

John C. Liebeskind History of Pain Collection

**Oral History Interview
with
Kathleen Foley**

Ms. Coll. no. 127.14

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Biographical Sketch

Kathleen M. Foley was born in Flushing, New York, and received her B.A. from St. Johns University in New York and her M.D. from Cornell University Medical College. She completed an internship in medicine at the New York Hospital-Cornell Medical Center and spent a year doing genetic tissue-culture research at the laboratories of Drs. Shannon Danes and Alexander Bearn, before accepting a neurology residency in the Department of Neurology at The New York Hospital. After finishing her residency, she joined the Department of Neurology at Memorial Sloan-Kettering Cancer Center (MSKCC) as a Special Fellow in Neuro-Oncology (1974). Dr. Foley established the Pain Service (later the Pain and Palliative Care Service) at MSKCC and served as its first Chief (1981-98); she has also acted as Medical Director of the MSKCC Supportive Care Program and is now Co-Director of the Barbara Ziegler Palliative Care Education Program. Dr. Foley is best-known for her leadership of the first pain service at a cancer center in the United States, for her work in defining the epidemiology and classifying the common pain syndromes in cancer patients and in other patients. With her colleagues, she has prepared scientific guidelines for the treatment of cancer with analgesic drug therapy. Dr. Foley is currently the Professor of Neurology, Neuroscience, and Clinical Pharmacology at Cornell University Medical Center, the Director of the WHO Collaborating Center for Cancer Pain Research and Education, and the Project Director for the Project on Death in America of the Open Society Institute. She is also a Past President (1983-1984) of the American Pain Society.

Interview History

Dr. Foley was interviewed in her office at the Project on Death in America in New York City by Marcia L. Meldrum on June 25, 1996. The interview lasted for approximately 3.0 hours. The transcript was audit-edited by Betty Anderson and Marcia Meldrum and reviewed by Dr. Foley prior to its accession by the History of Pain Collection. The tape and transcript are in the public domain, by agreement with the oral author. The original recordings, consisting of two (2) 90-minute audiotapes, are in the Library holdings and are available under the regulations governing the use of permanent noncurrent records. Records relating to the interview are located in the offices of the History & Special Collections Division.

Topical Outline (Scope and Content Note)

The interview is organized chronologically at the beginning and then changes to a more thematic structure, starting with Dr. Foley's childhood in New York; her undergraduate and medical school education at St. John's University and Cornell University Medical School; her reasons for entering the field of medicine, neurology and then the pain specialty; her medicine and neurology residencies; her position in the Memorial Sloan-Kettering Cancer Center as a pain specialist; establishing the Pain Center at MSKCC; and founding the Project on Death in America. Major topics include funding for pain research and therapy; her philosophy about the use of opioid drugs in comparison with John Bonica's methods; research studies in the efficacy of opioid drugs; the introduction of palliative care treatment at the MSKCC Pain Center; the

definition and classification of common pain syndromes; doctor-assisted suicides; the multidisciplinary aspects of pain treatment; and the Project on Death in America. Important figures in pain treatment, including John Bonica, John Liebeskind, Raymond Houde, Ada Rogers, Stanley Wallenstein, Cicely Saunders, Robert Twycross, Bill Fordyce, and Vittorio Ventafridda, are discussed in the interview.

Access to the Interview

This oral history interview, in its audio and transcript forms, is held by the History & Special Collections Division. Those wishing to use the printed transcript (which is available through Interlibrary Loan) or the audiocassette version (which is available by appointment only) should contact: History & Special Collections Division, Louise M. Darling Biomedical Library, UCLA, Los Angeles, California 90095-1798. Phone: (310) 825-6940.

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Citation Information

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Related Materials in the *John C. Liebeskind History of Pain Collection*

The researcher is referred to the following related materials: oral history interviews with Raymond Houde, Mitchell Max, Russell Portenoy, Ada Rogers, Cicely Saunders, and Mark Swerdlow; and the American Pain Society Records.

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Kathleen Foley, MD

Neurologist

KATHLEEN FOLEY INTERVIEW

TAPE ONE, SIDE ONE

MARCIA MELDRUM: Okay! Good afternoon. Today is Tuesday, the 25th of June, 1996, and it's about ten to one in the afternoon, and we're starting an interview with Dr. Kathleen Foley here at the Project on Death in America in New York [City]. Dr. Foley, we'd like to thank you for giving us this interview. I'd like to start by asking you to tell me a little bit about where you grew up, what you remember about growing up, and what first gave you the idea that you might be interested in being a physician.

KATHLEEN FOLEY: I grew up in New York. I grew up in Flushing, New York, which is a suburb of the city, and I don't really think that during my period of growing up that, at least until the time that I got to college, that I thought particularly about being a physician. And really, it was during college that I decided, as I was choosing my major, that I had one of two choices, and that was either to go to medical school or to become a historian. And I for some reason or other decided that I would go to medical school.

MELDRUM: I see. Was there any family reason involved in that? Was there any --

FOLEY: I can reflect on it now and think maybe there was a family reason. But at the time, I would have said no. Retrospectively, one could analyze why you do what you do, and you can come up with reasons. When I was twelve, my mother became quite sick and eventually died when I was thirteen; and was very sick and, in fact, had a significant pain problem although I really didn't focus on that at that time. Not even until recently did I really focus on that relationship to why I do what I do. And she died, when I was thirteen, of a non-Hodgkin's lymphoma, and that had an impact on my life because it restricted some of my activities. I had a younger brother and a younger sister that I became responsible for caring for, and it made me stay home for college, because I was one of the responsible people being involved, along with my father, in caring for them. So it did impact on me in that perspective and probably has impacted on me to the present time.

MELDRUM: You went to St. John's [University], which is right there in Queens.

FOLEY: Right. And I went there in part, again, to be close to home, and that allowed me to be close to home.

MELDRUM: Yeah. So you decided to go to medical school. Was there any particular reason why you wound up at Cornell?

FOLEY: I always wanted to go to Cornell, so once I decided I wanted to go to medical school, I had a very, very strong sense of wanting to go to Cornell. And in part, that was related to the fact that I went to high school in the city and would travel every day into the city and went to high school at Park Avenue and 68th Street; but I had been to New York Hospital for various other reasons -- seeing people, having friends there, etc., as patients. So when I was looking at

medical school, here was a medical school that was exactly associated with a hospital that I thought was a good hospital. And it was in New York and close to my family, and so I wanted to stay. So it had a lot of natural reasons, and it was really my first choice. So it was a good thing that I got in there.

MELDRUM: It worked out.

FOLEY: Right. Stayed in the neighborhood. And at Cornell, really, during my undergrad, my four years there, I spent time as a fourth-year medical student doing research in a genetics laboratory, and we were doing tissue culture of genetic diseases. And I was very interested in that, and I was also testing out whether I wanted to do laboratory research for the rest of my life, and it was really an extraordinary experience. I did that for my fourth year of medical school. Then I graduated and did my internship in medicine at New York Hospital. And then I went back into that lab and worked for a year doing more studies on tissue culture. And academically it was very successful for me.

But it made me, I think, begin to realize that I really did like being a doctor, seeing patients, and that I probably wasn't going to be able to focus all of my attention into laboratory work, because that wasn't where my mind was and my heart was. So I then went back and did my neurology residency for three years and during that period of time continually toyed with what I would do but knew I needed, wanted, to be in an academic center and to do something clinically relevant. And then when I finished [in 1975], I was offered a position at Memorial Sloan-Kettering Cancer Center in the Department of Neurology to study pain. But when I interviewed for the job --

MELDRUM: To study pain specifically?

FOLEY: To study pain specifically. But when I interviewed for the job, I said, "I know nothing about pain," and then the person, Dr. Jerry Posner, who was the chairman, said, "Well, don't worry; no one else does."

MELDRUM: [she laughs] All that's very interesting. So let's go back just a little bit. Why did you choose neurology? Was there any particular reason for doing your training in that?

FOLEY: Well, as a student at Cornell, neurology was really a very, very strong department and a wonderful academic department and a wonderful clinical teaching department; and I just became very attracted to the people in that department as role models, and also to understanding the neurologic consequences of medical illness. I also thought it was a field that one could confine your knowledge to, so that it was something that one could embrace and probably learn and be relatively competent at. I also liked the interaction of the hypothesis-driven constructs in neurology and understanding the mind-body-brain interactions. So it was really in that context.

MELDRUM: So there was a lot of intellectual fascination with it.

FOLEY: Right.

MELDRUM: Was there any particular individual that influenced you particularly -- any instructor or a physician?

FOLEY: Well, clearly, Fred Plum, who was the chairman of the department, is someone that had -- was an important person, because as a medical student I had a great deal of respect for him as a clinician as well as an educator [Fred Plum, Anne Parrish Titzell Professor and Chair of Neurology at Cornell 1963-98, was also the founding editor of *Annals in Neurology*]. And Jerry Posner, who was the person who recruited me to Memorial, also was a very important person in my life [Jerome K. Posner was founding Chair of Neurology at Memorial-Sloan-Kettering from 1967-97]. So there were two people that I felt I had a great deal of respect for, both academically and clinically and personally. And so they were very important to me.

MELDRUM: Okay. So Dr. Posner actually knew you before he --

FOLEY: He was one of the training directors of our residency training program.

MELDRUM: Okay. And he must have had some reason for inviting you to come work in Sloan-Kettering on pain.

FOLEY: Well, he had a very different perspective about how he hired young faculty, and he really was not -- he felt that young faculty didn't necessarily have to embrace the topic. They had to embrace the job, and then would then embrace the topic. It was, again, in the early days of a field called neuro-oncology, which specializes and focuses on the neurological complications of cancer. So it was really in that context that he viewed that they needed an area that would support pain research. At the same time, at Memorial was Dr. Raymond Houde, who is well recognized for his own work in developing the methodologies for measuring pain and for analgesic studies. And so my job -- although appointed to the Department of Neurology and my job, appointed to be a neurologist investigating the causes of pain in patients with cancer -- it was to be able to interface and work with Ray Houde, who has been a very important mentor to me as well. [Raymond W. Houde was assistant professor of medicine at Cornell and had, from 1951, devoted his career to the evaluation of pain and analgesia in cancer patients at Memorial Sloan-Kettering].

MELDRUM: I may have mentioned I interviewed Dr. Houde last year. I enjoyed that very, very much.

FOLEY: Did you? Yes.

MELDRUM: Yes. A really wonderful guy.

FOLEY: Yeah.

MELDRUM: Okay. So tell me a little bit, then, about your work --

FOLEY: But there's another part of this that's important, and that is -- and because I think it's important for the field -- is that no one was racing to support pain research per se; but it was an

example of where the National Cancer Institute rehabilitation grant, had included [a position for a physician to study] pain in the salaries --

MELDRUM: Oh, that's very interesting.

FOLEY: -- for a physician to study pain within that context. So I was hired because that money had become available on this grant, which Dr. Houde and Dr. [J. Herbert] Dietz, who had been head of rehabilitation at Memorial, had applied for.

MELDRUM: I'm sorry, that was Deeks?

FOLEY: Dietz. D-I-E-T-Z.

MELDRUM: Okay.

FOLEY: And they had applied for this and obtained this grant as part of a cancer-control program at Memorial, and they had this slot for a clinician to look at pain. So that was another sort of coming together of people, thinking this might be important and having the funds to do so. It is a part of the reason why I think it's so important for there to be these funds to encourage new investigators, because I would have never come into the field. I would never have had that opportunity, and those that were recruiting me would never have had that opportunity. You couldn't plan for that.

MELDRUM: No. Sort of a serendipitous opportunity.

FOLEY: Right.

MELDRUM: Okay. So tell me a little bit about Sloan-Kettering, then, about what your work was like at that time. It sounds like you were starting out with a fairly open charge: study the mechanisms of pain.

FOLEY: Yes. It was really frightening and terrorizing because, first of all, I didn't know anything, and second of all, I was being placed in this environment with a group that clearly did know something -- with Ray Houde and Stan Wallenstein and Ada Rogers, this sort of triumvirate that were there, who clearly have a great deal of expertise in assessing pain and doing drug studies. [Stanley Wallenstein [1921-96], a psychologist, and Ada Rogers, research nurse, had both worked with Houde since the beginning of his research.]

MELDRUM: And had been working there for twenty years, I think. This was --

FOLEY: At that point in time they had been working on it since, really, since the late '40s, early '50s. I was coming into this very well-formed group of close friends, of colleagues, and here I was the new person on the block, so that was difficult, although they were really wonderful to me. But they are hard -- they are not easy judges. They are hard taskmasters; they always were. And in that setting, in coming there, then, it gave me the opportunity to want to learn from them and work with them. And they were all generous in their time that they gave me. But at the

same time, working with them, [I was] trying to develop a more clinically oriented service, in a setting of a research group that had worked together. And so I'm really indebted to the time that Ada Rogers spent with me, teaching me how to manage pain in patients and spending time on the clinical service.

I also, at that same time, in trying to figure out what we did, you know, how would we develop this program, I went out to Seattle, and I met with John Bonica and I met with Dr. [Dick] Black, and I met with a whole variety of people -- Dr. [Terry] Murphy was there at the time -- with a variety of people who were then active in the pain clinic, to see how they organized their pain clinic. And it became apparent that what was done in Seattle and done in the sort of Bonica world was different from what we were doing at Memorial, because we were caring for so many people with medical illness.

So ours became the model of patients with serious medical illness and pain. And immediately we were conflicting over drug issues; and all of the controversies, really, that arose came, I think, in part out of these differences of the populations that we were studying. We were studying people with cancer who happened to have pain. They were studying people with pain who happened to have other medical illnesses. So there were these differences that rapidly became apparent.

At a personal level, it was very difficult because I didn't know anything, yet I had to set up this clinic. And I had people coming with these terrible pain problems and I didn't have a clue except that I was a neurologist, so I could examine them, and I was a doctor, and I could think of ways to treat them. But I really didn't know what to do, and I didn't know what to say. And it was very hard for me to adjust to the idea that when they came with these terrible pain problems, that I had to sort of calm myself down and not think that there was an emergency I had to deal with -- even though for many people it was an emergency. But for me, every patient couldn't be an emergency because I was not able to be able to meet their needs and I didn't know what to do. So it was very lonely. I just remember it as lonely and frightening and being not sure of oneself, and clearly having people to ask. Dr. Posner was enormously helpful to me from the neurologic perspective, and helping sort out issues with patients, and being someone to be a mentor. And, again, Ray and Ada were particularly helpful to me from the other side, from the pain perspective. But I remember it as hard.

