ADVANCE CARE PLANNING

What is in the pill?

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Outline

- What is Advance Care Planning and why does it matter?
- Law, ethics and care where is the intersection and what are the implications?
- What are the current practices?
- What are the challenges and what are the regional priorities?

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Advance
Care Planning
international

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Definition Statement (Sudore 2017)

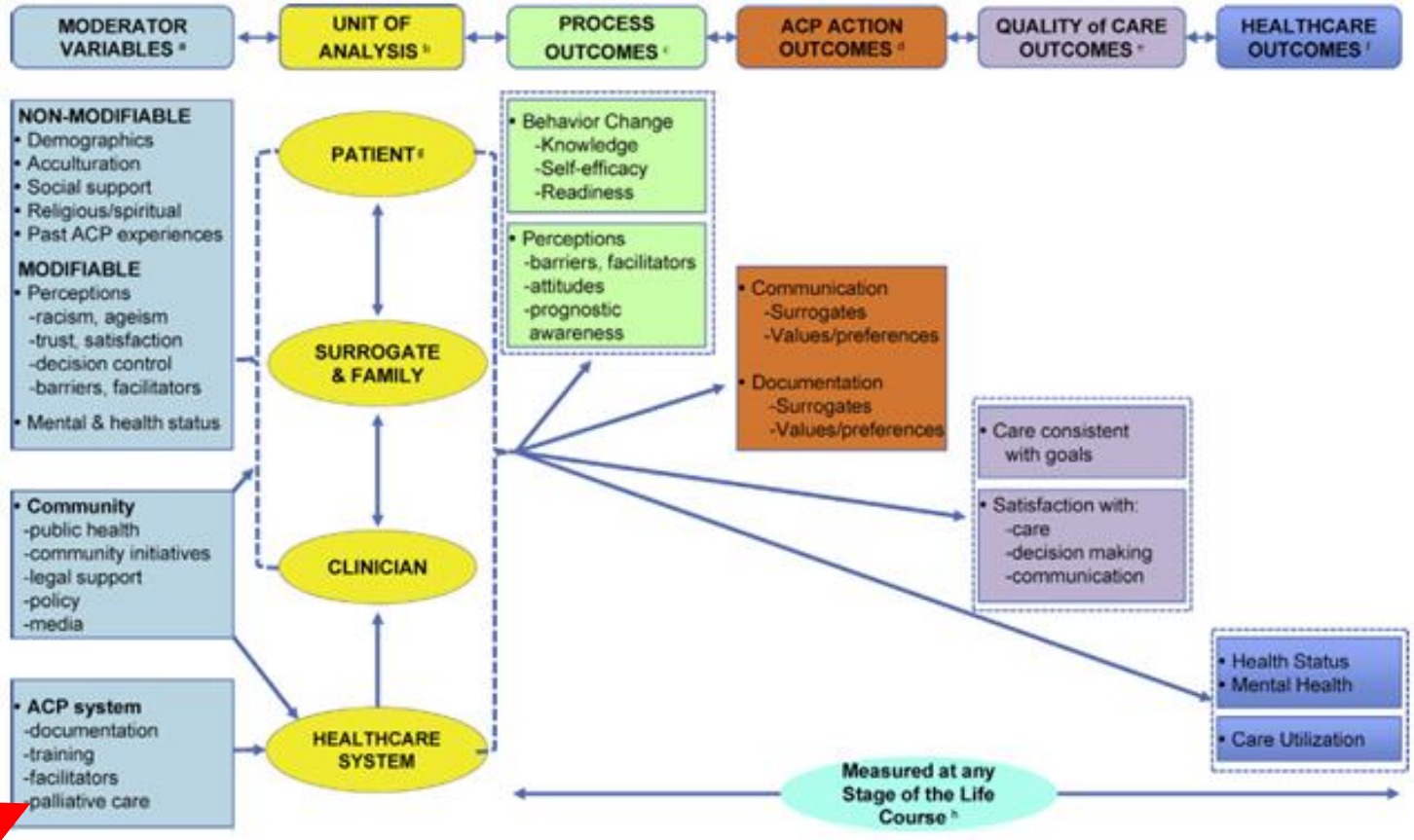
(1) Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

(2) The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.

