



Ethical challenges in end-stage dementia: Perspectives of professionals and family care-givers

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Abstract

Background: In Israel, caring for people with end-stage dementia confined to home is mainly done by home care units, and in some cases by home hospice units, an alternative palliative-care service. Because life expectancy is relatively unknown, and the patient's decision-making ability is poor, caring for this unique population raises ethical dilemmas regarding when to define the disease as having reached a terminal stage, as well as choosing between palliative and life-prolonging-oriented care.

Objectives: Exploring and describing differences and similarities of professional staff members' (PSMs') and family caregivers' perceptions of caring for people with end-stage dementia in two different settings.

Design: Qualitative research, using semi-structured interviews analyzed through a thematic content-analysis approach.

Participants: Sixty-four interviews were conducted (24 PSMs and 40 family caregivers) in two care-settings—home hospice unit and home care unit.

Ethical considerations: The study was approved by the Ethics Committee (BBL00118-17).

Findings: We found dilemmas regarding palliative care to be the main theme, including definition of the disease as terminal, choosing “comfort” over “life-prolonging,” clarifying patients' wishes and deciding whether or not to use artificial feeding.

Discussion: Both PSMs and family caregivers deal with ethical dilemmas and have reached different conclusions, both legitimate. Comprehending dementia as a terminal disease influenced participants' perceptions of the relevancy of palliative care for people with end-stage dementia. Discrepancies between PSMs and family caregivers in caring for people with end-stage dementia were found in both home hospice unit and home care unit environments, raising potential conflicts regarding decisions for end-of-life care.

Conclusions: Communication between PSMs and family caregivers is crucial for the discussion about the discrepancies regarding the unique dilemmas of caring for people with end-stage dementia and bridging the gap between them. Lack of communication and resources can hamper the provision of an acceptable solution for quality and equality of care in the best interest of people with end-stage dementia.

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Keywords

Artificial hydration and nutrition, end-stage dementia, ethical dilemmas, family caregivers, home hospice care, professional staff members, qualitative research

Introduction

Dementia affects 4% of people over the age of 70, increasing to 13% for those over the age of 80. The median length of survival from diagnosis to death is 8 years, during which there is a progressive deterioration in their abilities and awareness.¹

In the end-stage of the disease, the person loses the ability to speak, smile, or move.² The common symptoms include mental confusion, depression, incontinence and urinary tract infections, constipation, pain, and aspiration pneumonia.³ Eating and drinking difficulties are a major source of both morbidities and stress for people living with dementia and their family caregivers. Eventually, there is insufficient fluid intake, malnutrition, hospitalization, need for artificial nutrition and hydration (ANH), aspiration pneumonia and shortened life expectancy.^{3–5} These characteristics intensify the family caregiver's physical and emotional burden and grief, as they slowly lose the person known to them. The strongest predicting mortality factors of dementia are related to nutrition and weight loss (86%), pneumonia (41%) and pressure ulcers (40%).^{6–8}

People with dementia may benefit from the palliative-care approach at any point after dementia diagnosis. Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, especially those near the end of life. It aims to improve patients' quality of life, as well as that of their families and caregivers.⁹ As the patient's dementia progresses, palliative-care challenges include pain management and advance care-planning communication.¹⁰ Dementia's course and connecting dementia and death can be challenging; therefore, only 18% of all US hospice enrollments were in the context of dementia,¹¹ while in Israel, percentages are significantly lower.^{12,13} There are no clear criteria for the eligibility for hospice care, and many patients and families are unaware of this option.¹⁴ Professional staff members (PSMs) lacking palliative skills refrain from talking about end of life to patients or families, despite its ability to reduce anxiety, an effective mourning process and undesirable invasive end-of-life procedures such ANH, resuscitation, and hospitalization.¹⁵

In general, providing palliative care for people with end-stage dementia (PWESD) holds challenges to both professionals and family caregivers, including a range of attitudes and beliefs regarding the perception of death and dying,¹⁶ lack of knowledge about dementia and palliative care, limited time, and patients' multicultural backgrounds. Some cultures object to palliative care more than others, and accepting death is considered to be abandoning the patient.^{14,17}

The medical services given to the home-bound PWESD who live in the community are mainly the primary care clinics or the home care units (HCUs). These services are provided to all patients with chronic illness by the Health Maintenance Organization (HMO) as part of their basic medical insurance, and do not include specialized end-of-life care.¹⁸ The HCUs' professionals consist of nurses and physicians who, during planned visits every three to four months, evaluate the patients and treat them as needed. The visits can become more frequent if necessary, up to several times a week, limited to clinic hours (8:00–16:00). An alternate, uncommon service is the home hospice units (HHUs), specializing in palliative care for people with an estimated six-month survival prognosis, available 24/7 for both planned and urgent home visits.^{14,19} This multidisciplinary service also operates under the HMO.¹³

The medical services provided to PWESD and their family caregivers need to deal with ethical challenges due to the lack of objective indication as to how PWESD actually feel when they are severely demented, thus not knowing what their best interests are.²⁰ Ethics is a concept in philosophy that describes moral concepts and theories relevant to all people. Professional ethics include values and norms, principles

and rules, and policies and solutions for professional practice.²¹ According to Heidenreich et al.,²² one of the principles of the ethics of care is based on the claim that human beings are vulnerable and dependent upon one another. It demands engagement by professionals to support and promote a patient's autonomy in making judgments true to their wishes and values.²³ Good care relies on the concept of patient-centered care, by acknowledging the beliefs and values of service users at the center of decision-making.²⁴ There is limited information regarding ethical considerations for end-of-life palliative care and hospice care, specifically for home-confined PWESD.¹³ Understanding and elaborating the ethical dilemmas may be beneficial both to the care of PWESD and to the communication between family caregivers and professionals.

