CHAPTER 11

Artificial Nutrition and Hydration at the Terminal Stage of Dementia from an Islamic Perspective

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1 Introduction

Religious assessments of novel medical procedures are complex and end-of-life nutrition in the context of dementia is a contested topic from both a clinical and an Islamic perspective. The terminal stage of dementia in particular is characterised by difficulties in swallowing, malnutrition, and loss of appetite which usually lead to weight loss and dehydration. Consequently, this chapter aims to analyse the advantages and disadvantages of artificial nutrition and hydration (ANH) in consideration to Islamic law. It considers whether the latter perspective permits artificial nutrition and hydration in the terminal phase of dementia. Finally, this chapter aims to contribute to the Islamic discussion on end-of-life care while emphasising the need to consider all cases in their individual contexts and advising that the view presented here does not represent the entire spectrum of Islamic sects.

2 Dementia

Dementia (Ar., *kharaf*; al-Ḥifnī 1992, 842) is an umbrella term that refers to a large number of types of progressive cognitive decline such as Alzheimer's disease (Ar., *maraḍ alzhaymar*), which is the most common form of dementia. The common features of the different types of dementia,[1] such as Alzheimer's disease, cause a progressive deterioration in cognitive and memory functions which is associated with communication problems, changes in personality, and motor disorders. In classical and modern Arabic, the verb *kharifa* describes the process of becoming old and experiencing the typical cognitive changes (Lane and Lane-Poole 1955, 725) that are part of the ageing process.

1 Other common types are vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. A subset of people has a mixed dementia, which is a combination of Alzheimer's disease and another type of dementia.

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Old age is associated with a high risk of dementia. At advanced ages (75+ years), the risk of developing dementia is about 30–50% (Radman 2010, 18). The Alzheimer's Association estimates that more than 50 million people were living with dementia in 2019 and expects that the number of dementia cases will triple by 2050 (Alzheimer's Disease International 2019, 13).[2] There is no treatment to reverse the loss of cognitive functions experienced in dementia. Some studies show that cognitive training and medication are likely to preserve cognitive functions or at least slow the progress of the disease down.[3] The symptoms intensify as the disease runs its course, and the person living with dementia needs increasing levels of care and support. The caregiver faces the challenging task of finding the right balance between supporting the persons concerned by encouraging them to continue to do things for themselves without overstraining their capacity. People with dementia lose abilities but with assistance are still able to make use of those they retain.

The upcoming text will describe the stages of Alzheimer's disease, as it is the most widespread type of dementia. The most common signs of this type include memory loss, difficulties in performing familiar tasks, and changes in mood, behaviour or personality (Engel 2006, 11). Life expectancy after the diagnosis varies between approximately 2 and 20 years (Engel 2006, 29). The development of dementia is usually divided into three stages that merge into one another (WHO-ADI 2012, 7). At the early stage, the patients face problems with short-term memory and have mood swings, along with experiencing word-finding difficulties; communication is increasingly challenging (Laabdallaoui and Rüschoff 2009, 90). Further early signs are difficulties with solving problems and performing daily tasks, such as cooking meals and driving a car. The affected patients are aware of the changes and often withdraw from social life or conceal their difficulties from others. For this reason, relatives, friends, or the individuals themselves often misrecognise this stage and may consider the patients to be suffering from depression or simply experiencing the effects of older age (Radman 2010, 24). In the middle stage, it is no longer possible for the individuals to conceal the changes because they find themselves experiencing considerable difficulties in everyday tasks and personal care. The impairment of long-term memory increases, but actions learned early in life remain available and can be used in the individuals' care (Radman 2010, 27). People at this stage can live semi-independently with assistance provided. Though, they may

2 Alzheimer's Disease International is the global umbrella organisation of all Alzheimer's Associations.

3 On medical interventions, see Fellgiebel 2008, 45–48; for non-medical interventions see Stoppe and Maeck 2007, 33–36.

struggle to articulate themselves verbally in the correct context (Laabdallaoui and Rüschoff 2009, 90). Notably, changes in behaviour such as aggression and activity at night ("sundown syndrome") occur. People with dementia may be tired in the daytime and awake at night; they may want to go for walks and call for their caregiver, interrupting their sleep (Fellgiebel 2008, 46).

People with late-stage dementia are often bedridden and their speech is impaired, which makes articulation virtually impossible. They "are typically unable to walk or to feed themselves, they are incontinent and aphasic, and they have lost the capacity to have relationships with other people" (Gillick 2000, 206). In addition, difficulties in swallowing or incontinence occur (Radman 2010, 25). Loss of appetite and desire for food is likely to lead to lower food intake, malnutrition, and consequent weight loss, and ultimately to difficulties for caregivers in ensuring they take in a sufficient amount of food and liquids (Laabdallaoui and Rüschoff 2009, 90f.), notwithstanding the reduced need for both in people in old age with low activity levels (Vilgis, Lendner, and Caviezel 2015, 14–16). Assistance with eating counters malnutrition in moderate dementia. However, artificial nutrition and hydration (ANH) is an option at the late stage. In many cases, people in this terminal stage of dementia die from infections (Laabdallaoui and Rüschoff 2009, 91). It should be noted that death certificates in many countries do not record dementia as a cause of death because of the difficulty of assessing whether dementia or the accompanying illness(es) were the key causal factor(s) (WHO-ADI 2012, 12).

