping skills that we taught are things like stress management. It is very practical, and it comes out of psychology. One thing I loved about it as a nurse, as opposed to a therapist, was that the focus is on defining the problem, and what I need to do to get control of this problem. That problem isn’t the same for every family that has a child with diabetes. Part of the initial work was understanding that there’s not one coping skill, or one coping behavior, that matters. There are many of them. The questions are: What is the problem now? What’s causing all the angst in the family? Is the kid not taking his insulin or eating too many sweets? The coping skills also include things like being able to reframe a problem. The kid doesn’t want to take the insulin. The mother was screaming at the kid to take the insulin. That’s not helpful. So how can you reframe this?

I used to have conversations with teenagers, saying things like “You realize that you’re pissing your mother off, and that just makes this worse?” It is reframing the problem. It is reframing the question. It is coming up with different solutions. Families get into these ruts, such as it is time for the shot of insulin before dinner, and then they get into the cycle of a half an hour chasing the kid around the house with the needle. That’s not therapeutic; it doesn’t help. They need to come up with ways to think about it differently. Yes, you still must take the insulin, but what is it that you don’t like about this? Are you doing this to annoy your mom? Many times, that is the answer.

I became dean because people wanted to see the Yale School of Nursing become more focused on research. I was one of the first people there to have major NIH grants. I think that research and administration require different skills, although it requires a lot of coping skills to be an administrator!

One of the things that I learned was that there are some things you can fix, and there are some things you can’t fix. The sooner you recognize the things you can fix and do something about those, the better things are going to be.

There were days when being dean wasn’t fun. By the time I became dean of the Yale School of Nursing, I had pushed the research agenda, and the school had come way up in rankings. I remember when we first started talking about having a PhD program and people looked at me and said, are you insane? It wasn’t going to happen, but it happened! And we are now the number three ranked nursing PhD program in the country because we focused on science and doing research. That was what had to have happened if it was going to happen at Yale University.

There was pushback at the Graduate School, so we were very planful. We started with the Doctor of Nursing Science (DNSc) program, which was not a research degree, but we knew we had to show that we could do the work. We now have a Doctor of Nursing Practice (DNP) program in addition to the PhD program that is housed in the Graduate School.

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I have been asked about hierarchy and our relationship with the medical school. I have been here long enough to watch our school go from this tiny little place in that little building that used to be an elementary school to a world-class, top-ranked school of nursing. A lot of it is predicated on first growing our intellectual work. By intellectual work, I mean traditional research, NIH grants, etc. We were never going to compete with the medical school. They're Goliath. What they do is not what nursing does. People ask why we are doing clinical trials. We are doing clinical trials of behavioral interventions, as opposed to clinical trials of drugs, etc.

I was also admitted to the Yale School of Medicine, but I chose to go to the School of Nursing because it was a much better fit with my intellectual interests. If you look at the research happening in the medical school, except for maybe the psychologists and some others, it's about drugs. That's not what I wanted to do. I am very interested in the psychosocial and family aspects of chronic illness in kids. I did my master's thesis and graduated from the Yale School of Nursing. I then went to Columbia and studied psychosocial aspects of chronic illness. The rest is history, and now I am retired, taking care of my kitties.