



African Palliative Care Association

ASSESSMENT OF LEGAL NEEDS FOR PATIENTS AND PALLIATIVE CARE PROVIDERS: A CASE STUDY IN UGANDA

This report was prepared on behalf of the
African Palliative Care Association by:

**Lynn Atuyambe, Elizeus Rutebemberwa
and Paul Muhimbura**

Makerere University School of Public Health
College of Health Sciences
P.O. Box 7072
Kampala Uganda

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Abbreviations

AIDS	Acquired ImmuneDeficiency Syndrome
APCA	African Palliative Care Association
CAP	Chapter
FGD	Focus Group Discussion
HIC	High Income Countries
HIV	Human Immunodeficiency Virus
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic Social and Cultural Rights
IDT	Inter Disciplinary Training
INCB	International Narcotic Control Board
JMS	Joint Medical Stores
KI	Key Informant
LIC	Low Income Countries
MLP	Medico-legal partnership
MOH	Ministry of Health
NDA	National Drug Authority
NGO	Non-Government Organisation
NMS	National Medical Stores
NSSF	National Social Security Fund
PNFP	Private-Not-For-Profit
UCI	Uganda Cancer Institute
UDHR	Universal Declaration of Human Rights
WHO	World Health Organisation

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Introduction and Background

1.1 Introduction

The World Health Organisation (WHO) defines palliative care as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (WHO 2002).

In recent years palliative care, even for patients in an advanced state of their disease, has gained importance (Wiese, Bartels et al. 2008). Chronic pain can have a devastating impact on an individual’s relationships, daily functioning, and employment. Although treatment of pain is something that clinicians face every day, providing optimal care for these patients can be difficult (McCarberg and Stanos 2008).

Examples of life-threatening illnesses include cancer and HIV and AIDS, among others. Palliative care emphasises provision of relief from pain and other distressing symptoms, integrating psychosocial and spiritual aspects of patient care, offering support systems to help the family cope during patient illness and bereavement, as well as use of a team approach to address patient needs (Hospice Palliative Care Association of South Africa 2009).

It is important to note that palliative care for children is closely linked to that of adults. It is defined as “the active total care of the child’s body, mind and spirit, and also involves giving support to the family” (WHO 2002).

Palliative care practice in Low Income Countries (LIC) faces many challenges and barriers. First, patients are diagnosed late and there are fewer supportive mechanisms, especially in rural areas. Care for orphans appears to pose a challenge in social and financial terms. Secondly, clinical staff (doctors and nurses) may not have the necessary training

to understand or provide palliative care and end up ‘giving up’ on the patient. In addition, lack of communication skills among clinicians, institutional standards and access to palliative care centres are important barriers especially in LIC (Hospice Palliative Care Association of South Africa, 2009). Added to this are issues around legal and human rights aspects of palliative care, which are poorly understood by both patients and care providers. These are the issues this case study sought to address.

1.2 Legal and human rights needs of patients in need of palliative care

The successful practice of palliative medicine requires basic knowledge of its medico-legal aspects. The term ‘human rights’ refers to rights and freedoms to which all human beings are inherently entitled. Both palliative care and human rights are based on principles of the dignity of the individual and the principles of universality and non-discrimination. For clinicians and other personnel involved in palliative care, this therefore means that access to palliative care is a human right (Gwyther, Brennan et al. 2009). The value of understanding human rights and human rights instruments is that they can be used to:

- Document violations of palliative care rights, such as access to care and medication.
- Advocate for the provision of palliative care.
- Use legal recourse to ensure realisation of these rights.
- Complain to national or international human rights bodies about lack of compliance to human rights agreements.

It is therefore critical to point out that an unreasonable failure to provide adequate pain relief may constitute negligence on the part of health care systems. Breaches in reasonable pain care may take place in circumstances such as: unreasonable failure to take an adequate pain history; unreasonable failure to adequately treat the pain or in the context of uncontrolled pain; and unreasonable failure to secure expert consultation. Negligence cases against health professionals and hospitals, based on these principles, have resulted in multi-million dollar judgments (Cousins and Carr, 2004).

It is important to assert that the human rights approach to advancing palliative care development emphasises the fact that care of patients with life-threatening illness is a fundamental responsibility of governments, society and health professionals (Hospice and Palliative Care Association of South Africa, 2009).

This section reports on the literature review completed about palliative care services and patients’ legal needs. It focuses on issues of access, ethics, awareness of laws and rights of patients, preparation for death, family participation in palliative care, and provider challenges. The literature review draws largely from information on HICs as there is paucity of information with regard to legal issues around palliative care in LICs.

2: Literature Review

2.1 Access to Palliative Care

Access to palliative care can be considered along four dimensions.

- First, physical accessibility, where the patients would be in geographical proximity to the facility that is offering the care.
- Second, financial affordability, where the patients would be able to afford the treatment and care offered by the facilities.
- Third, service availability, where the services needed are available at the facility and
- Fourth, cultural acceptability, where the services that are offered are acceptable to the patients (Obrist, Iteba et al. 2007).

Some countries have championed the provision of palliative care at primary facilities but this is not the norm in all countries. Studies from Chile recommended that provision of palliative care at primary level increased the access to care (Cameron and Santos Salas 2009). However, even when the palliative care is offered by a certain level of health facilities, sometimes it also depends on the ownership of the facility. Some facilities owned by organisations like the Catholic church have been shown in high income countries to more likely offer palliative care than the public hospitals (Morrison, Maroney-Galin et al. 2005).

The availability of palliative care differs across countries and there are various experiences for providing palliative care to those who need it. In addition, there are different organisations that provide palliative care including public, private-not-for-profit and the private-for-profit institutions. At the service level the care providers are a mixture of health professionals informal carers and family members (Hasson, Spence et al. 2009). Normally, hospitals offer comprehensive care for the very seriously ill (Goldsmith, Dietrich et al. 2008). It is worth noting, however, that availability of different

services in palliative care will be determined by the level of specialty of the health facility and therefore different health services will offer components of care. For example, some facilities offer consultation alone and refer the patients to specialised centres while others offer consultation and inpatient service (Billings and Pantilat 2001; Pan, Morrison et al. 2001). Whatever components the health institution is providing, there needs to be a continuum of care for the patients that need the palliative care (Oleske and Czarniecki 1999).

Acceptability is the extent to which the patients are satisfied with the components of the services they receive, for example with regard to quality of care (Ricketts and Goldsmith 2005). Some people travel long distances because the services offered at the health facilities nearest to them are not acceptable for various reasons. This exposes the patients to increased costs as sometimes they may incur transport costs. In addition, seeking care from far away services may contribute to non-adherence because the patients would go less regularly.

Lack of access to palliative care in any of its dimensions has policy and legal implications. It has policy implications in as far as the government is obliged to provide its people health care services and if this is not embedded in the national health policy, then concrete steps should be taken to have them included. The legal implications stem from the fact that health is a fundamental human right and greatly affects the enjoyment of other rights.

2.2 Ethical issues

Individuals working in the field of medicine are faced daily with moral dilemmas and difficult decision-making, such as when does life begin and end. In addition they also face dilemmas like the withholding or withdrawal of treatment, due to allocation of

scarce medical resources and accessibility of resources. Practical decision-making is often influenced by family and community (including other health care professionals) as well as beliefs about what is right and wrong (Hospice Palliative Care Association of South Africa 2009). Clinical decision-making in hospices and palliative care has relied on bio-ethical principles which include: beneficence, non-maleficence, autonomy and justice. These principles assist the palliative care practitioner to assess issues that are often very emotive. Additionally, the principles can be used as a framework to guide the patient, family members and care team to a practical decision which is open to review as the patient's condition or wishes change (Beauchamp and Childress 2001). No-one has the right to infringe upon another person's autonomy or coerce them into making decisions.

Patient care, irrespective of whether palliative or not, entails respect for the ethical values in its practice. When it is palliative care, this is even more important because these are patients who have life-threatening illnesses and may even be at the terminal stage of the illness. Such patients, regardless of the stage of their illness need to be treated with the respect they deserve and their rights should not be abused. Some of the ethical issues health workers observe are confidentiality, autonomy and beneficence. These underpin the determination of decision-making capacity and informed consent. These issues guide the breaking of bad news and determine how shared goals of care are made between the patient, the family and the health provider (Kinlaw 2005).

