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SCIENTIFIC CONTRIBUTION

# Managing feeding needs in advanced dementia: perspectives from ethics of care and ubuntu philosophy

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**Abstract**
The response to feeding needs in advanced dementia patients is a subject of ethical inquiry. Advanced dementia is the debilitating result of a range of neurodegenerative diseases. As this terminal illness progresses, patients develop mild to severe dysphagia that can make swallowing difficult. Of the two available options, artificial tube feeding or oral hand feeding, an estimated one-third of these patients will receive artificial tube feeding. However, observational studies have failed to validate the clinical benefits of tube feeding. Ethics of care, the feminist philosophical perspective, and Ubuntu philosophy offer arguments for the choice of oral hand-feeding as a preferrable first option by caregivers as far as possible. These moral theories acknowledge that human beings can be dependent for long periods, mostly early and later years of life. Both views reflect an approach that draws people into a system of interdependent caring relationships. They encourage hand feeding as a way of exhibiting solidarity and respecting human dignity even at the end of life.

**Keywords** Advanced dementia · Ethics of care · Ubuntu philosophy · Hand-feeding · Tube-feeding

## Introduction

Addressing eating difficulties and improving the care of patients with advanced dementia (AD) are important areas of exploration in ethics. These inevitable problems around eating and feeding in advanced dementia could prompt responses that may not align with patient preferences or evidence-based care. A patient's preferences that are best elicited through living wills, expressed wishes or consent forms may often be unknown (Held, 2005, 32–33). Ethics of care (EOC) and Ubuntu Philosophy (UP) can offer fresh perspectives for caregivers engaged with decisions concerning the feeding of patients with advanced dementia, especially when the expressed wishes of patients are unknown. We draw on core values in EOC and UP to argue that careful handfeeding should always be attempted as a first option. Tube feeding may be the other option only to keep the patient alive, in situations when some degree of connection and meaningful interaction with the family is still a possibility. EOC acknowledges that human beings may depend on others for a significant duration of time, mainly in the early and later years of life. Similarly, UP encourages individuals in interdependent relationships to view the caring response as an action towards the common good that could improve the experience of these patients.

This study presents care as a way that basic human needs of patients are met by another, where one to one interaction between caregiver and patient is a critical component of the caring process; acting in a humane way to enhance a patient's life quality (Ter Meulen, 2011, 40). In the first section, the study provides a description of care and the clinical course of dementia. The study proceeds to the second section to highlight the nature of the feeding problem and the ethical dilemma experienced by caregivers and family in handling this problem. In the final section, philosophical perspectives from EOC and UP urge caregivers to seek humane solutions like hand-feeding, in the best interest of the patient.

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## Understanding care

We conceive care as meeting the basic human needs of an individual, where one to one interaction between carer and the subject of care is a critical component, given that the receiver cannot meet this need by himself/herself (Bubeck, 1995; Meyers, 1998). This description of care has an important implication because it is caring for self and others that makes us human.

Caring relations are typically grounded in trust that relates to a shared understanding of intention. For instance, children must trust those who care for them, and societies should endorse trust between citizens to achieve social progress (Held, 2005, 42f). To foster a caring community, individuals must trust each other to respond appropriately to mutual needs and support caring relationships (Held, 2005, 57). The process of caring is divided into four major interconnected phases: 'caring about' includes awareness and assessment of a specific need to be met; 'taking care of' involves assuming some responsibility to act for the identified need and deciding how to respond to it; the third stage is 'giving', which involves the actual physical work, and lastly 'care- receiving' which refers to the response of a person who received the care (Tronto, 1993, 105–108).

Care can have single or multiple dimensions related to human need; physical, mental, emotional, or spiritual, varying through the different phases of life. Caring does not necessarily conflict with the autonomy of persons. On the contrary, it encompasses the immediate needs and autonomy of patients (Vanlaere & Gastmans, 2011). The risk of compromising a patient's autonomy increases when there is no support of family members, personnel, or nursing staff (Ter Meulen, 2011, 47).

## Clinical course of dementia

Since the beginning of the twentieth century, average life expectancy has increased significantly in the industrialized world, mainly due to improvement in living conditions, availability of food, lifestyles, hygiene, a better understanding of disease etiology, and advances in medical care. Even as modern science has found a way to extend human life, the human struggle with chronic conditions has persisted, particularly at the end of life. People above the age of 80 commonly have an augmented risk of chronic physical and mental conditions, including dementia (Ter Meulen, 2011, 40).

