

Quality Care Conference 2013 Transitions of Care Summary

11.18.13

Introduction and Regulatory Background

Andrew Howard, MD; President, Forum of ESRD Networks

The National Quality Strategy has evolved rapidly over the past 5 years. There was a landmark publication in the NEJM in 2008 by Thomas Bodenheimer “Coordinating Care - A perilous journey through the health care system” which described the challenges and inherent flaws in navigating our health care system. In that same year Dr. Donald, Berwick brought his vision developed with the Institute for Healthcare Improvement (IHI) to the National Quality Forum (NQF) embodied in his statement that “we must fundamentally change the ways in which we deliver health care”. That year, the NQF convened the National Priorities Partnership (NPP) and articulated the National Priorities and Goals in a publication; “Aligning Our Efforts to Transform America’s Healthcare”. The Three Aims were the pillars of the NPP: Better care, Healthy people and communities, Affordable care. The Principles were: Patient centeredness and family engagement; Care for patients of all ages, populations, service locations and source of coverage; Elimination of disparities; Alignment of public and private sectors.

In 2010 the Affordable Care Act became law and required HHS to develop a National Quality Strategy. Dr. Berwick was nominated as the interim administrator for CMS and in March 2011 the Priorities for the 2011 National Quality Strategy were established in collaboration with AHRQ. These included the 3 Aims noted above and 6 priorities which included Making care safer; Patient and family engagement; Coordination of care and effective communication; Promotion of best practices in communities for healthy living; Making quality care affordable by developing new healthcare models. In September of 2011 the Partnership for Patients was established; it is a public private partnership with the goals of making care safer by reducing hospital acquired conditions and improving care transitions by focusing on reducing 30 day hospital readmissions.

In April 2012 in its 1st annual progress report to Congress, CMS identified 3 strategic opportunities; a national strategy for data collection, measurement and reporting; develop infrastructure at the community level; develop payment and delivery system reforms (value based purchasing). In October 2012, the NQF convened the Measures Application Partnership to have uniformity of measures for all payers to allow consistency in gauging performance and outcomes and reduce the reporting burden on providers. There is currently a focus on 4 topics including safety, care coordination, CV conditions and diabetes. The 2nd annual report to Congress was released in July 2013 and focused on the importance of alignment of measures across all reporting programs and identified aspirational targets for measures within the 6 priorities.

Subsequently care coordination has been a theme running through CMS initiatives. As of 2013, CMS framed the 2013 ESRD Network SOW based on the National Quality Strategy.

Healthcare as Organized Chaos

Jeff Permuter, MD; Chair, MRB ESRD NW 5, MAC (Medical Advisory Council of the Forum of ESRD Networks) member

Identifying Barriers in Care Transitions Physician perspective; It is really disorganized chaos

Dr. Perlmutter described the birth of the MAC transitions workgroup that will develop a toolkit for ESRD care transitions. At the spring 2013 meeting, the MAC identified a large number of transitions that ESRD patients experience, many of which are unique to ESRD. Most care transitions revolve around the dialysis unit; the sheer numbers of transitions in and out of the dialysis unit dwarf any other venues. His perspective is that transitions need to be managed through the dialysis unit.

He gave a recent example of a patient who missed dialysis on Friday and was admitted to the hospital that day, very ill with sepsis. Three specialists, including the inpatient nephrologist, saw the patient, and she was dialyzed on Saturday. All the inpatient doctors saw the patient in the morning on Sunday. On Sunday afternoon, the patient left the hospital AMA with no antibiotic prescription or instructions; the hospitalist but not the nephrologist was notified that the patient left. Blood cultures drawn at the time of admission were subsequently positive. Since her outpatient nephrologist generally sees patients on the 3rd shift on Mondays, but the patient dialyzed on the 2nd shift that day, he did not see her when he rounded. He looked up her record on the hospital EMR and found the positive blood culture report. Fortunately the organism was sensitive to an oral antibiotic which he then prescribed. Two days later, on Wednesday, the dialysis unit received a fax from the hospital with recommendations for ongoing antibiotics. The problems were additionally compounded by language barriers and difficult communication with the patient's family. This was another case of a "perfect storm". The nephrologist who saw the patient on Sunday did not know that she left the hospital; the dialysis staff at the dialysis unit on Monday was not the usual staff and did not realize that she missed her last outpatient dialysis and was hospitalized; the patient and her family were not proactive. If her outpatient nephrologist had not accessed the hospital EHR, he would not have known to prescribe antibiotics until later in the week and the patient would have likely have been rehospitalized. Fortunately the patient survived.

