

Karen Mercereau, RN: Patient Advocacy—Filling in the Gaps to Prevent Medical Errors, Improve Outcomes, and Reduce Costs

Interview by Craig Gustafson

Karen Mercereau, RN, has been a clinical nurse for 48 years, also serving as an independent RN patient advocate (iRNPA) for the past 14 years. Recognized by the University of Arizona College of Nursing as a visionary leader in health care, Mercereau founded RN Patient Advocates in 2002. The RN Patient Advocates Learning Intensive she developed supports this distinct area of practice, and her program at the University of Arizona is nationally known for preparing qualified RNs for this innovative practice model.

Integrative Medicine: A Clinician's Journal (IMCJ): Please describe what an independent registered nurse patient advocate, or an iRNPA, is.

Karen Mercereau: An iRNPA is an experienced clinical nurse with a broad and varied clinical background, who is well schooled—not only in the medical model—but in functional and integrative medicine. It is an absolute requirement they all have gone through the University of Arizona–endorsed program, the RN Patient Advocate Learning Intensive, which is based upon systems biology and functional and integrative medicine.

Our mission statement is to advocate, educate, and guide people through the health care system. Education is the central tenet of everything that we do. An iRNPA is community based and may go into corporate wellness, may go into nutrition, or may do individual client work, either in the acute setting or in the chronic, and is trained to be very collaborative throughout the entire health care team. That is it, in a very brief nutshell.

IMCJ: What developments in medical practice have led to patients abdicating their role in the treatment conversation?

Karen Mercereau: One of the reasons that people have abdicated their role in the treatment conversation is because they don't have time. A typical encounter with a physician is 8 to 15 minutes, and if somebody walks in with 3 chronic conditions, how much do you think is going to happen in there? People do not know what questions to ask, and it is alarming. Another big reason is

that Health Literacy,ⁱ the latest big national study, demonstrates that only 12% of patients are health literate. People are becoming accustomed to chronic illness. It is seen as something that is part of normal progression through your life. They see messages on the TV all the time and they think that is the way to go.

IMCJ: Has the landscape of medical economics pushed patients out of the treatment conversation?

Karen Mercereau: Let me start off by saying for all of your readers that doctors and nurses have not become substandard, but the system in which they are forced to practice has encouraged an environment of speed. Everything is related to how many patients you can see, or how many procedures you can do, which is how they get paid. These practitioners often have a big staff to support, because of all the paperwork related to the insurance industry. That being said, the system requires speed in order to carry the load, financially. So, people don't have time to actually talk to their doctor, first of all.

Then there is the “white coat” problem. They walk in and they are awed or afraid. They do not have time to gather their thoughts and they don't know what to tell the doctor. People don't know what is important to discuss. “Oh, I have this bruise on the back of my leg. It's been there for 4 months, but it's okay. Nothing's happening.” They don't know what to ask. They don't know what to tell. The system does not allow physicians the time to probe, to listen, or to ask careful questions. It is all done according to algorithms designed by the insurance industry.

In my view, that is a big part of the reason patients have opted out. They do not know there is a choice. One of the things that iRNPAs do is teach people how to question—with courtesy and respect always—and give them the confidence to speak with their physicians.

IMCJ: How does the failure to keep patients engaged affect outcomes?

i. Please visit <http://health.gov/communication/literacy/issuebrief/>

Karen Mercereau: If people do not understand what is going on, if people do not ask questions so that they have some comprehension, they will inevitably fall away from the treatment plan. Their compliance is dramatically reduced because they do not understand what is going on. They do not know why they shouldn't eat white bread—and they like white bread—and no one has the time to teach them what they need to know to be compliant with the treatment plan.

Another aspect is the high price of drugs, which, as you know, is egregious. When people have to choose between food and drugs and they do not know that there is another way, what do you think they are going to do? They are going to feed their family. They are going to pay their rent, and if it means they use 1 pill instead of 3 a day, then that is what they do. The economics have driven patients into this position, in my opinion.

IMCJ: The way that medicine has evolved into specialties, with clinicians practicing in parallel, opens other opportunities for failures in the system. What types of situations have been documented that a patient advocate could help address?



Karen Mercereau: Let's go to the root of your question. The medical model teaches us—it certainly taught me—that your skin is a bag and it has all of these systems inside. There is a different doctor for every system. They do not talk—they do not have time to talk. Records are lost between office to office, and who has got time to read all those records, anyway?

