Caregivers as Surrogate Decision Makers for Patients with Serious Illness

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Organization for Comments

Important observation about the power of family caregiving in the hospital (outside my direct area of expertise)

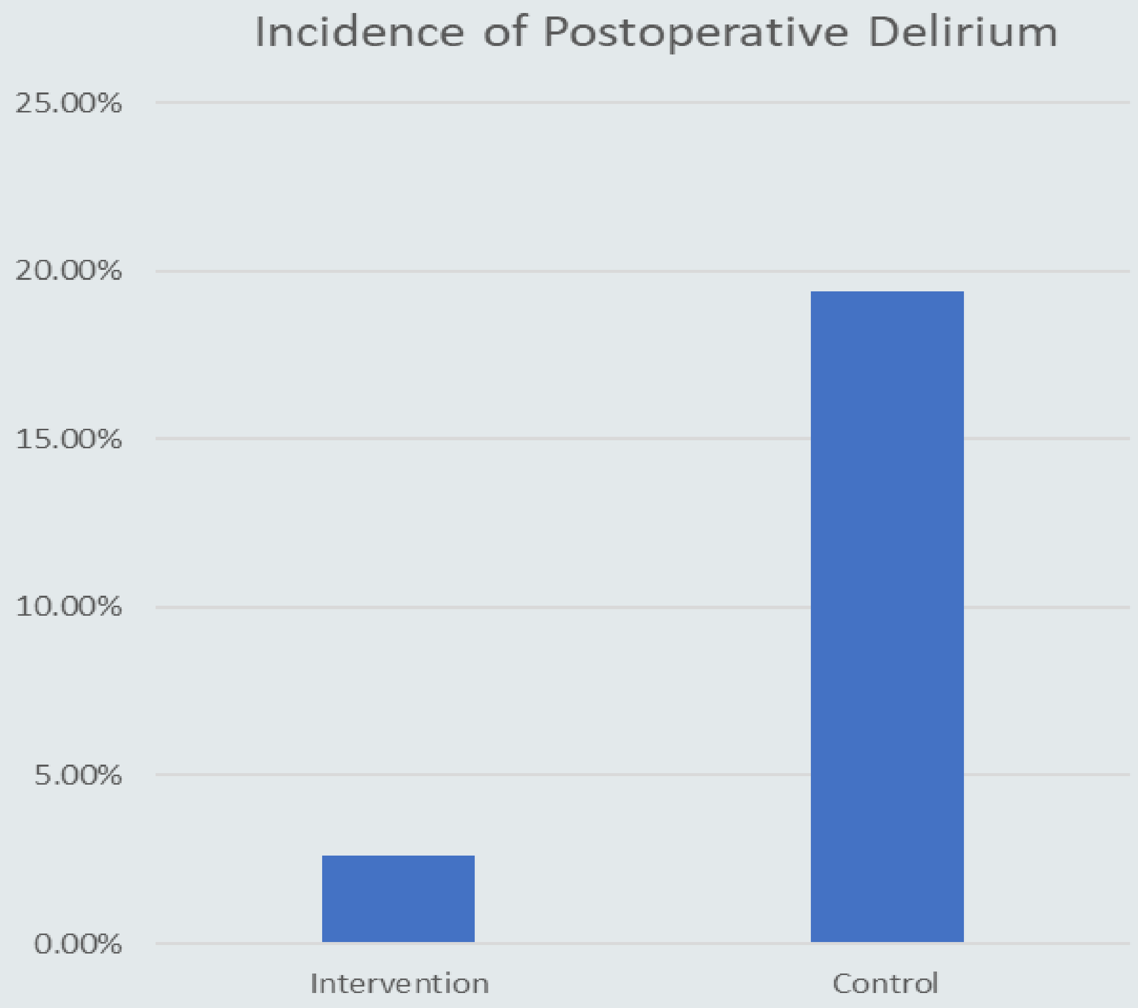
Caregivers as surrogate decision makers

- Their needs for information and for support
- Meeting these needs

Caregivers and effectiveness of delirium prevention

Multidisciplinary intervention can prevent delirium in at-risk hospitalized patients: Hospital Elder-Life Program (HELP)

HELP tailored to include family members as part of the treatment in RCT conducted in China among postoperative patients age 70 and older