In this study, we aimed to explore and describe the differences and similarities of the perceptions, of professionals, and family caregivers caring for PWESD and discover the main themes regarding the ethical challenges in caring for PWESD emerging from interviews in two different homecare models, HCU and HHU. Following the initial findings of this study, we decided to further discuss one of the themes that emerged—feeding and hydration in the last stage of the disease.

Research objectives

Our research goals were to explore and describe differences and similarities of the perceptions of professionals and family caregivers in two different settings; HHU and HCU, focusing on their views and the ethical and moral dilemmas they face. Understanding the ethical dilemmas and elaborating upon them may improve quality of homecare for PWESD and their families.

Research design

A descriptive-qualitative phenomenology study was carried out using thematic content analysis. This method was used for making replicable and valid inferences from the data.^{25,26} The data were collected from interviews with PSMs and family caregivers treating PWESD in the two units of care, HHU and HCU. These two units are considered to have inherent differences in structure and perception of care.

Research participants

The study included 24 PSMs (physicians, nurses, and social workers) working in either HCU (medical homecare team from the second-largest HMO in Israel) or HHU (services that are outsourced and coordinated with the homecare program), and 40 family caregivers (spouses and adult sons/daughters), all of whom had been caring for people with advanced dementia in the past year. The process of recruiting PSMs as participants for the study included preliminary interviews with leading PSMs in both units. They provided a list of PSMs with varied-characteristics regarding profession, age, religion, cultural background, and place of residence (i.e. Israel's central or peripheral areas). Family caregivers were recruited based on a list provided by PSMs. Participants were mostly female, secular Jews, living and working close to Israel's central area (Table 1).

The PSMs from the different units described major differences and variations of services provided, although both frameworks cared for people with similar disease characteristics and belonged to the same HMO. Both units cared for PWESD—the HHU for around 100 and the HCU for around 1500 PWESD per year. Both units made home visits regularly—the HHU once a week and the HCU every three to four months. Differences between the two care settings are presented in Table 2.

Data collection and analysis

Sixty-four semi-structured in-depth individual interviews, lasting 80 min on average, during one episode of fieldwork, were recorded using a digital recording device and subsequently transcribed.²⁶ Interviews were

Table 1*. Characteristics of PSMs and family caregivers from two care settings: HHU and HCU.**

	Professional staff members		Family caregivers	
	Home hospice unit, n = 13 (54)	Home care unit, n = 11 (46)	Home hospice unit, n = 13 (33)	Home care unit, n = 27 (67)
Gender				
Male	2 (15)	1 (9)	3 (23)	9 (33)
Female	11 (85)	10 (91)	10 (77)	18 (67)
Profession of PSM			Family relationship with the PWESD	
Physicians	3 (23)	2 (18)	Spouse 3 (23)	Spouse 8 (22)
Nurses	7 (54)	8 (72)	Son/daughter 10 (77)	Son/daughter 17 (63)
Social workers	3 (23)	1 (9)	Other 0	Other 1 (4)
Religious				
Jews	12 (92)	9 (82)	11 (84)	24 (89)
Muslim Arabs	1 (7)	0	1 (8)	2 (7)
Christian Arabs	0	2 (18)	1 (8)	0
Place of birth				
Israel	10 (78)	7 (64)	7 (54)	12 (44)
Other countries	3 (23)	6 (36)	6 (46)	13 (56)
Taking care of patients who were:			The family care giver was:	
Secular Jews	13 (100)	11 (100)	5 (38)	14 (52)
Religious Jews	13 (100)	11 (100)	7 (54)	8 (30)
Ultra-Orthodox Jews	5 (42)	3 (30)	1 (8)	2 (7)
Religious Arabs	5 (42)	3 (30)	2 (15)	2 (7)
Living Area				
Central Israel***	9 (69)	6 (55)	6 (46)	13 (48)
Peripheral Israel****	4 (31)	5 (45)	7 (54)	14 (52)

PSM: professional staff member; FC: family caregiver; PWESD: people with end-stage dementia.

*The data were also presented as a part of research by Halevi Hochwald et al.¹⁶

Data were presented as n (%); *Tel Aviv metropolitan area; ****More than 90 min from Israel's center.

Table 2*. Service characteristics: home hospice unit and home care unit.

