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Medical Decisions Made by Surrogates for Persons with Advanced Dementia within Weeks or Months of Death

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Abstract

Background—Surrogates make all medical decisions for persons with advanced dementia. This study describes the types of medical decisions that surrogates faced prior to the person's death and their perceived difficulty and satisfaction with those decisions.

Methods—Seventy-six surrogates of nursing home residents meeting hospice criteria for dementia were followed longitudinally and interviewed following the death of the person with dementia.

Results—The most common decisions made were related to transfer to hospital, diagnostic testing, and placement of a feeding tube. Surrogates perceived decisions to not treat to be more difficult than decisions to treat.

Conclusions—Surrogates frequently are faced with making medical decisions for persons with advanced dementia near the end of life. Clinicians can help surrogates by acknowledging the difficulty of making decisions to not treat.

Keywords

Dementia; Surrogate decision making; End-of-life care

Introduction

The predominant trajectory of people with advanced dementia is persistent, severe disability (Gill et al 2010). Alzheimer disease is listed as the sixth leading cause of death in the US, and at the time of their death, a majority of individuals with Alzheimer disease and dementia reside in long term care settings (Mitchell et al 2005). The care of individuals with advanced dementia raises several unique clinical and ethical concerns that deserve scrutiny (van der Steen 2010; Rabins and Black 2010). First, because most, if not all, individuals with advanced dementia lack decisional capacity, decisions about their health care must be made

by others. This limits the individuals' ability to make medical decisions based on their values and wishes (autonomy). Furthermore, the lack of decisional capacity means that individuals who have previously executed an advance directive cannot change these prior expressed or documented wishes although some capacitated individuals do so in the face of severe illness (Rosenfeld et al 1996). While advance directives do provide a mechanism for preserving autonomy before a person loses the capacity to decide, the disease robs the person of the ability to make or change a decision based on the facts surrounding a specific decision. Third, because the majority of people with advanced dementia reside in facilities, the detection and assessment of a worsening of their status is usually carried out by facility nursing staff rather than a family member or previously appointed surrogate. This may present a further barrier to carrying out the wishes of the person with dementia.

A large body of work has demonstrated that a high proportion of health care costs are incurred within the final year of life. While there are specific hospice criteria for dementia, the ability to predict death is not well established. Non-specific symptoms such shortness of breath, poor oral intake, bowel incontinence and not being awake most of the day (Mitchell et al 2004) and a single episode of pneumonia (Hicks, Rabins, and Black 2011) are better predictors of death within 6 months than specific cognitive symptoms of dementia. Difficulty in accurately prognosticating is a barrier to the appropriate use of hospice care for people with dementia (McCarty & Volicer, 2009).

To examine how surrogates make decisions for persons with advanced dementia, we longitudinally studied a cohort of individuals meeting hospice criteria for dementia in the CareAD study (Black et al 2006). Here we report on the medical decisions made within 6 months of death for subjects who died during the follow-up portion of the study, the consistency of these decisions as reported by the surrogate decision maker, and the surrogates' perception of the difficulty of and satisfaction with the decisions they made.

Methods

The CareAD study was conducted from 2000 to 2005 and has been described in detail elsewhere (Black et al 2006). In brief, 123 individuals meeting hospice criteria for dementia were identified in three long term care facilities in Maryland. The inclusion criteria for the study were meeting hospice criteria for dementia (Stuart and Alexander, 1996), having an available surrogate decision maker who also agreed to participate as a research subject, and having a physician who agreed to our contacting the surrogate to request participation. Informed consent for the participation of the person with dementia was obtained from the surrogate identified in the chart as their medical decision maker. Surrogates were also research participants and informed consent was obtained from them. The study was approved by the Johns Hopkins School of Medicine Institutional Review Board.

Persons with dementia were assessed and their surrogates were interviewed at entry and every three months thereafter until the death or discharge of the person with dementia or the end of the study. Information gathered at baseline included demographics, illness history, availability and content of advance directives, and surrogates' well-being. At each interview, surrogates were asked about the medical decisions they had made in the prior three months.

A medical record review was also performed every three months to ascertain medical care provided during that period. After the death of a participant with dementia, the surrogate was re-interviewed and questioned about satisfaction with and difficulty of the most recent medical decisions he or she had made since the surrogate's prior interview.

Results

Ninety-two individuals with dementia (75%) died during the follow up portion of the study. These 92 individuals had a mean age of 82.2 years (SD=7.1) and a mean of 11.6 years (SD=3.4) education. Seventy-seven (84%) were white, 50 (54%) were female, and 34 (37%) had a non-Alzheimer disease diagnosis. Participants averaged 10.6 (SD=9.8) months in the study.