I also was having difficulty, because at that point in time, pain wasn't a particularly respected clinical field, and I was in this very sort of highly respected Department of Neurology with these people doing highly respectable things, and I wasn't sure what my role was, and I was being sort of tainted by this pain issue of those crazy patients of yours who want more drugs and don't want anything other than that. So I was very unsure of my sort of own personal idea of who I was.

MELDRUM: So was there any particular approach you adopted?

FOLEY: Well, I just sort of stuck at it. I mean, you know, it's like Robert Frost; you just hang around until you get it, so I was like hanging around until I got it. [The poet Robert Frost [1874-1963] once advised a student that it didn't matter what course of study he pursued: "You need to just hang around. Take whatever you want to take until the spirit touches you."] And it

took a while, and I'm not sure I've gotten it, but it was of that order. So there's no better experience than doing it. And there's no better experience than trying to learn from it. And at the same time, there were organizations beginning to be formed that were a forum for talking about these issues, and there was the textbook that John Bonica had put together, so we had a reference text. And there were, at least in my own group, a group of people who could talk about the issues, which was extraordinary for me.

And the approach was to set up a pain clinic, which was called a medical pain clinic, that, at that point in time, Dr. Houde was the director of and in which I saw patients with him and we saw our own sets of patients in the clinic. And we tried to do the best we could. We then moved to, although there had always been an in-patient consultation service, we then realized that we needed to formalize that more. So we formalized our in-patient consultation service into a Pain Service. I think it was about 1981; I'd have to check exactly -- 1981 or 1982, where we were designated a real service [1981]. And that was a leap forward in being identified as a service within the institution, and I was made the chief of that service.

MELDRUM: And was that automatically called upon to consult with most cancer patients?

FOLEY: And then it was a consultation service available to the staff, who could call a request, who could call for a patient to be evaluated, and then the patient would be seen. And prior to that, we also, in realizing that this had to be a broad research and a clinical program, we developed a fellowship program that we would then train fellows in pain management. And at the same time, we realized that we needed to do research in this patient population, so we needed to expand the analgesic nurse observer group that Dr. Houde had developed with Ada Rogers to include more nurses. So we really went, in the late '70s and early '80s, into a big expansive phase of clinical studies.

MELDRUM: Right. That must have been pretty exciting.

FOLEY: And it was wonderfully exciting. We worked with wonderful patients; we had wonderful studies. We did the heroin studies during that period of time; we did the beta-endorphin studies [*beta-endorphin is a neuropeptide that binds to opiate receptors in various areas of the brain and has potent analgesic effects*]; we did a lot of really novel studies. We began to look at epidural and intrathecal opiates a little bit later. But the clinical experience gave me the, in a sense, the clout to be able to argue for different issues like the use of opioids in nonmalignant pain and the clinical expertise in thinking that things like transcutaneous stimulation, albeit helpful, were not profoundly helpful in these groups of patients. And that a lot of the surgical procedures that people did for patients really were not effective, that cutting nerves didn't make you hurt less, and that there really was a need for better understanding of molecular biology and the mechanisms. And we were, in a way, taking what those of -- [those] who were at the laboratory bench level and raising questions about -- we were raising the same kinds of questions in the clinical arena.

MELDRUM: Right. That's very interesting. This expansion of the program, was this funded, then, by grants from -- ?

FOLEY: Again, the way the pain service developed was one in which we initially -- my salary was funded out of the grant. We then, rapidly realized that we would need grant monies to do all sorts of things. I received an American Cancer Society junior faculty award, and that went to pay part of my salary. And when I finished that, I was then awarded a Rita Allen Scholar award. And both of those, again, were so important to me because they paid for my salary to allow me to do research. And they were so -- and still, really, to both of those groups I'm indebted for their early support, because they really did help me move forward by having the independence to have the time to do research.

Our strategy in developing the pain service was this consultation service and also, hopefully, being a system that we could access more patients with pain for our studies. It became apparent, however, that there was an enormous service need that needed to be met as well, and so that they were not necessarily candidates for our studies. So every patient we were seeing was not really a candidate for the study, and that has subsequently become even more apparent to us. But another strategy that we recognized was that we were taking care of patients with very significant pain problems and sending them back into a community that couldn't begin to deal with them.

MELDRUM: Yes. I'm sure that would be true.

FOLEY: So we developed a Supportive Care Program, which was a nurse-centered model that would serve as a liaison between the community and the institution to care for patients with advanced disease, advanced pain, complicated pain, who wished to die at home or who would die in the hospital, but needed a lot more care and more sophisticated pain expertise at home.

MELDRUM: Now, okay. So these people were essentially nurse-managed.

FOLEY: Yeah, those were nurse-centered; that's a nurse-centered model, and we have two nurses in that program.

MELDRUM: Right. And there would be a consultation and a specific protocol?

FOLEY: The majority of the patients were Memorial Hospital patients. They were often seen either in the hospital or in the pain clinic, and when it became apparent that they required this sophisticated oversight, the nurses would become involved in their care and act as the liaison. And that program, which has been in existence for fifteen years, was started philanthropically. And we obtained funds to support the salary of one nurse and then of the second nurse. Eventually [they were] put onto the budget of the institution. But that took a long time, to get to that point, and so that we really continuously needed philanthropic support. We also needed philanthropic support to pay for our pain fellows. We did not have a training program that was supported by the government, or by any other sources, and not by the hospital. I spent a lot of time going around to foundations that told me they didn't want to talk to me about pain --

MELDRUM: Mm-hmm. An uneasy subject.

FOLEY: -- requesting funds for fellowship applications. And it was a time where pain research people didn't know what it was. They didn't know how to understand it or articulate it. They didn't know there was an issue. And I think that, similarly, we weren't very good at articulating what the issues were because we didn't -- I think we recognize them much more now, at least I do, then I did then. So it was trying to articulate a need for studying pain.

It was at the same time that there was the discovery of the opiate receptor; there was the discovery of beta-endorphin [1972]; we understood that [there] were enkephalins. So there was a lot of excitement that we had the pain substance and the pain site. But there wasn't a lot more than that, and clearly, I mean, the work that John Liebeskind had done from the late '60s through the '70s [identifying the role of the brain in modulating pain and producing endogenous analgesia] was such exciting work that influenced and impacted on everyone who was at a clinical level. And we were clearly trying to take that kind of science and argue strongly that the clinical was equally important. We just didn't have a handle on it yet.

MELDRUM: Right. Exactly. Okay.

FOLEY: But I think, because I think what they did was so important, was that their work gave the scientific underpinnings that really drove it. So for those of us that needed to be able to do this at a clinical level in an academic center, who had to have the underpinnings and the scientific perspective, and that allowed that to happen. And at the same time, the science of just applying clinical survey techniques and defining syndromes and categorizing were the kinds of things that we were doing, while we waited for the best science to help us. So we were putting together this sort of basic background -- who had pain, what the epidemiology was, what the prevalence was, what the pain syndromes were, in a very characteristic fashion that one does when you create a field. And it was creating a field of cancer pain and defining who had pain and defining what the numbers were.

MELDRUM: Now, this is very interesting to me, and I must admit when I read it in your brief biography, it said, "Common cancer-pain syndromes," I said, "Oh?" [she laughs] People who have cancer should have pain; why do we have to define pain syndromes? So maybe you could talk a little about that and explain a little.

FOLEY: Well, we put an enormous emphasis on the idea that you can't treat pain unless you can assess it properly, and that's become even more apparent. And by calling these common pain syndromes, it's partially related to my role as a neurologist in that we were seeing patients with very characteristic symptoms, that had not been defined into a single complex, and therefore were not recognized as such. And we know that the way we teach medicine is by putting things into these common characteristic phenomena, that when people see them as a constellation, they know what the lesion is. Now, neurologists go from the lesion back to the syndrome, and we were attempting to do both of that.

So for example, we serve a large number of women who have significant pain in their arm, for example, that was secondary to tumor infiltration of the brachial plexus, the nerve that innervates the arm. Well, this is such a characteristic syndrome, and if it was not recognized and treated early, then these patients would have significant damage to the nerve. So it meant when the

doctor saw a patient with breast cancer who came in and said, "I have terrible pain in my elbow and numbness and tingling in the fourth and fifth fingers of my hand," forty bells should go off in their head and they should say, "She might have a tumor involving the brachial plexus. I need to have her radiated; I need to have her treated."

We were then viewing the construct that we could prevent many of these significant neurologic pain syndromes by early diagnosis, particularly in treatable disorders. In the same way, we identified a series of novel pain syndromes. From simple mastectomy on up to radical mastectomy was the common approach to treating breast cancer in the 1970s, and we identified a population of women who developed a very significant chest-wall pain syndrome after their surgery. And it was very stereotyped, very characteristic, and the women were thought to be crazy by their doctors seeing them.

MELDRUM: A variation of phantom limb, sort of?

FOLEY: Well, it's a neuropathic pain syndrome that comes from interruption of the nerve in the chest wall. But we were seeing these women coming to us, and their surgeons were saying, "I've never seen this before; this never happens." They were telling that to the patients, who were then thought, "Not only do I have breast cancer, but now I'm crazy." And we defined it and defined it in great detail as a syndrome and gave it -- one, a name -- and [two,] took it out of the realm of this psychological phenomenon in women, to a very real pain syndrome that was well defined, well described, has characteristic appearances, has a variety of treatments, and has, now we know, an anatomical variation associated with the size of the nerve.

So that, you know, in trying to build the field and very sort of plodding a long way -- and I would be the first to say it was plodding -- it was trying to identify these neurological complications of cancer, which was what our department was doing, and to define them in a way that could then be readily recognized by neurologists, who could then readily treat [them]. So part of the pain in cancer, because we decided pain was a neurological complication of cancer, we put it into that domain. And we put it into the field of neuro-oncology. There was this enormous need to describe the field.

Another example is back pain in patients with cancer. When a patient with cancer has back pain, this requires a very specific work-up, because they may not only have back pain but they may have a tumor compressing their spinal cord, which will paralyze them. So being able to differentiate simple back pain from tumor involving the vertebral body and compressing the spinal cord is an important issue.

We were really obsessive about defining these clinical phenomena, in order to teach other neurologists and, ideally, other clinicians. In doing so, it also became apparent that we were looking at really different types of pain. We were looking at somatic pain; we were looking at visceral pain; we were looking at neuropathic pain. And it became critical that we had to define and stratify cancer patients to address therapeutic approaches; we knew that analgesic drugs are the mainstay of therapy and helpful for patients with somatic pain and visceral pain, but not necessarily so effective for neuropathic pain.

MELDRUM: Okay. So it really did have direct therapeutic implications.

FOLEY: Yeah. Right. And you had to define what you did, so what you did was to do this.

MELDRUM: Now, how helpful in all this was the existence of Bonica's pain society and the pain field?

FOLEY: Well, you were not alone. You had a forum to discuss [ideas and problems]. They were helpful in many ways. First of all, after getting to Memorial in 1975, John Bonica had organized a meeting in Florence that was part of the first International Association for the Study of Pain [World Congress], and it was a one-day meeting on cancer pain. He had called and asked me to put together the epidemiology of pain in cancer patients. So I sort of rapidly had to put together and do a prevalence study, which we did -- with enormous help from Ada Rogers -- and in which we put together what the prevalence of pain was.

And the most fascinating aspect was that was a rather rapidly done study where we surveyed the entire hospital on one day, and we surveyed a whole series of patients, and then we surveyed our clinic populations. We did a variety of things to get this data quickly. And our data suggested that a third of patients in active treatment, and two-thirds of patients with advanced disease, had significant pain. Now, we were worried that we were a cancer center, that we were biased; but every study subsequent to that has come up with exactly the same numbers and have done it in more detail and in a more sophisticated way.

That meeting was particularly an important one, because it was the first opportunity that I had to even meet some of the players in the field at that point in time. It gave me that opportunity to meet with John Bonica, but internationally to meet with Robert Twycross, who was then working in England with Cicely Saunders, and to meet with Vittorio Ventafridda [Cicely Saunders, founder of the modern hospice movement, had opened St. Christopher's Hospice in London in 1967. Twycross, Consultant Physician and Reader Emeritus in Clinical Medicine at Sobell House in Oxford, was at that time, studying differential drug regimens at St. Christopher's. Ventafridda, who was then chief of anesthesiology at the Italian National Cancer Institute in Milan, is today Director of the WHO Collaborating Centre in Cancer Control and Palliative Care at the European Institute of Oncology of Milan.] And all of us, from that point onwards, became part of a group of individuals who had a major interest in this area and were trying to support each other in making the issues of cancer pain an important issue.

We also, at that time, could see that there were arguments that we were having and controversies that were arising, and that meeting was a very controversial meeting because Ray Houde and Ada Rogers and Stan [Wallenstein] had always held strong [ideas] on the oral-to-parental ratios of morphine. And Robert Twycross was at the meeting, and he was arguing to a different construct, and there was a lot of tension related to that. Vittorio Ventafridda -- whom I had not previously met before, but clearly Ada Rogers and Ray Houde had met before -- he was just then moving to the National Cancer Institute in Milan, and developing a pain program within that institute. And although his expertise had initially been in anesthesia -- he's an anesthesiologist, and that was his association with Dr. Bonica -- he was then broadening his expertise into drug therapy. And he was then seeing that we could do as well with drugs as he could do with

anesthetic treatment. So there was the beginning of the switchover from a very technological anesthetic field to the more pharmacologic management.

So that was the beginning of those relationships. Coming out of that meeting, Vittorio Ventafridda sponsored, in 1978, the first International Congress on Cancer Pain, that he held in Venice. It was really through those relationships and through us all working. And it was at that Congress that I presented what I had done in a two-year period, all of the work that we had put together in categorizing [cancer pain syndromes]. Because up until that time, no one had really categorized pain, into related to cancer, unrelated to cancer, related to cancer treatment. And no one had done it in a way that was systematic, that would allow us to talk about these issues, and talk about the pain syndromes.