Maribeth Sommer, RN, CNN VP of Clinical Services, Davita

Hospital Transitions Challenges of the ESRD Patient Nurse/Facility perspective

The dialysis center also has many challenges including the patient who is new to the unit or who comes from a visit to the ED or to a doctor visit. In many settings, the dialysis unit is not in the information loop.

With a new patient, the dialysis nurse often sees a patient who does not understand what is happening and frequently has just a temporary access. The patient and family are scared and overwhelmed. They may not even know that dialysis is a chronic therapy. They experience fear of the unknown, possible

death and feelings of hopelessness. They don't know much about medical insurance coverage and are concerned about the effects on employment. They have multiple medical appointments that have been scheduled but often don't even know why. There are lots of beeps and alarms going on and the unit seems chaotic. They do not have a single point of contact or detailed communication. They were often given lots of written information and even videos pre-dialysis, but at a time when they were scared and unable to process it. The first nurse who successfully connects with the patient and makes the patient feel better will be the be-all and end-all for the patient and will be identified as the person to communicate concerns and questions to the doctor. In this setting, the patient becomes dependent on caregivers not only to assist in but to drive key health care decisions.

So how do we approach the patient and family? How do we create a safe environment and start the conversations about modality, access and adjustment to dialysis? How does the facility prevent hospital admissions?

Communication and education are critical in the first 3 months of dialysis. The dialysis unit becomes the patients' health care home.

Q&A: How are transitions being addressed in the provider community? Davita, for example, has 1st 90 days program to address nutrition, access, knowledge about options, etc. But the emotional impact is hard to measure. Question is how to engage and how to measure engagement.

Maggie Carey; Chair of the BAC (Beneficiary Advisory Council) and NW 11 Consumer Committee Chair

Organized Chaos? Patient perspective

Introduction; Ms. Carey is the second of 4 generations of polycystic kidney disease (PKD) patients. She has a long term functioning transplant. Her mother died while on hemodialysis and her 11 year old granddaughter was recently diagnosed with PDK. As a person with ESRD, she has the same issues that other people have, including family/employment/aging/dogs that can't be housetrained/difficult kids - plus the burden of kidney disease.

Patients deal with multiple transitions. Most of the data we see is specific to hospital admissions and readmissions. But ESRD patients deal with frequent and unending transitions. Many transitions are unique to ESRD - modality, staffing changes, provider changes, hospital to unit, etc.

Importantly, the provider and patient perspectives are different with regard to transitions. She gave the example of her transition from hospital to dialysis when she began dialysis.

From the provider perspective, everything went smoothly; it was a textbook uncomplicated transition.

The patient perspective was much different. She had a bad infection, was hospitalized for 6 weeks, and required a nephrectomy for a severe infection. While she knew dialysis was in her future, and was an educated bright person, ESRD occurred 10 years before it was anticipated. She was terrified. She had

watched her mother die on dialysis. She internalized the fear, unlike those who externalize it and become hostile and aggressive. Her quiet panic was not recognized by her providers; when she was asked how she was, she always said “okay” but inside she was falling apart. She had 2 dialysis sessions in the hospital before discharge. The hospital gave her lots of information in the form of print matter and videos about ESRD treatment but she could not absorb it due to fear. She had to make a choice about modality in the middle of all this fear. She was “fortunate” enough to know about the options but was “bone” scared. A RN offered her a glimmer of hope at the right time by telling her that her 90 year old father was on home dialysis and could do it despite being blind. Things could have been even worse had someone not said the right thing and given her some hope. Then she was discharged but before she got to her scheduled dialysis, the dialysis unit changed her schedule. She became terrified that she would die due to not getting dialysis soon enough and did not know who to call for help. When she got to the unit, things were chaotic and unfamiliar. She got moved around, passed from one person to another. It was the first time she had been around groups of people on dialysis. There were buzzers, alarms and people running around. There were patients who were failing and it seemed like others were moaning. She saw young woman with bumps on her arm – and decided she would never have a fistula. The patient in the chair next to hers had large bandages on her neck following a parathyroidectomy, so Maggie was afraid her neck would also be slit. During this time she went back to work, 9-5, and went to the dialysis unit in the evenings. Finally someone from the home dialysis unit came in (Lee), sat with her, held her hand, and said she would take care of her. Lee made the arrangements for a PD catheter, educated her, made frequent contacts, and stayed with her at each step. Maggie still felt trepidation but not fear since she had Lee.

