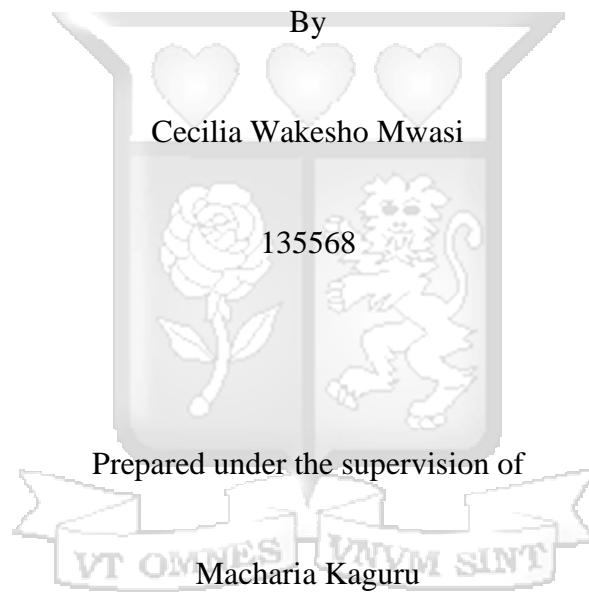


# THE PROSPECTS OF ADVANCE DIRECTIVES IN KENYA: A LEGAL ANALYSIS

Submitted in partial fulfilment of the requirements of the Bachelor of Laws Degree, Strathmore

University Law School



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**DECLARATION**

I, **CECILIA WAKESHO MWASI**, do hereby declare that this research is my original work and that to the best of my knowledge and belief, it has not been previously, in its entirety or in part, been submitted to any other university for a degree or diploma. Other works cited or referred to are accordingly acknowledged.

Signed:  .....

Date: 06/03/2025 .....

This dissertation has been submitted for examination with my approval as University Supervisor.

Signed: .....

Joseph Kaguru

Date: .....



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## **LIST OF LEGAL INSTRUMENTS**

### **National Legal Instruments**

Constitution of Kenya ,2010.

Health Act (2017)

Mental Health Act 9 (Cap 248)

Medical Practitioners and Dentists Act (Cap 253)

### **Foreign Legal Instruments**

Mental Capacity Act (2005)

Constitution of the Republic of South Africa, 1996.

The National Health Act (Act 61 of 2003.)

The Health Professions Act (Act 56 of 1974.)



## LIST OF CASES

Clarke v Hurst NO and Others (1992), Durban Coast Local Division, South Africa.

Kings College Hospital NHS Foundation Trust v C & Anor (2015), England and Wales Court of Protection.

Re B (Adult: Refusal of Treatment) (2002), England and Wales High Court (Family Division).



## **LIST OF ABBREVIATIONS**

ACP-Advance Care Planning

ADs – Advance Directives

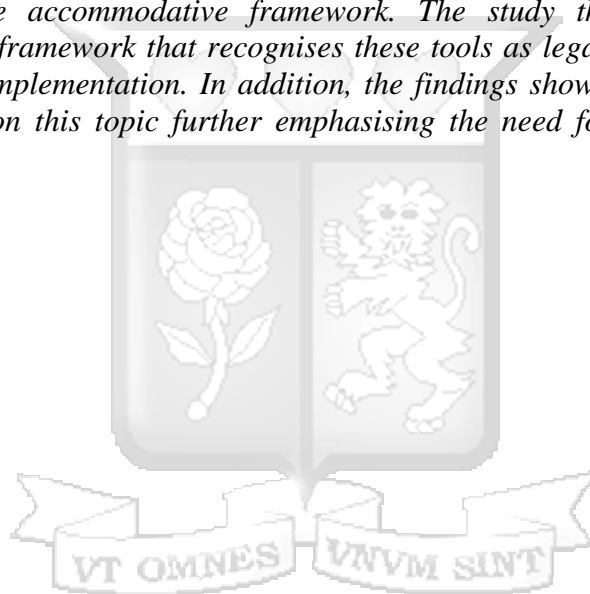
PADs -Psychiatric Advance Directives

WHO - World Health Organisation



## **ABSTRACT**

*Patient rights can be promoted by equipping individuals with legal tools such as Advance Directives that respect their autonomy and dignity by honouring expressed wishes on their healthcare preferences and future desires while they have the mental capacity to execute such a task. This study seeks to assess the viability of Advance Directives (ADs) and Advanced Care Planning (ACP) laws in the context of Kenya. Through qualitative research, the study takes a doctrinal approach that utilises primary legal sources, academic literature and commentaries in assessing the gaps in the legal framework and its implications. The study further makes a comparative analysis with other jurisdictions such as the United Kingdom and South Africa to facilitate research findings of how their implementation of such directives in their laws has enhanced key concepts such as dignity, patient-autonomy and informed consent. The findings highlight a significant gap in the protection of patients' health care preferences when incapacitated due to the inadequate legal framework in place as well the impact culture has in the development of a more accommodative framework. The study therefore recommends the establishment of a legal framework that recognises these tools as legally binding as well as one that pushes for proper implementation. In addition, the findings show that the lack of adequate research within Kenya on this topic further emphasising the need for more studies especially within the legal context.*



## **CHAPTER 1: INTRODUCTION**

### **1.1 BACKGROUND OF THE PROBLEM**

With the inevitability of death as part of life's cycle, humanity has devised ways to prepare itself for the impact it shall have, further ensuring their wishes are honoured even when they no longer have the capacity.<sup>1</sup> The systems have been designed in a way that leaves clarity, less of a burden to kin and courts and a chance for their voice and wishes to be honoured when they pass through the use of the legal system. Take property for instance, laws are provided to honour such wishes of how one would desire for their assets, that they have acquired in their lifetime, to be disposed of, as long as the deceased met a certain criterion set by said laws.<sup>2</sup> Notably, respecting the desires of the deceased is taken with much regard.<sup>3</sup> However, while the law provides for respect of wishes in cases such as property distribution, a significant gap exists within the legal space concerning the enforcement of the wishes of individuals during their most vulnerable health circumstances, particularly when they are alive but unable to communicate their desires of how their healthcare should be handled.

In cases where an individual becomes incapacitated, the decisions are typically left to family members.<sup>4</sup> There however, exists prominent influence of cases of some family members on healthcare decision-making that frequently trumps the patient's desires.<sup>5</sup> This impact is particularly noticeable when circumstances are dire or involve end of life and families are primarily in charge of the medical treatment plan.<sup>6</sup> Furthermore, some family members collude to conceal medical data from the patient which exacerbates this dynamic since they may feel that sharing this information would make the patient feel less hopeful and distraught.<sup>7</sup> Individuals should have the opportunity to dictate their wishes regarding healthcare decisions and end-of-life preferences while having the mental capability to do so. Having them down as directives that have

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<sup>1</sup> Barry R, 'Advance directives and the pursuit of death with dignity by Norman L. Cantor' 10 Indiana University Press 1,1993, 623.

<sup>2</sup> Musyoka W, Law of succession, Law Africa Publishing Ltd, Nairobi, 2006, 31.

<sup>3</sup> Musyoka W, Law of succession, 31.

<sup>4</sup> Chong JA, Quah YL, Yang GM, Menon S and Krishna LK, 'Patient and family involvement in decision making for management of cancer patients at a centre in Singapore',5(4) BMJ supportive & palliative care,2015 ,2.

<sup>5</sup> Chong JA et al, 'Patient and family involvement in decision making for management of cancer patients at a centre in Singapore',2.

<sup>6</sup> Chong JA et al, 'Patient and family involvement in decision making for management of cancer patients at a centre in Singapore',2.

<sup>7</sup> Chong JA et al, 'Patient and family involvement in decision making for management of cancer patients at a centre in Singapore',2.

been anticipated demonstrates intention and would guarantee their wishes are honoured when they are no longer able to speak for themselves and provide assurance that their wishes would be honoured through the law enforcement in our Kenyan System. As of now, only few details are catered for by law which we acknowledge such as the ability to appoint a Medical Power of Attorney under Section 9 of the Health Act.<sup>8</sup> However, the existing laws and avenues that may aid in the recognition of Advance Directives do not explicitly provide for them. At its core, this legal gap fails to safeguard vital principles in health and health law such as bodily autonomy, dignity, consent and more. The legal framework as is fails to then essentially cater for such situations that would streamline such a vulnerable time for patients and their loved ones. This highlights the need for the legal reform and advancement of laws and mechanisms to do so. The concept of making a potentially daunting task more bearable and functional by encouraging patients to, in advance, document their health preferences in a legally enforceable document would be an advancement in both the legal and medical field in Kenya.

Bodily autonomy, along with the extent to which the state is capable and willing to respect it, are the key factors influencing the relationship between the state and the body.<sup>9</sup> Capability possibly references the creation of such laws that govern one's autonomy while the willingness to respect it pertains to the manner in which it is upheld and enforced. Acknowledgement of the role of the legal system is therefore crucial as it reflects the broader social, political, and ethical stances of a state. Moreover, the human body plays a significant role in life which then bids the need for legal protection of how one's autonomy over their body is governed. Wicks highlights this significance of the body, stating that:

“My body is my home, my transport, my clothing, my identity. It is my greatest asset and my worst enemy. It is my constant companion, my means of financial support, a source of pain, a receptacle of pleasure, and one day it will kill me. We use our bodies in so many diverse ways: to give us pleasure, to earn a living; to portray our identities to the world; and to reproduce. Our bodies are central to the landmark events of our lives: being born, growing up, making love, having children, falling ill and dying”.<sup>10</sup>

This statement reflects the pivotal role of the body as well as its multifaceted nature further

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<sup>8</sup> Section 9, Health Act, 2017.

<sup>9</sup> Wicks E, The state and the body: legal regulation of bodily autonomy, Bloomsbury Publishing,2016,16,3.

<sup>10</sup> Wicks E, The state and the body: legal regulation of bodily autonomy, 1.

demanding proper protection. The inherent dignity and worth of a human being, including their body and personal autonomy, necessitate a level of respect at least equal to, if not greater than, that accorded to physical property within the framework of the law. This gap underscores the need for legal provisions that respect and enforce the wishes of individuals in their incapacitated state, reflecting the fundamental value of one's autonomy and dignity especially in the face of health-related hardships. This is where the concept of Advance Care Planning and Advance Directives come into play. Advance Care Planning allows individuals with the option to figure out and prepare for their care and support preferences in the future, including medical treatment decisions, during a period in which they are considered to have the mental capacity to make such arrangements.<sup>11</sup> This proactive approach ascertains that an individual's wishes and choices concerning their healthcare are documented and respected, in particular, situations where their judgement capacity may be compromised later on.<sup>12</sup> An advance directive, sometimes known as a 'living will', is a declaration in writing that instructs your healthcare providers on the decisions one has made from their advance care planning.<sup>13</sup> This information is crucial in the event that you become too ill to communicate your desires.<sup>14</sup> These directives can include a patient's requests, values, and beliefs that should be considered by the physician when making a treatment decision, or by the court should a legal enforceability question be raised.<sup>15</sup> These instructions do not limit themselves to advance refusals, even though they usually take the form of an advance refusal of specific medical care.<sup>16</sup>

Advance care planning has grown significantly in many parts of the world, however, the same cannot be said for Kenya where cultural norms and beliefs inhibit conversation causing a lag in adopting this practice.<sup>17</sup> In Kenyan society, discussing death and making plans for living loved ones that you may leave behind is almost taboo.<sup>18</sup> This study aims to investigate the viability of

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<sup>11</sup> <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/advance-care-planning> on 18 May 2024.

