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## Advance Directives in Pakistan: Religious, Cultural and Social Influences

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### 15.1 Introduction

The Islamic Republic of Pakistan falls into the category of developing nations. Pakistan is abundant in human resources. According to United Nations (UN) data, it is the fifth most populous country in the world, with a total population of 223,103,549 as of January 2021.<sup>1</sup> The median age is 22.8 years, and life expectancy is 67.79 years.<sup>2</sup> With approximately 90 per cent of the population currently under the age of 54, only a very small number of Pakistanis are elderly.<sup>3</sup> The country's very high birth rate creates innumerable challenges, as well as compromised living conditions and a poor quality of life. According to the UN's Human Development Index (HDI) 2020, Pakistan ranks 154th out of a total of 189 countries.<sup>4</sup> Such a low position on the HDI reflects the condition of the population in terms of health, education and well-being. With its rapidly increasing population, inadequate healthcare facilities, low literacy rates and extreme poverty, Pakistan is in a predicament. Although the country is blessed with the demographic dividend of a large youth population, palliative and end-of-life care cannot be ignored, as terminal illness can strike at any age or stage of life. The relatively short life expectancy and poor health conditions in Pakistan demand better healthcare policies and the ability to delegate responsibility appropriately in the event that a person loses the capacity to make decisions.

<sup>1</sup> "Pakistan Population (LIVE)", *Worldometer*, 17 January 2022, [www.worldometers.info/world-population/pakistan-population/](http://www.worldometers.info/world-population/pakistan-population/).

<sup>2</sup> *Ibid.*

<sup>3</sup> *Ibid.*

<sup>4</sup> M. Haider, "Human Development Index 2019: Pakistan Ranks Lower than All South Asian Countries", *The News*, 12 December 2019, [www.thenews.com.pk/print/582826-human-development-index-2019-pakistan-ranks-lower-than-all-south-asian-countries](http://www.thenews.com.pk/print/582826-human-development-index-2019-pakistan-ranks-lower-than-all-south-asian-countries).

Advance directives (ADs) are an important way of specifying the type of treatment a person would like to receive at the end of his or her life. Owing to a range of economic, social, cultural and medical factors, however, no laws or legislation on ADs have thus far been passed in Pakistan. This chapter explores the many influences, perspectives and challenges pertaining to ADs to examine why they have not yet surfaced on the legislative agenda. The remaining sections of chapter are laid out as follows. Section 15.2 describes the governance system, healthcare structure and legislative process in Pakistan. Section 15.3 details the subtleties of the factors creating obstacles on the path to AD legislation, including religious, socioeconomic, cultural and medical factors. Section 15.4 discusses the key issues affecting the feasibility of legislating and implementing ADs in the context of Pakistan, and Section 15.5 concludes.

## 15.2 Governance, Healthcare Structure and Legislation

Pakistan lags behind other countries in legislating many important issues. Healthcare is a largely neglected sector, and the lack of legislation thereon results in a complex situation. The absence of laws and legislation on such important issues as ADs is due in part to Pakistan's convoluted governance system and its multi-tiered, mixed public and private healthcare system. To gain insight into the lack of AD legislation, it is important to outline the governance structure, map out the healthcare system and briefly describe the legislation related to individual autonomy in healthcare.

### 15.2.1 Governance Structure

Healthcare was a federal matter in the 1973 constitution, but the 18th constitutional amendment in 2011 transferred healthcare to provincial health departments.<sup>5</sup> Accordingly, the four provinces of Balochistan, Punjab, Sindh and Khyber Pakhtunkhwa assumed legislative and executive responsibility for healthcare in their provinces.<sup>6</sup> The federally

<sup>5</sup> "Cabinet Approves Devolution of Seven Ministries", *Dawn*, 28 June 2011, [www.dawn.com/news/640139/cabinet-approves-devolution-of-seven-ministries](http://www.dawn.com/news/640139/cabinet-approves-devolution-of-seven-ministries).

<sup>6</sup> S. Nishtar, *Health and the 18th Amendment. Retaining National Functions in Devolution* (Islamabad: Heart File, n.d.), [www.heartfile.org/pdf/HEALTH\\_18AM\\_FINAL.pdf](http://www.heartfile.org/pdf/HEALTH_18AM_FINAL.pdf).

