

CAREGIVING IN THE REMARRIED CONTEXT

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Remarried Couples and Caregiving

- Extensive research has documented the intensive nature of spouse caregiving.
- Close social relations can be protective, but unresolved family dynamics can intensify stress when a couple transitions into a care relationship.
- Greater number of adults will enter later life with complex marital and family histories.
- Remarried /stepfamilies in later life and coping with disease are virtually unexamined.

Study Background

Study Goal:

- To provide expanded examination of AD spouse caregiving in remarried context.
 - Document the caregiving experience
 - Positive and Negative Support Network
 - Measure Remarried Caregiver well-being

Mixed Methods Approach

- Individual Interviews
 - Conducted by telephone
 - Scheduled at caregiver's convenience
- Survey measures and Open-ended questions
 - Demographic information
 - Detailed Social Support information
 - Experiences of caregiving, support
 - Health and well-being

Sample Description

- 55 completed interviews:
- Wife caregivers
- Age of Wives 65 yrs. (55- 84)
- Age of Husbands 76 yrs. (62- 92)
- Years since Diagnosis 3 yrs. (1999-2008)
- Years Remarried 15 yrs. (2- 28)
 - Wives: Divorced
 - Husbands: Divorced/widowed

Preliminary Qualitative Analysis

Remarried Spouses....

- Exhibit proactive approach to caregiving role
- Heightened Isolation in the Caregiving Role
- Report minimal support from adult stepchildren
- High degree of family disengagement / conflict

Proactive strategies...

- Quote:

“When we got his diagnosis, I went out and found all the information I could – on the disease, on services, on how to manage with all this. You’re pretty much alone with this, so I knew I was going to need help.”
- In-home assistance, respite, counseling

Isolation in the Role

- Quote:

“He has children – and they live 5 minutes away! But as far as they’re concerned, I’m one who should deal with all this. They say ‘just call us if you need us’, but when I do, they are never available. I think they see this as my problem. I’m the wife now, so I’m the one.”

“Unrequited” Support

- Quote:

“They just don’t come around. They don’t visit their Dad. They certainly don’t ask me what I need in terms of help, or even a little time off. They just don’t realize how hard this is. Oh, I’ve asked them once or twice to stay for a few days so I could see my grandchildren. Just to get a rest. But they can never do it. So, I have just stopped asking....”

Family Disengagement /Conflict

- Unresolved or ambiguous stepfamily relationships can add unique stress to the caregiving role: “Inherited family dynamics”
- Remarried caregivers attempt to mend distant relationships between husband and his children
“I don’t want them to realize too late”
- Most caregivers reported limited assistance, and a fair number refer to conflicts over finances, possessions, medical and long-term care choices.

- “Its hard for me to understand the dynamic- They give the appearance of being close, but it doesn't feel that close to me. They all agree to come visit their Dad . Well, it doesn't happen. I don't want to have to call. I asked (oldest stepson) to talk to his brothers. But I don't trust what's going on...But if their Dad didn't have me, they would be the ones doing all the doctor appointments....They count on me, but I can't count on them.”

Family Conflict

- Quote:
- “When I think of it, I realize this (family conflicts with adult stepchildren) has been the biggest stressor in the whole thing. I’m ok with caring for (husband). I chose that. But I did not choose to deal with these people. I’m expecting a law suit any day... how ‘bout that? And I’m the one caring for their Dad!”

Exceptions to the Rule....

- Quote:

“I’ve been lucky. I think they realize its lucky that I’m here , too. They have really stepped up. One son takes him to lunch once a week, and his daughter has even stayed here so I could go to a wedding. That kind of help has made all the difference... I think they feel closer to their Dad now, too.”

Next Steps in the Research...

- Continue to recruit more participants; especially husband and minority caregivers.
- Analyze qualitative data as well as the social network and well-being measures. Interesting patterns emerging....
- Conduct follow-ups with participants
- Conduct a 'core network' study of adult stepchildren and other family members.

Next Steps in Practice...

- Remarried caregivers represent an important example of “Complex Caregiving” ...
- Face potentially unique and increased risks.
- Research and intervention must move beyond a ‘nuclear family model’ to accommodate complex family structures.
- We need to tailor services to provide for family members who may not share an understanding of “the family” to improve our care of caregivers and persons with dementia.



Still Recruiting!



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