(3) For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions

Outcomes That Define Successful Advance Care Planning

Sudore et al., 2018



Outcomes of ACP

Table 2

Top 10 Advance Care Planning Patient-Centered Outcome Constructs Rated by Advance Care Planning Delphi Panel Experts

Outcome Constructs[a]	Domain[b]	Overall Ranking	Mean Rating (SD)
Care received is consistent with goals	Quality of care	1	6.71 (0.04)
Patient decides on a surrogate	Action	2	6.55 (0.45)
Document the surrogate decision maker	Action	3	6.50 (0.11)
Discuss values and care preferences with the surrogate	Action	4	6.40 (0.19)
Documents and recorded wishes accessible when needed	Action	5	6.27 (0.11)
Identify what brings value to patient's life	Action	6	6.20 (0.12)
Medical record contains physician treatment orders (e.g., POLST, code status) when it is clinically appropriate	Action	7	6.13 (0.17)
Discuss values and care preferences with clinicians	Action	8	6.08 (0.24)
Document values and care preferences	Action	9	6.02 (0.25)
Medical record contains advance directive or documentation patient refused	Action	10	6.01 (0.21)

Sudore et al., 2018

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Quality of death and dying

Quality of Death and Dying: What matters? An African perspective

October 29, 2019
Community Engagement, Research
Author: Dr. Eve Namisango, Board Member, International Association for Hospice & Palliative Care

ACP is associated with positive grief and bereavement outcomes

Uganda as a case study

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Schwerpunkt / Special Issue „Advance Care Planning around the World: Evidence and Experiences, Programmes and Perspectives"

Advance Care Planning and palliative care for patients with advanced cancer in Uganda

Advance Care Planning und palliativmedizinische Betreuung von Patientinnen und Patienten mit fortgeschrittener Krebserkrankung in Uganda

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ABSTRACT

The study sought to identify the extent to which Advance Care Planning (ACP) is practised by palliative care health professionals providing care to patients with advanced cancer and their families in Uganda.

A mixed methods study design using qualitative and quantitative methods was used for the assessment. In-depth interviews with a group of nine highly experienced health professionals were conducted using a semi-structured interview guide. Quantitative data were retrieved and analysed from a survey administered to 124 health professionals of whom only 57 (45.9%) responded. The qualitative data were analysed using inductive thematic analysis and descriptive analysis was used for the quantitative data.

Of the 57 health professionals who participated in the survey, 87% were aware of ACP and 55% reported regular practice. Fifty-five (55%) percent reported regular provision of ACP for their patients and 46% reported engaging in informal ACP practices. However, 58.5% resp. 37.5% reported that they routinely provide ACP to more than 50% resp. 75% of their patients. A group of nine highly experienced palliative care professionals had a pooled ACP prevalence of only 1.2%. There was a generally good attitude towards ACP with 98.2% acknowledging that patients should be able to determine their future care. However, 32% reported being uncomfortable withholding or withdrawing life sustaining treatment. There are a number of socio-cultural beliefs and barriers, for instance that discussing death and dying is a "taboo", as well as witchcraft, family influence in decision-making, religious beliefs that do not agree with palliative care practices and a preference to use aggressive treatment like chemotherapy for terminally ill, etc. Institutional barriers like lack of a legal framework for ACP, limited time for health professionals to engage in ACP and other patient factors such as denial of diagnosis and collusion to withhold information from patients were reported by 78.2% resp. 84% of the respondents.

Despite the good awareness and attitude to ACP, there is a range of barriers that are affecting the implementation of ACP in Uganda. There is need for development of a legal framework for ACP, more research to understand the contextual barriers and develop appropriate education and public sensitisation programs.