Wang Y-Y, et al. JAMA Intern Med 180:17-25, 2020

Caregivers as Surrogate Decision Makers

Responsibility of the medical team to prepare caregivers to serve as surrogate decision makers

Recognition of the stress and burden of decision making

Facilitation of communication between patients and caregivers

Preparation for in-the-moment decision making

Surrogate decision making and caregiver outcomes:

Proportion of family members of ICU patients with PTSD at 90 days after death or discharge: 33%

Proportion of family members involved in end-of-life decisions with PTSD: 60%

Azouley E, et al. Am J Resp Crit Care 171:987-94, 2005

Caregivers of seriously ill patient want more communication…

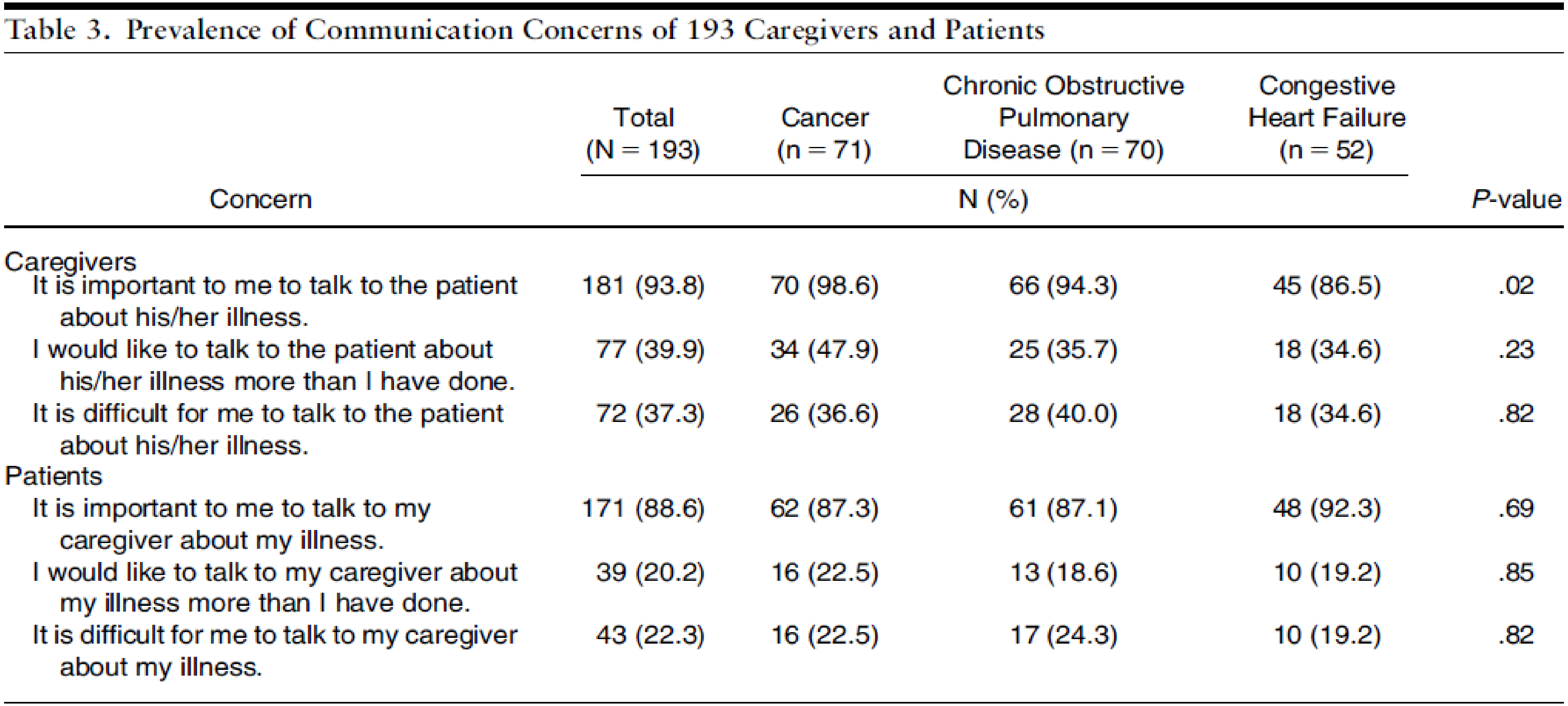
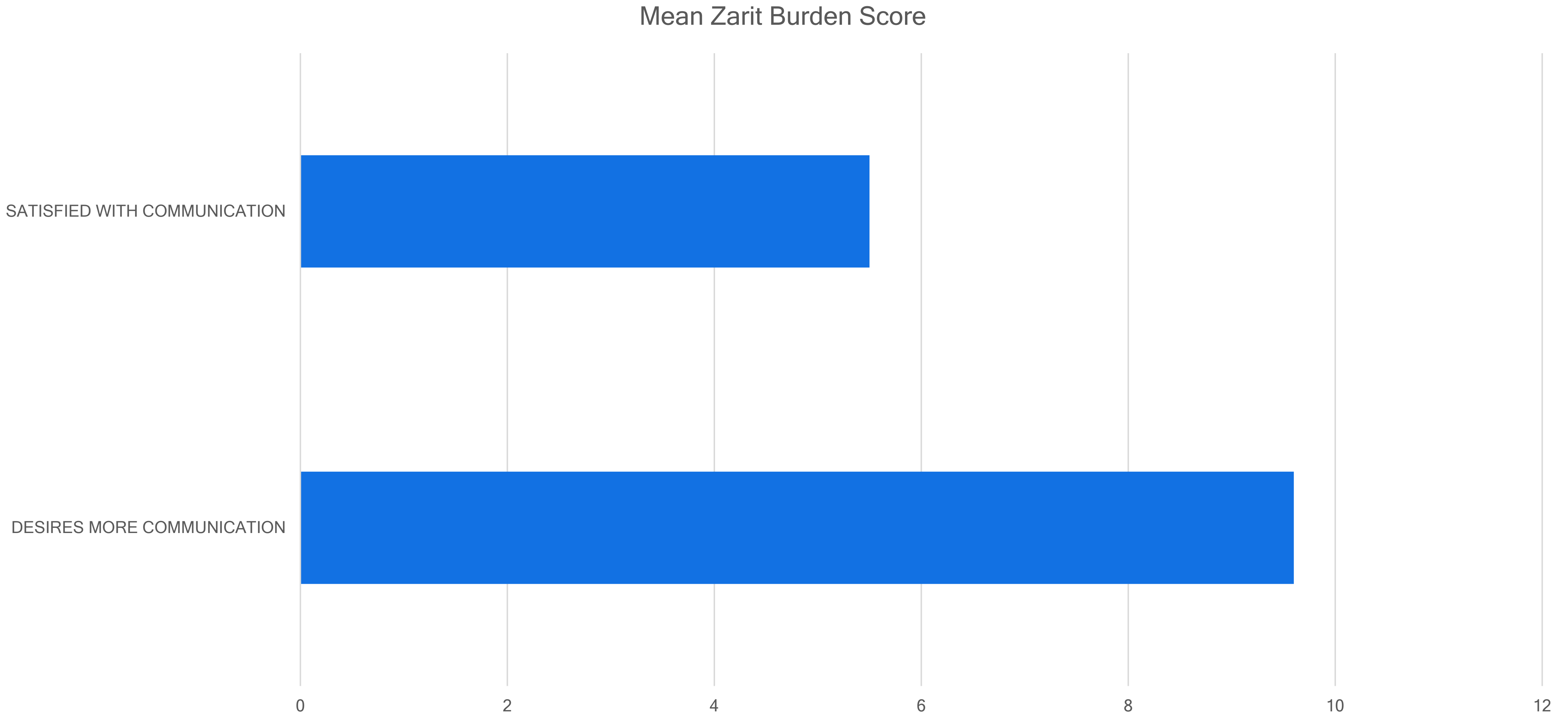


