

The University of Iowa
College of Nursing
Alzheimer's Family Role Trials Study

Staff Perceptions of Caregiving Role (SPCR)

I.D.# _____
(Col. 4-9)

Date: _____
(Col. 10-13)

DIRECTIONS: Each of the statements in this questionnaire describes something about your role in the care of residents who have Alzheimer's Disease. You are asked to indicate your feelings about each statement in terms of the extent to which you agree or disagree. Please tell me the extent that you agree OR disagree with these statements. **A rating of 1 means that you "strongly disagree"; a rating of 7 means that you "strongly agree" with the statement.** Circle the number for each statement that best indicates the extent you agree or disagree.

We greatly appreciate your assistance with our study. **PLEASE TURN THE PAGE AND BEGIN.**

	STRONGLY DISAGREE							STRONGLY AGREE							Col.
1. I feel like some families' suggestions and requests interfere with staffs' abilities to care for the Alzheimer's residents.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	15
2. I feel like families should visit but leave the care of the Alzheimer's residents to the staff who are most familiar with their needs.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	16
3. I usually ask family members to leave the room when care is being provided for their relatives.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	17
4. A family member is usually included in decisions about the care of the Alzheimer's resident.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	18
5. Families need only give them information to staff about their relative's habits and preferences.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	19
6. The family member's role as caregiver is clearly secondary compared to staff after the relative is admitted to the nursing home.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	20
7. Most family members have control over the care their relatives receive.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	21
8. Most families would like to visit their relatives more often than staff want them to.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	22
9. Family members seem to be checking up on staff to see that care is delivered like they want it to be.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	23
10. Staff listen to family members' directions for their relatives' care but ignore the directions if they choose.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	24
11. It is clear that staff have the real say about what care will be provided and how.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	25
12. I feel like staff are there to help family members provide the best possible care for their relatives.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	26
13. The primary caregiving role of most family members has remained essentially unchanged since their relatives entered the nursing home.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	27
14. Although families don't provide all of their relative's care, most continue to be the primary caregivers.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	28
15. What families see as important in their relatives' care staff often see as not as important and too time consuming.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	29

	STRONGLY DISAGREE				STRONGLY AGREE				Col.
16. Staff are more concerned about policies and procedures in order to care for all of the residents, while family members are more concerned about caring for their relatives as individuals.	1	2	3	4	5	6	7	30	
17. Most families and staff agree that it is important for family members to be with their relatives as much as possible to participate in their care.	1	2	3	4	5	6	7	31	
18. Families and staff usually agree on the care priorities for the Alzheimer's residents.	1	2	3	4	5	6	7	32	
19. No major changes are made in the care of residents without family members' approval.	1	2	3	4	5	6	7	33	
20. Staff just want family members to be visitors, while family members want to be more involved in their relatives' care.	1	2	3	4	5	6	7	34	
21. I feel resentful of some family members who could but who do not do more things for their loved ones.	1	2	3	4	5	6	7	35	
22. I feel that the Alzheimer's residents often make requests that I perceive to be over and above what they need.	1	2	3	4	5	6	7	36	
23. I feel stressed between trying to provide care for residents with Alzheimer's as well as attend to other family and job responsibilities.	1	2	3	4	5	6	7	37	
24. I sometimes feel embarrassed over the Alzheimer's residents' behaviors.	1	2	3	4	5	6	7	38	
25. I feel guilty about some of my interactions with Alzheimer's residents.	1	2	3	4	5	6	7	39	
26. I feel that I don't do as much for the Alzheimer's residents as I could or should.	1	2	3	4	5	6	7	40	
27. I sometimes feel angry about my interactions with families.	1	2	3	4	5	6	7	41	
28. I feel nervous or depressed about my interactions with Alzheimer's residents.	1	2	3	4	5	6	7	42	
29. I feel that most families don't appreciate all that I do for the Alzheimer's residents.	1	2	3	4	5	6	7	43	
30. I feel that my stress from caring for Alzheimer's residents affects my relationships with my family members and friends in a negative way.	1	2	3	4	5	6	7	44	
	STRONGLY				STRONGLY				

	DISAGREE							AGREE							Col.
31. I feel resentful about caring for Alzheimer's residents.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	45
32. I feel the Alzheimer's residents are too dependent on staff.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	46
33. I feel comfortable in my interactions with Alzheimer's residents.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	47
34. I feel that my health has suffered because of my work with Alzheimer's residents.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	48
35. I feel that Alzheimer's residents don't appreciate what I do for them as much as I would like.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	49
36. I feel uncomfortable when families/friends visit their loved ones in the nursing home.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	50
37. I feel that Alzheimer's residents often try to manipulate me.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	51
38. I feel that some Alzheimer's residents expect me to take care of them as if I were the only one they could depend on.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	52
39. I feel that there often are not enough resources to care for the Alzheimer's residents adequately.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	53
40. I feel that more staff should be provided to care for Alzheimer's residents in nursing homes.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	54
41. When family and staff have different ideas about care the disagreements are negotiated and resolved.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	55
42. I feel that I can interact purposefully with families about the care of the residents with Alzheimer's.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	56
43. I have mostly positive interactions with families.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	57