Medical records are scattered all over the place. We have big companies vying for ownership of them, because they sell that deidentified data—it is a nice profit center. When you have medical records scattered, where people have several doctors and then they change insurance. Now they have a whole new set of doctors and so you have

records all over the place. When you have a specialist, let's say you see a GI or cardio doctor, whatever—they do not know what everybody else is doing. They do not know your history, and that is why we have created the MEDiKEY, which I'll tell you about later.

One of the things that doctors need to know is the most appropriate information in the right format at the right time. There simply has not been anything like that out there. Those are some of the problems created by this vast field of specialization. They are being paid for procedures and unnecessary surgeries. There are approximately 26 000 unnecessary surgeries a year and

that is probably a low number. Unnecessary drugs. Doctor A does not know what doctor B is doing. The patient has not told them. The records have not gotten over there, and so they are giving you a drug that is probably contraindicated in the presence of these other medications.

It is reductionist thinking and, in my view, it is backwards thinking. We need to go back to square 1, which is the patient. Every patient is unique, and if you do not understand the environment, the terrain within which the condition—whatever it is—is occurring, then you

are not going to be very successful in your treatment. You may be able to reduce or alleviate some of those symptoms, but you're not going to do anything about root causes. Those are going to continue to get worse.

IMCJ: How did the iRNPA develop? When was the seed for this idea sewn?

Karen Mercereau: I've been a nurse since birth ... actually, 48 years this year. I had been in practice mostly in critical care settings but doing a lot of other projects on the side for 34 years. I was watching a friend of mine who had been in a bad motorcycle accident. His wife was a nurse and

when she could not be with him, I was with him. He was in a magnet hospital. Everything was supposed to be just grand. He was comatose. I was appalled ... appalled. I mean, all nurses know things are in a terrible state, but to sit there with my friend in this magnet hospital, with all of these things going on, and I saw mistake after mistake after mistake after mistake.

I started thinking I need to find out more about what is really going on, not just what I see. I spent probably 3 or 4 months reading every paper, every source of data that I possibly could, doing the research. Where are the holes? What I learned was that the situation was far worse than I had imagined. It was far worse than I had been able to observe just in my own world, and I thought, "People need me. People need an experienced clinical nurse to advocate on their behalf, to teach them how to advocate on their own behalf, to ask those questions they do not know how to ask, to teach them what is going on, to refer them to the right doctor, and to guide them through, so that when I am not there, they are far better prepared to be active participants in their own care."

I thought, "That's a wonderful idea, Karen. There must be somebody out there doing it who can teach me how to do it, because this is what I plan to do." This was in early 2002 and nobody was doing it. Patient advocacy was not even on the horizon. I am a risk taker, so I thought, "I'm doing this. I'm just, darn, doing it!" I incorporated in 2002 and never looked back. This is my life. This is my breath. This is my passion.

IMCJ: What was the most challenging obstacle to overcome in the process of establishing iRNPA's?

Karen Mercereau: I had done national projects before, so I knew how to do that. I had an amazing mentor, but I was a nurse who had never been in business doing something that had never been done. But I am nothing, if not persistent and passionate about this, because people are dying. So off we went. For the first 4 years, I knew generally what needed to be done, as dictated by all of the research I had done. It had shown me where all the pitfalls in the system were. I practiced here, in Arizona. I started my first Web site. It was a tiny little thing, but I started getting e-mails—*toe curlers*—from people all across the United States and Canada, from as far away as Saudi Arabia. I was the only one on the Internet with patient advocacy at the time. I was it.

I decided to see if I could do this long distance, because this was very scary stuff. For the next 3 years, I worked with patients, long distance, and it was a blessing because the chaff fell away. When you have phone, fax, e-mail, and the occasional site visit, you had better be darned clear on what you are doing, how you are going to do it, and how you are going to make this happen. You cannot walk in with big boots on and tell people what to do. That is not going to work.

For 3 years I did that and, at the end of that time, the

advocacy process was clear. You could throw anything at it and it worked, no matter what. It is a matrix model and has many, many steps. You take what you need, for whatever your client's needs are.

After 7 years of solo practice out there, learning from physicians and learning from my patients what was the best way to make this happen, I was ready to teach. I engaged RN PhDs whose specialty was curriculum development. That is not my field. It is now. I wrote the first curriculum and taught the first iRNPA learning intensive in 2009.