<sup>12</sup> <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/advance-care-planning> on 18 May 2024.

<sup>13</sup> <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/advance-care-planning> on 18 May 2024.

<sup>14</sup> <https://www.hopkinsmedicine.org/patient-care/patients-visitors/advance-directives#:~:text=What%20is%20an%20advance%20directive,unable%20to%20speak%20for%20yourself> on 18 May 2024.

<sup>15</sup> Grove G, 'Living wills: what is the current legal status in South Africa?' 31 Stellenbosch Law Review 2, 2020, 272.

<sup>16</sup> Grove G, 'Living wills: what is the current legal status in South Africa?', 272.

<sup>17</sup> <https://kehpc.org/advance-care-planning-in-kenya-starting-the-conversation/> on 18 May 2024.

<sup>18</sup> <https://kehpc.org/advance-care-planning-in-kenya-starting-the-conversation/> on 18 May 2024.

Advance Care Planning (ACP) in Kenya through Advance Directives with respect to individuals' autonomy and dignity, the goal being to empower individuals in expressing their healthcare preferences and future desires while they have the mental capacity to execute such a task.

## **1.2 STATEMENT OF PROBLEM**

As it is, there exists a notable gap in the health sector within the legal framework with regards to the acknowledgment and enforcement of individuals' health care preferences and directions, more specifically, in the event of incapacitation occasioned by illness or other circumstances. This raises a fundamental issue on the protection of bodily autonomy and dignity in advocating for one's own healthcare choices according to the law. In addition, the lack of clear-cut provisions is further highlighted by the various disputes that arise typically among family members from the lack of certainty as to what a patient's true wishes are with regards to their preferred healthcare, their preferred medical representative and other various details in the event of incapacity.

## **1.3 RESEARCH QUESTIONS**

- 1) What is the legal framework currently governing Advance Directives in Kenya?
- 2) How are the existing inadequacies in the legal framework failing to properly address Advance Directives and in turn giving rise to legal, ethical and cultural challenges?
- 3) How does the Kenyan framework compare to that of the United Kingdom and South Africa in their approach to Advance Directives and the concept of patient autonomy?
- 4) How do cultural beliefs inform and impact the development of laws on Advance Directives in Kenya?
- 5) What are the necessary reforms that should be considered to align the legal framework of Kenya with promotion and protection of healthcare preferences concerning Advance Directives?

#### **1.4 RESEARCH OBJECTIVES**

1. To assess the current legal framework governing Advance Directives in Kenya.
2. To investigate how the existing inadequacies in the legal framework fail to properly address Advance Directives and how the legal and cultural aspects of Kenya impact the legislative framework.
3. To assess the approach of other jurisdictions such as the United Kingdom and South Africa in their legislative approach to Advance Directives and the concept of patient autonomy.
4. To assess the extent to which cultural beliefs inform and impact the development of laws on Advance Directives in Kenya.
5. To propose necessary reforms and recommendations that would be in line with promoting healthcare preferences of individuals with regards to Advance Directives.

#### **1.5 HYPOTHESIS**

Supported informed decision-making guarantees individuals are in control of the choices they make regarding their lives. Such is present in various branches of the law however, there seems to be a gap with regards to a legal framework providing for the protection of individuals' healthcare preferences. The lack of these provisions compromises people's agency and dignity during critical life moments including serious illnesses or hospice care when nearing or at the end of life. The introduction and implementation of Advance Directives and Advance Care Planning, within Kenya's legal framework, could be a potential solution to this by facilitating the articulation and documentation of an individual's future healthcare preferences.

#### **1.6 JUSTIFICATION**

This study being policy driven, shall be of benefit to legislators in the reformation of laws with regards to advanced health care regulation. More thought should be put into enacting laws that cater to the people's healthcare needs rather than them being second hand thoughts in other documents. Legislators can take into account the gaps in the health care sector that shall be highlighted. Furthermore, it would be key for the judicial system in determining outcomes of cases of such a nature. The scholarly realm, especially with regards to Kenya, shall gain novel and differing perspectives that could further enhance the legal framework. Citizens stand to benefit the most as the project seeks to fight for the protection of individuals' healthcare rights and preferences.

## **1.7 CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW**

### **1.7.1: The concept of person-centred care**

More often, we think of ourselves and are termed as patients when seeking healthcare professionals, nevertheless, we would not commonly use this term to describe who we are.<sup>19</sup> Our expectations of healthcare providers are based on a deeper awareness of our responsibilities within this dynamic, rather than just clinical interactions.<sup>20</sup> The word “patient” has particular connotations that are frequently overlooked. It causes us to see the conversation as one purely between an informed “helper” and a person “needing help,” rather than as two people with an equal footing.<sup>21</sup> This small change on the surface may not seem detrimental for it is not false that the medical field entails a noble profession that requires much knowledge, various skills and experience that we do seek.<sup>22</sup> However, this mental shift may also encourage a more paternalistic approach in which the collaborative nature of healthcare is subordinate to the competence of the healthcare provider and very little considered by the patient themselves.<sup>23</sup> Although patient centred care and person-centred care are often used interchangeably, the meanings of these phrases can deeply alter how we view healthcare. The shift from patient to person reduces the unconsciously present power imbalance and gives a more wholesome outlook on a person including their needs, values and preferences rather than just the medical problem they are facing. The World Health Organisation (WHO) acknowledges this approach where individuals, families and communities are given priority because they are recognised as active participants in and beneficiaries of trustworthy health systems.<sup>24</sup> This strategy seeks to provide for their preferences and wishes in a compassionate and efficient way.<sup>25</sup> It is crucial for people to have access to the information and assistance essential to make educated decisions and participate in their own healthcare for the approach to be effective.<sup>26</sup> It further enhances shared decision making which despite not having a proper definition, is characterised by a partnership fuelled by mutual respect, equally valuing preferences of patients, discussing all options, benefits, and dangers, enabling appropriate and engaging in discussion, contemplation, and seeking common

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<sup>19</sup> Barnett N, ‘ Person-centred over patient-centred care: not just semantics’ 10(4) Clin Pharm,2018,2.

<sup>20</sup> Barnett N, ‘ Person-centred over patient-centred care: not just semantics’ 2.

<sup>21</sup> Barnett N, ‘ Person-centred over patient-centred care: not just semantics’ 2.

<sup>22</sup> Barnett N, ‘ Person-centred over patient-centred care: not just semantics’ 2.

<sup>23</sup> Barnett N, ‘ Person-centred over patient-centred care: not just semantics’ 2.

<sup>24</sup> World Health Organization, Global strategy on people-centred and integrated health services interim report,7.

<sup>25</sup> World Health Organization, Global strategy on people-centred and integrated health services interim report,7.

<sup>26</sup> World Health Organization, Global strategy on people-centred and integrated health services interim report,7.

ground on health care choices.<sup>27</sup> It leads to positive health outcomes such as reduced unnecessary tests, malpractice lawsuits and anxiety as well as increased treatment adherence, improved health literacy, and overall health improvement.<sup>28</sup> This is due to patients feeling like full participants in the clinical encounter, rather than passive recipients or imposed decisions.<sup>29</sup> This concept would also be helpful in understanding the position of bodily autonomy with regards to health care laws and policies. It considers the possibility of factors that may lead one to make use of Advance Directive with legal standing where the law seems to be lacking.<sup>30</sup>

The discourse around advance directives brings to light the intricate relationship that exists between the law's respect for patient autonomy and moral principles of beneficence.<sup>31</sup>

According to Maclean, the legalisation of advance directives aims to safeguard patient welfare, ease the delivery of healthcare, and shield medical personnel from liability rather than upholding personal autonomy and that autonomy protection is secondary to those overarching objectives.<sup>32</sup>

Maclean further states that an advance directive's legal legitimacy does not guarantee its seamless integration or lack of opposition.<sup>33</sup> Observing an advance directive may not seem to be in the best interests of the patient, according to family members and caregivers.<sup>34</sup> This leads to conflict between the patient's autonomy and these third parties' well-intentioned worries, which fuels various arguments opposing advance directives.<sup>35</sup> Morrison, in addition, argues that there exists a disconnect in the current areas that practise Advance Care Planning. He states there exists administrative and policy support with regards to Advance Care Planning, but the effectiveness of the concept seems to be close to zero in influencing the decisions of many.<sup>36</sup> Some of the reasons being lack of quality indicators as to the improvement of healthcare for seriously ill patients and what he deems as unreliable documentation.<sup>37</sup>

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<sup>27</sup> Milligan E and Jones J, 'Rethinking autonomy and consent in healthcare ethics', 32.

<sup>28</sup> Milligan E and Jones J, 'Rethinking autonomy and consent in healthcare ethics', 32.

<sup>29</sup> Milligan E and Jones J, 'Rethinking autonomy and consent in healthcare ethics', 32.

<sup>30</sup> Milligan E and Jones J, 'Rethinking autonomy and consent in healthcare ethics', 32.

<sup>31</sup> Maclean A, 'Advance directives and the rocky waters of anticipatory decision making,' 16 (1) Medical Law Review 2008,2.

<sup>32</sup> Maclean A, 'Advance directives, future selves and decision making', 293.

<sup>33</sup> Maclean A, 'Advance directives, future selves and decision making', 293.

<sup>34</sup> Maclean A, 'Advance directives, future selves and decision making', 293.

<sup>35</sup> Maclean A, 'Advance directives, future selves and decision making', 293.

<sup>36</sup> Morrison R, Meier D and Arnold R, 'What's wrong with advance care planning?' 326 Journal of the American Medical Association 16 ,2021,2.

<sup>37</sup> Morrison RS et al, 'What's wrong with advance care planning?', 2.

