

## **Supplementary Material**

### **Assessing What Matters to People Affected by Alzheimer's Disease: A Quantitative Analysis**

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**Table S1. Background Characteristics of Patient Respondents Groups**

<b>Background Question</b>	<b>Group 1 (n = 54)</b>	<b>Group 2 (n = 51)</b>	<b>Group 3 (n = 50)</b>
<b>Concerned about problem with memory or thinking, n (%)</b>			
Yes	31 (57.4)	45 (88.2)	45 (90.0)
No	9 (16.7)	3 (5.9)	3 (6.0)
Don't know or not sure	14 (25.9)	3 (5.9)	2 (4.0)
<b>If concerned, discussed concern with doctor, n (%)</b>			
n	31	45	45
Yes	27 (87.1)	43 (95.6)	43 (95.6)
No	4 (12.9)	2 (4.4)	2 (4.4)
<b>If discussed with doctor, how long ago, n (%)</b>			
n	27	43	43
1 year ago, or less	10 (37.0)	16 (37.2)	18 (41.9)
More than 1 year ago, but less than 2 years ago	10 (37.0)	17 (39.5)	10 (23.3)
More than 2 years ago, but less than 3 years ago	4 (14.8)	8 (18.6)	10 (23.3)
More than 3 years ago	3 (11.1)	2 (4.7)	5 (11.6)
<b>Patient-reported physician diagnoses of health conditions that affect memory and thinking, n (%)<sup>a</sup></b>			
Normal aging	15 (27.8)	9 (17.6)	11 (22.0)
Age-related memory loss	15 (27.8)	23 (45.1)	20 (40.0)
Dementia	11 (20.4)	13 (25.5)	15 (30.0)
Mild cognitive impairment (MCI)	5 (9.3)	14 (27.5)	7 (14.0)
Alzheimer's disease	13 (24.1)	17 (33.3)	30 (60.0)
None of the above	13 (24.1)	2 (3.9)	2 (4.0)

<b>Background Question</b>	<b>Group 1 (n = 54)</b>	<b>Group 2 (n = 51)</b>	<b>Group 3 (n = 50)</b>
<b>Cognitive symptoms in the last month, n (%)<sup>a</sup></b>			
Forgetting events, tasks and/or plans, misplacing things	37 (68.5)	37 (72.5)	40 (80.0)
Getting confused about dates, the time, getting from place to place, and/or where you are	19 (35.2)	25 (49)	32 (64.0)
Difficulty planning and organizing things	13 (24.1)	22 (43.1)	21 (42.0)
Difficulty following instructions, writing things down, managing finances	12 (22.2)	20 (39.2)	24 (48.0)
Difficulty speaking and understanding others, finding the right words	11 (20.4)	15 (29.4)	21 (42.0)
Difficulty concentrating, thinking clearly, losing your train of thought, and/or making decisions	25 (46.3)	28 (54.9)	25 (50.0)
Having strong emotions, moods, and feelings that may change unexpectedly	13 (24.1)	9 (17.6)	18 (36.0)
Losing interest in the things you used to enjoy	12 (22.2)	19 (37.3)	16 (32.0)
Doing or saying things without thinking (for example, things that may be embarrassing to yourself or others, or hurtful to others)	4 (7.4)	6 (11.8)	8 (16.0)
Having trouble sleeping	14 (25.9)	17 (33.3)	22 (44.0)
Pacing around or doing or saying the same things over and over	5 (9.3)	8 (15.7)	8 (16.0)
Changes in appetite and/or preferred foods	6 (11.1)	7 (13.7)	11 (22.0)
None of the above	5 (9.3)	3 (5.9)	0 (0.0)

<b>Background Question</b>	<b>Group 1 (n = 54)</b>	<b>Group 2 (n = 51)</b>	<b>Group 3 (n = 50)</b>
<b>Have other people told you they have noticed changes in your memory and thinking, or your ability to do everyday tasks?, n (%)</b>			
Yes	30 (55.6)	43 (84.3)	41 (82.0)
No	24 (44.4)	8 (15.7)	9 (18.0)
<b>Have you ever known anyone (e.g., friend, family member, or co-worker) who has had Alzheimer's disease or dementia?, n<sup>a</sup></b>			
Yes	45 (83.3)	35 (68.6)	37 (74.0)
No	7 (13.0)	7 (13.7)	10 (20.0)
Do not know or not sure	2 (3.7)	9 (17.6)	3 (6.0)

<sup>a</sup> Respondents could select more than one response, so total responses may add up to more than 100%.

**Table S2. Background Characteristics of Care Partner Respondent Groups**

<b>Background Question</b>	<b>Group 4 (n = 65)</b>	<b>Group 5 (n = 54)</b>
<b>Care recipient diagnoses of health conditions that affect memory and thinking, n (%)<sup>a</sup></b>		
Normal aging	7 (10.8)	10 (18.5)
Age-related memory loss	11 (16.9)	16 (29.6)
Dementia	37 (56.9)	30 (55.6)
Mild cognitive impairment (MCI)	13 (20.0)	13 (24.1)
Alzheimer's disease	36 (55.4)	41 (75.9)
None of the above	0 (0.0)	2 (3.7)
<b>Cognitive symptoms of the care recipient in the last month (as reported by care partner), n (%)<sup>a</sup></b>		
Forgetting events, tasks and/or plans, misplacing things	60 (92.3)	47 (87.0)
Getting confused about dates, the time, getting from place to place, and/or where they are	54 (83.1)	47 (87.0)
Difficulty planning and organizing things	42 (64.6)	38 (70.4)
Difficulty following instructions, writing things down, managing finances	48 (73.8)	39 (72.2)
Difficulty speaking and understanding others, finding the right words	24 (36.9)	39 (72.2)
Difficulty concentrating, thinking clearly, losing their train of thought, and/or making decisions	44 (67.7)	43 (79.6)
Having strong emotions, moods, and feelings that may change unexpectedly	33 (50.8)	35 (64.8)
Losing interest in the things they used to enjoy	35 (53.8)	36 (66.7)
Doing or saying things without thinking (for example, things that may be embarrassing to themselves or others, or hurtful to others)	28 (43.1)	35 (64.8)
Having trouble sleeping	18 (27.7)	25 (46.3)

<b>Background Question</b>	<b>Group 4 (n = 65)</b>	<b>Group 5 (n = 54)</b>
Pacing around or doing or saying the same things over and over	25 (38.5)	33 (61.1)
Changes in appetite and/or preferred foods	22 (33.8)	28 (51.9)
None of the above	0 (0.0)	0 (0.0)
<b>Care recipient relationship to care partner, n (%)</b>		
Spouse/partner	19 (29.2)	11 (20.4)
Parent	33 (50.8)	24 (44.4)
Another family member	9 (13.8)	14 (25.9)
A friend	3 (4.6)	4 (7.4)
Missing	1 (1.5)	1 (1.9)
<b>Total time each week providing direct care for the care recipient, h</b>		
Mean (SD)	40.3 (37.2)	46.9 (41.6)
Missing, n (%)	1 (1.5)	3 (5.6)

SD = standard deviation.

<sup>a</sup> Respondents could select more than one response, so total responses may add up to more than 100%.