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Ziel der Studie war es zu ermitteln, inwieweit Palliativmedizinerinnen und -mediziner, die Patientinnen und Patienten mit fortgeschrittenen Krebserkrankungen und deren Familien in Uganda betreuen, Advance Care Planning (ACP) praktizieren.

Für die Bewertung wurde ein Mixed-Methods-Design mit qualitativen und quantitativen Methoden

To identify the extent to which Advance Care Planning (ACP) is practised by palliative care health professionals providing care to patients with advanced cancer and their families in Uganda.

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Uganda as a case study

- Awareness - Of the 57 health professionals who participated in the survey, 87% were aware of ACP

- Practice was 1.2%
- Despite the good awareness and attitude to ACP, there is a range of barriers that are affecting the implementation of ACP in Uganda.

Key messages from Uganda case study

There is need for development of a legal framework for ACP, more research to understand the contextual barriers and develop appropriate education and public sensitisation programs.

Survey on ACP in Africa

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Schwerpunkt / Special Issue „Advance Care Planning around the World: Evidence and Experiences, Programmes and Perspectives"

Insights into Advance Care Planning in Africa

Erkenntnisse über Advance Care Planning in Afrika

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ABSTRACT

Advance Care Planning is an important element of palliative care whose relevance has over the years shifted from focusing on patients at end of life to being applicable at any stage of an individual's health. It is said to be beneficial not only to the patient but also to the general health care system. It may facilitate a peaceful death in addition to minimizing unnecessary costs and the use of resources yet its use among health care workers in Africa is not well researched.

This study therefore aimed to explore the use of Advance Care Planning among health care providers in sub-Saharan Africa. It was a survey that targeted health care professionals across Sub-Saharan Africa who were either current staff or alumni of Hospice Africa Uganda (HAU) between 2012 and 2023. These were conveniently sampled from HAU data base. An electronic survey was sent out, data was collected into an excel sheet and it was analysed descriptively.

Responses to the survey came from nine out of 37 countries with PC services across Africa and there was a 14% response rate. 83% of the respondents had insight into Advance Care Planning and a surprise finding was that 40% had cared for patients with ACP. The majority (96%) would respect Advance Care Plans of their patients. These findings gave some insights into the use of ACP although the results cannot be generalised to a wider demography of healthcare providers.

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ZUSAMMENFASSUNG

Advance Care Planning (ACP), vorausschauende Gesundheitsplanung, ist ein wichtiges Element der Palliativversorgung; dabei hat sich die Bedeutung von ACP im Laufe der Jahre gewandelt: Im Blickfeld steht nicht mehr nur der Patient oder die Patientin am Ende seines/ihres Lebens; vielmehr lässt sich ACP auf den Gesundheitszustand eines Menschen in allen seinen Lebensphasen anwenden. Man geht

- 40% (n=47) had cared for patients with advance care plans.
- 19% of the respondents did not know whether their patients had an advance care plan.

Key messages from the Afro survey

- Most (96%) of the respondents noted they would respect a patient's advance care plan.
- 86% had not completed an advance care planning form for themselves but 76% reported that in the event of their incapacitation they would like to have an ACP for carers to follow. In addition, 72% believed that their care plan would be respected by carers.