Then a most wonderful thing happened. I got a call several weeks later from Joan Shaver, PhD, RN, who is dean at the College of Nursing here at the University of Arizona. She said, "Would you please come in and tell us what you are doing?" So I did. It was a roomful of PhDs and me, and I took 2.5 hours to go over everything. I knew what they wanted to know and I gave it all to them. At the end of that time, Dean Shaver looked at me and said, "Karen, this is a new practice model." I said, "Yeah, that is exactly what it is." She said, "Would you partner with us?" That was a game changer. The credibility of one of the leading colleges of nursing in the United States saying, "Listen to this woman. She knows what she's doing." That was huge.

IMCJ: What kind of response did you get from the doctors as you developed this practice?

Karen Mercereau: Surprisingly, only a few thought that my head was spinning. Some thought, "You are trying to be a doctor." If I wanted to be a doctor, I would be a doctor. That was not my goal. Most physicians were a little puzzled. They watched me closely and began to see that their patients who worked with me did better than those who did not. They had better success, more compliance with the treatment plan, and more patients becoming involved in their own care. I would bring all of the information that they needed in the right format, so they would have all of the information that they need to make the most appropriate diagnostic and therapeutic choices. It did not take long before there was a great acceptance. Now, physicians are squarely behind what we are doing.

IMCJ: You had pointed out fairly early in our conversation that the integrative perspective is organic to your program. How did that evolve?

Karen Mercereau: I already knew about the integrative approach. I had put myself through Andrew Weil's program just to see what it was like. I also wanted to know what it was like to be a patient in there. My sister was a 40-year cancer survivor, having worked with Donald Kelley, DDS, if you are familiar with the Kelley protocol.

So I was familiar with integrative medicine and I kept hearing about this thing called *functional medicine*. Now, I am an old ICU nurse. What I learned when I started reading

about systems biology, about functional medicine, got me so excited, because I saw the validity. I started going to conferences. I read everything I could lay my hands on and determined that this would be a central element of everything that I did with iRNPA. It is a requirement in the RNPA Learning Intensive. I include functional medicine in the material throughout the entire program. By the time nurses successfully complete my program, and it is a pretty big one, they are familiar with the basic tenets and they are very excited about pursuing that role.

IMCJ: How do you select nurses to enter the program?

Karen Mercereau: In order to get into my program, a nurse must pass a number of hurdles. It starts with a clinical background that satisfies me in terms of its depth and breadth and then there is a 14-page questionnaire with 3 sections to it. Then a candidate is interviewed twice, once by an iRNPA and then by me. If a candidate gets through all that, then comes the learning intensive. I want to know how open their minds are. I want to know if they are life learners. I want to know if “Why?” is a central part of their vocabulary.

The learning intensive itself is tripartite: Component 1 is an extensive Reading List; component 2 is an 8-week online program comprised of about 20 hours per week of work; component 3 is a 6-day immersion of 10 hours a day in a residential program at the University of Arizona.

IMCJ: In the course of developing this practice, you have not only developed the process and the curriculum, but you have also developed some tools that the advocates use to go about their business. Could you tell me about those?

Karen Mercereau: It was very apparent from the very beginning that communication is, to put it politely, fragmented. There are financial reasons for that. In the presence of the very high number of deaths and mishaps due to preventable medical errors and in the presence of misdiagnoses, which the Institute of Medicine has reported to be up to 12 million a year,ⁱⁱ it became very apparent that doctors need the most complete and accurate historical information on their patients. There was nothing out there like that, so I started creating this back in 2003.

It started out as a simple timeline, and it has now evolved into this amazing tool called a MEDiKEY. Physicians love it. They can sit in their appointments and read this while they are asking questions. ER doctors truly wish everyone had one. I cannot tell you how many times I have heard that. The MEDiKEY itself is a tripartite tool. The first part has 2 sections. One is the highlights from our intake, which is actually based on Mark Hyman’s protocol—systems biology and functional medicine. Our intake is extensive. We pick the highlights from that and

then we give a chronology.

Now, keep in mind that iRNPA are experienced clinical nurses. We know what doctors need to know and we know what is wheat and we know what’s chaff, so we go through the record and we pick out all of the very specific highlights that physicians need to know.

IMCJ: When you start working with a patient, are you doing a specific interview with that patient or are you gleaning all this directly from tracking down their fragmented records from all over?

Karen Mercereau: Both. I have gone back 40 years. I want everything. Typically, our intake is about 2.5 hours long. Then, we go through the records, which takes a lot longer. I can take a 6- or 7-inch stack of records—and that is not unusual for an older person with multiple chronics—and I can turn that into 5 to 6 pages, including the intake. And it is written in medecalese. Lay people would have a hard time reading it. Doctors and nurses can just look through and they see everything that they need to know. Of course, if they wish, we have got the raw data. We will send whatever they want, but that is requested very rarely, because they do not have time.

