

Supplemental Table S1
Original and Adapted Quality of Communication Instruments, Sample Characteristics, and Responses from the Pilot and Efficacy Trials

Table of Contents

A.1 Quality of Communication Form, original patient version fielded in pilot.....	2
A.2 Quality of Communication Form, original family caregiver version fielded in pilot.....	3
B.1 Quality of Communication Form, adapted patient version fielded in efficacy trial.....	4
B.2 Quality of Communication Form, adapted family caregiver version fielded in efficacy trial.....	5
C. Demographics of patients and family caregivers in pilot and efficacy trial.....	6
D.1 Patient and Family Responses to Original QOC in pilot.....	7
D.2 Patient and Family Responses to Adapted QOC in efficacy trial.....	9

A.1: Quality of Communication Questionnaire for Patients, Fielded in Pilot Study	
Using a scale where '0' is the worst you can imagine, and '10' is the best you could imagine, please tell me the best number for each statement. When talking with your primary care doctor and their team about important issues like becoming ill, how good are they at:	
General Communication Subscale:	
1. Using words that you can understand:	_____
2. Looking you in the eye:	_____
3. Answering all your questions about your illness and treatment:	_____
4. Listening to what you have to say:	_____
5. Caring about you as a person:	_____
6. Giving you his/her full attention:	_____
EOL Communication Subscale:	
7. Talking with you about your feelings concerning the possibility that you might get sicker:	_____
8. Talking with you about the details concerning the possibility that you might get sicker:	_____
9. Talking about how long you might have to live:	_____
10. Talking about what dying might be like:	_____
11. Involving you in treatment discussions about your care:	_____
12. Asking about the things in life that are important to you:	_____
13. Asking about your spiritual or religious beliefs:	_____
Note: Original instrument directs interviewer to use a response of "888" when doctor "did not do".	

A.2: Quality of Communication Questionnaire for Family Caregivers, Fielded in Pilot Study	
Using the following scale where '0' is the worst you can imagine, and '10' is the best you could imagine, please tell me the best number for each statement. When talking with the primary care doctor and their team about important issues like becoming ill, how good are they at:	
General Communication Subscale:	
1. Using words that your [RELATIONSHIP] can understand:	—
2. Looking your [RELATIONSHIP] in the eye:	—
3. Answering all questions about your [RELATIONSHIP]'s illness and treatment:	—
4. Listening to what your [RELATIONSHIP] has to say:	==
5. Caring about your [RELATIONSHIP] as a person:	—
6. Giving your [RELATIONSHIP] his/her full attention:	==
EOL Communication Subscale:	
7. Talking with your [RELATIONSHIP] about their feelings concerning the possibility that he/she might get sicker:	—
8. Talking with your [RELATIONSHIP] about the details concerning the possibility that they might get sicker:	—
9. Talking about how long your [RELATIONSHIP] might have to live:	—
10. Talking to your [RELATIONSHIP] about what dying might be like:	—
11. Involving your [RELATIONSHIP] in treatment discussions about their care:	—
12. Asking about the things in life that are important to your [RELATIONSHIP]:	—
13. Asking about your [RELATIONSHIP]'s spiritual or religious beliefs:	==
Note: Original instrument directs interviewer to use a response of “888” when doctor “did not do”.	

B.1: Adapted Quality of Communication Questionnaire for Patients, Fielded in Efficacy Trial		
Using a scale where '0' is the worst you can imagine, and '10' is the best you could imagine, please tell me the best number for each statement. When talking with your primary care doctor and their team about important issues like becoming ill, how good are they at:		
General Communication Subscale:		
1. Using words that you can understand:	_____	
2. Looking you in the eye:	_____	
3. Answering all questions about your illness and treatment:	_____	
4. Listening to what you have to say:	_____	
5. Caring about you as a person:	_____	
6. Giving you his/her full attention:	_____	
EOL Communication Subscale:		
7a. Has your primary care team, including your doctor, talked with you about your feelings concerning the possibility that you might get sicker? <i>[IF 'NO' SKIP to Q8] [IF YES, "how good is the primary care team at...]</i>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
7b. Talking with you about your <u>feelings</u> concerning the possibility that you might get sicker:	_____	
8a. Has your primary care team, including your doctor, talked with you about the details concerning the possibility that you might get sicker? <i>[IF 'NO' SKIP to Q9] [IF YES, "how good is the primary care team at...]</i>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
8b. Talking with you about the <u>details</u> concerning the possibility that you might get sicker:	_____	
9a. Has your primary care team, including your doctor, talked with you about how long you might have to live? <i>[IF 'NO' SKIP Q10][IF YES, "how good is the primary care team at...]</i>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
9b. Talking about how long you might have to live:	_____	
10a. Has your primary care team, including your doctor, talked with you about what dying might be like? <i>[IF 'NO' SKIP to Q11] [IF YES, "how good is the primary care team at...]</i>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
10b. Talking about what dying might be like:	_____	
11a. Has your primary care team, including your doctor, involved you in treatment discussions about your care? <i>[IF 'NO' SKIP to Q12] [IF YES, "how good is the primary care team at...]</i>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
11b. Involving you in treatment discussions about your care:	_____	
12a. Has your primary care team, including your doctor, asked about the things in life that are important to you? <i>[IF 'NO' SKIP to Q13] [IF YES, "how good is the primary care team at...]</i>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
12b. Asking about the things in life that are important to you:	_____	
13a. Has your primary care team, including your doctor, asked about your spiritual or religious beliefs? <i>[IF 'NO' SKIP to Global Communication Subscale] [IF YES, "how good is your primary care team at...]</i>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
13b. Asking about your spiritual or religious beliefs:	_____	