Studies from HICs, have demonstrated that even in their terminal stages, patients take charge of their decisions. Patients value their autonomy greatly (Terry, Olson et al. 2006). However, some of these decisions they take, such as choosing to end life, challenge the

practices of medical workers. Questions arise whether the patient in their terminal stages would still be in control of their faculties to make an informed and free decision. Despite these challenges, the principle of autonomy has to be respected (Valente 2004). Palliative care is less challenging when there is cooperation between the family of the patient and the health providers, as well as coordination and continuity of care (Plu, Pursell-Francois et al. 2008). Clinicians make judgments as to how much information to disclose and when to do it, but this is better done with the close members of the family of the patient (Epstein, Korones et al. 2010).

2.3 Awareness of laws and rights of patients

Literature largely from HICs shows that there is a high level of awareness with regard to palliative care patients' rights, legal services and to some extent laws and conventions affecting palliative care. Palliative care has emerged as the interdisciplinary approach to relieving suffering and improving quality of life. Unfortunately, it is not yet available to all who need it. Von Gunten et al, (2002) observed that although legislation may ultimately be needed, regulatory changes can quickly improve the situation. Many cancer patients die after a prolonged period of deterioration with intense physical and emotional suffering. However, in an effort to control the illegal market, many countries have adopted regulations that restrict or prohibit the therapeutic use of opioid analgesics (De Lima 1997), which could improve the patients' quality of life. The WHO responded by making palliative care a priority of its cancer control programme. The problem is the lack of enthusiasm in health workers and lack of awareness in patients to demand opioids. In recent times the simple principles of beneficence and non-maleficence have been

augmented and sometimes challenged by an increasing awareness of patient/consumer rights, and the public expectation of greater involvement in medical, social and scientific affairs which affect them. Concepts such as utility and distributive justice can easily come into conflict with the individual's right to autonomy. This was observed in a study on lung disease where possible treatment options include transplantation and long-term invasive ventilation, which are challenging in terms of resources (Simonds 2003). This is also confirmed by an earlier study where it was emphasised that the public has a right to be educated about available financial, social and medical provisions for them to prepare for death (Mathew and Scully 1986).

Medico-legal partnerships could be important in fulfilling patient palliative care needs. A study was undertaken in the USA where a medico-legal partnership (MLP) was incorporated as part of a comprehensive palliative care model to address unmet social and material needs for patients demonstrated positive results. The legal service programme received multiple numbers of referrals and resolved multiple legal issues. Several patients' benefits denials were overturned. The study concluded that the MLP demonstrated the ability to help both patients and health care institutions effectively address the needs of patients with cancer (Rodabaugh, Hammond, et al. 2010). One could say that medico-legal partnerships could be an important component of a comprehensive palliative care model. Moreover, legal matters were identified as one of eight most important issues in groups of social problems identified in oncology patients (Wright, Kiely et al. 2002).

2.4 Preparation for death

In terminal illnesses there is a need to prepare for death. This could take the form of making wills or succession planning, but also preparing

the family for the loss of a member. A will is a means through which a person can dispose of his or her property and therefore plan for life after their death. A will is a document made during a person's lifetime in which he or she directs or states how his or her property and other affairs should be dealt with after his or her death. In Uganda this is embedded in the Succession Act which allows any person of sound mind to dispose of his or her property in any manner they please through a will. The patient's wishes in the will are then implemented by the executors of his will. A situation where a person dies leaving a will is known as "testate succession". Making of a will is one way persons with life-threatening illness can safely ensure that their properties/assets are in order and their resources benefit their surviving family members in accordance with their perceived vision and intention. This is an aspect of palliative care which impinges on the psychological pain and social unrest associated with succession disputes.

In the revised Laws of Uganda (Uganda Law Reform Commission 2000), under the Succession Act for a will to be valid, it must be written by a person of sound mind and must be attested by at least two adult persons equally of sound mental capacity. Under the Uganda legal regime, it is arguable and indeed a question of evidence whether a person faced with life-threatening illness can actually be said to have the mental capacity to make a valid and legally enforceable will. Moreover, advocates who are experts at such work charge high fees to already overstretched patients.

It is also important to note that due to limited awareness, very few people know the stringent legal requirements of a valid will. Consequently, even those who try to make a will can find their will dismissed in the courts of law for falling far short of the legal requirements. In the end, most people

die intestate (i.e. without making a will).

Where a person dies intestate or makes a will but the will does not appoint an executor to administer the estate, the Administrator General by operation of the law takes over the management of the estate of the deceased person.

If the family of the deceased is interested in managing the estate, they must agree on who should manage it on their behalf and then apply to the Administrator General's Office for 'a certificate of no objection'/clearance to administer the estate. Once this is granted, the applicants proceed to court to obtain Letters of Administration and documents which empower the administrators to claim benefits to allow the estate to distribute property or savings to beneficiaries and to pay debts (Uganda Law Reform Commission, 2000).

Intestate succession also raises gender issues. In many African cultures there is little or no recognition of women and children in terms of control/authority over property of the deceased. Many cultures are male-dominated and female emancipation movements have achieved minimal success in reversing these entrenched cultural practices. The succession law in Uganda offers a guide to the distribution formula of property where a person dies intestate, but the formula is often ignored (Uganda Law Reform Commission 2000).

Therefore, succession is an important area in the full realisation of palliative care provision. In this issue, the problem is not only with the law but also customary practices which hinder appreciation and application of the law on succession. The law does not work in isolation but applies to circumstances as they are and accordingly the conditions that permit its application must be available.

Studies have indicated that carers would prefer that preparation should start when

symptoms are difficult to control (Sekelja, Butow et al. 2009). This demands a multidisciplinary team of doctors and nurses giving supportive care (Grande, Farquhar et al. 2004; Chunlestskul, Carlson et al. 2008), as well as other providers for psychological and social support (Hales, Zimmermann et al. 2008) while considering people's culture (Shimoinaba, O'Connor et al. 2009).

Palliative care involves more than care for the patient. It involves care for family members and carers. Studies have demonstrated that great support is needed for carers to prepare them for the eventual loss but also after the loss to assist them to cope with it (Hasson, Spence et al. 2009). This therefore has necessitated offering palliative home care both before and after the death of the patient (Yao, Hu et al. 2007). This offers the carers and the patients the privacy they so much desire (Terry, Olson et al. 2006).

In Uganda, there is little information that has been published on the preparation for death in respect of palliative care.

2.5 Family participation in palliative care

The community approach is largely the most realistic model for achieving significant coverage of care for two thirds of the world's population requiring palliative care. Meaningful palliative care requires a combination of socio-economic, cultural, and medical solutions. Only by the active involvement of the community in addressing all three factors can palliative care reach all those in need. The cultural and socio-economic factors are equally or more important to the kind of death faced, than the purely medical. Today there is an overemphasis on the medical approach, and only by empowering the community can this be balanced (Stjernswärd, 2004; WHO 1990).

Family participation is important when it comes to palliative care. The family can give social care, and take charge of financial needs and other personal needs of patients. The family participates in patient care both while in medical care institutions or at home. Literature appears to suggest that most patients, including children, wish to remain or go back to their homes at the end-of-life stage. Another study completed in Germany where a new palliative care programme was instituted, 69 per cent of families preferred their children to be at home at the end of life compared to 18 per cent before the programme was instituted (Wolff, Robert et al. 2010). A study completed in Uganda among palliative care patients indicated that a good death occurs when the dying person is being cared for at home (Kikule 2003).

Palliative care at home seems to offer more and better opportunities for family participation. However, the provision of home-based palliative care requires a substantial unpaid contribution from family and friends (i.e. informal care). A cross-sectional study among carers in Australia found that care recipients required help with household tasks and many needed assistance with the personal activities of daily living, taking medications and organisational tasks. In the majority of cases, the principal carer provided all or most of this help. Many carers reported effects on social and family relationships, restrictions on their participation in work and leisure activities, and a range of emotional reactions to their caring situation. The study concluded that effective support for carers must recognise the pre-existing relationship between carer and recipient, and the differing needs of individual carers (Zapart, Kenny et al. 2007). In a research project in Germany, 75 per cent of 272 patients undergoing palliative therapy said they wanted to die at home and 15 per cent in a hospital. According to their relatives, 36 per cent of the

patients looked after by the palliative care team had an advance directive. The survey of the relatives showed a significant relationship between the preparation of an advance directive and dying at the desired place. According to the relatives, medical and health reasons, hope for an improvement up to the very end, acute worsening of the condition, and deficits in medical care were important reasons for dying in hospital against the patient's wish (van Oorschot, Hausmann et al. 2004).