So that was when I presented that data, and, again, Twycross and Saunders and Ventafridda and a large number -- John Bonica -- a large number of people who helped move that field forward were at that meeting, and it gave us again this forum, and scientific underpinnings for our clinical work, and interactions. Subsequent to that, the series of meetings that the International Association for the Study of Pain sponsored, giving time to the cancer pain arena, and placing a priority on that topic.

MELDRUM: So that really allowed you to tell your story to a very large audience.

FOLEY: Well, there began to be a sort of heightened awareness to it. And then, John Bonica had met with Dr. Jan Stjernswärd, from the World Health Organization, and then subsequently with Vittorio Ventafridda. [Stjernswärd, Swedish oncologist and former chief of the WHO Cancer and Palliative Care Unit, is now Director of the Oxford International Centre for Palliative Care.] They together, the three of them together, had talked about doing some kind of a program with the World Health Organization. And they really originated the whole discussions related to the WHO effort. And then Vittorio Ventafridda sponsored a meeting in, I think it was 1979 or '80, outside of Milan, where we put together a [set of] guidelines for cancer pain treatment [it was the WHO Expert Group Meeting in October, 1982]. And then, subsequent to those guidelines, we then moved to have them validated, which Vittorio did, and then eventually developed the monograph on cancer pain relief [*Cancer Pain Relief*. WHO, 1986]. That led to sort of moving out of the pain world and into the cancer world, but bridging the two. And it was moving also from the pain world that was very, very focused on procedures, to pushing the concept of drug therapy.

And if you would look at each of the meetings and look at the history of each of the meetings, they all had different historical constructs. The meetings in the early '70s or mid-'70s were focused around nerve blocks and neurolytic techniques. Then they moved to the beginnings of drug therapy, but with a lot of resistance to drug therapy. There was also the heyday that began with the Bonica [University of] Washington construct, that if you didn't do nerve blocks, you did behavioral treatments. So the heavy focus on chronic pain, and [its] recognition, then moving with the cancer pain medical world into drug therapy. And then the clash of the drug people against the non-drug people. Then the move to more procedures when the epidural intrathecal catheters came in, that heyday. And then moving again from that. And in each of the meetings we had varying support or nonsupport, depending upon the arena.

MELDRUM: So you were sort of moving from one marginal position into the center --

FOLEY: Right. And then out. And then being marginalized and on the fringe again.

MELDRUM: [she laughs] I see. I see. So there really is a perception, you have a perception, then, of a sort of changing, obviously scientific, but also political constellations.

FOLEY: There was a major change in political constructs, because first of all we were -- the group at Memorial was viewed as the drug group. We really held that historical perspective. Then we were not only the drug group, but we spent so much time trying to dispel myths that people had created, and we were quite resentful of that. These were myths of Robert Twycross that argued that the Brompton cocktail was the answer. [The Brompton cocktail was a mixture of morphine, cocaine, and alcohol, in a flavored syrup, that was a mainstay of hospice treatment, until the work of Twycross, Balfour Mount, and others established that straightforward morphine worked equally well.] We had to spend a lot of time taking apart each piece of the Brompton cocktail, to prove that morphine was as good as the cocktail alone. So we had to do each of those studies. And I think what it's a wonderful model of is the risk you run, when you don't study what you're saying works.

MELDRUM: Exactly. Never mind *why* it works; it works.

FOLEY: It works, so don't touch it. And when you tease it apart, you can have the opportunity to learn much more, and I think the Brompton cocktail does work well and has all the benefits and was a cheap, effective way to deal with the problem -- but one can be very anti-intellectual, and by diminishing the kind of research [needed] to tease that apart, can make people take cocktails they don't need. It had enormous clinical ramifications. We spent a lot of time arguing on that [the Brompton cocktail]. We continue to argue about the morphine issue, which has never been fully clarified, and it's still an argument.

MELDRUM: I guess there are just two major things I want to ask about -- not just the Brompton cocktail versus morphine, but the Twycross-Saunders approach has been pain pretty much on patient demand -- or, I mean, sorry, pain medication on demand. And certainly the approaches at Sloan-Kettering, that I know about from the '50s and '60s, were doses per hour and very specific regimens, which, of course, were very, very helpful if you're doing comparative studies of different drugs. You really need to be comparing dosages and times of administration. So do you want to comment a little bit on this?

FOLEY: Yeah, I think that's a good point, that you're comparing two very different groups. You're comparing a Memorial group that is focused on trying to look at the side effects and the efficacy of a drug regimen compared to the Saunders-Twycross, which was, "We have a terrible problem, people with significant pain; let's titrate their medications to effect, and we don't have to do studies in that way." And if you look at the kinds of studies that did come out of the Twycross program, they were wonderful survey studies that told you what worked. But they didn't give patients placebos, they didn't give them varying doses, and they didn't drop things out of the cocktail to see if one versus the other worked.

But I wouldn't be critical, because they were looking at a survey of their practice and trying to define what happened and then beginning to explain it, and that had enormous value. They were collecting the kind of information we needed to see how it worked. What they also did as well -- and this really is a tribute to Cicely Saunders, although Robert Twycross played a major role in it subsequently -- was to really have the vision to take these very sick and dying patients, to put them in a hospice and to give them oral narcotics on a chronic basis. And that's an extraordinary, extraordinary thing. And to do that with the idea that you're going to titrate to what the patient says, so you're believing their complaint, and to prove that you could do that.

So the contribution was this sort of vision that, one, pain was a priority; that two, these patients needed to be placed in hospice or into a circumstance where you could care for them, and then to do that with a recognition that drug therapy may well be the mainstay of treatment and to be able to avoid and to run the risk of being accused continuously that they were killing the patients, they weren't really improving their functional status, so that they really ran enormous interference, to their credit.

MELDRUM: Yes. A brave thing to do.

FOLEY: They made a critical contribution. So they were doing that. We were back in a very different world, in this academic world of comparing drug to placebo, deciding if they worked, deciding what doses worked, because we were holding tightly to this idea that you needed to have scientific guidelines that were based on scientific underpinnings. So we were at that level, where what they were doing was clinically relevant and clinically practical.

But there's another part of that that is also quite fascinating to me, that we haven't sort of captured how we think about this. It relates to the fact that when you're in an institution like Memorial, we were caring for and working with a group of individuals who didn't want to die; they came to Memorial to live. So in contrast to the hospice, that had to really focus on issues of risk-benefit ratio.

MELDRUM: These were patients who were definitely terminal.

FOLEY: These were patients where this was a major, major issue. Even though our patients might be terminal, their mindset was very, very different. So we were really looking at a different population. And therefore to go to a meeting with Cicely Saunders and saying, "Well, that patient, we'd never do a feeding tube in that patient," it made me again refocus on my construct that they were just letting these people die, really rather than recognizing that they were caring for them as they died. So it was hard for me to make those kinds of distinctions between what they were doing and what we were doing.

MELDRUM: It is a difficult distinction.

FOLEY: And it was also something that I had not been exposed to because I had no education, really, in caring for the dying. Part of why we set up our Supportive Care Program was, however, was in recognizing that at an institution like Memorial, we could not call it a hospice,

because the majority of our patients, or ninety percent of our patients, were getting active therapy as they died. So we needed to be able to have a program, but we needed to call it something other than a hospice program. So we called it a Supportive Care Program. But then it became apparent to us that fifty percent of the patients we saw died within six months of our seeing them, so we were being confronted with this group of patients who were so sick and were dying, yet we didn't call them dying. We didn't put them in a hospice, but we thought that they needed good pain management.

MELDRUM: And do you think that your approach in that respect affected the way the patients thought about their illness?

FOLEY: I don't think it did because, you know, I don't think I was that smart.

MELDRUM: [she laughs]

FOLEY: I didn't catch on then. I really didn't. I mean, it sounds like you do what you do. I saw myself doing this; I saw myself trying to improve their pain; and then it happened that they died, but I didn't necessarily connect all of this together. And one of the things now, in working on this Project on Death in America and refocusing on my early life and my care of patients from a pain perspective, I really realized how I separated those and how I, too, like every other doctor, was not trained to take care of the dying. I was not trained to talk to them; I did not know how to talk to them; I didn't know what to say. And I didn't know how to articulate some of the issues that I now feel like I'm more comfortable articulating, but also maybe have a better understanding of. So that is a different -- in a way, that's a different issue, but it is amazing for me to say that because I'm like this expert, and I was doing this every day, and I didn't catch on.

MELDRUM: Well, you were directing your expertise in a different direction.

FOLEY: Right. But it speaks to the fact that when you do that, I can't be critical of other doctors not doing it because I'm there with them; I was there. But I didn't see that. I didn't catch on to it in a sense.

MELDRUM: Let me sort of turn this around a little bit. What you and your colleagues were doing at Sloan-Kettering was carrying on experimental studies with patients, testing drug and placebo. And there is an ethical issue there: the patient is in pain, and the patient gets a placebo. Would you like to comment on that?

FOLEY: I think that's a very good point. There is an ethical issue -- or there *was* an ethical issue, I think, at the time that we were doing those studies -- it was less of an ethical issue in a sense than there is, even now it's more of an ethical issue. It was less then because of the culture of the time, and the culture of the time was clinical research was at its pinnacle, so anything goes. However, built into all of those studies was the advantage that having a nurse at your bedside during post-operative pain was better than not having anyone, and this was someone who was asking you about your pain every fifteen minutes. And now, if you did not get adequate relief, you could have a rescue medication built into the study. So the protection we

had for the patient was exactly that kind of protection -- recognizing, though, that eighty-five to ninety percent of our patients had placebo effects.

So realizing how powerful those placebo effects were that could really dramatically impact on your studies. So it made us realize that you had to have placebo in there, but you had to have protection for the patient. And we always felt -- I don't think we duped ourselves into believing this, that these studies didn't impede care of patients, and if anything, maybe helped.

MELDRUM: I have to turn the tape over now.

KATHLEEN FOLEY INTERVIEW

TAPE ONE, SIDE TWO

MELDRUM: Okay. We're resuming our discussion, then, with Dr. Kathleen Foley, and we were talking about placebos and testing placebos versus active drugs.

FOLEY: There are a series of studies that we did that were focused on post-operative pain. These were studies that clearly included a placebo, because we were really trying to tease apart the efficacy of the drug from a placebo; this became important in trying to sort out the issues related to doses. We also began to look at studies in patients with chronic pain, and began to develop clinical trials focused on chronic pain and in chronic pain patients, and beginning to look at pharmacokinetic and pharmacodynamic models. These were studies that we gave infusions to patients and then we would stop the infusion and decrement it and be able to determine when their pain recurred. And these, again, were studies in which we told the patient we wouldn't tell them when we were doing the decrement; and that we would just see when their pain returned. That was acceptable to patients, again because, very much like the post-operative studies, they had rescue medication available. So we didn't ask them to stay in pain.

One of the things that became apparent was that as we were doing these different kinds of studies, we became even more aggressive in the kinds of studies we did. We did studies in which we gave patients drug directly into the ventricle of their brain, and then we sampled their cerebrospinal fluid to analyze the drug we administered. We also placed epidural catheters in patients' backs, and then we did serial lumbar punctures to be able to determine the amount of drug in the spinal fluid. And then we had patients that we implanted with pumps and in which we then measured drug in the cervical spinal fluid and in the lumbar spinal fluid so that they had to undergo these spinal taps. And these were in patients with pain whom we were studying, with whom we had a close relationship, and they were patients that were quite helpful to us in doing these kinds of studies.

But it's quite amazing to me now to reflect back on those kinds of studies that we did with these patients, for the simple fact that I don't think we could ever do them again. The patients won't participate in them, society won't allow them, and yet at the time none of us felt that we were being overly aggressive with this patient population. We did one study in which we gave patients a compound that had never been tested in a human before, beta-endorphin. And then we gave patients some compounds that we had demonstrated their safety, but [they] had really not been studied in humans, through injecting it into their back. They had to have a lumbar puncture. So these were really extraordinary times, looking at mechanisms and doing these studies. It is amazing to me now, and only looking back on it do I see that. And so the -- how difficult it was to do these studies, we did them in the hospital, but it was at a time where patients were allowed to stay in the hospital longer, for longer periods of time.

MELDRUM: I have read studies from that period; the patients were described, in any case, as being very motivated and interested in participating in the studies that --

FOLEY: Right. Absolutely. And the man -- the one man that we published who we did the greatest amount of, [on] whom we did the most extensive studies -- looking at the effects of beta-endorphin -- was a man who had carcinoma of the lung and a tumor infiltrating his brachial plexus, but he was so committed to doing these studies with us, because he really had this altruistic sense that he would help someone else in the studies. That part of altruism doesn't exist any more. I don't blame that on [anyone], but people don't feel that they can endure, that they can suffer, that they want to be put through these, and that they might even potentially be getting a placebo. I think the studies have similarly been adjusted so that no one gets a placebo; they get altered or graded doses of a drug, and that makes a very big difference. I think, though, the whole culture, again, that made that acceptable was the culture that was at that same time very aggressively treating Hodgkin's disease, very aggressively treating leukemia. So it was the culture to be aggressive, because that's how it worked. That was the world you lived in. And patients expected and anticipated that.

One of the hard or down sides of it was that patients came to Memorial to be treated for their tumor, not necessarily for their pain. So when pain became the focus and their tumor couldn't be treated, that became often a difficult position for the patient, because they then saw the meaning of their pain as really potentially meaning their death, and the interactions related to that. There also was a lot of silence about death; that wasn't sort of widely discussed by patients and widely discussed within the hospital. Yet we, caring for these patients with pain, were seeing an enormous amount of death secondary to their progressive disease, which pain was the signal of. So there were these sort of complicated issues that I don't think at the time [we] would have seen -- and only see in this different world.

MELDRUM: It's a changing perspective, and it's only been twenty years.

FOLEY: Oh, big changes; big changes. The other kind of change that was happening at an academic, sort of intellectual level, was that there was this science that was rapidly moving forward; and clinical approaches were catching up; then there was the move to oral drugs and the availability of an oral, slow-release morphine that really changed the landscape. Because then we went from not having very potent drugs orally give to patients, to an oral morphine form and to a pharmaceutical industry that wanted to promote it. So we, for the first time, then, had a marketer and a distributor for a drug that we had, and an educator. We knew then that oral morphine was effective. Now we have a slow-release preparation. We can get away from these silly elixirs and cocktails into tablets that people take once or twice a day, and we're into a revolutionary field of pain management, and that has been extraordinary.

