

American Medical Informatics Association Nursing Informatics History project

Purpose

The overall purpose of the Nursing Informatics History Project is to document and preserve the history of nursing informatics.

Copyright Statement

The contents of the AMIA Nursing Informatics History project which includes the digital images, text, audio, and video recordings may be protected by United States copyright and/or other laws. The compilation of all content on this Web site is the property of AMIA and is protected under U.S. copyright laws. The materials on this Web site are made available for use in research, teaching, and private study, but may not be used for any commercial purpose. For these non-commercial purposes only, you may reproduce a single copy (print or download) of materials from this Web site without prior permission. Usage of some items may also be subject to additional restrictions imposed by the copyright owner and/or the repository. Thus transmission or reproduction of more than a single research or teaching copy or a protected item requires the permission of the copyright owner. Please contact the collection holding repository for available information regarding copyright status of a particular digital image, text, audio or video recording. Unauthorized use of the Web site content may violate copyright and other laws, and is prohibited.

The nature of historical archival and manuscript collections often makes it difficult to determine the copyright status of an item. Whenever possible, the AMIA NI History project and the collection holding repository provide available information about copyright owners and other restrictions in the catalog records, collection finding aids, and other metadata associated with digital images, texts, audio and video recordings. AMIA is providing this information as a service to aid users in determining the copyright status of an item. Ultimately, it is the user's responsibility to use an item according to the applicable laws and terms governing its use. AMIA is eager to hear from any copyright owners who are not properly identified.

Conditions of Use

By their use of these digital images, texts, audio and video recordings, users agree to follow these conditions of use:

- for purposes of research, teaching and private study, users may reproduce (print or download) in accordance with fair use materials or link to materials from this Web site without prior permission, on the condition they give proper credit
- materials may not be used for any commercial purpose without prior written permission from AMIA and any other copyright owner
- materials may not be re-published in print or electronic form without prior written permission from AMIA and any other copyright owner
- materials may not be mounted on an additional server for public use, or for use by a set of subscribers

Betty Chang

(tape begins with interview in progress)

Introduction: **Betty L Chang, DNSc, RN, FNP-C, FAAN.** Betty L. Chang is currently a professor at the University of California, Los Angeles. She received her baccalaureate and Master's Degrees from Teachers' College, Columbia University, New York City, New York, and Doctorate in Nursing Science from the University of California, San Francisco

Interviewer Question: How did you come to Nursing Informatics?

Betty Chang: Primarily, in the practice of caring for the elderly, but also in education and research in the area of patient decision-making and their participation in their own health care. Within this arena, I have used multiple multimedia interventions to facilitate patient care. One of my first projects was on the use of videotapes to look at technical aspects of care, patient participation in psycho-social in terms of patient satisfaction. And from there I moved on to look at a number of other issues. At this time I became interested in computer applications. I developed some educational materials such as computer-aiding instructions and patient participation decision making. I also was asked by Dr. Werley to write a chapter on the outcomes of computer-aided instructions in terms of synthesizing the literature from the beginning of time until the time I was asked to do it. So that gave me some insight on computer-aided instruction use.

Interviewer: Your involvement came first through education?

Betty Chang: That's correct. But I educated nurses in the practice of nursing, and I realized that there was a great deal of reluctance toward computer utilization in the health care system. So I developed a survey to look at computer use and nurses' expectations and concerns. I found that during the '80s, nurses were concerned about the use of computers then, which required the to get away from their own work and, in effect, service the computer rather than to have the computer facilitate their work. At that time, we had physicians' order-

entry, we had billing systems, pharmacy, laboratory and very little or none of the charting was on nursing diagnoses. We have progressed considerably since that time.

Interviewer: Were there any “a ha” moments, i.e. the computer is going to improve patient care...?

Betty Chang: Absolutely. I taught Masters students in the school of nursing preparing clinical nurse specialists (CNSs). I found that the very use of nursing diagnoses was quite good. However, the underlying signs and symptoms – we call them defining characteristics – differed from what was recommended in the textbook. As a matter of fact, very often with the same pattern of signs and symptoms and etiologies, our CNSs came up with different diagnoses than those recommended in the text. That gave me an impetus to work toward an expert system to provide decision support for nurses in deciding upon nursing diagnoses.

