NINR History Project
Telephone Interview with Dr. Pamela Hinds
Conducted on August 23, 2009, by Philip Cantelon

PC: I'm speaking with Pamela Hinds, H-I-N-D-S, on August 23rd, 2009. I have your permission to record the call and to use the information in the book?

PH: Yes indeed.

PC: Thank you. I'd like to start with just a quick background. I tried to dig up some information on you, and I got so far and then it stopped. You're a graduate, your Ph.D. is from?

PH: The University of Arizona in Tucson.

PC: Were you there when Ada Sue was out there?

PH: She was the chair of my dissertation committee.

PC: Okay. May I ask you to speak up just a bit?

PH: Oh sure. I'm sorry.

PC: The topic was?

PH: My topic was hopefulness in adolescents hospitalized for substance abuse or emotional disorders.

PC: And your current position?

PH: Is the director of nursing research for the department of nursing research at Children's National Medical Center here in Washington, DC.

PC: What kind of grants have you held from NINR?

PH: I've had R01s and R21s.

PC: Which are?

PH: I've also had R01s and RS13s[RF13s?] from the National Cancer Institute.

PC: And from NINR, can you explain what the grant was for?

PH: Sure. The R01 was to help us examine the effects of dexamethasone, which is a steroid, on fatigue and sleep in children and adolescents who were at a certain point in their treatment for acute lymphocytic leukemia.

PC: I'm sorry. I didn't hear all that.

PH: Let me start up from the very beginning. It's a grant was to allow us to look at sleep and fatigue before and during a steroid pulse, and the steroid was dexamethasone which is part of the backbone therapy for children and adolescents who are being treated for acute lymphocytic leukemia. We were able to enroll one hundred children and adolescents over a—we studied each one of them for a ten-day period, five days before they began the pulse of dexamethasone, and then five days during the dexamethasone. And it was a three-site study. And then the R21 mechanism was to allow us to assess the feasibility of an end-of-life communication intervention between parents and staff, for parents who had made one of three end-of-life decisions on behalf of their child with incurable cancer.

PC: It certainly is coming back in the news in the last few weeks, isn't it?

PH: Oh yes, isn't it though. Yes, I agree.

PC: Was this part of the initiative that NINR has been running on end-of-life?

PH: Yes it was.

PC: So it's a relatively recent study.

PH: Yes.

PC: From your viewpoint, what has been the impact of NINR on nursing research, let's start out for you personally?

PH: I would say for me personally as well as for others, the impact is probably immeasurable, and that is that it has assisted many of us with having an entirely new identity and new expanded definition of what it means to be a nurse. It's also allowed us as individual nurses to be much more helpful to a wider variety of others, certainly including other nurses, but as well other disciplines and helping them to craft their own ideas for research. It's exciting for me to see all the different people from many, many different backgrounds—medicine, pharmacy, physical therapy—who share interest in the very same concept that we do in nursing, and who want to benefit from interacting with us as nurse researchers to learn how we approach particular concerns in patient care and how we solve that issue. So all of that, I really relate to the National Institute of Nursing Research.

PC: Were you with the NCNR before it became NINR as well?

PH: Yes, I was. In fact, that's when I think I got my first grant from them, or maybe it was just after it became the institute. But yes, I was associated then as well.

PC: In terms of more generally, what has it had on the impact for nursing research, in your opinion?

PH: In multiple ways. One is it's been inspirational, and that inspiration and the finance support that came with the inspiration has led to a huge incremental increase in the number of nurses prepared to do research and in the number of nurses who appreciate and understand research and collaborating, even if they are not the independent investigator for a study. And I very much credit NINR with that kind of inspirational effect. The second major influence in my opinion is NINR has helped to sophisticate the research that we were doing, and we are doing many more interventional trials now, many more multisite trials, and many more interdisciplinary trials. All of that is because of the expansive viewpoint of NINR with its priorities, its collaborative nature on the NIH campus, and its resources distributed to investigators. So I think that has been—those are profound influences. I also credit NINR with changing our vista about what can be studied.

There are other disciplines who often ask me two questions about NINR. One is exactly how was it that nursing achieved institute status. They are amazed by any discipline having achieved that and really wanting to learn how that was done. And the second is how it was that we were able to develop methods to study what we study because many of the topics that we study, although of shared interest to others outside of the nursing

discipline, were seen as topics that could not be studied, and therefore other disciplines would not have tackled those because of their viewpoint that they were impossible to study. And all of that eagerness about being able to study what might have been seen as impossible to study came from NINR and its formalization of opportunity.

