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Biography

Gary Walco, Ph.D, is the Director of Pain Medicine at Seattle Children’s Hospital in Seattle, Washington, a Professor of Anesthesiology and Pain Medicine at the University of Washington School of Medicine, and an adjunct professor of Pediatrics and Psychiatry & Behavioral Sciences. Dr. Walco received his bachelor’s degree in Psychology from UCLA, his Master’s degree in Clinical Child Psychology from Ohio State University, and his Ph.D. in Clinical Child Psychology from Ohio State University.

Dr. Walco has spent over three decades developing and influencing the sub-specialty of pediatric pain management. His research and writings examine psychological and pharmacological pain treatment in infants, children, and adolescents, ethics of pain management in children, and assessing pain and stress responses expressed by children. Dr. Walco has served in leadership and advisory roles for the American Pain Society, American Psychological Association, the Children’s Arthritis and Rheumatology Research Alliance, the Children’s Oncology Group,, and the United States Food and Drug Administration.

Dr. Walco is the recipient of the (2006) *Lee Stalk Distinguished Service Award for outstanding contributions to pediatric psychology* from the American Psychological Association, the (2003) *Jeffrey Lawson Award for Advocacy in Children’s Pain Relief* from the American Pain Society, and the (2019) *Distinguished Service Award* from the American Pain Society.

In his spare time, Dr. Walco is a “die-hard” L.A. Dodgers fan.

Interview Abstract

Dr. Walco discusses his career beginnings in pediatric pain medicine. He describes field observations of “barbaric” practices that were founded on the notion that children did not experience pain the same way adults do. Dr. Walco recounts some landmark events in the 1980s and 1990s that gained public notoriety and aided in developing the field of pediatric pain medicine, including the Jeffrey Lawson case-study of a premature baby who was administered thoracic surgery while awake and conscious. Dr. Walco then describes early experiences in a field with general disregard for the pain and suffering of pediatric patients. The need for pediatric health care advocacy drove him to connect with other health care providers to investigate multi-disciplinary, multi-organizational level solutions to improving the quality of life for pediatric patients. Dr. Walco describes the barriers and successes he has experienced in pain medicine as the sub-specialty has evolved in the last thirty-five years. Dr. Walco also describes the vision he seeks to achieve within pediatric pain medicine, as well as the work he is doing to continue to advance the field in establishing the best evidence-based practices.

Glossary of Acronyms

<i>Abbreviation</i>	<i>Definition</i>
HEAL	Helping to End Addiction Long-term Initiative
NIH	National Institutes of Health
OR	Operating room

Interview Roadmap

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[00:00:00]

Bryan Sisk: Today is April 24, 2019. I am Bryan Sisk, and I'm in St. Louis, Missouri, and I'm interviewing Dr. Gary Walco over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Walco is in Seattle, Washington. Thank you, Dr. Walco, for joining me today. To get us started, could you just tell me when your mind turned toward pediatric pain as a career focus?

Gary Walco: Sure, that would be in the early 1980s when I was still in graduate school and I started working with the pediatric oncology population. It was pretty clear that a lot of what was going on then was pretty barbaric.

[00:00:45]

Bryan Sisk: Could you tell me a little more about what was going on then?

Gary Walco: It was standard procedure to do bone marrow aspirates, biopsies, and lumbar punctures with children wide awake, sometimes with a little local lidocaine, but it was pretty horrific. A lot of the data showed that those kinds of situations induced some post-traumatic stress experiences. It's been probably since the early to mid-90s, we've been doing those procedures either with deep sedation or, more typically, general anesthesia, so we've come a ways, but back in those days it was pretty gruesome.

[00:01:29]

Bryan Sisk: It didn't really change until the 90s? Is that when you were saying the tipping point was, where we started having more aggressive pain management and sedation?

Gary Walco: I think the way the field emerged; it was 1985 when Neil Schechter published his paper on the undertreatment of pain in children. I think it was in *Pediatrics*.¹ In 1988 was the first International Symposium on Pediatric Pain, where we learned about some of the deleterious effects of poorly treated pain in children and strategies to treat it better. I think a fair number of us were pretty motivated at that point to start trying to invoke changes in our home institutions, and more broadly if possible. That process took a few years before people generally adopted the idea that those procedures are pretty horrific, especially if you get them multiple times, and so people started to look at more significant pharmacologic interventions.