Interviewer: Where were you then and what year was it?

Betty Chang: I was at the University of California, Los Angeles. It was in the '80s and this project spanned quite a few years. This nursing diagnosis expert system – as we sometimes called it – actually provided decision support. I emphasized to the CNSs that this system did not substitute for or provide a nursing diagnosis, but the program examined the pattern of signs and symptoms, particularly the symptoms provided by the patient, and in recognition of these patterns, we could provide several recommendations.

One of the complexities to developing this system is to develop the decision-making rules for the system. This process requires people who are expert in the subject matter and it's a matter of developing the rules and obtaining consensus for the decision upon which we base the nursing diagnoses. That is an ongoing process and neither medicine or nursing or any other discipline has completely solved the problem.

Interviewer: When did you start considering yourself a “nurse informatics?”

Betty Chang: Yes, when I was deeply involved in this project. Initially, when I looked at nurses' expectations and concerns I had an idea of how the nurses were viewing the workplace in relation to health information systems. I had various ideas on how to improve the situation so that systems, instead of only taking care of billing and (hospital) census, could be implemented to promote and support nursing. In the end, it would promote improved health care. That was in the early '80s.

Interviewer: What do you consider your major contribution to the field of nursing informatics.?

Betty Chang: I feel that one of my major contributions would be drawing attention and awareness of nurses to the use of decision support in making nursing diagnoses and subsequently in selecting nursing interventions, and finally, in the evaluation of care. Previously, of course, we knew cognitively that these steps were involved in nursing processes. However, these steps did not include the use of nursing informatics or any of the information systems applications.

Interviewer: Who were some of the people you worked with who really influenced this field?

Betty Chang: A number of people have influenced me in this field. From the beginning, Harriet Werley has been a very strong influence in my life. Even though we never lived near each other, I saw her at every nursing informatics conference. She always gave me encouragement. She would say, "It's really great you're basing this on nursing theory....this other theory needs to be involved...don't forget to consider this and that and the other." She was a great mentor of mine.

Also, Virginia Saba in her study of home health nursing diagnoses. We very much dovetailed with each other in our work. Others were Judy Ozbolt in her early work on nursing diagnostic systems, Sue Bakken in her work, as well as Patty Brennan, and others in the medical field who have done a great deal on diagnostic systems. For example, Ted Shortliffe had a very early program on Mycin that evolved into a number

of versions. I was very much influenced by his work and the group at Stanford on their development of diagnostic systems.

Interviewer: Did you feel alone out there; what was the social political situation within nursing at that time.

Betty Chang: The first year of the SCAMC meeting I went to, we only had 35 nurses from the entire country. I found my core support there. Nurses outside of there in different work places would say, “Oh you know, you can’t use computers for this.” Also, nurses in hospitals at that time would say, we are not basing this (medication) system on models. We’re into practice; this is not education.” However, I had a core group of supporters and I knew that nursing informatics could be theory-based and it could contribute to health care in terms of including nursing care in the broad spectrum of health care, whether it be in the hospital setting, ambulatory setting, or home health care setting. I also knew that there were ways we could input and represent the data so that they could be extracted and retrieved. We could synthesize the data; we could look at different patterns; and ultimately use these data, which will become information and knowledge, to create more nursing theory – or to add to and refine nursing theory that we have. I saw it as a cycle that we obtain our data from the patients, we synthesize the data, make sense of the data, interpret the data into information. We retrieve , examine, analyze the information , and discover that we can use this information to refine our nursing knowledge and theory.

Interviewer: How did you handle that; what kept you going?

Betty Chang: I felt they had a different perspective, so I tried to explain to them how to examine the data set from a different perspective, how to look at it differently, to determine what we can see from it, and what we can gain from it – other than the simple mechanics. We don’t have to be techies; we don’t have to be able to open the computer and look inside at the circuit boards but we can use the nursing information that all of us nurses have had a great deal of experience in. We use our knowledge to build nursing practice and theory.