Of the 92 subjects who died, 75 surrogates agreed to be interviewed after the death of the person with dementia. One other surrogate was interviewed two days prior to the death of the person with dementia and these data are included. This provided a total of 76 surrogates who were interviewed and provided the data for this study.

The 16 residents whose surrogates were not interviewed after the death of the participant were similar to the 76 individuals whose surrogates were interviewed based on age ($t=0.92$, $p=.362$), sex ($\chi^2=2.21$, $p=.14$), education ($t=0.82$, $p=.42$), and length of time in study ($t=-0.71$, $p=.48$). Those whose surrogates were interviewed after their death were more likely to be white (88% vs. 62.5%, $\chi^2=6.38$, $p=.012$) and have a non-Alzheimer disease diagnosis (68% vs. 38%, $\chi^2=5.42$, $p=0.20$).

The 76 interviewed surrogate decision makers had a mean age of 61 (SD=12.7). Twenty-two (29%) were spouses, 39 (51%) were children or children-in-law, 11 (14%) were related in other ways to the person with dementia, and 4 surrogates (5%) were not related.

Fifty-seven (75%) of the 76 persons with dementia whose data are included in this paper had at least one type of advance directive; 13 (17%) named a health care agent only, 6 (8%) provided formal health care instructions only, and 38 (50%) both named a health care agent and provided formal health care instructions. In the final interview, 55 surrogates (72%) answered a question about the helpfulness of having an advance directive for the making health care decisions; 44 (80%) found it helped a great deal, 5 (9%) reported that it helped a little, and 6 (11%) found it of no help.

Table 1 lists, from most common to least common, the decisions that surrogates reported making during the time period between the last interview while the person with dementia was living and the death of the person with dementia. This covered a mean period of 7.1 weeks (median=6.7 weeks, range=0.14-26.3 weeks). For all issues except resuscitation, at least one surrogate reported making decisions both for and against an intervention. Because we do not have the dates of specific decisions we are unable to ascertain whether the final decision was more likely to be made *to do* or *not to do* (i. e., limit) that specific test or treatment.

Table 2 lists the number of times surrogates faced making a decision and their rating of the difficulty of and satisfaction with the last decision they made on that issue. To determine whether surrogates' perception of the decision making process was influenced by whether their final decision was *to treat* or *to not treat*, we performed Chi square analyses comparing the surrogates' ratings of difficulty and satisfaction on all treatment decisions they made. The difficulty of making a decision was rated for 214 decisions. Comparing no difficulty to any difficulty, surrogates rated decisions *to treat* as less difficult than decisions *to not treat* ($\chi^2=22.51$, $p<0.001$). Satisfaction was rated for 196 decisions. Comparing very satisfied to not or somewhat satisfied, surrogate-rated satisfaction with their final decision did not vary by whether they chose to treat or to not treat ($\chi^2=0.811$, $p=.37$).

Discussion

More than half of individuals with advanced dementia in this sample were considered for transfer to a hospital for an emergency evaluation or admission during the final months of their life. A range of other medical treatments were offered and decided upon by the surrogate decision makers. Other investigators have also found high rates of hospital transfers in the last six months of life (Lamberg, 2005) and high rates of potentially "burdensome" interventions in the last three months of life (Mitchell et al., 2009) for nursing home residents with advanced dementia. Thus, meeting eligibility criteria for hospice, an indication that the dementia was severe, does not mitigate the fact that serious medical issues arise and that surrogates must make decisions regarding a range of evaluation and treatment options.

Even in the setting of severe dementia, surrogates find it difficult to decide to limit treatment and evaluation, in spite of the fact that a majority had some advance directive available. We believe this is important information for professional care providers, especially those who are presenting the treatment and evaluation options to the surrogate, as this finding suggests that professionals can help support the surrogate by acknowledging the difficulty of the decision. Whether earlier discussion would have mitigated this perceived difficulty cannot be determined from these data. The finding that surrogates report high satisfaction with their decision making process has also been reported by Givens et al (2009), suggesting that existing procedures and social networks often provide meaningful support to surrogates at a difficult time. However, they also found that inadequate support from nursing home providers was the greatest source of dissatisfaction with decision making.

Our findings also support recent recommendations that highlight the complexity of surrogate decision making and the reliance on advance directives in adults lacking decision making capacity (Berger et al, 2008). We agree with Muramoto (2011) that decision making in late stage dementia be construed as a "temporally and socially extended ... collective" process and that it include the perspectives of the patient, family members, named non-family surrogates, and clinicians.