[00:02:39]

¹ Schechter, N., Allen, D., and Hanson, K. "Status of Pediatric Pain Control: A Comparison of Hospital Analgesic Usage in Children and Adults." *Pediatrics* 77, no. 1 (Jan 1986): 11-5.

Bryan Sisk: What do you think were the barriers to recognizing the pain and the distress of the kids going through these procedures?

Gary Walco: For years, people genuinely believed that the youngest children, like neonates and infants, really did not experience pain, at least not the same way as adults. There was the landmark issue with Jeffrey Lawson, who was a premature baby who had thoracic surgery with no anesthesia. They basically used a paralytic, cut into the kid's chest, repaired his heart, sewed him up, and he was wide awake and conscious for the whole thing. When his mother, Jill Lawson, found out that's what happened to her baby, she went public and really brought a lot of attention to the fact that children's pain was hideously undertreated. Just as an aside, the American Pain Society gives out the Jeffrey Lawson award every year for advocacy in children's pain, and it's named after him. Anyhow, that was one piece that got the public's attention. Then other people like Neil Schechter, Don Tyler, Elliott Krane, who were then here at Seattle Children's, and I, and some others just became more and more active as advocates and started to move the field a little bit.

[00:04:17]

Bryan Sisk: When you were first noticing this, did you find a community of similar minds, or did it take a while for that community to develop?

Gary Walco: This was pre-email, etc. The way that people communicated back in the mid-80s was by writing letters to each other and occasional phone calls. The first International Symposium on Pediatric Pain took place in 1988 and it was truly inspiring because it was the first time we all met face to face. The commonality of perspective, cause, and passion was really terrific. I think that was a fairly significant turning point.

It took a while. Generally speaking, for whatever reason or reasons, pain is undertreated. It is undertreated more in children than in adults, and it's counterintuitive. Most people would think that you would go out of your way to ease the suffering of children, yet, even today, we still have to fight for people to recognize when kids are in pain and to be proactive in preventing or treating. There are a lot of cultural biases. There are a lot of—I think when one goes through training in medicine or nursing, you learn in some fashion to become a little bit immune to displays of suffering and distress, but we're working on it.

[00:06:00]

Bryan Sisk: You think learning a trained inattention to these things is part of the problem?

Gary Walco: It's a combination. Number one, if you are doing something to a person that is creating discomfort, you need to distance yourself from that. We can go back in history to look at what happened with surgeons before there was anesthesia. If they listened to the screams and pleas of the patients on whom they were doing surgery, they would have not been in that profession for very long. You have to just learn to do what you've got to do and keep going, and I think, sadly, that has spilled over to some degree.

I also think that if you internalize, really empathize and feel what the patients are feeling, it would be really difficult to work in pediatrics. You have to, to some degree, maintain that objectivity. My concern, as well as others, is, has that gone too far? I think most people going in would say, "Oh, my God. Hearing a child screaming and crying would be intolerable to me," yet when you work in a children's hospital, then that's what you are exposed to all day. Obviously, to some degree, you're going to become a little bit immune.

[00:07:43]

Bryan Sisk: When you started out, and before that 1988 conference, who did you learn from?

Gary Walco: I had a serendipitous introduction in that, when I was in training, the medical school offered a seminar one summer in hypnosis for medical settings, and so just on a lark thought, "That's interesting. I'll go do that," and I did. I was intrigued by it, and talked to the professor, and said, "If I want to keep doing this, where can I go?" and wound up on an adolescent cancer unit. That, combined with the research I was doing on kids with cancer, just all brought it together and got me going in that direction. I don't think I had a specific mentor. I think a lot of us were just doing our thing in our different settings. Then, as papers started to come out, people reached out to each other and said, "I've got similar interests," *et cetera*, but it really didn't gel or get organized until that meeting. I think all of us who were at that meeting, almost nobody had a mentor because the field wasn't established enough for people to be in a mentoring position.

[00:09:24]

Bryan Sisk: Part of my interest is in how the palliative care field developed in pediatrics. Do you think that the development of pain medicine and palliative medicine came from the same starting points, or do you think they started differently? Can you talk me through how that process worked from your perspective?