3 Artificial Nutrition and Hydration at the End-of-Life

Food intake, swallowing, and drinking are considered among the last everyday activities to be impaired in people with dementia. The results are malnutrition, difficulties with swallowing, pneumonia, and food refusal (Volkert et al. 2015, 3). Artificial nutrition and hydration is the most common medical intervention in advanced dementia. This section of the chapter discusses the drawbacks of this treatment and situations in which it may be suitable, before going on to consider it from an Islamic perspective.

In the advanced stage of the disease, people with dementia "no longer know what they are supposed to do with the food and/or utensils put in front of them, behavioural problems emerge and eating skills are lost" (Volkert et al. 2015, 3). The malnutrition that may result from a decrease in food intake causes weight loss and a decline in muscle strength which then heightens the risk of falls (Knels, Lauer, and Schrey-Dern 2018, 143). Studies show that a low BMI increases the mortality of people with dementia (Volkert et al. 2015, 3).

However, food refusal may additionally be related to other factors. A distracting environment, for example, or a poorly fitting dental prothesis causing pain or gum inflammation may impact food intake (Vilgis, Lendner, and Caviezel 2015, 4). In advanced dementia, a functional impairment in swallowing (dysphagia) leads to aspiration before, during and after swallowing (Volkert et al. 2015, 3). Dysphagia causes choking and increases the risk of pneumonia when bacteria enter the lungs. Pneumonia is one of the common causes of death in people with dementia (Volkert et al. 2015, 3). A medical procedure that is finding more and more use in this case is artificial nutrition and hydration (ANH), which can be given through a gastrostomy tube or a nasogastric tube. The latter is used to bridge temporary periods of insufficient nutrient consumption. As soon as it is foreseeable that tube feeding is needed in the long term, the patient receives a PEG (percutaneous endoscopic gastrostomy) after consideration of the individual case (Knels, Lauer, and Schrey-Dern 2018, 155). The Saudi Commission for Health Specialties, for instance, declares that artificial nutrition is to be used in cases when natural food intake is impossible, regardless of the type or duration of the illness (SCFHS n.d., 32).

Furthermore, artificial feeding is claimed by some physicians to satisfy hunger. Mohammed Ali Al-Bar (Muḥammad ʿAlī l-Bārr, b. 1939) and Hassan Chamsi-Pasha (Ḥassān Shamsī Bāshā, b. 1951) argue that "[i]f hydration and feeding is stopped the patient does not die peacefully and comfortably. He suffers dehydration and hunger for 10–14 days" (al-Bar and Chamsi-Pasha 2015, 250). However, in the case of end-of-life, both take a decreased food intake into consideration. Referring to the *ḥadīth* which discouraged forcing the sick to take food and drink, al-Bar and Chamsi-Pasha see the importance to inform the families about occurring biological changes that lead to the loss of weight. They recommend reducing the amount of nutrition and justify that:

> [T]he reason for this approach is to prevent the potential feelings of guilt and sorrow that could be experienced by the family if nutrition or hydration support was withdrawn or withheld completely.
>
> AL-BAR and CHAMSI-PASHA 2015, 254

Notably, al-Bar and Chamsi-Pasha disagree with the complete discontinuation of basic nutrition because this would mean starvation to death which is a sinful act from an Islamic view (al-Bar and Chamsi-Pasha 2015, 254). Studies in palliative care show, however, that many persons at the end-of-life do not feel hungry and thirsty and consequently do not starve (Vilgis, Lendner, and Caviezel 2015, 44; Sitte 2016, 34). A dry mouth is not in and of itself a sign of thirst (Vilgis, Lendner, and Caviezel 2015, 71). The dying person may suffer

from a painfully dry mouth, and oral care is essential to alleviate the suffering (Stiefelhagen 2018, 14). In fact, dehydration and reduced food intake support the dying process because they aid the release of endogenous opiates in the brain, which is likely to make the patient's state more comfortable (Post and Cicirella 1995, 105; Sitte 2016, 34). Hence, it is argued that in palliative caring one should consider both on a case-by-case basis in order to balance pain management and actual needs (Sitte 2016, 21). Gillick regards the necessity to raise awareness of the effectiveness of dehydration and contends that withholding tube feeding can be considered as a part of palliative care (Gillick 2000, 209).