Table 3. Prevalence of Communication Concerns of 193 Caregivers and Patients

Concern	Total (N = 193)	Cancer (n = 71)	Chronic Obstructive Pulmonary Disease (n = 70)	Congestive Heart Failure (n = 52)	P-value
	N (%)				
Caregivers					
It is important to me to talk to the patient about his/her illness.	181 (93.8)	70 (98.6)	66 (94.3)	45 (86.5)	.02
I would like to talk to the patient about his/her illness more than I have done.	77 (39.9)	34 (47.9)	25 (35.7)	18 (34.6)	.23
It is difficult for me to talk to the patient about his/her illness.	72 (37.3)	26 (36.6)	28 (40.0)	18 (34.6)	.82
Patients					
It is important to me to talk to my caregiver about my illness.	171 (88.6)	62 (87.3)	61 (87.1)	48 (92.3)	.69
I would like to talk to my caregiver about my illness more than I have done.	39 (20.2)	16 (22.5)	13 (18.6)	10 (19.2)	.85
It is difficult for me to talk to my caregiver about my illness.	43 (22.3)	16 (22.5)	17 (24.3)	10 (19.2)	.82

Fried TR, et al. J Am Geriatr Soc 53:59-65, 2005

…and desire for communication is associated with increased burden



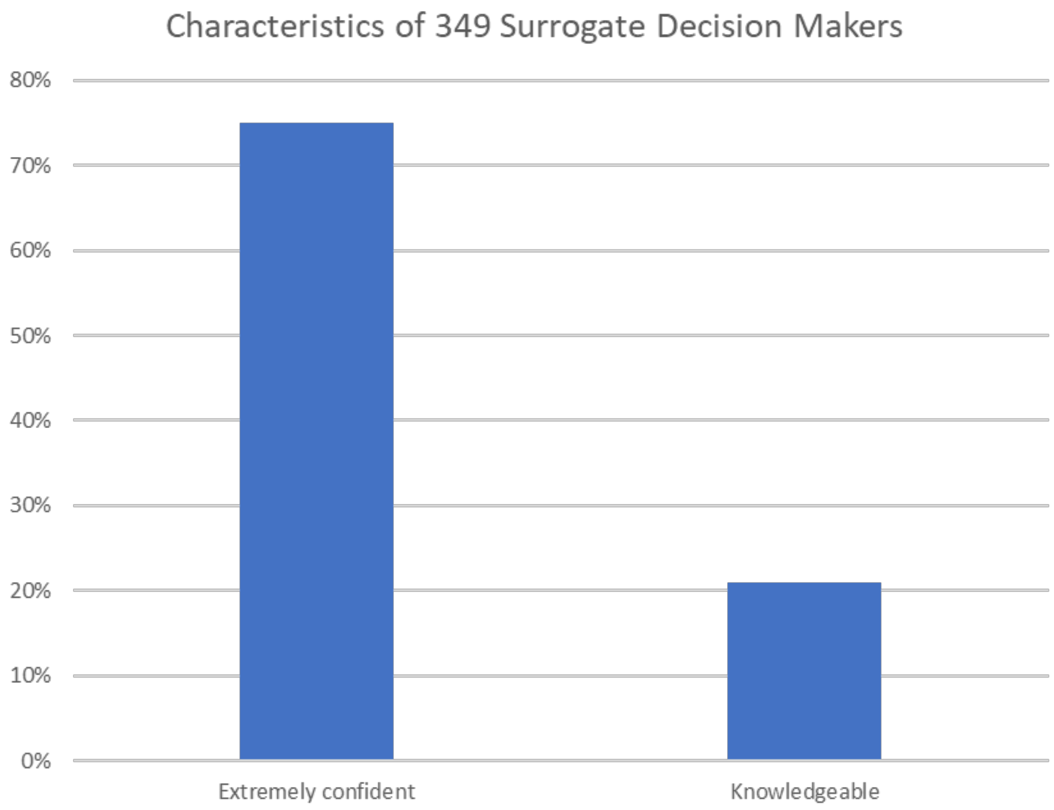
Missed Opportunities for Communication

But what I didn’t know until after he had died – two weeks before he died, he called my sister in Long Island and told her he wasn’t going to be around much longer. He knew he was going but he didn’t want to tell me because I’d get mad at him.... I just wanted him to fight, and he just wanted to tell her what he felt for me.

The social worker from Hospice came to talk to me, and I found out after he died that he already knew he was dying, but he did not want to tell me, and I did not want him to know that I knew he was dying, so I told them not to say anything. So, between the two of us, we were trying to keep each other from knowing that he was dying.

Fried TR, et al. JGIM 23:1602-07, 2008.

