Safety vs. Autonomy: The Struggles of Adult Children Assisting Parents with Mild Cognitive Impairment

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ABSTRACT

The purposes of this qualitative analysis were to understand when, why, and how adult children decide to provide more intense support when a parent has mild cognitive impairment (MCI) and to identify gender similarities and differences in their responses to the new challenges they face. At Time 1 we interviewed 43 adult children (33 daughters) aged 27-65 by phone using semi-structured questions; 18 of them (12 daughters) participated in multiple interviews over 56 months. Analyses revealed perceived risks to parental safety as the main reason adult children stepped in to assist parents in new ways. Adult children struggled with balancing parental autonomy vs. safety needs. They were uncertain how much to intervene when the parent with MCI developed problems with routine independent living activities such as driving, finances, home maintenance, medication management, or meal preparation. Sons typically provided indirect support relating to financial planning and household maintenance, laterally supporting parents while focused on promoting long-term independence. Sons also tended to receive information about the MCI condition through the parent assisting the person with MCI. Daughters provided more direct nurturing support such as daily visits or phone calls to both parents as well as more immediate chores such as grocery shopping and transportation. Findings confirm that gendered patterns of assisting with MCI are similar to those found in other care situations. With MCI diagnosis, adult children struggle with transitioning into care partner roles and balancing parental independence while actively adhering to safety concerns.

PURPOSE

When older adults experience memory loss, family members often assume new roles as they and their relatives need additional care and support. If older persons are married, the spouse usually assumes the position of primary care partner and adult children often transition into the secondary care partner role.

The purpose of this study was to explore the secondary care partner relationship of adult children, and to investigate if, why, when, and how adult children provide extra support after MCI diagnosis. Furthermore, for those providing additional support identifying what specific care needs change, including overlapping care partner expectations and preferences, and the influences those changes have on interpersonal adult child-parent dynamics

METHODS

Sample
➢ 43 Adult Children (33 females; 10 males)
➢ Age Range 27-65 (M = 47.5; SD = 8.5)
➢ 81.4% live within 120 miles of parents

Data Collection
➢ Semi-structured, open-ended telephone interviews
➢ 1 to 3 interviews over 56 months

Data Analysis
➢ Multiple readings of transcripts, family notes, process notes; systematic charting
➢ Used open coding to examine, conceptualize, and categorize narrative data to generate a comprehensive understanding of themes and patterns; refined codes
➢ Compared responses across gender, interview occasions, residential proximity, and availability of siblings

OVERVIEW OF FINDINGS

➢ Adult children approach filial maturity as a process. At diagnosis, emotional support was offered in the form of phone calls, weekly visits, and social outings. Over time, as the parent becomes less able to conceal MCI manifestations, adult children move forth, addressing instrumental needs and safety, driving concerns, and medication management; all the while balancing parental autonomy within the power structure of the adult child-parent relationship.
➢ Gender was less important than proximity when increased support became necessary.
➢ Families with multiple children tended to divide parental care needs in relation to the supplemental care givers area of expertise, time availability, and proximity to parents.

CONCEPTUAL FRAMEWORK

Filial Maturity   *Parental Maturity*
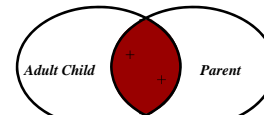
Adult Child + *Parent*

Care Expectations and Preferences

Filial Maturity refers to the reciprocal ability of adult children and parents to progress through developmental stages of the life course and negotiate supportive boundaries of mutual respect and choice. **Parental maturity** means parents accept adult children as adults, let go of previously established relationship rules, and move towards acceptance of help from them.

EMOTIONAL SUPPORT

Initial Interview
➢ All adult children provided emotional support in the form of weekly phone calls, visits, and advice.

"My contact with mom and the support that I've given… that's increased. We talk a lot more often, plus we do e-mail about three or four times a week. If they need anything, they let me know or if I ask them how things are going and find out there's a need, then I help out. My sister and I also communicate [regarding them] via e-mail probably four or five times a week too." ~Rory, 49

➢ Siblings often shared support responsibilities by means of divided vacations, visits, and social outings.