administered territory of Islamabad was left to the federal mechanism even though the federal Ministry of Health (MoH) was dissolved.<sup>7</sup> After dissolution of the federal MoH, its remaining functions were dispersed across several other federal institutions, including the Planning Commission, Federal Bureau of Statistics and newly established Inter-Provincial Ministry.<sup>8</sup> This decentralisation of the healthcare system created a plethora of issues, including national coordination of global health commitments, drugs licensing and the regulation of medical and nursing professionals.<sup>9</sup> To mitigate the challenges being faced at the federal level, the Ministry of National Health Services Regulation and Coordination (MoNHSRC) was created in 2012.<sup>10</sup> However, the MoNHSRC has struggled to establish legitimacy, as its creation has been contested by both provincial governments and the other federal entities to which its functions were originally assigned.<sup>11</sup> Further, not having a federal MoH means that there is no federal health minister. Pakistan is likely one of the few countries in the world to lack a permanent health minister at the federal level.<sup>12</sup> The devolution of healthcare to the provincial level has created a vacuum, as the lack of a federal health minister has resulted in the absence of coordination and advocacy on health-related issues in the federal cabinet or two upper houses: the National Assembly and Senate. The absence of a federal minister for health has created unsurmountable challenges for the healthcare system. Even though legislative and executive authority now lies with the provinces, the lack of a central authority leaves a significant gap in the development of overarching policy norms, provision of health information and management of interprovincial regulation and coordination, which are roles ascribed to the federal government.<sup>13</sup>

<sup>7</sup> S.A. Khan, "Situation Analysis of Health Care System of Pakistan: Post 18 Amendments" (2019) 7 *Health Care Current Reviews* 1, 2.

<sup>8</sup> S.A. Zaidi et al., "Health Systems Changes after Decentralisation: Progress, Challenges and Dynamics in Pakistan" (2019) 4 *BMJ Global Health*, e001013, 3–4.

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

<sup>11</sup> Ibid., p. 3.

<sup>12</sup> Khan, note 2, p. 2.

<sup>13</sup> Ibid. Although the MoNHSRC is a federal entity, it is limited in its scope of work and is used to manage specific issues such as issues related to the COVID-19 pandemic. It is unable to take on a more holistic role owing to its contested legitimacy and opposition from the provincial assemblies.

### 15.2.2 *Healthcare Structure*

In addition to governance issues, Pakistan has a convoluted healthcare system. The system is multi-tiered and multifaceted, comprising a large network of government health facilities, private individual practitioners, philanthropic organisations and private medical entities.<sup>14</sup>

*Public sector healthcare* service delivery is organised into three tiers: Basic Health Units and Rural Health Centres form the core of primary healthcare, whereas Tehsil Headquarters and District Headquarters are the spine of the secondary care structure.<sup>15</sup> Both primary and secondary healthcare are supported by tertiary care from teaching hospitals.<sup>16</sup> Although public sector hospitals are the lifeline of the underprivileged and provide critical and tertiary care, a large percentage of the population, approximately 78.08 per cent, depend on private healthcare facilities.<sup>17</sup> Healthcare delivery in the public sector, although free, is not the preferred choice of most, as it is basic and of mediocre quality.<sup>18</sup>

*Private sector healthcare* facilities are generally favoured over those in the public sector owing to the latter's poor performance.<sup>19</sup> Private facilities also offer a swifter service,<sup>20</sup> although the service provided can be placed on a continuum ranging from extremely low to very high quality.<sup>21</sup> Private healthcare fees are unregulated and depend on the physician, infrastructure and quality of care.<sup>22</sup> A number of private philanthropic organisations also offer reasonable quality treatment to the underprivileged segment of society.<sup>23</sup>

### 15.2.3 *Laws and Legislation*

In light of the aforementioned issues with governance and the unsatisfactory healthcare system, it is perhaps unsurprising that there are

<sup>14</sup> Zaidi et al., note 8, pp. 1–8.

<sup>15</sup> A. Hassan et al., "Healthcare System of Pakistan" (2017) 1 *International Journal of Advanced Research and Publications* 170.

<sup>16</sup> Ibid.

<sup>17</sup> S. Nishtar et al., "Pakistan's Health System: Performance and Prospects after the 18th Constitutional Amendment" (2013) 381 *The Lancet* 2193, 2193.

<sup>18</sup> Ibid.

<sup>19</sup> M.T. Abdullah and J. Shaw, "A Review of the Experience of Hospital Autonomy in Pakistan" (2007) 22 *International Journal of Health Planning and Management* 45.

<sup>20</sup> Zaidi et al., note 8, pp. 1–8.

<sup>21</sup> Nishtar et al., note 17, p. 2193.

<sup>22</sup> Ibid., 2201.

<sup>23</sup> S. Kassim-Lakha and J. Bennett, "Philanthropic Funding for Health in Pakistan" (2013) 381 *The Lancet* 2236.

currently no laws in Pakistan that deal with ADs.<sup>24</sup> The concept of respecting patient autonomy in a healthcare setting, however, can be seen in two pieces of legislation: the Mental Health Ordinance 2001 and the Transplantation of Human Organs and Tissues Act 2010. Both are noteworthy because they espouse to a certain extent the concept of individual autonomy in the healthcare context. They are briefly described here to provide a sense of what that concept means in Pakistan.