MELDRUM: That must have helped a lot.

FOLEY: And there it was the drug-delivery device that changed, not the drug, and with that the whole mentality, "Well, now that we have this drug, we can treat pain." Really extraordinary. So I think that the discovery of slow-release morphine is one that needs to be starred, for changing the field from simply the hospice movement that put oral morphine on the map, to the marketers that made it available. But they have been the major educators, so I don't want to malign them in any way, because I view them as our colleagues in education. It was not the

government that wanted to educate; it was not the National Cancer Institute that wanted to educate. It was the drug company that wanted to improve pain management.

MELDRUM: So what particular drug companies were these?

FOLEY: Well, there were a series. At first, there really were two at the beginning -- Purdue-Frederick and Roxanne. And really both have enormously contributed to moving the field forward. That's a whole study of its own.

MELDRUM: It certainly sounds like it. That's quite interesting. Do you want to stop now?

[PAUSE]

MELDRUM: Okay. I'd like to ask you about your study with the opiate drugs. Were there any particularly interesting findings that came out of that?

FOLEY: There were so many things I think we learned in studying opiate drugs. The first of the issues, in looking back on the time frame, would be that we, the hospice movement, introduced the concept of using oral narcotics on a chronic basis, focused predominantly on the dying patient, on the terminally ill patient. That, then, moved to focusing on the patient with cancer and pain, because such patients were in hospices. And then to hospitals for the treatment of pain for patients with cancer pain; and now the barriers for the use of these drugs for patients with non-malignant pain. It's been constantly moving closer back to recognizing that all of these patients share a common feature, and the common feature is their pain, not what disease they have or what point they are in their life. But clearly that the dying cancer patient was the wedge issue for beginning this treatment.

What we learned that I think is a critical factor, was that patients can and would take drugs; and could take drugs and have continuous relief of their pain and that this continuous relief was not interfered with over time. One of the major concepts, that still is held to this day because of lack of knowledge, is the idea that if a patient took a drug on a chronic basis, that they would become tolerant to it, and then it would not be effective if they continued to take it. What the clinical experience, this natural experiment of treating patients with cancer and pain for this twenty-year period -- the natural experiment has shown that this concept of tolerance is not an all-or-none phenomenon, but has a broad continuum in which patients can chronically take opioids for long periods of time without developing significant tolerance. They do develop tolerance to the side effects of the drug, but not to the analgesic effect. And we would have never known this, if we didn't have this opportunity to treat patients in this way.

Yet we continue to have a lack of understanding of all the phenomena that go with it. Why is that important? Well, it was this fear of the development of tolerance that was really dictating who would receive the drug or who would not receive the drug. So that's one thing we've learned.

I think the second thing we've learned -- that I've learned and therefore I hope other people learned -- is this ability to look at the cancer population who's sitting in one patient room and

then move into the next room with a patient who doesn't have cancer, and they're both using the same language and saying the same things and have the same pain problem. And for the cancer patient, we have no concern that we'll give them [too much] medication, yet for the non-malignant pain, we put up all of these barriers. Yet it's the same pain and the same kind of person, who doesn't have a history of drug abuse, and is a legitimate citizen trying to live their lives. What is it, how is it that we look at this that makes it so different? Our brain doesn't say, "Well, you have cancer versus not." Why do we make these distinctions in patients? And I think that so much of that is how culturally imbued the treatment of pain is and how we are so impacted by our culture and what we are, what we think are normative behaviors and standards, and placing people in these positions. So I think that's a second thing that has changed.

A third aspect is that the clinical experience allows you to see how patients can, in fact, successfully take these drugs and get relief of pain and be more comfortable. We demonstrated at least their safety and their efficacy, the critical factors. When one then moves more broadly to the developing countries where so little of these drugs are available, but, hopefully, there's increasing attention to this sort of need, we need to have this broad experience in this population, in this country. But none of this [she sighs] really gets at the issue of why wouldn't we treat patients with pain? What are our personal attitudes and behaviors?

And another thing, therefore, that we've learned is that I thought that if you had the science, if you had the knowledge, that you could get people to treat pain. And I was wrong; I'm still wrong. Because the knowledge doesn't really change it. It's all of these cultural, attitudinal, and behavioral constructs around the topic that impact on how we treat patients with pain. And those are being chipped away, but they're really an enormous problem. And they are an enormous problem because I thought that we could convince people that they didn't have to fear addiction or tolerance; we did that by knowledge and we did that with science. But we haven't done it enough.

But going back to what I said previously, I do think that science drives it, so great science is allowing -- and a better understanding at a molecular level of what this is, has given the field a credibility that has moved it from pain in the realm of the psychological sort of quackery medicine-man stuff, to the scientific laboratory, where you could begin to tease it apart, to a bedside where you can talk in a jargon that makes people think that you're interpreting the science. The pain issue having a scientific underpinning has helped. But we may be fooling ourselves, because then what we're doing is we're talking about all of this neurophysiology and neuropharmacology, and we're still not attacking and not addressing the emotional, psychosocial constructs of it.

MELDRUM: Which is very, very strong. Have you made any particular observations about -- is it the patient that seems most resistant, the family, the nurse, the doctor?

FOLEY: I think the evidence would suggest that it's the patient that is quite resistant because they feel that they should not complain, they feel that it's supposed to hurt, and they have been so imbued with this idea that drugs of any type are not good for you, so you don't take them. So if we had a non-drug approach, they clearly would choose that, and, in fact, they do. I mean, many more people would choose relaxation and meditation before they'd want to choose taking

a drug. So there is the negative socialization related to drugs even though this is a society that likes to take them in other arenas [she laughs], but it clearly is a group that there's a negative connotation.

And at the same time, I think there is this personal belief that pain is a weakness and has all of that connotation. And from the perspective of the physician, it's not their pain. And the inability of the physician to closely empathize with the patient in pain, and then even if they do, he or she does, they can't do much about it, because they still have to do what they are doing to the patient. So there is a necessity for them to put pain aside to do what they're doing, as it is necessary for them to put their emotions aside to do what they do. But when you do that across the board, then you end up not treating it well.

MELDRUM: Yeah. I've sometimes wondered about that because it does seem to me that physicians are socialized exactly in that sense. They have to be. You have to build a certain shell around yourself or you could not treat sick and dying people, and people who are in great pain on a steady basis. You would emotionally overload; you have to do that. But in a sense, if you become a pain physician, don't you sort of, you have to open yourself up a little bit, and isn't that very risky?

FOLEY: Well, people have argued that that may be risky, that opening yourself up to these pain issues -- but the question is, risky to what? Because if in opening them up and you acknowledge that the patient has them, then you're really a witness to them, and that's powerful for the patient. So I think the wonderful thing that the pain world has done has been to say, "We're witnessing your pain. We can't make it better, but we're witnessing it." I have a view that I think this issue of witness is very problematic for men versus women. And there's some evidence linguistically that when you present men with a problem, they want to solve it. When you present women with a problem, they want to talk about it. And if that's true, if our society is linguistically cultured and linguistically based on that kind of interaction, then maybe that's what we're seeing. And there's a lot of evidence to suggest that these issues of pain are psychosocial.

And it may be that this sort of caring ethics or feminist ethics or whatever that's may be moving in that direction. But I think -- I'm constantly confronted with the construct that in this area, men want to solve the problem and women want to talk about it, and one of the issues--and this is where I think the physician-assisted suicide debate comes in for patients with pain -- is that those physicians feel that they no longer can be a witness to it; they think they have to act. And doctors, again, are never asked to be witnesses; they're always asked to be actors. So we're socialized to be actors. And as we're socialized to be actors or actresses, then it's hard for us to be witnesses.

So for the pain world we need to be the witnesses; because many times, I have a series of patients for whom I've never done anything more than witness their pain in this ritualistic construct of seeing a patient, examining them, talking with them, treating them, giving them drugs... And maybe this is the ritual that we do for those that we don't have another treatment. And pain people are very much into rituals. They don't call it that, I mean, but it's something that I'm quite fascinated with: how we think about this. Because there is a sense that we're supposed to do something. And I panicked when I first started doing this, because I thought I

had to do something until I realized that I couldn't do anything. All I could do was be with them; all I could do was say, "This is really terrible"; all I could do was try to manipulate around the medication. But I couldn't get it better. But I had to see them once a month.

MELDRUM: Right. And keep doing it.

FOLEY: And keep doing it.

MELDRUM: And that's very stressful, isn't it?

FOLEY: I think that's very hard. So the issue -- yes, it is very hard. So then, this question is, well then, do you open yourself up? Well, you open yourself up differently if you think you don't have to do anything about it. Then, if you say, "Look, this is awful; we're in it together," then there's a sadness you share with them, but it's not your fault. "I didn't give this to you; I didn't cause it." So I think that there's a potential protective mechanism. But I don't think -- again, I'm one of the people that does not think that you should spend your whole time seeing pain patients because I think it is too hard. It is too hard to hear suffering that's unrelieved continuously.

MELDRUM: Actually, my own mother died of cancer three years ago, so I remember this very much. It was certainly my instinct to do something. I yelled at the nurses and I yelled at the doctor. But that was not really, probably, it was actually probably much more helpful just to spend more time with her. But nobody explained that to me at the time.

FOLEY: And how would you have known?

MELDRUM: Yes. Exactly.

FOLEY: How would you know that?

MELDRUM: You wouldn't.

FOLEY: That's what I mean. How would you know that?

MELDRUM: Yeah. So anyway, that's a side issue. Let me just go back to something you said a little bit earlier about this difference between women and men. Do you think it's possible that when you were selected to work on the pain service way back, several years back, that they might have selected you in part because you're a woman?

FOLEY: No. I think it had nothing to do with that.

MELDRUM: It was just that you were the best person.

FOLEY: Well, I was finishing up in the program. I was known, I was interested, I was staying in New York, and I was a good clinical neurologist. No, I think it had none of those issues.

Because if they said, “Do epilepsy,” it would have been epilepsy, you know what I mean? It wasn’t differentiating that, as best I could tell.

MELDRUM: Now in terms of doing work with patients, in terms of assessing them, this is something that interests me also -- not assessing them, but sort of working with the patient. There’s a very interesting book, which John and I have just received, that was written by Isabelle Baszanger [a French anthropologist. The English edition is *Inventing Pain Medicine: From the Laboratory to the Clinic*. Rutgers University Press, 1998.] -- you may not -- do you know who she is?

FOLEY: No.

MELDRUM: Well, I think you will be interested in the book [she laughs], when the English edition comes out. It’s presently only out in French, which means that I haven’t been able to do more than sort of skim through it. But Dr. Baszanger came to Los Angeles and met with us for a while; and what she did was she observed several French pain services and observed great differences in the methods of treatment. The emphasis in one was very strongly on, “Well, let’s do something,” still a lot of emphasis on nerve blocks, I think, and on different kinds of medication regimens. An emphasis in the second one was on assisting the patient to sort of define and work with the pain and almost -- and this is the way she talked about it -- almost as bringing the pain out of the body and sort of looking at it in this. I won’t say objective, but --

FOLEY: External?

MELDRUM: -- yes, an external fashion so that the patient could define a relationship which was not totally victimized. I was just wondering if you think of your own work in any sense related to this or if you observe the work at Sloan-Kettering in any sense related to this?

FOLEY: No, no, I think that’s a good point, because I think you could do that the same in this country. And I think it would be more dictated by, well, it’s clearly dictated by place, but I don’t think that means anything. I think it’s more dictated by the multidimensional nature of pain and therefore the multidimensional and multidisciplinary ways of treating it so that, for example, the kinds of patients that we see -- this is interesting, because I’ll give you an example -- the kinds of patients we see are patients who have significant physical pain. They may or may not have psychological components, but their physical pain is so overwhelming, we can’t even address their psychological until we get their physical under control. And then once their physical is under control, we then can move to address their psychological, in which we can then get them to image their pain out of their body and do any one of those approaches. But they can’t get to that because they’re in so much physical pain.

For those for whom there is a sense that their pain is a mixed physical-psychological construct and in which there appears to be more psychological factors that are adding to and escalating the pain, then that would lead to this construct of externalizing it. So I think a lot has to do on where the pain is. For example, if a patient has terrible bone pain and metastatic cancer, and I want them to image their pain out of their body, I think that’s a great thing to do, but I better give them drugs, too.

So our construct is that those kinds of techniques really need to be individualized in the patient and combined. I don't think that somebody getting aggressive drug therapy couldn't learn to still image their pain out of their body, in the same sense that I don't think that some people with very significant physical pain don't have incredible chronic-illness behavior. So I think that this idea that -- how people look at their pain in different arenas it is just all the blind men at the elephant; it's just like where you are.

MELDRUM: Actually, I think Isabelle used that same analogy.

FOLEY: But I mean that's just where you are. But it doesn't diminish, you see -- when people talk about it in that way, it's almost like it's diminishing that technique or it's emphasizing that technique. And I think one of the smartest things we could do is to say every patient needed every one of those techniques, but they would assume different priorities depending upon where you were with that patient.

I'll give you the example. Today, we had a patient we were talking about, who has very advanced breast cancer and very significant pain problems and complicated medical regimens. We went through this whole discussion, and then it was that the patient said, "I just want to die, and I want you to help me." And we then, one of the physicians, commenting on that, commented that really, this was someone you had to sit down and figure out who she was and what her goal was going to be for her life and, you know, where she was going -- which was not to go up on her steroids, down on her drugs, you know, give her more antidepressants -- but it was readdressing this other question. And I think that that's the problem, is that this mind-body issue for pain is extraordinary.

So why would we not think that we shouldn't be attuned to both and just play off one versus the other, and not think that one is less or more important. I mean, one thing that I have with patients is I'm always asking them, I'm always thinking when I have a very difficult patient -- I have one right now whom I like a lot and I haven't made better, and there's a profound psychological component to this pain. And I'm trying to find sort of the magical figure for her, the magical doctor, the magical person who somehow or other will help her cognitively restructure where she puts this pain. So I'm someone who believes in cognitive restructuring and making people know something or see it differently than they had not seen it so they could think about it differently, so they could think about the meaning differently. Do I think this approach makes people's pain less? No. But I think it helps them function better.