Dehydration could be an accessible component of palliative care in view of the lack of availability of end-of-life care, such as in the Middle East. In a survey conducted among Muslim medical staff, Al-Awamer and Downar found that

> [i]n the Middle Eastern model, PC [palliative care] practitioners faced a shortage of skilled medical staff, limited drug availability, limited availability of home care, and [the challenge of] integrating services across care settings.
>
> AL-AWAMER and DOWNAR 2014, 3255

When considering the availability of palliative care for Muslims, it is crucial to consider the geographic distribution of the majority of Muslims who live outside the Middle East and North Africa. The comparative study on palliative care and especially the use of medication in Muslim-majority countries by Aljawi and Harford shows that there is a "virtually nonexistent consumption," except for Turkey and Saudi Arabia which are on a very low level, although a *fatwā* in Saudi Arabia exists, supporting the use of opioid analgesics for relief of physical pain. They identify not only a lack of palliative service, but also religious barriers such as the fear of diversion from opioid use (Aljawi and Harford 2012, 143). However, palliative medication is no modern invention. Physicians such as Ḥunayn b. Isḥāq (d. 260/873) recommended certain extracts of plants as well as opium to alleviate severe pain and to cause lethargy (Klein-Franke 1982, 104). Furthermore, cultural factors play a role as well. For example, Muslims in non-Muslim majority countries may feel that inferior care is offered to them because of their religion or ethnicity (Hedayat 2006, 1288).

The availability and barriers to accepting palliative care are important when considering that the request for treatment at the end-of-life, such as ANH, reflects a strong hope in its effectiveness, but the survival rate with ANH is controversial. Compared to assisted hand feeding, Chou and colleagues show that nasal feeding could not significantly lower the mortality rate in late dementia (Chou et al. 2020, 4). Proponents of this therapy argue that ANH reduces the

risk of pneumonia. However, Chou and his colleagues have shown that there is no significant evidence that ANH decreases the incidence of pneumonia (Chou et al. 2020). Another problem with ANH is its elimination of the social component of food consumption. Chou et al. suggest that tube feeding leads to isolation and that "an adequate environment setting (e. g., removing distractions and scheduling mealtime with family) could make patients enjoy their social time, as opposed to isolated tube feeding" (Chou et al. 2020, 6).

Considering that food intake is one of the last activities people with dementia can undertake in the context of their loss of cognitive skills, the withdrawal from social life which may take place with artificial feeding is a concern, as is the important therapeutic measure of retention of routines – such as mealtimes – within the structure of the patient's day. Therefore, Gillick recommends oral food intake for people with dementia in the terminal stage of their disease (Gillick 2000, 208; Post and Cicirella 1995, 96–109; Chou et al. 2020).

Further disadvantages of artificial nutrition outweigh its few advantages in the dementia context. Artificially fed dying persons have stomach and bowel content which leads to vomiting, nausea, and diarrhoea. They suffer pain and discomfort during connection, repositioning, and disconnection of the tube. Tubes may become blocked or infected, and fixation is needed to avoid the patient manipulating them (Stiefelhagen 2018, 14). Other side-effects are risks of bleeding and traumata to abdominal organs, whose prevention may necessitate the use of restraints and chemical sedation. Moreover, changing tubes requires an invasive procedure in a hospital, which can be stressful in advanced dementia (Alibhai 2008, 46). Hence, Alsolamy contends that the complications of ANH, as detailed above, should be accepted as the "lesser of the two evils" due to the greater harm, from a religious point of view, caused by responsibility for a person's starvation (Alsolamy 2012, 99). This point is to be discussed later.

Swallowing problems can be treated by non-invasive methods. There are three ways to encourage independence in eating: 1) assisted hand feeding (AHF, assistance with eating and drinking); 2) adjusting the setting of meals and the position of the patient during feeding (Chou et al. 2020, 6); 3) modification of food texture (Vilgis, Lendner, and Caviezel 2015, 137–248). What follows is a concise discussion of these three methods, in order.

1) Assisted hand feeding, that is the assistance of another person with food intake, is a favourable alternative to ANH. AHF requires nursing staff or carers as opposed to medical intervention, and therefore represents an instance of interpersonal interaction for people with dementia. This form of food intake is time-consuming and makes significant demands on staff or caregiver time which engender a high cost in staffing or in loss of earnings for economically

active caregivers. When AHF is possible and the person ingests enough food, from a medical point of view ANH is not necessary. In cases where AHF ceases to be viable or food and/or liquid intake is insufficient despite AHF, ANH can

be considered, provided that its benefits are likely to outweigh any potential harm (Osterfeld, Lababidi, and Langfeldt 2018, 497). Alibhai contends that AHF is often not possible at this stage (Alibhai 2008, 40). The question arises whether AHF is unfeasible due to swallowing problems or impracticable due to a lack of staff or carer resources for the more time-consuming process of AHF.