*Mental Health Ordinance 2001* – Prior to our discussion of this legislation, it should be noted that the Mental Health Ordinance 2001 is in fact a lapsed ordinance. Ordinances do not become valid laws in Pakistan if they fail to pass Parliament; they remain presidential orders and lapse after three months if left idle.<sup>25</sup> This was the case for the Mental Health Ordinance 2001, although, unlike in other jurisdictions where lapsed ordinances hold no value in the legal landscape, in Pakistan ordinances form a crucial part of the law, so much so that they carry the same weight as any Act passed by Parliament.<sup>26</sup> Accordingly, the Mental Health Ordinance 2001 can still be said to be of influence.

The purported purpose of the ordinance was to consolidate the laws pertaining to the care and treatment of mentally disordered persons and to make better provisions for their care and treatment and the management of their property and affairs and matters connected therewith or incidental thereto.<sup>27</sup> Although the Mental Health Ordinance 2001 was a step towards giving individuals autonomy by affording mentally disordered persons the right to make decisions about their care, specifically the course of their treatment, the mental health legislative framework remains fragmented and ineffective.<sup>28</sup> The ordinance assumes that such persons have the capacity to comprehend their diagnosis and prognosis.<sup>29</sup> It also fails to define capacity or specify how it should be measured,

<sup>24</sup> See also other factors discussed in Section 15.3.

<sup>25</sup> A.I. Gilani et al, "Psychiatric Health Laws in Pakistan: From Lunacy to Mental Health" (2005) 2 *PLoS Medicine* e317, 1106.

<sup>26</sup> *Ibid.*, pp. 1106–7.

<sup>27</sup> *Ibid.*

<sup>28</sup> This ordinance is also sparingly implemented in practice (see Gilani et al., note 25). Despite the fact that health has shifted from a federal to a provincial matter since the 18th amendment of the Constitution, only three provinces have enacted mental health acts replacing the Mental Health Ordinance 2001, namely, Singh, Punjab and Khyber Pakhtunkhwa (see further S. Dey et al., "Comparing Legislation for Involuntary Admission and Treatment of Mental Illness in Four South Asian Countries" (2019) 13 *International Journal of Mental Health Systems* 1, 4).

<sup>29</sup> Gilani et al., note 25, pp. 1105–9.

leaving it open to debate and discretion,<sup>30</sup> which may in turn raise concerns in relation to mentally disordered persons' right to access healthcare. Nevertheless, the granting of the right to make their own decisions about healthcare constitutes an important step towards recognising the value of individual autonomy in the context of medical treatment decisions.

*The Transplantation of Human Organs and Tissues Act 2010* – This Act is a major milestone for two reasons: firstly, it is a step towards recognising individual autonomy, and, secondly, it goes against long-standing Islamic ideology. The Act facilitates individual autonomy by granting the right to donate one's organs after death.<sup>31</sup> Whilst this legal regulation is not directly relevant to ADs, as the decision takes effect only after a person dies, the Transplantation of Human Organs and Tissues Act 2010 affords individuals the autonomy to decide what is to happen to their body after death. Most people in Pakistan believe that performing any kind of medical procedure on a dead body constitutes mutilation of the body.<sup>32</sup> Some Muslim sects even discourage the performance of an autopsy or post-mortem, as the removal of organs is believed to be unIslamic.<sup>33</sup> This legislation thus demonstrates the significance of respecting individual autonomy in relation to one's body even when doing so may conflict with established religious principles.

Thus, although AD legislation does not yet exist in Pakistan, respect for individual autonomy, upon which the concept of ADs is typically predicated, is gaining recognition. This suggests that despite the factors discussed in this chapter that may make AD implementation difficult, there may well be room for the development of ADs in Pakistan. Having considered the laws and healthcare structures in place in Pakistan, we now turn to its religious, socioeconomic, cultural and medical contexts.

### 15.3 Factors Influencing Legislation on ADs

The religious, socioeconomic and cultural environments in Pakistan exert a strong influence on both its legislative structure and healthcare delivery system. It is imperative that the factors related to these

<sup>30</sup> Ibid.

<sup>31</sup> Transplantation of Human Organs and Tissues Act 2010.

<sup>32</sup> M.A. Al-Bar and H. Chamsi-Pasha, *Contemporary Bioethics: Islamic Perspective* (Cham: Springer Open, 2015), pp. 250–7.