Eighty percent of surrogates who had an advance directive available found them very helpful. This supports the movement to encourage all adults to either appoint a health care agent or to express their specific wishes for care in case they become decisionally

incapacitated (Triplett et al 2008). Nonetheless, the fact that having an advance directive did not eliminate the perceived degree of difficulty for many decisions suggests that there are limits to “prophylactic” discussion of potentially difficult decisions.

Limitations of this study include sample composition (nursing home residents only, from a single geographic area), a relatively small sample size, and exclusion of individuals without an identified surrogate. Also, because the recruitment procedure required several weeks to complete, individuals who died soon after admission to the facilities or screening as eligible could not be included as participants. Strengths of the study include its prospective design, assessments at three month intervals, and access to advance directive documents.

Future studies should examine the impact on the well-being of the person with dementia of the many medical procedures being offered to them (van der Steen et al 2009; Robinson et al 2005), the basis upon which surrogates are making their decisions, and the challenging issue of whether surrogates should be able to override a wish previously expressed by a now permanently incapacitated person.

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Table 1
Surrogate Decisions within the Final Weeks and Months of Life Final Surrogate
Interview Data (n=76)

Type of Treatment	Faced with Decision n (%)	Decided Only For %	Decided Only Against %	Decided For and Against %
Hospital transfer	39 (51.3)	12.8	82.1	5.1
Blood test/ diagnostic test	30 (39.5)	46.7	33.3	20.0
Feeding tube ^B	25 (33.3)	8.0	84.0	8.0
X-ray/ scans	24 (31.6)	70.8	25.0	4.2
Infection treatment ^A	19 (25.0)	57.9	26.3	15.8
Respirator/ ventilator ^B	17 (23.0)	23.5	58.8	17.6
Pneumonia treatment	17 (22.4)	70.6	17.6	11.8
Resuscitate ^B	14 (18.7)	--	100.0	--
Surgery ^B	4 (5.3)	--	75.0	25.0
Oxygen	4 (5.3)	75.0	25.0	--

^A Excludes pneumonia

^B Surrogates did not know if they made the decision: Respirator/vent (n=2), feeding tube (n=1), resuscitate (n=1), surgery (n=1)

Table 2
Frequency, Difficulty, and Satisfaction with Decision Making in the Final Weeks and Months of Life Final Surrogate Interview Data (n=76)

Decisions ^A	Made Decisions n (%)	Number of Times Decision Made ^A n				Difficulty of Making Last Decision ^A n				Satisfaction with Last Decision ^A n			
		1	2	3+	DK	ND	S/V	D	DK	N/S	S	VS	DK
		To Treat											
To do blood/dx tests	20 (26.3)	7	5	5	3	16	4			7	13		
To do x-rays/scans	18 (23.7)	14	4			18				3	14		1
To treat infection ^C	14 (18.4)	10	1	3		12	2			4	10		
To treat pneumonia	14 (18.4)	13	1			12	2			3	10		1
To send to hospital	7 (9.2)	5	2			7				1	6		
To use resp/vent ^B	7 (9.5)	6	1			5	2			2	5		
To use feeding tube	4 (5.3)	3	1			4				2	2		
To provide oxygen	3 (3.9)	3				3					3		
To perform surgery	1 (1.3)		1				1			1			
To admit to another NH	1 (1.3)	1					1			1			
To Not Treat/ Limit Tx													
Not to send to hospital	34 (44.7)	30	4			20	14			5	26		3
Not to use feeding tube ^B	23 (30.7)	22	1			12	11			5	16		2
Not to do blood/dx tests	16 (21.1)	12	2	2		8	8			1	13		2
Not to resuscitate ^B	14 (18.7)	13	1			9	5			5	7		2
Not to use resp/vent	13 (17.1)	12	1			6	7			4	7		2
Not to treat infection ^C	8 (10.5)	8				5	3			2	5		1
Not to do x-rays/scans	7 (9.2)	6			1	5	2				5		2
Not to treat pneumonia	5 (6.6)	5				2	3			1	3		1
Not to perform surgery ^B	4 (5.3)	3	1			2	2			1	2		1
To remove oxygen	1 (1.3)	1				1					1		

^A Abbreviations: NH 'Nursing Home', DK 'Don't know', ND 'Not difficult', S/V D 'Somewhat or very difficult', N/S S 'Not or somewhat satisfied', and VS 'Very satisfied'.

^B Surrogates did not know if they made the decision: Respirator/vent (n=2), feeding tube (n=1), resuscitate (n=1), surgery (n=1)
^C Excludes pneumonia.