The elephant in the room

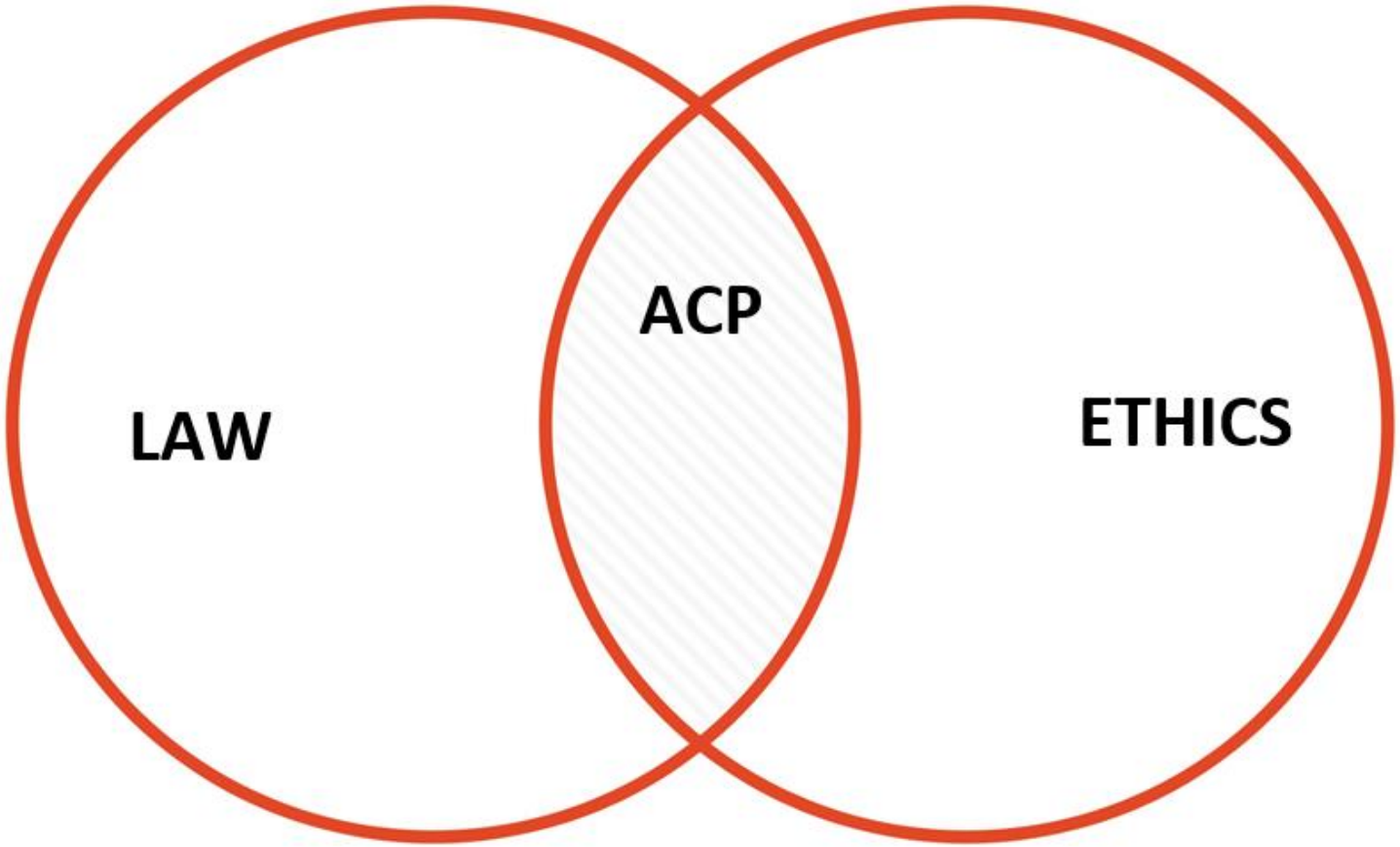
The elephant in the room

Despite the wide spread awareness about the benefit of “living wills” for end of life care for both the patients and the physicians the latter are usually concerned about the risk of legal issues during the implementation of the patient’s wishes during end of life care (Bull & Mash 2012).