B.2: Adapted Quality of Communication Scales for Family Caregivers, Fielded in Efficacy Trial		
“Using the following scale where ‘0’ is the worst you can imagine, and ‘10’ is the best you could imagine, please tell me the best number for each statement. When talking with the primary care doctor and their team about important issues like becoming ill, how good are they at:		
General Communication Subscale:		
1. Using words that your [RELATIONSHIP] can understand:	_____	
2. Looking your [RELATIONSHIP] in the eye:	_____	
3. Answering all questions about your [RELATIONSHIP]’s illness and treatment:	_____	
4. Listening to what your [RELATIONSHIP] has to say:	_____	
5. Caring about your [RELATIONSHIP] as a person:	_____	
6. Giving your [RELATIONSHIP] his/her full attention:	_____	
EOL Communication Subscale:		
7a. Has your [RELATIONSHIP]’s primary care team, including their doctor, talked with them concerning the possibility that they might get sicker? [IF ‘NO’ SKIP to Q8] [IF YES, “how good is the primary care team at...]	Yes <input type="checkbox"/>	No <input type="checkbox"/>
7b. Talking with your [RELATIONSHIP] about their <u>feelings</u> concerning the possibility that they might get sicker:	_____	
8a. Has your [RELATIONSHIP]’s primary care team, including their doctor, talked with them about the <u>details</u> concerning the possibility that they might get sicker? [IF ‘NO’ SKIP to Q9] [IF YES, “how good is the primary care team at...]	Yes <input type="checkbox"/>	No <input type="checkbox"/>
8b. Talking with your [RELATIONSHIP] about the <u>details</u> concerning the possibility that they might get sicker:	_____	
9a. Has your [RELATIONSHIP]’s primary care team, including their doctor, talked with them about how long they might have to live? [IF ‘NO’ SKIP to Q10] [IF YES, “how good is the primary care team at...]	Yes <input type="checkbox"/>	No <input type="checkbox"/>
9b. Talking to your [RELATIONSHIP] about how long they might have to live:	_____	
10a. Has your [RELATIONSHIP]’s primary care team, including their doctor, talked with them about what dying might be like? [IF ‘NO’ SKIP to Q11] [IF YES, “how good is the primary care team at...]	Yes <input type="checkbox"/>	No <input type="checkbox"/>
10b. Talking to your [RELATIONSHIP] about what dying might be like:	_____	
11a. Has your [RELATIONSHIP]’s primary care team, including their doctor, involved them in treatment discussions about their care? [IF ‘NO’ SKIP to Q12] [IF YES, “how good is the primary care team at...]	Yes <input type="checkbox"/>	No <input type="checkbox"/>
11b. Involving your [RELATIONSHIP] in treatment discussions about their care:	_____	
12a. Has your [RELATIONSHIP]’s primary care team, including their doctor, asked about the things in life that are important to them? [IF ‘NO’ SKIP to Q13] [IF YES, “how good is the primary care team at...]	Yes <input type="checkbox"/>	No <input type="checkbox"/>
12b. Asking about the things in life that are important to your [RELATIONSHIP]:	_____	
13a. Has your [RELATIONSHIP]’s primary care team, including their doctor, asked about their spiritual or religious beliefs? [IF ‘NO’ SKIP to Global Communication Subscale] [IF YES, “how good is the primary care team at...]	Yes <input type="checkbox"/>	No <input type="checkbox"/>
13b. Asking about your [RELATIONSHIP]’s spiritual or religious beliefs:	_____	

