

Supplemental Table 1: Full Interview Questions for Caregivers of both Typically Developing Children and Children with a Rare or Undiagnosed Disease

Question 1	Can you please state your name and age, as well as the name of your family member? What is your relationship to him/her?
Question 2	How does your family balance the needs of [child's name/ relative's name] and the needs of other family members?
Question 3	What do you appreciate about the way that your family works?
Question 4	What do you wish would change in your family? What coping strategies has your family used that might not have been effective?
Question 5	Describe what a typical day looks like in your home.
Question 6	How does being a caregiver affect your physical health?
Question 7	Are you doing anything to maintain your physical health?
Question 8	Are you doing anything to maintain your mental/emotional health?
Question 9	What are the different emotions you experience in this role as a caregiver?
Question 10	Do you talk to your doctor or mental health professionals about your emotional health? Do you discuss feelings of depression, anxiety, or guilt? Do you receive treatment for these feelings?
Question 11	Have you heard of the term "burnout"? What is "burnout" for you? Do you experience caregiver "burnout"? How often?
Question 12	What do you do to take care of yourself during periods of high demands and high stress? Are you able to take a break when you feel as though you need one?
Question 13	Do you get regular respite or a regular break every now and then from caregiving? How often do you get these breaks?
Question 14	Do you receive services from community or government social service organizations? If so, what type of services or resources do you receive from where? How often do you receive them? Do you feel that you receive enough help? What other services would help you?
Question 15	What goals do you have for your family's future? How do you envision your family's future?
Question 16	What was it like for you to talk with me about these things?
Question 17	Is there anything else that we haven't talked about that you would like to speak about regarding how the caregiving process has affected you?

*Note: Adapted from Murphy N.A., Christian B., Caplin D.A., & Young P.C.. The health of caregivers for children with disabilities: caregiver perspectives. Child Care Health Dev. 2007;33(2):180-187.*

Supplemental Table 2: Full Model Links of We-talk and I-talk to Caregiver Well-being

	Perceived Stress	Perceived Stress	Self-Rated Health	Self-Rated Health	Growth	Growth
<i>Predictors</i>	<i>Estimates</i>	<i>Estimates</i>	<i>Estimates</i>	<i>Estimates</i>	<i>Estimates</i>	<i>Estimates</i>
(Intercept)	2.31***	2.34***	75.88***	76.14***	2.71***	3.43***
Rare Disease	0.14*	0.08	-6.44**	-8.38	-0.17	-1.17
Age	-0.01***	-0.01***	0.19**	0.20**		
Male			4.32*	4.85**	-0.42***	-0.39**
We-talk	-0.01	0.05	-0.44	3.62	0.34**	0.27
I-talk	-0.01	-0.02	-1.56*	-2.47	0.09	-0.04
RD*We-talk		-0.07		-4.75		0.09
RD*I-talk		0.03		1.35		0.18
<b>Random Effects</b>						
$\tau_{00}$	0.02 <sub>familyID</sub>	0.02 <sub>familyID</sub>	78.19 <sub>familyID</sub>	76.17 <sub>familyID</sub>	0.26 <sub>familyID</sub>	0.25 <sub>familyID</sub>
N	158 <sub>familyID</sub>	158 <sub>familyID</sub>	158 <sub>familyID</sub>	158 <sub>familyID</sub>	158 <sub>familyID</sub>	158 <sub>familyID</sub>

All models here are hierarchical linear models with caregiver report nested within family. Estimates shown are Beta coefficients  
 \*  $p < 0.05$  \*\*  $p < 0.01$  \*\*\*  $p < 0.001$

Supplemental Table 3: Full Models Examining Links of We-talk and I-talk to Network Structure

