Chapter 1: Developing a Research Program on Transitional Care

Kathleen -

I know for the last 20 years you’ve been working in this interdisciplinary model for the frail elders who are community based. Could you talk a little bit about the development of that model?

Mary -

So I had this chance then to continue this work about building new programs at Penn and innovative programs and still very much being engaged in this path of trying to figure out how to help chronically ill people in this country who were now faced with much shorter lengths of stay who were sent home with very little in the way of safety net. Many of them, you know had those five days and six days when they were just two months before the prospective payment system went into play, to work with the patients and the family caregivers to position them for success after discharge. Now we’re sending them home in two or three days, they still feel terrible, they have no idea how it is to really continue what was 24/7 care yesterday, now all of their responsibility is on them and their families to deliver today and still have positive outcomes.

So that became our work and we began an initially, not as a program of research, people always say how did you design this program of research, for me it was the first study I wanted to get funded, I wanted to get on this path, but the question we raised initially was could we improve discharge planning for this population, and have an impact on their outcomes after discharge. And we learned very quickly that you could. But we also learned that the impact on both their health outcomes and on reducing hospital readmissions was short-lived. It was not something particularly for a group of people that were of higher risk that was going to be sustained over time. And so we set as a, and I say we, this is a multidisciplinary team of nurse scholars, scholars from medicine, scholars from communication and health care economics, we set as a mission not just to fix gaps in care, which we call transitional care, but to figure out how to use an opportunity, called a sentinel event hospitalization to interrupt a chronic illness trajectory, the downward path for people who wake up every day with multiple complex chronic conditions. And so our next set of studies was designed to really say, could we really target a high risk population.

Individuals that who are coming into emergency rooms or hospitals every day and whom if we don't do something different that we are doing today, we'll fix them, we'll send them home, they'll be able to breathe better, but in two weeks or two months we can predict with great accuracy that they are going to be back in our hospital. And so our path has been to try to figure out how to really do something that impacts for the long haul the quality of lives of these individuals of their family caregivers, and at the same time, does something important for society, helps us to reduce healthcare costs. And so we've been on this through now, we're on our fifth NIH study, continually expanding the way in which the population we are bringing into the program, we are now focused on patients with cognitive impairment who are coming into
hospitals, we’re not just focused on just patience hospital to home, but on patients who are going from hospital to any site, long term care etc.

To really create a new model of care delivery for people in this country that is nurse led. It’s a team-based model and that will have a major impact on how people experience chronic illness as they live longer. And we’re all doing that, living longer with multiple chronic conditions. So that's been our journey. It's been extraordinary. It didn't start out with us knowing exactly what we were going to do but it resulted from us being open to everything we learned along the way. We always have randomized clinical trials, but we always used a qualitative approach to understand the stories of these patients and their family caregivers because it is in the stories that we understand what the real experiences of these patients and family caregivers are. It's in the stories that we understand the barriers and the challenges that even the best nurses, who are very clinically and systems savvy, confront in trying to do something good, something right for people and their family caregivers. And it's in their stories that we've been able to make the case for policy change. That's our journey so far, not over, not over.

Chapter 2: Translating Research into Policy and Practice

Mary -

Our mission, our goal as I said, was so in my lifetime, in our team's lifetime, was to make a difference, was to have an impact. Not interested in just the papers that sit on the shelves in all of our wonderful journals and yet we couldn't figure out, with what we had found, why people weren't running to change. I mean these were consistent findings in rigorous studies, published in all the best places that had no impact whatsoever. And so we did begin a journey and honestly it was a journey of many failures, many many failures along the way. We decided to, partner with our office of technology transfer at Penn, to say… which the office of technology transfer group takes ideas generated from science… scientists, usually around drugs, or widgets, and creates business opportunities or opportunities to move them into practice and so we formed a partnership with them and over the course of I don't know how many years, we wrote I don't know how many business plans, I mean I literally have cartons of business plans, so if any of you need to know how to do it, I'm not sure we obviously knew how to do it, at one point the university invested $100,000 because we made the case to set up a business called “Transitional Care for Older Adults”.