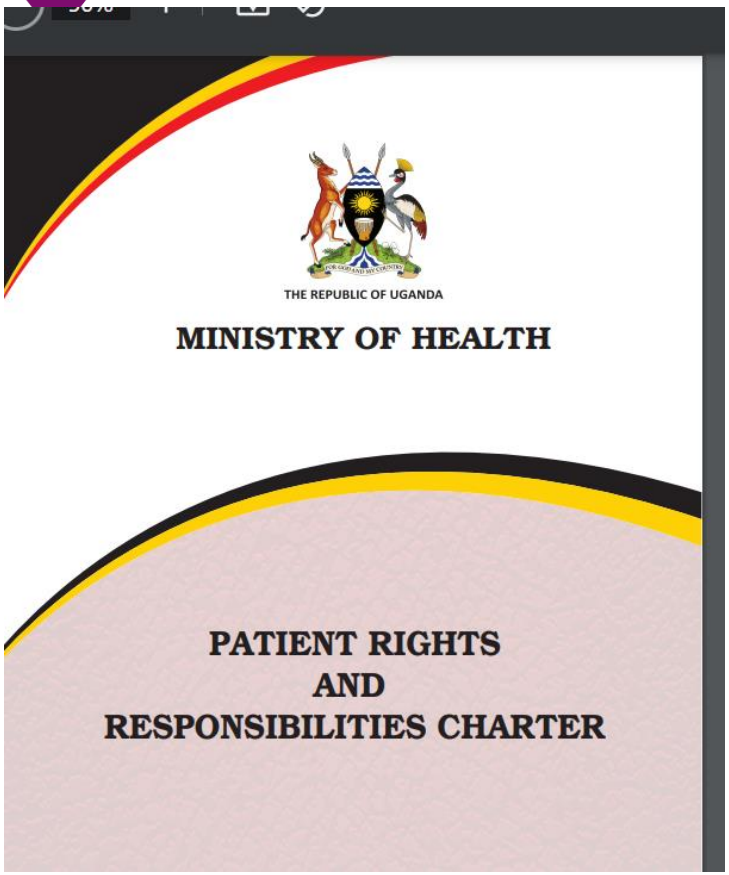
Facilitators and barriers

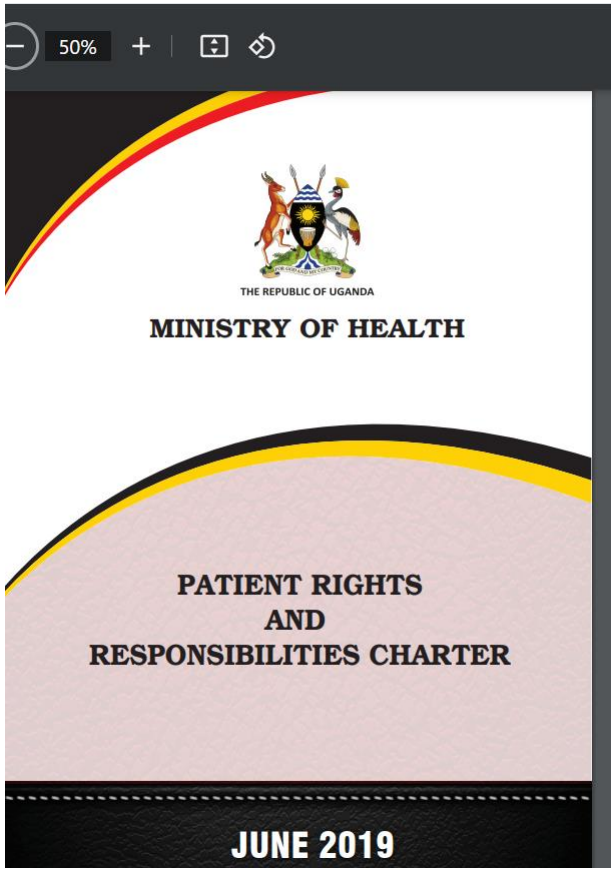
- physicians who have the knowledge and experience with ACP find it easier to initiate the discussion with patients and their family members. knowledge about ACP and advance directives among physicians is a major determinant of whether this crucial service can be delivered to patients with life threatening illnesses. (Snyder et al (2012),

Law- Ethics and ACP



Existing frameworks





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1.2 Refusal of treatment

12. Refusal of Treatment Refusal of treatment may occur under the following circumstances: a) A person has the right to refuse treatment after receiving information to make an informed decision. Such refusal shall be verbal, in writing, or by conduct provided that such refusal does not endanger the health of others.

