

Models to Overcome Transition Barriers

As presented by Maggie Carey, ESRD Forum BAC Chair
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I would like to talk for a few minutes on a couple of the Transition Barriers you may face in relation to patients and give you some ideas on how to overcome them. One may be unexpected, and the other will probably be all too familiar to you.

The Barriers

The Unexpected Barrier is the Patient's Value System and, in some cases, the Family's Value System. In both cases the biggest barrier may be in not understanding and identifying with their individual value systems. And in many cases the value systems of the patient does not align with their family's value system. So you may be working with three or more value systems depending on how many care providers are involved in the situation.

The Expected Barrier is the all too familiar "Patient Mind Meltdown". It is the failure on the patient's end to comprehend or remember even the simplest instructions. And there is often an inability to effectively communicate with the care team.

This inability on the patient's part to communicate with the care team is often an inability to identify fears or concerns. If a patient can't identify what strong emotion has them in its grip, they really can't confront and control it. And that crippling, or at least "stunting", emotion could be Anger, Depression, Fear or Shame.

Don't underestimate the part shame may be playing in the equation. We are faced with a LOT of shame surrounding ESRD:

- Inability to provide for our family any more
- Inability to take care of some basic physical needs like bodily functions (vomiting evacuation, etc.) or just plain getting out of bed in the morning.
- Unattractiveness - we have tubes coming out of strange places and a perceived loss of our sex lives.

This last one, the loss of our sex lives, can be a real heart breaker for a lot of patients and I have seldom seen it addressed. I don't even know how it should be addressed. But what I DO know is that it is hard to feel attractive with tubes and needles and catheters and bandages. And it is hard for your significant other to overcome the fear of "hurting" the one they love in some way.

If you ASK a patient how things in “that area” are going they will probably say “fine”. What that often means is “we don’t do that anymore” which is a far cry from “fine”.

The Tools

So, on a practical side, how do you identify a Value System? It is actually pretty easy. For the patient, you just sit down beside them and chat. Ask open ended questions:

- What do you like to do for fun?
- What do you miss doing right now?
- What would you like to do when you are feeling better?
- Do you have any goals you want to work toward?

Don’t do it with a clip board in your hand that can be intimidating. And ask questions to prolong each topic. “Engage” the patient and get to know them as a person. This will give you a pretty fair idea of what is important to them and it probably won’t be a certain Kt/V or hemoglobin levels of less than 10 g/dL. Here is you have to set aside YOUR Value System and concentrate on identifying theirs.

Identifying Family Values is done pretty much the same but do it away from the patient if possible and look for areas where there is a substantial difference. This will show that there is a discrepancy between their value systems and that the decisions surrounding care transition may be substantially different depending on whom you are listening to.

Don’t try to align their value systems. This is an area of family dynamics you don’t want to get into. But maybe you can point out that their values are not shared. Just recognize that this exists and may pose a barrier to a smooth transition.

Okay, now on to dealing with Patient Mind Meltdown. And I know you have ALL seen this time and time again. The first thing you need to know is that we are using a different filtering system than you are. Everything we hear, read, or see is filtered through:

1. Am I going to die?
2. Is it going to hurt?
3. Am I going to look foolish while it is happening?

All three of these filters can result in a myriad of emotions that we can’t even identify and I don’t have the skill set to advise you on identifying all of them. But if they manifest in such a way that you CAN identify them, here are some ideas on how to deal with them.

Anger

Do NOT try to minimize the anger (“calm down”, “it’s not that bad”) Doing so will only intensify their need to PROVE their anger to you. Instead, recognize it and validate it (“Yep, I bet you ARE pissed off. I would be to. This is really awful.”) As soon as you validate it, they can stop trying to prove it and you can start moving on toward solutions (“Do you think it might help to . . .” or “Have you considered . . .”)

Depression

Clinical Depression is outside of my ability to address. But plain ole’ Sadness can be addressed like Anger. Validate it (“You look so sad . . .” and “Do you want to talk about it a little bit?”) and gently lead on to a cognitive step or two that might lift them out of the “bad place”. Often helping someone else can lift you out of sadness but that can be risky. Sadness can be very contagious so don’t have them help another patient. If they can give YOU a hand at something, that might be effective.

Fear

Again, validate the fear. When appropriate do NOT underestimate the effectiveness of human touch. Take and stroke their hand while you are talking. (But don’t try this if you are not a genuine “touchy, feely”. We can spot a fake as quickly as a two year old and it won’t go down well.) Point out that this “place” is a tunnel, not a cave. There is light at the other end. Point out and provide Patient Success Stories, they are what pulled me through my dark places. And try to align them with a Peer Mentor or a Buddy who has successfully gone through whatever they are dealing with.

Shame

Overcoming the barriers created by Shame is kind of like Depression and this is above my pay grade to deal with. But if you identify it as a barrier and you need to address it, you are halfway there. Personally, I dealt with all of the shame issues and it was mostly because I couldn’t control what was happening TO me and WITH me. That was a very foreign feeling to me. What I CAN say is do NOT verbally identify the overriding emotion as Shame. That is just enough reason to be ashamed. This is probably another instance where other Patient Success Stories may be your most effective tool. Shame is very isolating. There is less shame if you are one of a group.

And whatever the emotion is that is creating the barrier, often just a smile and a nice little chat will help. It may not resolve the situation, but it can at least help.