Gary Walco: Yeah, it was a little of both. The palliative care movement really got its roots in London, and more with adults. There was a woman

who was active, named Ann Goldman, who was certainly a presence in the pediatric pain community but also was doing a lot in the palliative care community. She was from London. It's interesting in that, the way things have shaken out now, a lot of us who do pain medicine, dabble in palliative care, but to a large degree the fields, while they overlap, have not really merged. There are some centers that have a pain and palliative care program that do have both, but the individuals working in those settings tend to really focus more on one rather than the other, and I think it's a matter of expertise and training. There was a Palliative Care Committee in the Children's Oncology Group, that formed some time in the mid-90s, if I'm remembering correctly. Among that group, there were a lot of excellent people who had an interest in palliative care, but I was the only one who had any real background in pain. There's just been an interesting parallel development with some integration, but not nearly as much integration as I think would be adaptive.

[00:11:38]

Bryan Sisk:

What do you think it is that continues to keep these fields separate?

Gary Walco:

I think it's different expertise to some degree. Depending on your background in pain, a lot of people are trained as anesthesiologists, and then they get into pain, and so, not surprisingly, their focus is going to be a lot on either pharmacologic or procedural interventions for pain. Psychologists do pain and probably do have a focus on the broader context of quality of life and that would be more of a bridge, but again, if you're working in chronic pain, that's a different focus and some different expertise than would be palliative care. I made the argument many years ago that the critical focus has to be on quality of life, whether you're talking about palliative care, where a child is moving toward the end of their life, you're still looking to maximize quality. If it's palliative care for a child with a chronic condition who is going to be living with it for years, you're still focusing on quality of life. If you do chronic pain, similarly—sometimes we can actually cure it and get rid of it, but principally the focus is on function and quality of life. The emphasis, the interest, in terms of what outcome you're shooting for, I think, is similar if not identical, but it's just a different skillset when you're applying it to palliative medicine than when you're doing pain medicine.

[00:13:34]

Bryan Sisk:

When you think about suffering more broadly and pain more broadly, there's the symptom of pain, but there's also the psychological aspects and the social needs—I'm thinking of something like Saunders' total pain concept. When you were

starting out, how were the psychological and the social aspects of distress appreciated?

Gary Walco:

Very, very much. I have to say that one of the greatest things about being in the pediatric pain field from day one, it did not matter what letters came after your name. If you had something to bring to the field, people were interested and embraced it. The very first textbooks on pain in children—and I'm looking at them on my shelf—they go back to the mid-1980s, late 1980s. Three for three of the first textbooks were all authored or principally edited by psychologists. Right from the get-go, the field was focused on development, on pain as it related to the family, pain as it related to emotional status and emotional development from day one. When that first meeting took place in '88, there was a huge representation of psychology, nursing, *et cetera*, in addition to physicians. It's just been natural from the get-go.

[00:15:16]

Bryan Sisk:

Do you feel that, outside of the pain and palliative community, it was accepted similarly by the oncologists, cardiologists, pediatricians, *et cetera*?

Gary Walco:

The "it" being psychological and social issues? No, they're slower [*laughs*] If you think about the mindset of the average pediatric cardiologist, for example, they're principally going to be focused on cardiac functioning, they're going to be focused on medical and surgical interventions to improve cardiac functioning, and the idea of integrating psychological factors is secondary. Having said that, there was a big movement in pediatrics toward comprehensive treatment centers, comprehensive asthma centers, comprehensive sickle cell centers, *et cetera*. NIH [National Institutes of Health] started to look at those programs in a much more favorable light and fund them more. That was the effort to really look at the psychological adjustment to the chronic condition and not just, "What medicines do we give?" *et cetera*. There was that recognition, not just with pain but more broadly.

Having said that, I was a card-carrying member of the Children's Oncology Group for many years, and the funding for those studies was miniscule compared to the funding for, "Let's find a big-C cure for cancer studies." There was some interest, but funding always lagged. I think at this point, in 2019, if you look at the major medical journals in pediatrics, like *Pediatrics*, *Journal of Pediatrics*, *et cetera*, there are tons of articles on psychological issues and social issues related to illness. I think that part has clearly advanced significantly.

[00:17:21]

Bryan Sisk: When do you think that this holistic view of suffering took root? Was it when you were starting out? Was it before you started? What are your thoughts on that?