So, from my world of seeing patients, because I'm seeing so many with medical illness, I think that what we do in medical illness is fail to recognize the degree to which patients' psychological phenomena are interacting and inter-playing, and also we tend to minimize and then trivialize them. But we run the risk that when we can't find a cause for someone's pain, then we put those into a greater emphasis.

MELDRUM: Right. It becomes more and more, in fact, it becomes sort of definitive.

FOLEY: And it becomes much more important, and that probably isn't wise, either. So it just shows how primitive we are in trying to figure all of this out. And you know, our advances in molecular biology haven't given us a clue to really the "mind" side of this.

MELDRUM: No, it's quite interesting to me because I also study molecular biology and it's [she laughs] very, very interesting that we're at this [point] in some areas so advanced --

FOLEY: And so primitive in others. We're really primitive.

MELDRUM: Very, very basic level.

FOLEY: Very primitive. And the primitive aspects of it, even more, are that patients with pain are so vulnerable, and they need to be cared for. And they become, and can readily become, quite dependent on those caregivers. But how needy they are!

MELDRUM: Yes, it's very difficult. One thing that's certainly been around a lot lately is PCA, patient-controlled analgesia. I was wondering what your thinking was on this, if this --

FOLEY: Oh, it's a great story. Years ago -- and I'm forgetting; he has a double name--this wonderful man, who was blind, was the first to really suggest this as an approach. And I remember hearing him talk; I remember seeing him. He was a very tall man with white hair and, as I said, blind or almost blind, telling me about it. And I'm like listening to him, saying, "I can't believe this guy is for real!" you know, like, "People would be allowed to control their own drugs?" So you can see where I was. I never catch on; it takes a while. And I remember him talking about it, and it was at this meeting, and it probably would be, you know, like in the mid-, maybe late-'70s. And he then died.

But out of that era came the PCA world. And, again, that was a matter of a device. Once the device was patented, you could do anything with the device. So we had a device. So I think what he did for us was conceptually raise it at a time when the culture wasn't ready for it. Then the culture got ready, and it worked. And then it worked for different reasons -- not because even the culture thought it was ready; because it was the science. You know, if you have a basal infusion, clinical pharmacology use these basal infusions. But we had this pharmacology thing that emphasized it. But it was really because nurses didn't have enough time to treat pain that it got institutionalized.

MELDRUM: [she laughs]

FOLEY: It wasn't because of the science. So here, you know, we could all think it was this great science. But it wasn't the great science. It was great science to create those little machines. But the real issue was that they didn't have enough nurses to get around to do it [give the medication], so they needed machines to do it. So it was a technological revolution that was happening that had to do with staffing, not with, "we want to treat pain." Then it became a money-making thing for doctors, so then there was money in it. And then there was visibility in it. All of those issues. That all of that together, drove it and continued to drive it, in part. But it's a wonderful technique and the ability for patients to have this and to rapidly have it.

But the best PCA we always had, which was the patient had control of their drug and they took it by mouth, so that the concept of letting patients titrate themselves to their own pain relief was really well established, by giving people oral medication and telling them when to take it. So that was there, but what we put onto it was a science of basal infusions and rescue doses and breakthrough pain and baseline pain, all that language, and then what we put on top of that further was the cultural aspects of it.

MELDRUM: Yeah. When you think about it -- I mean, PCA -- if you have a bottle of pills, that's exactly what you have.

FOLEY: Well, what do you think people have been doing at home all the time when they took Tylenol or aspirin? Typical PCA. So I mean, let's not -- I think we look at it -- What we did was we formalized a treatment, and it was based on the construct that first we would believe that the patient could understand their own pain and that, second, that they could push a button to respond to their own pain, and, thirdly, that we would believe this and trust it.

MELDRUM: It seems to me that's the hardest step.

FOLEY: Right. But that was this issue of trust and lack of familiarity with drugs and not having enough experts to know how to do it. However, at the same time was the expansion in the field of anesthesiologists, who knew how to use these drugs. So concurrent with this was the group of doctors who could translate this into practice. So it wasn't the discovery; it wasn't the knowledge; it wasn't the pump. It was all of them together, with the translator. Because we had someone who could do the technology and transfer it. So I think the PCA again has been a wonderful advance.

But if you look at the advances that we've had in the last twenty years, they've either been at a very molecular level or they've been at the clinical level with new delivery systems, not with new drugs -- not true. With new delivery systems, with new drugs in the anesthesia world, the whole fentanyl, sufentanyl, alfentanyl series, and with understanding that there are specific sites of drug action so that putting the drug into the spinal fluid gives you a specific site. By putting the drug into the ventricle, you get a specific site.

MELDRUM: Okay. So it's a much more targeted delivery.

FOLEY: But there still are the medicine men around with the gimmicks. I'm pretty hard on this field, but I think the people doing electrical stimulation of the spinal cord have the machinery, and it costs a lot of money, and they're doing it. And I don't think we know where it fits in, but I don't think it's at a level that makes it work as well, although it looks like they've got something.

MELDRUM: Yes. Well, I have the impression through all of this that for -- particularly for cancer patients -- that you continue to think that morphine and the opiates are the best treatments. Do you want to comment on that?

FOLEY: Oh, I think that's a really good comment, or question [she laughs], and I don't know the answer. I think that we should probably say that for the largest number of people, they are the best treatments. You know, if you have to look at it as a public health issue, you can treat the largest number with it, so it has that value. As you look at it for an individual, it might not be the right thing. But we did live in an era that using chronic drugs like that was unacceptable, and the patients were forced to have procedures done to them, even when they were ineffective, because that's all that there was.

So we placed on a pedestal these neurosurgical procedures, because we said that drugs were bad. And I think that's, you know, I'm forgetting my days of that. [she laughs] And I'm forgetting being, seeing patients going for cordotomy that wasn't the right treatment for them, because no one would give them a drug. And I'm seeing people going for epidural catheters or going for limb amputation or going for those kinds of treatment, because no one would give them a drug. And patients going for limb amputation I can think of, without ever having had an epidural catheter put in, and saying, "Look at it, they're dying. Let's just give them a local anesthetic."

Because we wouldn't buy into the idea that we would treat them in a different way. We didn't have that knowledge, or we didn't have that experience. So there really were these incredible -- the '70s, in my mind, were the time, at least for me, when I was being confronted with the surgeons that did things to patients. Then in the '80s, it was the anesthesiologists. And during this period of time, we've had to fight with each for the fact the drugs might have had a role. And now we're in the drug era. But there's no question that's going to have a backlash. And the Bonica group, long arguing that the worst thing for a chronic-pain patient would be to be on drugs. And our arguing that for some people it was the best.

MELDRUM: When you say "the Bonica group," do you mean Bonica personally? Certainly, he started out as an anesthesiologist.

FOLEY: I mean John Bonica and his group including Fordyce [Wilbert E. Fordyce, who introduced behavior modification into the rehabilitation of chronic pain patients].

MELDRUM: Ah. Okay.

FOLEY: And the whole model of treating chronic pain was that drugs were bad for you. So it was the West Coast against the East Coast, the West Coast saying drugs are bad for you, the East Coast saying they're not so bad. And the West Coast eventually buying into what we said, not completely, but clearly acknowledging that there were subsets of populations, and that behavioral approaches, as good and as wonderful and as terrific as they were, weren't the whole thing.

MELDRUM: What we seem to be talking about here is a kind of contest among different fields because Fordyce certainly came from psychology, and anesthesiologists have developed this long series of nerve blocks --

FOLEY: I wouldn't even say it was a contest, though. I think it was a competition -- and that's the same as a contest, I guess; that's the same; sorry. [she laughs] That's how I look at words; it's so interesting! -- because in a contest I think you have to win.

MELDRUM: A debate?

FOLEY: Maybe a debate. That's a better word. Great. Okay. And the debate was everybody always had some new pieces of information to put forth, but the catch is that the behaviorists, the psychology people, in a way always win out, because they sort of get you in the end, you know; those drugs are bad for you, in a way, and we still don't understand the mind. And one of the things that early on -- This is something that Bill Martin said to me -- he was the man who had studied drug addiction and had done an incredible amount of research in opiate drugs -- and we were together at a drug company, and we were advising this drug company on their drug trials in pain, in analgesics. And Bill Martin said, "Well, find a drug that treats suffering, and you'll really be ahead of it." [Billy R. Martin, chair of Pharmacology and Toxicology at Virginia Commonwealth University, 2000-] And I think that what we don't know how to do is treat suffering. So what we're doing all the time is we're so focused on treating the pain, and we still haven't figured out the pain-suffering complex, and we don't have good drugs for suffering, and maybe we'll never have good drugs for suffering. And that's why we pain people don't have it.

MELDRUM: Yeah. You can't win.

FOLEY: No. And I think -- the other aspect is, from my perspective, is, in looking at what's happened over this period of time is that in the last -- and this is the best for me -- is that in the last several years, but clearly, to me, the most in the last year because of wearing a different hat and getting into the issues of death and dying, of having all these people continually say to me, "You know, pain is really important." And I'm like, you know, "Thanks for catching on." Like it's only taken, you know, like I've spent my -- I mean, I'm leaving the field when you're all of a sudden deciding it was important?

MELDRUM: Twenty-five years later.

FOLEY: And this wonderful sense of people saying, "You know, doctors don't treat pain," and being able to sort of quote everything that we have been trying to get them to pay attention to. And it took this long for them to catch on.

MELDRUM: Or really even longer, because there was a period of time when Bonica --

FOLEY: Oh, sure.

MELDRUM: -- was talking about it before that.

FOLEY: Right. I'm only saying, you know, like, history only begins when I begin it, you know what I mean? [she laughs] So this is my history! But no, it's fascinating, and you're absolutely right. And Ray Houde, I mean, they're of the era of the '50s and being able to tout this. So look at how, you know, if you really look, like, where are we? I'm not saying anything different than

Ray Houde said in 1950, but now people hear it and now we have a lot of data behind it. And the other thing in all of this is the fact that it wasn't until the '80s that we got people to believe that we could measure a drug in the plasma of a patient and correlate that blood level to their report of pain.

MELDRUM: Okay. So again, there was science to back this up.

FOLEY: So we had these pieces of science that continually were reinforcing it, but maybe we're tricking everyone because the culture doesn't rely so much on that science. If it doesn't rely on that science, then why are we putting so much hope into it or something like that? So what does it rely on? And so I think it does rely on the science, but it's in such a sort of convoluted way you can't tell.

MELDRUM: It's not the perception of cause and effect. There's something different there, and I agree with you, and I'm not sure entirely what all is going on there. When you say, though, you correlate the level --

FOLEY: So we can measure a level of drug in a patient and we look at their pain relief, and then we know that when their blood level falls below that, they won't have pain relief, and when it goes above that, they may have side effects. Well, that's a big thing that we can do that. So that kind of methodology takes this kind of, the way your brain sort of subjectively sees all of this and suffering and everything else, and says, "I'm getting relief," and then we can convert that to this.

MELDRUM: Yes. Exactly. Which brings me to something else, which is a particular interest of mine, so I just thought I would touch on it here, is how do you measure the pain relief? Because the only way you can do it is to ask the patient. And we do know that patients have -- [she sighs] that there are a lot of different factors which are going to affect a patient's perception of relief, but we have to rely on that. And I just wondered if you have any particular thoughts about that, about methods which are better than other methods.

FOLEY: Again, that's a really good question because I think so much focus has been on pain intensity. But we did a study -- Baruch Fishman, in fact, a psychologist working with us -- did a study in which he looked at the relationship between pain intensity and pain relief and mood, in using our visual analog scales in a study that we were looking at the Memorial Pain Assessment Card. [Dr. Fishman is in the Department of Psychiatry at Weill Medical College, Cornell University.] And what Baruch noted, which had been in fact previously observed by Stan Wallenstein in using those same kind of scales, was that patients could really tolerate any degree of pain intensity; it was their perception of pain relief that had the impact on their mood. So pain intensity and mood were not directly related. It was pain relief and mood that go together. So we documented that observation. But, more than documenting that observation, what we were able to look at is how reliable people were in being able to document their relief, and that that a lot had to do with how you measured it and how you looked at it. And that, if you were to test a drug by looking at a change in pain intensity, that was a less sensitive method than to look at testing a drug by pain relief scores.

MELDRUM: Yeah. I mean, when you think about that, that makes perfect sense.

FOLEY: So, if somebody gets seventy-five percent relief, that's relief. If they get seventy-five percent change in their pain intensity, that doesn't correlate to seventy-five percent relief.

MELDRUM: Wow. That's very interesting. Let me see how much time we have on this tape. Oh, none at all.

KATHLEEN FOLEY INTERVIEW

TAPE TWO, SIDE ONE

MELDRUM: Okay. We're starting tape two of our interview with Dr. Foley. Yeah, I think that is very interesting about the difference between intensity and relief and which matters most to the patient.

FOLEY: But methodologically, I think it's a very important issue when you're doing studies because of the fact that if people only look at change in pain intensity, there may not be a way to fully analyze the data appropriately. Measurement is a critical issue.

MELDRUM: Now, in terms of, you were saying a few minutes ago that people were just beginning to catch on. What kinds of efforts -- I mean, obviously, you go to professional meetings; you make speeches; you publish papers in professional journals. But are there special kinds of educational efforts going on which are directed specifically at internists and oncologists working in the field? And do you have any sense that these are becoming more successful as time is going on? Do you want to comment on that?

FOLEY: Well, I think educating the public and educating the professions about pain has been a very tedious process, and it has focused clearly on the cancer population, because they were a group that you could target a rather simple message to. And the simple message was that "drugs do work; use them." And that concept came out of the WHO expert committees and came out of the WHO thrust, that if you were to introduce a simple program that advocated for freedom from cancer pain and if you provided a simple, inexpensive method for people to do it, it was more likely to happen because it would be a broad public-health kind of strategy. And that you did it at the level of educating the professions; at the same time you would explain to the public why this could work; you did it. What has evolved from that is that kind of a program has had the underpinnings of an authority -- the World Health Organization. It has an expert panel that says it was the right thing to do, and it got translated into many individuals in many different countries so it would work effectively.