### **1.7.2 Informed Consent**

The theoretical frameworks of moral philosophy and law have largely structured the conversation around informed consent.<sup>38</sup> Its practice too has historical roots in a variety of fields such as medicine, law and moral philosophy. The origins of informed consent can be found in a variety of disciplines, including law, moral philosophy, and medicine. It is closely related to the philosophical ideas of respect for individuals and their autonomy, which include privacy, liberty rights, and self-governance. The main basis for informed consent in this ethical paradigm is the patient's ability and right to make decisions that are consistent with their own beliefs and preferences. Informed consent can be examined from at least two different angles.<sup>39</sup>

The first viewpoint, which is in opposition to the paternalistic notion that doctors should only make judgments that are in the best interests of their patients, centres on the idea of autonomous authorisation for medical procedures.<sup>40</sup> The other viewpoint, which places consent that is informed within the confines of institutional and social norms, emphasises the necessity of legally valid consent prior to a medical intervention.<sup>41</sup> According to this definition, informed consent is not an independent act but rather an informed patient's authorization that operates under institutional or legal bounds.<sup>42</sup> The five components of voluntarism, capability, disclosure, understanding, and decision-making are necessary for valid informed consent.<sup>43</sup> Milligan and Jones refer to autonomy as the principal principle in healthcare ethics while further stating that it is operationalised by patients giving informed consent through access to information that would allow knowledgeable decisions.<sup>44</sup> However, there is strong evidence suggesting that numerous patients fail to fully comprehend the medical objectives, constraints, or ethical ramifications of the operations they agree to, despite its significance and the strong protocols that are presumably in place.<sup>45</sup> Physician and ethicist Jay Katz is recognized for having ushered in a period of time

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<sup>38</sup> Carmen M and Joffe S, Informed consent for medical treatment and research: a review, 10 *The Oncologist* 8, 2005, 636.

<sup>39</sup> Carmen M and Joffe S, Informed consent for medical treatment and research: a review, 636.

<sup>40</sup> Carmen M and Joffe S, Informed consent for medical treatment and research: a review, 637.

<sup>41</sup> Carmen M and Joffe S, Informed consent for medical treatment and research: a review, 637.

<sup>42</sup> Carmen M and Joffe S, Informed consent for medical treatment and research: a review, 637.

<sup>43</sup> Carmen M and Joffe S, Informed consent for medical treatment and research: a review, 637.

<sup>44</sup> Milligan E and Jones J, 'Rethinking autonomy and consent in healthcare ethics' in Clark P, *Bioethics - Medical, Ethical and Legal Perspectives*, 2016, 21.

<sup>45</sup> Milligan E and Jones J, 'Rethinking autonomy and consent in healthcare ethics', 21.

that prioritised patient autonomy, hence improving the standard of medical care in general.<sup>46</sup> However, Gawande, as cited by Timothy J, criticises this change, pointing out that although respecting patient autonomy is vital, many people would rather not be fully in charge of their medical decisions and occasionally opt to accept their doctors' professional judgement.<sup>47</sup>

### **1.7.3 Self-determination and Bodily/ Patient Autonomy**

Dworkin articulates the value in the concept of autonomy in that an individual's life plans and projects make them who they are, and that in pursuing autonomy, it shapes one's life and constructs its meaning as it gives purpose for existence.<sup>48</sup> According to Kant, a person's will is only considered free when they establish an agenda for themselves based on an in-depth understanding of the reality of their circumstances and the conditions that permit them to be given opportunities, maintain their relationships, and maximise their capacities and when one exercises autonomy, they take into account their own reality and make wise decisions based on what is actually desirable.<sup>49</sup>

Berlin proceeds to opine that if men's fundamental nature is they are independent beings who create their own values and goals, with their own volition serving as their ultimate authority, then treating men as though they are not autonomous but rather natural objects subject to casual influences by outside factors, and whose decisions are subject to manipulation by their rulers through coercion or rewards is the worst possible treatment.<sup>50</sup> He further states that men should not be treated this way because it implies that they lack self-determination and proceeds to quote Kant who stated that "Nobody may force me to be happy in his own way".<sup>51</sup> Wicks refers to this general value of self-determined decision making as intuitively appealing, however acknowledges that exists details yet to be determined as to what autonomy requires.<sup>52</sup> Some of these include what the role of rationality, reflection, capacity and intention would be and gives examples of questions pertinent to the subject such as whether an autonomous choice need be

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<sup>46</sup> Paterick T, Carson GV, Allen MC and Paterick TE, 'Medical informed consent: general considerations for physicians' 83(3) Mayo Clin Proceedings ,2008, 318.

<sup>47</sup> Carson G, Allen M and Paterick T, 'Medical informed consent: general considerations for physicians' 83(3) Mayo Clin Proceedings ,2008, 318.

<sup>48</sup> Wicks E, The state and the body: legal regulation of bodily autonomy, 3.

<sup>49</sup> Grant G, 'Autonomy and selfishness',1214.

<sup>50</sup> Berlin I, 'Two concepts on liberty; four essays on liberty' Oxford University Press, 1969, 11.

<sup>51</sup> Berlin I, 'Two concepts on liberty; four essays on liberty' 11.

<sup>52</sup> Wicks E, The state and the body: legal regulation of bodily autonomy,3.

based on desires considered to be rational and whether there exists a meaningful distinction between liberty and autonomy and between mere voluntariness and autonomy.<sup>53</sup>

Gillet's take on autonomy is also aligned with truth, similar to Kant's view and he states that autonomy when practised truthfully is consistent with reality and rational behaviour and as a member of society, with interdependence being unavoidable, taking advantage of or profiting off of others for various needs irresponsibly goes against this dependency.<sup>54</sup> Moreover, he emphasises that although autonomy should be encouraged, enhanced and respected, selfishness should not be promoted under its guise when actions are incompatible with the truth.<sup>55</sup>

## **1.8 METHODOLOGY**

In understanding the study's goals and objectives, as well as evaluating past research on the subject, the suitable overall research methodology chosen for this project is qualitative. The research seeks to analyse the nature of advance directives and advance care planning, its impact legally and ethically and the interpretation of it in our legal system as well as the scale of its importance for future application. Hence, to facilitate this, this desk-based approach will feature the use of primary sources such as the Constitution of Kenya and relevant statutes and secondary sources such as books, journal articles, and reports and case law.

More specifically, there shall also be an analysis of the best interest approach as well as Person-centred approach in Advance Care Planning in order to fulfill the aims of the project. This will be useful in understanding the best application of the directives as has been applied severally from different countries and help understand the rationale behind it while also taking a critical analysis approach on the same to showcase a different viewpoint. In addition, in order to properly analyse the consequences that may arise from any contradicting provisions of statutes or provisions that may affect the application of Advance Care Planning, history and case law shall be used to shed light on the past consequences of the lack of use of Advance Care Planning and its impact from use in other countries. In gauging the morality of Advance Directives, the use of philosophy and ethical considerations shall be carefully explored as they shall be of great importance to this part of the project. Lastly, in search for a more suitable solution, a doctrinal approach of analysis shall be taken to propose a solution more efficient for legislation in law

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<sup>53</sup> Wicks E, The state and the body: legal regulation of bodily autonomy,3.

<sup>54</sup> Grant G, 'Autonomy and selfishness' ,372(9645) The Lancet ,2008,1215.

<sup>55</sup> Grant G, 'Autonomy and selfishness' ,1215.

through a critical analysis of its nature.

## **1.9 CHAPTER BREAKDOWN**

Chapter one shall function as the introduction of the dissertation. It details among others the research objectives of the project, the methodology to be used, the theoretical framework of consideration and the hypothesis of the project.

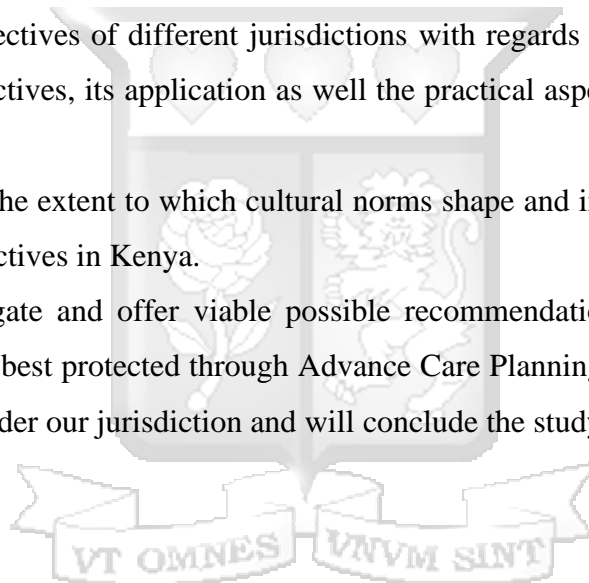
Chapter two will examine the legal framework concerning advance care planning and advance directives as is in Kenya.

Chapter three will analyse the implications of the lack of a proper legal framework governing Advance directives and Advance Care Planning in relation to the rationale and legality.

Chapter four offer perspectives of different jurisdictions with regards to their legal frameworks governing Advance Directives, its application as well the practical aspect of the use of Advance Directives.

Chapter five will assess the extent to which cultural norms shape and influence the development of laws on Advance Directives in Kenya.

Chapter six will investigate and offer viable possible recommendations as to how wishes of patients in Kenya can be best protected through Advance Care Planning and Advance Directives and can be interpreted under our jurisdiction and will conclude the study.



## **CHAPTER 2 : REGULATORY FRAMEWORK GOVERNING ADVANCE DIRECTIVES**

### **2.1 Introduction**

Many jurisdictions recognise and regulate the use of Advance Directives; Legal documents that enable one to specify their health care preferences while they have the mental capacity to do so. In Kenya, however, there exists no statutory law that acknowledges and regulates the use of Advance Directives. The current legal framework in Kenya, which includes laws on patient autonomy, healthcare, and constitutional rights, only vaguely addresses Advance Directive -related topics. This chapter shall critically analyse the current legal framework in place in order to determine whether it currently can support Advance Directives and the shortcomings and uncertainties within the law that necessitate the use and regulation of these directives as legal documents.

### **2.2 Current regulatory framework in Kenya**

#### **2.2.1. The Constitution of Kenya**

The Constitution of Kenya is the supreme law of the Republic of Kenya binding all persons and all state organs at both levels of government.<sup>56</sup> It sets out core principles that govern healthcare rights and responsibilities hence essential for analysis. The relevant articles are as follows:

Article 26 of the Constitution of Kenya speaks of every person having the right to life, that it starts at conception and that unless authorised by law, should not be deprived of it intentionally.<sup>57</sup> The right to life can be viewed as an integral part of, or as entwined with, other rights.<sup>58</sup> Therefore, it is evidently essential for both the right to liberty and the right to self-improvement.<sup>59</sup> When someone deprives us from this right, they also take away our freedom, our ability to become better versions of ourselves, and all of our other rights.<sup>60</sup> Therefore, one may argue for the right to life in light of other rights.<sup>61</sup> This right can then be viewed as a foundation to attaining health care related rights. It creates a duty to the state to not only protect life but also provide and create systems that promote and enhance the overall welfare of its people. Advance Directives are

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<sup>56</sup> Article 2(1), Constitution of Kenya (2010).

<sup>57</sup> Article 26, Constitution of Kenya (2010).

<sup>58</sup> McCloskey H. J., 'The right to life,' 84 *Mind*, 84 (335), 1975, 404.

<sup>59</sup> McCloskey H. J., 'The right to life,' 404.

<sup>60</sup> McCloskey H. J., 'The right to life,' 404.