Gary Walco: I'm not sure it has taken root [*laughs*]. If you look at chronic pain as an example, what still happens is a kid will have abdominal pain. They'll go to a gastroenterologist. The gastroenterologist will do their evaluation, scope the kid from both ends, motility studies, barium swallows, find no significant, underlying pathology, and will then say, "It's anxiety or stress. You need to go deal with that, and your abdominal pain will get better." That dichotomous view, going way back to Rene Descartes, still fundamentally exists. Then when you start talking about this, or hyperalgesia and downward modulation in the spinal cord from the brain with pain processing, and the physiologic aspects of how one could integrate, quote, "psychological," end quote, physiologic elements of pain—and I put those in quotes because I don't believe they're different; I believe they're all truly integrated—most people still do not see it that way. It's only now that medical school curricula are being changed to start to embrace more about what goes on with chronic pain and suffering.

I would say something similar about palliative care in that, for so many years, a patient dying was a failure. Once it was clear that your patient was no longer going to live, there was a certain amount of distancing from it. There was a certain amount of, "I can't do anything more for you." I think that mindset has clearly changed with palliative medicine, whereas there may not be that same intense level of involvement, but patients are not abandoned to the same degree. I'm not convinced that people are really, truly looking at patients holistically, even today.

You want evidence? Here's a simple little thing. Resident gets up to present a case, and it'll be, "So-and-so is a 15-year-old sickle cell disease patient, dot dot dot." If you look at how surgeons view their cases, they're going to do "a 15-year-old blah-blah-blah resection." What you do not typically hear is, "This is a 15-year-old young woman who has sickle cell disease." Now, it's subtle, but in one case you're putting the person first and the disease second, and in the other case, the focus is on the disease first and the patient second. When I'm teaching and I'm training people, I go out of my way to make sure that they understand that the focus and your language has to reflect this. The patient needs to be first and their condition is second. That's going to take a long time for people to really start viewing the human being first and the disease second. Antithetical to our training in medical schools.

[00:21:07]

Bryan Sisk: You had mentioned distancing from death. What do you think was the root of why people distanced from these kids that were dying?

Gary Walco: Two things. One is, when you're trained to be a physician, you're trained to cure people and you're trained to make them better. When you can't do that, clearly many people felt that it was their failure, even if, realistically it's, "Okay, I'm dealing with cancer," or "I'm dealing with cystic fibrosis," it's still, "Yeah, but is there something I could've done to have avoided this death?" That's part of it. The second part of it is people aren't trained. Who is trained on how to work with people as they approach death?

Again, if you look at pediatric curricula and medical school curricula over the years, that was not an element. Nobody got any training in that. Fortunately, now, with more and more pediatric palliative care programs, *et cetera*, it is being woven into postgraduate education. I still don't think there's all that much in undergraduate medical education, but I think it's becoming more of a focus. If you have no skill in an area, and you feel like that's outside your bounds and it's your failure, it's not a huge surprise you're not going to invest big time in being there.

[00:22:37]

Bryan Sisk: Was there anxiety about causing harm to the families, or more so do you think it was anxiety about, "I don't feel comfortable and I don't know what I'm doing?"

Gary Walco: What has happened is everybody is becoming increasingly specialized. Everybody has their window of expertise and their area where they feel strong, and once you get outside that, it's hard. You can either acknowledge that you're outside your expertise and improve your knowledge base or refer to somebody else. In some cases, I'm going to say this and hopefully it's not offensive, but you blame the patient: "I don't know what's wrong with you. Clearly, there's something going on here that is weird about you, so go see So-and-so," or, "Go deal with your anxiety," or, "Go deal with your family pathology." There's just no way to get the depth and breadth of training that one would need to really be able to cover all the bases.

[00:24:04]

Bryan Sisk: Thinking back about the late 80s, early 90s, when you had mentioned recognition of the child's pain and management of it was improving, when did the child's voice become important in assessing pain and these other symptoms?

Gary Walco: Very early. I think the challenge from day one with assessing pain in children was to, as accurately as possible with reasonably good focus on psychometrics, to really be able to evaluate elements of children's pain experience. Obviously, if a child is verbal and clear thinking, it's less of a challenge than when they're younger. I'm gonna be on a panel the end of this month in Washington, D.C., where we're still talking about, "How do you measure pain in neonates and infants for clinical trials?" because obviously they can't tell you what's going on with them, but I think there's always been a strong effort to evaluate pain in a reliable, valid, and clinically sensitive manner so that we could better target interventions.