C. Demographics of Patients and Family in Pilot and Efficacy Trial

	Pilot		Efficacy Trial	
	Patients (n=13)	Family (n=13)	Patients (n=43)	Family (n= 43)
Age				
Years, <i>Mean, (SD)</i>	84 (3.84)	66 (14.68)	86 (4.62)	67 (12.94)
Gender				
Male	38%	31%	56%	23%
Female	62%	69%	44%	77%
Race*				
Non-Hispanic White	92%	84%	74%	79%
Black	8%	8%	12%	14%
Asian	--	--	5%	2%
Other/Unspecified	--	8%	9%*	5%
Modified Telephone Interview for Cognitive Status (TICS-M) Score**				
No Discernible Impairment (score > 31)	46%	--	28%	--
Mild Impairment (score = 28-31)	31%	--	26%	--
Severe Impairment (score < 28)	23%	--	46%	--
Family Relationship to Patient				
Adult Child	--	46%	--	51%
Spouse	--	39%	--	42%
Other	--	15%	--	7%

*"Other/Unspecified" includes item nonresponse about race for n=2 patients in the efficacy trial.

**All patients enrolled in the study were deemed eligible on the basis of incorrectly responding to two or more items on the Six-Item Screen, a telephone screening instrument which has been validated to identify probable cognitive impairment for the purposes of clinical research enrollment.

D.1 Patient and Family Responses to Original QOC in Pilot Phase Work

	Patients (n=13)				Family (n=13)			
	Doctor Did Not Do (%)	Don't Know (%)	Numeric (%)	Mean Rating, including Numeric Substitutions (SD)	Doctor Did Not Do (%)	Don't Know (%)	Numeric (%)	Mean Rating, including Numeric Substitutions (SD)
Using words that you can understand	0%	0%	100% (n=13)	9.23 (1.17)	0%	0%	100% (n=13)	9.23 (0.83)
Looking you in the eye	0%	8% (n=1)	92% (n=12)	9.76 (0.60)	0%	15% (n=2)	85% (n=11)	9.54 (0.66)
Answering all your questions about your illness and treatment	0%	0%	100% (n=13)	9.69 (0.85)	0%	8% (n=1)	92% (n=12)	9.62 (0.77)
Listening to what you have to say	0%	0%	100% (n=13)	9.62 (0.87)	0%	0%	100% (n=13)	9.69 (0.75)
Caring about you as a person	0%	8% (n=1)	92% (n=12)	9.77 (0.44)	0%	8% (n=1)	92% (n=12)	9.85 (0.55)
Giving you his/her full attention	0%	0%	100% (n=13)	9.85 (0.38)	0%	0%	100% (n=13)	9.69 (0.75)
General Communication Summary Measures*	0% (0/78)	3% (2/78)	97% (76/78)	9.65 (0.34)	0% (0/78)	5% (4/78)	95% (74/78)	9.60 (0.58)
End of Life (EOL) Subscale:								
Talking with you about your feelings concerning the possibility that you might get sicker	46% (n=6)	0%	54% (n=7)	5.08 (4.96)	0%	31% (n=4)	69% (n=9)	9.00 (0.91)
Talking with you about the details concerning the possibility that you might get sicker	54% (n=7)	0%	46% (n=6)	4.54 (5.11)	0%	31% (n=4)	69% (n=9)	9.00 (0.91)

Talking with you about how long you might have to live	69% (n=9)	15% (n=2)	15% (n=2)	1.54 (3.76)	46% (n=6)	31% (n=4)	23% (n=3)	1.85 (3.67)
Talking with you about what dying might be like	69% (n=9)	8% (n=1)	23% (n=3)	1.38 (3.40)	46% (n=6)	31% (n=4)	23% (n=3)	1.62 (3.55)
Involving you in treatment discussions about your care	0%	15% (n=2)	85% (n=11)	9.54 (0.78)	0%	23% (n=3)	77% (n=10)	9.62 (0.77)
Asking about the things in life that are important to you	31% (n=4)	0%	69% (n=9)	5.77 (4.38)	8% (n=1)	46% (n=6)	46% (n=6)	7.69 (2.56)
Respecting your spiritual or religious beliefs	69 % (n=9)	0%	31% (n=4)	1.77 (3.75)	38% (n=5)	31% (n=4)	31% (n=4)	2.38 (3.84)
EOL Subscale Summary Measures*	48% (44/91)	5% (5/91)	46% (42/91)	4.23 (2.86)	20% (18/91)	32% (29/91)	48% (44/91)	5.88 (1.36)

*General Communication and EOL Subscale Summary Measures were calculated as following:

For response options, the proportion of response type across all responses was calculated by calculating the count by response type over the total number of items fielded in the subscale across all participants in a given group (ex: there were 29 “Don’t Know” responses out of 91 total EOL subscale items fielded across all family respondents, totaling 32% of all responses on this subscale for this group);

For mean rating, each respondent’s mean item rating across all subscale items was calculated, and these mean item ratings were averaged across all respondents.