What made the difference between the two transitions? The difference between the two transitions was like night and day though they were only 3 months apart. It was hope that held her together; because a 90 year old blind man could do it, she could do it too. When Lee held her hand so she had an anchor, and she started feeling better and was able to process better.

Q&A;

Comment to Ms. Carey; the experiences were diametrically opposed because she was informed and engaged in the 2nd one, unlike the first one. Response; there are times when a patient is incapable of being engaged. But when possible, engagement is important.

Comment from a provider; this is an important reminder that what we think went well really may not have gone well at all.

Question to Ms. Carey; would it have helped to have had a patient to talk to? Response; another patient may have credibility that helps with the fear.

Question; what is Ms. Carey’s approach to other patients? Response; Listen to the patient. Listen, find out what their values are, and set your own value system aside. Don’t tell patient how they should do it or what should be important.

Richard Formica, MD Yale University

A Model to Overcome Transition Barriers in Transplantation; A QI Initiative that Improves Access to Kidney Transplantation

Objectives;

1. Review disparities in access to transplantation
2. Discuss barriers to access to transplantation by racial and socioeconomic groups
3. Review Yale's approach to solving these problems

History of the initiative; when he started at Yale in 2007 he found that there were 150+ patients who had presented for transplant evaluation over several years but no decision had been made as to eligibility.

Background;

Access to transplantation varies among subgroups; it is the process of getting listing that determines disparities in access to transplant.

The Final Rule states that allocation policies shall not be based upon the candidate's place of residence or place of listing. It should be based on sound medical judgment. Once on the list, allocation of a transplant is blind to patient differences in race, religion, gender, disease process or economic status. Once a patient is listed, prolonged listing time contributes to greater dialysis exposure with more comorbidities and higher mortality. Shorter wait times lead to better outcomes even when one factors out other patient characteristics.

So what is required to have access to transplantation?

- Availability of a transplant center
- Knowledge of the benefits of transplantation by patients and providers
- Referral to transplant center
- Obtaining an appointment for transplant evaluation in a timely fashion
- Transportation to the center – very important
- Support system

The conventional wisdom is that access to transplant is defined as whether one gets a transplant once one is listed; he contends that access to transplant is a really a matter of access to getting listed since once one is listed, the disparities are no longer important. If not listed, there is no opportunity for transplant at all. We need to rethink about access to transplant as the access to becoming listed rather than whether you get transplanted once listed. Patients do not accrue waiting time until they are listed, and under the current system this is independent of how long they have been on dialysis (rules through 2014) and patients do not accumulate wait time until they are on dialysis.

Variables that have been shown to inhibit access to timely referral include lower educational attainment, lower socioeconomic status, not native English language, minority race, female gender, for-

profit or isolated dialysis center, obesity, and certain diagnoses including diabetes. Once referred, being health illiterate and poor leads to longer time before being listing.

In 2005 the time from referral to listing was more than 200 days nationally. We can't blame primary care for this. There are disparities in the time from starting dialysis to being listed for incident ESRD patients that depends on race, gender, socioeconomic and educational levels and nonprofit vs for-profit dialysis centers. In a 1999 study, Ayanian found that African Americans who voiced the desire to be transplanted were less likely to become listed than Caucasians who voiced the same desire. More highly educated patients get on the wait list faster and are transplanted. Once transplanted, poor and uneducated patients do just as well as their more affluent and better educated counterparts. Incomplete workups are more common among minority racial groups (African American, Hispanic, Native American). However, an article by Epstein in the NEJM in 2000 showed that Caucasians were more likely to be transplanted if even if the workup was incomplete or the patient was inappropriate for transplant.

What about pre-emptive transplants? The odds of being waitlisted are less for African Americans, Native Americans, diabetics or older patients. This holds true for patients followed by nephrologists, not just those who were not referred to nephrologists pre-ESRD.