Given that, that has been one approach to educating people and I think probably one of the smartest approaches that I wouldn't, I don't take any credit for because there were smart people who said, "Keep it simple." They were the smart people, [she laughs] and they were, you know, Jan Stjernswärd and Robert Twycross, who, when I was trying to make it complicated, they kept telling me to keep it simple. And I really learned a lot from them, from that. I give them a great deal of credit for that.

However, it's gotten more complicated, and it isn't so simple. But even by keeping it simple, a lot of people's lives have been impacted in a positive way. If we move to the issues now of education, we have these drugs -- if we look at the US -- we have these drugs out there and available. We have a clinical problem. We have a priority that's rising, because we've now called attention to it in highly visible journals. And so the education is now becoming one of quality improvement and continuous quality improvement and institutionalizing change.

Because all the data we have is that we might educate the doctor, or maybe we'd educate the nurse, or maybe we'd educate the public. But if the institution in which they lived or worked or were cared for didn't think it was important, it wouldn't happen. So this approach now to institutionalized change, which has been a major effort of the American Pain Society in developing quality improvement standards is, I think, a really smart way to go from a policy perspective.

Another level of education has been with the Agency for Health Care Policy and Research putting forth guidelines for acute pain, for cancer pain. The importance of them doing that has been that they've set a sort of standard for how we think patients should be cared for. So that's an educational [effort] alone, saying we have a standard is the education, and then implementing that.

But I recently wrote an editorial, which was called "Rhetoric without Reform," in which I have argued that we have all of this rhetoric out there, but we have not really reformed the day-by-day treatment of a patient with pain. And that's because it has to be with every doctor in every interaction in every patient with pain. And that means that we haven't been able to educate physicians enough for them to be able to be well aware of this. So I continue to see this deficit in education. And now, this deficit in education is coming at a time when, if anything, pain management is getting more complicated and becoming more sophisticated and more specialized. So how do we take the simple and keep it simple? How do we let the specialized be more specialized? And how do we educate and keep physicians up to speed in this area? I think that's a real challenge that we have not met. And we have not met [it] because the only ones that have put the money into doing this have been the drug companies.

MELDRUM: Yes. Well, they have the money, and they also have --

FOLEY: They have the money, but, you know, that shouldn't be where the responsibility for teaching doctors lies.

MELDRUM: Well, medical schools. [she laughs]

FOLEY: Well, let's say that. You know, well, they have the money, too, okay? So why are they not doing this? And residency training, they have it, too. And they clearly do it for a lot of other things. Why do they not do it for this? So I think that we have to push very hard to get this established. And it makes me now rethink my idea. I never thought that we needed a National Institute of Pain or a Office of Pain Research; and I'm getting to think we really need one because we don't have a public advocate, we don't have a governmental advocate, who is out there pushing this along. We don't have a spokesperson there. We don't have someone pushing for more research, and it really is necessary. So I, having not been someone that would have advocated for that, I think it's got to happen, because as much as the drug companies have been helpful in educating physicians, they have their agenda, too --

MELDRUM: Oh, yeah. Obviously.

FOLEY: -- and we need a more neutral agenda. And we need a neutral agenda that would incorporate this in a more centralized way.

MELDRUM: What about the American Pain Society? You were president of it for a while, weren't you?

FOLEY: Right. In the early days.

MELDRUM: In the early days.

FOLEY: I mean, it was a little group that got together and said, "This was the right thing to do," and then it grew and evolved. And I was a president in the very early days. I was a president during a period of time that we didn't have a meeting, because it was one of the off years we didn't have a meeting. But like everything that exists now, it was slowly, we were bringing together the individuals, we were trying to form a network of clinicians and scientists; we were trying to find our way, and it's been successful. I mean, I think it's been enormously successful. And I think each time, now, it's a much bigger organization. You know, then, we had a membership of maybe five or six hundred people; now it's I think three thousand or so. So it's moved up in its membership.

MELDRUM: Yeah. I went to the last meeting.

FOLEY: And it's integrated much better with basic science by linking it to the neuroscience meetings, and it has still a clinical relevance, and I think it's been a very good and respectful organization of trying to speak to the needs of patients with pain and to those that are working in it. It's tried to be mostly multidisciplinary; it's tried to be well aware of the differences within the organization, and I think it's trying -- it has not had a very strong public voice, so I think it needs to have a strong public voice, which it has not had. But again, it's growing, and that takes time to get there. So I think there's an opportunity for it to have a public voice of saying, "This is what we think," and commenting on all these. But that would mean tooling up a big public relations office that they haven't done.

MELDRUM: Well, what about this multidisciplinary? I mean, certainly, you know, we were talking a little bit earlier about this debate between different groups. Do the disciplines talk to each other? Clearly, well, I guess they do, but in what sense is there a sort of a sharing of perspectives, from your point of view? In what sense is it in fact a continuing debate -- "This is what I think is right"; "This is what I think is right, and here is my data"? What do you think about this?

FOLEY: Well, I think in the broad issues of chronic pain, there's still a lot of debate and controversy. I think, however, within groups that are working together, there's probably more like-thinking than separate-thinking. So I mean, I can only speak for our group, at least, but I think within our group, there's clearly is more like-thinking than different-thinking.

MELDRUM: Who's involved?

FOLEY: In that group would be, it would be multidisciplinary; and it would involve an anesthesiologist that sees patients with acute post-operative pain, and some of the chronic pain patients that would involve a psychologist and psychiatrist, who are seeing these patients from that perspective. It would involve a social worker. It would involve nurses. These are the people that I'm talking about. Occasionally, it will involve a rehab physician or physical therapist. And I think it's all recognizing that we all bring something to the table, and it just, what we do depends on who the patient is, what their needs are, what their pain issues are.

So I think the multidisciplinary still is there and important, but I am someone that, like many doctors, never did well working in teams. Teamwork is nice, but the patient needs a doctor so that the buck sort of stops with, like, who's their doctor? So it's nice to have this team thinking about you, but I want someone to take care of me; I want *someone* to take care of me. And that's the dilemma or dimension in all of that. So I think this language of multidisciplinary teams is wonderful for getting concepts together and for helping you look at the patient broadly to teach yourself, but, you know, somebody's got to take care of the patient. And that can be a problem in a team, because you can't take the problem to the team to solve. You get the input of the team. So I may be quibbling over words, but I think that there is a model system in which every patient has a doctor, yet every patient could be seen by the team or potentially discussed with the team. So I think the multidisciplinary sort of recognizes the complexity of the problem, and also acknowledges the complexity of it; and doesn't think that anybody can have it all.

MELDRUM: Right. Okay. Makes sense. Well, we probably -- I guess we should start talking a little more about your current work, about exactly how you made this move into Death in America -- well, I guess into the whole field of palliative medicine for the dying patient.

FOLEY: The moving from cancer pain into the broader field of palliative care really came and was prompted by Vittorio Ventafridda, always saying to me that I had to understand that pain was only one of the issues in caring for cancer patients, and that they really needed broad palliative care. And he was clearly way out in front on that discussion and on those issues, and we were, I would say, I myself was not, because of my focus personally in a major cancer center and, second of all, I had recognized the need to have a supportive care program, but clearly had not [defined that fully], and was a member of the Academy of Hospice Physicians, but I was from the pain perspective.

And I think I didn't broadly embrace, understand, accept, or whatever, all of the other aspects and needs of the patient population, which have clearly become much more apparent to me the more I've [thought] about it and have realized that cancer pain is only part of the symptom. And that if we're really to treat the patient well and be their ombudsman, we have to have something broader than that. Now, you know, I mean, I'm, like, smart, so I should have caught on sooner, but it's so interesting how you sort of get focused so in your area that you don't see these broader issues -- or not even that you don't see them. It's just that you're doing what you're doing and people are doing what they're doing.

With that, then, in 1986 we had a meeting at the WHO, which I chaired, on cancer pain relief and palliative care, trying to bring it together. And we published this monograph from that. And really, since that period of time, I have tried to participate as much as possible in the broader

concept of palliative care and with making that available. And, in fact, as of within the last month, the Pain Service at Memorial's name has been changed to the Pain and Palliative Care Service to broaden that. And that really is not my effort solely but the efforts of many people, including Russ Portenoy very particularly, who has seen a very strong need for us to have this broad concept. [Russell K. Portenoy, who trained at Sloan-Kettering, is the founding chairman (1997-) of the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center in New York; he was President of the American Pain Society 1998-99.]

The WHO Program in Palliative Care, then, moved us into the arena of dealing much more broadly with how one integrates pain and symptom control into hospital settings in the cancer arena, not just in the hospice setting, and trying to cross-link the hospice with palliative-care programs in the hospital. This particular project, the Project on Death in America, grew out of discussion with Patricia Prem [social worker on the PDA advisory board], who is a friend of George Soros [philanthropist (1930-) and founder of OSI and PDA], who was given the task of finding out who knew about death and dying in the country, and who was interested in issues related to that. And she came and spoke to me at Memorial, asking me what I knew. And I had her contact a variety of people whom she met with, and eventually we had a weekend meeting.

And from there, this project was, in part, created. And when the board was appointed to this project, they were told to choose the name and choose what we wanted to do. And in doing that, we intentionally put death in the title because we wanted to be able to be up front about the fact that we wanted to talk about this topic. More importantly, in wanting to be up front about talking about the topic, we wanted to be able to, in our mission statement that we put together, to transform the culture of death and dying, which implied that one had to talk about pain and one had to talk about suffering, and one had to talk about the issues of how people die, how we die and where we die, and how we want to die, and those kinds of issues, but really to get at it again at this cultural level.

And I think that what I learned in the pain world has taught me a lot -- that it's not knowledge that's going to make the difference; it's going to be attitudes and behaviors and culture that's going to make the difference. Within that framework, then, the pain issue has become a major issue as it relates to physician-assisted suicide, that the reason we should have it is because people are in terrible pain and they need to be treated for their pain, and this is a way to treat them for their pain -- that's sort of one school of thought. The other school of thought is that patients are in terrible pain and their doctors aren't treating them, and that is driving them to request physician-assisted suicide. And, clearly, some of the Kevorkian cases had significant pain problems --

MELDRUM: Yes. I mean, you know, you would hear about this all the time.

FOLEY: The public was seeing this; you were being confronted. And that's why I think the American Pain Society should have been much more forceful in using the media hook opportunity to have talked about this topic. Because there you were seeing these patients, who were complaining about terrible pain; what was the name -- it was Marjorie Wantz [who died in 1991 with the aid of Kevorkian's "suicide machine"], who had terrible pain problems, and here you could hear her saying that, and there was no one saying, "Well, really, this is a very complex

situation.” And this woman was seen by pain experts, who felt she had a major psychiatric problem, and that this is psychiatric disease when she’s complaining of pain. But there are many more complications here, and that she’d been in a psychiatric hospital, and all of the dimensions that had never been brought forth to the public.

And that other man, Dr. Khahili -- who had Dr. Kevorkian kill him -- was a rehab expert, had terrible bone pain from multiple myeloma, was inadequately treated for it, and was profoundly depressed; and never was the opportunity given to discuss how pain and depression are entwined and how one drives each other. So that’s the pain and physician-assisted suicide [issue]. [Dr. Jack Kevorkian (1928-) is currently in a Michigan prison, following a murder conviction in that state. Dr. Ali Khalili died in 1993 after inhaling carbon monoxide at Kevorkian’s apartment.]

Then, thirdly, the SUPPORT data that was published, that came out in the *Journal of the American Medical Association* in 1995 [v. 274: 1591-1598], that said that fifty percent of family members of patients who had died in the study -- which was a very large survey -- reported that their loved ones had moderate to severe pain in the last days of life. So we’re sort of being surrounded by the fact that while there’s a lot of pain out there, doctors don’t know how to treat it; they don’t have any knowledge. Well, why wouldn’t we kill people? Because why are we going to wait for doctors? And that’s where the public is on this topic.

MELDRUM: Yes, that’s exactly where it is, and that’s the way it’s been presented, you know: How can we let people suffer like this?

FOLEY: How can we let people suffer like this? Never to say that their suffering is much more complicated and that having -- I’ve reviewed all of this data, and the reality is people are not killing themselves because of pain. In fact, they’re less likely to agree to physician-assisted suicide. They’re doing it because they feel that they are a burden, they feel that they have no value, they feel that their life is meaningless. And there are many more existential issues. And they’re profoundly depressed.

MELDRUM: Which is a factor very similar to issues involving suicidal individuals who are not suffering from a painful disease.

FOLEY: Yes, and you’re making a very good point there because we’re making the assumption that every one of these patients is, or has, what’s called rational suicide, which I think is an oxymoronic statement. These patients are suicidal, and now we’re going to ask doctors to aid them in their suicidal thoughts. Well, that’s very complex. So my major thrust of the argument, which has multiple levels, is that pain is an issue for some patients, that depression is a much more important issue, that lack of meaning in life is even more profound. And that we should force doctors to treat patients’ pain better. We should force families to insist that the doctors treat pain better, and that the solution to not adequately treating pain doesn’t have to be physician-assisted suicide. But that’s a public policy issue, so I think if we’re going to have a constitutional right to die, I want a constitutional right to treat them for pain. I want a constitutional right to health care.

MELDRUM: Yes! Good point. Sorry.

FOLEY: But I think that this is the issue that we're seeing now at a point in our society where we're saying the old are burdening us, where the dying are suffering, and doctors lack knowledge. We are now going to make those who lack knowledge our murderers. And I'm using that in a very strong language, but I think we have to use it that way. Then you get to the legislation that has tried to address this, and the legislation doesn't really address the problem because all it does is protect the doctor. It doesn't do anything to get the patient better pain management, more medications, someone to pay for it, someone to stay home and take care of them, and all of the things that would be critically necessary for patients who require care. So I think that this debate on the physician-assisted suicide is really an epiphenomenon of our death anxiety, and it isn't getting at the issue, which is: How does our society take care of its patients in pain, its dying, its vulnerable, its retarded, its poor? And how do we decide it? How do you take care of your suffering? You kill the sufferer. I mean, Dan Callahan has used that kind of allusion, so I'm quoting him on saying that, but I think it's powerful. (Daniel Callahan (1930-) is a bioethicist and co-founder (1969) of the Hastings Center.)

MELDRUM: But it's perfectly, you know, if we read society's voice, what it seems to be saying is, "If something makes us intensely uncomfortable, what we want to do is -- "

FOLEY: "-- get rid of it."