	Home hospice unit, n = 13	Home care unit, n = 11
Nurses per patient**	1/17	1/80–120
Physicians per patient**	1/30	1/150
Social workers per patient**	1/50	1/clinic
Home visit frequency**		
Nurse	A weekly visit	Once every three to four months
Physician	Every second week (twice a month)	Once every three to four months
Social worker	Once every three months	Once a year (in the clinic or by phone)
No. of people with dementia being cared in the unit in Israel/per year	100	1500
Main characteristics of patients	Patients with palliative-care needs, mainly but not only with a terminal disease	Any patient who is home restricted due to a physical or mental condition

*The data were also presented as part of a research by Halevi Hochwald et al.¹⁶

**On average, more if needed.

The information was provided by all participants. The PSMs provided information regarding the home visits they are required to make and those they performed. These two sources of information matched each other.

conducted by an experienced qualitative researcher, a registered public-health nurse (IHH). The field notes and transcriptions were examined by additional researchers with an ethics expertise (GY and RNG). All interviews were done according to a topic guide that included: an explanation about the research goals—to explore PSMs'/family caregivers' experience, feelings, actions, and complexities when caring for PWESD over the past six months and also a consent to conduct the interview and to publish the information with no identifying details. The first part of the interview included closed socio-demographic questions, and the second, open-ended questions dealing with the research topic: the participants' experiences and challenges when caring for PWESD and their decision-making processes during this period, with additional questions emerging from the dialogue between interviewer and interviewee.²⁵ Prompts included: experience and challenges of caring for PWESD, concerns and planning for end-of-life care at home, relationships and expectation between family caregivers and PSMs in exacerbation situations regarding end-of-life care.

We performed a thematic approach analysis²⁷ by three independent researchers that reviewed the transcripts (IHH, GY, and RNG). The researchers noted areas of interest and potential themes independently, compared ideas, and discussed these codes. Once the framework was agreed upon, this was applied to all transcripts. The inductive process enabled identification of the prominent ideas. Eventually subthemes were combined to form higher level conceptual themes, which were verified and refined as the analysis proceeded.²⁸ Data analysis eventually led to a point where no new themes emerged.²⁹ The findings of the four groups (family caregivers and PSMs from the HHU and from the HCU) were described qualitatively and quantitatively (frequency) and a comparison of the family caregivers and the PSMs from each frame of care was performed. The findings were summarized alongside existing theory and literature, thus comparing whether the information had complemented or renewed existing knowledge.

Ethical considerations

All participants gave written informed consent after receiving oral and written information. Family caregivers were asked to participate in this study by the PSMs, and a meeting with the researcher was scheduled only after initial approval. The Research Ethics Committee approved the study (BBL00118-17).

Findings

In the interviews, the participants addressed several topics related to end-of-life decision-making. The main themes that emerged in the interviews for both PSMs and family caregivers were the ethical dilemmas and the moral conflicts arising during palliative care for PWESD. The findings included the following sub-themes: (1) defining dementia as a terminal illness; (2) the complexity of clarifying patients' wishes; (3) choices and preferences—comfort versus life-prolonging care; and (4) ANH \neq patients' best interest.

Defining dementia as a terminal illness

PSMs in both settings of care were found on the continuum between the conception of dementia as a terminal illness at one end and a non-life-threatening illness at the other. In the HHU PSMs group, a higher percentage determined dementia as terminal as compared to the HCU group (84% versus 64%, respectively). HCU PSMs mentioned that based on their experience, with “good-care,” for example, intensive and invasive interventions, a patient could experience a long, drawn-out deterioration, even at the advanced stages of the disease.

Contrary to the high percentage and differences among PSMs, less than half of family caregivers in both frames defined dementia as a terminal condition, while minority (~20%) never considered or discussed the prognosis with the PSMs in either HHU or HCU. Some of the family caregivers presumed, like HCU-PSMs, that

Table 3. Sub-theme no.1: Defining dementia as a terminal illness—brief summary and selected quotes from the interviews.

	Home hospice unit (HHU)	Home care unit (HCU)
Professional staff members (PSMs)	Briefly: in both, PSMs were on the continuum between the perception of dementia as a terminal illness or a non-threatening disease. The HHU PSM had a higher tendency toward terminality. I think dementia is erroneously not seen as a terminal illness, and it is very terminal, by definition, from the time it becomes moderate or severe it is a palliative disease and no longer a neurological disease. (Male physician)	It's a disease, and you can't predict what or when. It comes like waves or walking down the stairs. Sometimes the patient talks and recognizes you and suddenly there is a sharp drop. (Female nurse)
Family caregivers	Briefly: in both HHU/HCU family caregivers, less than 50% saw dementia as a terminal disease and only a few discussed it with the PSMs. It is not a disease that people die from. It affects the brain, the way they think. It can influence their ability to swallow, but there are ways to help them with that problem. (Jewish, secular, female, spouse) The word hospice is not suitable for this intervention. We are here (under HHU care) because taking him to a hospital will kill him . . . he will die one day, but people with dementia can also live for 10 years. (Jewish, orthodox, female spouse)	My mom does not respond, she doesn't talk or recognize anybody, she is nothing, an empty shell. She lost weight, she eats almost doesn't nothing, but she is a healthy woman. . . . It is going to take years until she dies. (Jewish, religious, daughter)

proactive care and support could prolong the life expectancy of PWESD. (The interviewees' references to this theme can be found in Table 3, where PSMs' and family caregivers' words in both care settings are compared).

Complexity of clarifying patients' wishes

HHU PSMs' first meeting with PWESD was only at the final stage of the disease, when significant cognitive impairment already existed and communication with the patient was impossible. Yet, they noted their need to identify the patient's wishes regarding the end-of-life stage and related to the family caregivers as representing those wishes. HHU PSMs emphasized that when the family caregivers' wishes conflicted with the principles of palliative care, they followed the preferences, despite the complexity it caused. Nevertheless, about half of HHU PSMs did not delve for the patients' or the family caregivers' wishes for end-of-life care.