Dementia is a condition that generally afflicts elderly patients, is progressive, incurable, and also the leading cause of dependency and disability in this population (Bunn et al., 2016, 2). Advanced dementia is the result of a range of neurodegenerative diseases, including Alzheimer's disease, which is characterized by grave physical and cognitive disability (Ribeiro Salomon & Carvalho Garbi Novaes, 2015, 169).The last years before the death of an advanced dementia patient are significantly different from the earlier years of the disease. Profound memory deficits, total functional dependence, incontinence, lack of mobility, and a near absence of verbal communication, are features of advanced dementia in its final stage which can last between 6–24 months (Mitchell, 2015). Studies (Goldberg & Altman, 2014, 1734) estimate that one-third of dementia patients would live to the advanced stages of the disease.

As the current population ages, the total burden of advanced dementia will also rise globally. In the United States (U.S.) in 2012, an estimated 5.2 million persons over 65 years of age had Alzheimer's disease (A.D.), and this number is anticipated to reach 6.7 million by 2025. In Israel, 19% of individuals above 65 years, and 47% of those above 84 years have dementia (Gil et al., 2018, 138). The prevalence of dementia is expected to double every five years.

Similarly, aggregate health care expenditure for dementia is projected to reach $1.1 trillion by 2050, increasing the societal burden significantly (Mitchell et al., 2012). Most patients with advanced dementia are placed in nursing homes, where terminal care of these patients is, consequently, located (Mitchell, 2015, 45). While some symptoms of advanced dementia are responsive to treatment, others persist even after aggressive treatments (Mitchell et al., 2012, 46).

## Feeding problems in patients with advanced dementia

As opposed to curative interventions, people with advanced dementia usually need long-term care that may be problematic for family members to provide. This type of supportive symptomatic care in chronic illnesses requires altruism, compassion, and commitment. The care provider in the family or institution needs to exercise patience to understand and accept the limit of the disease, and yet convey respect for the distinctness and worth of the human individual involved. For people with advanced dementia, long-term care is aimed at symptom mitigation, assistance with routine activities, and palliation. Feeding is an essential part of the long-term care and is particularly vexatious at terminal stages of the disease. Difficulty in swallowing (oral or pharyngeal dysphagia), slow chewing, hand- mouth coordination, spitting or pocketing, and loss of appetite, are common eating problems in progressive dementia. Eating problems can even lead to pneumonia and aspiration events. A recent study

entitled 'The Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life Study', has found that more than 85% of advanced dementia patients experienced eating difficulties, with half of those dying within six months (AGS, 2014, 1590).

When eating difficulties persist, family and institution caregivers are challenged with the decision to continue with hand feeding or start tube feeding. The interplay of economic factors, cultural factors (such as family-oriented decision-making model and abhorrence of death by starvation) and religious beliefs (such as the belief that life and death are in the hands of God) as well as apprehensions about the burdens of tube feeding, can complicate this decision-making process aimed at addressing eating difficulties (AGS, 2014, 1590). Further, these eating difficulties may exist alongside other problems such as walking and bathing difficulties.

In the U.S. roughly around one-third of nursing home residents with advanced dementia who face feeding problems are tube-fed. Significantly, in two-thirds of these cases, feeding tubes are introduced during incidental hospitalization for other reasons. The analysis shows that three-quarters of hospitalizations among patients with advanced dementia are avoidable, either because hospital-level care is pointless, or conflicts with preferences (Mitchell, 2015). Hospitalizations can also be traumatic for these patients who encounter new care providers inexperienced in dealing with their specific needs, and unfamiliar with their preferences; and this could lead to undesirable interventions. (Mitchell et al., 2012, 46).

## Feeding tubes vs. careful hand feeding

Approaches to managing feeding problems in advanced dementia can inform strategies for managing other aspects of care in these patients. A thoughtful examination of patient choices, options of care, and outcomes, can modify decision-making and experiences in this area. Oral hand feeding and artificial nutrition/hydration (ANH) are the two conventional means of managing feeding problems encountered in AD. The common types of ANH include nasogastric tubes, percutaneous endoscopic gastrostomy (PEG), and parenteral nutrition. This study refers to all forms of ANH as tube feeding.