Interviewer: Vision or philosophy that has guided your work?

Betty Chang: Yes, the outlook I have is that ultimately nursing informatics will improve the health of all people, particularly the underserved with whom we as nurses have a great deal of contact. . Many of our schools of nursing have clinics for the homeless and the underserved. Many of our nurse practitioners are in clinics for the underserved. But even more than that, I feel we have a great deal to contribute nationwide and even globally. Nurses are currently on very many if not all of the decision-making and policy-making bodies. We are involved in bioinformatics and how new information – genomics and phenomes – can contribute to our nursing care, for example, genetic counseling, and, we're involved in public health in looking at the systems and nursing involvement necessary for bioterrorism preparedness and disaster nursing. The current Katrina disaster brought to our awareness how much nurses were doing in this area.

We're also involved in standards development. That's a very major arena for nurses to be in. Without standards, vocabulary and terminology, it would be impossible for us to exchange information from one system or agency to another. It's imperative that we have standardized vocabulary. We also need to look at interoperability,. which also speaks to the fact that we're not stand-alone entities. We need to collaborate not only on an inter-agency, but also a regional, national and even a global level. We need to look at varied aspects of other issues, such as literacy – not only health literacy but actually reading literacy. Many of our patients' education materials may or may not address the level for all consumers. Right now, we have a number of educational materials, including printed, website, and radio announcements. We must make sure these communications and information are given at a level our consumers can understand.

Interviewer: Are you teaching now?

Betty Chang: Right now, I'm in a transitional period. I'm not teaching. However, I'm very active in the working groups and I'm placing emphasis on our interactions with consumers – how we can help them to realize the importance of personal health records, what kinds of

information that can be kept, how they are keeping records now, how those kinds of records can be incorporated into a comprehensive record that should eventually become a subset of the electronic health record system so we could have a global record wherever we travel, wherever we go, at any time we need health care--We should be able to access the record.

Interviewer: Let's take a step back – history, people who were important? Personal anecdotes from the early days?

Betty Chang: There have been many instances. I have always enjoyed collaborating with colleagues. One of the early experiences I had in my nursing diagnosis project was working with nurse clinicians. We were the only group in those days where nurse clinicians from the units as well as CNS students worked Friday evenings to look at what could be developed into a rule based systems for decision making. People often remarked it was the only group that worked Friday evenings that could get students and staff members together.

Another very exciting part was that when we were funded by National Institute for Nursing Research (NINR), we were able to pay our nurse clinicians on the units for the time involved. That was very unusual because traditionally almost all disciplines used nurses as data collectors or in other roles to advance research. Staff nurses very seldom saw their labor rewarded. That project very well brought to the forefront that nurses were valuable and that they had information that could contribute to the overall health care system.

Interviewer: Thinking to earlier AMIA conference, for example, were there any events that helped move the field of nursing informatics?

Betty Chang: Each meeting has taken the field one step forward. Every meeting I came to – whether it be the American Medical Informatics Association or the International Medical Informatics Association, or our own international nursing group – [we meet every three years independent of the medical informatics associations. But we are also a nursing

interest group within the International Medical Informatics Association] --whatever meeting it was, I could see that we have made subsequent progress. It's been cumulative.

Interviewer: Are you surprised by growth, faster/slower than expected?

Betty Chang: In some ways we feel the progress is slow because we have been working in the area of nursing diagnoses, vocabulary, interventions and evaluations. For example. We work at it from year to year, month to month and whenever there's an international meeting, we go forth and we try to talk to our international colleagues about our terminology. We work with them to see how different cultural aspects can be incorporated, how different aspects can be applicable to different population groups. So it seems slow that way because we're constantly working at it. But, in retrospect, we can see that we've come a long way. The day to day struggle – like anything – seems like a long time.

Now we're represented on almost all the policy-making committees. There was one time when every time we turned around, we felt nursing was left out. But it's like raising children. You think: the days are long, but the years are short.

Interviewer: Lessons you've learned that might be of interest to others coming into the field?

Betty Chang: One thing is we need to be very grounded in our nursing practice and our nursing theory.

[short section here that's garbled – something like Mycin was mentioned.]