In almost half of the HCU PSMs interviews, the end-of-life decision-making theme did not emerge. Only a few mentioned the importance of clarifying the patient's wishes for end-of-life care in the early stages, when the person with dementia was still able to express them. Most HCU PSMs considered the family caregivers' wishes as equal to that of PWESD, but some felt that in times of severe deterioration, life-saving intervention needed to be performed regardless of the family caregivers' preferences.

Contrary to the differences between HCU and HHU PSMs, the family caregivers from both groups displayed similar opinions and perceptions. Only a minority (around 15%–20%) of family caregivers were confident regarding the patient's wishes prior to deterioration, either by having written testaments, such as end-of-life directives or by verbal communication. Less than half (40%) indicated that they had no way of identifying the patient's wishes, and the rest tended to base their preferences on interpretation of the patient's responses and/or similar-situations in the past when the PWESD, prior to dementia, had made decisions for their own loved ones. The family caregivers also based their preferences on their own wishes if she or he had a similar disease or

prognosis. In both care-groups, it was not uncommon to find confusion, lack of knowledge, or an unwillingness to deal with future decision-making among the family caregivers. (The interviewees' references to this theme are found in Table 4, where PSMs' and family caregivers' words in both care settings are compared).

Choices and preferences: comfort versus life-prolonging care

Most of the HHU PSMs preferred comfort over life-prolonging care. Some HHU PSMs even said that family caregivers who did not prefer comfort should be excluded from home hospice care. The HHU PSMs used a unified terminology promoting care-type management and support (e.g. organizing, balancing, choosing), and fewer technical-care concepts (e.g. feeding, wound dressing, measuring vital signs).

The HCU PSMs, in contrast, talked about a wider spectrum of care, with a tendency to prefer life-prolonging support through use of intensive, invasive interventions, despite their awareness that this would perpetuate discomfort and pain. In addition, some of the HCU PSMs expressed frustration due to lack of resources such as knowledge of palliative care and staff availability, which interferes with their ability to

Table 4. Sub-theme no.2: Complexity of clarifying patients' wishes—brief summary and selected quotes from the interviews.

	Home hospice units (HHUs)	Home care units (HCUs)
Professional staff members (PSMs)	<p>Briefly: the majority PSMs, in both HHUs and HCUs, considered the family caregivers' wishes as equal to that of PWESD. In the HCU, PSMs expressed less effort to clarify patients' wishes than in the HHU.</p> <p>What matters is that our loved one will receive the best care, emphasizing that he chose it for himself. So, they (family caregiver) don't put the patient's needs first and they worry about what others will say: in the neighborhood, in the synagogue, in the town, in the extended family When you deal with that nonsense instead of with the person in front of you, then it is very disappointing. (Male, physician)</p>	<p>I don't know what this lady wants because I have known her in the same condition for the last three years, and now she is getting worse, and she was unconscious. Her daughters are not her guardians, they don't have an advanced written directive, but they say that she (their mother with end-stage dementia) always wanted to stay at home instead of being hospitalized. They have no right to decide not to take her to the hospital When the ambulance came, I went into the bathroom, so I wouldn't yell at them. I told myself to relax, it's their decision and not mine, but I was still very angry with them. (Female, nurse)</p>
Family caregivers	<p>Briefly: in both HHH and HCU, there was confusion and lack of knowledge, only around 50% of family caregivers considered themselves as representing the wishes of PWESD for end-of-life planning process.</p> <p>I don't know what my mom wants for herself. We never talked about it, but before my dad passed away, the doctor asked my mom whether to give life-saving treatments and my mom (before her illness), who cared for him, said, "He's 92, he's sick, let him be". (Jewish, secular, daughter)</p> <p>We never discussed it, except that she told us she believes in us and that we will know what to do about her. (Jewish, secular, son)</p>	<p>His life is not worth anything, there is no doubt about it . . . and my dad didn't think it was worth anything . . . I think it would be a great relief for him to die. It's like he's dead and not dead . . . (Jewish, secular, son)</p> <p>I know my dad wants to live. My dad counted on me to do everything to keep him alive . . . I know him best. (Jewish, religious, daughter)</p>

PWESD: patient with end-stage dementia.

choose and provide comfort care. They used task-oriented terminology with dominant interventional concepts, and less care management and support terminology.

About half of the HHU family caregivers preferred comfort care, and around 40% leaned toward life-prolonging care. Similar preferences were found among the HCU family caregivers, with a higher tendency to avoid dealing with this dilemma. Despite this heterogeneous preference toward end-of-life care, the family caregivers from both groups tend to describe the life of PWESD as worthless, empty, full of suffering and pain. Religious family caregivers used more terms indicating an external locus of control, such as “God-will-help,” “God-will-choose,” or “It is not for us to decide.”

Some HHU family caregivers explained that the HHU’s main benefits were high availability and the possibility for intensive care at home, rather than the palliative care it provides. They preferred HHU over hospital care, especially because of the devastating experience they had during previous hospitalizations (e.g. disappointment with quality of care, deterioration following the hospitalization, pressure ulcers). Eighty percent of HHU family caregivers stated that they would not send the PWESD to the hospital, compared to only 26% in the HCU.