Process of listing;

UNOS requires that a transplant center has minimal listing criteria but does not specify what they should be. Yale did not want to lower its minimal listing criteria. In many centers, getting through the hoops necessary to get listed is used as a measure of compliance – e.g., getting an ultrasound, finding and seeing the cardiologist, etc. But Yale decided to do the whole workup at the first referral appointment, making a fundamental change in the listing process.

It took time to make the plan work. They initially hired an outreach coordinator who educates patients one on one and helps with risk management. Now they have a coordinator just to do risk management. Physicians travel and educate providers. Yale also developed a one day workup so that the evaluation could be done quickly and the decision to list could be made in a timely manner.

Planning the intervention meant they needed to maintain listing criteria, reorganize resources, develop a set of preferred consultants (made sure not to offend existing consultants – it took 1 ½ years to develop this part of the process – they traveled to every dialysis unit to get the okay), dialysis day treatment center utilization, and take ownership of the process. What do to with the positive cardiac stress test? – depending on the referring providers, interventions could be done at Yale or the patient could be referred back to the community providers. Cancer screenings such as colonoscopy cannot be done the same day.

Intervention outcomes; 905 patients, 378 conventional workup and 527 patients post intervention, retrospective analysis. They did a financial analysis of Medicare/Medicaid vs. private insurance patients because of the need to make sure it was financially feasible for the hospital. 2007 was the point of change.

There were a larger number of older patients in the intervention group, not a surprise given the aging of the ESRD population. Over all there was a significant decrease in time to listing in the intervention group, including a reduced time to listing in patients with Medicare/Medicaid only. They looked at those with Medicare/Medicaid only as a surrogate for financial status. They also found that the one day workup equalized the time to listing for patients with different educational status and race. The mean time to wait listing fell to 46 days and there were fewer patients who never got listed. Race fell out of the equation. From the hospital's financial standpoint, the number of encounters with the Yale medical system increased and the intervention generated more revenue which defrayed the increased nursing costs for the institution.

Was the change durable? Yes. Jan 1 2010 through December 31, 2011.

Limitations of the analysis; retrospective, nonrandomized, single center. There was no comparison with another center as control. They were unable to draw conclusions between reducing listing time and reducing dialysis related morbidities. The financial analysis was limited to Medicare/Medicaid.

Conclusions;

Disparities in access to kidney transplantation are well established.
Center-coordinated intervention reduces listing times.
Listing time reduction is beneficial across socio-economic groups.
One day workup requires a fundamental change in approaching the listing process.
This is likely exportable and able to be tailored to other institutions.
We must rethink how we are doing things.

Q&A;

Comment from a nephrologist; Patient engagement; in the old system, engaged patients who had the where-with-all got the workup done. Response; this process took away the idea of engagement as a measure of compliance. Cancer screening is the hard one to do on the same day.

Question; Query about a patient who was denied because of the lack of family support. The patient in question is very independent but lost a previous transplant through no fault of her own. The transplant center would not consider her due to lack of family support despite having a successful transplant previously for 15 years. Dr. Formica discussed some of the challenges that exist with lack of support especially as patient's age.

Question; Centers often use measures of adherence as a consideration in the listing decision. Is there data re: adherence post-transplant? Do we pay too much attention to these surrogates? Answer; Outcomes have improved despite getting older, sicker patients. He thinks the best tactic is asking the social worker and physician at the dialysis unit about adherence.

Question; Why is it that hospital based units have higher referral rates than non-hospital based units. Answer; There are different factors in different areas. He does not think there are conscious decisions about referrals and that no one conspires not to refer patients.

Pre-emptive transplant question; 18% of the Yale patients are pre-emptively transplanted, largely living donor. It is rare to get a cadaver kidney pre ESRD. The bigger question is how to get early referrals. 30-40% of the Yale referrals are pre ESRD.

Comment regarding the new policy (after 2014); Waiting time will be defined by when you are listed with a eGFR less than 20% or will be dated back to the day of first dialysis.

Question: Was there pushback regarding using consultants other than those used by the patient's nephrologist or PCP? Answer; It took time and effort to establish the program. If interventions needed, the patient referred back to their community physician(s).