1.2 Refusal of treatment

b) The health provider has the right to perform the treatment against the patient's will if the health worker has confirmed the following conditions: i. The patient has an illness that is of public health concern.

ii. Protection of the unborn, minor, or disadvantaged person. iii. Court order c) When the refusal of treatment by the patient or his/her authorized representative interferes with the provision of adequate treatment according to professional standards, the relationship between the patient and the health provider shall be terminated with reasonable prior advance notice.

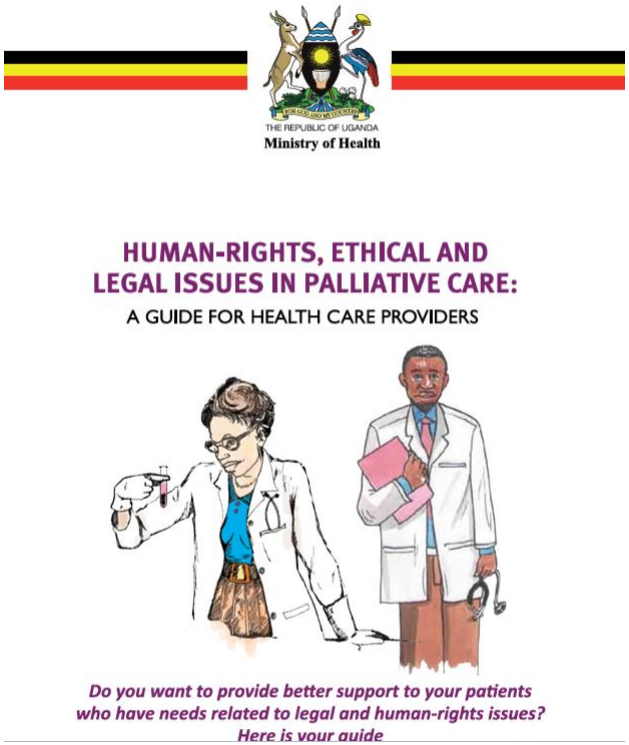
Existing legal frameworks

The Constitution of the Republic of Uganda, 1995

Supreme law

Article 22 of the Constitution of the Republic of Uganda protects an individual's right to life to the extent that no one must be intentionally deprived of the right to life. This goes without saying that the right to life is a qualified right in as much as the state can interfere with it as authorized by the law.

Pan- African open-source resources



Section 4: Legal issues in palliative care

Health care workers recognise the distress that legal issues may create for their patients and patients' families. As a result, health practitioners and clinical personnel can play a crucial role working at the intersection of law and health, combining legal knowledge with an understanding of health issues and the challenges facing a person with a life-threatening illness.

Health care workers are encouraged to assess the legal needs of their patients and offer the necessary support.

The main legal issues experienced in palliative care include succession planning (particularly will writing and property inheritance), appointing others to act for someone who is incapacitated through illness, following up on social security benefits due, and the custody of children. Some important aspects of these are considered in more detail below.

4.1 Succession planning

4.1.1 What is 'succession'?

Succession is when one individual inherits the property of another person. In Uganda, there are two types of inheritance: testate succession and intestate succession.

Testate succession occurs where a person dies leaving a testament or a will. When a person makes a will, they are called a 'testator'. The will sets out the wishes of the testator and how they wish their estate to be distributed after their death. A person should be named in the will as the one responsible for implementing the wishes of the testator after their death and that person is known as the 'executor'. After the death of the testator, the executor has a legal duty to ensure the testator's wishes, as expressed in the will, are fulfilled.

