Caregiver Communication

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Protocol ID:	Research Participant #	UPN:	Evaluation Code	Nurse ID:	Institution:
ProtocolID	RPN	UPN	EvaluationCode	NurseID	Institution

Because this is a computer read form, please use **BLACK ink only.** Please solidly fill bubbles for choice responses.

Family can be your partner and/or children. Family can also be the family you were born into, like your parents/guardians and brothers and sisters. As primary caregiver for your loved one, think about the family that is connected to you and your loved one (patient).

How many people are in this family? FamilySize

Choose the answer that best describes your family's situation:

		Frequently	Occasionally	Rarely	Very Rarely	Never
1	I talk with my family, which can include Facebook and text messages, about my loved one's illness.	TalkAboutIllness 1	2	3	4	5
2	After a medical appointment, I contact family members to share details of the visit.	TalkAboutMeidcalAppt 1	2	3	4	5
3	Family members ask me about my loved one's illness.	FamilyAskAboutIllness 1	2	3	4	5
4	I talk with my ill family member about his/her fears about treatment or dying.	CommunicatePatientFears 1	2	3	4	5
5	I talk with my ill family member about changes in our life as a result of illness.	DiscussWPtChangesInLife 1	2	3	4	5
6	Our family talks about death and dying with our ill loved one.	FmDiscussDeathWPt 1	2	3	4	5
7	My family talks about what might happen if treatment doesn't work.	FmDisucssIfTxFail 1	2	3	4	5
8	My family lets me know that they expect me to take care of my loved one and that I am to do most of the caregiving.	FmExpectMeTakeCarePt 1	2	3	4	5
9	When I am stressed from caregiving, I prefer to hide this from family members.	PreferHideStressFromFm 1	2	3	4	5
10	Family members don't want to disagree about medical decisions for my loved one.	FmDontDisagreeMedDec 1	2	3	4	5
11	Family members believe that the doctor's ideas are right and we shouldn't disagree with them.	FmAgreeToMDIdeas 1	2	3	4	5
12	My family hides their opinion about caregiving.	FmHideOpinion 1	2	3	4	5
13	My family tries to act as though my loved one is not ill.	FmPretendPtNotIll 1	2	3	4	5
14	My ill loved one lets me know that he/she expects me to provide care and do most of the caregiving.	PtExpectMeTakeCarePt 1	2	3	4	5

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Next, think about your family and extended family when responding to the statements, and in particular the adult members of your family.

	In this family...	**Strongly agree**	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
15	people don't openly express their opinion.	DontExpressOpinion 1	2	3	4	5
16	we keep our views pretty much to ourselves.	KeepViewsToSelf 1	2	3	4	5
17	we are polite rather than honest in how we communicate with each other.	CommunicatePolite 1	2	3	4	5
18	we regularly talk about things that concern us.	TalkOutConcern 1	2	3	4	5
19	people are not interested in each other's opinions.	FmNoInterestOpinion 1	2	3	4	5
20	we take time to listen to each other.	FmListenToEachOther 1	2	3	4	5
21	we bring issues out in the open, good or bad.	BringIssueOutInOpen 1	2	3	4	5
22	we are frank with each other.	FrankWithFm 1	2	3	4	5
23	we face challenges very effectively.	FaceChallengeEffectively 1	2	3	4	5
24	we are flexible and adaptable in how we deal with difficulties.	AdaptableToDifficulty 1	2	3	4	5
25	we are poor at dealing with the unexpected.	PoorAtUnexpected 1	2	3	4	5
26	we are always able to help each other when the need arises.	HelpOtherWhenNeed 1	2	3	4	5
27	in solving problems, we are not often willing to change our routines.	NoChangeRoutine 1	2	3	4	5
28	we approach problems with a positive mindset.	PositiveMindset 1	2	3	4	5
29	we know we have the power to solve major problems.	AbleToSolveProb 1	2	3	4	5
30	when we face difficulties we work together effectively.	FaceChallenge 1	2	3	4	5

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	I give care because...	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
31	It is my duty to provide care to dependent family members.	DutyToProvideCare 1	2	3	4	5
32	It is important to set an example for the children in the family.	SetExForChildren 1	2	3	4	5
33	I was taught by my parents to take care of dependent family members.	TakeCareOfFm 1	2	3	4	5
34	Of my religious and spiritual beliefs.	SpiritualBeliefs 1	2	3	4	5
35	By giving care to dependent family members, I am giving back what has been given to me.	GivingWhatWasGiven 1	2	3	4	5
36	It strengthens the bonds between me and them.	StrengthenBondsInFm 1	2	3	4	5
37	I was raised to believe care should be provided in the family.	ProvideCareToFm 1	2	3	4	5
38	It is what my people have always done.	CulturalExpect 1	2	3	4	5
39	I feel as though I am being useful and making a family contribution.	FeelUsuefulContribute 1	2	3	4	5
40	My family expects me to provide care.	FmExpectCare 1	2	3	4	5

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