<sup>33</sup> Ibid.

environments be charted in detail to understand the possible reasons for the absence of legislation on ADs. For example, as an Islamic country, religion features prominently in all spheres of life in Pakistan, including legislation, and religious beliefs intertwined with cultural influences, societal attitudes and socioeconomic structures have served to undermine both the importance and relevance of ADs.

### 15.3.1 *Influence of Religion on Legislation*

The Islamic Republic of Pakistan is a majority Muslim state that is guided by Islamic laws. In the Constitution of Pakistan 1973, Part IX: Islamic Provisions, Article 227 states that

All existing laws shall be brought in conformity with the Injunctions of Islam as laid down in the Holy Quran (the holy book of Muslims) and Sunnah (the ways of prophet Mohammad), in this Part referred to as the Injunctions of Islam, and no law shall be enacted which is repugnant to such Injunctions.<sup>34</sup>

According to this provision, all laws enacted, or legislation promulgated, have to be in accordance with Islamic teachings. Although there are many sects in Islam, and each sect interprets the religion according to its own understanding, there is consistency of interpretation amongst most Islamic jurists in the belief that life is sacred. As interpreted by some and believed by many, refusing invasive treatment is tantamount to hastening death, which is contradictory to the teaching of the Quran.<sup>35</sup> Saving lives is a duty, and taking lives unjustifiable.<sup>36</sup> In addition, clerics, who exert a strong influence on society, believe that the withholding or withdrawal of treatment is contrary to religious ideology. In fact, according to the Council of Islamic Ideology in Pakistan, “life is sacrosanct and one should do everything possible to save it”.<sup>37</sup> This directive to sustain life at any cost can be understood to be in direct conflict with the concept of ADs, as ADs give individuals the right to refuse life-sustaining treatment. There are, however, interpretations consistent with the concept that do not run contrary to the sanctity of life. For example,

<sup>34</sup> “Part IX: Islamic Provisions” (*The Constitution of Pakistan*), [www.pakistani.org/pakistan/constitution/part9.html](http://www.pakistani.org/pakistan/constitution/part9.html).

<sup>35</sup> Al-Bar and Chamsi-Pasha, note 32, pp. 250–7.

<sup>36</sup> *Ibid.*

<sup>37</sup> “Herald Exclusive: When Life Meets Death”, *Dawn*, 26 April 2011, [www.dawn.com/news/623972/herald-exclusive-when-life-meets-death](http://www.dawn.com/news/623972/herald-exclusive-when-life-meets-death).

some believe that life is given and taken by God and that the provision or withdrawal of treatment cannot prolong life or hasten death because the time of death is preordained; hence, death will occur irrespective of the treatment choice.<sup>38</sup> The religion may thus allow a person to make decisions on their course of treatment based on personal choice.<sup>39</sup> Given these differences in interpretation, families often rely on the advice of religious scholars before making decisions about end-of-life treatments for terminally ill patients because they lack confidence in their own knowledge of what is permissible in the Quran. In hopeless situations, religious scholars may allow families and patients to take decisions regarding the course of treatment, not with the intention to hasten death but to refuse treatment that is emotionally and financially exhausting and painful, in addition to being of no benefit.

Another aspect worth exploring is the assignment of responsibility for the elderly and women in the Quran. Some Quranic injunctions place such responsibility on the male members of the family. Islam encourages a sense of obligation towards caring for elderly parents and being responsible for women while also emphasising the inherent goodness of looking after the sick. Chapter 17 of the Quran, *Al-Isra'*, states: "Allah has ordered you to worship none except Him, and to be good to your parents. If either or both of them attain old age with you, do not say 'fe on you', nor rebuke them, but speak to them with words of respect". Chapter 4, *An-Nisa*, discusses the husband's role as "protector and maintainer". Verse 34 of *An-Nisa* states: "Men are the caretakers of women, as men have been provisioned by Allah over women and tasked with supporting them financially". A *hadith* (saying of the Prophet Mohammed) narrated by Muslim [2699] on caring for the sick reads as follows: "The one who stays with the one who is sick, and takes care of him and looks after him has done good by serving him and caring for him, and Allah, may He be glorified and exalted".<sup>40</sup> These Quranic verses and *hadith* are indicative of the responsibilities of male family members.<sup>41</sup> Whether those responsibilities are limited to specific situations or extend to all matters is unclear.<sup>42</sup> However, prevailing religious values give male members of the family the right to make decisions on

<sup>38</sup> Al-Bar and Chamsi-Pasha, note 32, pp. 250–7.

<sup>39</sup> Ibid.

<sup>40</sup> R.I. Khan, "Palliative Care in Pakistan" (2017) 2 *Indian Journal of Medical Ethics* 37.