We recruited… spent a year, building recruiting the president of this company. The president went off to generate venture capital and the venture capitalists recruited the president so the company failed before it even started. I mean it was unbelievable the numbers of things that didn't go right. So I will tell you it's not the easiest path at all. So then we kept saying, “Who out there will get this? Who out there will not only see that this is good, the right thing to do but also will see the business case, in the vernacular of the day, that will see that we should grab this because it's going to do something in terms of our own mission and value. So there was a dinner at Penn one evening and Jack Rowe, who was then president of Aetna, was seated and I got myself seated right next to Jack Rowe. The reason I thought he would be really important is he's a geriatrician. And I thought if anybody's going to get it, both from the world of clinical and understanding the issues that the beneficiaries and family caregivers are facing, and also as a business model he would.
Within a week, now mind you this is after years of things not working, and I could tell you unbelievable stories, but anyway, within a week he had his medical director, Randy Krakauer, who was a director of all Medicare beneficiaries at Aetna, down to talk with us and within a couple of weeks we were able to start a partnership funded by many foundations… Our program officer Mary Jane Coran of the Commonwealth fund which was the first group to fund us, said bring around the table in an advisory group everyone you want to influence. People from advocacy groups, so we brought AARP, people from CMS because we don't pay for this approach to care, people from the state because in which we were going to translate it because of their are regulatory barriers to doing this, etc. etc. So other insurers, other health care systems, and we did. Kaiser Permanente joined as a partner and we began an effort to roll out this approach to care and collaboration with Kaiser as well as Aetna along the way. So at the end of this what we were able to show, the Aetna work is complete is that you could replicate what we had learned in clinical trials in the real world. That you could improve the care and outcomes of Aetna's beneficiaries and that you could save money.

So that becomes a really great case to bring for policy change. And I would say that I've spent pretty much the last year on the Hill, back on the Hill, doing the thing I love, trying to convince policymakers to include provisions in the healthcare legislature related to transitional care. We testified in front of the Senate Finance Committee on a group around health system design, we had legislation introduced in the House and Senate, the Medicare Transitional Care Act, introduced first in the house, companion bill in the Senate that still exists and we have… were successful in getting a number of provisions in the current final healthcare legislation that focus on care transitions, on the need to measure it, on the need to create incentives for it. There’s a provision for $500 million to target hospitals that are really struggling in terms of hospital readmission rates, to figure out how to improve it. So we're not all there yet, we are I think at a beginning. I do believe that the new Center for… Innovation Center in Medicare and Medicaid is going to position us beautifully to continue to implement the approaches to care that are so driven by nurses. In redesigning our health care system in the future, but that was our path.

**Chapter 3: The Future of RNs: Leading Care in Communities**

Kathleen - What do you think are the major issues facing healthcare today and what are they for nursing?

Mary -

Well as I think many of you know, I'm sure all of you are glued to C-SPAN over the last several months etc. So you've seen a debate unfold in this country that is very much grounded in different values. And I see what happened with the patient protection and affordability care act as a beginning. It created the critical access to 32 million Americans who do not have insurance to have insurance. It created access for people with pre-existing conditions to now be covered and to feel safe. It did not at all, or only minimally I should say, tackle the issues around cost containment, and around assuring that we maintain quality as we're moving to achieve cost containment, bending the cost curve. The Medicare program is still predicted to run out of resources in 2017, 2019, someone told me in a meeting yesterday… Tuesday that 2015 as the result of the vastly aging of our population, the baby boomers, longevity, many people with multiple chronic conditions who will be needing our services and we don't have the resources. So for me it represents an enormous beginning, but a beginning that we as a profession are in the best position to take advantage of.
I think everyone in this room, every nurse across the country should become very familiar with every provision in that act. And every opportunity that it affords nurses working in collaboration with other team members to participate in. There is no greater match between the needs of our population today and into the foreseeable future in the areas of population health, prevention of chronic illness, risk management, better management of chronic illness, when it occurs palliative care, end-of-life care, these are, this is our domain, not absent physicians and social workers and others, but in collaboration, in the community, and in for which we have both evidence and the basis and history and socialization as a discipline to take advantage of.

So this is your opportunity. We need everyone to become very fully informed about the opportunities. We need at local levels, because lots of what's going to be happening in the future is going be at a local community level. And you are all part of communities. And you need to be an active player as accountable care organizations are being built, as your health system is figuring out how to reduce hospital readmissions or take advantage of bundled payments…hospitals are working with home care agencies or skilled nursing facilities, nurses are the bridge. Nurses are the ones that can holistically look at what the experience is like for these patients and family caregivers and really effect the kind of change that improves quality and reduce costs. Nurses are in the position to redesign a care delivery system that is much more aligned with people's needs, with family care givers needs. You must, must, we must, take full advantage of every opportunity to do so.

