

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

Family Perceptions of Caregiving Role (FPCR)

Family Member's I.D. # _____
(4-9)

Date _____
(10-13)

DIRECTIONS: Each of the statements in this questionnaire describes something about your role in the care of your family member who has 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 I have to be careful about how I make suggestions or requests about my relative's care or staff will think I am interfering.	1	2	3	4	5	6	7	(15)
2. I feel like an outsider in the care of my relative.	1	2	3	4	5	6	7	(16)
3. I am often asked to leave the room when care is being provided for my relative.	1	2	3	4	5	6	7	(17)
4. I am usually included in decisions about the care of my relative.	1	2	3	4	5	6	7	(18)
5. Staff expect me only to give them information about my relative's habits and preferences, not to provide care.	1	2	3	4	5	6	7	(19)
6. My role as caregiver is clearly secondary compared to staff since my relative was admitted to the nursing home.	1	2	3	4	5	6	7	(20)
7. I feel that I have control over the care my relative receives.	1	2	3	4	5	6	7	(21)
8. I would like to visit my relative more often than staff want me to.	1	2	3	4	5	6	7	(22)
9. I feel like the care of my relative will not be done as I want if I am not there.	1	2	3	4	5	6	7	(23)
10. Staff listen to my directions for my relative's care, but ignore them if they choose.	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	(25)
12. I feel like staff are there to help me provide the best possible care for my relative.	1	2	3	4	5	6	7	(26)
13. My primary caregiving role has remained essentially unchanged since my relative entered the nursing home.	1	2	3	4	5	6	7	(27)
14. Although I don't provide all of my relative's care, I feel like I am the primary caregiver.	1	2	3	4	5	6	7	(28)
15. Things that I see as important in my relative's care staff often see as trivial or inconvenient.	1	2	3	4	5	6	7	(29)
16. Staff are most concerned about rules, routines and efficiency while I am most concerned about caring for my relative as an individual.	1	2	3	4	5	6	7	(30)

	STRONGLY DISAGREE				STRONGLY AGREE			Col.
17. Staff and I agree that it is important for me to be with my relative as much as possible to participate in his or her care.	1	2	3	4	5	6	7	(31)
18. Staff and I usually agree on the care priorities for my relative.	1	2	3	4	5	6	7	(32)
19. No major changes are made in the care of my relative without my approval.	1	2	3	4	5	6	7	(33)
20. Staff just want me to be a visitor, while I want to be involved in my relative's care.	1	2	3	4	5	6	7	(34)
21. I feel resentful of other relatives who could but who do not do things for my loved one.	1	2	3	4	5	6	7	(35)
22. I feel that my relative with Alzheimer's makes requests that I perceive to be over and above what he/she needs.	1	2	3	4	5	6	7	(36)
23. I feel stressed between trying to give to my loved one with Alzheimer's as well as to other family responsibilities, job, etc.	1	2	3	4	5	6	7	(37)
24. I feel embarrassed over my loved one's behavior.	1	2	3	4	5	6	7	(38)
25. I feel guilty about my interactions with my loved one who is ill.	1	2	3	4	5	6	7	(39)
26. I feel that I don't do as much for my loved one in the nursing home as I could or should.	1	2	3	4	5	6	7	(40)
27. I feel angry about my interactions with my loved one who is ill.	1	2	3	4	5	6	7	(41)
28. I feel that in the past, I haven't done as much for my loved one who is now in the nursing home as I could or should.	1	2	3	4	5	6	7	(42)
29. I feel nervous or depressed about my interactions with my loved one in the nursing home.	1	2	3	4	5	6	7	(43)
30. I feel that my loved one who is in the nursing home currently affects my relationships with other family members and friends in a negative way.	1	2	3	4	5	6	7	(44)
31. I feel resentful about my interactions with my loved one who is ill.	1	2	3	4	5	6	7	(45)
32. I feel my loved one in the nursing home is dependent.	1	2	3	4	5	6	7	(46)
33. I feel comfortable in my interactions with my loved one.	1	2	3	4	5	6	7	(47)

