Communication and Identity: Patient-Caregiver Relationships in Dialysis Patients

Greg Zhang [1], Dan Weiner [2], Susan Koch-Weser [2], Keren Ladin [2,3]

[1] Tufts University School of Arts and Sciences, [2] Tufts University School of Medicine , [3] Tufts University School of Occupational Therapy

ABSTRACT:

- Studies show caregivers of dementia patients have weakened interpersonal relationships and higher burden.

- 10 in-depth interviews to informal caregivers of patients on dialysis (June-August 2015).

- Questions about communication between patient and caregiver, as well as how caregivers navigate and cope with the caregiver role.

- Openness and honesty, a retained social identity, and caregivers staying positive towards their patients had positive effects on patient-caregiver interactions.

- Informal caregiving for dialysis patients has the potential to strengthen interpersonal relationships by binding patient and caregiver together in a shared experience.

BACKGROUND:

The estimated value that unpaid caregivers provide to the healthcare system compared to other amounts of spending. As the baby boomer cohort reaches retirement, this number is only going to rise.

http://cdn.aarp.net/content/dam/aarp/relationships/caregiving/2011_07/420-caregiving-high-costs-chart.imgcache.rev1311021165261.web.jpg

AARP Public Policy Institute

METHODS:

Table 1: Caregiver Sample Characteristics

	In-Center Hemodialysis n=5	Home-based dialysis n=5
Age (years)	60.4 ± 8.44	64.2 ± 10.89
Female Sex	60%	60%
Race		
White	60%	100%
African American	40%	0%
Partner relationship with patient	60%	80%

Note: two of the home-based dialysis patients were on home hemodialysis, the rest were on peritoneal dialysis. All data are mean ± standard deviation, or percent

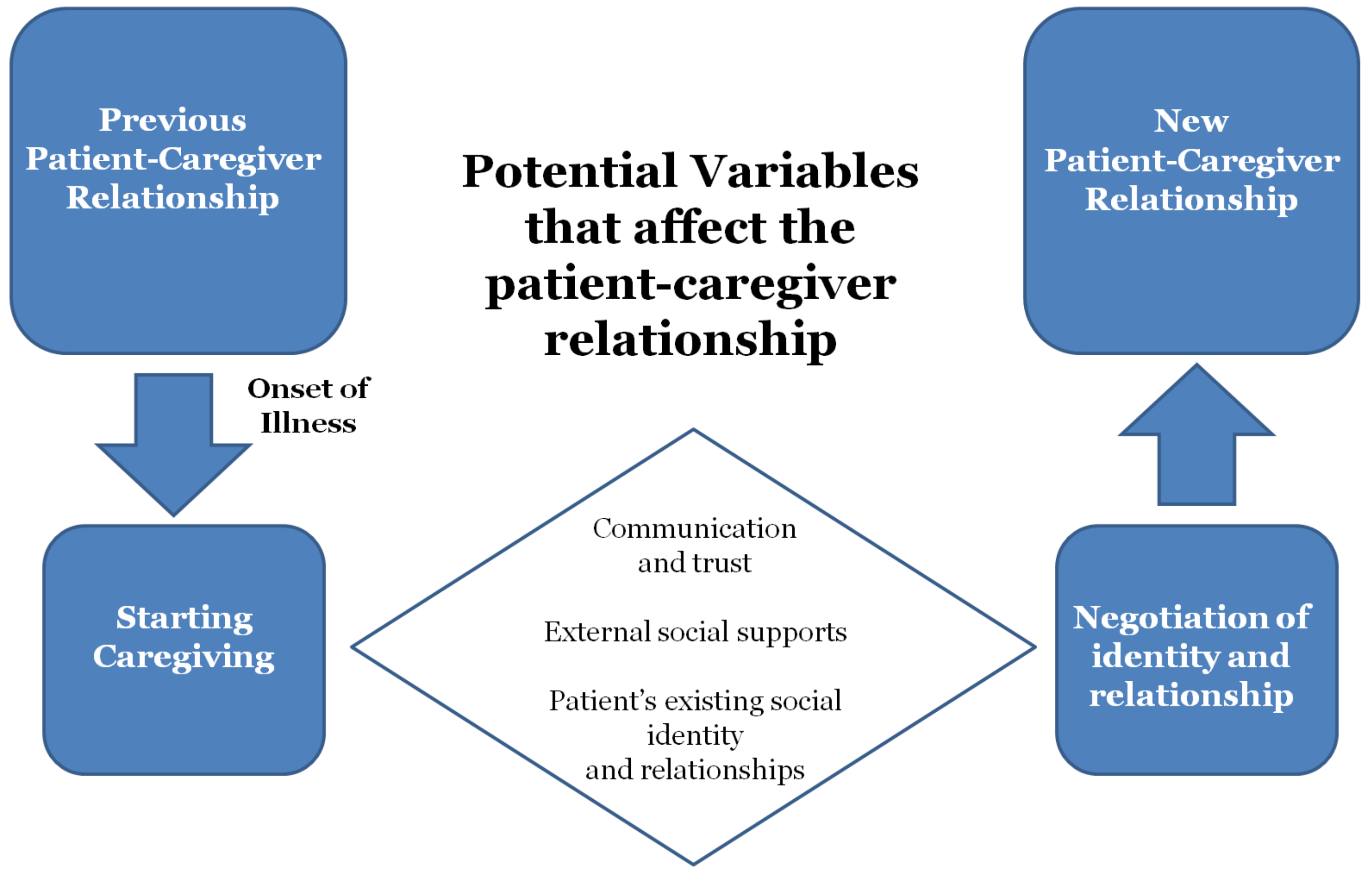
SELECTED QUOTES:

"[Our Relationship is] stronger, it's deeper, I think sometimes it can be on edge, it can be scary. **We've both admitted that we're both, we're both afraid of dying.** I'm afraid of living without him."

"One thing my father is good at, whenever I drive him to dialysis, take him to the store, do his grocery shopping for him, take him to buy clothes or whatever we do for him, he always makes sure to thank me, and say thank you, I'm fine with that. But that's pretty much the most rewarding, when he thanks you. **I'll be frustrated sometimes doing stuff with him but you know, when he says thank you, just taking him to dialysis or whatever else I do, that's fine.** That's reward enough. "

"**I try to avoid arguments but still deal with issues.** That's a hard thing to do for anyone. So, um, some of the negative sides of it are more difficult, are things that I wouldn't have to deal with if she didn't have, like things like, she gets tired, she'll be irritable, she might take it out on me, I'll point that out to her, she must be tired or something like that, but I um, try to not get irritable myself."

CONCEPTUAL MODEL:



Previous Patient-Caregiver Relationship

Onset of Illness

Starting Caregiving

Potential Variables that affect the patient-caregiver relationship

Communication and trust

External social supports

Patient's existing social identity and relationships

Negotiation of identity and relationship

New Patient-Caregiver Relationship

Figure 1: Conceptual model based on the data collected. We propose that how patient-caregiver relationships are renegotiated following the onset of illness depends on a number of variables of the relationship and the patient.

THEMES:

Openness, Honesty, and Vulnerability: Openness can lead to criticism and reveal trust weaknesses from patient, but also sets groundwork for strengthening the relationship.

Intact Social Identity: When the patient retains an identity that is sociable and easy to get along with, the caregiver has to provide less social support and actually gets social support from the patient.

Staying Positive: In response to patients showing signs of sadness and depression, caregivers focus on being positive to patients and trying to avoid negative triggers.

DISCUSSION:

- Dialysis caregivers we studied were caring for a more physical disease, rather than dementia caregivers. While many of them had to spend hours of their day assisting their patients with treatment and appointments, their patients were mentally competent and **maintained their identities and relationships from before the illness.**

- Caregivers were able to **rely on pre-illness social expectations and relationship guidelines** to fall upon. Spouses caring for their partners saw the process of caregiving as simply an extension of being together, while children were able to navigate a shift in the balance of responsibility by talking it through with their parents.

- When **patients expressed fear and vulnerability**, caregivers could provide comfort and express their own fears, knowing that their patients were **emotionally responsive** to their efforts. Several patients reported tense situations being diffused through honest heart to heart talks with their patients.

CONCLUSION:

- Caregiving, while a time-consuming part of life, can have a strengthening effect on relationships between patients and caregivers.
- Illnesses manifest differently, dementia or Alzheimer's caregivers might have much different experiences in their relationships with their patients.
- It is important to recognize differences in caregiver experience as we seek interventions to alleviate caregiver burden.

ACKNOWLEDGEMENTS:

Thank you to Anne Moore and the Summer Scholars Program for making this research possible. Thank you to Professors Keren Ladin and Susan Koch-Weser, as well as Drs. Dan Weiner and Klemens Meyer. Thank you to Emily Hahn for her assistance in conducting and transcribing the interviews.