<sup>61</sup> McCloskey H. J., 'The right to life,' 404.

tools used in health care that acknowledge this right to life and further extends to the bodily autonomy that comes with it. It provides a secure form of communicating one's health care preferences that an individual wishes to have carried out in the event that they are unable to. In addition, as it relates to this article, the refusal of life sustaining treatment is provided for under The Kenya National Patients' Rights Charter issued by the ministry of health.<sup>62</sup> This provision that allows for the right to refuse life sustaining treatment reflects an understanding that protecting the right to life also means protecting an individual's autonomy and therefore how they wish for their life to progress. The use of an Advance Directive would in such a scenario be for the promotion of this right. In line with the aforementioned reasons, Article 26 remains a paramount foundation in the acknowledgement of health care related rights and more specifically Advance Directives.

According to Article 28 of the Constitution, each and every person has an inherent right to respect and the preservation of their dignity.<sup>63</sup> In various settings, the need of upholding human dignity is frequently mentioned without always providing a clear definition.<sup>64</sup> As a result, there is no universal definition of dignity, leaving each health practitioner to characterize it according to their own interpretation.<sup>65</sup> Theoretical and empirical studies are therefore useful for expanding our knowledge of dignity in the context of health care.<sup>66</sup>

From a moral perspective, dignity embodies the essence of all that it means to be human; as a human right, it legitimizes the idea that humanity's essence must be acknowledged and valued equally.<sup>67</sup> Although there is a lack of consensus on the theoretical underpinnings of dignity, scholars such as Schachter, Neuman and Feldman have noted that dignity typically exhibits three fundamental components when evaluating claims for freedoms enjoyed by individuals.<sup>68</sup> They include ; the ontological claim, relational claim and limited state claim.<sup>69</sup> According to the ontological assertion, each person's inherent dignity is comprised of their unique attributes, which

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<sup>62</sup> The Kenya National Patients' Rights Charter (1), 2013, 4.

<sup>63</sup> Article 28, Constitution of Kenya (2010).

<sup>64</sup> Sæteren B and Nåden D, 'Dignity: an essential foundation for promoting health and well-being' in Haugan G's Health promotion in health care-vital theories and research, Springer, 2021, 72.

<sup>65</sup> Sæteren B and Nåden D, 'Dignity: an essential foundation for promoting health and well-being' 72.

<sup>66</sup> Sæteren B and Nåden D, 'Dignity: an essential foundation for promoting health and well-being' 72.

<sup>67</sup> Steinmann R, 'The core meaning of human dignity' North-west University, 19, 2016, 6 --- <https://www.saflii.org/za/journals/PER/2016/23.html> on 10 February 2016.

<sup>68</sup> Steinmann R, 'The core meaning of human dignity', 7.

<sup>69</sup> Steinmann R, 'The core meaning of human dignity', 7.

are irreplaceable and priceless.<sup>70</sup> The second component is referred to as the "relational claim" by McCrudden and it underscores the individual's relationship and expectations as they pertain to his community's perceptions; the "dignity of recognition," which is the social dimension of dignity.<sup>71</sup> It essentially states that for dignity to be protected it requires respect from others. Expanding upon the relational claim, the third common attribute, known as the "limited-state claim", reflects the Kantian concept that the state should exist for the benefit of the individual rather than the other way around.<sup>72</sup> The second-generation social and economic human rights represent the state's increasing need to offer existential basic living circumstances to recognize intrinsic human dignity.<sup>73</sup>

The aforementioned elements as well as the general understanding of the right to dignity then provides a foundation for various rights to be upheld and more specifically here, health care - related rights. The ontological claim for example, supports the right that every human being has inherent worth that is owed recognition; it is more about who we are as humans rather than how we're treated hence its intrinsic nature. This can be connected to the concept of patient autonomy in that it affirms that individuals have a right to make their own medical decisions with respect to their dignity. The concept of Advance Directives further promotes this right under article 28 by providing for the obligation to have one's choice and dignity respected beforehand in the event of incapacity. Similarly, the relational claim provides for the understanding that such decisions need to be respected and honoured by the surrounding community and that the lack of would be a violation of this dignity and likely lead to mistreatment. In finalising, the last element on limited-state can be interpreted as a call to action to the state and its duties in providing the legal frameworks, policies and enforcement mechanisms to ensure that health care rights are promoted. This in turn then provides more assurance for access to Advance Directives if basic essential health care is provided for as well.

Article 31 of the Constitution provides for the right to privacy.<sup>74</sup> For all healthcare professionals and organizations, protecting patient data's confidentiality, privacy, and protection is essential. This is more important than ever in this era of constant developing information technology.<sup>75</sup>

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<sup>70</sup> Steinmann R, 'The core meaning of human dignity', 7.

<sup>71</sup> McCrudden C, 'Human dignity and judicial interpretation of Human Rights' Oxford Legal Studies, Research Paper No. 24/2008, 679--- <https://ssrn.com/abstract=1162024> on 10 February 2025.

<sup>72</sup> McCrudden C, 'Human dignity and judicial interpretation of Human Rights' 679.

<sup>73</sup> Steinmann R, 'The core meaning of human dignity', 7.

<sup>74</sup> Article 31, Constitution of Kenya (2010).

<sup>75</sup> Tariq R and Hackert P, 'Patient confidentiality' StatPearls Publishing 23 January 2023 — <https://www.ncbi.nlm.nih.gov/books/NBK519540/> on 15 February 2025.

Patient privacy consists of various elements, such as physical privacy that entails one's personal space being respected, informational privacy that relates to your personal data, associational privacy that relates to personal relationships with family and other intimates and decisional privacy that concerns respect of one's choices even on matters such as cultural and religious affiliations.<sup>76</sup> Safeguarding data collected in connection with patient treatment is a fundamental principle in healthcare.<sup>77</sup> Nonetheless, it is also essential to preserve patient privacy in additional capacities as a sign of respect for patient autonomy and as a prerequisite for building trust.<sup>78</sup> Advance Directives can be considered an additional tool that aligns with the respect for patient autonomy and that needs privacy protection.

Moreover, Article 43(1)(a) of the Constitution provides for the right to the highest attainable quality of health, encompassing having access to medical services including reproductive health care.<sup>79</sup> The World Health Organisation describes it as right to enjoy a range of products, amenities, services, and conditions required for its realisation.<sup>80</sup> It puts an obligation on states to provide the same. Advance Directives are one of the ways that enjoyment, promotion and fulfillment of this right can be attained. The translation of this core right into actionable protections such as Advance Directives would be of benefit.

In addition, Article 57 is also an important provision of the Constitution of Kenya as it outlines the state's role with regards to the rights of older persons to actively engage in societal activities, pursue personal growth, to be free from abuse and to enjoy a life of respect and dignity, and to get appropriate support and care from their family and the State.<sup>81</sup> This concept of dignity presents itself here as well as the prioritisation of support by family and the state. This aligns with the aim of Advance Directives that provides protection for this dignity and allows appropriate support consented to. This demographic of older people is especially vulnerable due to the decline in health that comes with older age. For the same reason, they remain vulnerable due to the likelihood of incapacitation based on their state of health. Decisions are left to family members on their health care needs. This legislation therefore remains relevant in expanding the ways through

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<sup>76</sup> <https://code-medical-ethics.ama-assn.org/ethics-opinions/privacy-health-care> on 12<sup>th</sup> February 2025.

<sup>77</sup> <https://code-medical-ethics.ama-assn.org/ethics-opinions/privacy-health-care> on 12<sup>th</sup> February 2025.

<sup>78</sup> <https://code-medical-ethics.ama-assn.org/ethics-opinions/privacy-health-care> on 12<sup>th</sup> February 2025.

<sup>79</sup> Article 43(1)(a), Constitution of Kenya (2010).

<sup>80</sup> Office of the United Nations High Commissioner for Human Rights, Fact Sheet 31, 2008, 5.

<sup>81</sup> Article 57, Constitution of Kenya (2010).

which the healthcare rights of affected persons and vulnerable populations healthcare can remain uncompromised and be promoted.

### **2.2.2. The Health Act (2017)**

This Act has the aims to create a unified health system and offer oversight of medical products and services providers, health commodities, and medical technologies and for related objectives.<sup>82</sup> It accordingly provides for every individual being entitled to the best possible level of healthcare.<sup>83</sup> This includes progressive access to services for promotion, prevention, cure, palliative care, and rehabilitation.<sup>84</sup> In line with the Constitution and the Act, every individual has the right to be treated with respect, dignity, and privacy.<sup>85</sup> This Act from its recognition of important concepts such as dignity, respect and privacy ,moreover, its goals in areas such palliative and promotive care are a substratum for the concept of Advance Directives . In defining ‘health’ as more than just the absence of illness or infirmity and more as a state of whole physical, mental, and social well-being, it further aligns with the aim of Advance Directives which seeks to create a holistic, patient -centred approach towards health care.

A key provision in this Act that hints to the underpinnings of the concept of Advance Directives is section 9 of the Health Act.

Sections 9(1)(a) to (d) more specifically touch on informed consent and provides that health services should not be carried out without a patient's informed consent and where the patient is unable to give consent, it should be given by the person granted permission to give such consent if in writing by the patient or by law or court order .<sup>86</sup> If there is no one mandated, the law states that the responsibility shifts to the next of kin and if not may be authorised by an applicable law or court order .<sup>87</sup> As is, the law can be understood to be providing for a Medical Power of Attorney (an assigned individual that makes healthcare decisions on behalf of another). This essentially provides for the right to appoint an individual to make decisions on your behalf when lacking the capacity to do so and is typically considered a type of Advance Directive although

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<sup>82</sup> Section 3, Health Act (Act No 21 of 2017).

<sup>83</sup> Section 5, Health Act (Act No 21 of 2017).

<sup>84</sup> Section 5, Health Act (Act No 21 of 2017).

<sup>85</sup> Section 5, Health Act (Act No 21 of 2017).

<sup>86</sup> Section (9)(1), Health Act (Act No 21 of 2017).

<sup>87</sup> Section (9)(1), Health Act (Act No 21 of 2017).

not labelled so depending on the jurisdiction.

Although progressive, this provision further sheds lights on the limitation of individuals autonomy by narrowing their choice to the use of a proxy. It, however, also supports the potential for a broader framework that would enhance the right to a person and their agency in the healthcare system.

### **2.2.3: The Mental Health Act**

This Act is primarily concerned with promotion of mental health by lowering mental illness, coordinating prevention, availing treatment and rehabilitation facilities, reducing stigma and promoting recovery.<sup>88</sup> It also seeks to ensure that an individual with mental illness has their rights protected as well as providing comprehensive community -based care and mental health services offered by primary healthcare providers.<sup>89</sup> There exist jurisdictions that have progressed in healthcare by considering the protection of rights in line with autonomy and respect to dignity even in their Mental Health Act. This goes to show that even the Kenyan Mental Health could potentially be more progressive as well. Although not explicitly mentioned, the need to protect the patients' rights are alluded to as being pivotal thereby providing a conceptual basis for Advance Directives.

