

Force-Feeding and Resuscitation of Patients with Advanced Dementia: A Public Opinion Study

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ABSTRACT: **Background:** The treatment of advanced dementia patients is very complex and presents a difficult dilemma for physicians, and especially for the patient's family. In many cases, when the advanced dementia patient has no decisional capacity, the family needs to decide about force-feeding and resuscitation for their relative.

Objectives: To examine public opinion regarding force-feeding and resuscitation of patients with advanced dementia.

Methods: Data from 1002 people who accompanied a patient to a hospital emergency department in Israel were collected and analyzed.

Results: We noted the following results: the more religious the orientation of the respondents, the more likely they were to agree to forcefully feed and resuscitate advanced dementia patients and advanced dementia patients older than 80 years; those accompanying younger patients were more likely to think that the medical staff should resuscitate advanced dementia patients and advanced dementia patients older than 80 years compared to those accompanying elderly patients; younger people were more likely than older people to agree to force-feed and resuscitate patients.

Conclusions: This paper attempts to provide decision-makers and medical staff with some knowledge about public opinion regarding a sensitive and complex issue. This awareness may guide physicians in making critical medical decisions about those with dementia.

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KEY WORDS: advanced dementia, force-feeding, religiosity and medical treatment, resuscitation patients, treatment

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded [1]. Aging is closely linked to the development of dementia and cognitive impairment. Older people are more likely to suffer from these conditions, and the prevalence of severe cognitive impairment is rising [2]. Unlike the dying trajectory in more acute illnesses, individuals with dementia are severely impaired,

both functionally and cognitively, for a prolonged period before death with many manifesting difficulties in swallowing, leading to poor oral intake, malnutrition, weight loss, and recurrent episodes of aspiration pneumonia [3]. According to a study by Prince and colleagues [4], 46.8 million people worldwide were living with dementia in 2015. This number is expected to almost double every 20 years, with 74.7 million cases by 2030 and 131.5 million by 2050. In 2015, 58% of all people with dementia were living in low- and middle-income countries; this amount is expected to rise to 63% by 2030 and 68% by 2050.

In the final stages of dementia, patients are typically unable to walk or feed themselves, they are incontinent and aphasic, and they have lost the capacity to relate to other people. One of the marked changes in advanced dementia patients is their resistance to eating. Previous studies that examined the opinions of the elderly about feeding options and medical treatments if they were to develop dementia found that most of the respondents would refuse to be forcibly fed. Almost all those who were questioned expressed their wish to write a detailed will about the future treatment they would like to receive if they become dementia patients. Their basic request was to receive minimal medical support and feeding when life extension would cause unnecessary suffering for the patient and the family [5]. Dementia was found to be one of the clinical characteristics of older adults who were assessed in Israeli emergency departments due to deliberate self-harm [6].

As the population ages, a large and increasing number of people are caring for a relative or friend with dementia. In many cases, when the advanced dementia patient is unqualified to decide, families need to decide about force-feeding and resuscitation for their demented relative. The treatment in advanced dementia patients is very complex in many ways and presents a difficult dilemma for the physicians and especially for families. Jox and colleagues [7] found that most family members had thought about limiting life-sustaining treatment. Most based their treatment decisions on the patient's well-being, and very few relied on the patient's previously expressed wishes. Another study assessing family opinions about relatives of those with brain injuries showed that some described the current condition of their relative as, "a fate worse than death" [8].

Family members of persons with advanced dementia may be asked to make complex treatment decisions without adequate

knowledge regarding the risks and benefits. These family members, who were primarily involved in assisting the dementia patient, emphasized the practical and emotional importance of receiving the perspective of other family members, some of whom may not be so immediately involved in taking care of the patient, as well as support from professionals and voluntary organizations, in making decisions. Such support is not always available. Livingston and co-authors [9] found that dementia patient family members who participated in focus groups showed increased levels of regret if they had requested aggressive end-of-life interventions. As the state of the dementia patient deteriorates, families undergo varying degrees of feelings of loss, depression, anxiety, guilt, frustration, and hopelessness. Often, they do not get an opportunity to express these feelings since they are too busy with caring for the patient and fear being judged [9].

The effect of an intervention consisting of face-to-face conversations about end-of-life care options with family members of nursing home residents with advanced dementia supports the importance of increased education and support for families [10]. Lack of adequate clinical information and poor documentation about the preferences of patients and relatives hinders good decision-making of the general practitioner [11]. End-of-life decision-making includes families and clinicians, but not necessarily the patients themselves, sometimes explicitly marginalizing the previous decisions of the patient [12]. Despite the very large number of dementia patients receiving enteral tube feeding, there is insufficient evidence to suggest that this feeding is beneficial to patients with advanced dementia. Some studies have shown that in elderly individuals with dementia and eating problems, long-term feeding increases the risk of mortality and should be discouraged [13]. Feeding seldom achieves the intended medical aims, and rather than prevent suffering, it can cause it [14]. Family opinions that regard eating as symbolic of caregiving in our society and family concerns that without adequate intake, patients will suffer from hunger or thirst, impact their force-feeding-related decisions.