Table 5. Sub-theme no.3: choices and preferences—comfort care versus life-prolonging care—brief summary and selected quotes from the interviews.

	Home hospice units (HHUs)	Home care units (HCUs)
Professional staff members (PSMs)	<p>Briefly: the majority of HHU PSMs support comfort care versus life prolonging care, compared to only 15% in the HCU PSMs. In both teams, around 50% thought that it was not their decision, but the family caregivers’.</p> <p>HHU is for families who say, “Enough. We have decided to let him die at home instead of fading away in a hospital bed.” (Male, physician)</p> <p>The real challenge is to get into their homes, to build trust and support them on this journey . . . Sometimes we are not the family’s real choice . . . They just want to stay home. (Female, social worker)</p>	<p>There are no right or wrong ethical decisions here. It’s OK to choose comfort and it’s OK to choose life extension. Medically, I think there is no reason to prolong life when there is so much suffering. (Female, nurse)</p> <p>We cannot give sedation in the HCU. We are not available 24/7, so sometimes we call for an ambulance and resuscitation instead of support care. Support requires resources we don’t have. (Male, nurse)</p>
Family caregivers	<p>Briefly: in both groups, around 50% of the family caregivers preferred comfort care versus life-prolonging care. The HHU family caregivers were more decisive than the HCU family caregivers, who were less certain.</p> <p>We are staying and doing everything for her at home. But when it becomes too complicated, and we will not know what to do, then, we will take her to the hospital. I want to save my mother. I want more time with her! . . . I’m very scared. It’s more for me than for her. (Muslim, religious, daughter)</p> <p>I will tell you the hardest thing in the world, I wish it to end. I think it’s not fair to keep him alive . . . I’ve said goodbye many years ago. This is not my dad, whoever is sitting there on the chair is not my dad. (Jewish, secular, daughter)</p>	<p>The fear of losing him is the hardest thing, nothing else is difficult . . . and I’ll do everything in my capability to keep him alive. If God takes him, I have no control over it. But I am not God. Who am I to decide when it’s time? (Jewish, religious, daughter)</p> <p>I think it is unnecessary to keep him alive, he is an empty shell. (Jewish, secular, daughter)</p>

A substantial number of family caregivers in both settings reached their decisions and preferences regarding end-of-life care without professional guidance, but rather independently while struggling with the complexity of their relative's situation (The interviewees' references to this theme can be found in Table 5, where PSMs' and family caregivers' words in both care settings are compared).

ANH ≠ patient's best interest

ANH, that is, nasogastric tube (NGT), percutaneous endoscopic gastrostomy (PEG), and parenteral nutrition, was considered to be futile and maleficent by some PSMs and family caregivers, and as crucial and beneficent by others. ANH was a dominant theme in all interviews, but with varied ethical perceptions.

HHU PSMs presented a dogmatic argument that ANH at end-stage dementia is an unnecessary, unacceptable medical intervention and abstaining from it constitutes accepted ethical and professional behavior. None of them considered NGT-feeding to be in the patient's best interest. Relying on the professional literature and their own experience from caring for other end-stage diseases, many of them declared that even with very little food consumption, PWESD did not starve or feel hunger. HHU PSMs considered ANH to be a leading cause of discomfort, physical restrictions, pain, and aspiration pneumonia, but with no influence on survival. They encouraged only "comfort-feeding" (i.e. intended to provide comfort and soothing rather than meeting nutritional/hydration needs). They defined NGT-feeding as a line they would not cross. If family caregivers demanded ANH, they preferred a "compromise" of PEG-feeding, despite the discomfort it might cause.

Some HHU PSMs mentioned that meaningful and trustworthy communication could reduce dispute with family caregivers regarding ANH. One-third stated that the family caregivers' opinion outweighed theirs. Sometimes disagreement with family caregivers occurred due to cultural differences or their short-term acquaintance which influenced communication.

In contrast to this stance, most HCU PSMs provided ANH. They were aware of possible complications, but overall, they considered nutritional needs to be basic support and, therefore, a lack of adequate nutrition constituted a life-threatening situation, malpractice, and maleficence. PEG was considered safer, with limited discomfort. Despite this attitude, some HCU PSMs who considered ANH to be basic support, admitted they would not recommend it to their own family members.

Other HCU PSMs supported and legitimized family caregivers who decided to avoid ANH but were not proactive and did not lead the decision-making process toward this decision. Around 30% of the HCU PSMs thought it was the family caregivers' decision and not theirs. HCU PSMs did not mention cultural or religious gaps as a source of conflict regarding ANH.

Attitudes toward ANH varied among family caregiver, regardless of the type of care used. Some regarded ANH to be basic life-prolonging care, and withholding it to be a crime, while others considered it to be forced-feeding and a violent act against their helpless relative. This sub-theme provoked emotional distress and agony among family caregivers. Most stated they had never discussed ANH versus comfort-feeding with the PSM. (The interviewees' references to this theme can be found in Table 6, where PSMs' and family caregivers' words in both care settings are compared).

Discussion

In our study, we describe ethical dilemmas and challenges emerging from in-depth interviews with PSMs and family caregivers caring for PWESD in two different homecare settings. The main dilemmas were the challenge of defining dementia as a terminal illness by both PSMs and family caregivers, providing palliative versus life-prolonging care, and making decisions based on PSMs' beliefs versus family caregivers' preferences as the PWESD surrogates. Those three dilemmas converge into a fourth, practical dilemma, regarding the decision to provide full nutritional support (ANH) versus comfort-feeding only.