"There are 3 children that look after her [mom]. She's at lunch with my sister today. I will go over and mow her grass, and we have someone come in every night at about 5 or 6 o'clock to fix dinner and spend the night with her. All 3 of us children live less than a mile from her." ~Rick, 52

Follow-up Interview
➢Stress and frustration associated with MCI were reported as prevailing concerns for increased empathy.

"I am talking to him more because he really feels the need to complain about having to do everything. He's frustrated and he doesn't know what to do. I think because he's a man and has never really had to take care of anyone like that, and he just gets frustrated." ~Esme, 41

"My mother is very stressed. She feels like she has to take care of him all the time and watch him, what he does. She does not feel comfortable leaving him by himself, and I can understand that." ~ Ginger, 33

➢ When addressing MCI concerns, secondary care partners adjusted their communication style, providing additional support.

"I talk to my mother much more than I talk to my father about it [MCI]. I'm reluctant to, to bring them up. He occasionally will bring something up, but not very often, and he's not comfortable talking about it." -Holly, 44

"He's harder to spend quality time with because he gets on my nerves. I help them when he'll let me. Mom sometimes tells me things he needs done and he wouldn't ask me to do them, but I kind of have to go down there and say, well, why don't you let me do this right here? And kind of sneak and do things for him." - Hank, 49

INSTRUMENTAL ASSISTANCE

➢ Adult children's perceptions of their parent's need for help were associated not only with their parent's memory difficulties, but also their depressive symptoms, personality changes, and physical ailments.

"Dad was getting very mean and touchy. My dad is very laid-back, he is probably the nicest, softest, squishiest, teddy bear-of-a-person you've ever met, but he would just go off the deep end. It seemed like he was always very suspicious and he thought everybody was lying to him. But I think the pills [for depression] seemed to have taken care of that. He's back to being a much friendlier, nicer person." ~Kelly, 49

➢ Concerns about parent's ability to continue driving presented new challenges for the adult children.

"I see mom driving more especially when they are going out of town. We won't let him go out of town by himself. Those are things they told him not to do; drive places you know that he really wasn't familiar with, that type of thing. So, I think just the awareness is the main thing."-Kerry, 43

"He shouldn't be driving. I won't ride with him, and I won't let my kids ride with him. My sister and I have approached that several times, and my mom is very defensive and says, 'well, I have no problem riding with him. I've never seen any problem.' So, it's a touchy issue ." ~Stacy, 49

SAFETY VERSUS AUTONOMY CONCERNS

➢ Financial concerns prompted safety-boundary transitions.

"I have hired someone to handle their financial affairs because my dad has gotten too confused to handle his bank account, and writing checks, and paying bills and so forth. He has also forgotten and applied for credit cards and, and made a mess of the financial stuff." ~Valerie, 53

➢ Addressing parental independence and safety concerns was common across all interviews.

"I do think that when he moved from the independent living to assisted living, it was extremely difficult for him. It was kind of like a mourning loss. That was an extremely difficult year for him." ~Zeta

"Mom and Dad are doing okay other than he's frustrated with life every single day because it's not what they banked on in this point of life. I think they are going to have to find different living arrangements. He wasn't interested in that though, but mom is thinking more intelligently about it. So, I don't think it's something you're going to decide on a Friday and go ahead and do on Monday. It takes planning." ~Jeremy, 47

IMPLICATIONS FOR INTERVENTION

➢ Assess the degree of closeness in the adult child-parent relationships.

➢Identify areas of current conflict and process "carry-over" conflict.

➢Explore the care partner role, including real and perceived expectations and preferences of support.

➢Discuss allocations of familial roles, including gender-associated roles, age-related role changes, and cultural considerations.

➢Provide supportive education about the biological, psychological, and social aspects of aging. Discuss feelings of anticipatory grief and ambiguous loss.

➢Identify areas of stress, including safety issues . Validate the care partner role, highlight positive coping patterns, and provide alternative coping strategies.

➢Generate a list ideas to promote self-care. Discuss alternatives for, "caring for the care partner."

➢Provide community services information and options, including specialized geriatric services, support groups for care partners and care receivers, and respite care options.