Caregivers Overestimate Their Ability to Make Surrogate Decisions



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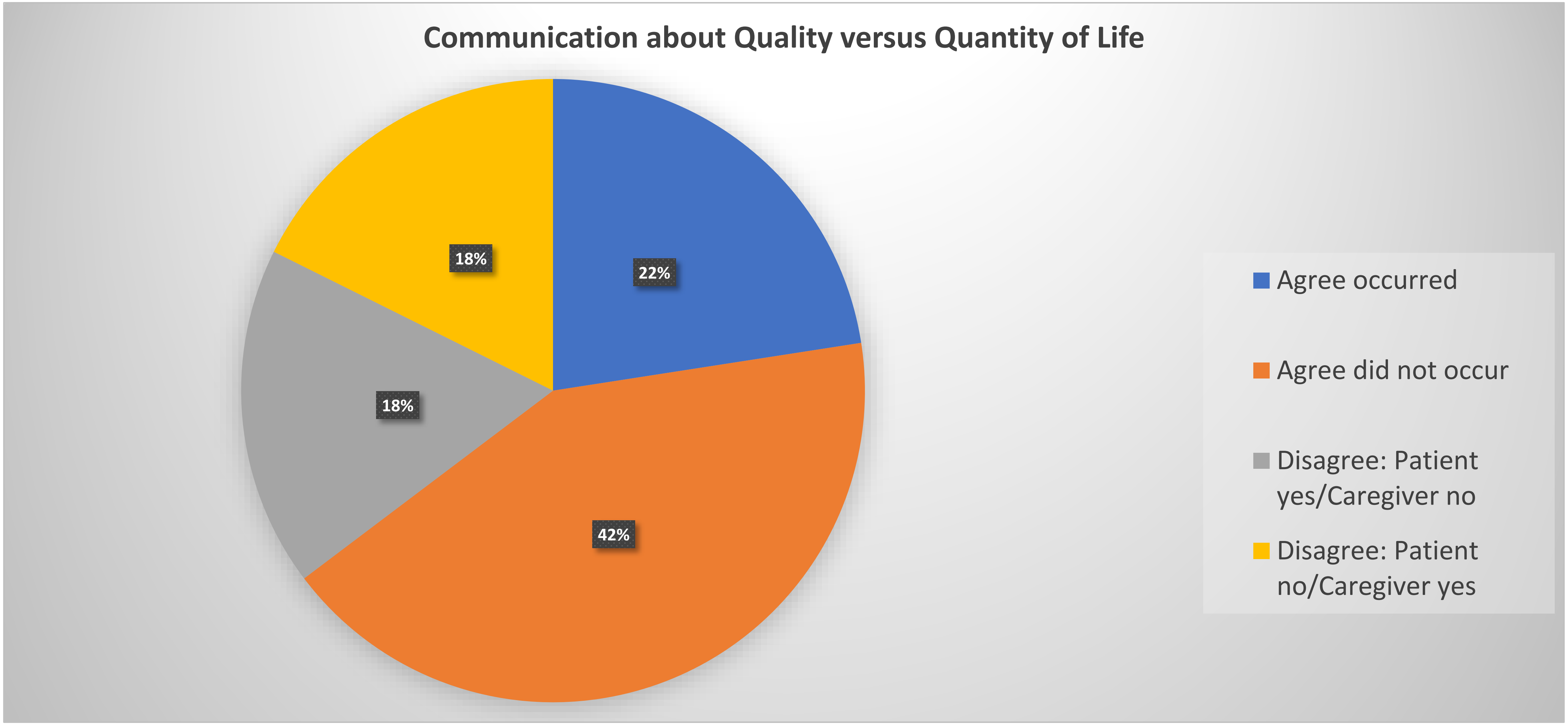
Fried TR, et al. JAMA Intern Med 179:267-268;2018

Caregivers and Patients Need Help Overcoming Barriers to Communication



Fried TR, et al. J Am Geriatr Soc 65:1712-1718; 2017

What Wise Caregivers Have to Say

He knows that he does not want life support but he doesn't understand the fact that there can be illness that you can still live but will affect the way you live.

The whole issue of life support, to me anyway, is at what point the person does not want continued life support or even life support to be initiated?. . ..How compromised do you have to be? What chances are there for any level of recovery? All of those things play into it and that we have never discussed.

: Fried TR, et al. J Am Geriatr Soc 65:172-178; 2017

Preparing Patient and Caregivers for “In-the Moment” Decision Making

- Purpose of advance care planning (ACP) is NOT having patients make treatment decisions in advance

    - Preferences change

    - Best interests change

    - Most patients want their caregivers’ needs to be taken into account

- Instead, patients and caregivers need to be encouraged to discuss “what matters most” at the end of life. What will the final illness trajectory look like? When is life no long worth living? How much leeway do caregivers get?