### **2.2.4: Medical Practitioners and Dentists Act**

This Act carries out various functions; the establishment of a framework that medical practitioners and dentists should meet as well ensure compliance with this set out framework.<sup>90</sup> The Act provides for a council and also ensures proper licensing and accreditation of practitioners.<sup>91</sup> It works to amend and consolidate the law to provide for the registration of dentists and medical practitioners as well as for related and incidental purposes<sup>92</sup> In light of this, the Act remains crucial in ensuring quality care and patient safety in working to achieve the right to highest attainable standard of health care. This as well as means that quality care would extent to even concepts like Advance Directives if put in place as they would be regulated, and practitioners would be held accountable and made knowledgeable on the same.

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<sup>88</sup> Section 2A, Chapter 248, Mental Health Act.

<sup>89</sup> Section 2A, Chapter 248, Mental Health Act.

<sup>90</sup> Section 4, Chapter 253, Medical Practitioners and Dentists Act.

<sup>91</sup> Section 4, Chapter 253, Medical Practitioners and Dentists Act.

<sup>92</sup> Chapter 253, Medical Practitioners and Dentists Act.

### **2.2.5: Conclusion**

The Constitution of Kenya as well as other aforementioned provisions and statutes remain relevant in forming the framework responsible for governing the health care and medical sector. They guard rights and establish duties and obligations to achieving these rights and essentially have a goal to protect core elements in this field such as autonomy, dignity, informed consent, privacy and access to the highest standard of health care services. These laws further provide for oversight of the practitioners in the industry in facilitating services that would actualise these rights as illustrated above. They in turn all lay a foundation for the enactment of Advance Directives and their potential use.



## **CHAPTER 3: A CRITIQUE ON THE CURRENT LEGAL FRAMEWORK AND THE INFLUENCE OF CULTURE**

### **3.1.0: A Critique on Kenya's Legal Framework**

Kenya's legal framework on Advance Directives falls short in addressing and reflecting the reality of what is being practised on the ground. This becomes a problem because it firstly, fails to fully realise the rights of its people as well as it creates legal ambiguity and uncertainty. This can be reflected in how the Constitution has been applied and interpreted so far as well as relevant statutes mentioned earlier with how they are drafted and the lack of. Although the constitution establishes a foundation for fundamental rights and freedoms, the legislative framework remains deficient in offering the required mechanisms for realisation and implementation of these rights in the context of Advance Directives.

#### **Privacy and confidentiality vulnerabilities in the law**

The Healthcare Act of 2017 is the main statute in Kenya that governs patient privacy.<sup>93</sup> It aims to safeguard patient-provider confidence and protect sensitive personal data, compliance with patient privacy legislation is crucial.<sup>94</sup> Advance Directives, however, remain susceptible to confidentiality breaches. This is due to Kenya's legislative framework lacking specified Advance Directives provisions that provide for privacy protections unless practised under an institutional policy. Health care institutions ought to put safeguards in place to prevent illegal access to health data regarding patients.<sup>95</sup> This involves changing security procedures on a regular basis too to counter emerging threats.<sup>96</sup> National laws however remain inadequate in supporting the institutional policies. This underscores the necessity for precise legislation to protect these documents as they are of a sensitive nature.

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<sup>93</sup><https://www.bmmusau.com/patient-rights-and-privacy-in-kenya/#:~:text=Patient%20consent%20is%20typically%20required,when%20required%20by%20court%20order.&text=Healthcare%20facilities%20should%20implement%20measures,health%20information%20from%20unauthorized%20access> on 11 December 2024.

<sup>94</sup><https://www.bmmusau.com/patient-rights-and-privacy-in-kenya/#:~:text=Patient%20consent%20is%20typically%20required,when%20required%20by%20court%20order.&text=Healthcare%20facilities%20should%20implement%20measures,health%20information%20from%20unauthorized%20access> on 11 December 2024.

<sup>95</sup><https://www.bmmusau.com/patient-rights-and-privacy-in-kenya/#:~:text=Patient%20consent%20is%20typically%20required,when%20required%20by%20court%20order.&text=Healthcare%20facilities%20should%20implement%20measures,health%20information%20from%20unauthorized%20access> on 11 December 2024.

<sup>96</sup><https://www.bmmusau.com/patient-rights-and-privacy-in-kenya/#:~:text=Patient%20consent%20is%20typically%20required,when%20required%20by%20court%20order.&text=Healthcare%20facilities%20should%20implement%20measures,health%20information%20from%20unauthorized%20access> on 11 December 2024.

### **Legal protection of vulnerable groups of patients**

Besides matters relating to privacy protection, the framework's inadequacies are evident in the handling of vulnerable groups and those seeking reproductive healthcare relevant to Advance Directives. There are not enough legal safeguards put in place to uphold Advance Directives on reproductive health care that fall in line with one's beliefs and values. Furthermore, there is no guarantee that these directions are followed within the healthcare system which in turn fails to realise Article 43(1)(a) of the Constitution which provides for the right to the highest attainable quality of health.<sup>97</sup> It should also be noted that older people fall under a demographic that commonly uses Advance Directives. Such vulnerable groups of those of old age are done an injustice despite Article 57 of the Constitution providing the state's role with regards to the rights of older persons to be free from abuse and to enjoy a life of respect and dignity, and to get appropriate support and care from their family and the State.<sup>98</sup> There are currently no measures in existence to ensure that this vulnerable group's health care preferences when exercised are going to be respected and protected with regards to advance wishes. It also remains unclear as to whether other key articles such as the right to life and the right to respect and preservation of dignity can be extended and interpreted to provide for the use of Advance Directives. This is taken into consideration as one of the core foundations for these directives is that they are centred around dignity and the quality of life one hopes for and is let to lead. According to Cantor, if a human life is devoid of personal dignity, its intrinsic value is diminished.<sup>99</sup>

### **Legal barriers to patient autonomy in informed medical decision making.**

There exist other statutes that vaguely or inadequately address issues surrounding Advance Directives such as the Health Act. As is, the law can be understood to be providing for a medical power of attorney under section (9)(1) of the Health Act (an assigned individual that makes healthcare decisions on behalf of another).<sup>100</sup> This can be considered as one type of Advance Directive depending on a region's or a state's understanding and laws. However, there is no provision for Advance Directives that allows one to state their preferences and authorise consent individually for certain healthcare services that can be foreseen with the assistance of a medical

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<sup>97</sup> Article 43(1)(a), Constitution of Kenya (2010).

<sup>98</sup> Article 57, Constitution of Kenya (2010).

<sup>99</sup> Barry R, 'Advance directives and the pursuit of death with dignity by Norman L. Cantor' 10 Indiana University Press 1, 1993, 623.

<sup>100</sup> Section (9)(1), Health Act (2017).

professional. One is not able to participate in their healthcare decisions and choose options that best align with their value systems. Furthermore, the lack of reference to Advance Directives creates a legal vacuum in terms of the hierarchy of obtaining consent as there may be neglect to the possibility of pre-existing directives written by a patient and this eventually reflects neglect of a patient's autonomy. The inadequacy of such a law in providing for Advance Directives within the framework may reflect an outright disregard of patient autonomy.

### **Slow adaptability of the law to evolving patient needs**

The disregard for patient autonomy remains evident even in relation to mental health patients. There exist Psychiatric Advance Directives (PADs), which are written or verbal declarations through which adults with the capacity to make decisions can express their treatment preferences and/or name proxy decision makers to act on their behalf if they are later found to be incapable of making knowledgeable choices for themselves.<sup>101</sup> The Mental Health Act does not reflect any consideration for individuals that may be susceptible to mental health illness. The law falls under one of the disciplines that adjusts with developments such as technology especially in medical law and bioethics to cater for the potential and very plausible legal gaps that arise with the developments hence the need for foresight on such matters. There exists a rise in genetic and imaging research that shows the possibility to forecast major mental illnesses such as schizophrenia and depression before they manifest with ever-increasing precision.<sup>102</sup> Such an advancement highlights the need for a legal system that anticipates and responds to possible challenges in the future. The scope of the Mental Health Act of Kenya is, however, limited in that it does not provide for nor extend to the application of Advance Directives. This poses a challenge and further highlights a legal vacuum in cases where individuals may wish to declare their healthcare preferences, in advance, in the event they are declared to be lacking the mental capacity to make their decisions due to mental illnesses.

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<sup>101</sup> Zelle H, Kemp K and Bonnie R, 'Advance directives in mental health care: evidence, challenges and promise.' *14 World psychiatry: official journal of the World Psychiatric Association (WPA)*, 3, 2015, 278.

<sup>102</sup> Lawrie S, Fletcher-Watson S, Whalley H, and McIntosh A, 'Predicting major mental illness: ethical and practical considerations' 2019, 1 — <https://pmc.ncbi.nlm.nih.gov/articles/PMC6469234/#:~:text=Summary,ill%20with%20ever%20improving%20accuracy> on 15 December 2024.

## Conclusion

Patients who have knowledge of their legal rights are more likely to be satisfied with their medical care, communicate with their doctors more effectively, and participate more actively in treatment decision-making.<sup>103</sup> The rights of patients are human rights that are enshrined to uphold, defend, and fulfill an individual's dignity.<sup>104</sup> From the above analysis, various gaps exist that delay the realisation of these rights ,this includes shortcomings with respect to privacy concerns, the concept of autonomy and informed consent ,mental health considerations as well as those considered to be vulnerable groups.



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<sup>103</sup> [https://www.bmmusau.com/advance-directives-in-kenya-ensuring-your-end-of-life-wishes-are-respected/#:~:text=Advance%20directives%20\(ADs\)%20are%20essential,unable%20to%20communicate%20their%20wishes](https://www.bmmusau.com/advance-directives-in-kenya-ensuring-your-end-of-life-wishes-are-respected/#:~:text=Advance%20directives%20(ADs)%20are%20essential,unable%20to%20communicate%20their%20wishes) on 14 December 2024

<sup>104</sup> [https://www.bmmusau.com/advance-directives-in-kenya-ensuring-your-end-of-life-wishes-are-respected/#:~:text=Advance%20directives%20\(ADs\)%20are%20essential,unable%20to%20communicate%20their%20wishes](https://www.bmmusau.com/advance-directives-in-kenya-ensuring-your-end-of-life-wishes-are-respected/#:~:text=Advance%20directives%20(ADs)%20are%20essential,unable%20to%20communicate%20their%20wishes) on 14 December 2024.

## **CHAPTER 4: A COMPARATIVE STUDY OF THE LEGAL FRAMEWORK OF ADVANCE DIRECTIVES IN THE UNITED KINGDOM AND SOUTH AFRICA.**

### **4.1: Introduction**

The legal gaps portrayed by Kenya's healthcare framework in relation to Advance Directives are a number. Jurisdictions greatly differ in their legal recognition of Advance Directives. In contrast to Kenya, the United Kingdom (UK) is an example of a country that has made significant progress in embracing the concept of Advance Directives and its legal enforcement. South Africa's efforts as well reflect the need for this system and also showcase potential challenges that may arise within the African context. The comparative study of the United Kingdom and South Africa is used to show the measures taken to fill the legal vacuum and how best we can apply them to the Kenyan context.