Staff may feel sad because of the illness of the resident with Alzheimer's and the changes that the illness causes: To what extent do you agree or disagree that you feel **sad** over:

	(NOT AT ALL SAD)				(VERY SAD)			Col.
	STRONGLY DISAGREE				STRONGLY AGREE			
44. Inability to help the AD resident improve?	1	2	3	4	5	6	7	58
45. Inability to help the family members cope with the deterioration of their loved one?	1	2	3	4	5	6	7	59
46. Seeing AD patients lose the abilities that give them human dignity?	1	2	3	4	5	6	7	60
47. Loss of meaningful interaction with residents?	1	2	3	4	5	6	7	61
48. Inability to know what the Alzheimer's residents used to be like?	1	2	3	4	5	6	7	62
49. The continued deterioration of the Alzheimer's residents?	1	2	3	4	5	6	7	63
50. Lack of privacy for the Alzheimer's residents?	1	2	3	4	5	6	7	64
51. Inability to control how the Alzheimer's residents are cared for?	1	2	3	4	5	6	7	65
52. Loss of part of my role as primary caregiver of the Alzheimer's residents to the family members?	1	2	3	4	5	6	7	66

Here are some thoughts and feeling that people sometimes have about themselves when they are caregivers of a relative who is ill. How much do you agree or disagree that each statement **describes your thoughts about your caregiving?**

	STRONGLY DISAGREE				STRONGLY AGREE			Col.
53. Wish you could care for AD residents like you can residents who are cognitively intact?	1	2	3	4	5	6	7	67
54. Feel trapped by your inability to help the Alzheimer's resident?	1	2	3	4	5	6	7	68
55. Wish you could transfer to a unit where there are no Alzheimer's residents?	1	2	3	4	5	6	7	69
56. Wish you had more time to spend with other residents?	1	2	3	4	5	6	7	70
57. Wish you could turn more of your caregiving role over to the family?	1	2	3	4	5	6	7	15
58. Feel like AD residents really don't exist anymore as human personalities but still have to care for them as if they do?	1	2	3	4	5	6	7	16

Hassles are irritants - things than annoy or bother you; it can make you upset or angry. Some hassles occur on a fairly regular basis and others are relatively rare. Some have only a slight effect, whereas others have a strong effect. Listed below are hassles that may occur in your day to day caregiving. You will find that during the past week some of these things will have been a hassle whereas others have not. For each item indicate the extent that you agree or disagree that the event was a hassle during the past week.

	STRONGLY DISAGREE			STRONGLY AGREE				Col.
59. Residents declining mentally.	1	2	3	4	5	6	7	17
60. Assisting residents with walking.	1	2	3	4	5	6	7	18
61. Assisting residents with grooming.	1	2	3	4	5	6	7	19
62. Residents not showing interest in things.	1	2	3	4	5	6	7	20
63. Assisting residents with bathing.	1	2	3	4	5	6	7	21
64. Residents' agitation.	1	2	3	4	5	6	7	22
65. Assisting residents eat or drink.	1	2	3	4	5	6	7	23
66. Changes in residents' personalities.	1	2	3	4	5	6	7	24
67. Assisting residents with exercise/therapy.	1	2	3	4	5	6	7	25
68. Assisting residents with toileting.	1	2	3	4	5	6	7	26
69. Residents' yelling/swearing.	1	2	3	4	5	6	7	27
70. Residents not cooperating.	1	2	3	4	5	6	7	28
71. Residents' forgetfulness.	1	2	3	4	5	6	7	29
72. Residents being confused/not making sense.	1	2	3	4	5	6	7	30
73. Residents asking repetitive questions.	1	2	3	4	5	6	7	31
74. Residents not recognizing familiar people.	1	2	3	4	5	6	7	32
75. Residents living in the past.	1	2	3	4	5	6	7	33
76. Being in residents' presence.	1	2	3	4	5	6	7	34
77. Residents talking about seeing things that aren't real.	1	2	3	4	5	6	7	35
78. Helping residents dress.	1	2	3	4	5	6	7	36

THANK YOU FOR FILLING OUT THE QUESTIONNAIRE!