

Supplemental Table 1: Interview Guide Key Topic Areas

Key Topic Area	Prompts
1. The overall experiences and responsibilities of caregivers across the disease trajectory	Tell me about how you began to care for your <i>relative</i> ?
2. Thoughts on the availability, effectiveness and use of supports received by the caregiver and care recipient across the disease trajectory	Can you tell me about any health care services or support services you used? Was there any other support given to you or your family member?
3. Any support, training or resources the caregiver would have liked to receive at any point in time	What wasn't available or wasn't something that you knew about, but that might have helped you?

Supplemental Table 2. Participant Characteristics

Characteristics	Total Sample	Wives	Husbands	Daughters
Age (mean, SD)	65 (11.9)	73 (4.1)	76 (7.6)	54 (5.5)
Income				
Less than \$35,000	5 (12.5%)	2 (20%)	1 (10%)	2 (20%)
\$35,000-70,000	17 (42.5%)	7 (70%)	2 (20%)	5 (50%)
\$70,000-90,000	8 (20%)	0	2 (20%)	2 (20%)
\$100,00+	9 (22.5%)	0	5 (50%)	1 (10%)
Prefer not to answer	1 (2.5%)	1 (10%)	0	0
Education				
high school (9-12 years) or less	16 (40%)	6 (60%)	5 (50%)	1 (10%)
college (diploma) or university (Bachelor's degree), including	24 (60%)	4 (40%)	5 (50%)	9 (90%)

Characteristics	Total Sample	Wives	Husbands	Daughters
university with advanced degree (Master's, PhD)				
Employed Full Time	24 (60%)	4 (40%)	4 (40%)	6 (50%)
Lives with the Person with AD	31 (77.5%)	10 (100%)	10 (100%)	7 (70%)
Length of Time Providing Care Related to AD				
1 year	6 (15%)	2 (20%)	1 (10%)	1 (10%)
2-3 years	12 (30%)	3 (30%)	4 (40%)	3 (30%)
4-7years	17 (42.5%)	4 (40%)	4 (40%)	4 (40%)
➤ 7 years	5 (12.5%)	1 (10%)	1 (10%)	2 (20%)

Supplemental Table 3: Summary of Findings

Caregiving Phase	Key Characteristic of this Phase and Service Need	Experience by Gender and Relationship	Supporting Quotation
Monitoring initial symptoms	<p>This is the start of caregiver responsibilities as caregivers as monitor the symptoms of their family members and begin to assist them.</p> <p>Caregivers rely on educational services to obtain information about cognitive changes in normal aging.</p>	<p><u>Adult children:</u> Great concern their parents' lasting symptoms which they are able to relate to a sign of a medical condition.</p> <p>No gender differences between sons and daughters.</p> <p><u>Spouses:</u> Less concern over symptoms due to the perception that they are age-related.</p> <p>Wives are even less concerned than husband caregivers and do not recognize symptoms on their own.</p>	<p>"I was absolutely petrified of dementia. I even thought about leaving at one point"- (Caregiver 7, Daughter)</p> <p>"I never thought it was Alzheimer's until I saw that something medically wrong was going on. My symptoms did not go away until I was diagnosed." (Caregiver 1, Daughter)</p> <p>"I just thought it was a normal part of aging. I didn't really pay too much attention to it until I was 37, Husband)</p> <p>"I did not even realize what was going on until people kept pointing it out to me. I thought he was just getting older." (Caregiver 1, Wife)</p>
Navigating diagnosis	<p>Caregivers help with obtaining a dementia diagnosis for the person with Alzheimer's disease by relying on diagnostic services</p>	<p><u>Adult children:</u> Obtained a diagnosis earlier than spousal caregivers and responded with acceptance.</p> <p>Adult children caregivers are concerned about maintaining a balance between caregiving and their other occupations.</p> <p>Daughter participants react with empathy for their parents' medical condition whereas sons worry about the added responsibilities of caregiving.</p>	<p>"I just felt so so sorry that I was the one to do this" – (Caregiver 14, Daughter)</p> <p>"I didn't really struggle with the dementia diagnosis, no. I just guess it was faster than I expected. I accepted it [...] but I was worried about what this would mean for me." (Caregiver 22, Son)</p>