2) A noisy environment might be distracting to the person receiving feeding, and their physical position and posture affect their swallowing function. The chin tuck position and head rotation toward the weaker side can facilitate food intake (Chou et al. 2020, 6).

3) Swallowing problems can arise from the texture of the food offered, where it requires physical effort when chewing, and fluids are difficult to control. Modification of the physical features of the food, such as mashing, thickening and foaming can make food appetising and serve as an opportunity to increase enjoyment when eating, as well as countering swallowing difficulties.

Difficulties with swallowing can be treated using invasive and non-invasive methods. The latter are preferable, but not always possible. However, the medical and psychological side-effects of ANH should be considered.

4 An Islamic Perspective on Artificial Nutrition and Hydration of People with Late-Stage Dementia

Nutrition at the end-of-life is a controversial topic. Clearly, starvation is an ethically unacceptable route. The weight loss and loss of appetite often experienced – for various reasons, as discussed above – by people at the terminal stage of dementia appears to call for the administration of food to prevent starvation. Offering too little food or drink can be viewed as neglect, and relatives in particular may feel a sense of co-responsibility for the death of their family member. Some relatives may understandably opt for ANH to avoid feelings of guilt at inactivity in the face of their loved one's state which may overcome them if they withhold or withdraw ANH (al-Shahri and al-Khenaizan 2005, 434). It is believed that the fear of the death (*al-khawf min al-mawt*) of this person may indeed induce physical pain in those left behind; Ibn Ḥazm (d. 456/1064) recounts various stories in which unrequited love or the loss of loved ones lead to grief (*ḥuzn*), physical weakening, and even to the death of the loving person (Ibn Ḥazm 1943, 179–187).

The following chapter discusses the permissibility of artificial nutrition and hydration at the end-of-life from an Islamic perspective, including a look at studies on the advantages and disadvantages of ANH.

4.1 Qatl al-Ṣabr *Analogy*

The Islamic Fiqh Academy (IFA), affiliated with the Muslim World League, declared in 2015 that continuing feeding is "significant" for the care of a patient (IFA 2015). Hence, refusing or withdrawing ANH would be equal to (quasi-intentional) homicide.[4] This conclusion derives from the following precedent of the prohibition of killing detainees (*qatl al-ṣabr*) (Ghaly et al. 2018). It was reported by Khālid ibn al-Walīd (d. 21/642) that Prophet Muḥammad prohibited to confine someone to die (Ibn Ḥibbān n.d.). The analogy is questioned because the underlying situation differs. The killing of a detainee is an active act which certainly leads to death.

There are a few *fatwā*s discussing the permissibility of refusal of ANH. *Fatwā*s as an "expression of the religious-Islamic law and Islamic jurisprudence" are requested to examine not yet specifically regulated situations, acts, and circumstances for their godliness (Krawietz 1991, 21, 29) – which is the case in the majority of medical issues. Sachedina criticises this approach in tackling bioethical questions. In his view, moral reasoning in Islamic ethico-legal deliberations on medical interventions should not be limited to *fatwā*s alone. He states:

> Instead, [...] this emerging discipline needs to define its epistemic parameters and develop both a methodology and a justificatory mechanics of moral reasoning that explore and open venues for deriving ethical "recommendation (*tawṣīya*)" rather than "judicial opinion (*fatwā*)" on issues that confront human health and medical research in Muslim societies.
>
> SACHEDINA 2009, 13

However, Sachedina points out not to dismiss juridical opinions which could serve as basis for further moral discussions (Sachedina 2009, 13f.). The search for a similar precedent can support the ethical deliberations on a present problem in order to extract the underlying moral purpose. Hence, research in Islamic bioethics should bear in mind that the specific medical problem(s) may change with new medical technology and the ethical consideration constitutes only a preliminary evaluation.

4 Intentional homicide (*qatl ʿamd*) involves the use of a lethal weapon in contrast to quasi-intentional killing (*shibh ʿamd*), see on another three types of homicide and bodily harm (*qiṣāṣ*), Hallaq 2009, 320.

The limitation of the juridical approach appears from the *fatwā*s which address the refusal of ANH as a form of killing. On the one side, it is contended that the physician would cause the death by terminating tube feeding. For example, in a *fatwā* from Kuwait it is argued that if the physician terminates any treatment, he would be guilty of unlawful killing (Krawietz 1991, 106). He should rather act out of inner motivations, such as mercy, to save the life and leave it in the hands of God, whether healing will occur (Krawietz 1991, 106). In the same vein argues another *fatwā* which denies a patient who has an artificial lung and about 1% probability to improvement his or her right to die. Otherwise, the physicians would be liable for assisted suicide. If they cannot convince the patients to continue – even futile – medical treatment and the patient demands for letting die the physicians should not be involved in any related act (IslamWeb 2002). On the other side, the underlying disease – and not the act of the physician – is considered to cause the death (Ilkilic 2016, 97). Hence, it cannot be regarded as voluntary active euthanasia because the intention here is to allow a person to gain release from an untreatable suffering and no lethal injection is administered (Sachedina 2009, 169–171).