Chapter 4: High Quality Care –Every Time

Kathleen -

Can you talk a little bit about the strategies that you’ve thought of that nurses and the nursing profession need to undertake as we move into this new world of healthcare reform?

Mary -

I'm going to say something because I think this is a really on the one hand our best opportunity and I think it's our best challenge. I think that every nurse needs to work to the highest performance level. One of the challenges that we faced in the profession is a public, is when the one hand says, “We trust you more than any other group”, we constantly receive this. On the other hand, in my community and I suspect in your community and in your circle of friends, you hear people who say, I don't want to go into that hospital or leave my loved one in that hospital because I don't trust the care that's being delivered. And I think that the biggest challenge we have is to promote our own sense of accountability for delivering the most reliable, consistently high performing care that we can do. I think that requires each of you to begin, and I'm not talking... this is the audience that is already doing this, but I am talking about you are working in environments where there maybe some of your colleagues are not performing at the level that they should and we need to figure out how to change that so that every person coming into any part of the health system, a patient going to a nurse led clinic, patients coming to a heart failure clinic, in any context in which they're coming, into contact with nurses, consistently walk away thinking, that person knew what they were doing, they were responsive to my needs, I trust the care.
So we need, as a profession, to commit ourselves to the highest performance standards and to assure that we deliver them all the time. So that's number one. The second is we need to position ourselves to take much greater advantage of the opportunities going forward and some of that will be in terms of what happens in educational programs. I think we need major reform, in our educational programs to prepare nurses to deliver care which is in the course of teams, which is caring for patients over time across systems which are caring for people as they ebb and flow in terms of their illnesses etc. It is highly collaborative, it... they see themselves as the point person, the broker of care for patients and families etc.

So we need to figure out, both in our own educational programs, but also for those of you that are out there now, how to quickly position us to be able to take advantage. A simple thing you can do on this bill... is I went to that kind of Google... Thomas website and I hit “care coordination transitions” and it runs out every opportunity on care coordination and transitions. Every one of those opportunities is calling for a different skill set that many of us have today. So we as a profession and you as individuals have to think about how do I get myself positioned to become a really high-quality deliver of care that is continuous, that is really... engages families and patients, that is really... places a premium on continuity. Some of the skills that we haven't spent as much time... so I'm thinking that there are many opportunities both at a local level within your own health system and across the profession to take advantage of this.

Chapter 5: The Importance of Prevention

I want to return to the issue of prevention. From a policy perspective secondary prevention is about managing disease after it has already occurred, as well as acute exacerbations. I'm wondering how you foresee policy and partnerships developing between the business sector and the world of the nursing profession in terms of that prevention, that is if business actually sees prevention as a money making opportunity, at least at this juncture. The issue is about managing disease after it's already occurred.

Mary -

Right. This is a really excellent questions and I think that there have been a number of studies which suggest that we still haven't made the business case for prevention. You know, I mean, In a society that prides itself on all that we do in other worlds to make people give high quality of life, you would think that just having a high quality of life as a result of an investment in prevention is a good enough return. And I think businesses are awakening to this there's much more understanding now that if I invest in an employees, and in fact Safeway and many other organizations have made major investments in prevention in partnership with health professions that have shown a yield, a return. Much more productive employees, these companies have begun to look at how I can help not just the employee but the employee who is the caregiver of somewhat at home for whom they might come to work, I forget what that term is when you're there and you're not there. In terms of productivity, but the productivity goes down dramatically.

American businesses lose $34 billion a year as a result of people either not coming to work or coming to work and not being present. And doing their work because of... because of chronic illness, either they have it or they are caring for a loved one. So we’re beginning to see, with all of these factors, purchasers of health care, employers, beginning to wake up to say, well maybe if
you don't actually have the business case for prevention that I know if I invest in “x” screening, I
do know that if I promote a healthier lifestyle I going to have a more productive employee or
employee who is happier with their life and that is going to give me a greater return. I'm going to
have an employee it's not going to be using as much of my benefits for acute services etc. So I
think things are turning, the national business group for health has really been making a play to
try to have much more attention in benefit programs around prevention, to have much more
employee-based preventive services accessible right away, so I think we’re moving slowly and I
think that partnership with businesses is exactly where we need to go.