The second part is called lab trends. Lab trends are the selection of what lab values are essential for a physician to know regarding the clinical presentation. We take all of those different lab values and we trend them out over the years. First of all, nobody has time to plow through records and try to see the scope beyond the past 2 months of lab progression. We lay it out in this beautiful format, showing physicians: Here is an assay and what has happened over the past 5 or 10 years, and this one and this one. This is arguably one of the physicians’ favorite things about MEDiKEY, because it is visual.

The third part is my favorite. It is called the roadmap to health. We go system by system, state what the problem is, and ask all those questions that have never been asked. We teach people what to ask their physicians. This is a learning tool and it is indeed a roadmap. Systems biology is the loom on which we weave this. There are suggestions for additional physician consults, nutritional implications, supplements, medications, procedures, and everything that has never been considered that we, based on the systems biology and functional approach, deem to be important to be asked.

When a person actually goes through and does that, first, they come out a whole lot smarter and far more engaged in their own health care, and second, they see much greater health outcomes than they had before.

IMCJ: Has the program garnered support from professional or academic organizations other than the University of Arizona?

Karen Mercereau: We are endorsed by the American

ii. Please visit <http://iom.nationalacademies.org/Reports/2015/Improving-Diagnosis-in-Healthcare.aspx>

Holistic Nurses Association. We are a big part of the National Nurses in Business Association. I am talking to Laurie Hofmann in the beginning of the year about possibly partnering with the Institute for Functional Medicine. I am looking for as many connections as possible to spread this further and wider, because independent RN Patient Advocacy needs to happen.

IMCJ: How many advocates have been trained today and how far has the network spread?

Karen Mercereau: We are in 22 states now. iRNPAs are independent. I don't own them, although I keep in touch through the network. I have only taught maybe 160 or 170 nurses to this point. I started by getting the smartest and most experienced ones that I possibly could—RN PhDs, nurse practitioners—most of the nurses are master's-level nurses. We are pulling in the good ones. One of them, Karen Demarco, has created what is arguably the nation's leading innovative wellness program, which she is putting into corporations. There are so many things that can be done. Getting all of these smart nurses in one place through the RN Patient Advocate National Network at one time is fostering amazing changes. iRNPAs can do anything. This is pure nursing. We do not do hands on. We do not diagnose. We do not prescribe. Education is the central tenet. *Collaboration* is our byword. We are not bound by the politics and the economics of the clinical situation. We are not stuck in academia, which has many good points, but it is a slow-moving creature.

IMCJ: You have laid out some big-picture goals and where you want this to go in the future, so what are the next steps?

Karen Mercereau: First of all, I need to demonstrate to the insurance industry that everyone should have a MEDiKEY. That will save them money. You need to tie it all together, and it does. It saves money, prevents many medical errors and misdiagnoses. I want colleges of nursing all across the United States to be turning out qualified iRNPAs to work in as many creative ways in their own communities as possible and join together in the network. The network is a hotbed of ideas. We support each other in many ways.

IMCJ: You said that the rate for these services is \$100 an hour, so what are the costs to develop the MEDiKEY for a patient?

Karen Mercereau: Roughly \$1200 to \$1500. It will be less than that with some additional tools that we are working on incorporating. It takes a great deal of time. Not everybody wants a MEDiKEY, however. The advocacy process allows a great deal of latitude in how you work with the clients. If somebody does not want a MEDiKEY, then you can still do a roadmap or you can just do lab trends. The important thing is that you get a grasp of the

entire clinical situation and your client and what is driving them. What are their environmental exposures? How has that impacted their health? What is going on with them? Historically, what is their family background? What is their current social environment? All of those things. You have to get to know your patient really well and that is why our intake is typically about 2.5 hours and it is guided. We are not just having a chat.

IMCJ: I would imagine that even in 2.5 hours, you'd have to be very strategic about how you go about it or you're not going to get it all.

Karen Mercereau: Exactly. When insurance realizes just how much money we can save them, then that is the end of that problem. A typical patient, who you normally have from 1 to 3 months, can count on about \$3000, if they include the MEDiKEY.

IMCJ: That is a small amount compared to what the costs in dollars and losses in quality of life could be if misdiagnoses, unneeded procedures, or medical errors occur.

Karen Mercereau: This is very exciting for nurses. It certainly is for me. I am free, 48 years into it now. As long as I follow that advocacy process and work in a collaborative manner, I can make change and do it. This needs to happen. People are dying needlessly and that keeps me going.