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 *relative*?                                                                               |
| 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?                                         |

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                           | 9 (22.5%)    | 0      | 2 (20%)  | 2 (20%)   |
| $100,000+                                | 1 (2.5%)     | 1 (10%) | 0        | 1 (10%)   |
| Prefer not to answer                     |              |        |          |           |
| 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

| 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%)   |
| 4-7 years                                    | 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 Quotations |
|------------------|---------------------------------------------------|--------------------------------------|-----------------------|
| Monitoring initial symptoms | This is the start of caregiver responsibilities as caregivers as monitor the symptoms of their family members and begin to assist them. Caregivers rely on educational services to obtain information about cognitive changes in normal aging. | Adult children: Great concern their parents’ lasting symptoms which they are able to relate to a sign of a medical condition. No gender differences between sons and daughters. Spouses: Less concern over symptoms due to the perception that they are age-related. Wives are even less concerned than husband caregivers and do not recognize symptoms on their own. | “I was absolutely petrified. I didn’t know it was dementia. I even thought it was a brain tumour at one point” – (Caregiver 7, Daughter) “I never thought it was Alzheimer’s but I knew that something medically was wrong when the symptoms did not go away” – (Caregiver 8, Son) “I just thought it was a normal part of aging, so I didn’t really pay too much attention” – (Caregiver 37, Husband) “I just felt so so sorry that dad had to go through this” – (Caregiver 14, Daughter) “I didn’t really struggle with getting the dementia diagnosis, no. I mean, in hindsight I guess it was faster than I thought… I just kind of accepted it […] but I was worried about what this would mean for me and my to-do list” – (Caregiver 22, Son) |
| Navigating diagnosis | Caregivers help with obtaining a dementia diagnosis for the person with Alzheimer’s disease by relying on diagnostic services | Adult children: Obtained a diagnosis earlier than spousal caregivers and responded with acceptance. Adult children caregivers are concerned about maintaining a balance between caregiving and their other occupations. Daughter participants react with empathy for their parents’ medical condition whereas sons worry about the added responsibilities of caregiving. | “I just felt so so sorry that dad had to go through this” – (Caregiver 14, Daughter) “I didn’t really struggle with dementia diagnosis, no. I guess it was faster than I accepted it […] but I was worried about what this would mean for me” – (Caregiver 22, Son) |
| Caregiving Phase | Key Characteristic of this Phase and Service Need | Experience by Gender and Relationship | Supporting Quotations |
|------------------|-----------------------------------------------|-------------------------------------|-----------------------|
| Spouses: Obtained a diagnosis later than adult children caregivers. Spouses reacted with shock. Husband participants eventually accept the diagnosis whereas wife participants remain in denial. Female caregivers receive a diagnosis of Alzheimer’s disease later and with more difficulty then male caregivers. | | “I was shocked when he said Alzheimer’s. I was also shocked that it went from dementia to Alzheimer’s in a week” – (Caregiver 5, Husband) | |
| “I had to insist on a specialist appointment for them to finally tell me it was Alzheimer’s. I think it took maybe a whole year of fighting. And I mean fighting.” – (Caregiver 3, Wife) | | “I couldn’t be the mother I wanted to be because I also had to support my parent. That is really hard to admit now that I said it” – (Caregiver 17, Daughter) | |
| “I did all I could for my dad. I don’t have regret over it. I just wish - wait no, I don’t think I could change anything. I did my best” – (Caregiver 32, Son) | | “Sex is non-existent. Yup, even at our age” – (Caregiver 30, Husband) | |
| “Yeah, I mean, the relationship changed. Like we couldn’t be intimate as embarrassing as that is to admit at my age” – (Caregiver 29, Wife) | | “I am, even to this day, bitter. I feel like everyone judges me for having the ladies in, but I need help. I needed help. They don’t get it and I’m sick of having to justify my choice to my siblings who don’t even look after dad” – (Caregiver 12, Daughter) | |
| “I do not know how to clean, nor do I want to. Especially if you can get someone to do that.”- (Caregiver 23, Son) | | “I do not know how to clean, nor do I want to. Especially if you can get someone to do that.”- (Caregiver 23, Son) | |
| “Bathing my wife. I mean I’d do it if no one else was around, but I really really needed it. It’s uncomfortable to see her so helpless in that way” – (Caregiver 38, Husband) | | “Bathing my wife. I mean I’d do it if no one else was around, but I really really needed it. It’s uncomfortable to see her so helpless in that way” – (Caregiver 38, Husband) | |
| “I was reluctant to let someone else do what I spent all those years doing. I mean even now I stay so I can keep an eye” – (Caregiver 38, Husband) | | “I was reluctant to let someone else do what I spent all those years doing. I mean even now I stay so I can keep an eye” – (Caregiver 38, Husband) | |
| Caregiving Phase | Key Characteristic of this Phase and Service Need | Experience by Gender and Relationship | Supporting Quotations |
|------------------|--------------------------------------------------|---------------------------------------|----------------------|
| Preparing for the future | Caregivers begin exploring options for the future and desire information about assisted living options and support accessing available services. | **Adult children:** Believe they cannot sustain care in the community and thus, long-term care placement is inevitable. No gender differences between sons and daughters.  
**Spouses:** Both husbands and wives initially describe doubt over long-term care placement. Husband caregivers see long-term care as a better care option then care at home, whereas wives see it as their 'worst fear'.  
Female caregivers are emotional in discussing the future. | “I think it’s inevitable and I think of people in long term care as people with dementia” – (Caregiver 36, Wife)  
“I’m already thinking about it. I’ll have to get on with it. Long term care is something I have to think of and explore” – (Caregiver 11, Son)  
“At least if she’s in a home she’ll be better taken care of. That’s all I tell myself” – (Caregiver 39, Husband)  
“Everyone keeps telling me he’ll end up in a home or that I will end up hospitalized because of the strain. That is my worst fear. Him in a home and thinking I forgot and didn’t want to care for him. I don’t want to think about it” – (Caregiver 31, Wife) |