I think it's well known, I hope it is, that NINR is also leading the charge for palliative and end-of-life research on the NIH campus. This is quite thrilling for me, not just because that's one of the areas that I study, but because NINR has gone after the area of science, how to benefit it, and has funded nurses and non-nurses to do that work. I don't have the statistics in front of me now, but they're impressive when you look at the number of different disciplines represented on each of the funded NINR grants. It's very exciting for me as a reviewer to see the diversity of co-investigators and investigators who are being funded. It's really quite exciting. It speaks to that collaborative nature that I think NINR represents.

I think NINR has also done something quite remarkable in the area of genetics. NINR funded, created, and implemented the Summer Genetics Institute at a time when this was a topic that was rarely seen in nursing curricula. Nurses at all levels of preparation were not being exposed to genetics and the role of genetics in health and the role of nursing with genetics. But that has changed at amazing rates since NINR created the Summer Genetics Institute and began funding very important research related to genetics. So it's

exciting to see how NINR can take an issues approach and develop the content area by formalizing, galvanizing, and then funding efforts in each of those respective areas.

PC: In all of this, has NINR—I guess the question I want to ask here is, who is setting the agenda for these areas of research now?

PH: What NINR has done over the last ten years, at least that I know of, is to pull together funded investigators and leaders from nursing around the country, bring them together in various forms, but mostly focus groups and ask for formal feedback about where the science is now headed and where it needs to go. And in that way, it's kind of an informed grassroots interaction with NINR leadership to identify priority areas, and I find NINR quite responsive to those feedback sessions. Just this year we had another round of those, and I am not sure of the exact number, but I think it was five different feedback sessions, and I was invited in to facilitate one of those and it was for palliative and end of life.

PC: This was in May?

PH: You could be right. It seems it was about May. I think that's a great strategy that NINR has used. In addition, NINR goes out to nursing conferences and healthcare conferences and interacts. I've always been impressed with how skillfully with attendees to really learn where again the science needs to go. So I find this back and forth very

encouraging, it's clearly good listening going on, and you will see how that shapes the priority setting and shapes the funding direction.

PC: If these groups are made up of seasoned and funded investigators, sometimes that tends to sort of pick the same folks over and over again and somewhat stifle innovation from people who perhaps are not on the forefront but may have other ideas in nursing research or nursing science.

PH: Well said. I like what you just said, Phil. But if I could just offer you an example of what happened with our palliative and end-of-life focus group or feedback session. We had an advocate there, we had nurses and non-nurses, we had individuals who had never been funded before but represented very important voices in terms of palliative and end-of-life care and research, and we then had funded researchers who were around that table. So as well as [inaudible] two leaders at NINR and four of their staff members. So from my perspective, there was a tremendous cross-cutting of interested others so that it wasn't just your senior funded investigator, and I can very much respect what you just said about the risk of that. It certainly can happen, and probably does happen in some instances. But I don't think that my group was any different in its construction than all the others, meaning that I think there was a lot of thought that went into representation before those invitations went out.

PC: Over the years, what would you say has been the NINR's greatest success from your view from what I call the applied world?

PH: If I could answer that in a couple of different ways, because I think for anything at that level of influence, it's more than just the application. First of all it was legitimacy, and I think NINR has worked hard to become a legitimate, positive force for healthcare and healthcare research, not just on the NIH campus but most definitely on the NIH campus. I don't think that's a small accomplishment. There's a comfortableness in interacting with Congress, advocating for the kind of science that NINR wants to prioritize. That's really quite a maturational influence and a sophistication that is of course quite needed but successfully achieved. So I think that's huge and needs to be stated. From that of course comes a negotiation for budget, and out of budget then comes sort of the choice of where to fund and what to fund. And I think by choosing its collaborators on the NIH campus and therefore co-funding certain applications and by establishing its own priorities with that careful interactive process, NINR has indeed set the scientific agenda, not just for the immediate but into the longer term future, for where we are going to make our greatest gains. Where we are going to learn the most is where NINR is putting its resources.

PC: My follow-up would be what would you say was the biggest disappointment or failure of NINR over the past ten or fifteen years or twenty?

PH: I think one of my concerns, and this is not a failure at all, my concern is growing the NINR budget. Proportionately it has grown slightly, but I think given the meritorious work that it's doing that it needs to grow more than slightly, and I think that is going to probably require a special kind of collaboration. I don't have the wisdom to know enough about that, Phil, but it seems to me that we've gone and demonstrated very exciting research at the practical bedside, and I don't think yet that has translated into equally impressive increase in budget. So that's probably my only concern for the future is being able to continue to grow the program in a way that is reflected in the budget.