In the care of advanced dementia patients, tube feeding is sometimes seen as embodying 'hope of recovery'[1] and believed to be a better alternative to inaction by guardians of patients. 66% of physicians identified guardians' request as the principal reason for tube feeding in people with advanced dementia (Gieniusz et al., 2018, 67). The benefits remain questionable in the light of data (Schwartz, 2018, 381) that does not support tube feeding in persons with advanced dementia.

Careful hand feeding (CHF) is at least as effective as tube feeding concerning outcomes of aspiration, functional status, comfort, and mortality. Most physicians reported in one study (Gieniusz et al., 2018, 66) that careful hand feeding is at least as good as tube feeding for the outcomes of comfort (71%), functional status (61%), and aspiration pneumonia (58%). Tube feeding has not shown any benefit in reducing aspiration, mortality rates, pressure ulcers, or improving nutritional status in individuals with advanced dementia.

Further, tube feeding is linked with recurrent and new-onset aspiration, aspiration-related infection, oral secretions, poor oral hygiene, anxiety, tube malfunction, use of physical and chemical restraints, and development of pressure ulcers (Smith & Ferguson, 2017, 323). One study (Goldberg & Altman, 2014, 1739) showed no evidence that ANH or tube feeding improves survival rates in persons with advanced dementia. Another study (Gieniusz et al., 2018, 65) showed that individuals who receive tube feeding, particularly PEG, during hospitalization had 'higher 30-day mortality than those who received one 30 days after hospital discharge'.

Additionally, nursing home residents with advanced dementia on a feeding tube needed to be regularly moved to the emergency unit to tackle tube-related problems such as blockage and dislodgement (AGS, 2014, 1590). The cost of tube placement is equally staggering. The total cost of Medicare for tube-fed people with advanced dementia has been found by one study (Gieniusz et al., 2018, 66) to be significantly higher than hand-fed residents at a nursing home for people living with dementia. The appreciation that eating problems are a part of the natural history of advanced dementia has directed some specialists to advocate against the utilization of tube feeding (Mitchell et al., 2012, 46).

Careful hand feeding tends to be supported by scientific evidence and endorsed by the American Geriatrics Society (2014) as a feeding method that is likely to be more beneficial than artificial nutrition. There are other reasons hand feeding ought to be preferred. As the African philosopher Thaddeus Metz (2015: p. 182) observes, the core of improving well-being and honoring dignity, is a matter of meeting human needs. While food and water per se are considered to be basic needs of humans (Smith & Ferguson, 2017) the act of eating and drinking are intrinsically human. Denying food and drink to persons with dementia who can no longer feed themselves, plausibly entails a form of neglect. ANH or Tube feeding are ways to provide food and drink, but careful hand feeding perpetuates the human act of eating and drinking that may be more desirable or comforting and associated with sensations and memories. Moreover, psychologists have shown that positive relationships develop better through

[1] We demonstrate later that "hope of recovery" is unwarranted and tube feeding does not significantly prolong life.

closeness, touch, and physical presence amongst others (Christakis & Fowler, 2014; Seyfarth & Cheney, 2012). For these reasons, hand feeding ought to be preferred to artificial nutrition.

### Ethical approaches to feeding decisions

The moral reasons underlying the decision to start tube feeding are broad. However, family members or surrogate decision-makers often relate that they have no choice; they have a duty to prolong life and cannot allow a relative starve to death (Schwartz, 2018). This is a prominent reason for making this heart-wrenching decision to start artificial nutrition/hydration despite scientific evidence that these are not mandated (Gillick, 2000). Some health professionals too are unfamiliar with the scientific evidence or the law. Many health professionals in one study (Solomon et al., 1993) contend that nutrition and hydration should never be stopped even when other forms of life-support have been disengaged, to prevent patient from dying of hunger, maximize comfort, prolong life, prevent aspiration. "Decision makers," as Gillick (2000: p. 206) observes, "for demented patients who opt for feeding through a gastrostomy tube usually do so because they hope to extend life and prevent aspiration pneumonia, because they wish to prevent suffering, or because their values, particularly their religious beliefs, dictate that sustenance must never be withheld." These ethical reasonings have utilitarian and Kantianism undertones.