MELDRUM: "-- erase it, obscure it, kill it, put it in some place where we don't have to confront it."

FOLEY: What you said is very, very important. People don't realize that that's true, but what you're saying is absolutely -- is we've got to get it away from us. And that's how we do it. And we do it with the death penalty, we do it with abortion, we do it with this issue. And people can have varying perspectives, but that's how we're going to solve our problems. So I think that the sad part about this physician-assisted suicide debate is that although it's given an opportunity for us to improve, I think -- and it is a wonderful opportunity for us to improve pain management -- it's a wonderful opportunity that we need to take advantage of more than we have -- I think that it is really a very quick response of our society to deal with a very complicated issue. And it's this quick fix is not a good thing because we doctors, in having a relationship with a patient, have to always be the witness to their suffering. And this is making us now be there -- not as their witness, but as their executioner. And it all of a sudden gives us more power than anybody would ever want us to have.

MELDRUM: Yes. Certainly more than traditionally doctors have ever been allowed to have.

FOLEY: Right. And there's something very protective in the doctor-patient relationship, where the doctor's role is to do no harm. So I think that we have to understand what this would mean for us to do this. What would it mean to relationships? What would it mean to society when the caregiver is the killer? And how we are even going to look at this?

MELDRUM: Do you think there are instances in which -- I mean, Kevorkian's argument, as I understand it is: "Okay; the patient has the right to die. What I, the doctor, am going to do is assist the patient so that dying is not unnecessarily traumatic, and painful."

FOLEY: Right.

MELDRUM: Do you think there are instances in which that holds true?

FOLEY: Well, I think that, you know, I think that you could construct them. You could think of the times where that might be the case. And it only is the doctor, because he controls the drugs. It's not because the doctor has any more or less knowledge on this issue, because, clearly, when people were sent off to war, they were given cyanide capsules that they took when they wanted. So we could argue that every time you have the diagnosis of a serious illness, someone gives you a cyanide pill. "Take it when you want it." Or we hand people a gun and say, "Use it when you need it." Why would it have to be a doctor that has to do this if it's a right of the individual? Why wouldn't it be a pharmacist? Why are we saying that we need the expertise of the doctor to give the blessing to this? So I think that's the other question that we have to say: Why would we give it to the one person in society who we're asking to protect us, this vital thing? So if we want to do it, then let's give it over into someone different. So some people have proposed veterinarians to do it, because they're good at it.

MELDRUM: [she laughs]

FOLEY: Because that's what we're talking about, is rights. And I think the sad part is, having been involved in this debate and discussion, it turns into constitutional babble that has nothing to do with how doctors interrelate with patients. I see patients day in and day out who are thrilled to be alive for another hour, who are inadequately treated for their pain and asking me to help them die, and then their pain is relieved, and they say, "Well, why would I ever ask for that? But I didn't know this could be. I didn't know I could have relief. I didn't know I could be this comfortable. And now that I'm this comfortable, I don't need to die."

MELDRUM: You know, you're right. This is a terrific opportunity. We should, there should be more publicity right now about this. Golly. Okay.

FOLEY: You could work on that.

MELDRUM: Yes.

FOLEY: So I think that we have -- the first time that we've had the chance to talk about these issues. So in this position here -- with this wonderful board that we have that is appointed to this project -- I took a sabbatical of about eight months to come and work on it about eighty percent of my time. And we got it up and going and we've developed faculty scholars, and we have this grants program, and we're really trying to encourage death talk, and we're trying to encourage a national dialogue. And that's why when they were asking me this question, about the American Medical Association -- I think I'm happy, I was happy that they said no, because, in a way, it was a thoughtless no. But it was a good thing.

MELDRUM: But at least it wasn't a yes.

FOLEY: But at least it wasn't a yes.

MELDRUM: Or a maybe.

FOLEY: And I don't even care about a maybe. But we have this need, intensely, for this discussion. Because we have to say, "What does it mean?" And if we're going to view it as only a technical approach to solve a problem, then what does it mean to the discussions that doctors need to have with their families and their patients? And what does it mean to the discussions patients have to have with *their* families and doctors? The lack of our ability to articulate issues related to death and dying, to know that we're dying, to know what our prognosis is, to know what it means, to even know how we die, to know where we die, to be able to say goodbye to people, is all so painful. We want it quickly fixed by the doctor without ever anything more than that. And I just don't think it's good for us. I don't think it's good for doctors. I don't think -- the very same doctors that we don't trust to take care of us we have now benighted to kill us. The same doctors whose hubris, in a way, is the cause of our problems in the care at the end of life are the same ones we're now going to make our killers. I mean, haven't we caught on to this?

MELDRUM: It is interesting when you put it like that.

FOLEY: So I think the question is, really, why would I *want* my doctor to kill me? Well, because I don't want to suffer; I don't want to be abandoned; I don't want to make my family destitute. So all of those would be the reasons. But I'm going to then make a decision that I should end my life because of those reasons? Is that --? Maybe that's a reality, but is that the society we want?

MELDRUM: Ah. Yes. Exactly.

FOLEY: So we have to really decide as a group, as a society, is this the kind of society we have?

MELDRUM: It really challenges -- We're sort of buying into the value set instead of challenging it.

FOLEY: We're saying, if you're not -- yes, we're buying into utility here, a utility model. If you're not useful, get out. If we want to buy into a utility model for how we take care of our dying, then the pain patients ought to stop taking drugs now, because they don't fit this utility model. And it will become not a response -- you will no longer be a burden; but you will have a duty to die.

MELDRUM: Yes. That's, I think --

FOLEY: And this duty to die will be honored, and you will be thought a hero or heroine because you died.

MELDRUM: You do hear that, to some degree, in the debate.

FOLEY: Absolutely.

MELDRUM: That's one issue that people have brought up time and time again.

FOLEY: And total trivialization and a lack of recognition that many of those patients who are requesting this are patients who are profoundly depressed.

MELDRUM: Yeah. And, of course, all these things are caught up together.

FOLEY: And they're depressed because of their pain; they're depressed because of their disease; they're depressed because of their lack of social value; that they're a burden; that they don't have meaning. And they have, some have a major, first-rate depression!

MELDRUM: That's very interesting. So the main thrust of this present project --

FOLEY: So this particular project, then, is to transform the culture of death and dying in the United States, in America, through efforts in scholarship, the humanities, research, and arts -- and that's the major focus. And to as much as possible encourage a dialogue on the topic.

MELDRUM: And in terms of palliative medicine itself, in terms of the service at Sloan-Kettering, we're talking about pain management; we're talking about counseling of different kinds.

FOLEY: Right. But broadening it to focus it into the fact that pain is only one of the symptoms of patients with advanced cancer and that there are multiple other symptoms that require treatment, like fatigue, like weakness, like nausea, vomiting, dyspnea -- that there are, as well, significant psychological distress that needs to be addressed. And there are existential issues that need to be focused on both at a spiritual and cultural level. And that palliative care is a system of care -- or philosophy of care, rather, and a system in some instances -- that is focusing on trying to put those together in that group of patients in whom we don't have a cure for their disease and for whom medicine has traditionally looked on treating people and looked on them as a disease. We're looking them on as a person.

MELDRUM: Now, in terms of actual patient management, patients come to Sloan-Kettering looking for treatments, cures, magic drugs --

FOLEY: Right.

MELDRUM: Okay. Are they on a cancer service and palliative medicine simultaneously, or is -
- ?

FOLEY: Right. Well, now they will be. Previously, they came and we only had a pain service. And then we had a supportive care service for those patients that were out of the hospital. We've now decided to merge all that together so they'll be seen by a pain and palliative care service. If they have pain and that's their problem and not anything else, that's it. If they have pain in the setting of an incurable illness with advanced disease, then they'll be more broadly focused on as a palliative care patient. And we're hoping to move that together as the model. And our reason for doing that is that we need to be able to better address end-of-life care and end-of-life issues for patients, but at the same time we really need to be able to do it for ourselves. [she laughs]

MELDRUM: Yes, I see that. Okay. Whew.

FOLEY: I think the other aspect in all of this is how, from my perspective, what I thought would always have a way to influence treating pain, would be to have it recognized in the hospital as something that was good and special and academic and research based, and that in that way it could become a priority, because it was a respected arena. And I think that making it a priority within institutions is very important in that one has to do that over time, constantly stressing the importance of where this fits in, and that's where the science has allowed us to make it an academic area. But that's not where it necessarily has taken us. And I think there are so many challenges that are coming forth. And the challenges are: Who has time for the pain? And who's going to spend the time to take care of patients, this kind of way, in this kind of intensity, in this complex way?

MELDRUM: And there's always an issue about time, which of course is also an issue of money, since the people who are going to spend the time will get paid.

FOLEY: Precisely. And who's going to spend that time without getting paid? And, more importantly, who's going to train to do this if you don't get paid to do it? And, more importantly, how can we filter, how can we make available as much expertise to those that are seeing patients every day to heighten their level of expertise? Well, I think that I haven't given up on education, and I think education does this. But along with education has to be some form of accountability, and some kind of pressure to move the system. And that's what we need, these sort of very, very fully organized, fully integrated kinds of policies, that, you know, if you didn't treat pain adequately, then that's unacceptable. That's not what we do. And then in morning rounds, when the patient was thrashing about all night in terrible pain, that's not acceptable. We don't do that.

MELDRUM: Right. Yeah. Something that needs to be corrected.

FOLEY: That's the culture. [she laughs] Rather than "you killed the patient last night."

MELDRUM: Okay. I'd like to ask you a little bit about your students. John mentioned that Russ Portenoy had been one of your students?

FOLEY: Yeah. A lot of them. A lot of good people.

MELDRUM: And a couple of others. I guess, is there, you know, in particular, if someone comes to you, is there anything particular you look for in a student? Or any particular people you might steer away from palliative medicine and pain management?

FOLEY: I think, getting back, it's who you educate, is clearly, you want the best and the brightest, so you sort of start with that as a first construct. Second of all, someone, at least at Memorial, our focus was to try, was really focused on training academic neurologists or academic physicians, and we wanted to focus on that because we wanted to really be training the teachers and training the trainers. And we viewed ourselves as able to do that and wanting to do that. So we were not interested in necessarily training people who are going to go out and see a hundred thousand pain patients -- not that I trivialize that, but that wasn't what we saw as our mission. And it wasn't what we did, because we were an academic center. So the thrust of our fellowship program was to try to identify individuals who had that goal -- that is, to be more academic, to be doing research, and to be doing clinical work in pain.

And so good, we've had wonderful people -- Mitchell Max is at NIH (Chief of the Clinical Trials Unit, NIDCR, 1982-), Rich Payne, who's at M.D. Anderson [Richard Payne is now Chief of Pain Management at MSKCC], Russ Portenoy, who's at Memorial, Gil Gonzales, who's at the University of Arizona at the Mayo Clinic there [now with Xanodyne Pharmacal], and that's only naming a few of the people. Donna Salzburg, who's in Cleveland, Beth Popp, who's in Brooklyn at the moment, John Farrar's at the University of Pennsylvania [Center for Epidemiology and Biostatistics], and many more people.

Our construct was that we wanted to be able to identify these individuals, give them a research project and hopefully launch them in that way, and then see them move on. And Mitchell stayed with us for eighteen months, plus the time that he did during his residency, and then he went to NIH [National Institutes of Health] and has been enormously successful. And he's sort of one model in that he was a model who came saying, "I really want to learn enough skills to do research," and then went somewhere else, where he developed that in a wonderfully mentoring environment with Ron Dubner [(1934-), then chief of the Neurobiology and Anesthesiology Branch at NIDR, now (since 1996) Chair of Biomedical Sciences at the University of Maryland School of Dentistry].

Rich Payne was someone who finished his neurology residency at Cornell and then stayed on and worked in Chuck Inturrisi's lab, and developed an animal model, looking at spinal fluid, pharmacokinetics. [Charles Inturrisi, Professor of Pharmacology at Weill Medical College at Cornell, is a leading investigator of the pharmacodynamics and pharmacokinetics of the opioids.] So Rich was another kind of model.

And then Russ was a third kind of model where he was with us, went back to [Albert] Einstein after he finished, and then we recruited him back to Memorial. And that was critical in which he's run, really, our clinical analgesic trials. John Farrar is at the University of Pennsylvania, and he went first to Europe -- he went first, in fact, to Asia for a period of time and then came back and is running and starting up a clinical research program there [at Penn]. Donna Salzburg is an oncologist who stayed predominantly in the area at North Shore Hospital [Nassau County, NY].

And they all have common features of having a passion to take care of these patients and seeing it as a cause, and being able to handle doing both clinical and research work and sort of balancing that. So they had those qualities; they *have* those qualities, which are very important qualities. They're also all really nice people, which is a nice sort of quality. We place high value on people being nice people and treating each other in nice kinds of ways. And also, they come from different disciplines, obviously, both coming out of the oncology world and coming out of the neurology world; they come somewhat differently.

So therefore, it's unusual to think that a neurologist will be a palliative care physician. They'll be much more of a pain specialist, where the oncologist sees the broader dimensions of needing to do palliative care. Some fellows that we had, have gone off and done very focal pain treatment, like Alex Mauskop, who does headaches, as an example. There are others that have focused in pediatric pain. Gerri Frager is one of those persons, and we have another fellow, John Collins, who's there now. There, the support to maintain them during their fellowship came from an NIH/NCI fellowship, where we received about half of their salary for two people for each year. But if they took that fellowship, they had to go back into academic medicine for a period of time. So that, again, the kind of people we took was in part [based on] the kind of money we had, with the kind of goals that we had for them. So that has, I think, influenced us in part.

Of the people that are out there running major programs, the majority of them passed through Memorial at a point in time, which I think is wonderful; and I think, again, like all programs they don't function unless -- and we're going back to this multidisciplinary team -- as much as I dismissed that for taking care of patients, I don't dismiss that for taking, for developing research programs.

And so the people that I've had the opportunity to work with have been extraordinary. Chuck Inturrisi, who's a Ph.D. pharmacologist from whom I've learned all the pharmacology I need to know, and he's been a major force in helping us create a program. Gav Pasternak, whom we recruited to Memorial after I got there, with the focus of his doing basic research in pain, and Gav has done that incredibly well. He's a neuropharmacologist doing opiate receptors, cloning and opiate receptors, you know, real molecular biology, using antigens to look at different receptors and identifying receptors on that basis. [Gavril Pasternak is Head of the Laboratory of Molecular Neuropharmacology at the Sloan-Kettering Institute.]