	Network Size	Network Size	Primary Caregivers	Primary Caregivers	Kinship	Kinship	Inner Circle	Inner Circle
<i>Predictors</i>	<i>Incidence Rate Ratios</i>	<i>Incidence Rate Ratios</i>	<i>Incidence Rate Ratios</i>	<i>Incidence Rate Ratios</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>
(Intercept)	9.06***	13.56***	1.16	0.69	5.09***	8.58***	1.07	1.10
Rare Disease (RD)	1.14	0.67	1.15	2.23	0.70**	0.35	1.09	1.04
Gender (Male)	0.76***	0.76***			1.38**	1.40**		
Married	1.13*	1.14*			0.60***	0.60***		
Age					1.01**	1.01**		
We-talk	1.07	0.93	1.04	1.32	0.93	0.87	0.84*	0.90
I-talk	1.04	0.98	0.97	1.02	0.99	0.90	0.94	0.92
RD*We-talk		1.19		0.74		1.10		0.93
RD*I-talk		1.07		0.93		1.13		1.02
<b>Random Effects</b>								
$\sigma^2$	0.07	0.07			3.29	3.29	3.29	3.29
$\tau_{00}$	0.15 <sub>familyID</sub>	0.15 <sub>familyID</sub>			0.27 <sub>StudyID</sub>	0.27 <sub>StudyID</sub>	0.22 <sub>StudyID</sub>	0.22 <sub>StudyID</sub>
ICC	0.66	0.67			0.08	0.08	0.06	0.06
N	158 <sub>familyID</sub>	158 <sub>familyID</sub>			307 <sub>StudyID</sub>	307 <sub>StudyID</sub>	311 <sub>StudyID</sub>	311 <sub>StudyID</sub>
Observations	306	306	311	311	4336	4336	4401	4401
Marginal R <sup>2</sup> / Conditional R <sup>2</sup>	0.105 / 0.698	0.112 / 0.706	0.023	0.033	0.024 / 0.098	0.025 / 0.098	0.003 / 0.067	0.003 / 0.067

Notes: Models differ by outcome: network size (2-level hierarchical poisson model nested with family cluster), primary caregivers (poisson regression), kin and inner circle (2-level hierarchical binomial models nested within caregiver). \*  $p < 0.05$  \*\*  $p < 0.01$  \*\*\*  $p < 0.001$ . \*  $p < 0.05$  \*\*  $p < 0.01$  \*\*\*  $p < 0.001$

Supplemental Table 4: Full Models Examining Links of We-talk and I-talk to Network Member Caregiving Involvement

	CG Health Comm	CG Health Comm	NM Health Comm	NM Health Comm	Malfeasance	Malfeasance	Nonfeasance	Nonfeasance	Uplift	Uplift
<i>Predictors</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>	<i>Odds Ratios</i>	<i>Incidence Rate Ratios</i>	<i>Incidence Rate Ratios</i>
(Intercept)	0.02**	1.34	0.06 **	0.23	0.30*	0.38	0.14**	0.35	2.38***	3.68***
Rare Disease	22.06***	0.06	7.39 ***	1.16	1.22	0.89	1.64	0.47	0.98	0.55
Age	0.97*	0.97*			0.98*	0.98*	0.97**	0.97**		
Married	1.40	1.47								
We-talk	3.66***	1.69	1.40	1.32	0.98	1.03	0.60*	0.63	1.19*	1.04
I-talk	1.17	0.59	1.11	0.86	0.89	0.85	1.09	0.91	0.96	0.91
RD*We-talk		2.91		1.10		0.95		0.96		1.17
RD*I-talk		2.68 **		1.42		1.08		1.29		1.09
<b>Random Effects</b>										
$\sigma^2$	3.29	3.29	3.29	3.29	3.29	3.29	3.29	3.29	0.35	0.35
$\tau_{00}$	6.32 <small>StudyID</small>	6.14 <small>StudyID</small>	6.19 <small>StudyID</small>	6.16 <small>StudyID</small>	2.33 <small>StudyID</small>	2.33 <small>StudyID</small>	3.48 <small>StudyID</small>	3.46 <small>StudyID</small>	0.36 <small>StudyID</small>	0.36 <small>StudyID</small>
ICC	0.66	0.65	0.65	0.65	0.41	0.41	0.51	0.51	0.51	0.51
N	307 <small>StudyID</small>	307 <small>StudyID</small>	311 <small>StudyID</small>	311 <small>StudyID</small>	307 <small>StudyID</small>	307 <small>StudyID</small>	307 <small>StudyID</small>	307 <small>StudyID</small>	311 <small>StudyID</small>	311 <small>StudyID</small>
Observations	4336	4336	4401	4401	4336	4336	4336	4336	4401	4401
Marginal R <sup>2</sup> / Conditional R <sup>2</sup>	0.226 / 0.735	0.249 / 0.738	0.079 / 0.681	0.083 / 0.681	0.014 / 0.423	0.014 / 0.423	0.031 / 0.529	0.034 / 0.529	0.018 / 0.520	0.021 / 0.519

Notes: All models reported are 2-level hierarchical linear models with network member outcomes nested within caregiver. Covariate selection was chosen by those demographic variables that are linked to both the independent and dependent variables. CG Health Comm refers to caregiver-initiated health related communication while NM Health Comm refers to network member initiated health communication. \*  $p < 0.05$  \*\*  $p < 0.01$  \*\*\*  $p < 0.001$ .