In the same vein, Ando (2003) observes that home is where a patient feels most comfortable. To provide the best possible care, it is important to respect the decision of the patient and his family.

A study completed in Brazil regarding home care's contribution to alternative health care networks, examined seven home care initiatives. Results revealed a number of positive aspects of care, including the bond developed with patients and family; quality and humanisation of care; team work; the sense of responsibility taken on by the health workers, and the effective participation of caretakers and families in carrying out therapy plans. The study concluded that home care is possible even in economically disadvantaged environments and that it may effectively contribute to providing integrated and continued care. Home care should be expanded in the context of the public health system (Feuerwerker and Merhy 2008). Psychosocial group interventions have been developed to help cancer patients cope better with cancer diagnosis and treatment. Support groups include a variety of different approaches, some of which focus on behavioral aspects and symptoms (e.g. pain, fatigue) and some on the expression of emotions. Most of these support programmes are structured and short-term, and include elements such as delivery of information, emotional and social support and stress management strategies.

Beyond individual therapy, group therapies can address cancer-related issues to enable patients to gain emotional support from other patients with similar experiences and to use these experiences to buffer the fear of dying and the unknown future. Weis (2003) points out other research emphasising that avoidance of feelings, denial of concerns, feelings of helplessness and social isolation are correlated with poorer health outcomes and poorer quality of life. Many empirical studies also provide evidence-based knowledge that structured group interventions for cancer patients improve psychological wellbeing, reduce anxiety and depression, and improve quality of life, coping and mental adjustment (Weis 2003).

Involvement with palliative patient care affects family carers, who may need support themselves. The concept of family support groups could be an effective solution. A qualitative study where relatives were invited to take part in a support group programme during the late palliative phase of their family member's care revealed interesting results under five broad categories: insight into the gravity of the illness; a sense of belonging created by similar experiences; participation in the care system; being able to rest; and strength to provide support for the patient. These five constituents resulted in a sense of safety in relation to the patient, the illness, the nursing staff and the care unit. The study's findings show that interventions of this kind may be integral to the relatives' ability to handle their situation when caring for a terminally ill family member (Henriksson and Andershed 2007). Further, another qualitative study where focus group discussions (FGDs) were conducted with family members regarding their experiences of a support group in Sweden revealed positive experiences. The participants reported experiencing increased perception of support and knowledge, and would recommend that a person in a similar situation join a

support group. Categories that emerged in the qualitative content analysis included group cohesion (which increased its effectiveness), meaningful dialogue helped to solve everyday problems, and that group sessions and post-session reflection increased perception of inner strength. The study recommended that support groups for family members seem to be a valuable contribution during ongoing palliative home care (Milberg, Rydstrand et al. 2005).

2.6 The provider and the health care system

In recent years, palliative care has emerged as a major public health care issue, both in developed and developing countries. The HIV and AIDS epidemic and the rising number of cancer deaths as a result of increased tobacco consumption, lack of preventive programmes, and the difficulties of accessing curative treatments in many countries have made palliative care and pain relief the appropriate, and in many cases, the only option for patients with advanced disease.

In order to optimise palliative patient care there must be a health care system responsive to patient needs; for example, medical care in the hospital and hospices as well as home care. Moreover, health workers ideally ought to be constituted as a multi-disciplinary team of specialists, nurses, social workers, psychologists. Specifically, as an example, the role of the social worker in the palliative care team is defined by five main functions: assessment, counselling; liaison with local resources and agencies; training and development activities; and staff support. Ann Adac (1994) points out that the social workers bring to the team particular skills in working with families, children and groups. Their training helps them to locate the patient and family within a social and cultural context and thus to exploit resources

which may help the family to resolve the difficulties they face (Monroe 1994). In order to get the multi-disciplinary teams on 'the same page' while offering care for the patients, consensus was discovered as an important tool in this process. Findings from a qualitative study show that consensus is integral to good end-of-life care both in terms of prognosis and in developing a palliative care plan (Bern-Klug, Gessert et al. 2004).

One important aspect of care is availability in the health system of medicines especially in LICs. As an example, Jagwe and Merriman (2007) described how palliative care drugs became more available in Uganda. Hospice Africa Uganda introduced palliative medicine to Uganda in 1993. Training in the medical and nursing schools was introduced in 1994. Since then, Uganda has achieved the three essential components of an effective public health strategy. It has also been the first country to have palliative care described as an essential clinical service and included in both the government's Strategic Health Plan (2004-10) and its HIV and AIDS National Strategic Framework (Government of Uganda 2000) and to change the law to allow nurses and clinical officers who complete special training in palliative medicine to prescribe oral morphine. In collaboration with others, the Ministry of Health (MoH) and other palliative care organisations working under two umbrella organisations, the Palliative Care Association of Uganda and the Uganda Palliative Care Country Team, Uganda has seen palliative care spread to other districts across the country (Jagwe and Merriman 2007; Jagwe and Merriman 2007).

2.7 Legal framework in Uganda

The WHO describes palliative care as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychological and spiritual.

Palliative care therefore has essentially two components; firstly, pain and symptom control including administration of oral morphine for severe opioid-sensitive pain, and secondly, supportive care, which covers the psychological, social, spiritual and cultural needs of both the patient and their family (Hospice Palliative Care Association of South Africa, 2009).

The current legal support available to patients under palliative care found in the international, regional and domestic instruments/legislations has been summarised by Twinomugisha, 2004 as follows:

a) Obligation of states to respect, protect and fulfil the human right to health under international instruments;

Under international and regional instruments, it is now agreed that for every human right (including the human right to health and specifically the right to palliative care), every government has responsibility at three levels, i.e. to respect, protect and fulfil the right to palliative care.

These instruments include the Universal Declaration of Human Rights (UDHR), the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Child and the Convention on Elimination of all forms of

Discrimination Against Women, and the European Convention for the Protection of Human Rights and Fundamental Freedoms, which all contain specific provisions, resolutions and procedures that aim at strengthening the right to palliative care (Cook, Dickens et al. 2003). The regional instruments, including the African Charter on Human and People's Rights, the African Charter on the Rights and Welfare of Children, the Protocol to the African Charter on the Rights of Women in Africa, and the African Youth Charter and treaties adopted by the African Union such as the Phyto-Sanitary Convention for Africa, the African Convention on the Conservation of Nature and Natural Resources, mean the right to health is also directly protected (Mubangizi and Twinomugisha 2008).

The provisions of the above international instruments are reflected in the 1995 Ugandan Constitution and are enforceable at the national level through litigation and at regional and international levels through a variety of treaty-monitoring mechanisms, complaints procedure and courts (Ahluwalia 2004).

The legal obligations imposed on states (including Uganda) are to:

- **Respect the right to palliative care**
The said obligations with regard to palliative care include refraining from denying or limiting equal access for all persons to palliative care for their medical needs, abstaining from enforcing discriminatory practices as a state policy, and abstaining from imposing discriminatory practices relating to the status and needs of palliative care patients.
- **Protect the right to palliative care**
This entails adoption of legislation policies that ensure equal access to health care and health-related services with regard to palliative care, ensuring that medical practitioners and other health care professionals meet appropriate standards of education, skill and ethical codes of conduct, and take measures to protect all vulnerable or marginalised groups of society (in particular women, children, prisoners, refugees, adolescents and older persons) in light of gender-based expression of violence.
- **Fulfil the right to palliative care**
This encompasses giving sufficient recognition to the right to health (specifically palliative care) in the national political and legal systems; which means that the state must take all appropriate practical measures, legislative, budgetary, judicial or otherwise towards fulfilling the right to palliative care. The state, for example, must put in place legislation, policies, guidelines and monitoring mechanisms to ensure effective provision of palliative care to persons in need (Torres 2004).

b) The right to non-discrimination and equality

The right to non-discrimination and equality is a fundamental principle upon which the Ugandan constitution is grounded. Under the 1995 Constitution of the Republic of Uganda, everyone is equal before the law and has a right to equal protection and benefit from the law. The Constitution further guarantees the right to non-discrimination in the delivery of health services, which include palliative care provision to patients. Any victimisation based on health status (including outright failure to provide the necessary medications and support required in palliative care) amounts to a legal violation.