Caregiving Phase	Key Characteristic of this Phase and Service Need	Experience by Gender and Relationship	Supporting Quotation
		<p><u>Spouses:</u> Obtained a diagnosis later than adult children caregivers. Spouses reacted with shock. Husband participants eventually accept the diagnosis whereas wife participants remain in denial.</p> <p>Female caregivers receive a diagnosis of Alzheimer’s disease later and with more difficulty than male caregivers.</p>	<p>“I was shocked when he also shocked that it was Alzheimer’s in a week” (Husband)</p> <p>“I had to insist on a specialist to finally tell me I think it took maybe a week. And I mean fighting.” –</p>
Assisting with IADLs	Caregivers provide assistance with IADLs and rely on support groups for informational and emotional support.	<p><u>Adult children:</u> Daughters now join sons in worrying about the impact caregiving has on their lives. Adult children aim to be available at all times. Adult children participants use support groups to get information. Adult children are confident that they are providing the best care they can and report positive relationship changes due to the caregiving role.</p> <p><u>Spouses:</u> There is a loss of intimacy. Spouses use support groups as a source of emotional support. Spousal caregivers describe guilt. Husbands describe taking things ‘day by day’. Wives are more reluctant to discuss intimacy.</p>	<p>“I couldn’t be the mother. I also had to support my hard to admit now that (Daughter)</p> <p>“I did all I could for my over it. I just wish- wait- change anything. I did not (Son)</p> <p>“Sex is non-existent. Yes (Caregiver 30, Husband)</p> <p>“Yeah, I mean, the relationship we couldn’t be intimate is to admit at my age”-</p>
Assisting with Basic ADLs	Caregivers provide assistance with Basic ADLs and use support from home and community care services.	<p><u>Adult children:</u> Discuss the role of other family caregivers within the family unit. Adult children use services to receive respite. Sons describe not expecting any family support whereas daughters are resentful that they do not have any. Daughters describe feeling like ‘case managers’. Sons do not wish to complete housekeeping tasks.</p> <p><u>Spouses:</u> Both husband and wife participants were not comfortable leaving their spouses home alone. Wives want to have control over care.</p> <p>Male caregivers are not comfortable completing personal hygiene tasks (e.g., bathing, toileting).</p>	<p>“I am, even to this day, everyone judges me for need help. I needed help. I’m sick of having to judge siblings who don’t even (Caregiver 12, Daughter)</p> <p>“I do not know how to do. Especially if you can get do that.”- (Caregiver 23)</p> <p>“Bathing my wife. I mean was around, but I really really needed it. It’s und helpless in that way” –</p> <p>“I was reluctant to let spend all those years do stay so I can keep an eye</p>

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			but I trust my care better (Caregiver 36, Wife)
Preparing for the future	Caregivers begin exploring options for the future and desire information about assisted living options and support accessing available services.	<p><u>Adult children</u>: Believe they cannot sustain care in the community and thus, long-term care placement is inevitable. No gender differences between sons and daughters.</p> <p><u>Spouses</u>: Both husbands and wives initially describe doubt over long-term care placement. Husband caregivers see long-term care as a better care option than care at home, whereas wives see it as their ‘worst fear’.</p> <p>Female caregivers are emotional in discussing the future.</p>	<p>“I think it’s inevitable a think of people in long people with dementia”-</p> <p>“I’m already thinking a I’ll have to get on with long term care is somet and explore” – (Caregiver 36, Wife)</p> <p>“At least if she’s in a ho care of. That’s all I tell Husband)</p> <p>“Everyone keeps telling home or that I will end of the strain. That is my home and thinking I for care for him. I don’t wa (Caregiver 31, Wife)</p>