The philosophy of UP and EOC, as we shall demonstrate in subsequent sections, supports ethical decision making that will more likely improve the care of patients with advanced dementia irrespective of whether the individual has moral worth to the society, has lost capacity for rational autonomy, or the burden outweighs benefits. These philosophies believe that human moral worth is never lost, even at the end of life, and invite individuals to be physically present to patients with dementia, to see the terminally sick patient as worthy of compassion and altruism (Metz, 2007a: p. 336). We also demonstrate that careful hand feeding, rather than tube-feeding, is more supported by this combination of ethical approaches, as behaviorally and emotionally exhibiting solidarity with them, consequent to good motives (Pezzati et al., 2014). Careful hand feeding can also create opportunities for positive psychological and emotional bonding with patient, creating connection between caregiver and patient, honoring their worth, and taking responsibility for caring about their wellbeing.

In the next sections, we describe EOC and Ubuntu philosophies and the reasons they recommend careful hand feeding as the better option in patients with advanced dementia.

## Perspectives from UP and EOC

### Ubuntu philosophy (UP)

Ubuntu is an African philosophy, which according to Metz (2007b, 375), 'is informed and defended by beliefs that are common in sub-Saharan Africa, and particularly beliefs that are more common there than among western societies.' These beliefs and practices are not necessarily unique to Africa but play a vital role within local societies in decision-making. Prominent scholars of UP include Thaddeus Metz (2007a, 2011), Mogobe Ramose (2002), Christian Gade (Battle, 1999, 2000, 2011, 2012), Kevin Behrens (2013, 2017), and Motsamai Molefe (2011; 2014).

UP is one of several existing African ethical theories, and the particular formulation of UP applicable here has been substantially described in a systematic review (Ewuoso & Hall, 2019) which contributes towards a definition of *ubuntu* and its application in a variety of ethical problems. The review describes UP as an inherently relational philosophy that "prizes relationships of interdependence, fellowship, reconciliation, relationality, friendliness, harmonious relationships and other-regarding actions, and in which actions are morally right to the extent that they promote social integration….and reduce discord" (Ewuoso & Hall, 2019, 100). The former Chair of the Truth and Reconciliation Commission, Archbishop Desmond Tutu, aptly captures this description in the following way:

> When we want to give high praise to someone we say, "*Yu, u nobuntu"*; he or she has Ubuntu. This means that they are generous, hospitable, friendly, caring and compassionate. They share what they have. It also means that my humanity is caught up, is inextricably bound up, in theirs. We belong in a bundle of life…I am human because I belong, I participate, I share. A person with *Ubuntu* is open and available to others, affirming of others, does not feel threatened that others are able and good; for he or she has a proper self-assurance that comes with knowing that he or she belongs in a greater whole and is diminished when others are humiliated or diminished, when others are tortured or oppressed, or treated as if they were less than who they are (Dreyer, 2015, 195).

These values of friendliness and harmonious relationships are essential in prescribing duties and defining personhood or humanness in UP with its maxim, *umuntu ngumuntu ngabantu* 'I am because we are,' or 'a person is a person through other persons."

The preceding maxim has both descriptive and prescriptive implications. First, the maxim describes how to

be a person, and secondly, how to behave towards other persons. Being a person comprises relating with others in specific ways. Specifically, one is more or less of a person or a human being to the extent that the individual prizes other-regarding behaviors in two ways (Metz, 2016, 138): identifying with others, and solidarity with others. Identifying with others implies enjoying a sense of togetherness or thinking of oneself as part of a 'we' (cognition). It also implies expressing shame/pain/pride in what the group does (emotions). One could also identify with others by engaging in joint projects (conation). Finally, one can identify with others by adopting goals consistent with those of others (volition) and coordinating behaviour to realize shared ends because this is who we are (motivation).

Second, being a person implies exhibiting solidarity with others. Solidarity involves empathic awareness of others' conditions, helping altruistically, acting in ways that benefit others, and improve their capacity for communal relationship. Both identifying with others and exhibiting solidarity are necessary conditions for communal relationships and affirmation of persons in the philosophy of Ubuntu. In UP, one is either a subject of communal relationships or an object of communal relationships. To be human is to be deeply involved in a caring relationship that displays humanity and empathy.

## Ethics of care

It is important to state at the outset that in describing ethics of care (EOC) in this section, we do not suggest a fixed way of thinking about this, or even that scholars necessarily agree on what EOC is. Instead, we describe the relevant aspect of this theory, which we then combine with UP to think critically about feeding problems in the care of advanced dementia patients.