In the precedent, the focus is on the moral responsibility of the guardian. Does it differ when the detainee decides to refuse food? The main argument – why medical treatment is not obligatory – is based on the assumption that the therapeutic benefit is speculative (Padela and Qureshi 2016). Furthermore, from Prophetic sayings such as the duty to seek healing but also receive reward from being steadfast and trustful (*tawakkul*) in God as the sole healer (Q 26:80) it can be concluded that there be either a recommendation or obligation to seek medical treatment, but also some reward for abstaining (Padela and Qureshi 2016, 598).

Padela and Qureshi elaborate on how the jurists of the four Sunnī law schools differ in their view on the compatibility of *tawakkul* and receiving medical treatment. The majority of legal scholars representing the Ḥanafī, Shāfiʿī and Mālikī law consider medication as a confirmation of the trust in God if the effectiveness is certain and regard the refusal in this case as a lack of *tawakkul*. Only a few Ḥanbalī jurists preferred the trust in God over a medical treatment (Padela and Qureshi 2016, 599–604). Patience as general command should be the stance during suffering, especially in futile cases (Krawietz 1990, 97–101). Notably, the Ḥanafī jurists al-Mawṣilī (d. 683/1284) and Ibrāhīm al-Ḥalabī (d. 956/1549) differentiate between the consequences of refusal of food and medication in the hereafter. They agree upon that the one who fasts and starves to death is sinful whereas the one who refuses medical treatment until he dies does not commit a sin (Padela and Qureshi 2016, 599). The juristic argument is agreed upon that the human being who does not take food and

starves to death is sinful because the prevention of harm is certain by nutrition – in contrast to medical interventions (Kellner 2010, 150). In contrast, al-Ghazālī (d. 505/1111) emphasises the role of the patient in deciding to refuse medication. He contends that if sick persons realise that they reached the end-of-life and, hence, every medical treatment is futile, they can decide to refuse all kinds of medications (Klein-Franke 1982, 126).

Starvation for a higher objective is viewed differently. It is still possible that the detainee starves even though he has been offered food and drink. Hunger strike could represent a means of resistance. For example, Muḥammad Aḥmad Ḥusayn (b. 1966), *muftī* of Jerusalem and the Palestinian Territories, legitimised the hunger strike of Palestinian prisoners in 2015 and declared that the victims of force-feeding were "martyrs" (Al Jazeera 2015). In this context, resisting force-feeding is permitted and is not considered as suicide.

However, the analogy of *qatl al-ṣabr* is contested in the case of refusal of ANH, i.e., when no tubes are placed. If the person or his relatives decided not to undergo ANH, then refusal of this is permitted because refusing a medical treatment not warranting to prevent death is not forbidden. For example, a *fatwā* released in 2017 states that refusing treatment (from fatal disease) is not considered suicide (IslamWeb 2017). Whereas, if they wish ANH to be administered, then it is permitted, too.

Another ruling derived from Islamic ethico-legal deliberations applies in this case: the tenet of "no harm, no harassment" (*lā ḍarar wa-lā ḍirār fī l-Islām*), which functions both as a principle and a source for the rule that "hardship necessitates relief" (*al-mashaqqa tajlib al-taysīr*). According to Sachedina, it means that there can be no legislation, promulgation, or execution of any law that leads to harm of anyone in society. For that reason, in derivation of a legal-ethical judgment the rule is given priority over all primary obligations in the Sharīʿa. In fact, it functions as a check on all other ordinances to make sure that their fulfilment does not lead to harm (Sachedina 2009, 228).

In a nutshell, the analogy has shortcomings: the intention (*niyya*) in the precedent is to confine someone to die who would normally continue living if not confined. Whereas the intention in refusing or withdrawing ANH is to let someone die who has no chance of improvement with any medical treatment. Rather, considering the higher objectives of the Sharīʿa (*maqāṣid*) would serve better in this novel situation. The Sharīʿa promotes the safeguard of three universal goals: 1) essential needs (*ḍarūriyyāt*), 2) necessary needs (*ḥājiyyāt*), 3) secondary needs (*taḥsīniyyāt*). The common good (*maṣlaḥa*) in applying the universal goals in the context of public health care is to ensure essential needs are met and probable harm is averted (see Raissouni 2016). Both, withdrawing and refusal of ANH permits a natural course of dying for patients with

dementia at the end-of-life. The majority argues that neither the physician, nor the family members are morally responsible for the death of the person concerned because the underlying disease and not the act itself caused the death. Withdrawing and refusal of ANH can support the dying process appropriately because reduced food and liquids intake releases hormones that eases pain, whereas food intake causes discomfort and infections.