[00:25:21]

Bryan Sisk: Do you think it was the development of psychometrics that made it apparent how poorly we were managing pain, or do you think that people recognized from Gestalt that pain wasn't being managed and said, "We need a way to measure this?"

Gary Walco: I think it was a two-way street. I think initially we recognized that pain was being horrendously undertreated, and then obviously in medicine, if you're going to say, "Okay, we need to tackle the problem," one of your first moves is going to be, "How do you measure it? How do we evaluate what's going on so that we know that there's improvement?" As more and more clinical trials were being done to treat pain in children, the premium on effective ways of measuring it went up even more. Then, obviously, once you start evaluating something, it's going to hopefully impact your treatment. The whole idea of evaluating pain regularly amongst people who are in-patients in hospitals was, "Well, gee, if the patient's reporting moderate to severe pain, maybe we should be doing something about it." I think the impetus focused initially on getting good assessment data, but now some of the assessment data are driving improvements in care.

[00:26:36]

Bryan Sisk: As you were forging this career in pain medicine, as you said before, there really was a big international presence. What were your biggest challenges you faced?

Gary Walco: People who were fairly closed-minded and said, "This is how we've always done it, and I don't necessarily want to do it differently." People not paying as much attention as they could or should to pain. For example, back in the day, if a kid had abdominal surgery, the surgeon would limit their pain treatment so that when they did rounds in the morning, they'd get information from the patient's pain reports and pain responses to what their status was with healing. The kid needed to be in pain for 24 hours

a day so that when the surgeon did their rounds at 6:30 in the morning and was in that patient's room for five minutes, they could get the information they needed, and that was thought to be reasonable.

My perspective was, "Why can't you treat the pain for the other 23 hours and 50 minutes, then do what you need to do to get the information you need?" Which is what prompted—I don't know if you came across it, but I was the lead author on a paper in *The New England Journal*² on the ethics of pain in children, way back, where, basically, we pursued those issues. If you're not going to treat pain in children adequately, that needs to be justified and these are the possible justifications, but otherwise the default is you need to be paying attention to it and treating it. I think the whole issue of where does pain, suffering, and quality of life fit in the whole diagnostic and treatment process, remains a work in progress.

[00:28:52]

Bryan Sisk:

Do you think these were the same types of challenges that your colleagues in pediatric palliative care experienced—

Gary Walco:

Yes.

Bryan Sisk:

- or do you think they had unique problems?

Gary Walco:

No. I think it was the same, and I think the additional burden of—they had a model where their idea was, if a child has a chronic health condition, regardless of outcome—whether the kid's going to live with it or ultimately it will lead to that child's demise—they wanted to be involved as early as possible. What I found, was palliative care would get consulted at the 11th hour-plus, because once you referred to palliative care, it was your acknowledgement that you were not gonna be able to save this child. I think their challenges early on, and I would venture to say still, are getting relationships so that they can get involved early rather than later to focus on quality of life.

[00:30:07]

Bryan Sisk:

From your perspective, what was it that really drove the development of pediatric pain medicine as a specialty?

Gary Walco:

A core of people who were committed to it and continued to push it. I think your timing's interesting because obviously a lot of people who were there at the beginning are reaching the age where retirement is becoming an issue, and there's a lot of discussion

² Walco, G.A., et al. (1994). Pain, hurt, and harm. The ethics of pain control in infants and children. *New England Journal of Medicine*, 331(8):541-544.

about, "Who's going to pick it up and keep it going?" In some ways, there are some people who look like they're poised to do that, but it's a real question mark about what will happen when the initial drivers hang up their cleats.

[00:31:06]

Bryan Sisk:

When pain teams were consulted, how were they initially viewed by families and by children?

Gary Walco:

With open arms. If you're the parent of a child in the hospital, and there are data to support this, your number-one issue coming into a children's hospital is, "Please accurately diagnose and treat my child." Your second issue is, "I don't want my child to suffer." A lot of times, the pain medicine teams would be the people on white horses coming in, right? The kid's suffering. Here comes the pain team and zap! Suddenly, they're more comfortable. I think overall, there was a huge amount of positive for families. I don't know of any time there's been pushback.