Interviewer: let's go back to lessons you've learned.

Betty Chang: Oh yes, we must be grounded in nursing practice. We must see where nursing practice is going and how nurses can influence health care and this is not only in our own institutions but we need to be aware of the regional, national, and global networks, so that we can be aware of what is going on.

We need to know what is going on in terms of interoperability, how we can interconnect with our colleagues and other health care systems so that we can bring forth more comprehensive care to patients no matter what settings they're in.

We also need to keep abreast of certain privacy, confidentiality, and security issues. This is a huge area. I've recently been looking at personal health records and one of the concerns is that of privacy and access. Who can access the data? We as nurses have a great deal of contact with patients. We have advocated that patients not only have access to their data but have control as to who else can access their data: what level of data others may access, what kind of health care provider may access what kinds of information. So, I'm seeing now more and more control in the hands of the consumer or the patient.

Interviewer: Let's talk about your involvement with the American Nurses Association.

Betty Chang: The ANA, at one of their biannual meetings in 1984, had passed the recommendation that a council on computer applications be formed. I was an early member of this council around 1985 or 1986, in which we worked toward a number of issues. We looked at incorporating nursing informatics competency as one of the nursing requirements and we developed a brochure and information material on this basis. We also developed guidelines for vendors that could be approved by the ANA if, in fact, they had included one of the systems of standardized vocabulary for nurses. Those were two major steps. We subsequently developed a competency exam for beginning nurse informatics.

Interviewer: Earlier you mentioned Mycin; what was that project?

Betty Chang: Mycin was a decision support project for the use of antibiotics, which began at Stanford University by Ted Shortliffe and his team. Subsequently, there were a number of iterations and versions, and there were also other expert systems or decision-support systems in institutions elsewhere in the country. The importance of this initial project was that the systems provided decision-making support. I saw from these projects that the

decision-making was derived from the patients' signs and symptoms. It didn't come from classroom teaching or a guidebook where we could go down categories and then find the signs and symptoms. Selecting a category, and then looking for supporting evidence is like looking for a lost key. You may know the joke: a policeman saw a man looking under a spotlight, and asked, "What are you looking for?" The man said, "I'm looking for the key." The policeman asked is that where you lost it? He answered: "No but that's where the light is, (and something may be found that looks like a key)."

Interviewer: Let's talk about looking where you really need to look.

Betty Chang: We need to look at the patients or the consumers' signs and symptoms. It's often said that in making a diagnosis, 90 percent of the information comes from the patient. Therefore, we need to first look to see what the consumer or patient or client has to say to us, what they are feeling, how they see their issues. From there, look at the clinical information – the lab reports, blood pressure, etc. We combine the pattern formed by these signs and symptoms and synthesize our thinking to develop our nursing diagnoses. Prior to this time, people first looked at the patient and sorted through quickly or pounced on one of the statements the patient said or one of the lab reports and developed a categorical nursing diagnosis. And then, because we had textbooks that said the diagnosis is such and such, we looked under the category for a list of signs and symptoms. We'd say, "let's see if he has this. Let's see if he has that." Seek and ye shall find. That is, we first decided on the diagnosis, then we looked for the symptoms, which is one way of doing it. But I would like to start with the patient and see what problems are there, see what kinds of signs and symptoms they have, and what patterns they form. In my research, I have found that in given sets of signs and symptoms, there is a great deal of overlap among the nursing diagnoses. And this is not unique to nursing. Medicine has the same problem. That is not to say we should not use diagnoses. We should use what we have but continually work to refine the diagnostic process.

Interviewer: What do nurses bring to the table, vis-à-vis informatics?

Betty Chang: We bring a number of different areas that are separate from medical informatics. On the other hand, we have areas of overlap with medicine. For example, nurses as I mentioned before, have very close contact with patients. We could do a great deal, and perhaps more, in terms of encouraging patients and consumers to bring their opinions and perceptions to the fore. At times we may need to coach them, we may need to help them to link their vocabulary to that of medicine. In fact, one of the contributions of informatics for consumer health would be that of developing some vocabulary that begins from patients, consumers, families, and look at the terminology and expressions they use and what they mean by their terminology – and then link their vocabulary to medical terminology. This is one of the areas in which nurses can contribute.