4.2 *Medical Treatment or Nutrition?*

It is debated whether ANH is considered a medical treatment or a kind of nutrition at the end of life. Muḥammad Aḥmad al-Shāṭirī claims that the person who restrains another one's food and liquids so that it leads to death is to be penalised with retaliation and thus is guilty of murder. He is also a fervent opponent of switching off ventilators. This he deems even graver than starvation because a human being may live without nutrition and hydration for a certain period of time, but not without oxygen (Kellner 2010, 150). The IFA does not share this view and allows withdrawal of respirators in futile cases.

According to a *fatwā* that follows the IFA ruling on ANH – as stated above – removing resuscitation devices is allowed in a child with cancer in an incurable stage, after three specialist doctors have testified that death is certain. However, nourishing him is not permissible to stop (IslamWeb 2019).

Sachedina criticises that previous bioethical researchers in Islam consider bioethics a subcategory of Islamic jurisprudence, pursuing the overall goal to determine the permissibility or prohibition of a certain medical treatment. However, the reasoning why something is permitted or prohibited from an ethical perspective does not concern them (Sachedina 2009, 18). The Islamic scholar Yūsuf al-Qaraḍāwī (d. 2022) argues in the same vein. Stemming from the conviction that medical care is not obligatory, he has a different view on ANH. In a *fatwā* he raised the question if therapeutic substances – e.g., nutrition in the form of injection – extends the duration of the illness and suffering, then it apparently is neither obligatory nor preferable (Kellner 2010, 149). It becomes obvious that al-Qaraḍāwī envisions a different approach on bioethical dilemmas weighing up the benefits against the potential harm of a specific medical procedure. The principle of *maṣlaḥa*[5] (public or common good) serves as a useful tool "in providing solutions to the majority of novel issues in biomedical issues" (Sachedina 2009, 47). Sachedina states that legal scholars from all law schools have met on a regular basis and established common decisions, often prioritising the common good. Besides, they applied the principle of

5 See Opwis on the definition and understandings of *maṣlaḥa* in the Islamic ethico-legal tradition and in contemporary discussions (Opwis 2005).

proportionality (*tanāsub*) in rulings on individual and social interests of the community whereby in a few cases collective interests set aside the interests and rights of an individual (Sachedina 2009, 48).

The same controversial discussion on artificial nutrition and hydration can be found in Judaism. On the one hand, Rabbi Moshe Feinstein and Rabbi Shlomo Zalman Auerbach contend that ANH is imperative and may be administered involuntarily even if the patient is suffering from it. On the other hand, Rabbi Hershel Schachter and Rabbi Horowitz argue that ANH is a medical procedure which may rightfully be refused by terminally ill patients (Schostak 1994, 97f.). Standing between those opposing poles, Rosin and Sonnenblick demand to consider the ethical questions to assess the benefits of ANH against the risks and suffering caused to the patient (Rosin and Sonnenblick 1998, 45).

In Catholicism, ANH is rather discussed in the context of persistent vegetative state. Opponents of ANH raise awareness of the serious side-effects which should be considered when evaluating the procedure as proportionate care. Proponents of ANH, such as Pope John Paul II (d. 2005), state that ANH is basic nutrition – rather than a medical means –, hence obligatory and always proportionate (Zientek 2013, 151f.).

The question remaining is whether it is considered to prevent death or satisfy appetite. To what extent does one speak of nourishing in artificial feeding, or could it rather be regarded as a medical treatment? At this juncture, the ethico-legal question of whether artificial feeding via injection (*ḥuqna, ibra*) during Ramaḍān breaks the fasting is highly debated (IslamOnline n.d.) and may help reflection on ANH. One form of parental nutrition is probably addressed where the feeding takes place intravenously only to support the intake of nutritional components such as glucose – not the complete replacement of nutrition. The discussion mainly focused on the two issues: entry and the circulation in the human body, whereas the contemporary debate addresses the question of the overarching goal of fasting.[6] The use of a nourishing injection is normally intended to restore health and not for the satisfaction of hunger. Al-Qaraḍāwī contends that although the substance infiltrates the blood, it does not break the fasting rule because it does not satisfy the appetite (Krawietz 1991, 303f.). However, as shown above, this is not necessary at the end-of-life. Finally, the person with advanced dementia may remove the tube because of the lack of understanding its purpose. Hence, artificial feeding should not be obligatory.

6 See Krawietz on contemporary ethico-legal deliberations on injections during Ramaḍān and the cited precedent in classical literature (Krawietz 1991, 298–313).

