Partners' Experiences of Daily Home HD Compared to In-center HD

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The Problem

- Patients—and potential partners—perceive that home HD will be a tremendous burden on partners
- Previous research dates to the days of standard machines & in-center schedules
- Updating perceptions could help improve pickup & retention for home HD

Approach

Study goal:

Explore lived experiences of partners of DHHD patients (for ≥ 1 year) who had been in-center for (for ≥ 6 mo.)

- Mixed qualitative & quantitative Methodology:
 - Participants approached by DaVita home training RNs
 - Participants called MEI toll-free number
 - Informed consent obtained by mail
 - Demographics and SDT questionnaire completed
 - Telephone interviews of ~ 1 hour
 - Participants received a \$50 honorarium

Analysis

- Each call audiotaped (completed)
- Verbatim transcripts prepared (completed)
- Transcripts analyzed thematically using NVIVO software (underway)
- Demographics compiled (completed)
- SDT survey results analyzed using SPSS (underway)

Partial Coding List (Will Guide Themes)



- Independence
- Confidence
- Learned from prior challenge
- Compassionate
- Mastery of other domains
- Purpose/meaning
- Spirituality
- Self-regard/care
- Positive relationships

- Personal growth/learning
- Relationship type
- Quality of relationship
- Dialysis experience
- Deciding on HHD
- Training
- Satisfaction
- Doing home HD
- Mastery & learning styles
- Barriers and facilitators

Demographics (n=16)

- Age: 3: 20-39; 7: 40-59; 6: 60+
- Gender: 4 male; 12 female
- Race: 9 white; 6 black; 1 Native American
- Education:
 - 5 high school
 - 6 some college/technical school
 - 4 college degree
 - 1 master's degree

Continuum of HHD Partnership

- "I just kind of had to sit there, while she was doing dialysis. Well, I have to be in the house. But, I mean, I can do whatever."
 Boyfriend
- "I do everything, from the setup, to getting him on, to cleanup, and, you know, ordering all the supplies, and keeping everything up. He just doesn't have the ability to do that." Wife

30,000 Foot View

- Women did more as patients & as partners
- Healthy relationships grew stronger; less healthy ones suffered
- Faith helped many people get through
- Travel easier for patients than partners
- Positive balance most partners felt their efforts were worthwhile

In-center vs. Home

- "The center we had to go to was an hour and 15 minutes away. So it was very, very exhausting for him, being in a wheelchair, recovering from a stroke, to get there and go through treatment, and then to get home."
- "It's [DHHD] very satisfying for me, because we are a team and we work for his health. We work together to get him a better quality of life. And it just gives me a lot of, I feel good about it. I feel like I'm really helping him."

In-center vs. Home

- "He would feel achiness, headaches, a whole range of different things. He would feel, a lot of times, very cold a lot. It made him like have the shivers, you know...worn out, run down."
- "It [DHHD] gives more energy, you know, does give us more time to be intimate. Whereas, with him not being there, of course, that wouldn't happen at all. More time for social, because we can fit other things in where we couldn't do it really before. We had to just either not go or I had to leave him home."

Conclusions to Date

- Caregivers want to know what to expect
- Negotiation of tasks is needed
- Relationship strength is a key factor
- Caregivers require sources of support