Panel Discussion Models to Overcome transition barriers

Jean Moody Williams, R.N., MPP; CMS Office of Clinical Standards and Quality, Director, Quality Improvement Group. Panel Moderator

We have heard the history of the National and CMS Quality Strategy. Once the Affordable Care Act (ACA) was passed, the Secretary charged HHS to develop the National Quality Strategy as a public-private undertaking. All of the agencies across HHS came together to create the Strategy. The message was heard from many providers that many activities needed alignment as opposed to having different expectations from different agencies. Each agency was charged with developing a quality strategy, and it has taken over a year to develop a CMS Quality Strategy, based on the National Quality Strategy, with the input of selected stakeholders including the ESRD Networks. The draft is now with the Office of the Secretary for clearance and hopefully will go out for public comment soon. The Aims are better health, better care and lower cost. The Principles are to enable innovation, foster learning organizations, eliminate disparities and strengthen infrastructure and data systems. The Goals are to make care safer, strengthen person and family engagement, promote communication and coordination of care, promote effective prevention and treatment, promote best practices for healthy living, and make care affordable. We are determined not to let the Strategy sit on the shelf; note that the ESRD Statements of Work are based on the Strategies, as are the QIO Statements of Work, the value based purchasing program and measurement redesign.

The culture requires commitment and action and testing. PDSA cycles, measures are critical.

Teresa Casey; CMS Office of Clinical Standards and Quality, Division Director EPCH (ESRD Population and Community Health division)

Ms Casey presented the broad view by reviewing national programs aimed at reducing hospital readmissions and improving transitions between care settings and the community. She wants to pique interest in learning more about the initiatives and consider how to connect for benefit of ESRD pts.

CMS has many tools or levers in order to push quality of care forward. She highlighted HHS and CMMI, high tech, readmission payment policy initiatives as well as ESRD Network and QIO initiatives.

There have been many federal initiatives since 2006; there are many more now aimed at improving care transitions and hospital readmissions. CMS now appreciates the importance of including providers and community collaboratives. She highlighted many of the Federal initiatives since 2006, as well as the decline in 30 day readmission rates over the past 7 years from 62 to 52 readmissions per 1000 beneficiaries. There were 3 early QIO special studies that were critical to understanding the barriers to care transitions. There is now a much more robust set of initiatives aimed at care coordination and reduction of preventable readmissions.

Highlighted National initiatives; the Office of the National Coordinator (ONC) patient engagement framework is a model to guide health care organizations in developing their patient engagement strategies via the use of ehealth tools and resources. It is intended to be a roadmap to engaging patients as partners and moving along the continuum of the meaningful use of technology. See reference;
[www.nationalehealth.org/ckfinder/userfiles/files/NEHC_Patient%20Engagement%20Framework_FINAL\(1\).pdf](http://www.nationalehealth.org/ckfinder/userfiles/files/NEHC_Patient%20Engagement%20Framework_FINAL(1).pdf)

Payment policy;

As of fiscal year 2013 CMS reduces payments to hospitals with high readmission rates within 30 days for AMI, CHF or pneumonia. The plan calls for public reporting of readmission rates. In 2015, three additional diagnoses will be added including COPD and THA/TKA (total hip or knee arthroplasty).

CMMI has numerous initiatives. In conjunction with the Partnership for Patients, there is a collaborative initiative that targets a 40% reduction in preventable acquired conditions and a 20% reduction in preventable 30 day readmissions by the end of this year. Initiatives under Partnership for Patients include hospital engagement networks, community based care transitions programs and patient and family collaborative efforts.

Financial models to support state efforts for dual eligible patients; CMS is testing 2 payment models to integrate primary care, acute care, behavioral health and long term care for dual eligible patients. There is the new ESRD seamless care model to test the effect of a coordinated system of care with appropriately aligned financial incentives using Pay for Performance methodology.

For more information re: CMMI efforts, see; <http://innovation.cms.gov/initiatives/#views=models>

QIO program; 2008 – 2011 CMS piloted interventions in 14 QIO communities. CMS evaluated whether improved care transitions are associated with reduced hospitalizations. Results were positive in reducing hospitalizations and rehospitalizations. Interventions included community organizing,

technical assistance and monitoring of participation, implementation effectiveness and adverse effects. Now all 53 QIO's are engaged in care transitions work.

The Community Based Care Transitions Program (CCTP) falls under the Partnership for Patients. Launched in 2011, it tests models for improving transitions for high risk beneficiaries and allows the transitions work to continue for at least a 5 year period. There are 102 communities participating.

