

Religious Needs of Dialysis Patients and their Families

ECRSH 14

May 23, 2014

Barbara A. Elliott, PhD, MDiv, BCC

Charles E. Gessert, MD, MPH

Background - Dialysis

- 500,000 end-stage renal disease (ESRD) patients in US
- 350,000 on dialysis
- 23% annual mortality (~100,000)
- 24% of deaths of dialysis patients are preceded by termination of dialysis

Projected number of ESRD deaths in the U.S. (in thousands)



Termination of Dialysis Prior to Death – Local & National

Year		SMDC Sites	US
2004	Deaths	65	74286
	Terminated	35 53.85%	17840 24.02%
2003	Deaths	86	73783
	Terminated	42 48.84%	17263 23.40%
2002	Deaths	72	71112
	Terminated	31 43.06%	16478 23.17%
2001	Deaths	75	68093
	Terminated	38 50.67%	15360 22.56%

Background – How and why do patients make dialysis decisions?

- The decision to discontinue dialysis is
 - “highly individualized and is influenced by culture, religion and family” – Lewis Cohen 2007
 - “...an existential problem” – Kulbir Bajwa, 1996
- Predictive models are weak

Methods

- Need for qualitative work
- Older dialysis patients; family members
- Interviews in homes
 - Recorded, transcribed
- Analysis by three co-investigators (medicine, sociology, nursing)
- Nodes, themes

Subjects

- 27 dialysis patients; 31 interviews
 - 21 interviews with dialysis patients
 - 10 interviews with family members (7 children, 3 spouses)
- Dialysis patients: mean age 80.6 (70-100)
- Dialysis patients: 15 male, 12 female
- Dialysis patients: 27 White
- 15 of 18 who could respond considered self spiritual person

Findings:

Religious Themes and Practices

- Medical Decision Making
 - Faith-based beliefs
 - Meaning from beliefs
- Coping
 - Religious practices
 - Perceived community support
- Spiritual pain

Beliefs: Dialysis = Gift from God

- *God gave people the wisdom to do that too, so I believe those things are from God.*
- *I believe that if we are living in God's will, there isn't always just one choice that's right...and that extends into medical choices too.*
- *Ya know, I think from a faith standpoint, I see dialysis, kidney dialysis, as a life support. And I personally from a faith standpoint, I don't have any problem with taking away life support.*

Beliefs: A Time to Die

- *Well, I know we're only on this earth for a specified period of time. As I grow older, I know I'm getting closer to that magic day.*
- *I think our view is that when your life is over or it should be over (slight chuckle and then very sincerely), it's time to go to heaven.*
- *I think she was tired out. She was done. She was ready to go.*
- *My preferred way would be that she pass in her sleep, and that it's totally in God's hands.*

Beliefs: What comes after Death

- *It doesn't bother me, I still believe in my church, and feel that I'm going somewhere better, hopefully.*
- *[I] believe that there is goodness and kindness out there. Yes I do, and that there's more than this life.*
- *I'm just looking forward to the passing away and going to heaven. That's the most important thing in my life.*
- *My mom and I have talked many, many times about faith and heaven and spirituality...I think there is no question in her mind she will be joined again with her dad, my dad, and watch over our little boy for us until we can be there.*

Meaning: ESRD

- Meaning was grounded in their beliefs about God's role in their continued survival and their dying.
 - *I think that's the blessing. With most things that happen.... there is what you do with it...*
 - *I'm not very orthodox in my religious views but, that doesn't stop me from saying 'Thank you for unexpected wonderful things that have happened.'*
 - *Well I think it strengthened my belief in God, and my reliance on Him, and my overall outlook on life.*
 - *We think God cries with us over our sorrows and that He is there to ask for strength.*
 - *And God blessed her with more good years when we were able to...do a lot of things with her.*

Meaning: (Dis-)Continuing Dialysis

- *Both/And*
 - *INTERVIEWER: "...Can you see any connection between your faith and your decision or your attitude towards your dialysis?"*
 - *PATIENT: It's [Dialysis is] part of my life. It's not against my religion to give up. And my faith is strong.*
 - *INTERVIEWER: It's also not against your religion to have the dialysis? PATIENT: No, no it's not."*
- *Fear*
 - *Ending dialysis: "I have no worries about it. Not at all. Yah...if you have that [faith], there's nothing to fear. No fear of death."*
 - *Continuing dialysis: INTERVIEWER:" Let me ask about how religion, how your faith, has helped you with it all. PATIENT: Yeah, I'm not scared at all. But I still want to live."*

Religious Practices: Prayer

- Community: *Yeah, it's been helpful. They've prayed with me, and I know a lot of them were praying for me.*
- Relationships: *I do pray with my mom...thanking God for our mom and what a great person she has been.*
- Suffering: *I realized that those guys were just finishing up with their prayer session down there, and they must've been praying for her...M had gotten up and taken a bath, got dressed and swept the kitchen floor, and all of this happened by about 8 o'clock.*

Religious Practices: Liturgy

- *No, he never missed church. He might have forgot what he ate for lunch but, boy, he remembered every prayer, so he always went.*
- *Father F offered a great deal of support...and read him his last rites and everything.*
- *INTERVIEWER: Has a priest been involved?
SON: No, but he will be. My mom wants to have a priest.*

Community Support: Attendance

- *So I kept going [to church], and I needed somebody else to drive me, and I seemed like I managed to get somebody to pick me up.*
- *That's really good because they have a widow support group there [at church]. I belonged to it for a while before I was in the wheelchair.*
- *Her social life was mostly go to church every Sunday and...participate in some of the church activities, until she couldn't do it anymore. She would make a salad for a potluck, but that's about it. And then that stopped 6, 8 months ago.*

Community Support: Visits

- *When I was in the hospital, the interim pastor came to visit me several times, and he's been over here to visit me too.*
- *She enjoyed the visits when Pastor Mike would come.*
- *Father said that everything was fine, and it was...according to the church's beliefs...He understood the situation, and he told us...that we were doing the right thing.*

Spiritual Pain: 1

- INTERVIEWER: *“Could you help me understand a little bit how your relationship to your church helps you or how it doesn’t help?”*
- PATIENT: *“We had to fire our minister. He was breaking peoples’ confidence. And you can’t, you can’t tolerate that from a minister.”*

Spiritual Pain: 2a

- *[My parents '] minister was over...and as he was leaving, I said, "D, I just want to let you know that I'm gay. My partner is my soulmate. My mother has asked that both of us walk her down to the pew [at Dad's coming funeral]." I wanted him to recognize that, and let him know who this person is going to be, and how important she is to the family. I got a call a couple hours later from the minister. He wanted to talk to me and [tell me] ultimately what he felt he needed to say. He said "I think you know how/what we believe about your situation." --->*

Spiritual Pain: 2b

- *I don't need that kick at this time, but... I will do whatever my parents need. He [the minister] is coming over to offer communion. In my heart of hearts, I don't want to receive it from him, because I don't truly believe I'm being honored, but I will suck it up because this is their time...*

Conclusions: Faith and Religious Practices in ESRD

- Medical Decision Making:
Faith-based Beliefs and Meaning
- Coping:
Prayer, Ritual and Practices, and
Community Support
- Spiritual Pain: where beliefs and
practice collide

Conclusions: Clergy Role

- importance of clergy presence for
 - Discussions about faith-based beliefs and meaning
 - Prayer, ritual and sacraments
 - Liturgical Traditions
 - Connections to community
 - Discussions: church doctrine and views re: end-of-life care and decisions

Discussion Questions

belliott@d.umn.edu