<sup>41</sup> Ibid.

<sup>42</sup> Ibid.



healthcare matters for the elderly (primarily parents) and women. This automatic assignment of rights suggests that ADs have little role to play, as the male members of the family are essentially substitute decision-makers in end-of-life situations.<sup>43</sup> Hence, issues related to patient autonomy, ADs, end-of-life medical treatment and other matters have perhaps not been addressed by the legislature based on the assumption that such decisions lie with male members of the family.

This section thus demonstrates that whilst religion generally has a guiding influence on legislation in Pakistan, different interpretations of Islamic teachings result in varying attitudes towards ADs. It is perhaps for this reason that no AD legislation has thus far been discussed. Legislators may well feel that they are in no position to make decisions on such a controversial subject rooted in religious ambiguity.<sup>44</sup>

### 15.3.2 *Economic, Social, Cultural and Medical Landscape*

A medley of religious values, social and cultural norms, and economic stratification has resulted in a distinct economic, social, cultural and medical landscape in Pakistan. Both patriarchy and hierarchy feature heavily in Pakistani society, owing to which the family takes centre stage as opposed to the individual. The patriarchal system is supported by religious beliefs, traditions, and local social and cultural values, which in turn result in extended families that expand horizontally and vertically across generations. These beliefs and values further reinforce familial prioritisation and solidify the role of the family in undertaking decisions on terminal illness for competent and incompetent patients alike. Familial hierarchy, patriarchy and, as mentioned previously, religious teachings all select the oldest or most competent male family member as the pivotal decision-maker.<sup>45</sup> As a result, all healthcare decisions, including end-of-life care and treatment, are generally made by the selected male family member, leaving little space for individual autonomy and eroding the need for ADs. This power imbalance in itself reflects inadequate representation of the interests and perspectives of female family members, who, ironically, are often the primary caregivers

<sup>43</sup> F. Moazam, "Families, Patients, and Physicians in Medical Decisionmaking: A Pakistani Perspective" (2000) 30 *The Hastings Center Report* 28.

<sup>44</sup> J. Akhtar, "Living Wills in Health Care: A Way of Empowering Individuals" (2010) 60 *The Journal of the Pakistan Medical Association* 240.

<sup>45</sup> See note 43.

in such situations. The patriarchal system is likely also rooted in socio-economics, with limited resources often dictating that the survival of the family as a whole takes precedence over individual autonomy.<sup>46</sup>

Furthermore, many patients themselves refuse to discuss death or terminal illness, and thus the responsibility falls on the family members who decide whether patients are to be informed of their diagnosis or prognosis.<sup>47</sup> Families channel their love and compassion by hiding painful realities or cloaking diagnoses in abstraction. Medical professionals accept this state of affairs as well, respecting family decisions and refraining from revealing the diagnosis to the patient.<sup>48</sup> Disease and death are viewed as happening to families rather than individuals, with the family of the individual in question playing a significant role in decision-making and responsibility.<sup>49</sup> For example, children are socialised to believe that caring for parents and grandparents is their duty, with sons often expected to live with their parents and take care of them in their old age.

This emphasis on the family in end-of-life decision-making may make it difficult for individual-oriented ADs to be accepted and used, as demonstrated by a study on advance care planning conducted amongst 57 South Asian individuals (including Pakistanis), which found that many of the participants considered planning ahead to be unnecessary because of close family ties and predefined familial roles and trust in the context of medical decision-making.<sup>50</sup> Most participants believed that one should focus on concrete activities, with advance care planning thought to be irrelevant, vague and unnecessarily worrying.<sup>51</sup>

In addition to the role of the family, that of healthcare professionals is also relevant. A substantial number of people in Pakistan are uneducated and lack the ability to comprehend complex medical conditions, meaning that they depend on the advice of physicians. Physicians and nurses in Pakistan are often drawn towards taking on a decision-making role owing to a combination of factors. In line with the centrality of the family in Pakistan, healthcare providers are often symbolically “inducted” into the family in such a way that they end up directing

<sup>46</sup> Ibid.

<sup>47</sup> Ibid.

<sup>48</sup> See note 40.

<sup>49</sup> See note 43.

<sup>50</sup> P.D. Biondo et al., “Understanding Advance Care Planning within the South Asian Community” (2017) 20 *Health Expectations* 911.