### **4.2: Advance Directives in the United Kingdom**

The primary statute that speaks to the use and governance of Advance Directives in the UK is the Mental Capacity Act of 2005. It is an Act enacted to create a superior court of record known as the Court of Protection in lieu of the Supreme Court's office with that name, to make provisions in relation to the Convention on the International Protection of Adults signed in The Hague on January 13, 2000, and for other related purposes.<sup>105</sup>

#### **4.2.1: Guiding principles of the Mental Capacity Act; Autonomy and Best Interest**

Individuals who might not have the mental capacity to make decisions about their own care and treatment are protected and empowered by the Mental Capacity Act (MCA).<sup>106</sup> It extends to people of 16 years of age and above and caters for everyday choices as well as more significant life-altering choices like whether to have major surgery or transfer into a care facility.<sup>107</sup> Under article 1, it provides for ; the presumption of capacity unless proved otherwise, also that until all reasonable attempts to assist an individual in making a decision have been made without success, that person should not be considered incapable of making a decision.<sup>108</sup> In addition it provides that just because someone makes a poor choice does not mean that they are incapable of making

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<sup>105</sup> Introductory text, Mental Capacity Act (No.9 of 2005).

<sup>106</sup> [https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/#:~:text=The%20Mental%20Capacity%20Act%20\(MCA,people%20aged%2016%20and%20over](https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/#:~:text=The%20Mental%20Capacity%20Act%20(MCA,people%20aged%2016%20and%20over) on 12 December 2025.

<sup>107</sup> [https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/#:~:text=The%20Mental%20Capacity%20Act%20\(MCA,people%20aged%2016%20and%20over](https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/#:~:text=The%20Mental%20Capacity%20Act%20(MCA,people%20aged%2016%20and%20over) On 12 December 2025.

<sup>108</sup> Section 1, Mental Capacity Act (No.9 of 2005).

decisions and that any action taken in line with this Act on behalf of an incompetent individual must be in the individual's best interest.<sup>109</sup> Lastly it also states that prior to taking action or making a decision, consideration must be given to whether the desired outcome can be accomplished as successfully and less restrictively to one's rights and freedoms.<sup>110</sup> Articles of further relevance are articles 24 to 26 of the Mental Capacity Act which all make reference to Advance Directives. In general, the provisions aim to integrate the existing common law norms into the Act's larger framework by codifying and clarifying them.<sup>111</sup> Otherwise, there would be a lacuna in the Act's framework and the new court's authority.<sup>112</sup>

#### **4.2.2: Validity and Applicability of Advance Directives in the UK**

The Act states that an advance decision must be made by an 18 year old at a time when they have the capacity to make it and that it must specify the treatment (lay terms also permitted ) being refused and specific circumstances.<sup>113</sup> A person can change or withdraw the decision, and it doesn't need to be written as it can be by any means, however, alterations to an advance decision refusing life-sustaining treatment require formalities to apply.<sup>114</sup> The same Act only provides for the concept of 'Best interest' under section 4 where it provides an extensive list that describes the factors that someone must take into account before acting or choosing for you when you are unable of doing so.<sup>115</sup> This section and concept is of relevance as it is what can be used in the event a directive is declared invalid or inapplicable. The Mental Capacity Act expressly acknowledges Advance Directives under section 25 and 'best interest' does not override them unless in specified circumstances. The presence of this hierarchy guarantees that people's autonomy and freedom to self-determination are respected above opinions of third parties about what is in the best interests of the affected patient. The Mental Capacity Act 2005 therefore recognizes exercise of autonomy by acknowledging anticipatory decision making and enabling people to make decisions on their own in daily life.<sup>116</sup> In relation to Advance Directives, it guides on important matters pertaining to decisional capacity such as when the directive will take effect

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<sup>109</sup> Section 1, Mental Capacity Act (No.9 of 2005).

<sup>110</sup> Section 1, Mental Capacity Act (No.9 of 2005).

<sup>111</sup> <https://www.legislation.gov.uk/ukpga/2005/9/notes/division/6/1/6/1> on 15 December 2024.

<sup>112</sup> <https://www.legislation.gov.uk/ukpga/2005/9/notes/division/6/1/6/1> on 15 December 2024.

<sup>113</sup> Section 24, Mental Capacity Act (No.9 of 2005).

<sup>114</sup> Section 24, Mental Capacity Act (No.9 of 2005).

<sup>115</sup> <https://www.mind.org.uk/information-support/legal-rights/mental-capacity-act-2005/best-interests/#:~:text=Health%20professionals%20must%20act%20in,you%20while%20you%20lack%20capacity> on 15 December 2024.

<sup>116</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2598235/> on 28 August 2024.

for instance.<sup>117</sup> It provides for the validity of Advance Directives stating that a health care provider cannot be held liable for carrying treatment or the withdrawal of the same if they are acting in line with the directive as long it is valid and applicable to the treatment.<sup>118</sup> It is invalid if the person withdraws the decision, confers authority on a lasting power of attorney, or does anything inconsistent with the advance decision.<sup>119</sup> The decision is not applicable to the treatment if the person has capacity to consent to or against it at that material time.<sup>120</sup> Inapplicability also applies; if the treatment is not specified in the advance decision, if any circumstances are absent, or if there are reasonable grounds for believing that current circumstances would have affected the decision had they anticipated them.<sup>121</sup> For the same to apply to life-sustaining treatment ,it requires a verified statement and also compliance with subsection 6 as well which states the formalities and requirements that must be met such as; it being in written form, needing the signatures of the one making the decision and that of a witness and even caters for situations where the one making the decision is not able to sign ,one can be appointed to do so but must be in the presence of the person or acknowledged as it being theirs by them.<sup>122</sup>

#### **4.2.3: The role of courts in relation to Advance Directives in the UK**

Courts have played a major role in the development, recognition and enforcement of Advance Directives. There exist foundational cases that paved the way for Advance Directives by further solidifying essential principles and concepts and those that spoke to their validity. The judicial interpretations and outcomes of cases are able to clarify and speak to also areas where the law might struggle to anticipate. In briefly mentioning the history, Advance Directives were initially not considered legally binding until the introduction of the Mental Capacity Act. It was practised but not legislated.<sup>123</sup> Medical law had already recognised the right to refusal of treatment typically when one had the ability to consent, but issues arose when it came to honouring of wishes to withdraw consent to treatment in advance in the event of incapacity due to various reasons.<sup>124</sup> Cases like Airedale NHS Trust v Bland and Re B (Adult: Refusal of Treatment) established fundamental legal principles and concepts such as self-determination and the right to

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<sup>117</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2598235/> on 28 August 2024.

<sup>118</sup> Section 25 (1), Mental Capacity Act (No.9 of 2005).

<sup>119</sup> Section 25 (2), Mental Capacity Act (No.9 of 2005).

<sup>120</sup> Section 25 (3), Mental Capacity Act (No.9 of 2005).

<sup>121</sup> Section 25 (4), Mental Capacity Act (No.9 of 2005).

<sup>122</sup> Section 25, Mental Capacity Act (No.9 of 2005).

<sup>123</sup> [https://www.mentalhealthlaw.co.uk/media/39ES\\_Advance\\_Decisions\\_Note.pdf](https://www.mentalhealthlaw.co.uk/media/39ES_Advance_Decisions_Note.pdf) on 15 December 2024.

<sup>124</sup> [https://www.mentalhealthlaw.co.uk/media/39ES\\_Advance\\_Decisions\\_Note.pdf](https://www.mentalhealthlaw.co.uk/media/39ES_Advance_Decisions_Note.pdf) on 15 December 2024.

refusal of treatment but also highlighted gaps in enforceability of the same when done so in advance.

The case of *Re B (Adult: Refusal of Treatment)* for instance, involved a woman with a spinal cord abnormality who in a living will executed prior, had expressed her desire for treatment to be halted in the event that she became unconscious, had a life-threatening illness, or suffered a permanent mental disability.<sup>125</sup> She eventually became tetraplegic and needed a ventilator to survive. Her physicians believed that her living will was too ambiguous to support withdrawing her care when she became ventilator dependent. After having surgery that returned some of her speech and head movement, she repeatedly asked for the ventilator to be removed. Two psychiatrists did assessments to ascertain her capacity to make such a decision to which they first believed she was capable of, but they later changed their minds. In August 2001, she was determined to be competent to make a decision about whether she should proceed with treatment after taking part in rehabilitation evaluations. However, the hospital proposed to her a weaning program, which she declined because it would be painful and prolong her suffering. The patient refused all attempts at rehabilitation and filed a lawsuit with an aim to get a declaration of her mental competence to refuse medical care, even if it meant her death, a declaration that the facility had engaged in illegal treatment, and she also sought nominal damages for trespassing on her person. The court held that a competent patient has the right to refuse medical treatment, even if doing so may cause their death, and that the patient in question was deemed competent of making all pertinent decisions regarding her treatment, including stopping artificial ventilation, since she exhibited great mental competence, intelligence, and decision-making capacity.<sup>126</sup> The court further stated that despite offering exceptional care, the hospital failed to promptly address the ethical dilemma and this made the treatment illegal, and the patient was entitled to nominal damages for trespassing on her person as well as the declarations she sought, granted by the court.<sup>127</sup> This 2002 judgement helped solidify the principle of autonomy over one's body specifically on refusal of treatment and the importance of establishing capacity as well the necessity of protecting the wishes of a patient well before the enactment of the 2005 Mental Capacity Act. After the Act's enactment, a lot of the cases seen do not necessarily challenge whether Advance Directives as a whole, but rather the application of elements necessary to

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<sup>125</sup> *Re B (Adult: Refusal of Treatment)* (2002), England and Wales High Court (Family Division).

<sup>126</sup> (2002) EWHC

<sup>127</sup> (2002) EWHC

enforce the directives, such as whether an individual had the capacity, whether it is in the best interest of the patient or even whether the decision made must be considered wise or not.

For instance, in the case of *Kings College Hospital NHS Foundation Trust v C & Another*, the main issue was whether the patient had the capacity to refuse her dialysis treatment as stated in her Advance Directive given her history of mental health troubles and the possible effect of her personality disorder which also left medical specialists divided on whether she had the competence to refuse treatment.<sup>128</sup> In referencing the Mental Capacity Act of 2005, the court was satisfied that the patient could make her own decision about whether to consent to treatment and that the decision should be based on her personal values and preferences, not on what society considers to be the "normal" course of action in this case, if there is such a thing.<sup>129</sup> In addition, the judge closed off by stating that the patient was a capacitous individual who was sovereign over her own body and intellect.<sup>130</sup> It remains relevant in how the court in recognising the capacity of the patient enabled enforcement of their Advance Directive and in turn furthered their protection of their right.<sup>131</sup> This is just but one case among many that has shown consistency in judicial efforts to uphold Advance Directives that meet criteria under the current legal framework.

A key takeaway for Kenya would be to assess the UK's legal framework for guidance on various matters including, the validity and applicability tests for ADs as well the assessment of capacity which is essential. The UK's framework demonstrates respect for self determination and the principle of autonomy and is keen on ensuring informed consent is respected and the wishes of people with regards to their health care are respected. In essence, their framework ensures the progressive realisation of the rights of their citizens. Moreover, the courts as well are seen to play a pivotal role in realising the same rights, something the Kenyan judicial system can also consider on such matters.