However, a low level of awareness renders the Constitutional provisions a paper tiger. Nevertheless, the fact that those rights are provided means there is provision for support that can be invoked to promote and fulfil the needs of palliative care patients.

c) Affirmative action in favour of marginalised groups under the Constitution of Uganda, 1995

Under Article 32 of the Constitution of the Republic of Uganda, the state is obliged to take affirmative action in favour of groups marginalised on the basis of gender, age, disability and any other reason created by history, tradition or custom for purpose of redressing imbalances which exist. The same article enjoins Parliament to make relevant laws for purposes of giving full effect of the above article.

Therefore, taking palliative care patients as a marginalised and/or vulnerable group, it is possible to develop a legal framework that can offer additional support to persons in need of palliative care (Twinomugisha 2004).

The Constitution is therefore supportive in so far as it creates a basis for the legislative

organ as well as policy makers to take appropriate actions to avoid marginalisation on the basis of health status.

d) Obligation to ensure availability of essential drugs

The National Drug Policy and Authority Act obliges the National Drug Authority (NDA) to ensure availability at all times of essential, efficacious and cost-effective drugs to the entire population of Uganda, as a means of providing satisfactory health care and safeguarding appropriate use of drugs. These drugs include those required in palliative care including opioids.

The NDA is further obliged to formulate a national list of essential drugs from time to time on the national formulary depending on the available resources and existing diagnostic and therapeutic capacity. It is therefore evident that the NDA is obliged by the law to allow and ensure the availability of essential drugs and to continually review the needs assessment of essential drugs in medical treatment, including those required in palliative care service provision.

It is argued that the restrictions on essential medicine in palliative care are largely based on the attempt to strike a balance between the medical needs of palliative care patients and drug/substance abuse, which in effect raises serious legal and human rights issues (World Health Organisation 2002). Discrimination against palliative care patients on the basis of their health status and medical needs contravenes the Constitution and other international and regional instruments which guarantee dignified existence, irrespective of one's health and social status (Twinomugisha 2004).

However, the restrictions notwithstanding, there is clearly a legal basis in the Statutes through which drugs and other services

required by palliative care can be adequately met. Failure if any by the NDA to exercise its mandate under the law is a violation which can be challenged in the courts of law (Uganda Law Reform Commission, 2000).

e) Prescription and use of morphine oral solution and morphine tablets under the National Drug Authority (Prescription and Supply of Certain Narcotic Analgesic Drug) Regulations SI 24 of 2004

The above Regulations were made under the National Drug Policy and Authority Act in 2004 with the following objectives:

- To promote and correct adequate use of certain narcotic analgesic drugs in palliative care for the relief of severe pain and control of symptoms.
- To improve access to certain narcotic analgesic drugs for relief of severe pain and control of symptoms in the provision of palliative care services by making them more easily available at the lower levels of the health system and by enabling trained workers to prescribe the drugs as recommended by the International Narcotic Control Board (INCB) and the WHO.
- To ensure the implementation and maintenance of effective systems of control and handling of certain narcotic analgesic drugs.
- To ensure appropriate prescription and recording of certain narcotic analgesic drugs in order to promote their correct use for legitimate medical purposes, and;
- To avoid illicit or inappropriate use of certain narcotic analgesic drugs in conditions or for patients where the use is not therapeutically indicated. (Statutory Instruments No.4 of 2004).

Under these regulations, the narcotic analgesic can be used in medical treatment upon prescription by a clinical officer or nurse holding a certificate in specialist palliative care.

The prescriptions are, however, strictly limited to the five categories of morphine listed in the schedule to the regulations, namely: morphine oral solution 1mg, morphine oral solution 50 mg/5ml, morphine tablets SR 10mg, morphine tablets SR 30 mg and morphine tablets SR 60mg.

These regulations present a basis, inroad and legal support in the promotion of palliative care and service delivery in Uganda, which until 2004 were unavailable.

f) Social security under the National Social Security Act and the Pensions Act.

Under the Pensions Act, a person who has served the Government in public service for 10 or more years is entitled on retirement to monthly pensions, whose computation is based on the salary scale obtaining at the time of retirement. This pension is intended to help the ageing servant to plan ahead of time.

Under the National Social Security Fund (NSSF) Act, the law also offers three categories of benefits from which patients under palliative care can be legally supported, including old-age benefit with the common objective of replacing income security to the elderly through payment of their savings accumulated during the period they were employed' invalidity benefit, which is paid to a contributing person who has lost his or her earning capacity due to physical or mental incapacity as certified by a medical doctor, and physical invalidity benefit paid to an employee upon certification by the medical doctor that a contributing person has lost his or her physical capacity to work/earn. Survivor's benefit is paid when a contributing employee dies while in

employment; in which case the spouse and children are the immediate beneficiaries.

Despite the loopholes in the social security sector, as outlined later, there is some legal support which nevertheless has elements of palliative care and can be used to promote palliative care service provision.

g) Obligation to procure drugs under the National Medical Stores Act

Under the National Medical Stores Act, the National Medical Stores (NMS) are obliged to ensure for the national benefit effective and economical procurement of certain medical supplies of good quality to public health services; to ensure safe and efficient storage, administration and supply of drugs having regard to national needs; and to estimate the current and future needs as basis for procurement, planning and budgeting. NMS also supplies medicines for use in private health care against payment of money. The NMS Act and the NDA Act oblige the state to ensure procurement, storage, supply and availability of the necessary drugs based on the needs assessment of the populace, and that invariably includes all drugs needed in palliative care (Uganda Law Reform Commission 2000).

In Uganda, like many other African communities, it is a taboo to even mention word the “will” because it is strongly believed that doing so occasions an immediate death. Moreover, the legal requirements of making a valid will, when persons faced with life-threatening illness can hardly comply either due to ignorance, lack of awareness or complexity of the law, mean that many people die intestate.

As earlier pointed out, palliative care is not just about pain and symptom relief but covers other problems (physical, psychological and spiritual) that are associated with loss of a family member. Succession, therefore, is a crucial area in the full realisation of palliative care provision.

A number of regulations and special considerations are in place in Uganda as listed in the box below:

Regulations and law on dispensation

- The National Drug Authority Act Cap 206
- The National Drug Authority (Prescription and supply of certain Narcotic Analgesic Drug) Regulations, Statutory Instrument No.24 of 2004
- The Medical Stores Act Cap 207
- The Penal Code Act Cap 120.
- The Pharmacy and Drug Act Cap 280.
- Medical and Dental Practitioners Act, Cap 272
- The Public Health Act Cap 281
- Food and Drug Act Cap 278
- The Mental Treatment Act Cap 279
- The Nurses and Midwives Act Cap 274
- The Veterinary Surgeons Act Cap 277

I) Restrictions

The laws, policies and legislations that regulate palliative care include the 'National Health Policy, the Ministry of Health Strategic Plan II 2005/2006-2009/2010, the National Policy and Drug Authority Act, the Constitution of the Republic of Uganda 1995, the National Drug Authority (Prescription and Supply of Certain Narcotic Analgesic Drug) Regulations SI 24 of 2004. However looking at them against the universally acceptable standards they are very restrictive (WHO 2004, Narcotics and Pyschotropic Drugs).

There also exist laws that regulate the practice and dispensation of drugs that may be required by persons in need of ongoing palliative care. These include the Pharmacy and Drug Act, Allied Professionals Act, Nurses and Midwives Act, the Dental Practitioners Act and the Penal Code Act. The challenge still remains in putting into practice these laws and statutes (Byamukama 2007).

j) Criminal Law approaches

The criminal law is a rather crude instrument directed against the more severe violations of standards of the conduct and safety. It governs deliberate, wanton, intentional and grossly negligent wrongs (Twinomugisha 2004).