<sup>51</sup> Ibid.

rather than facilitating medical interventions and care.<sup>52</sup> In addition, physicians hold an esteemed position in Pakistani culture owing to their knowledge and expertise. Perhaps as a result of this status, as well as a lack of training in communication skills and ethics education, healthcare professionals assume responsibility for making decisions, often sharing limited information with family members and refraining from fully disclosing a diagnosis or prognosis to patients or doing so only in ambiguous terms, as they do not want to convey bad news to patients. Deeply entrenched in cultural values, medical professionals often ignore ethical values.<sup>53</sup> Undoubtedly, accepting cultural norms is easier and less exhausting than critiquing them or forging an alternative involving patients' informed consent.<sup>54</sup> According to one study, nurses and physicians often adopt the role of care provider, counsellor and, most commonly, decision-maker.<sup>55</sup> Most physicians view themselves as independent decision-makers, particularly with regard to patients in a critical condition, assuming that they are best equipped to understand the needs of an incapacitated patient.

Recognising this practice as unethical, several healthcare organisations across the nation have formulated and implemented do-not-resuscitate, end-of-life care and withdrawal of life support policies and practices at an institutional level.<sup>56</sup> Palliative care services have been established in many of the leading tertiary care hospitals and comprehensive cancer care centres in the nation. Palliative care providers tend to have lengthy discussions with patients and their extended families to explore the goals of such care.<sup>57</sup> These discussions are often transcribed and documented in the patient's medical record. Although such records serve to facilitate patient care, they hold no validity in the courts.<sup>58</sup> It is also unclear whether the goals transcribed in these informal records are met.

It can thus be seen that the economic, social, cultural and medical landscape of Pakistan erects numerous obstacles to the introduction of ADs. In addition to the role of the family in end-of-life decision-making,

<sup>52</sup> See note 43.

<sup>53</sup> R.I. Khan, "End of Life Care in Pakistan; Some Ethical Issues" (2012) 22 *Journal of the College of Physicians and Surgeons Pakistan* 745.

<sup>54</sup> See note 43.

<sup>55</sup> *Ibid.*

<sup>56</sup> See note 53.

<sup>57</sup> W. Zafar et al., "Preferences regarding Disclosure of Prognosis and End-of-life Care" (2016) 30 *Palliative Medicine* 661.

<sup>58</sup> *Ibid.*

healthcare professionals in Pakistan have also taken on the role of decision-maker even in situations where doing so may not be ethical. We consider possible solutions to these issues in the following section. Whilst some steps are being taken to involve patients and their families in processes akin to advance care planning, their effectiveness cannot be ensured without a more formalised regime.

## 15.4 Discussion

The current scenario in Pakistan presents an image that points towards the non-acceptance of ADs. The governance structure, laws and legislation, and the healthcare system, along with the religious, social and cultural landscape, seem to be unprepared for the legislation and implementation of ADs. Although such legislation/implementation in Pakistan appears to constitute a daunting and time-consuming task, we believe there is a dire need to start a conversation about AD legislation given the importance of respect for autonomy. In the following, we lay out five key issues that require further examination and discussion in the Pakistani context.

### 15.4.1 Perceived Taboo versus Patients' Actual Preferences

The belief that death is preordained and inevitable is prevalent in the Pakistani community, and yet talking about death remains a taboo and to-be-avoided subject. There is an overemphasis on optimism and a widespread belief that speaking negatively will give life to what is feared. Healthcare issues thus generally have a negative connotation and are considered bad news. Perhaps as a result, decision-making on and discussions of end-of-life care take place at a relatively late stage or do not take place at all.<sup>59</sup> As discussed previously, families generally want to ensure that their loved one maintains a positive outlook until the end, and the perceived taboo surrounding death often prompts families to collude with healthcare professionals to "protect" the patient from anxiety, stress and fear of losing hope by keeping a terminal illness diagnosis and prognosis from the patient, thereby avoiding any discussion of what course of treatment the patient would want in the event of incapacity. In certain circumstances where the patient has some knowledge of his or her diagnosis, the extent of the disease, its terminal or

<sup>59</sup> See note 53.

life-limiting nature, as well as the prognosis, may not be disclosed to the patient. Physicians also respect the wishes of the family and refrain from discussing end-of-life care and treatment in such situations.

There are limited data suggesting that this perceived taboo may not in fact be in line with patient preferences and that some patients would prefer to be informed of their prognosis and life expectancy.<sup>60</sup> In one study, 13 per cent of respondents reported feeling uninformed about their medical condition, and more than half expressed the importance of being informed about their medical condition, prognosis and management options. About two thirds wanted their families to be actively involved in decision-making on management options, and half wanted their families to make medical decisions if they themselves ever became incompetent, with 27 per cent preferring their physician to make decisions on their behalf. Whilst two thirds said they were comfortable discussing end-of-life care, 81 per cent said that they had never discussed life expectancy with their physician, and 42 per cent reported no discussions of choices concerning end-of-life care in the past year. Fifty-six per cent of the patients studied wanted to discuss end-of-life care only should the need arise. Many said they wanted to know their prognosis but only a few reported ever having had such a discussion.<sup>61</sup> This study thus seems to demonstrate a mismatch between patient preferences and actual practice in relation to end-of-life discussions, which may be a result of the taboo described previously. If the reluctance to discuss end-of-life matters is indeed merely perceived, then it would appear that engaging in larger conversations with the public about legislating ADs would be well worth the effort.