So added to the other dimensions of Ray Houde and Stan and Ada doing the clinical, we then had Chuck for pharmacology and so a very, very powerful group of people who, each in their own right, are very well recognized in the pain field. So it sort of gave us a nexus of people that we -- and we're very close to each other and work very closely. And, again, that was for me an extraordinary experience because of what I learned from all of them. And having that opportunity -- and that's a richness of opportunity, to be able to work with everybody.

MELDRUM: What you've done here in having all these fellows trained here and then go to all these centers all over the country, I mean, in a sense, this is sort of seeding the educational process.

FOLEY: Well, that was it. You can't do it without role models, and they're the role models. And we needed to get them out there into these programs to be role models and, ideally, to run these programs. So we're very committed to that area, to that arena.

MELDRUM: And you may begin seeing those effects. I mean, those don't happen immediately.

FOLEY: No. They don't. But now each of them have fellows, and they are increasing the number of people that they're seeing, so, you know, it's that wonderful domino effect that takes an awful long time for people, yeah?

MELDRUM: Yes. Exactly.

FOLEY: Yeah. No, I mean, you know, and these are -- I mean, if you look at the people that John [Liebeskind] has trained who are the stars around the country, it's extraordinary, really extraordinary.

MELDRUM: Yeah. A wonderful group of people.

FOLEY: Oh, my gosh. Absolutely. I sort of really feel that about John, that at times we don't sort of really realize the incredible contributions that he has made to the field because he's really quiet about it, in a way.

MELDRUM: Yeah, he is. He always pushes his students.

FOLEY: That's right.

MELDRUM: Since I've been working with him, he pushes *me* all the time. [she laughs]

FOLEY: Yeah. But that's a wonderful quality.

MELDRUM: You know, it's terrific; it's such a generous giving.

FOLEY: It really is, because when you look at the people that he has trained and that have worked in his laboratory and that he has influenced in whatever ways, it's really quite extraordinary.

MELDRUM: Yeah. Really. It's quite a legacy.

FOLEY: What a history there, you know.

MELDRUM: Yeah. Well, [she laughs] yes, there is a history there. Okay. I'd like to ask you a little bit about how you think your work has affected your personal life. I believe you're married and have --

FOLEY: I'm married and have two boys.

MELDRUM: Two boys. Golly.

FOLEY: I think your work affects your personal life in ways that you don't even know it does, probably. And I'm probably not so candid about it, because I don't think at times I know how it does. And I'm not sure that it's the work -- I'm not so sure that it's the nature of the work as much as it is the work. And I think that's a really important construct. Eric Cassell [Clinical Professor of Public Health at Weill Medical College, Cornell University], in talking about patients and working with them, said that he liked working with patients with heightened emotions, and that was sort of how he defines the kinds of patients that we take care of. And I think I sort of probably like taking care of patients with heightened emotions.

Within that construct, then, the challenge is how you take care of those patients and do research and live a life -- or get a life, as they say -- and I think that's a very hard balance to strike, and I think that people need to strike it. But they need to strike it by deciding what their goal is, and being really good at one thing. So my advice to young scientists is: Be really good at one thing. Don't think you should be good at forty things, because no one cares about the forty. Just be good at one thing because the world loves an expert on one thing. So like, catch on and figure out what that is for you, and do that well.

MELDRUM: And that way you can sort of keep control of things?

FOLEY: Well, you can have some control over it, right; I think that's one part. But, you know, you take it home with you. You take it home with you day in and day out, and to the degree that you're psychologically healthy, you handle it, and to the degree that you're not, you don't handle it. And the guilt that one has, in my instances of being a mother and not doing things I should have done, is enormous. [she laughs] And you live with that. And then there are times you think it's okay, and you live with that, too.

I think -- the other thing that I think is important is that doctors, particularly -- and that's why doctors are different than Ph.D.'s -- is that doctors spend their lives putting their lives on hold. So that's part of their pathology to begin with, and then it only gets enhanced in how aggressive you are in sort of developing your own career and that sort of thing. So I think that there are these emotional tolls that you put into your life, and sometimes they're more acceptable to you and sometimes they're less acceptable. But I think it's really hard. And I think that people ought to get a life. I think they should have a life outside of their work. But some people are more able to do that.

My youngest son -- I have two boys -- and my youngest son, when he first started college, he was not happy in school, and he said to me that he had figured it out, that he was more into *being*, and that his father and his brother and I were into *doing*. It was quite profound.

MELDRUM: [she laughs] I like that.

FOLEY: I loved it. I loved it a lot. And he said, "You ought to be more into being."

MELDRUM: Very good insight. Yes.

FOLEY: So he was right. I should be more into being.

MELDRUM: So your boys are out of --

KATHLEEN FOLEY INTERVIEW

TAPE TWO, SIDE TWO

MELDRUM: Okay. Your oldest son just came back from Sri Lanka.

FOLEY: He just came back from Sri Lanka, and he's going to graduate school at Harvard in September to get a Ph.D. in economics. And my youngest is going into his senior year in college. But I think the one thing that I do focus on is that, you know, you think that they should think it's wonderful, what you do. But they don't necessarily think it's wonderful what you do if it interferes with their life. And so I think we all have very much narcissistic views of what is our life.

And Arnold Relman [former Editor-in-Chief, *NEJM*] wrote an editorial in the *New England Journal of Medicine* ("Here Come the Women." 302 (1980): 1252-53), and it was entitled "The Women are Coming," or "Here Come the Women." I can't remember; one of those two titles. And he said that the world suffered much more from a lack of mothering than it did from a lack of doctoring. And I think that what I worry -- because it's been hard for me to contain myself -- what I worry about is that you really have to know what's important, and you have to keep remembering and reminding yourself that what's important.

So taking care of pain patients makes you understand that it's important not to have pain; taking care of the dying makes it important, makes you think that you should like life and live your life. And those are both -- in this crazy world we live in -- the competitive and aggressive and pushing -- how do you balance, how do you put that together? And what's healthy in it, and how people do it. And I think we should not, in training people and then creating environments in where they work and how they work, that those environments should respect all of these differences among people and what they can do and not do. But I wish I had an answer to it. I sort of don't know, and I'm pretty guarded about what impact it's had on my life, because I think I haven't sorted it out.

MELDRUM: Yeah. I think a lot of us struggle with that.

FOLEY: Yeah. So it's a struggle. I don't know the answer. You do the best you can. Sometimes you could have done better; sometimes you could have done worse. But I think it's really hard. And what I see happening to me [she laughs], which is so terrible, is that the older I get, looking on young people doing this, I sort of want to protect them from themselves.

MELDRUM: Right. Because it's very easy when you're very young to think that you really can do everything.

FOLEY: And I did! I mean, I always -- I never thought I couldn't, so that wasn't an issue. And when I see these people doing that again, I say, I sort of want to protect them, and I think, you know, "People wanted to protect me and I didn't care; why would I do that to them?" This is like crazed. It's so interesting to me. It really is interesting.

And I think the other aspect that probably has been the hardest all along is, How do I come to terms with suffering, [with] people suffering? And why would I not treat someone suffering? Why would I not do that? What would drive me to not want to do that? And try to understand that. And if treating their pain is a form of treating their suffering, then that's important. And I really think, how we take care of patients with pain and how we look on them and how we respect them and how we give them a voice is really a much greater aspect of our humanity. And how we do that. And why we don't do it, and why we wouldn't do it, or why we don't even articulate it. And having said all of that, I'm continuously humbled by the people that do this day in and day out, without any recognition and thanks for doing it. And so you sort of feel phony.

Last night we had this project [letters to "Dear Death"]. And here were these individuals who work in the South Bronx who, as they were describing the people that wrote these letters, said, "If you met them on the street, you'd grab your pocketbook; if you saw them coming near you as you got into a cab, you'd jump in. If you knew about what they'd done in their lives, you wouldn't feel good." And here they are, sitting down, writing these articulate statements that are expressing the same feelings that you and I have and sort of humanizing who they were and humanizing that. And that, you know -- and then having some of those individuals read their letters, who, themselves, in this case, have AIDS -- two of the people reading the letters. And you're sitting there, saying, "And I'm, like, talking about suffering? I'm talking about pain?"

MELDRUM: Right. These are the people who know.

FOLEY: What a fraud here! So -- and I think the problem now is that we've intellectualized pain. And how do we sort of like say, "Wait a minute," like you just wouldn't do this -- like this isn't the right thing to do. So how do you convince people that you treat it? Well, it's not the right thing to do to *not* treat pain! You know, it's like as simple as that. Why are we making it harder than that? And one of the things I've learned when you talk to the press is they can't believe it when someone says, well, their doctor didn't treat the pain. They say, "Well, isn't that what doctors are about? Isn't that what they're for? What do you mean, they wouldn't do it? What do you mean, they didn't do it?" The public can't believe that.

MELDRUM: Right. They don't understand it unless it's happened to them.

FOLEY: Right. They can't believe that.

MELDRUM: I think it feeds into the Kevorkian thing because if someone's suffering, then, obviously --

FOLEY: Absolutely. Then they think that the doctor would have done everything they could do --

MELDRUM: Right. That they just can't do any more.

FOLEY: -- so it means they can't do any more. So that's part of this umbrella, under which we're sort of seeing these arguments play out, but that they're not, that umbrella concept isn't the right one. [she laughs]

MELDRUM: People don't treat pain. I know, it's -- Because there's certainly been material come out in the popular literature, and yet it doesn't seem to sink in. I was going to ask you one final question about your religion. You're a Catholic?

FOLEY: Yes. I'm Catholic. Right.

MELDRUM: And that has -- Can you --?

FOLEY: Yes. I think that without question it influences me, because I am, I go to church, I believe in some but not all things that are practiced by the Catholic Church. But religion is a source of comfort to me, and it's a source of faith, a source of who I am. And again, I think as much as in this physician-assisted suicide debate, I've not wanted to argue on the sanctity of life issue, because people then think you're just a religious fundamentalist. That's probably where the line in the sand has to be drawn if you can't get any other argument. I think there are better arguments, even. But I think that probably my religion is more important to me than I will articulate it is. It is more who I am as a person, which is the underpinnings of a sense of respect for human life, and not thinking that you have control over it, and a sense that something beyond you has control over it, which is something I say to my patients, like "I don't control your life or death; I'm just here with you in this."

And what was wonderful when we had this meeting that was addressing care at the end of life, and they had a whole variety of hospital systems and HMOs talking, and the Catholic hospital system got up and said, "Well, we're not really going to deal with the physician-assisted suicide because we just don't do it. I mean, our job is to be here to take care of people. So if somebody wants it, that's not our system. That's not what we do." But it was a wonderfully [she laughs] sort of clear articulation of that construct. So I think the other interesting thing to me is that there are a lot of Catholics in pain. It's a very interesting thing to me, which, again, may be this issue of -- not that I'd ever say that Catholics have more heightened humanity, but there's sort of an underpinning of this that puts people in that -- I'm quite fascinated with that. Is that true? Or do you know?

MELDRUM: There's --

FOLEY: It's probably, it wouldn't come out in the academic world, I don't think, but it does come out --

MELDRUM: Not so much in the academic world, but there is this phenomenon of Catholics being involved in movements which have a kind of uncompromising foundation. They were, I mean, a lot of the people who were originally involved in the Vietnam antiwar movement, for instance, were either Catholic or Jewish.

FOLEY: That's true.

MELDRUM: And you see this sort of, you know, going throughout -- that they were people who articulated moral positions at a time when it was unpopular to do so, and then tended to stick with them. And, you know, it is something -- coming from a [she laughs] Protestant background -- you don't get that sort of training. It doesn't get instilled in you at a young age.

FOLEY: Right. But there is the rigidity of Catholic education. [she laughs] That we all know about that. Right?

MELDRUM: [she laughs] Well, it plays out in different ways.

FOLEY: Right. Well, I always warn people -- I mean, this is something -- [she laughs] you'll like this -- I always sort of warn this to my fellows by saying, "You don't understand. I went to Catholic school. So I think you should look a certain way, should dress a certain way, should address patients a certain way, should be on time, because that's the rules I grew up with. You may not like them, but, you know, remember where I come from. That's it." And we laugh! Absolutely. About that. I had one fellow who said he didn't want to wear a white coat because it interfered with his doctor-patient relationship. So I told him that if he didn't wear a white coat, he wouldn't *have* one.

MELDRUM: [she laughs]

FOLEY: But, you know, he was like, "I'm not into this." So part of my, clearly, my Catholic upbringing from a regimentation perspective is very much, has dramatically influenced me. No, I think that as much as I've wanted to deny it, it's a reality; I am who I am, and being Catholic is part of who I am. However, because so many of my friends are Jewish, I don't see a difference between Catholics and, I mean, we're like still the same. It's fascinating to me. It's quite a fascinating kind of construct, with the rituals and belief in family systems --

MELDRUM: Yes. Rituals.

FOLEY: -- and all of our rituals.

MELDRUM: Yeah. There is that common framework.

FOLEY: And family-related issues. But I haven't figured it out. I think that's sort of -- and some people are able to be very, are able to articulate how they figured it out. I haven't quite been able to do that. But you have to spend a lot of time defending yourself on the pain area, that's all I can say. [she laughs] I've become very defended.

MELDRUM: I was kind of wondering about that.

FOLEY: Because you've got to -- you know, when people are not effectively treating somebody's pain and you have to confront them and say, "Why would you do that?" like it's not the right thing to do.

MELDRUM: Yeah. Difficult.

FOLEY: I don't know.

MELDRUM: Okay. Is there anything else you'd like to comment on?

FOLEY: I don't think so.

MELDRUM: Well, no, I really appreciate your time.

FOLEY: No, you know, I appreciate you're willing to listen to this! [she laughs]

MELDRUM: This is great. I enjoyed this interview very much. Okay.

FOLEY: Okay? Good.

MELDRUM: It's just about five? What time do you have?

FOLEY: I have five after five.

MELDRUM: Five after five, and we're signing off.

END OF INTERVIEW