Intestate succession occurs when no valid will has been left by the deceased person. In these circumstances, special legal arrangements have to be put in place to deal with the person's estate.

4.1.2 Making a will

As stated above, a will is a document made during a person's lifetime in which that person directs or states how their property and other affairs should be dealt with after their death. Most often Will making is not talked about in our society. It's related to dying and yet it's a concept that everyone despite their health status needs to understand and apply in their lives. It is therefore important to introduce the topic of will making during routine care delivery.

Anybody can make a will, whether they are a man or woman, married, single, widowed or divorced. However, for a person to make a will, they must have what is known as 'legal capacity' to do so. A will reduces conflict in a family when

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Case study

- 50-year-old gentleman who had end stage liver failure
- Had no opportunity to have Advance Care Planning
- He was admitted in hospital for further management and investigations
- Discharged himself against medical advice
- Went home but was forced into admission due to his symptoms
- Later went into ICU against his will
- He never informed close family members beyond the wife
- Died a few days later
- Left no will / siblings think he has not given chance to live
- Mother has had to live with prolonged grief disorder
- Family has had a closure and lives in distress

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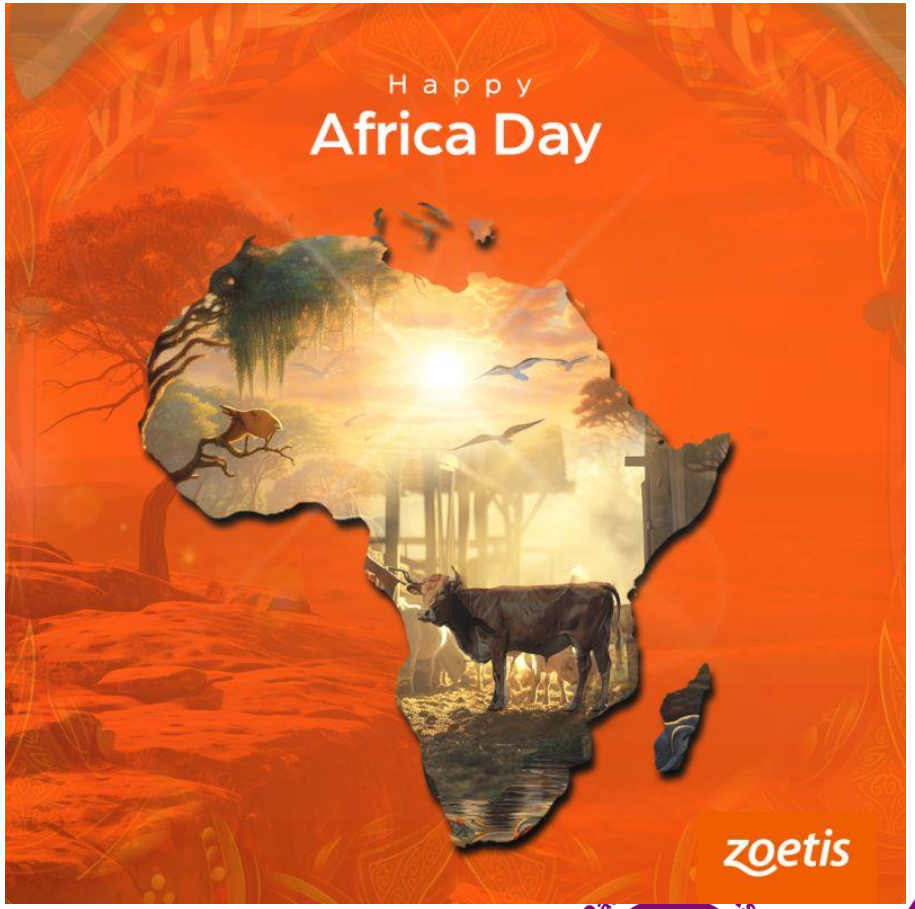
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