	<u>STRONGLY DISAGREE</u>				<u>STRONGLY AGREE</u>			Col.
34. I feel that my health has suffered because of my involvement with my loved one who has Alzheimer's disease.	1	2	3	4	5	6	7	(48)
35. I feel that my loved one doesn't appreciate what I do for him/her as much as I would like.	1	2	3	4	5	6	7	(49)
36. I feel uncomfortable when friends visit my loved one in the nursing home.	1	2	3	4	5	6	7	(50)
37. I feel that my loved one tries to manipulate me.	1	2	3	4	5	6	7	(51)
38. I feel that my loved one seems to expect me to take care of him/her as if I were the only one he/she could depend on.	1	2	3	4	5	6	7	(52)
39. I feel that I don't have enough money to support my loved one in the nursing home home in addition to my other expenses.	1	2	3	4	5	6	7	(53)
40. I feel that I would like to be able to provide more money to take care of my loved one than I am able to now.	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	(55)
42. I feel that I can interact purposefully with staff about the care of my loved one.	1	2	3	4	5	6	7	(56)
43. I have mostly positive interactions with staff.	1	2	3	4	5	6	7	(57)

Family caregivers of Alzheimer's patients sometimes feel that they lose important things in life because of their relative's illness. To what extent do you agree or disagree that **you personally have lost** the following?

	<u>STRONGLY DISAGREE</u>				<u>STRONGLY AGREE</u>			Col.
44. Being able to confide in your relative?	1	2	3	4	5	6	7	(58)
45. The person that you used to know?	1	2	3	4	5	6	7	(59)
46. Having someone who really knew you well?	1	2	3	4	5	6	7	(60)
47. The practical things he/she used to do for you?	1	2	3	4	5	6	7	(61)
48. A chance to do some of the things you planned?	1	2	3	4	5	6	7	(62)
49. Contact with other people?	1	2	3	4	5	6	7	(63)

Family members may feel sorrow over the illness of their loved one and the changes that the illness has made in their lives: To what extent do you agree or disagree that you **feel sorrow** over:

	STRONGLY DISAGREE					STRONGLY AGREE		Col.
	1	2	3	4	5	6	7	
50. Loss of companionship?	1	2	3	4	5	6	7	(64)
51. Other's inability to know how your loved one used to be?	1	2	3	4	5	6	7	(65)
52. Having to place your loved one in an institution?	1	2	3	4	5	6	7	(66)
53. Lack of privacy with your loved one?	1	2	3	4	5	6	7	(67)
54. Inability to control how your loved one is cared for?	1	2	3	4	5	6	7	(68)
55. Loss of your role as primary caregiver of your loved one?	1	2	3	4	5	6	7	(69)

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.
	1	2	3	4	5	6	7	
56. Wish you were free to lead a life of your own?	1	2	3	4	5	6	7	(70)
57. Feel trapped by your relative's illness?	1	2	3	4	5	6	7	(71)
58. Wish you could just run away?	1	2	3	4	5	6	7	(72)
59. Wish you had more time to spend with friends?	1	2	3	4	5	6	7	(73)
60. Wish you could get out of your role as caregiver?	1	2	3	4	5	6	7	(74)
61. Feel like you have lost your relative but still have the same role responsibilities as if you hadn't?	1	2	3	4	5	6	7	(75)

Hassles are irritants - things that 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.
62. Relative declining mentally.	1	2	3	4	5	6	7	(15)	
63. Assisting relative with walking.	1	2	3	4	5	6	7	(16)	
64. Assisting relative with grooming.	1	2	3	4	5	6	7	(17)	
65. Relative not showing interest in things.	1	2	3	4	5	6	7	(18)	
66. Assisting relative with bathing.	1	2	3	4	5	6	7	(19)	
67. Relative's agitation.	1	2	3	4	5	6	7	(20)	
68. Assisting relative eat or drink.	1	2	3	4	5	6	7	(21)	
69. Changes in relative's personality.	1	2	3	4	5	6	7	(22)	
70. Assisting relative with exercise/therapy.	1	2	3	4	5	6	7	(23)	
71. Assisting relative with toileting.	1	2	3	4	5	6	7	(24)	
72. Relative yelling/swearing.	1	2	3	4	5	6	7	(25)	
73. Relative not cooperating.	1	2	3	4	5	6	7	(26)	
74. Relative's forgetfulness.	1	2	3	4	5	6	7	(27)	
75. Relative being confused/not making sense.	1	2	3	4	5	6	7	(28)	
76. Relative asking repetitive questions.	1	2	3	4	5	6	7	(29)	
77. Relative not recognizing familiar people.	1	2	3	4	5	6	7	(30)	
78. Relative living in the past.	1	2	3	4	5	6	7	(31)	
79. Being in relative's presence.	1	2	3	4	5	6	7	(32)	
80. Relative talking about seeing things that aren't real.	1	2	3	4	5	6	7	(33)	
81. Helping relative dress.	1	2	3	4	5	6	7	(34)	

THANK YOU FOR FILLING OUT THE QUESTIONNAIRE!

Research Staff ID# _____
(35-36)