EOC has its roots in the Feminism movement of the late 1960s in Europe and the United States although some care ethicists reject the idea that the notion of care is a feminist morality (Robinson, 1997). Nonetheless, EOC understands that dependent persons place moral demands on individuals who care for them. It asserts that there are significant moral reasons for developing relationships of caring that allow human beings to live and advance. On the other hand, individualist-based theories fundamentally forego the reality of human interdependence and the ethics based on this dependence. EOC queries the universalistic and theoretical laws of these theories (Held, 2005, 9–11). Dominant moral theories tend to focus on two extremes; the universality of moral principles and individual interests. What lies in between is mostly overlooked by these dominant theories but recognized by the EOC. EOC recognizes that the welfare of each person is linked with another's interests and seeks to endorse authentic human relationships between individuals and particular others. For this reason, care ethicists like Fiona Robinson (1997, 2011) think of EOC as practices that tend to conceive of the self within the context of relations with others. EOC sees the world as consisting of relationships, rather than individuals standing alone; of interconnection and interdependence rather than independence. This differs from the Kantian view which tends to emphasize the capacity for autonomy and independent rationale; or social contract theories where cooperation aims to further individual self interests. Instead, EOC view is interpersonal, leading to the recognition of the moral value and importance of relationships between friends and family. More importantly, EOC highlights the significance, practices and values of caring; not only its moral core, but also as a useful tool for addressing fundamental bioethical issues and transforming society. In this way, care emerges as a practical principled morality rather than theoretical, referring to particular concrete contexts between concrete individuals (Robinson, 1997). Because EOC is practical, its core elements include attentiveness and responsiveness to the needs of moral subjects, as well as taking responsibility to meet those needs. It is attentive since it assumes no 'ideal" moral situation, but listens to and learns from the particular standpoint of real individuals. It is responsive since it is a morality that has a concrete vision of agency and action. Finally, it takes responsibility as its primary moral value because it argues that moral action requires a recognition of responsibilities, rather than the indeterminate picture of agency offered by rights-based theories (Robinson, 1997). It equally sheds light on both the public and private life of individuals because it views moral issues that arise between interconnected persons in the context of family, friendship, and social groups (Held, 2005, 11–13). It is for this reason that Robinson (2011) contends that ethics and politics cannot stand apart from one another, because EOC is necessarily relational requiring interaction between moral agents.

EOC values autonomy of both the patient and carer. Being a caring person is a matter of autonomous choice because learning and nurturing the significant capabilities of a caring person will depend on active efforts by a moral agent (Held, 2005, 49). This is important because the real needs and demands of individuals might be tremendous, sometimes beyond the kind of duty that the society can handle. When relationships between people are characterized by free agency, there can be acceptance of the degree of difficulty they necessitate. But the autonomy pursued within the EOC relates to the capacity to restructure and nurture new caring relations. A caring relationship requires sympathy and mutuality via an interdependent network in human life (Held, 2005, 50–52).

## Similarities in ethical approaches in UP and EOC

Both EOC and UP are philosophies that reflect care as possessing ethical value. They offer an analysis of moral behavior in the relationship between a patient with advanced dementia and the caregiver (Groenhout, 2004, 114). Care ethics and UP are both relational ethics. A relational ethics is the mid-point between holism and individualism. In relational ethics, relationships have moral significance; an individual deserves moral consideration to the extent that s/he can exhibits causal property towards other beings. In *Ubuntu* communal relationship occurs between subjects and objects. An individual is a subject who possesses capacity to commune with others. One is an object to the extent that others can relate with one, or that one has inherent capacity that draws others to oneself such as the capacity to be thought of as part of the "we" or to be identified with (Ewuoso & Hall, 2019). Causal properties towards other beings typically entails actions that are positively oriented towards the good of others and characteristically "include a belief that the other merits aid for her own sake, an empathetic awareness of the other's condition, and a sympathetic emotional reaction to this awareness" (Metz, 2019: p. 207). Against this background, relational ethics starts from the thought that care is a fundamental element in human existence and an approach that vitally merges human needs in a system of interdependent or interconnected relationships (Vanlaere & Gastmans, 2011, 164f). The relational understanding of the human person implies that care is essential to the survival and human experience of the patient (Vanlaere & Gastmans, 2011, 164f). Both EOC and UP understand that people with advanced dementia may be dependent on caregivers, but retain a moral entitlement or status (Held, 2005, 9–11).