The Penal Code Act categorises actions that fall below the acceptable standard as criminal negligence and are punishable depending on their gravity. The criminal approach as later observed can only help shape palliative care service provision when jointly applied with strict adherence to professional ethics and conduct.

A substantial amount of literature has been written about the ethical issues that face medical care in HICs. Much of the ethical issues that face providers in LICs settings like Uganda, have however, not been documented.

- The right to participate in a health care programme (i.e. participation in the health programmes) and decision-making.
- Access to information; the patients must be sufficiently informed of the type of treatment/medicine being administered, the associated benefits and risks/ side effects of the medications.
- The access to adequate nutrition which is an aspect of the right to food under the constitution.
- The right to euthanasia, the right to choose when to die.

The Uganda Human Rights Commission, established under an Act of Parliament, has confined itself to addressing cases of violent torture, illegal detentions and other abuses of a political nature by state agencies (Uganda Human Rights Commission 2008). There is need for the mandate of the Uganda Human Rights Commission to be expanded to practically cover all cases of human rights violation including cases involving the administration of palliative care services (Byamukama 2007).

3: Rationale and Objectives

3.1 Rationale

Failure to provide palliative care to patients who need it is a violation of human rights and the government is under obligation to ensure the aggrieved persons access adequate health care services. Most studies on palliative care have been undertaken mainly in the HICs. There is a paucity of information on the accessibility of palliative care in low-income countries. Many of the ethical issues that face providers in LICs settings like Uganda have not been documented. Also, there is a lack of documentation on the legal challenges that patients and their families face as the patients die; the role of families in caring for patients, and the interface between the health providers and the palliative care provision. There is therefore an urgent need to document access to palliative care services in Uganda and assess the legal needs of people in need of palliative care, their families and the health care providers. This case study attempts to address these issues and builds on similar work done in South Africa

3.2 Objectives

General Objective

To assess the legal needs of patients, their families and palliative care providers in Uganda.

Specific objectives

1. To assess access to palliative care.
2. To explore ethical issues encountered in palliative care in Uganda and how to address them.
3. To explore patients' awareness of laws and human rights in relation to palliative care.
4. To describe legal challenges faced by palliative care patients and how the law can address them.
5. To describe family participation in palliative care and the legal framework that can support them.
6. To describe the interface between health workers and the health system.

4: Materials and Methods

4.1 Design

The study design was cross-sectional and involved a legal documents review, key informant interviews with legal officers, health care providers, a survey and focus group discussions (FGDs) with patients.

4.2 Study area

The study was undertaken in institutions that take care of patients with either HIV and AIDS, cancer or both. Three institutions were identified and between them, they represented a mix of palliative and general care, cancer and HIV patients, rural and urban, faith-based / Non-Governmental Organisation (NGO) and government facility. The institutions were Uganda Cancer Institute in Mulago Hospital, Mildmay Uganda, and Kitovu Mobile HIV/AIDS Organisation.

The Uganda Cancer Institute is a government institution located within the national referral hospital complex and it caters for the HIV and AIDS patients who have developed cancer as well as the non-HIV infected cancer patients.

Mildmay Uganda is a NGO that caters for mainly HIV patients but when they present with other illnesses, it also offers care.

Kitovu Mobile HIV and AIDS Organisation is a faith-based palliative care organisation that offers counselling and treatment for HIV and AIDS patients, as well as end-of-life care.

The sites provided a mix between the public and the private, HIV and AIDS patients and non-HIV and AIDS patients on palliative care, and rural- and urban-based providers.

4.3 Study population

The study population consisted of staff key informants (KIs) and patients.

- a) Key informants: These included persons involved in the practice of medicine (i.e. health care service providers to patients who have HIV and / or cancer workers in the National Medical Stores, members of the National Drug Authority and legal officers as well as human rights law practitioners). The KIs were purposefully selected for the roles they played in the implementation of palliative care services.
- b) Patients: These were people with life-threatening and/or life-limiting illnesses in need of palliative care and their families. They were selected from the institutions named above. The patients had either cancer or HIV and AIDS as the primary diagnosis.
- c) Sample Calculation: Using the Kish Leslie (1965) formula for a cross-sectional study, a minimum of 384 respondents was required when the probability of getting the outcome of interest was 0.5 and the level of significance intended was at five per cent ($n = Z^2(p)(1-p)/e^2$). At Z value 1.96 (95 per cent confidence), p value of 0.5 to get the largest sample size, and e value of five per cent expected error.

4.4 Sampling

For KIs, snowball sampling was used where health workers and legal officers involved in the implementation of laws affecting palliative care were interviewed and afterwards asked for other people who could be contacted for more information on legal issues affecting palliative care patients. After securing informed consent, demographic details of the respondent

were recorded and, using an interview guide (see Appendix 2), an interview was conducted focusing on the availability, affordability, acceptability and accessibility to patients of various aspects of palliative care, such as legal support for the patients and the family.

All the patients who were available on the day of data collection, who were 18 years of age or above, were not very sick and gave informed consent were interviewed. The exclusion criteria were patients who were very sick or respondents who did not consent to participate in the study

4.5 Data collection

Key informant interviews:

KIs interviews were conducted by the Principle Investigators who made appointments with the interviewees in a place deemed convenient to them. All the interviews were conducted in the interviewee's place of work. KIs interview guides (Appendices 3-6) were used to collect qualitative data about the opportunities and challenges that patients experience before they access palliative care. KIs interviews were conducted to capture the experiences of the providers as they interfaced with the patients when the latter came for health care. The guiding questions for the KIs included:

- identification of the drugs which the patients use for treatment of pain
- ethical issues
- involvement of the family in health care and legal challenges especially concerning end-of-life preparations.

Other questions focused on the challenges health providers face in the procurement, distribution, monitoring and administration of opioids to the patients. A total of 25 KIs were conducted.

Focus Group Discussions

In total, four FGDs were conducted. Two FGDs were conducted in Mildmay Uganda (one male and another female) and another two were conducted in Kitovu Mobile (one male only and another female only). They were stratified by sex to allow free discussion (Rice and Ezzy 1999). A range of issues were explored and these included the problems they faced accessing care, and support given by the institution and the family, perceived needs, and issues relating to end-of-life and bereavement. FGDs were conducted with patients to explore the social-legal issues of access to palliative care (see Appendix 7). Research assistants (recorder/note taker, moderator) were recruited and trained with continuous assessment. All FGDs were conducted in the local language and recorded (with consent). Discussions took approximately 45 minutes on average. During the data collection phase, de-briefing meetings were held at the end of each day to ensure good quality data and share emerging issues. Expanded notes were prepared later in the day to capture what transpired in the group discussions and interviews. Purposeful sampling of FGD like-minded participants was employed.

The survey

An interviewer-administered questionnaire was used to collect data on the socio-demographic characteristics of the patients, their access to health care and ethical and legal issues. All the patients in the institutions who were available during the period of study and fitted the inclusion criteria were interviewed. An equal number of respondents (128) were interviewed per institution. The trained research assistants interviewed the patients from the health facility or in the places where the organisation offered services in the community, as for Kitovu Mobile, whose services are not facility-based.

4.6 Data management

For quantitative data, the research assistants read through completed questionnaires and cleaned the data. They checked for consistencies on the same day it was collected. Data was entered in the computer using Epi Data by the research assistants who collected it. This was later merged into a single file and transferred to SPSS version 11.5.

For qualitative data, the interviews were transcribed verbatim the day they were conducted or, at the latest, the next day using the interview notes to guide the transcription. The transcribed notes were cross-checked with the audio tapes and later typed into the computer. Focus group discussions were transcribed into English, and then typed into the computer.

4.7 Data Analysis

Quantitative data analysis was done using SPSS version 11.5 and Microsoft Excel Statistical packages and chi-square tests were administered. The results are presented in text, frequency tables, graphs and charts.