PC: Are you able to find enough nurse researchers to fill your staff coming out of schools now?

PH: Yes. We have had great and positive luck with that.

PC: One of the things when you talk about a focus group and funded researchers and the like, when the initial agendas were being set back in the 1980s, National Nursing Research Agenda, some of the big players were both the graduate school of nursing deans and faculty and then the nursing associations. Are they still big players in the agenda setting?

PH: They are, and I think the players have expanded however. So for example, there are those of us who are not in academia but are in service settings functioning as researchers, and NINR has been very thoughtful about including us in the priority-setting processes.

And I think the inclusiveness has gone way beyond our own discipline. It has included as in the example of this [inaudible], non-nurses, advocates, and interested groups that really have experience, wisdom, and even resources to bring to bear. And I think that's really quite an evolution of the process and maybe that's a maturational sign as well, but it's clearly an evolution of that initial process.

PC: How would you evaluate the ability of these focus groups to pick out future directions for nursing science, let's say over the next ten years?

PH: Phil, I [inaudible] that our group felt listened to, and we are actually monitoring now the visible signs such as RFAs, PAs, priority setting as noted on the website and other publications by the staff at NINR for signs of the outcomes of our focus groups, and I fully anticipate seeing at least one or more of our recommendations coming to the forefront.

PC: With all the debate over healthcare and the renewed interest in end-of-life care, what directions do you think nursing research will go over the next ten years? Do you think there will be more funding for that? Will this be an even higher priority? I'm just throwing out some things here. The status of NINR at NIH will come closer to what the nurses always wanted but never quite have attained?

PH: I think that NINR will always maintain more than a single thrust. For me that means, in response to your question, that I don't think NINR will ever back away from its very strong health promotion and health prevention focus. At the very same time, I think NINR will continue to push for palliative and end-of-life excellence in care and research as well. And this is part of what excites me about NINR is that the complexities of everyday care at the bedside are reflected by the complexity and the multiplicity of their priorities. We are not a single-focus institute. It might advance the science notably in that one area if we were, but in fact the interest of our discipline is quite broad, from moment of birth to end of life, and from maintaining perfect health to maintaining all efforts to decrease suffering at end of life. I mean it's just so comprehensive, so complex that I don't think NINR will ever not reflect that in its breadth and its scope.

PC: Will healthcare costs become a greater issue for science research or for research data?

PH: Yes. I definitely think it will. I think we're all going to have to learn how to measure costs, and that's going to have to be one of the outcomes routinely of our interventions. I couldn't agree with you more.

PC: There was an article in the *New York Times* a couple of weeks ago or a letter, no I guess it was an article on the op-ed page, about redefining what healthy meant.

PH: Oh really. And what was the conclusion there?

PC: Well, the doctor who was arguing it said that they really had to redefine healthy because we were spending too much money on people who were generally healthy but who always felt they had to have more care. I thought it was a very interesting piece.

PH: Did he give an example of that kind of a person?

PC: Well, there are people who had good insurance and went off and used it because they could but who were basically quite healthy.

PH: I can appreciate that point. I wasn't sure if this person might have been referring to elective surgery or something like that, trying for self improvement when in fact they were quite healthy to begin with.

PC: I don't recall that. I'll have to dig the thing out. I think I have a stack of newspapers here that I have to go through before I come back to Washington.

PH: [Laughs] I always think I'm going to get to that stack, Phil.

PC: One of the things that the NINR had asked me to ask is what do you see the future trends being, whether it's more collaboration, a number of people have mentioned this fact that

the nursing institute has been I think some used the words pretty gutsy in funding people who aren't nurses.

PH: Oh, I think we should. I thought that was something we should do from the very beginning. I have never seen us as being created to only fund a nurse in his or her efforts to promote science. I have always seen us as going after promoting nursing and non-nursing investigators to promote the science that is needed to provide excellent care to a patient. That excellent clinical approach will include disciplines who share the same concerns that nurses have at the bedside, but might offer a slightly different twist in the conceptualization there in the operationalization. When I think about the best care that we give in healthcare, it's almost always as an interdisciplinary team. And for me, that excellence in care really should be [inaudible] in our investigations or research. So I've never thought that we were created just to fund nurses in doing their research but instead to fund research that will improve nursing care at the bedside, the bedside meaning quite broadly.

PC: And this also means it has to be cost effective as well for translation?

PH: We've got to. We've got to look at that issue. We've really got to look at fairly low-cost interventions, and maybe what that will also mean is that we will start doing more international research with selected partners who are from low-resource countries, because my guess is they have tackled some of the same issues we are tackling, and

because of limited resources, they may well have identified low-cost interventions that will assist us in reassessing how we are giving care in that same area.