Table 6. Sub-theme no. 4: artificial nutrition and hydration \neq patient's best interest—brief summary and selected quotes from the interviews.

	Home hospice units (HHUs)	Home care units (HCUs)
Professional staff members (PSMs)	<p>Briefly: significant differences were found between two groups: no HHU PSMs considered ANH to be in the patient's best interest. However, around 40% thought it was the family caregivers' decision. In the HCU, around half of the PSMs considered ANH to be in the patient's best interest and only 30% thought it was the family caregivers' decision.</p> <p>What strengthened us with the "do no feed" attitude was the American Geriatric Association's Guidelines that had state that it is ok to not feed at this stage, and even if the patient eats only three teaspoons of ice cream a day, that's great! Because what matters is the comforting element of food, the interpersonal touch and not calorie intake. (Male, physician)</p> <p>I told the son, I will insert the NGT in you, and if you think it's ok, then we will do it to your father. (Female, nurse)</p> <p>Families, especially orthodox, that will do everything for feeding, they have NGTs or PEG, they will use hand restraints . . . but if I want to make a change, it is a long process, and if I do it after the first few meetings, they will throw me out of their house. (Female, nurse)</p>	<p>It's hard for me. I don't think people should starve. We live in a developed country. On one hand, I can understand them (the families). It means prolonging suffering. It's a lot of internal ups and downs. Would I do it to my grandfather? Probably not. But as a professional, as a nurse, I do recommend artificial feeding. I have a lot of conflicts. I'm aware of that and it is not easy. (Female, nurse)</p> <p>If someone refuses to eat, it depends on the case. Usually we will give guidance and support, because maybe it may be temporary. But if there is consistent refusal, there is no other choice but to insert an NGT for feeding. (Male, nurse)</p>
Family caregivers	<p>Briefly: two groups had similarities regarding ANH for their loved one. In both groups of family caregivers', around one-third considered ANH to be in patient's best interest and around one-third did not. The rest never considered or discussed this matter.</p> <p>We sat down with the social worker who was very helpful, and my brother agreed to let go. We stood there hugging each other when they took the tube out . . . It was six months ago . . . she is still with us. (Jewish, secular, daughter)</p> <p>She must eat. She has all these pressure sores. But everything is fine now, I don't know about later, I don't want to think about it. It scares me, why would she stop eating? No way. (Muslim, religious, daughter)</p>	<p>I am not going to connect him to any feeding tube, PEG or NG. I have consulted about this with some doctors who said it leads to infections, to a couple of months of life extending, and eventually they die anyway, without any quality of life. So, for me, as a complete heretic (agnostic to the Jewish religion), I do not see any point in living without any quality of life. He doesn't understand where he is, he doesn't enjoy anything. (Jewish, secular, daughter)</p> <p>I don't want to force her to eat, but the question needs to be asked—is it possible? I don't want to extend her life, I know that for sure, but I don't know anything. You ask about swallowing problems, but I don't know anything about that (crying). (Jewish, secular, daughter)</p>

ANH: artificial nutrition and hydration; NGT: nasogastric tube; PEG: percutaneous endoscopic gastrostomy.

The philosophy of treating people with dementia is "person-centered-care," including support for the well-being, dignity, and autonomy of the whole unique person.^{24,30} Because of limited information regarding the patient's wishes, the consensus is usually that a close family member's decision will be similar to what the patient would likely decide if she or he could.³⁰ However, PSMs hold values and beliefs regarding

end-of-life care influenced by their experience and framework of care. Therefore, PSMs and family caregivers may differ in the way they perceive the best care. Unrecognized discrepancies between how PSMs and family caregivers relate to the above-mentioned dilemmas can potentially interfere with providing care, which is in the best interest of PWESD.

Ethical dilemmas around end-of-life care include choosing hospice and palliative care, which alleviate suffering rather than prolonging life.³¹ However, many family caregivers and PSMs do not recognize the terminal nature of dementia and have little access to formal information due to a limited dialogue with health services.^{32,33} End-of-life definition restricted to terms of diagnosis and prognosis does not always match the PWESD status. Therefore, despite endorsements by the World Health Organization (WHO) and geriatric societies, recommendations for palliative care for dementia are not always implemented.¹

In the following discussion, we elaborate on the essence of the dilemmas, and the gaps and hurdles between PSMs and family caregivers, focusing on the decision process of providing ANH versus comfort-feeding. ANH does not yield positive health outcomes and can have a negative effect, despite the fact that many PSMs lack knowledge about the use of ANH and its consequences for PWESD.³⁴

We found diversity and ambivalence in attitudes and beliefs toward the perception of death, ranging from acceptance of death as part of natural life or even wishing for death, leading to minimal and noninvasive treatments or even non-treatment, to denial of a poor prognosis leading to providing intensive, life-prolonging treatments. Our findings were similar to those reported in research regarding other, non-homecare, settings.^{35,36}

Both HHU and HCU PSMs combine values, knowledge, and professional experience to guide the care provided to the PWESD, as well as the recommendations given to the family caregivers. However, their approach and recommendations differed. HHU PSMs present a homogeneous determined attitude toward palliative management, while HCU PSMs advocate a more heterogeneous, active-care approach, including life-prolonging interventions. HHU PSMs meet and treat their patients mostly at the end-of-life stage of different diseases, when comfort and minimizing suffering is an important goal, while most HCU PSMs treat mainly patients who are not at end-of-life stage, rarely providing palliative care, and thus only a minority supported a complete palliative-care approach. HCU PSMs met the PWESD at an earlier stage of the disease and witnessed a slow deterioration. Furthermore, urgent home visits due to severe deterioration produced a sense of a need for intensive care.