High Tech initiatives; 3 special innovation projects (Minnesota, Colorado , Pennsylvania) have special projects looking at improving communications between hospitals and long term post-acute care settings. The project targets moving away from paper based information exchange.

ESRD patients; admission and readmission rates are much higher than for the general population; 30 day readmission rates are 34% vs 18% for the general population. This presents a huge opportunity for improvement.

Network tasks; Care transitions can touch every task of the Network SOW. Aim 1 addresses better care for individuals which includes access to incenter dialysis, vascular access management, patient safety and healthcare acquired conditions. Aim 2 (better health for the population) presents opportunities to consider care coordination and transitions; the aim is to improve dialysis care coordination with focus on reducing hospital utilization and improve transplant coordination

Question for further thought – how do we smash barriers as patients move between providers and within their communities?

**Shiree Southerland, PhD, RN, BSN; CMS, Center for Clinical Standards and Quality, Quality Improvement Group
Integrating Care for Populations and Communities**

Ms. Southerland gave a brief Overview of the QIO program with a focus on care transitions, care coordination and how the QIO program can collaborate with ESRD networks and dialysis facilities. The 9th SOW included a pilot program that involved 14 community projects and was very successful; with the advent of the 10th SOW care transitions programs were spread to all 53 QIO's. The aim is to improve care transitions as well as reduce admissions and 30 day readmissions nationally.

What are care transitions? Care coordination and care transitions are not the same though the terms are often used interchangeably. Transitions are defined as the movement between providers and locations, as well as levels of care as patient needs change. What are the QIO's charged with under this AIM? What have they been doing? One of the primary things has been community coalition formation. How is that done? Most in the community have the same aims, but how do you bring them together around a common theme? How do you identify the problem? Why do patients get readmitted? The first thing to do is community specific root cause analysis – QIO's can assist with this. Even communities next to each other may have different readmission drivers. Medication

reconciliation is a big cause of transition failures across the board. There are unique factors in ESRD patients. QIO's can help communities apply for funding and help with intervention and measurement.

QIO's are working with over 400 communities nationally to improve transitions of care. Stakeholders must be convened and interventions tracked at a community level. As of September 2013, 92 dialysis facilities are engaged in projects. The projects include more than 14 million patients, 878 hospitals, more than 1600 SNF's, 957 home health agencies as well as individual providers and other institutions.

How can QIO's and dialysis facilities collaborate? Participate with local care transitions communities; find a nephrologist to be a Physician Champion, share tools for QI, Care transitions and Community Building with each other. Utilize learning and action networks (LAN's). There needs to be lots of work around interventions and measurement. The ESRD community is encouraged to be active in the LAN's. Check out resources;

Learning sessions, archived; http://www.cfmc.org/integratingcare/learning_sessions.htm

Toolkit: <http://www.cfmc.org/integratingcare/toolkit.htm>

Cynthia Kristensen, MD Forum of ESRD Networks Past President, current Forum BOD and MAC member; MRB chair Network 15

ESRD Patient and Provider Perceptions of Care Transitions

At our Quality conference last year, we initially thought that an important product coming out of the conference would be a form that could be used when patients transitioned from one setting to another; this was naïve. There are a lot of unique transitions in the ESRD world. There is massive work being done by the QIO's on transitions but there is a lot more that we need to look at than readmissions, and there are data that are not captured that likely cause admissions, readmissions, non-adherence, poor outcomes and poor quality of life.

The Forum BAC is creating a patient centered toolkit that will address some of the issues of transitions. The Forum has a MAC committee that is, with the help of the BAC, creating a care transitions toolkit for use by ESRD facilities, providers and patients. We began with a nonscientific survey of MAC and BAC members and associates and asked questions about how many of those transitions are perceived as being challenging, unsafe or important. We had responses from 28 patients, 15 physicians and 9 RN's. For patients, the transitions that were most challenging included moving from transplant to dialysis and transitioning from pediatric to adult care. For providers, the most challenging transitions included hospital discharge to the dialysis facility and transfer from a SNF to dialysis. Perceived safety threats included nursing home to dialysis transfer, changing facilities, changing dialysis staff including staff turnover or even changing dialysis shifts. Patients perceived modality changes including the transition from transplant to dialysis as very risky. Patients were less likely than physicians to perceive the transfer of care from hospital to dialysis as being unsafe. Patients also commented that travel is

difficult and potentially risky. One of the problems is that some dialysis facilities will not take a patient with a catheter.