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<sup>128</sup> *Kings College Hospital NHS Foundation Trust v C & Anor* (2015) EWCOP.

<sup>129</sup> *Kings College Hospital NHS Foundation Trust v C & Anor* (2015) EWCOP.

<sup>130</sup> *Kings College Hospital NHS Foundation Trust v C & Anor* (2015) EWCOP.

<sup>131</sup> *Kings College Hospital NHS Foundation Trust v C & Anor* (2015) EWCOP.

#### **4.3.0: Advance Directives in South Africa**

South Africa is quite similar to Kenya within the context of Advance Directives. There exist no statutes that support the legal standing of advance directives or living wills under South African law. No South African court as well has issued a documented ruling directly addressing the legality of a living will or advance directive.<sup>132</sup> However, the Clark v Hurst case of 1992, addressed the question of whether to stop life-sustaining care was resolved by considering sociocultural-legal arguments and whether it would be appropriate to terminate the patient's artificial feeding considering them.<sup>133</sup> The patient, in a living will, asked that he be permitted to pass away rather than be kept alive artificially in the event that there was no realistic hope of his recovery to which the court stated that, in general, even in cases where a person is terminally sick and in excruciating agony, it is not justified to quicken their death.<sup>134</sup> However, the court also affirmed that it is not a hard-and-fast rule and that a patient's preferences as stated when he was still competent should be followed.<sup>135</sup> The judge stated that he believed the patient's intentions, as stated when he was in good health, should be carried out, just as a living person has an interest in how his body is disposed of.<sup>136</sup> This case remains significant in the acknowledgement of patient preferences.

Even though there are questions over whether living wills and advance directives are lawful and enforceable in South Africa, these documents are still utilized in practice.<sup>137</sup> The main statutes however that govern health laws in South Africa, however, still fail to address them. Section 27 of the Constitution of South Africa provides the right to the access health care services and further provides that the state is obligated to undertake legislative measures for the progressive realisation of this right in subsection 2.<sup>138</sup> The National Health Act as well aims to establish a framework for a structured, uniform health system throughout the Republic; and address issues related thereto.<sup>139</sup> In addition , is the Health Professions Act which aims to combine and modify the laws that establish the South African Medical and Dental Council that regulates the education and registration of physicians, dentists, and practitioners of other health service professions, regulate

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<sup>132</sup> Skeen A, 'Living Wills and Advance Directives in South African Law' 23 Medicine and Law 4 ,2004, 973.

<sup>133</sup> Clarke v Hurst NO and Others (1992), Durban Coast Local Division, South Africa.

<sup>134</sup> Clarke v Hurst NO and Others (1992), Durban Coast Local Division, South Africa.

<sup>135</sup> Clarke v Hurst NO and Others (1992), Durban Coast Local Division, South Africa.

<sup>136</sup> Skeen A, 'Living Wills and Advance Directives in South African Law' 973.

<sup>137</sup> Grove G, 'Living wills: what is the current legal status in South Africa?', 273.

<sup>138</sup> Article 27, Constitution of the Republic of South Africa (1996).

<sup>139</sup> The National Health Act (Act 61 of 2003), South Africa.

the education and registration of psychologists, and address related issues.<sup>140</sup> The three can be considered the main legislation governing health care and yet none has so far been amended to include or used to recognise the presence of Advance Directives. Similarly to Kenya, the closest connotation of the same is the indirect recognition of a health care proxy through the Health Professions Council of South Africa (HPCSA) guidelines.

Several draft bills and measures have been sent to Parliament including the End of Life Decisions Act in an effort to address the legal gap present, nevertheless, Parliament has not yet discussed or approved any of these bills.<sup>141</sup> Of importance, is that although these documents have not been declared legally recognisable in South Africa law, these documents have likewise not been declared legally unenforceable.<sup>142</sup> They are in accordance with public policy, acceptable, and have not yet been outlawed by legislation.<sup>143</sup> Due to this, patients who are no longer able to communicate their desires are now treated on an ad hoc basis, which causes ambiguity for both the public and medical professionals.<sup>144</sup>

Due to the lack of a statutory framework, medical professionals in South Africa are left to rely on ethical guidelines instead that were prompted by the Clark case and various others in the use of Advance Directives such as the 2008 Health Professions Council of South Africa (HPCSA) guidelines for healthcare professionals to which patient autonomy serves as the foundation.<sup>145</sup> According to these standards, healthcare professionals must honour any legitimate prior treatment refusals made by patients while they were still mentally competent.<sup>146</sup> In addition to allowing for the creation of a living will, the guidelines also allow for proxy decision-making through an enduring power of attorney.<sup>147</sup> The guidelines also provide that if there is no advance directive,

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<sup>140</sup> The Health Professions Act (Act 56 of 1974).

<sup>141</sup> Shreepal S, 'Considerations for the legal recognition of advance directives: a comparative analysis' University of KwaZulu-Natal, Durban, 2019,11.

<sup>142</sup> <https://www.macroberty.co.za/insights/posts/the-enforceability-of-obligations-created-by-advance-directives> on 15 December 2024.

<sup>143</sup> <https://www.macroberty.co.za/insights/posts/the-enforceability-of-obligations-created-by-advance-directives> on 15 December 2024.

<sup>144</sup> <https://www.macroberty.co.za/insights/posts/the-enforceability-of-obligations-created-by-advance-directives> on 15 December 2024.

<sup>145</sup> <https://www.macroberty.co.za/insights/posts/the-enforceability-of-obligations-created-by-advance-directives> on 15 December 2024.

<sup>146</sup> <https://www.macroberty.co.za/insights/posts/the-enforceability-of-obligations-created-by-advance-directives> on 15 December 2024.

<sup>147</sup> <https://www.macroberty.co.za/insights/posts/the-enforceability-of-obligations-created-by-advance-directives> on 15 December 2024.

the doctor must speak with the patient's authorized proxy or, if that is not possible, the patient's close relatives, who can offer information on the patient's expressed care choices and therefore the best understanding of the patient's desires and best interests will then be used to make a choice.<sup>148</sup> The medical professional in charge of the patient's care may make the choice if none of the aforementioned possibilities are available.<sup>149</sup>

Although South Africa is in a similar position as Kenya, there notable strides in their approach to Advance Directives, including the legislative attempts to create a framework as well the formation of ethical guidelines to guide practitioners as they await proper legislation. Kenya could take note of such efforts to reduce the legal gaps as well protect the rights of its people.



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<sup>148</sup> <https://www.macrobert.co.za/insights/posts/the-enforceability-of-obligations-created-by-advance-directives> on 15 December 2024.

<sup>149</sup> <https://www.macrobert.co.za/insights/posts/the-enforceability-of-obligations-created-by-advance-directives> on 15 December 2024.

## **CHAPTER 5: THE IMPACT OF CULTURAL BELIEFS OF SOCIETY ON THE DEVELOPMENT OF LAWS ON ADVANCE DIRECTIVES IN KENYA.**

As the saying goes, ‘the law does not exist in a vacuum’. Rather it is shaped by the ethics and morality of a people, their culture as well as their religious inclinations. Often, these areas end up overlapping. This subchapter shall majorly focus on the influence culture has on the development of law in relation to Advance Directives.

For conversations on Advance Directives to be had, the topic of potential death must arise, and a society’s view on the same impacts how they perceive the concept of Advance Directives. In Africa, death is typically viewed from both a religious and cultural standpoint.<sup>150</sup> It is said that religion can assist in giving purpose and solutions to the issues of uncertainty, helplessness, and absence brought on by death.<sup>151</sup> In many African cultures, the thought of and discussion on death is considered taboo.<sup>152</sup> It is, in a sense, forbidden to think about or discuss the possibility of dying and as a result, in contrast to western custom, people often do not draft living wills or save funds for their funeral while they are still living.<sup>153</sup> She further states that death is viewed as an adversary of life, and that they believe that life should be saved at all costs, even in the direst of circumstances.<sup>154</sup> The typical African does not support any artificial termination of life and is unlikely to stop life-sustaining therapy once it has begun.<sup>155</sup> Africans are perceived as being raised with a sense of relatedness and belonging from an early age which makes them feel a sense of duty to a greater group of other individuals.<sup>156</sup> This is among the factors contributing to African tradition's blindness to the functions of advance directives in an incompetent patient's final decision-making.<sup>157</sup> Rather, the family members of the individual in question make decisions near the end of their life, which many times causes unpleasant disputes as events progress.<sup>158</sup>

It should, however, be highlighted that the above reasoning possibly creates a cultural bias that generalises the views of 54 African countries each with citizens that have their own needs and unique experiences as individuals. Such generalisation is reflective of the harmful effects of

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<sup>150</sup> Ekore R, and Bolatito LA, ‘African cultural concept of death and the idea of advance care directives’ 22 Indian journal of palliative care 4, 2016, 369.

<sup>151</sup> Ekore R, and Bolatito LA, ‘African cultural concept of death and the idea of advance care directives’ 369.

<sup>152</sup> Ekore R, and Bolatito LA, ‘African cultural concept of death and the idea of advance care directives’ 371.

<sup>153</sup> Ekore R, and Bolatito LA, ‘African cultural concept of death and the idea of advance care directives’ 371.

<sup>154</sup> Ekore R, and Bolatito LA, ‘African cultural concept of death and the idea of advance care directives’ 371.

<sup>155</sup> Ekore R, and Bolatito LA, ‘African cultural concept of death and the idea of advance care directives’ 371.

<sup>156</sup> Ekore R, and Bolatito LA, ‘African cultural concept of death and the idea of advance care directives’ 371.

<sup>157</sup> Ekore R, and Bolatito LA, ‘African cultural concept of death and the idea of advance care directives’ 371.

<sup>158</sup> Ekore R, and Bolatito LA, ‘African cultural concept of death and the idea of advance care directives’ 371.

stereotypical and reductive narratives that Chimamanda Adichie refers to as the ‘danger of a single story’. It risks ridding culture of its complex nature and fluidity having in mind that culture is far from static.

Culture can be referred to as the collective habits that are formed by people's environment, including geography and society.<sup>159</sup> Given the potential for environmental change, it's critical to recognize that culture is always changing to accommodate new surroundings and that due it being so changeable, it may be challenging to assess how it affects development.<sup>160</sup> Kenya for instance is a reflection of the dynamic nature of culture. Typically, end of life decisions or conversations in relation to Advance Directives and Advance Care Planning would be shunned by many due to their cultural and religious perspectives and this would make the acceptance of Advance Directives more challenging and quite slow. However, research also shows that Advance Directives are also being embraced by a number of Kenyans as well.