Family caregivers presented uncertainty and a heterogeneous approach toward the prognosis of PWESD, its definition as terminal, and its discrepancies about the role of palliative care. Approximately half of them considered dementia a terminal illness with a short-term prognosis, while the remainder were unable to deal with death or dying, and/or avoided doing so. These findings are similar to research findings regarding family members in other care settings.²⁰

Some family caregivers chose HHU regardless of its palliative-care philosophy, only because of the high availability and accessibility it provided (i.e. patients/staff ratio, 24/7 accessibility; see details in Table 2), and despite their preference for life-prolonging treatment. Furthermore, there were family caregivers who preferred palliative and comfort care over life-prolonging treatment, and who used HCU services because of the low availability of the HHU. Not surprisingly, culture and religion influenced comfort care versus life-prolonging decision-making.

Gaps in approaches and lack of knowledge led to conflicts between families and PSMs when the goals for end-of-life care were different or even opposed.^{16,17} Usually there were no conflicts and the PSMs supported family caregivers' decisions, but once the conflicts existed, they generated staff-paternalism evolving from the belief in preventing major harm or providing important benefits to PWESD.³⁷ This was reflected in the PSMs interviews in the discussion about defining a line they would not cross. For example, some PSMs decided to call an intensive-care ambulance and hospitalize the PWESD, despite the family caregivers' objections, while others refused the family caregivers' request to insert an NGT into PWESD

who had stopped eating. Thus, paternalism and autonomy can cause conflicts around a wide spectrum of decision-making processes. Communication between PSMs and family caregivers is the key element in decreasing paternalism and serving the best interest of both PWESD and family caregivers.³⁸ PSMs have the role of providing knowledge as well as assisting and supporting family caregivers during the natural course of the disease, allowing for an open and knowledge-based discussion about challenges and questions once approaching and reaching the terminal stage of the disease.⁷

Family caregivers play a significant role in assisting patients with dementia, including their involvement in making legal and moral medical decisions for the patient.³⁹ The legal, ethical model used in the Western world emphasizes patient autonomy and choice of care,³⁹ but in dementia, establishing autonomy is more complicated when an advanced-directive is absent. Only a minority of PWESD signed an advanced directive, and in only a few cases had a legal guardian been appointed or power of attorney granted.¹⁴ Therefore, in most cases, family caregivers, despite their great-involvement, have no formal legal standing in decision-making according to the Capacity and Guardianship Law of 1962, the Patient Rights Act of 1996, and the Dying Patient Act of 2005.¹⁴ However, usually PSMs recognize the patient and the family caregiver as a single unit,³⁹ and the family caregiver as a mediator and representative of the PWESD.²³ Surprisingly, some senior HHU PSMs argued that as family caregivers chose HHU care, they should accept the palliative-care philosophy, or else they might be disappointed by the services provided.

Family caregivers expressed a need for support when making sensitive decisions but were divided regarding their preferences. Approximately half had made their decisions, either knowing or making a good guess regarding the intentions of PWESD for end-of-life care or projecting their own decisions, had they been in his or her shoes. The rest of the family caregivers did not know and felt uncomfortable about the decision-making process.

PSMs should make their best effort to both help the family caregivers reach a decision and then implement it. This complicated process must include PSM–family caregiver structured-accessible communication.⁴⁰ Relational autonomy is a broad concept arguing that people’s identities, needs, interests, and autonomy are shaped by their relationships to others.⁴¹ Regarding caring for PWESD, relational autonomy supports and reinforces the family caregivers’ role in the decision-making process.^{22,41} It demands PSMs’ engagement to support and promote the patient’s wishes and values, with sensitivity to cultural diversity⁴¹ by learning about their patients and their families as people and by striving to capture the patient’s perspective, resulting in good care.²² PSMs trained in palliative care may influence family caregivers toward making end-of-life care decisions, simply by knowing that comfort can be targeted when treatments become ineffective.⁴⁰ Timely planning discussions, recognition of end of life, and co-ordination of care may also affect the communication between PSMs and family caregivers.⁴²

Dysphagia and aspiration pneumonia secondary to dementia are the two most serious comorbidities.² In our study, one of the most challenging decisions for PSMs and family caregivers to make dealt with choosing comfort-feeding versus ANH. Comfort-feeding for PWESD has received increased support from both physicians and bio-ethicists since the mid-1980s.²⁰ Once consumption of solid food is no longer possible, there is no consensus about the preferred method for long-term feeding for PWESD.² It ranges from comfort-feeding, that is, providing oral feeding based on the patient’s wishes only without trying to meet his or her nutritional needs, to providing full nutritional needs using ANH (e.g. PEG or NGT). In between, there are several methods, such as feeding fork-mashed, liquidized, and thickened food.⁴³ PEG is often indicated as a relatively minor alternative procedure, although not risk-free.⁵ NGT is seldom recommended, because it may lead to aspiration pneumonia, discomfort, physical restraints, and reintubation.