Almost all the transitions were considered important by both patients and providers; most of the transitions are unique to ESRD.

Comments from patients included fear of medication errors at the hospital, confusion because of conflicting advice by different providers, not being listened to by medical professionals, not knowing who to contact with questions or problems and lack of preparation for returning from transplant. Most were concerned about medication errors and providers who don't know much about ESRD. They perceive poor transition preparation between modalities and that there are many barriers to travel.

Providers were most concerned about information transfer and medication reconciliation. They commented on the lack of critical information, the fact that other providers make inappropriate medication or diet changes and don't communicate, HIPPA misunderstandings between hospital and dialysis, that patients don't know why they were hospitalized, poor communication regarding medications, hospitals don't notify nephrology providers and hospital personnel do not know what the dialysis facility can or cannot do (e.g., what antibiotics are available or can be administered per regulations). Also of concern were the poor transitions from transplant back to community nephrologist and lack of patient preparation for dialysis following transplant failure. There is poor medication reconciliation at all levels.

We divided transitions that occur within the ESRD world – for example, the first dialysis treatment, modality changes, changes in staff, pediatric to adult care - and those that are between the ESRD world and other settings. There is poor communication between almost all settings, lack of understanding regarding ESRD patient needs by non-ESRD providers, and lack of communication. The dialysis unit is the default medical home for many if not most patients. Medication reconciliation is a major concern at all levels.

There are also significant IT challenges including the lack of access to the numerous IT systems that are utilized by outside providers especially hospitals and the fact that dialysis EMR's are not designed to be complete medical records, do not interface with other EMR's and do not meet meaningful use standards.

Conclusions; ESRD patients experience numerous unique care transitions; patient and provider perceptions of challenges and safety may differ; information systems have major short fallings; we have limited understanding of what lead to readmissions and hospital admissions/readmissions often are unrelated to what happens in the facility.

Renee Garrick, MD Two hats; Renal Physicians Association representative and member of the local ESRD Network MRB; the other as the Executive Medical Director and Vice Dean Westchester Medical Center and the Medical Director of a DCI dialysis unit

Enhancing Safety in Kidney Patient Care

Dr. Garrick describe the characteristics of the dialysis facility for which she is the medical director; 110 patients both in- center and home dialysis, affiliated with an large academic medical center, has both beds and chairs (unusual), has nephrology fellows who rotate through the unit, 10% patients live in SNF/assisted living. They have tracked hospitalization for the last few years. 8 months of data presented.

Data; 64 patients were hospitalized (both fully admitted and observations), 36 had more than one admission, often to more than one hospital. Total of 127 hospitalizations including observation stays. There is no common EMR between hospitals. There were 14 different hospital care sites, over 100 different providers. 26% of admissions were just 1-2 days. 27% were 3-5 days. Patients were in 9 different SNF's. Data included 24% readmissions, and a number of admissions from the hospital to a SNF or assisted living. There were 5 deaths not due to admissions per se. One important finding was that "observation" patients may have more risk due to short stays – very different (incomplete) transition information was provided to the dialysis facility.

Her facility has a transition of care communication tool and the dialysis nurse will not resume dialysis without it. The tool is helpful but does not really solve the problem; they have particular problems with SNF/Assisted Living Centers and medication reconciliation. The dialysis facility was not a part of the hospital discharge information transfer and nephrologists are generally not the PCPs of record. The hospitalists and nurse practitioners were not always knowledgeable about ESRD patient medication needs, drug dosing, medication interactions, diet, etc. Now the protocol is that the dialysis RN contacts the SNF; they use a HIPPA compliant communication book for each patient transferring between dialysis and a SNF, and the SNF and dialysis facility share all information including all the hospital discharge information. There is also a phone call between the SNF and dialysis RN for any significant information. They found that paperwork alone did not work. When a patient is discharged to a SNF, the SNF RN and dialysis RN communicate by phone. Each patient goes back and forth with their book which is updated by the nurses.

Medication reconciliation remains a key source of error. The average number of medications is 16+ per patient and the nephrologist is not the physician who directs the hospital discharge. A lot of information was being missed. They worked with hospitals to have medication list reviewed by a nephrologist (they have fellows or physician extenders onsite in many of the hospitals) and then faxed or otherwise sent to the facility at the time of discharge. In her dialysis unit, all medications are re-ordered at time of readmission to the unit. Every medication must be cancelled and all medications re-ordered. While this has been very time consuming, the process has definitely helped. They are working on getting pharmacists routinely involved in the transitions between the hospital and dialysis unit.