4.3 *"Duty to Feed" Whom?*

Proponents of ANH argue that the refusal of artificial nutrition and hydration would lead to death by starvation. Islamic scholars and physicians are therefore inclined to allow artificial food intake when the patients are not able to eat and drink by themselves (as mentioned above). The view outlined above ultimately stems from the Qurʾānic directive to save life, as is expressed in numerous verses on the duty to feed poor, hungry, and needy individuals (see, for example, Q 90:12–18; Alibhai 2008, 43–45). It is obvious that this imperative implies the giving of drinks and could be interpreted as a basic human right to access to food and drink. Does the duty to feed as a necessity imply artificial nutrition and hydration? Does the duty to feed apply to the end-of-life when the dying person refuses food and liquids? The context of withdrawal of feeding in the terminal stage of dementia differs from that of the hungry person outside of this situation. The dying person does not feel hungry or thirsty because this is part of the dying process, while the non-dying person aims to survive. Furthermore, the question remains who is meant to be provided with food. Here, the person in need of food lives in privation and has no access to it because of financial reasons. In the final analysis, the Qurʾānic "duty to feed" those wanting to be fed cannot be applied in the end-of-life context.

I would argue, however and furthermore, that if the person expresses hunger or is able to eat with assisted hand feeding, then AHF is acceptable, and he or she should not be force-fed. Gillick argues that the fixation of tubes to people with advanced dementia is ethically unjustifiable with respect to the disadvantages of ANH and the lack of understanding of the process in people with dementia (Gillick 2000, 207). They cannot comprehend why tubes are attached to their stomach and may try to pull them out. This procedure can lead to stress and aggressive behaviour which makes the use of restraints and chemical sedation necessary. According to the Islamic tradition, there should be no constraints placed upon a sick person. Ibn Qayyim al-Jawziyya (d. 751/1350) refers to a *ḥadīth* which states that one should not force sick people to eat or drink because God gives them food and drink (Ibn Qayyim al-Jawziyya n.d., 70f.). This understanding stems from the Islamic view that the mental disposition of a person influences the physical healing process, as the human mind and body are considered to form a unit (Haque 2004, 357–377). Additionally, the directive to refrain from applying force emphasises the moral agency of sick persons. The Islamic tradition asserts the Prophet Muḥammad's concern that the needs of people in illness be met. In a Prophetic saying reported by Ibn ʿAbbās (d. *c*.68/687), the Prophet visits a sick person and asks him what he would like to have. The man answers: "Wheat bread." The Prophet says that whoever has wheat bread, should give it to the sick person. He adds that whenever someone

is sick and has appetite for something, then he or she should eat it (Aksoy and Elmali 2002, 216). This raises the question of what serves the "best interest" of a sick person. The bioethicists Aksoy and Elmali argue that even if there is something harmful in the food itself (from a religious perspective), it would bring a benefit and may heal the sick person, and would be less harmful than if the individual ate something they did not wish to eat – even if it were in their best interests from a medical perspective (Aksoy and Elmali 2002, 217).

In this view, the focal issue should be the will of the person with dementia and whether it is ethically justifiable. Jaworska argues that the wishes and desires of people with dementia must be considered because the capacity for appreciation remains functional even in the terminal stage of the disease. For example, a person recognises the work of another person which is addressed but because of communication problems it is difficult to understand. A person closely associated with him or her could assist in translating the expression of appreciation (Jaworska 2010, 71–96). In this case, such consideration would mean respecting the expression of the individual's need or refusal to eat. However, understanding these needs is challenging for caregivers and medical staff and may sometimes only be the "best interpretation" of what is known about the patient's former and present wishes (Flynn 2018, 157–174). Given that the capacity to act is rooted deeply in the Islamic tradition (Ghaly 2019, 257–261), Advance Care Planning (ACP) represents a useful instrument for the recording of personal preferences. ACP is a method in end-of-life care which enables a step-by-step approach to questions of life, death, and life-sustaining measures with the involvement of the individual concerned. This would relief the family members from the burden of moral responsibility. In the case of dementia, there is a need to provide understandable information and to involve relatives and other caregivers (Voß and Kruse 2019, 286). However, in the actual situation, the patient's wishes are often ignored, with a concomitant impact on the rights of the person affected by dementia. Current regional initiatives aim to promote the rights of older people and to enshrine them in legislation. For example, the Beirut-based Institute for Development, Research, Advocacy and Applied Care (IDRAAC) seeks to raise awareness of the rights of people with dementia and in old age and has launched a national awareness campaign using the slogan "Even if you lose yourself, you don't lose your rights" (*ḥattā law ḍayyaʿat, mā tuḍayyiʿ ḥaqqak*) (IDRAAC n.d.).