Treatment for PWESD should be thoughtfully decided for the patient’s well-being, always trying to benefit the life an individual still has, even when that life has been diminished by dementia, no matter what the PSMs’ or family caregivers’ perceptions are about the quality of his or her life. There is a moral

obligation to provide or withdraw life-sustaining treatment (i.e. ANH) based on patient autonomy. However, PWESD, by definition, are incapable of conscious autonomy. Therefore, decisions can be made according to the patient's presumed will as far as this can be determined.²⁰ Therefore, withholding nutrition is controversial. Studies have found that patients with ANH had fewer cases of aspiration pneumonia and survived twice as long as patients using oral intake.^{44,45} Furthermore, many people perceive meeting nutritional needs as a basic component of care and, therefore, withholding it is considered a form of euthanasia.² However, other studies have found no long-term advantage for ANH,⁴⁶ and that natural comfort-feeding promotes comfort and dignity but may not influence survival.^{47,44} The uncertainties, as well as the sensitivity associated with communication regarding the choice of comfort-feeding over ANH result in widespread use of ANH in clinical practice worldwide.⁴⁴ Lack of formal education regarding nutrition in advanced dementia,⁴⁸ as well as cultural difficulty in dealing with death and dying,¹² were also identified as barriers of PSMs in communication with family caregivers.

Pro-palliative-care interviewees (mostly HHU PSMs), usually preferred comfort-feeding, presenting a structured homogeneous argument in order to persuade the family caregivers that there was no advantage to ANH. Most HCU PSMs, especially those who did not recognize dementia as a terminal disease, felt that ANH is part of "good" and "accurate" invasive care that can extend life.

Approximately half of the family caregivers held a decisive opinion about future plans regarding the time when the patient's condition will worsen and feeding problems may occur, preferring either ANH or comfort-feeding. The family caregivers' preferences were not related to the frame of care, thus creating discrepancies between family caregivers' and PSMs' attitude toward ANH. Despite this causing emotional distress, approximately half of the family caregivers never considered feeding problems or ways of resolving them, nor discussed this issue prior to our interview.

Strength and limitations

Our study had several strengths and limitations. By recruiting both PSMs and family caregivers from both HHU and HCU, we were able to describe themes of various settings of care and different roles involving care and decision-making for PWESD. The sample size was relatively large for a qualitative study. However, it cannot be assumed that the findings are typical of all professional teams or family caregivers. The sample of physicians and social workers was not as large as the sample of nurses in both groups. The use of in-depth interviews, as well as the use of consensus meetings to verify the credibility of the data strengthens our results.⁴⁹ Data were collected from different parts of the country in an attempt to represent different populations. Although we believe that different units that care for PWESD have the same mix of palliative and non-palliative attitudes from both PSMs and family caregivers, our findings may not necessarily be applicable or generalizable⁴⁹ to other HMOs or other countries.

Conclusion

There are only a few studies describing the ethical dilemmas and challenges concerning PWESD treatment in homecare that compare two frameworks of care, one less and the other more palliative-care oriented. In the present study, we presented the leading ethical challenges that arose from interviews with PSMs and family caregivers especially around the perception of dementia as a terminal disease as opposed to an illness that lasts until death. Unpredictable life expectancy led the PSMs to make different professional choices, usually going in two main directions—palliative care versus life-prolonging and more interventional care.

Families' choices of a care framework do not always originate from their preference for either palliative care or a more invasive life-prolonging approach, but rather from a lack of information regarding the

accessibility of the HHU on one hand, or the higher availability afforded by HHU compared to other care options on the other. This choice, which is not always based on care preferences, partially explains the existence of fundamental differences in approach between PSMs and family caregivers. Palliative care should be a standard of care for PWESD emphasizing comfort,⁴⁰ but with a major emphasis on the patient's preferences, represented by his or her family caregiver, as well as the complexity of determining dementia as a terminal disease.

Communication between the PSM and the family caregiver is a necessary tool in bridging the knowledge gaps and choosing a care path reflecting the values and wishes of PWESD, as well as his or her best interest, when the voice of people with dementia can be heard, but especially following deterioration, when this is no longer the case. Relational autonomy is a broad approach, which the PSMs can understand and use to seek in-depth information regarding the family caregivers' preferences as the representative of PWESD.

A structured, albeit personalized, conversation between PSMs and family caregivers based on the themes emerging from our study is recommended: family caregivers' knowledge and expectations for life expectancy and life quality of their loved one, based on the wishes of PWESD if known, or their own wishes if the patient's wishes are unknown. Attention should be paid to nutritional preferences and hospitalization in case of further severe deterioration.

Our study may enhance nurse's communication with family caregivers about end-of-life care and decision-making. We recommend professional ethical consultation groups that will promote conducting a dialectical approach: to apply the individual needs by their goal of care, regardless of the PSMs' perceptions or the organization's characteristics as well as interventions based on accumulated organizational experience and insights.

Professional knowledge and skills, sensitivity, and empathy are all required for providing care. Caring is a dynamic and ongoing process requiring more than making the right decision at a certain moment.

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