[00:32:11]

Bryan Sisk:

What about the other clinicians that were consulting. How did they view the teams?

Gary Walco:

There was a little bit of an interesting development there. A lot of times, the anesthesiologists, who were doing acute pain, like post-operative pain, would just be an extension of the anesthesiologists in the OR [operating room]. They'd be the same people, so the surgeons and the other anesthesiologists all knew them, *et cetera*. When it became more of a focal issue and not just immediate post-op pain, there were some growing pains. I think one of the \$50 million questions that we ask every single time we get a consult is, "Who's actually going to be managing the patient?" Am I consulting to you to give you information on what regimens you could use, or are you saying, "No, no, no. You are here, you take this, and you do the kid's pain meds." Without that clarification, there was always a little bit of tension, like, "Who's doing what and why?"

That happens here at Seattle Children's, unless I'm seriously out to lunch, most people view the pain team very positively. As we've become more consistent and systematic in our approach so that there's less variation every time the attending on the service changes, it's become much more integrated. We do collaborative programs with other sub-specialties, like we do a pancreatitis clinic, we do a limb lengthening clinic with orthopedics, so that these kids that are going to have recurrent pain—we are seen as a critical support team who's partnering with these people. From where I'm sitting, there's been a lot of positive advance, and the

attention to pain is much greater. There are very few training programs for pediatric pain, and the graduates of those programs are swooped up into jobs, oftentimes in leadership positions, immediately.

[00:34:40]

Bryan Sisk:

The timing of this development in pediatrics, how does it compare to the timing of the development in adult medicine?

Gary Walco:

That's an interesting question. Adult medicine is quite different in that A, there are way more adults that have pain issues, and B, adult pain medicine is less focused on comprehensive approaches. The average pediatric pain program in this country, and there aren't a lot of them, but almost all of them are interdisciplinary. You go to a pediatric pain center and you're seen by more than one person almost always, whereas adult pain programs are just waking up to the idea that you need a more comprehensive and integrated approach. The emphasis way more in the adult world has been drugs and interventions: nerve blocks, epidural steroid injections, Botox injections, various pain medicines. I think the opioid issue is partly a function of that, and it's just completely different in pediatrics. I think what we've done in pediatrics that has not happened in the adult world, that is starting to happen, is that more integrated, comprehensive approach—and, because of funding and epidemiology, the adult world has gotten way more attention in terms of pain treatment. So in some ways, we're further behind.

[00:36:31]

Bryan Sisk:

The adult world and the pediatric world, early on, how did they influence each other? Or did they?

Gary Walco:

They still don't very much. Way back, I can remember—this was probably the early 90s—I would put together symposia for the American Pain Society meeting on pain throughout the lifespan. I remember one in particular, we had a pediatrics person, an adult person, and a geriatric person, and the idea was to get some cross-fertilization and communication going here. If the symposium was an hour and a half long, what would happen is there'd be people in the audience to hear the pediatric person, and when they were done, they would leave, and the other people would come in to hear the adult person, and then just turnover. Other people would be there to hear the geriatric person, and the whole idea that people would stay there for the whole hour and a half and really try to get a more integrated approach, did not really work out.

Recently, within the past few years, there's been an effort to come up with a new classification system for chronic pain syndromes. This was being pursued, and yours truly said, "Timeout. Where

does pediatrics fit in here? Where does geriatrics fit in here? Because you're describing all of these pain syndromes and using data focused on, quote-unquote, "adults," but do people not exist on the planet prior to their 18th year? Why are we not looking at these relationships?" We ended up writing a paper on pain throughout the lifespan that basically gives people a model for how you can view these things, literally on a lifespan level, not just focused on this specific age group. It remains a huge challenge. People who train in pediatrics don't learn about adult stuff very much and vice versa. It remains two separate worlds.

[00:38:44]

Bryan Sisk:

Is pain medicine a recognized board-certified specialty now?

Gary Walco:

It's a sub-specialty of several other boards. Pain's a sub-specialty in anesthesia, rehabilitation medicine, psychiatry, and neurology, family medicine. I feel like I'm leaving somebody out. Those are the major ones.