4.4 *Prolonging Death*

The ability to take in food and liquids independently is one of the last activities to be lost at the terminal stage of dementia. It is likely that ANH prolongs the dying process of people with dementia. From an Islamic view, it is rejected

to manipulate the natural course of dying. As outlined above, and in this context, ANH cannot be considered a curative treatment in terminally ill dementia patients. Opinions diverge on the application of ANH from ethico-legal perspective in both Sunnī and Shīʿī Islam, but a consensus is apparent on the discontinuation of therapy where the intervention proves futile (Alsolamy 2012). Islamic law permits the refusal of futile medical treatments at the end-of-life when there is no hope of restoring health (Sachedina 2009, 170f.). This tenet stems from the Prophetic saying that God sends remedies for all illnesses except for death (Ibn Qayyim al-Jawziyya n.d., 57f.).[7] From this position one can conclude that once the terminal stage has begun, it is permitted to refuse life-extending measures, as they may be considered an interference with the divine plan. Islam holds that the time of death is fixed by God (*ajal musammā*, i.e., Q 7:34). However, *ajal* is not the terminal point of existence and should not be viewed pessimistically; it is rather a threshold into eternal life (*khulūd*) (Izutsu 2002, 138). The prolonging of life or of the end-of-life phase with artificial resuscitation postpones death; delaying of death, then, may appear as a manipulation of the process of dying (Krawietz 1991, 109). Al-Bar and Chamsi-Pasha point to the limitations of medicine in the terminal stage:

> Islam acknowledges that death is an inevitable phase of the life of a human being; medical management should not be given if it only prolongs the final stage of a terminal illness as opposed to treating a superimposed, life-threatening condition.
>
> AL-BAR and CHAMSI-PASHA 2015, 244

The physician is not liable for prosecution after the withdrawal of a medical treatment if the decision of letting the patient die has been decided and confirmed from the patient and stakeholder (Sachedina 2009, 169). ANH may appear as opposing to the authority of God as He is the only authority that can give and take life. In the Islamic belief system, God is the One who brings beings into life and lets them die (Q 2:258). Thus, withdrawal or withholding of ANH means accepting that only God is the author of life and death. As discussed above, food refusal cannot be regarded as active euthanasia because accepting the natural course of dying is in accordance with the divine will. However, the question of delaying the appointed time of death (*taʾjīl al-mawt*) is contested. It is stated that from an Islamic perspective, it is not possible to hasten or postpone the death (Krawietz 1991, 109). Yet, ANH could be considered as prolonging the end-of-life phase.

7 Another version has it that God sends remedies for all illnesses except for old age.

From an Islamic perspective, survival and death are equivalent because both are contingent to the will of God. Neither of them has an intrinsic value. The purpose of death is the induction of created beings to eternal life in the hereafter. A *ḥadīth* sets out that believers should not seek for death or induce their premature death by refusing effective remedies (Brockopp 2003, 188). Once the time of death has come, however, the Islamic faith prescribes the adoption of a passive role (Brockopp 2003, 188), which nevertheless permits the alleviation of pain via palliative care. Lastly, artificial feeding cannot change the appointed time of death but rather prolong suffering in the dying phase. Therefore, it should be permissible to refuse ANH and to alleviate pain by palliative care.

5 Concluding Remarks

Artificial hydration and nutrition at the terminal stage of dementia should not be the preferred therapy from a medical and an Islamic perspective, respectively. ANH can be a reasonable intervention for short-term use in situations where a person with dementia has lapsed into a coma and is unconscious. However, ANH should not be obligatory in the terminal stage of dementia if the patient or the relatives refuses it. Hence, it is crucial that at least two physicians agree upon the dying phase having started and any treatment being futile. I therefore strongly advocate the provision of greater resources for assisted hand feeding and palliative care, particularly in light of the argument – which I hope to have supported convincingly in this chapter – that the disadvantages of ANH at the terminal stage of dementia outweigh the benefits.

Besides the medical considerations, the ethical arguments from an Islamic perspective have been discussed on four topics. In my view, the precedent of the prohibition of the killing of a detainee (*qaṭl al-ṣabr*) cannot support the ethical deliberation on ANH. Rather, considering the higher objectives of the Sharīʿa (*maqāṣid*) would serve better in novel medical situation (Raissouni 2016, 220–223). Furthermore, the Qurʾānic imperative of the "duty to feed" may apply only to the terminally ill dementia patient who still shows interest in food and can eat with assisted feeding rather than with ANH. Where a patient with dementia does not wish to eat with assistance, the duty to feed does not apply because the perspective of Islamic law would consider force-feeding non-permissible; instead, the patient's comfort should be ensured, and pain relief provided if the patient or a stakeholder request it after an informed consent. The Qurʾānic "duty to feed" cannot be applied in the end-of-life context; the majority position in the Islamic scholarship agrees that there is no moral responsibility for the death on the physician or the family members. Finally,

ANH could be considered as prolonging the end-of-life phase, not as postponing death but rather extending the dying period.

At the terminal stage of dementia, weight loss, decreased food intake and food refusal, and swallowing difficulties signal the approaching end-of-life. From an Islamic ethical perspective, acceptance of this dying process is permitted. Letting the patient die in futile cases does not interfere with the moral duty of a physician to save life. The duty is rather to allow the person to die with dignity. On this note, I will conclude by stressing the ongoing need for intensified research in palliative care to the end of raising awareness of its effectiveness, necessity, and permissibility.

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