She additionally commented that dialysis units should not be penalized for readmissions; the dialysis unit is often out of the loop and readmissions are due to events out of control by the dialysis facility.

Q&A;

Question; How often does an outside physician call you when a patient arrives or is being discharged?

Answer; As an example, a patient went to a hospital a little further away than usual, was admitted on Thursday, missed dialysis on Saturday, showed up at dialysis on Tuesday. It turned out that she had been hospitalized in another city, had a cardiac catheterization with a stent placement and no data was sent to the nephrologist or dialysis facility. So now they have a card for each patient on which the nurses report events that happened between treatments. Discharge information is still very difficult if the patient goes to a remote facility; they are working with case managers at the hospitals to get them to call the unit when patients are hospitalized.

Audience member response; physicians still have the professional responsibility to make the call and provide communication. We need to do everything we can.

Additional response from Dr. Garrick; We pulled the acute inpatient nurses into the mix. The acute nurses actively try to find out who is in the hospital and can help facilitate information transfer.

Lou Diamond MD (audience member) comment; Discussed “Blue Button” technology. This was developed at the VAH, adopted by ONC which is pushing it. The idea is that it downloads information that is owned by the patient and exists in the Cloud, is owned and operated by the patient, can be accessed when the patient goes to another provider. It could replace much of the proposed interoperability challenges between EHR’s.

Maggie Carey Patient representative, Chair of the BAC

A Patient’s Perspective

Ms. Carey described an unexpected barrier to successful transitions; Value systems – provider, patient, family – which are not congruent. Patient and family value systems are seldom fully aligned, and there is misalignment within the family. Providers must figure out who values what and what values are in play.

Second barrier; Patient Mind Meltdown; this involves anger, shame, fear and depression. The meltdown is the inability of the patient to understand or retain the simplest things and or communicate to provider. The patient is unable to identify what his or her own fears and concerns are. She or he does not understand their own emotions and can’t separate all the panoply of emotions. Do not underestimate the impact of shame. It crosses gender lines but there are differences in the genders. One can’t control one’s own bodily functions (e.g. vomiting), can no longer keep up the usual roles (e.g., men no longer able to provide for the family and are no longer physically strong). Physical appearance – tubes sticking out, bumps on the arm – may be a particular issue for women. There is a perceived loss

of sex life. Significant others may be afraid that they may hurt you. Patients will not open up about sexual issues to providers in general. It is a barrier to moving forward.

How do you identify value systems? You must sit and chat. What do you like to do for fun? What do you miss, what do you want to do when you feel better, what are the goals that you want to work toward? Don't take notes! – The patient's fear is that it will go into the permanent record. Help patients work toward their goals. Family involvement; talk to family away from the patient if you want to know what the differences are in the patient and family goals and value systems. You may get different answers from patients and families. The decisions you make as a provider may be different depending on whose goals you are looking at. Don't try to align the value systems. Point out that the values are not shared. The patient has different goals than the family or the provider which may pose a barrier to smooth transitions. It is important to help patients identify goals.

How to deal with a Meltdown. What patients are seeing is different than what the provider looks at. Am I going to die, will I suffer, and what will it look like – will I look foolish? If you can identify the overriding feeling, you can deal with it. Anger; do not minimize the feeling. That will make it worse. Validate the feeling– there is a lot of sadness. Give patients something to do, go for a walk, work with the cognitive side of things. Do you think it might help if ...? Validate the fear, do not brush it off. Yes, you are in a dark place right now but there is light at the end of the tunnel. Provide patient stories for light at the end of the tunnel. Peer mentoring and buddy system programs can be very valuable. Patients go for patient stories as opposed to all the science and medicine information. With regard to patient programs for mentoring and buddy systems; find something that works for your unit and is sustainable – find something that is not too much of a burden on the patients who are doing the mentoring.

Shame; identify it as a barrier that must be addressed because it is a barrier than can get in the way of a transition. Do not verbally identify the emotion as shame – that makes the patient feel even worse. Find social networking groups, local support groups. There is less shame if you are one of a group than if you are isolated.