Bryan Sisk:

When did that sub-specialty develop officially?

Gary Walco:

In the 90s, if I'm not mistaken. I believe it was anesthesia first, and then rehabilitative medicine, and then some of the others.

[00:39:35]

Bryan Sisk:

Thinking more broadly over your entire career from when you started in the 80s to now, what have been the biggest changes in the care provided to these children that are suffering and dying from serious illnesses?

Gary Walco:

I think the biggest is just people attending to it and recognizing it's an issue that needs to be addressed. I don't think there's been tons of advancement in terms of the technology of treating pain and suffering. Obviously, when indicated, we could be more aggressive and do things like implantable pumps or various catheters to treat different pain or end-of-life issues, but the biggest advance is people recognizing that it's an issue that needs to be addressed.

[00:40:30]

Bryan Sisk:

How do you think your body of work has contributed to these changes?

Gary Walco:

[*laughs*] I think I'm probably seen as a pretty vocal advocate. That's a hard question to answer from my perspective [*laughs*] but I constantly look for opportunities for children's needs to be represented. I started the first special-interest group in the American Pain Society years back, and it was on pediatric pain. I did work with the FDA to make sure that pediatric trials are done well so that we can understand more about how drugs work in

kids. Making it an ethical issue, I think, was helpful at one point. I just got elected President of the American Pain Society, and it's the first time there's a pediatrics person in that kind of a leadership role. I try to push the advocacy issues, and that's probably where my impact has been the most.

[00:42:02]

Bryan Sisk: What do you think are the biggest remaining challenges facing the care of these children?

Gary Walco: The first thing that popped into my mind was rigor, meaning I would love to see the day that there are more studies to truly understand the role of medications for children and the role of genetics in terms of how that plays out with people's experiences with pain. There's going to be a lot of movement on looking at new drugs for pain, given the opioid issues and where funding is going, and I would love for children to not be a complete afterthought in that process, but to be more of a focus as early as possible. I think those are the major ones. Funding's always an issue.

[00:43:23]

Bryan Sisk: Over this history, was there a time where funding had a big increase, or has it just been a gradual increase over time?

Gary Walco: The last two years, with the HEAL [Helping to End Addiction Long-term] Initiative, in response to the opioid problem. That was the first time there was a significant infusion of funding for pain research. Prior to that, given the magnitude of the problem, the funding was miniscule. Chronic pain costs this country more money than cancer, heart disease, and diabetes combined, so you would think it would get a big chunk of NIH funding, and for years, it got about 1 percent.

Bryan Sisk: Wow.

Gary Walco: Have a look at the Institute of Medicine report³ that came out, I think 2011 or 2012. It's got some shocking data in there about the cost of pain and how little funding it gets.

[00:44:27]

Bryan Sisk: Having said that, what do you think are the strongest areas of the field right now?

Gary Walco: I think we've pushed the issue far enough that people are more likely to pay attention and embrace efforts to prevent and treat pain in children. I don't think that's gonna go away, and it's going to

³ Institute of Medicine Committee on Advancing Pain Research, Care, and Education. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Washington (DC), National Academies Press .

need to be attended to and cultivated to make sure that it doesn't go away.

[00:45:01]

Bryan Sisk:

Perfect. Then, lastly, I'd just love for you to dream aloud. If budget, and politics, and all of the other issues we've talked about were no obstacle, what would you want the care for these kids to look like in another 10 years?

Gary Walco:

I would want every provider—I would want to see a culture, where every individual who works in children's healthcare has an internalized value and takes on the individual responsibility to attend to children's pain; to prevent it and to treat it. If a child is in the hospital and is lying in a bed crying, nobody ignores that, whether you're the attending physician or you're the person who comes in to clean the room. It's your job to make sure that that human being is not suffering, and if there was that attention, there would be more studies looking at strategies to prevent, minimize, or eradicate pain. My dream would be a culture shift where suffering is truly optional. Pain is going to be inevitable. You're going to have pain. If you have surgery, if you have a disease, if you injure yourself, you're going to have pain, but we can certainly do better in minimizing suffering, and I would love to see a culture where that's the case.

[00:46:54]

Bryan Sisk:

Is there anything else about this history that I haven't hit on with my questions that you think I should know?

Gary Walco:

No, but you're making me feel really old.

[End of Audio]