Unfortunately, the preferences of the patients with advanced dementia about the treatment they will get are seldom known. Therefore, family members are often required to make the difficult decisions about the treatment their relative is to receive. Religion and culture are factors that influence the decision about force-feeding, leading to different prevalence of force-feeding in different countries. In a study that covered six hospitals in Canada and Israel, Clarfield and colleagues [15] found that the prevalence of tube feeding for end-stage dementia patients in Israeli hospitals was 51.9%, significantly higher than 19.6% in Jewish-affiliated Canadian hospitals and dramatically higher than 3.2% in Canadian hospitals that are not Jewish affiliated. Like in Canada, low prevalence is common in Western societies like the Netherlands [16] while high prevalence is common in Chinese culture like in Hong Kong [17].

The current study examines opinions of those accompanying a patient to the emergency department in an Israeli hospital, regarding force-feeding patient (when they refuse to eat) and to resuscitating patients (when they enter a life-threatening condition) with advanced dementia. Our research study focuses on the following demographic parameters: religiosity of the accompanying individual, the patient's age, and the age of the person accompanying the patient (the survey respondent). The study examines whether these demographic parameters impact opinion.

PATIENTS AND METHODS

The current research is part of a wider study on healthcare in Israeli hospitals. The data were collected from 1002 people who accompanied a patient to a hospital emergency department 6 months prior to when the study was conducted. The data were collected randomly from an internet panel comprising more than 50,000 people over the age of 18 years. The rationale for using a sample from among those accompanying a patient was to determine the reasoning behind the decisions of whether to force-feed and resuscitate patients with advanced dementia.

The sample included 1002 people who accompanied a patient to a hospital emergency department (for any medical reason). Of these, 51% were male and 49% female. With regard to the age (in years) of the patients, 19% were > 75, 22% were 60–74, 14% were 45–59, 15% were 30–44, 16% were 19–29, and 14% were < 18. The sample of responders was comprised of 55% who defined themselves as secular, 23% as conservative, 14% as religious, and 8% as ultra-religious. The age (in years) distribution of the 1002 respondents that accompanied the patients was 15% > 60 years, 26% aged 45–59, 30% aged 30–44, and 29% aged 18–29.

The questionnaire defined advanced dementia (including damage to memory, thinking, orientation, comprehension, communication; lack of ability to recognize close family members; loss of physical abilities; pain; medical complications; distress; and short life expectancy). It did not detail the procedure or medical considerations of force-feeding and resuscitation.

RESULTS

To the question of whether patients with advanced dementia should be force-fed when they refuse to eat, 34.5% answered that force-feeding should be used, 38.2% thought it should not be used, and the rest had no opinion. Thus, 47.5% of the those who had an opinion supported force-feeding.

To the question of resuscitating patients with advanced dementia (when they enter a life threatening condition and resuscitation is possible), 53.7% answered that resuscitation should be implement, 28.6% thought it should not be used, and the rest had no opinion. Thus 65% of the those who had an opinion supported resuscitation.

FORCE-FEEDING AND RESUSCITATION OF ADVANCED DEMENTIA PATIENTS AND RELIGIOSITY

Table 1 shows that there are significant differences between the religious groups (chi-square = 89.97, $P < 0.001$). The more religious the respondents were, the more likely they were to agree to forcefully feeding advanced dementia patients who refused to eat (ultra-religious 65%, religious 50%, conservative 39%, and secular 24%). The more religious were the more likely to agree to resuscitate advanced dementia patients who were in a life-threatening condition (ultra-religious 89%, religious 70%, conservative 65%, secular 39%; chi-square = 120.63, $P < 0.001$).

Table 1 also shows similar results when the question was about force-feeding and resuscitating advanced dementia patients who were over 80 years old. A significant difference was found among the religious regarding force-feeding (chi-square = 116.69, $P < .001$) and resuscitating (chi-square = 109.79, $P < .001$) advanced dementia patients over 80 years. It shows that the more religious were more likely to agree to force-feed advanced dementia patients over 80 years old (ultra-religious 70%, religious 53%, conservative 38%, secular 22%). This finding suggests that the more religious are more likely to agree to resuscitate advanced dementia patients over 80 years of age (ultra-religious 84%, religious 70%, conservative 57%, secular 37%).