#### 15.4.2 Unclear Legislative Responsibilities at the Federal and Provincial Level

That being said, beginning a conversation about ADs at the legislative level is likely to prove challenging. Between the constitutional role of the federal government and the devolution of power to the provinces following the 18th amendment, healthcare has sunk into great confusion, particularly with regard to who will legislate and regulate policies. The healthcare legislative process has suffered immensely from the unclear

<sup>60</sup> Ibid.

<sup>61</sup> F. Saeed et al., "Dialysis Decision Making and Preferences for End-of-Life Care: Perspectives of Pakistani Patients Receiving Maintenance Dialysis" (2020) 60 *The Journal of Pain and Symptom Management* 336.

demarcation of federal and provincial roles and responsibilities.<sup>62</sup> Thus, as a consequence of the 18th amendment, it is not always clear whether it is the responsibility of the federal government or provincial governments to promulgate laws and legislation for the welfare of the people, and important issues are often left unlegislated by either. Some of the reasons attributed to such apathy are rooted in provincial governments' lack of capacity.<sup>63</sup> The situation is further complicated by the influence of such factors as illiteracy, a lack of understanding and poor critical-thinking skills permeating all tiers and strata of society, including the legislative assemblies. Elected representatives are not required to have any educational attainments or qualifications.<sup>64</sup> Low literacy and education levels and a lack of exposure to the external world limit thinking capacity and logical reasoning ability, which is reflected in the absence of imperative legislation.<sup>65</sup> Building up the capacity of the provincial legislatures is thus key to promulgating laws on important healthcare issues.

#### 15.4.3 Lack of Resources

Although legislating for ADs will inevitably be an uphill battle, ADs could well play an important role in the delivery of end-of-life care in Pakistan owing to the general lack of resources. Apart from a few cases of malicious intent and family disputes, the premature withdrawal of treatment is generally the result of insufficient financial resources. Much of Pakistan's large population lives on very meagre resources, with many struggling to afford two meals a day. Although public sector hospitals are available, they are few in number and poor in quality, forcing people to turn to private sector hospitals,<sup>66</sup> which offer better facilities but are expensive. Seventy-eight per cent of the underprivileged resort to costly private healthcare, placing families in a precarious position.<sup>67</sup> Many struggle between expending all of their finances on treating and sustaining the life of a loved one and making ends meet. The lack of an option to formally specify in advance that one wishes to have life-sustaining treatment withdrawn at a particular stage of the end-of-life process

<sup>62</sup> Khan, note 7.

<sup>63</sup> Ibid.

<sup>64</sup> T. Ahmad, *National Parliaments: Pakistan* (Washington, DC: The Law Library of Congress, February 2017), <https://tile.loc.gov/storage-services/service/ll/lglrd/2016478970/2016478970.pdf>.

<sup>65</sup> Ibid.

<sup>66</sup> Nishtar et al., note 17.

<sup>67</sup> See note 40.

unnecessarily prolongs the agony of patients and places families in a dire financial situation, with many burdened with a large amount of debt to pay back.<sup>68</sup> In these circumstances, the ability to make an AD would be beneficial for both patients and their families.

#### 15.4.4 Physicians and the Implementation of ADs

If and when the legislative bridge is crossed and legislation on ADs is promulgated, the task of making that legislation implementable and acceptable will come into play. The implementation of ADs will not be easy, but training healthcare professionals in effective communication skills and medical ethics would pave the way for wider societal acceptance. Such training needs to occur in at least two key areas. The first is in relation to the AD concept itself. Although there is a scarcity of research data, a few studies have explored medical practitioners' understanding of ADs. For example, one study revealed medical professionals to have a limited understanding of ADs, to be unaware of proxy decision-making and to believe that ADs are prepared only for the terminally ill.<sup>69</sup> After being given an explanation of what ADs are, however, they recognised them as an important component of end-of-life quality of care, and almost all of those surveyed said they favoured ADs for themselves. One physician stated that more palliative care services need to be established before ADs can be followed.<sup>70</sup> The medical professionals in the study as a whole emphasised that legal mechanisms, infrastructure, mass education and renowned hospitals taking the lead are all crucial to pave the way for ADs in Pakistan.<sup>71</sup> The barriers that they identified with respect to ADs included ineffective communication, inadequate and inappropriate information and a delay in information being given to patients and families, the paternalistic culture, the possibility of document forgeries, and inequitable resource availability.<sup>72</sup>

The second area in which training is required is how to break news to patients and families and discuss diagnoses and prognoses, as well as end-of-life treatment and palliative care, which are important

<sup>68</sup> N. Panjwani, "Advance Directives: A Policy Required in the Asian Countries" (2013) 3 *I-manager's Journal on Nursing* 30.