While relations with others are evidently important, some formulations of EOC also recognize one's relationship to self as among one's morally important relationships. In other words, self-care also matters, and is the basis for caring about others. One needs to be ethical to remain "in the caring relationship and to enhance the ideal of ourselves as one-caring [that is, as givers of care]. It is this ethical ideal… that guides us as we strive to meet the other morally" (Noddings, 1984: p. 5).

While both UP and EOC are relational approaches, they differ in significant ways. In EOC, solidarity is often valued to a much greater degree than identifying with others, while in UP, the combination of identifying with others as well as solidarity is the necessary condition for displaying *Ubuntu*. Nel Noddings says for caring to be genuine, it ought to be for the sake of those being cared for. Specifically genuine caring entails engrossment and motivational displacement. Engrossment means that care is given without judgment and evaluation, allowing the carer to be transformed by the one being cared for. In motivational displacement, the carer adopts the goals of the one he is aiding, helping the objects of his caring relationship to directly or indirectly achieve these goals (Noddings, 1984: pp. 15–20, 33–34, 86, 89). Noddings' remarks about EOC are also shared by Virginia Held who argued that the starting point for care ethics is attending to and meeting the needs of the particular others for whom we take responsibility, consequent to sensitivity, sympathy and empathy (Held, 2005). Some care ethicists believe that genuine caring entails exhibiting sympathetic solidarity, consequent to compassion and/or altruism – though not all care ethicists necessarily accept this formulation.

The combined emphasis on other-regarding orientations such as compassion and sympathy (which are unique ways of exhibiting solidarity and caring behaviors) make both UP and EOC useful approaches for this study's objectives. Metz (2017) puts this well in the following way:

> [UP] includes everything that care ethicists prize, as it prescribes acting to improve others' quality of life consequent to certain attitudes of sympathy and altruism. However, it also includes a certain kind of relationship that care ethicists typically do not prize, or at least not in a way they normally expound their view. African moralists tend to value both caring for others' quality of life and sharing a way of life with others(Metz, 2017, 116).

## UP and EOC applied to feeding problems in advanced dementia

Advanced dementia places patients in an extremely vulnerable position in need of care. In EOC and UP, family members and caregivers are subjects of communal relationships, morally required to respond in respectful humane ways.

Care providers act because they are rightly concerned about the needs of the patient. The fact that care in institutions is supplied by professional caregivers who are compensated with an income, does not lessen the importance of humane care and human connection or relationship (Ter Meulen, 2011, 42–45). A failure to act in this way implies a failure to exhibit solidarity or identify with others, who are objects of our communal relationships. It is also a failure to display *Ubuntu*. It is the failure to recognize the humanity in patients with advanced dementia and treat them humanely. Therefore, caregivers must use a particular moral language that not only communicates knowledge but also demonstrates caring attitudes like compassion and sympathy.

Furthermore, UP and EOC are both ethical approaches that highlight the need to acknowledge the vulnerability and dependency of the person needing care in the hospice or home (Ter Meulen, 2011, 42–45). It involves

relationships between unbalanced powers; the caregiver on one hand, and the patient in need. EOC and UP call for a human relationship that encourages and accepts the emotional, physical, and psychological care and support received as well as extended to others (Groenhout, 2004, 45).

While care ethics is not normally described in terms of fostering human dignity, some care ethicists believe that dignity is an important value (in EOC) that is relational, and good care can be dignifying. "When we care well for others," the care ethicist Sarah Miller (2017: p. 113) contends, "we acknowledge and highlight their inherent worth and dignity. We recognize, represent and reflect their value back to them, to ourselves, and to others who stand in social relation with them." Miller believes that individuals do not have dignity because we care for them. Rather we are invited to care for them and for their own sake because they have an inherent worth and value. By caring for them, we are only acknowledging and preserving their dignity which they possess simpliciter (Miller, 2017: p. 119). Based on this, a genuinely caring attitude would consider patient's preferences and responses to the issue of feeding and nutrition options, evaluating the state of the science, to adopt options that are more likely to foster comfort in the dying patient.

If caring for others and honoring their dignity require that we do what has been shown to be more likely to improve their capacity for relationship, then careful hand-feeding rather than tube feeding ought to be the desired method of nutritional support in patients with advanced dementia, since it is accepted to be a more humane way of caring for people with dementia. The American Geriatrics Society, the Canadian Geriatrics Society, and the American Board of Internal Medicine's *Choosing Wisely* Campaign describe careful hand-feeding as a more comfortable form of care for advanced dementia patients (Mitchell, 2015). There are other benefits of hand-feeding, such as the pleasure of tasting food (as long as it remains comfortable for the patient), and interaction with family members and care providers during feeding times (Mitchell, 2015). When an advanced dementia patient can no longer eat, hand feeding may be forgone or stopped.