AGE OF PERSON ACCOMPANYING ADVANCED DEMENTIA PATIENT TO HOSPITAL IN RELATION TO FORCE-FEEDING AND RESUSCITATION OF PATIENTS

Table 2 indicates that there is a marginally significant difference between respondents who accompanied an elderly patient (≥ 75 years) and those who accompanied a younger patient (< 75 years) with respect to forcefully feeding advanced dementia patients who refused to eat (chi-square = 5.85, $P < 0.06$). More specifically, 36% of those who accompanied a younger patient

(< 75 years) thought that the medical staff should feed them forcefully compared to the 29% who accompanied an elderly patient (≥ 75 years). However, there is a more significantly difference concerning resuscitating patients (in a life threatening condition) with advanced dementia (chi-square = 15.13, $P < 0.01$). That is, the majority (56%) of those who accompanied a younger patient (< 75 years) thought that the medical staff should resuscitate patients with advanced dementia compared to 43% of those who accompanied an elderly patient (≥ 75 years).

Table 2 also indicates that there is no significant difference between people who accompanied an elderly patient (≥ 75 years) and those who accompanied a younger patient (< 75 years) with respect to force-feeding of advanced dementia patients over 80 years of age (chi-square = 2.08, $P = NS$). However, significantly (chi-square = 9.42, $P < 0.01$) more people (52%) who accompanied a younger patient (< 75 years) thought that the medical staff should resuscitate advanced dementia patients over 80 years of age while only 44% of those who accompanied an elderly patient (≥ 75 years) thought that they should.

FORCE-FEEDING AND RESUSCITATION OF PATIENTS WITH ADVANCED DEMENTIA IN RELATION TO THE AGE OF THE RESPONDENT

Table 3 shows that there are significant differences between the age groups of the respondents who accompanied the patients with respect to force-feeding (chi-square = 89.97, $P < 0.001$) and resuscitation (chi-square = 105.89, $P < 0.001$). The younger the respondents were, the more likely they were to agree to force-feeding advanced dementia patients who refused to eat (64% in the age group < 18 years, 46% in the age group 19–29 years, 37% in the age group 30–44 years, 27% in the age group 45–59 years, and 20% in the age group > 60 years) and the more likely they were to agree to resuscitate advanced dementia patients (82%, 72%, 58%, 39%, and 20% for the respective age groups).

Table 1. Religiosity and force-feeding and resuscitation of patients advanced dementia, based on religiosity of the respondent

		Religiosity			
		Secular	Conservative	Religious	Ultra-religious
Force-feeding	Yes	24%	39%	50%	65%
	No	46%	37%	19%	8%
	Don't know	29%	24%	30%	27%
Resuscitation	Yes	39%	65%	70%	89%
	No	41%	19%	13%	3%
	Don't know	20%	16%	16%	8%
Force-feeding of patients over 80 years	Yes	22%	38%	53%	70%
	No	51%	39%	19%	10%
	Don't know	27%	23%	28%	20%
Resuscitation of patients over 80 years	Yes	37%	57%	70%	84%
	No	45%	25%	13%	4%
	Don't know	18%	18%	17%	12%

Table 2. Force-feeding and resuscitation of advanced dementia patients, based on the age of the patient

		Patient's age	
		< 75 years	≥ 75 years
Force-feeding	Yes	36%	29%
	No	36%	45%
	Don't know	28%	26%
Resuscitation	Yes	56%	43%
	No	26%	40%
	Don't know	18%	17%
Force-feeding of patients over 80 years	Yes	35%	30%
	No	40%	45%
	Don't know	26%	25%
Resuscitation of patients over 80 years	Yes	52%	44%
	No	30%	42%
	Don't know	18%	14%

Table 3. Force-feeding and resuscitation of advanced dementia patients, based on the age of the respondent

		Respondent age (years)			
		18-29	30-44	45-59	≥ 60
Force-feeding	Yes	46%	37%	27%	20%
	No	28%	29%	49%	55%
	Don't know	26%	34%	24%	25%
Resuscitation	Yes	72%	58%	40%	35%
	No	14%	22%	41%	47%
	Don't know	14%	20%	19%	18%

DISCUSSION

The research results presented here examined public opinion regarding force-feeding and resuscitating advanced dementia patients among individuals accompanying a patient to a hospital emergency department in Israel. The decisions about force-feeding and resuscitation that family members and physicians must make in advanced dementia patients are very difficult, sensitive, and painful, especially for the families. The high support for force-feeding (47% of those who had an opinion) correlates with the high prevalence of force-feeding in Israel compared to other Western societies.

Religious people were more likely to agree to force-feeding and resuscitating advanced dementia patients who refused to eat or who had entered a life-threatening situation. Since in Judaism, human life is of paramount value, the religious respondents were more likely to believe that life should be sustained by whatever means are available. In the balance between the sanctity of life and the principle of autonomy, secular individuals tended to believe more in the autonomy of the individual and in freedom of choice, leading to lower support in implementing force-feeding and resuscitating advanced dementia patients. Doron and colleagues [18] found that religiosity factors influenced attitudes of Israel physicians toward euthanasia.