According to research conducted at Nairobi's Aga Khan University Hospital, 41.2% of patients who were terminally ill had completed an Advance Directive.<sup>161</sup> Compared to several Western nations, this rate is comparatively high, suggesting rising awareness and acceptance.<sup>162</sup> Nonetheless, the majority of patients who are near death still do not have ADs, suggesting that there is still much space for improvement.<sup>163</sup> The study's goals were to ascertain the percentage of critically ill patients with ADs and the variables influencing these patients' completion of ADs.<sup>164</sup> This research is possibly East Africa's first on the subject hence heavily relied on.<sup>165</sup> The research was a survey conducted retrospectively and included an analysis of all accessible data of terminally ill patients who received medical care at Aga Khan University Hospital in Nairobi from July 2010 to December 2015, and who fit the inclusion requirements of the survey.<sup>166</sup> According to an analysis of 216 records pertaining to terminally ill patients, 41 % of patients with

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<sup>159</sup> Hyun D, ‘Does African culture impede development?’ 3 Undergraduate Journal of Global Citizenship 1,2019, 2.

<sup>160</sup> Hyun D, ‘Does African culture impede development?’ 2.

<sup>161</sup> <https://www.bmmusau.com/advance-directives-in-kenya-ensuring-your-end-of-life-wishes-are-respected/> on 11 December 2024.

<sup>162</sup> <https://www.bmmusau.com/advance-directives-in-kenya-ensuring-your-end-of-life-wishes-are-respected/> on 11 December 2024.

<sup>163</sup> <https://www.bmmusau.com/advance-directives-in-kenya-ensuring-your-end-of-life-wishes-are-respected/on> 11 December 2024.

<sup>164</sup> Omondi S, Weru J, Shaikh A and Yonga J, ‘Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya’ 16 BMC Palliative Care 9, 2017, 1.

<sup>165</sup> Omondi S *et al*, ‘Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya’ 1.

<sup>166</sup> Omondi S *et al*, ‘Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya’ 2.

terminal illnesses had completed Advance Directives; 89 of these records contained patients with ADs, whereas 127 did not.<sup>167</sup> The study carried out used bivariate and multivariate analysis where the former refers to using two observations from a single sample or person to examine the connection between two data sets and the latter referring to where several variables are examined to identify one or more that predict a given result.<sup>168</sup> Bivariate analysis revealed that the following factors were associated with the completion of AD: the patient's level of functioning, history of hospitalization in the intensive care unit, history of intubation of the endotracheal tube, the medical specialty administering treatment to the patient, the patient's caregiver talking about the AD together with the patient, and an overview by a palliative specialist.<sup>169</sup> Multivariate regression study revealed that the patient's level of functioning and the discussion of AD with a caregiver were the factors that were statistically significantly correlated with AD completion.<sup>170</sup>

Unfortunately, due to the retrospective nature of the study, key factors in this discourse were not able to be investigated. The researchers were unable to examine several patient characteristics related to ADs, such as patient knowledge and attitude as well the facets of the patient-physician relation that are crucial for AD completion.<sup>171</sup> It was also unable to research the integral role that absence of Advance Directives legislation contributed to the results and their completion.<sup>172</sup> It was also not possible to investigate how ADs are influenced by the family of patients.<sup>173</sup> In addition, due to the study being retrospective in nature, the researchers were unable to zero in on the influence of family members on decision-making, the role of religion and spiritual beliefs, patients' prior knowledge of advanced directives, and the patient-physician interaction.<sup>174</sup> Nonetheless, it is clear that each of these elements contributes to AD completion.<sup>175</sup>

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<sup>167</sup> Omondi S *et al*, 'Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya' 3.

<sup>168</sup> Bush J, 'The difference between bivariate and multivariate analyses' Sciencing, 24 March 2022 <https://www.sciencing.com/difference-between-bivariate-multivariate-analyses-8667797/> on 10 December 2024.

<sup>169</sup> Omondi S *et al*, 'Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya' 1.

<sup>170</sup> Omondi S *et al*, 'Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya' 1.

<sup>171</sup> Omondi S *et al*, 'Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya' 9.

<sup>172</sup> Omondi S *et al*, 'Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya' 9.

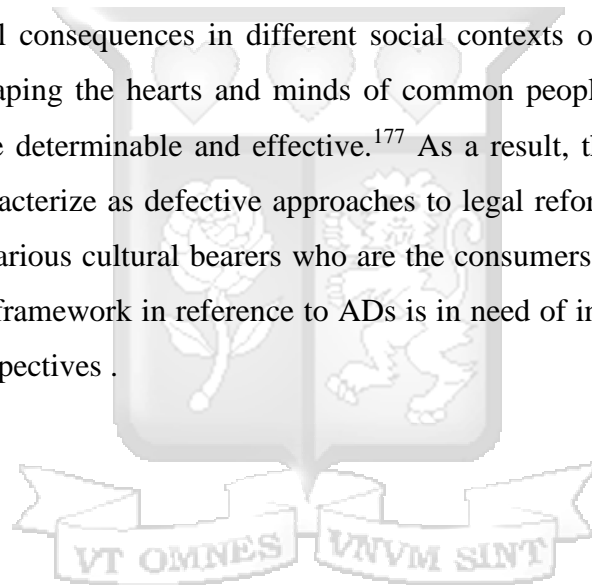
<sup>173</sup> Omondi S *et al*, 'Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya' 9.

<sup>174</sup> Omondi S *et al*, 'Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya' 9.

<sup>175</sup> Omondi S *et al*, 'Factors that influence advance directives completion amongst terminally ill patients at a tertiary

In light of the foregoing, the study although of great importance, does not provide comprehensive data that factors in culture, religious and ethical views that are highly likely to impact the execution of such documents as well as the lack of legislation. This makes it difficult to figure out the extent to which they influence the use of directives or lack of. This would assist in the formation of regulations in a manner that fits the context of Kenyans. A major issue can arise if states do not do so in an effective manner. Copy pasting of frameworks from one jurisdiction to another ends up doing a disservice to the state applying them as they do not consider the history, culture and development of the people it governs.

A suggested approach is then one generally in line with that of neocultural interventionists. Neocultural interventionists contend that imported institutions, laws, and regulations are unlikely to have the desired social consequences in different social contexts or to have any impacts at all.<sup>176</sup> They propose reshaping the hearts and minds of common people in order to make these institutional reforms more determinable and effective.<sup>177</sup> As a result, they seek to contextualize what they accurately characterize as defective approaches to legal reform approaches that fail to adequately consider the various cultural bearers who are the consumers of the law.<sup>178</sup> Essentially development of the legal framework in reference to ADs is in need of intersectionality of culture, healthcare and policy perspectives .



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hospital in Kenya' 9.

<sup>176</sup> Cohen A, 'Thinking with culture in law and development' Buffalo Law Review, Ohio State Public Law Working Paper No. 126,2009 ,512 — <https://ssrn.com/abstract=1409161> on 10 December 2024 .

<sup>177</sup> Cohen A, 'Thinking with culture in law and development' 512.

<sup>178</sup> Cohen A, 'Thinking with culture in law and development' 512.

## **CHAPTER 6: CONCLUSION**

### **(a) Findings**

It is well-established in contemporary medical ethics and law that patients are free to accept or decline any offered medical treatment.<sup>179</sup> The informed consent requirement is based on respect for patients' autonomy, and it also guarantees that patients have the right to refuse treatment, even if doing so could result in death.<sup>180</sup> However, an issue occurs when individuals who have a condition that is unlikely to be reversible such as dementia, serious head injuries, comas, prolonged vegetative states and so on, have lost their ability to make decisions.<sup>181</sup> What standards ought to be applied when making decisions in these circumstances?<sup>182</sup> What happens if family members cannot agree on the best course of action?<sup>183</sup> What if medical professionals and family members disagree about whether treatments are unnecessary or excessive?<sup>184</sup> These are questions that have been grappled with by every country that has either considered or eventually adopted Advance Directives and incorporated it into their legal system.

The study's aim was to investigate the viability of Advance Directives and Advance Care Planning (ACP) in Kenya through Advance Directives with respect to individuals' autonomy and dignity with the goal being to empower individuals in expressing their healthcare preferences and future desires while they have the mental capacity to execute such a task. From the above research, it was found that there exists a population of Kenyan citizens that do practice the use of Advance Directives. It was highlighted that there exist gaps in the Kenyan legal framework to regulate the use of these instructional documents in addition to them not being recognised as legally binding. In the absence of national legislation, different institutional policies govern the practice of Advance Directives, resulting in inconsistent recognition and enforcement hence the need for it. Moreover, from other jurisdictions, the lack of such a legal framework and its subsequent effects on the rights of individuals was emphasised such as those discussed in the United Kingdom. The research, in turn, also brought to light the importance of respecting and understanding key concepts such as self-determination, informed consent and capacity as well as

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<sup>179</sup> Andorno R, Shaw D and Bernice E, 'Protecting prisoners' autonomy with advance directives: ethical dilemmas and policy issues' 18 *Medicine, Health Care and Philosophy* 1, 2015, 33.

<sup>180</sup> Andorno R *et al*, 'Protecting prisoners' autonomy with advance directives: ethical dilemmas and policy issues' 33.

<sup>181</sup> Andorno R *et al*, 'Protecting prisoners' autonomy with advance directives: ethical dilemmas and policy issues' 33.

<sup>182</sup> Andorno R *et al*, 'Protecting prisoners' autonomy with advance directives: ethical dilemmas and policy issues' 33.

<sup>183</sup> Andorno R *et al*, 'Protecting prisoners' autonomy with advance directives: ethical dilemmas and policy issues' 33.

<sup>184</sup> Andorno R *et al*, 'Protecting prisoners' autonomy with advance directives: ethical dilemmas and policy issues' 33.

the need for equipment of legal tools to uphold them on top of them being central to the core of Advance Directives. The research further highlighted the impact that ethical, cultural and religious beliefs have on a country's development and implementation even in the field of medical law.

(b) Recommendations

With this in mind, it is recommended that a legal framework that acknowledges and recognises Advance Directives as legally binding documents enforceable by law is put in place.<sup>185</sup> This would lead to the promotion of the realisation of individual's constitutional rights and would be a wholesome and pro-active approach to self-determination.

Additionally, systems should be put in place to ensure implementation and compliance of these laws by health care providers and professionals. This can be done through integration of this knowledge into the education system, modules and supervision by bodies such as the Kenya Medical Practitioners and Dentists Council carries out registration and licensing of medical practitioners and of healthcare institutions. Public education campaigns and seminars are essential as well in order to educate the public and teach medical professionals on these documents as well as their rights in relation to these documents. A final recommendation would be to encourage more research in this area with the Kenyan context in mind as it is only then that we can see how best to apply such laws in a manner that works for the people of Kenya and in their interest.

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<sup>185</sup> [https://www.bmmusau.com/advance-directives-in-kenya-ensuring-your-end-of-life-wishes-are-respected/#:~:text=Advance%20directives%20\(ADs\)%20are%20essential,unable%20to%20communicate%20their%20wishes](https://www.bmmusau.com/advance-directives-in-kenya-ensuring-your-end-of-life-wishes-are-respected/#:~:text=Advance%20directives%20(ADs)%20are%20essential,unable%20to%20communicate%20their%20wishes) on 15 December 2024.

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