D.2 Patient and Family Responses to QOC with Adapted EOL Subscale in Efficacy Trial

	Patients (n=37*)				Family (n=43)			
	No/ Doctor Did Not Do (%)	Yes, Don't Know (%)	Yes, Numeric (%)	Mean Rating including Numeric Substitution (SD)	No/ Doctor Did Not Do (%)	Yes, Don't Know (%)	Yes, Numeric (%)	Mean Rating including Numeric Substitution (SD)
Using words that you can understand	0%	0%	100% (n=37)	9.11 (1.17)	0%	2% (n=1)	98% (n=42)	8.53 (1.83)
Looking you in the eye	0%	0%	100% (n=37)	9.08 (1.32)	0%	7% (n=3)	93% (n=40)	8.88 (1.59)
Answering all questions about your illness and treatment	0%	0%	100% (n=37)	9.32 (1.20)	0%	2% (n=1)	98% (n=42)	9.21 (1.23)
Listening to what you have to say	0%	0%	100% (n=37)	9.51 (1.07)	0%	2% (n=1)	98% (n=42)	9.05 (1.69)
Caring about you as a person	0%	5% (n=2)	95% (n=35)	9.43 (1.17)	0%	2% (n=1)	98% (n=42)	9.09 (1.49)
Giving you his/her full attention	0%	3% (n=1)	97% (n=36)	9.32 (1.29)	0%	2% (n=1)	98% (n=42)	9.21 (1.21)
GC Subscale Summary Measures**	0%	1% (3/222)	99% (219/222)	9.30 (1.08)	0%	3% (8/258)	97% (250/258)	9.00 (1.30)
End of Life (EOL) Subscale:								
Has your primary care team talked with you about your feelings concerning the possibility that you might get sicker?	86% (n=32)	0%	14% (n=5)	1.26 (3.30)	79% (n=34)	0%	21% (n=9)	1.74 (3.59)
Has your primary care team talked with you about the details concerning the possibility that you might get sicker?	84% (n=31)	0%	16% (n=6)	1.57 (3.63)	81% (n=35)	0%	19% (n=8)	1.58 (3.50)

Has your primary care team talked with you about how long you might have to live?	100% (n=37)	0%	0%	0.00	95% (n=41)	0%	5% (n=2)	0.35 (1.69)
Has your primary care team talked with you about what dying might be like?	100% (n=37)	0%	0%	0.00	98% (n=42)	0%	2% (n=1)	0.23 (1.52)
Has your primary care team involved you in treatment discussions about your care?	22% (n=8)	5% (n=2)	73% (n=27)	7.38 (4.08)	19% (n=8)	0%	81% (n=35)	7.14 (3.67)
Has your primary care team asked about the things in life that are important to you?	51% (n=19)	0%	49% (n=18)	4.62 (4.86)	51% (n=22)	0%	49% (n=21)	3.93 (4.44)
Has your primary care team talked with you about your spiritual or religious beliefs?	92% (n=34)	0%	8% (n=3)	0.73 (2.52)	91% (n=39)	0%	9% (n=4)	0.84 (2.66)
EOL Subscale Summary Measures**	76% (198/259)	1% (2/259)	23% (59/259)	2.23 (1.74)	73% (221/301)	0%	27% (80/301)	2.26 (1.89)

* For 6 of the original 43 patients, patient responses were unable to be collected due to communication deficits resulting from severe cognitive impairment

**General Communication and EOL Subscale Summary Measures were calculated as following:

For response options, the proportion of response type across all responses was calculated by calculating the count by response type over the total number of items fielded in the subscale across all participants in a given group (ex: there were 29 “Don’t Know” responses out of 91 total EOL subscale items fielded across all family respondents, totaling 32% of all responses on this subscale for this group);

For mean rating, each respondent’s mean item rating across all subscale items was calculated, and these mean item ratings were averaged across all respondents.