PC: But so far NINR hasn't funded any international things.

PH: I think it's inevitable.

PC: But you think that's the direction it's got to go.

PH: I think it's the direction. I really do. I think because of the cost issue and the resource issue in general, we are going to start looking at international partners, probably from countries that are quite different from ours so that we can have new eyes to look at possibilities that we might not otherwise be able to have.

PC: Examples of countries?

PH: There are some countries in South America who have done some very unique kinds of care for premature babies related to how they maintain body temperature, and we share their interest in that end point, and we have taken far more costly approaches in the States. So I think the more we can partner and then carefully study the intervention in its low-cost setting but now in our setting that has more resources, I think the more we can learn about the mechanis of action, which is probably what our partner site which may

not have the resources to look at mechanis of action can do, we could do here in the United States. So couldn't that be a fantastic partnering?

PC: Who do you think will be the major players in deciding the directions that nursing research will go? Will it be institutions? Groups? Individuals? Associations? Congress?

PH: I believe that if trends continue, it will be all of the above but with different weights on them. And I think the clear path that NINR leadership has taken in the last at least two rounds of priority setting that I've been a part of is being quite far-reaching in who they involve in this process. And by virtue of being federally funded, Congress is going to be a part of that so I think we can expect congressional influence, I think we can expect nursing influence from the sources that you've mentioned in non-nursing as well, and I think because NINR has been so collaborative in its efforts to influence policy and care and science, you will see NINR continuing to collaborate with advocates and patient care recipients. I think it's going to be a very wide scope of voices.

PC: What about HMOs?

PH: I think depending upon what happens with President Obama's healthcare plan, that's a very likely voice that will be heard. When I think about some of the interventions that are now being tested based on funding from NINR, those interventions are going to have

to have a test in real everyday care settings such as HMOs, and we have to know if our outcomes are the same in academic centers as they are in HMOs as they are in private practice. We've got to look at those issues. So yes, I think that'll be a voice.

PC: Anything you would like to add?

PH: You've done a wonderful job, Phil. I appreciate what you're doing for NINR. This is a great way for us to self examine, and I think that's terrific.

PC: It's hard for me to figure out exactly where things will move. I'm a historian, not a prognosticator, but they said to talk to people like you who knew all these things.

PH: I don't think any of us would claim to be knowers of the future, but if trends and needs unite, I think we know some things that are likely to happen, which is pretty exciting.

PC: And just to recap those, you talked about interdisciplinary work, international work, more studies for cost effectiveness in healthcare.

PH: And including the work of health promotion and health prevention, all the way to end of life. I think that spectrum's going to continue as well.

PC: It'll be an interesting progression I think for NIH which is disease oriented and not . . . do I use the term wellness oriented?

PH: I think you can use that term. I think it's a fair historic statement to make. But I think we are not going to be allowed to do that anymore—well, of course some of that's going to continue. Forgive me for sounding quite so inclusive in that statement. I think we have new challenges about to be set down for us, and I think it's going to come from our new White House administration, and I'm quite excited about it. I think Obama's administration has already been collaborating very nicely with nursing and other healthcare professionals, so I anticipate that we will have some influence coming from that direction and hopefully we can also influence in return.

PC: Well, I want to thank you very, very much for taking time tonight, and have a great trip.

PH: Oh, thanks.

PC: I envy that.

PH: I wish you could go. It's something I wish everyone could do, and I mean that so sincerely.

PC: I remember how stunned I was. I was in China in 1979 and watching a rural doctor pull a tooth using acupuncture. It was really something, and we talked to the guy afterwards. We were with someone who spoke Chinese, and it was just marvelous, and the doctor said that he was so disappointed that he was too old, he could never go back to the United States. It was in a commune outside of Pengzhou.

PH: Well, you just gave a great example of why we need that international collaboration. Maybe as this eastern science clearly identifies the positive outcome and maybe combined with western science we can figure out how it is that it works so well.

PC: Well, it certainly worked. The difference is would you have had to pull the tooth if he'd had proper care in the first place.

PH: Great point.

PC: And I don't know. China was just opening up, and it was a very interesting trip for us. But I do want to thank you, and I hope I may call you again as I get some of this written down and wrestle with it some more.

PH: I so appreciate what you're doing on behalf of NINR.

PC: Thank you.

PH: Take good care now.

PC: Thank you very much, Pam. I appreciate it.

PH: My pleasure, Phil. Good night.

PC: Good night.

[End of interview]