<sup>69</sup> N. Panjwani et al., "Physicians' and Nurses' Perspectives on the Importance of Advance Directives in Tertiary Care Hospitals" (2019) 1 *Journal of Shifa Tameer-e-Millat University* 3.

<sup>70</sup> *Ibid.*

<sup>71</sup> *Ibid.*

<sup>72</sup> *Ibid.*

prerequisites to the development of ADs. Unless patients feel confident in their ability to make decisions, they will be unable to document their preferences with regard to end-of-life treatment and care. Formal ethics education would assist medical practitioners in dealing with ethical dilemmas and difficult end-of-life decisions.<sup>73</sup> Whilst issues such as end-of-life care, palliative care and ADs are recognised and taught in many undergraduate and postgraduate medical and nursing schools nationally, such courses are often optional or elective.<sup>74</sup> The regulatory bodies do not require them to be a mandatory part of the core teaching curriculum.<sup>75</sup>

Training in these two areas would be particularly helpful in relation to the issue of healthcare practitioners, at times problematically, taking on a decision-maker role, as discussed previously. As some healthcare professionals working with terminally ill patients have expressed, appropriate training would be highly beneficial to themselves and the patients they treat.<sup>76</sup> In the absence of formal training, medical care practitioners often do not know how to define their role; they either become overly involved and assume the role of a family member or prime decision-maker or distance themselves to the point that the patient and family feel abandoned.<sup>77</sup> Healthcare professionals' understanding of their role in relation to decision-making is highly important because whilst the superior medical knowledge of physicians vis-à-vis patients and families is beyond question, the risk of physicians misinterpreting patients' wishes and infringing upon autonomous decision-making cannot be ignored.<sup>78</sup> Owing to the unchallenged power and authority that physicians possess against the backdrop of a population that is largely illiterate, financially insecure, unaware of individual rights and without access to judicial redress, a physician's decision to continue life-sustaining treatment without any clear benefit may not be disputed. The absence of a comprehensive framework for ADs may therefore exacerbate the exploitation of unchallenged clinical discretion, which can be cloaked in references to divine predestination.<sup>79</sup>

<sup>73</sup> See note 53.

<sup>74</sup> See note 43.

<sup>75</sup> *Ibid.*

<sup>76</sup> See note 68.

<sup>77</sup> See note 53.

<sup>78</sup> See note 43.

<sup>79</sup> *Ibid.*



### 15.4.5 Religious Interpretation

With an array of interpretations on the meaning of Islamic teachings, as discussed previously, whether ADs will be viewed as permissible remains an open question. A healthy debate involving people from all walks of life is needed, including religious scholars who could review relevant clauses in the Quran and put forward a comprehensive proposal on AD legislation. In light of technological advancement, interpretations of Quranic texts may need to be reviewed to determine what exactly is meant when it comes to using technology for end-of-life treatment and how laws on ADs fit into the religious context. An updated interpretation of the Quran and a major shift in mindset are imperative if ADs are to be placed on the legislative agenda in Pakistan.

## 15.5 Conclusion

The complex governance structure and healthcare system in Pakistan, together with various religious, cultural, social and medical factors, have contributed to a distinct local context that makes the adoption and implementation of ADs extremely difficult. Given the growing importance of individual autonomy, as demonstrated by the Mental Health Ordinance 2001 and the Transplantation of Human Organs and Tissues Act 2010, and interpretations of Islamic teachings that are consistent with the use of ADs, however, we believe there is room for the development of ADs. There remain a number of hurdles to be overcome, and in this chapter, we have put forward suggestions for how we believe this can be accomplished. Despite the many challenges that lie ahead, we feel that ADs are an important goal to work towards. Not only would ADs educate healthcare practitioners about patient choices concerning end-of-life care and treatment, but they would also empower individuals, safeguard patient autonomy and ensure compliance with individual choices. In light of the patriarchal and hierarchical nature of the Pakistani family structure, ADs would also empower women to make decisions related to their healthcare. Accordingly, we believe it is worth deliberating on the viability and effectiveness of ADs, as well as advocating for them, within the context of Pakistan.