For qualitative data, the initial step was to read through the FGDs and KIs interview transcripts several times while making notes in the transcript. All investigators participated in this process. Disagreements or issues needing further clarity were resolved through discussions and triangulation of data source. The qualitative content analysis technique was used. This technique refers to what the text talks about with relationship aspects and involves in-depth interpretation of the underlying meanings of the text. Data was therefore condensed i.e. shortened without losing quality. Open coding was done and codes were grouped into categories and then themes (Graneheim and Lundman 2004).

4.8 Quality control

The following measures were put in place to ensure good quality of data and therefore increase the validity and reliability of the study results.

- Pre-visits were made to the organisations where the study was undertaken to secure an updated numbers of patients attending the organisation. Arrangements were made with health workers and the leaders of the organisations so that they can assist the investigators and the research assistants in their work.
- Two research assistants experienced in research were selected and trained for three days on the objectives of the study and the data collection. They had a good knowledge of English, and the local language, Luganda.
- The questionnaires for the survey, the KIs interview and the FGDs guide were designed so there was a logical flow of questions.
- The data collection instruments were translated from the original English version into Luganda by the research assistants together with the investigators and then translated back to English. The original English version was compared with the one translated from the local languages to ensure consistency of meaning. The local language and English versions were discussed by the research assistants and the investigators and the meaning harmonised. This was undertaken because most of the patients would be using the local language for communication.
- The investigators supervised the research assistants closely. Issues of clarification were discussed and the challenges in data collection shared.
- Tape recorders were used to record KIs informant interviews and FGDs.

Transcription was done verbatim so as not to miss any information and later compared with the audio tapes.

- All the tools used in the study were pre-tested at Hospice Africa Uganda in Makindye, which was not one of the targeted organisations for the data collection. The tools were later adjusted for the main field work.

4.9 Study limitations

Since the selection of the organisations was purposive, this created a selection bias as the organisations were chosen on how they fulfilled the criteria of: being rural and urban, caring for both HIV and cancer patients, public and private, and offering palliative care and general care. However, this may be a source of strength for the study because the stratification ensures that all types of patients will be represented even if in a non-representative manner.

The use of both qualitative methods in addition to the quantitative methods helped to add on information which could not have been captured in the survey; however, most of the respondents were patients in pain. They may have given information which was greatly influenced by their condition of need for pain killers. This was mitigated by having information from the providers to provide another view of palliative care availability.

4.10 Ethical considerations

Ethical clearance was sought and received from Uganda National Council of Science and Technology (SS 2261). Permission to carry out the research was sought from the senior management of the respective organisations. The objectives, benefits and risks of the study were explained to the prospective study respondents and informed consent sought before interviewing them. All information obtained during the study was and will be treated as confidential: anonymous identifiers have been used. Data access has been restricted only to those involved in the study.

5: Results

5.1 Introduction

A total of 384 patients were interviewed – 128 patients from each of the participating organisations, of which the Uganda Cancer Institute was governmental and the other two, Kitovu Mobile and Mildmay Uganda, were NGO facilities. There were also 25 KIs interviews. The respondents were eight nurses, five doctors, five legal officers, four persons involved in drug supply chain management, two pharmacists and one sociologist.

5.2 Socio-demographic characteristics of the respondents

The majority of the respondents (59 per cent) were female aged between 25 – 45 years. Many of the patients were married or widowed. The highest education attained by the majority of patients was upper primary or secondary education. More than half of the respondents reported that they had been told they had HIV and AIDS. (Please see Table 1 below for the socio-demographic characteristics of the patients)

Table 1: Socio demographic characteristics of the patients

Characteristic	Variable	Frequency (n=384)	Percentage
Sex	Male	159	41.4
	Female	225	58.6
Age Group	18-24	24	6.3
	25-35	120	31.3
	36-45	143	37.2
	≥45	97	25.3
Marital status	Single	85	22.1
	Married	104	27.1
	Divorced/separated	56	14.6
	Widowed	102	26.6
	Cohabiting	37	9.6
Education attained	None	40	10.4
	Primary 1-4	55	14.3
	Primary 5-7	110	28.6
	Secondary 1-4	114	29.7
	Secondary 5-6	15	3.9
	Tertiary	50	13.0
Reported illness	Cancer	83	21.6
	HIV/AIDS	225	58.6
	Not willing to disclose	2	0.5
	Other conditions	74	19.3

Respondents were asked how long they had their illness and almost three quarters of them reporting being ill for five years or less (See Table 2).

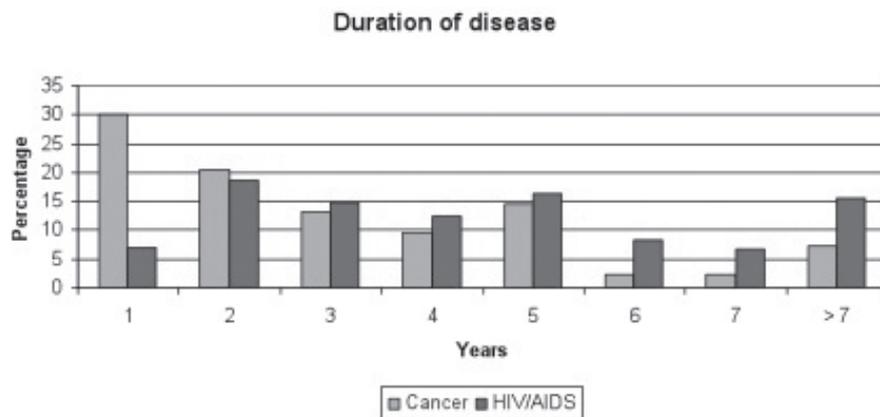
Table 2: Duration of Illness

Duration of illness (years)	Frequency (n=384)	Percentage
1	46	12.0
2	71	18.5
3	59	15.4
4	50	13.0
5	61	15.9
6	26	6.8
7	23	6.0
>7	48	12.5
Total	384	100

The range of illness duration in years was from 1 year to 21 years. Very few patients had had the illness for more than 10 years (N=9)

When the patients were stratified according to the illness they reported they had, 30.1 per cent of the cancer patients (25/83) had just had the disease for a year, and half of them (50.6 per cent) had only had the cancer for two years, possibly due to the high mortality rate among patients with cancer.

Figure 1: Proportion of patients and duration of illness: cancer or HIV and AIDS



Time spent on the programme

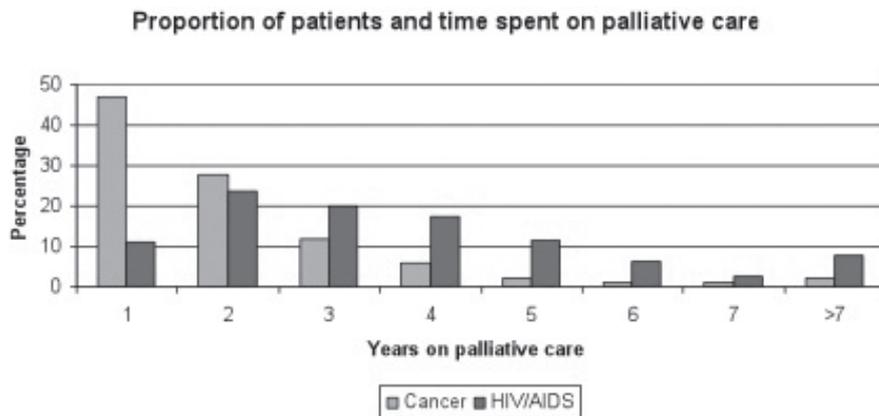
Very few patients had spent more than five years on the programme. Few patients survive beyond five years (mode: two years, median: two years, and mean: 4.41 years). When the patients were stratified among those who reported having cancer and those who reported having HIV and AIDS, 47 per cent of the cancer patients had only been there for one year and the numbers decreased very rapidly in the second and third year.

Table 3: Time which patients had spent on palliative care programme

Time spent on the programme (years)	Frequency (n=384)	Percentage
1	87	22.7
2	101	26.3
3	73	19.0
4	48	12.5
5	31	8.1
6	17	4.4
7	7	1.8
>7	20	5.2
Total	384	100

Once again this demonstrates the high death rates among patients with cancer in Uganda. Nonetheless, even for those with HIV, the numbers steadily decrease from the second year onwards.

Figure 2: Proportion of patients with cancer or HIV and AIDS and time spent on a palliative care programme.