In most cases, the levels of discomfort decrease in the days after the decision is made to forgo oral nutrition. Loss of appetite and the absence of a desire to eat are not painful to the patient (Arcand, 2015). In fact, artificial nutrition might actually increase pain and discomfort (Smith & Ferguson, 2017). Guardians and family members should be counseled that the correlation between earlier eating habits and starvation/hunger for people with advanced dementia who find oral-feeding distressing, is weak or at best, very modest. Knowledge and ethical approaches to terminal care are vital to ensure that individuals with advanced dementia achieve a peaceful death without needless pain at the end of life.

As a study (Muurinen et al., 2015, 182) has shown, the 'nutritional status and nutritional care of residents with dementia [are] significantly associated with their psychological well-being. The residents suffering from malnutrition had poorest psychological well-being.' In this regard, solidarity can also become an opportunity for improving the psychological well-being of persons with advanced dementia through real communication and collaboration with them. Care providers should ideally try several caring approaches to improve oral intake, such as varying the consistency and texture of food, providing finger foods, smaller portions, preferred foods, and nutritious additions (Mitchell, 2015). Careful hand feeding is labor-intensive, requiring roughly 45 to 90 min daily. Certain factors have been determined in published studies (Murphy et al., 2017, 5f) that enhance responsiveness to eating for people with late-stage advanced dementia. The patient's mood, the presence of the preferred caregiver, and dining space features can also enhance feeding. Flexible menu, modified cutlery, fewer interruptions, sensory signs, assistive feeding utensils, pleasant setting, and planning meals at times of highest attentiveness and function are other factors that can enhance comfort-feeding (Mitchell, 2015). Additionally, relationality may require caregivers to eat alongside patients or use aromas to foster copycat behaviors or stimulate appetite, thereby enhancing feeding. Oral feeding might be one of the exceptionally few remaining delights and gratifications for these patients and valuable time for socialization.

It could be criticised that food and water are not basic human needs; rather, what matters is nutrition and hydration, which tube-feed could achieve. Basic need is sometimes described as implying an end in itself, or something beyond which no further justification/demonstration is required, or derivative of other motives (Pittman & Zeigler, 2007). Further, if tube feeding were safer for the patient, it might allow interaction with loved ones, in meaning-making activities. It supposes that tube-feeding would create presence and not distance, availability and not non-availability. In that case, the combination of EOC and UP will endorse tube-feeding. However, as already observed in this paper, studies (Schwartz, 2018, 381) suggest is that tube feeding is discomforting to patients with advanced dementia. Our intuition is that tube-feeding also creates distance, depersonalization and separation between carer and patient. The combination of EOC and UP, which we appeal to in this paper, favors closeness, presence and availability. These are realized through careful hand feeding. Moreover, the reduction of human needs to elements of survival tends towards a thinking of distancing and depersonalizing of patients with feeding needs.

Various studies (Chiappero-Martinetti, 2014; Pittman & Zeigler, 2007; Watson, 2013) tend to suggest that water and food are more basic human needs than sustenance and

hydration. Hydration could be achieved in a number of ways, but water is the best way to stay hydrated or rehydrate (Van de Walle, 2019). Similarly, food is basic to sustenance. Because food and water are basic human needs, denying food and drink constitutes neglect and dishonor of human dignity. As opposed to tubes and PEGs that bypass the mouth and eliminate the need for personal engagement with the patient, careful hand feeding affirms the patient's human dignity by the very presence of the caregiver; taking time, stimulating the gustatory experience, speaking, and encouraging the act of eating and drinking that until now, constituted a basic everyday activity in the patient's life. Thaddeus Metz remarks that the core of honoring individuals who have moral status by virtue of their capacity for communal relationships entails meeting their basic needs including those necessary for exercising the capacity for interactions with others, and meeting these needs in ways that are more dignifying of them (Metz, 2015). This supports hand feeding as a more dignifying way of meeting these needs.

In cases where hand feeding cannot be accomplished, EOC and UP ask healthcare providers to look beyond the clinical efficiency of tube feeding, but rather delve deeper into the human connection of the patient with his family. Our approach suggests that physicians should be more open to requests of the patient and his family and emphasizes that the goal of medicine should always have a moral element of human connection.