The results of the current research show that people who accompanied an elderly patient (≥ 75 years) were less likely than those accompanying a younger patient (< 75 years) to agree to resuscitate patients with advanced dementia. Regarding force-feeding, there was no similarly significant difference between those who accompanied an elderly patient and those who accompanied a younger patient. The difference between the two groups can be explained by the exposure of the accompanying people to the difficulties and health problems of the older patient they were accompanying, leading them to avoid treatment that would cause additional suffering.

The results show that younger people were more likely to agree to force-feed and resuscitate advanced dementia patients. This increased likelihood was consistent across the four age groups that were compared. The younger people may behave or

act in this way because they regard the question as more theoretical than the older age groups. Furthermore, younger people may hold more idealistic view of the sanctity of life and be less aware than older people of the practical and painful realities associated with caring for older people. In a study in Japan, Kissanea and colleagues [19] also found that older people were less likely than younger people to prefer to receive life sustaining treatment for dementia and other end-of-life scenarios. These findings are similar to patient preferences found in other studies. In a study conducted in Israel [20], it was found that most adults aged 70 and older did not want to accept resuscitation and force-feeding if they become demented and such treatments were possibilities that they might have to undergo.

A study of nursing home residents with advanced dementia showed that when proxy family members understood the prognosis and expected complications from interventions whose benefits were potentially unclear, patients were likely to receive less aggressive care [21]. Ying [22] emphasized the role of family physicians and generalists, some of whom may hold a holistic perspective that might be lacking among subspecialists, in counseling families on the risks and benefits of artificial nutrition and hydration in advanced dementia. A position statement issued by the American Geriatrics Society [23] emphasized the importance of declining or accepting tube feeding in accordance with advance directives, previously stated wishes, or what it is thought the individual would want, and the responsibility of all members of the healthcare team to incorporate these wishes into the care plan. Several values are involved in treating dying patients: the value of life, autonomy, beneficence, non-maleficence, and distributive justice. The basic dilemma is how to strike a balance between the sanctity of life and the principles of autonomy. In Israel, there should be a balance between these principles based on the Israel value system as a Jewish and democratic state. There is a need to determine the boundaries of prolonging life versus the avoidance of unjustifiable and unwanted suffering. The Israeli law, as reflected by the Dying Patient Act legislated by the Knesset (Israeli parliament) in 2005 [24], tries to strike this balance and establishes mechanisms for mentally competent individuals to complete advanced medical directives at any time during their lifetime (treatments in the event they become terminally ill and unconscious) and a national registry of advanced medical directives maintained by Ministry of Health. The law views food and fluids as a basic need of any living being, rather than a form of treatment. It allows withdrawing food and fluids when the patient approaches the final days of life (defined as 2 weeks) if such was the clear wish of the patient before becoming incompetent [24]. To actually implement the Dying Patient Act, health funds need to initiate and even mandate the discussion of advanced directives in a formal user friendly process [25]. The Dying Patient Act is relevant to patients with a life expectancy of up to 6 months, while advanced dementia patients have a longer life expectancy.

The respondents of the research were people who accompanied any patient to a hospital emergency department and not specifically patients with dementia. As such, it is limited to reflecting the general public opinion and not specifically people who experienced the complexity of taking care of advanced dementia patients. The opinion of those accompanying old patients to emergency departments gives the perspective of those who are more likely to be exposed to medical problems and quality of life of the elderly.

CONCLUSIONS

The study presents a survey of public opinion in Israel regarding force-feeding and resuscitating patients with advanced dementia. High support for force-feeding in the study, about half of those who had an opinion, correlates with the high prevalence of force-feeding in Israel compared to other Western societies. Cultural aspects are known to impact opinions about intervention in end of life conditions and are reflected in the study findings that religious people were more likely to support force-feeding and resuscitation. Family members who take the decision about the intervention may have a different opinion from the dementia patients, when they were mentally competent. Age difference can be one reason for this difference in opinions, as we found that age impacts the opinion: younger people were more likely to support force-feeding and resuscitation. Encouraging mentally competent individuals to complete an advanced medical directives form is therefore very important for honoring the patient's preferences regarding force-feeding and resuscitation. If the patient is unable or has never previously expressed his or her wishes, medical staff should provide relatives with all the information on the treatment, chances of survival, and risks involved in force-feeding and resuscitation so they will be able to decide for the benefit of the patient.

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“The worst thing that can happen in a democracy—as well as in an individual's life—is to become cynical about the future and lose hope: that is the end, and we cannot let that happen”

Hillary Clinton, (born 1947), American politician who was First Lady of the United States (1993–2001), U.S. Senator from New York (2001–2009), 67th United States Secretary of State (2009–2013), and the Democratic Party's nominee for president of the United States in the 2016 election