5.3 Access to palliative care

Patients in Uganda face several challenges in accessing health care. These include a lack of knowledge that the services actually exist, living far from where the services are offered and inadequate knowledge about the services or an inability by health workers to refer the patients appropriately.

Respondents among the KIs interviews were of the view that some people who are in need of palliative care may not be aware of the services given in the facilities that offer them. Being a special type of care that is not commonly offered in the primary level facilities, some of the patients do not know that palliative care exists in certain facilities. One medical doctor remarked:

I think people in the communities are not aware (of the palliative care services here). If you go deep into the villages, I think

some people are not able to think of a swelling as a cancer when it becomes painful, when it is bleeding; ... but also I think many people are not aware that cancer is treated (KI Medical Officer)

This is similar to information gathered from the nurses who also attend to the palliative care patients. Nurses were of the opinion that there was widespread lack of knowledge of palliative care services. They alleged that patients keep going to health facilities that do not offer palliative care and some patients die even before they access any palliative care at all.

Respondents among the KIs as well as FGDs indicated that some of the patients were unable to access palliative care because of the long distances to the facilities where palliative care is offered. This is an issue of coverage of services. The facilities that offer palliative care are so scattered that there

are some patients who live very far from any facility that offers the care. This was also shared by the patients in the FGDs who lamented that health centers are far away, yet the patients who need palliative care are not strong enough to walk to those centres.

Some of the respondents intimated that some of the health workers who should refer the patients for care sometimes are not able to recognise cancer. There is a low threshold for suspecting cancer even when the cancer is a very aggressive. The health workers will first suspect other illnesses and by the time the person presents, the cancer would have worsened.

5.3.1 Affordability

It was reported that lack of money for transport contributed to inaccessibility to palliative care services to those who need it. According to the patients who were interviewed in the survey, about half of them incurred transport costs of more than USD 2.50 from their homes to the place of treatment. Compared to the cost of treatment per week, 46.1 per cent (177/ 384) of patients said they do not spend any money and 68.8 per cent (264/384) spent USD 2.50 or less. The comparison is illustrated in the table below:

Table 4: One-way transport costs compared with one week treatment costs

Cost (USD)*	Cost of transport		One week treatment cost	
	Number	Percentage	Number	Percentage
≤ 2.5	183	47.7	264	68.8
2.5 ≥ 5	119	31.0	6	1.6
...≥ 5	82	21.4	114	29.7
Total	384	100 per cent	384	100 per cent

* USD 1 = UGX 2000.

Treatment per week ranged from USD 0 to USD 500, while one-way transport ranged from USD 0 to USD 50 (1 USD = UGX 2000). A higher percentage of patients (29.7 per cent) spent more than USD 5 on weekly treatment than those who spent it on transport (21.4 per cent).

Since transport was expected to take a proportion of people's expenditure, patients were asked how many times they came to the facility per month in order to get treatment. A bi-variate analysis was done to assess whether there were any differences that would be related to inability to pay for transport. The results have been stratified according to sex, marital status and level of highest education.

Table 5: Frequency of coming to the facility according to sex

Number of times coming to a facility in a month	Sex		Total
	Male	Female	
Once	137 (86.2 per cent)	180 (80.0 per cent)	317 (82.6 per cent)
Twice	15 (9.4 per cent)	30 (13.3 per cent)	45 (11.7 per cent)
Three	7 (4.4 per cent)	15 (6.7 per cent)	22 (5.7 per cent)
Total	159 (100.0 per cent)	225 (100.0 per cent)	384 (100.0 per cent)

Of the males 86 per cent came to the facility once a month, while with females it was 80 per cent. There was no significant difference between the frequency of male or female patients coming to a facility (OR 1.56; 95 per cent CI 0.86 – 2.82, Chi square 2.46, p-value 0.117). However, members in the FGDs for men indicated that though poverty would affect both men and women and hence be a common factor in making access to care difficult, the women are affected more than men.

I have a feeling that women are affected the more since they have to look after the families. They have to make sure that the children have something to eat and besides, the men no longer have jobs, so that the families are catered for. Women are like chickens that do look after their young ones while the cocks are just moving around. (FGD Men)

Table 6: Frequency of facility visits versus marital status

Frequency of facility visits per month	Marital status					Total
	Single	Married	Divorced/ Separated	Widowed	Cohabiting	
Once	63 (74.1 per cent)	92 (88.5 per cent)	45 (80.4 per cent)	86 (84.3 per cent)	31 (83.8 per cent)	317 (82.6 per cent)
Twice	16 (18.8 per cent)	10 (9.6 per cent)	5 (8.9 per cent)	9 (8.8 per cent)	5 (13.5 per cent)	45 (11.7 per cent)
Thrice	6 (7.1 per cent)	2 (1.9 per cent)	6 (10.7 per cent)	7 (6.9 per cent)	1 (2.7 per cent)	22 (5.7 per cent)
Total	85 (100 per cent)	104 (100 per cent)	56 (100 per cent)	102 (100 per cent)	37 (100 per cent)	384 (100 per cent)

There was no significant difference between the patients with respect to their marital status and frequency of visiting a palliative care facility (Chi square 12.65, p-value 0.125).

Table 7: Frequency of facility visits versus level of education

Frequency of facility visits	Highest level of education						Total
	None	Primary 1-4	Primary 5-7	Secondary 1-4	Secondary 5-6	Tertiary	
Once	38 (95.0 per cent)	50 (90.9 per cent)	100 (90.9 per cent)	82 (71.9 per cent)	9 (60.0 per cent)	38 (76.0 per cent)	317 (82.6 per cent)
Twice	2 (5.0 per cent)	3 (5.5 per cent)	7 (6.4 per cent)	26 (22.8 per cent)	3 (20.0 per cent)	4 (8.0 per cent)	45 (11.7 per cent)
Thrice	0 (0.0 per cent)	2 (3.6 per cent)	3 (2.7 per cent)	6 (5.3 per cent)	3 (20.0 per cent)	8 (16.0 per cent)	22 (5.7 per cent)
Total	40 (100 per cent)	55 (100 per cent)	110 (100 per cent)	114 (100 per cent)	15 (100 per cent)	50 (100 per cent)	384 (100 per cent)

The less educated were more likely to come only once a month compared to the more educated who would come twice or three times (Chi square 43.12, p-value 0.000)

Among the KIs interviews, most of them were of the view that patients were poor and were hence affected by the costs of accessing palliative care.

5.3.2 Availability

There are different services that are needed at the health facilities that offer palliative care. These include counselling, screening for HIV and/or cancer, laboratory or radiological investigations and medicines. Other services are spiritual support, nutritional services, social support (e.g. home care, psychological support and legal services). Medicines available included morphine, codeine, cotrimoxazole, anti-cancer drugs when they are available and laxatives, especially for those who were taking morphine. For the organisations in this study medicines were free.

From the survey, 67 per cent (257/384) of the respondents said that they received treatment to control pain and those who did not get the treatment, 79.5 per cent (101/127) of them said that the reason for not receiving pain-relieving drugs was because they did not have pain. Other said they had come for other issues, like CD4 counts and collecting ARVs. Other services given by the facilities reported in the survey were adherence to treatment and advice on diet. The services sought from the facilities according to the respondents are indicated in the table below.

Table 8: Provision of other services apart from offering drugs*

Service	Number (per cent)
Receiving pain control	257 (66.9 per cent)
Legal advice (e.g. how to make a will)	70 (18.2 per cent)
Spiritual talks	85 (22.1per cent)
Advice on diet	67 (17.4 per cent)
Advice on adherence to drugs	34 (8.9 per cent)
Health education on prevention of re-infection	36 (9.4 per cent)

* More than one answer was acceptable from the respondents

Males were less likely to report having received counseling compared to women (OR 0.64; 95 per cent CI 0.40 – 1.00, Chi square 4.30, p-value 0.038). However, there was no significant different between male and female patients with respect to having received legal service (OR 0.75; 95 per cent CI 0.42 – 1.32, Chi square 1.14, p-value 0.285), or spiritual talks (OR 0.87; 0.52 – 1.47, Chi square 0.30, p-value 0.584).