The soul of the moral experience that aspires from EOC and UP asks physicians to re-consider the individual experience of human connection. For example, if a dementia patient would still meaningfully interact with his friends and family, tube feeding as a last management option would be justified through our approach; regardless of the clinical efficiency of tube feeding for late-stage dementia patients. While physicians may regard the placement of feeding tubes as ineffective, an acceptable value of life must be determined by the richness and vibrancy of connection of the patient and his family.

It could also be criticized that the primary contribution of this paper *is empirical* rather than philosophical. Suppose we are correct that there is no scientific evidence to support tube feeding for patients with advanced dementia. In this case, the *philosophical* component of the paper seems unnecessary: why would we engage in a practice which does not work?

The reader would notice that we have not claimed in this paper that tube feeding is not a valid option for the care of advanced dementia patients. We claim that it is not necessarily a *better option* than careful hand-feeding. Even though empirical studies have not shown any particular benefit of tube feeding, this option is often selected either incidentally during patient hospitalization for other causes or because family members feel that something medical is being done for the patient when eating is no longer possible. In some situations, tube feeding tends to be over-utilized than hand-feeding, even when this is not necessary. To this end, the philosophical arguments from the combination of EOC and UP are necessary to influence health workers and families to at least, attempt hand-feeding in such situations as a humane first option that demonstrates responsiveness and solidarity towards the patient. However, we encourage future research studies to explore harms associated with tube feeding of advanced dementia patients.

Another critic may point out that much of what is said in the philosophical section of this paper depends on the idea that patients can either be hand-fed or tube-fed, yet this is not how nutrition support operates in many cases. Patients may, for instance, be provided with a sufficient level of nutrition through tube feeding then offered small amounts of carefully hand-fed food. How might our account interact with this?

We acknowledge that, in reality, hand-feeding may be combined with tube-feeding in some cases. This supports our argument that careful hand-feeding can play an important role in creating an emotional bond with the patient and is more humane than tube-feeding alone. However, experiences of practitioners tend to show that once tube feeding has been engaged, very few physicians, *if any,* combine this with careful hand feeding. Nicholas Chan (2021) has made this point. According to Chan, "in reality, once a tube goes in, because [it is] so much easier just to hang up a bag of artificial nutrition and hook it up and walk away, people don't get that human contact." This has also been confirmed by Ezekiel Ijaopo (2019). The combination of EOC and UP demonstrates that human contact should be maintained in the care of the patient as far as possible. Careful hand-feeding creates contact and has many benefits for patients and caregivers, creating connection and opportunity to comfort the patient or enjoy food taste (Chan, 2021). To this end, hand-feeding ought not to be abandoned, though we recognized that this may be combined with tube-feeding.

In summary, the patient with emotional and physical needs is the one who calls us into caring human relationships (Groenhout, 2004, 82–83). This call demands solidarity on the part of caregivers. Careful hand feeding can become a means of exhibiting solidarity upholding the dignity of the patient, and addressing human needs. Ubuntu's emphasis on humanity and compassion can guide people's thinking about the welfare of others particularly during a health issue or crisis. Ethics of care approach provides a moral significance of interdependent relationships. Together, our approach offers a new outlook for the management of advanced dementia patients because it does not solely look at the clinical outcomes of an intervention, but rather incorporates the strong and deep human relationships and offers a more personalized plan that best relates with the patient or family's wishes.

## Conclusion

Advanced dementia is a terminal illness that is debilitating and life-limiting. People with advanced dementia are highly dependent on the support of others and need continuous help to retain their autonomy and quality of life. Feeding and nutrition is one area that can be severely compromised in later stages. The combination of EOC and UP provides an inspiring perspective to manage feeding difficulties in these patients, which concurs with evidence derived from studies in this area. EOC and UP suggest that careful hand feeding can be a mindfully selected appropriate first option that is symbolic of true caring practices, as it affirms the identity of the patient and the changing human needs in advanced dementia, enriching the relationship between persons and bringing comfort to the patient. The decision to hand-feed also expresses solidarity with patients whom we are invited into caring relationships with, for their own sake.

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## Declarations

**Conflict of interest** The authors declare that he has no competing interest.

**Ethical approval** This study is a concept paper and does not require ethical approval.

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