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Coming Home: Care Transitions From the Perspective of Caregivers of Older Adults

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BACKGROUND

- With heightened interest around the study of care transitions, a key player often who is often neglected is the caregiver (Zakrajsek, Schuster, Guenther, & Lorenz, 2013).
- The caregiver is an integral member of a care recipient's team, and can have an impact on the overall success of the care recipient's transition home. (Coleman, 2003).
- Caregivers are essential to communicate with health professionals. They are also then required to provide the necessary care for their loved ones. With the vast number of roles that caregivers play in their care recipient's daily lives, this longitudinal exploratory study examined the unique experiences of informal caregivers of older adults transitioning from hospital to home in hopes to find where they can be better supported.

METHODS

Design

- Utilized mixed methods longitudinal approach

Participant Recruitment

- Recruitment was done at two hospitals in an ongoing inter-professional collaboration between Eastern Michigan University and the community partners from a large regional health system.
- Champions assisted with potential participant identification.

Time 1: (n=45)

- Face to face in hospital meeting
- Initial interview with basic data collection
- Researches recorded qualitative fieldnotes

Time 2: (n=29)

- 5 days post-discharge

Time 3: (n=22)

- One month post-discharge

Data Collection:

- Surveys completed online or via mail-in format
- Data recorded and cross verified

Data Analysis:

- Data was triple-checked for accuracy by research team before being uploaded to SPSS
- SPSS system was used to perform descriptive statistics and correlations between variables and over time.

LIMITATIONS

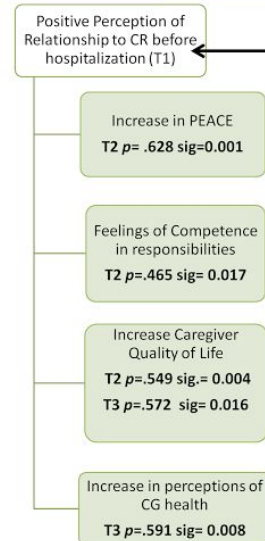
- Pilot study
- Small sample size
- Attrition rate =55.5%
- Length of study
- Delayed response times

RESULTS

Caregiver Characteristics n= 45	
Age Range/ Mean (Years)	Range: 29-84 Mean: 60.96
Gender	Female: 64.4%
Caregiving experience (months)	≤ 3 months: 34.1% 4-11 months: 6.8% ≥12 months: 59.1%
Relationship to caregiver	Spouse/Domestic Partner: 51% Child/In Law: 40% Grandchild/Great Grandchild: 8.9%
Ethnicity Time 2 n=29	Caucasian: 75.9% African American: 13.8% Prefer Not To Say: 10.3%

Change over Time in Characteristics Affecting Caregivers

Measures		Time 2 mean (SD)	Time 3 mean (SD)	t-Value and Significance
ZARIT BURDEN INTERVIEW (Short Form) (Bédard et al., 2001)		14.10 (9.61)	15.78 (12.43)	t= -0.42 p= 0.679
CAREGIVER RESPONSIBILITIES CHECKLIST (adapted from Brown & Dale, 2007; Reinhard, Levine, & Samis, 2012)	Number of Responsibilities	8.78 (4.18)	7.21 (5.37)	t=1.19 p= 0.247
	Competence	2.21 (1.18)	1.74 (1.26)	t=1.45 p=0.16
PERCEIVED SOCIAL SUPPORT FOR CAREGIVERS (Goodman, 1991)		11.10 (2.74)	10.47 (3.02)	t=0.66 p=0.516
ADULT CARER QUALITY OF LIFE QUESTIONNAIRE (Joseph, Becker, Elwick, & Silburn, 2012)		20.47 (5.03)	21.17 (4.86)	t=-0.41 p=0.685
RELATIONSHIP TO CARE RECEIVER		4.58 (0.50)	4.52 (0.61)	t=-.036 p=0.716



P.E.A.C.E

"Positive and Enjoyable Aspect of the Caregiving Experience"

- Measures:
- Role fulfillment/satisfaction
 - Joy around loved one
 - Pride in Role
 - Gratitude felt from Care Receiver
 - Positive Effects on other Relationships
 - Personal meaning in Role

> Strong internal consistency, with Cronbach's alpha = 0.82 <

PEACE correlations with Burden

Measures		Time 2	Time 3	t-Value and Significance
POSITIVE and ENJOYABLE ASPECTS of the CAREGIVING EXPERIENCE (Schuester, Silverstein, Zakrajsek)		Mean:16.2 SD (4.50)	Mean:16.5 SD (5.37)	t= -0.17 p=0.23
Correlation between Burden & PEACE	Time 2 Burden	r = -0.04 p = 0.838	r = 0.679 p = 0.001	
	Time 3 Burden	r = 0.155 p = 0.49	r = -0.550 p = 0.015	

DISCUSSION

- A prior positive relationship with the loved one before hospitalization may be more important to the caregiver's quality of life, health, role perception (PEACE), and competency with caregiving responsibilities than previously recognized in the literature (Zakrajsek, Schuster, Guenther, & Lorenz, 2013; Hooker, Grisby, Reigel, & Bekelman, 2015).
- Inverse relationship between time 3 burden and Time 3 PEACE only. Time 2 burden and time 3 PEACE have a positive correlation. The positive relationship may suggest burden as being both a positive and negative aspect for some caregivers (Huang & Peng, 2010).
- The study showed no statistically significant change over 5 days post-discharge to 30 days post-discharge in burden, caregiver responsibilities & competencies, perceived social support for CG, quality of life, or relationship to CR. This may not be a true representation of the population trends due to study's limitations.
- Higher levels of PEACE in the short- and long-term were correlated to more positive self-reports of health, implying the possibility of a relationship between PEACE and health (Huang & Peng, 2010).
- Supports previous findings that social support was important to a "successful" caregiver experience, with implications for caregiver health, experience of burden, and experience of the positive aspects of caregiving (Plank, Mazzoni, & Cavada, 2011).

IMPLICATIONS FOR OT PRACTICE

This knowledge may be used to improve the family caregiver's experience, potentially reduce hospital readmission rates, and inform best practices for health professionals, including occupational therapists, during transitions.

Occupational therapists should better understand that:

- Burden is complicated and not always a negative experience for caregivers.
- The social support caregivers have in transitions have a huge impact on many aspects of the caregivers' wellbeing.
- Experience with caregiving is not necessarily related to how competent they feel with tasks or amount of burden they may face.
- A perceived good relationship between older adult and their caregiver is important in fostering the more positive aspects of caregiving
- When working with older adults, it is important to set up their caregiver for success.