Interviewer: What did you enjoy most about your career?

Betty Chang: I enjoy almost every aspect of the career. I enjoy the collegiality of the nursing informatics group. I enjoy looking at the theoretical aspects and also combining theory with actual client/consumer/patient interaction. From there, I have been able to determine or find out from patients what it is they feel they need.

One of my other projects is on families and caregivers of people with dementia. In this study, I found from caregivers that they would like to know how to help their family member to do more for themselves. I attended one team meeting in a nursing home, in which the son was very frustrated. He said, “I can’t believe it. I brought my mother in here. She was walking. She was feeding herself and now, several months down the road, she’s hardly talking, she won’t feed herself...”, and so on. Based on much of the literature, primarily studies done by Cornelia Beck with improving independence for patients with dementia, we found that if we gave certain prompts to the patient, we could help them to maintain their independence longer. I extrapolated from the principles and developed a videotape, telephone, and website program for family members of people with dementia from which they could develop certain strategies to improve or maintain independence for their family members with dementia in the home. I have had many patients remark to me that they actually implemented the strategies we had

suggested and they were very satisfied, e.g. dressing, eating. We had strategies divided into different stages. If they were very mild, they could benefit from certain strategies. If they were a little more advanced, we had more advanced strategies for them to try.

Interviewer: Advice for nurses who are considering informatics?

Betty Chang: I would tell them that it's a very exciting field. And, depending on their preferences, there may be philosophical leanings that reside within the nurse: they may have certain perspectives, and then there are the perspectives of the health care settings in which they work to consider as well. I would try to bring all of these aspects together in considering their role in nursing informatics. For example, I talked to a nurse who looked at the critical-theory aspect of science development. She was interested in looking at various types of information in terms of deconstruction of public information and what it really meant for health care for the consumer. That's one area of looking at nursing information.

Another person might be more interested in the critical care or emergency care aspects. There are various aspects you can look at. I worked with a telephone nurse where we looked at protocols and guidelines in which nurses can approach technology to help family members. In this study, we found that we were able to benefit patients and, in some respects, reduce emergency room visits.

In another area in which we looked at telephone support, we recognized that many people use the telephone. We wanted to know why and how consumers found that nurses were particularly helpful. One of my articles looked at the reasons consumers found that nurses were particularly helpful when we contacted them by telephone.

Interviewer: Anything you'd like to add?

Unidentified questioner: What are some of the strategies you used to be successful that you would recommend they do?

Interviewer: Personal qualities?

Betty Chang: One quality is to become more involved in information and how information systems may impact nurses. Another, is to look forward to what nurses can accomplish, what nursing practice can contribute to the overall health care. A third quality is for a nurse to look beyond your own region, your own setting, and see how we can reach others nationally and globally.

Interviewer: Back to strategies to leadership; personal qualities, etc.

Betty Chang: First of all, you need to be strong in your own discipline. Secondly, you need to look at collaboration and interdisciplinary and multidisciplinary collaboration. You need to know what you can contribute. You need to know what the overall picture is and what other people can contribute so that you can work collaboratively. Collaboration is very important.

Thirdly, you need to continue to be in a learning environment. It's not enough to just offer to work on a committee – say you're in a health care field or hospital – but you need to educate yourself or enroll in one of the informatics programs if you're at that stage of your career, or enroll in some of the other programs available in informatics. There you'll find other colleagues who have the same interests.

Furthermore, you have to have some vision as to where you wish your profession could be -- we're not there, but envision that this is what we could do if there were opportunities. Just keep working at it because you have the vision ahead of you. As I mentioned before, it seems slow from day to day, but once you achieve your vision, you will be pleased with the work you have done. for example with the work on standardized vocabulary, once you get it there, you will have nursing information represented adequately in all nursing systems nationally, and hopefully internationally. You can retrieve the data, you can do more research, and incorporate cultural aspects into it and

many other characteristics of patients. As I mentioned, we're trying to achieve more collaboration globally.

End of Interview