

Profiles of Successful Daily Home Hemodialysis Patient-Care Partner Dyads: From Mutual Benefit to Martyrdom

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Introduction

- Understanding and accurately communicating the benefits versus burdens of short daily home hemodialysis (SDHD) is key to
 - successfully recruiting patients and care partners
 - preventing dropout



Study Methodology

- 13 patient and care partner couples (dyads)
 - Completed at least 6 months of SDHD after at least 6 months of in-center dialysis
 - Assessed strategies for screening, training, and support to improve SDHD retention
- Descriptive statistics were used to analyze the survey data
- Grounded theory methods were used to analyze the interview data

Demographics

- The 13 dyads (26 respondents)
 - 9 married couples and 4 cohabiting heterosexual couples
 - 13 males and 13 females
- Age
 - Patients' mean age was 57.1 ± 15.8 (range 36-82)
 - Care partners (CP) mean age was 56.5 ± 14.4 (range 32-81)
- Ethnicity
 - 17 Caucasian
 - 8 African-American
 - 1 care partner of a Caucasian patient reported her ethnicity as "Other"

Results

- All patients reported better well-being on SDHD than in-center
- 4 dyad profiles emerged
 - Thriving (n=5) — patients and care partners are flourishing
 - Surviving (n=4) — strong couples are adjusting to challenges using problem-focused strategies
 - Martyrdom (n=3) — one partner defers needs and resentments to make SDHD work
 - Seeking another option (n=1) — patient is unwilling to burden an anxious partner

Success Stories: Thriving

Patient, African-American, Male, Age 36

“...You’re locked down to that 4 hour time three days a week, your friends are hanging out....and here I am, 5:00, 4:00 on Friday, headed to a dialysis unit. What a bummer! When you’re at home, you can build it around your actual schedule...I’ve got a lot of control back in my life. My energy level is up!”

Success Stories: Surviving

Patient, Caucasian, Female, Age 44

"I knew I would not survive in-center hemo. I had to sleep for 6, 7 hours afterwards. I could never, ever feel okay for very long. When you're ill like that, you don't see a hope. ...I was so very depressed. Even when I took antidepressants, it didn't help, because, physically, I was so drained. Now it's very minor. I'm always going to have some level of depression, because of everything that I've gone through and will continue to go through. But I feel a lot more hope. It has really made a difference in how I view everything. I can enjoy the day. I try to get out and do something every day."

Success Stories: Martyrdom

Patient, Caucasian, Female, Age 36

“Since I have gone on home dialysis, this is the best I’ve ever felt...I feel like I have a life again. I have energy to do things, and I want to go do things. When I was in the center, I just slept all the time. Emotionally, it was very hard. I was seeing people losing their legs, people dying. You know, you build friendships with these people. You’re talking to them, you’re sitting next to them. It was so hard going to in-center dialysis.”

Checklist for Successful Retention

- ✓ Ensure training staff “takes their time” and makes the care partners feel just as valued as the patients
- ✓ Use a mix of learning approaches
 - Big picture overviews
 - Summaries or “cheat” sheets
 - Demonstrations
 - Graduated hands-on learning with reflective exercises



Checklist for Successful Retention, cont'd.

- ✓ Conduct a home visit on the first day of treatment
 - This helps transition couples from the safety of the training center to the greater uncertainty of the home
 - The results from this study, conducted prior to Conditions for Coverage, showed that most centers attempted to provide this, but it was not always feasible for couples who traveled a long distance
- ✓ Provide step-by-step phone support in lieu of a home visit, if necessary

Checklist for Successful Retention, cont'd.

- ✓ Use a driver to deliver supplies to their dialysis room
 - Spare the couple the burden of carrying boxes from a front porch or garage to a dialysis room, often on a second floor
- ✓ Create a family atmosphere among the staff
 - Especially the nurse and technician

Study Conclusions

- Patients who were more likely to thrive regardless of dyad profile
 - Took on more SDHD self-care
 - Performed Self-cannulation
- Strong relationships tended to become stronger when faced with the new challenge of SDHD
 - Thriving couples approached challenges with open communication, affection, appreciation and compassion for one another
 - Surviving couples used problem-focused coping strategies to work on unresolved issues that stressed the individual's or couple's well-being