Challenges to the availability of morphine hinged upon lack of morphine sulphate powder for the reconstruction of morphine elixir. However, the type of morphine available to health facilities was not always the strong one even when there would be patients that would benefit from it. Legal services were also sourced from outside and this depended on the ability of the client to source the services.

Another hindrance to accessing medicine was that the palliative drugs, especially opioids, were sometimes given through other organisations and not by the facility itself. This organisation would not offer the service every day and if a patient needed the drug on those days when the health workers were not coming, then the patient would not be able to access it.

Palliative care-providing institutions mostly concentrate on the medical and to some extent the social dimensions of care. Legal and spiritual services were sourced from outside the palliative care facility. Even when sourced

from elsewhere, the legal and spiritual services would be offered to those patients who were not benefiting from the medical treatment. There is need to see the person as not only being a physical body but having also the social and spiritual dimensions. Palliative care being offered to those in the terminal stages of sickness means that legal issues should also be part and parcel of the care provided.

Both FGDs and KIs noted that there is no standardised quality of service in the health facilities that offer care. Some facilities are much better than others as they offer other services such as food. When the patients are referred from these facilities to others, then patients resist leaving.

5.4 Ethical issues

Some of the ethical issues involved in the care of palliative patients are autonomy and confidentiality. Autonomy is the notion that patients have the right to take the treatment they agree on. Confidentiality is the notion that what transpires between the patient and the health provider is confidential between the patient and the health provider, unless the provider is consulting with another colleague and only for the benefit of the patient.

During the KIs, the providers indicated that the patients have the right to make their own decisions. This spans what treatment to take, investigations to be done or procedures to be done on them. The health workers provide information about the treatment to the patients.

When patients were asked in the survey whether the doctors had told them of their illness and the side-effects of the drugs, almost all [99.5 per cent (382/384)] reported that they had been told about the illness and the treatment side-effects.

Health providers also indicated that they respected the patients' rights to

confidentiality as noted in the quote below:

We observe confidentiality in examination, the ethical issues; the right to information, not to harm, not to kill, and the right to offer quality health services. (KI Nursing officer)

The challenge that health workers faced in their quest for observing confidentiality is that some of the patients who suffer from HIV and AIDS are reluctant to disclose their HIV status to their families, yet these patients would benefit more from the treatment if their families are involved. Health workers kept encouraging the patients to disclose and sometimes this would take a long time, hence patients missing out of the benefits of having family support in their sickness.

5.5 Patients' Awareness of Laws and Rights

One of the requirements in health care services globally is that patients are given full information about their condition or disease to enable them to participate and/or make informed decisions about their own health. However, it is not always possible that health services meet this standard requirement. This study delved into the extent to which patients as well as providers know the rights of patients, legal services, laws and conventions, and existing legal support to patients in palliative care.

5.5.1 Patients' Awareness of their Rights

Some of the health providers (nurses and doctors) knew the rights of the patients including the right to have a clear prescription, treatment, diagnosis, to give informed consent on the treatment to be given, and the procedures to be followed on the patient. Health workers revealed that ideally there is a consent form for the patients to fill before

receiving any services. In addition, there are other procedures, such as a biopsy, which the patient has to agree to. Technically, if the patient does not consent to the procedure, the provider should not force it.

Interviews revealed that the other rights specifically for children include the rights to a secure environment, food, care, security, play, access to information, education, voicing their grievances, and staying with their parents. This was emphasised by both health workers and legal experts. A multi-disciplinary approach to palliative care was emphasised and some of the units had social workers, doctors, nurses and counsellors. In some cases nutritional information was also given. Information was also in some instances given on rights as indicated below:

We also tell them their own right and also discuss what to do to make it comfortable for them to go to work during the day, then they come in at night (KI, nurse).

Children have a right to participate in the health care decision making. On access to information, children must know the type of medicine being administered and associated benefits and side effects. This is right under article 44 and now Access to Information Act (KI, legal expert).

FGDs with men and women revealed that palliative care patients were largely aware of their rights; such as staying with their own children, right to good feeding, owning property, inheritance of property, equal opportunities to employment, equal access to treatment and not to be discriminated against. There was not much difference between men and women patients.

We are told that these rights are God-given irrespective of what you are. Whether you are a man or a woman, lame or not, richer or poor, young or old, you have these entitlements (FGD, men).

As a mother I have a right to inherit property that my husband left behind upon his death. Though I have the virus, I have a right to work. Nobody should discriminate against me on grounds that I have the virus because I am a human being like any other person (FGD, women).

It ought to be noted that some palliative care patients were not aware of their rights. This lack of awareness makes it harder for patients to fight for their rights. KIs with providers and FGDs with patients revealed that in most cases patients do not sign the consent forms. The majority are ignorant of the laws and have no knowledge of the basic information written on medical forms. Palliative care patients complained that health workers do not give them the adequate information they require. This appears to be attributed to weakness in the health system and ignorance of the people. One key informant remarked that “They are supposed to consent but most of them don’t know their rights. Out of 10 patients about two know their, rights”. (KI)

Women also suffer a lot when it comes to violation of their rights, especially after the death of their husbands. The relatives come in and take all the property that was left behind. The law can’t protect these people that are left behind so that their rights are not violated (FGD, men).

5.5.2 Patients’ awareness of legal services

There are many legal issues concerning patients in need of palliative care. These were mainly related to inheritance of the property of the deceased, land disputes, separations in marriage and neglect of the terminally ill, among others. Some of the informants mentioned patients involve lawyers in drafting their wills and making agreements concerning

their properties when they die. This was mentioned to have a positive consequence on medicines adherence, depression and improvement for those on treatment. Some gender dimensions were reflected as well. Some of the males, due to the cultural position they enjoy, take advantage of situations and send away their partners. But also, in some cases, female partners abandon their husbands in hospital, blaming them for 'the disease' in the case of HIV and AIDS.

Yeah, especially the widows; their land is taken, they are chased out of their houses and it is not really good. So, I feel there is need for respect; they have problems with land, houses and children are denied a right to education by either their step-parents or their carers. I think since children also have a voice, these should be addressed (KI, medical officer).

They are there, in the field you may find a dying patient, say a lady and the husband dumps her there, stops caring for her, neglects and sells off the land ... with men, some ladies also neglect them and leave them in the house. Women actually suffer. (KI, nurse)

Results indicated that most palliative care patients did not know their legal rights and as such very few respondents discussed the legal issues. Those who discussed them were mainly concerned with the inheritance of property, particularly the widows, and problems associated largely with the family, relatives and neighbours as noted below.

Right now she is in the village selling all the property that belongs to the children. I don't have anywhere to run to for redress because I am also scared. There is no one to help me at all so my request is that we are helped in such situations. I can't even report her anywhere because she claims that she was related to my husband and is the rightful owner of that property (FGD, women).

Legal issues affecting children were discussed. These were mainly to do with child neglect, especially for those with HIV and were particularly pointed out by respondents from Mildmay's children centre. Therefore awareness of legal issues about children is important.

One KI said:

Most children are neglected; they are left alone. A child can be brought in, you take care of the child, you give drugs, nobody else; everybody is busy, most workers are busy and have nothing to do with the child. In fact there is a child who was chased away from home by a step-mother, telling the child that 'you do not resemble children of this home' and this child was taken to a nearby church. So what the church did was to bring this child here at night. That is a dilemma and it becomes worse for the women who are not working and have no money. The moment the husband knows the sero-status of the woman he chases her and the woman has nowhere to go with her family and at times she fears going back to her parents. (KI)

A similar scenario was expressed by a focus group of women patients who described their frustration that the law was weak. It did not offer adequate protection to children when the father died.

From my point of view, the law is very weak in protecting the children or the widow upon the death of the head of household. Personally, I was given land in the village but when my husband died, my mother-in-law took it. (FGD, women).

5.5.3 Awareness of laws and conventions

There was a general feeling that the majority of health providers were not aware of the international laws and conventions concerning the patient's rights. The few who knew mentioned some laws against

negligence. As a result of this many unethical practices are being committed by clinicians, but mostly in ignorance. The quotes below from health providers make the point:

“Well, I do not know what you mean by children’s rights but I think they are the same the world over” (KI, nurse).

No, I should know international laws and conventions but it’s not really something that I put into practice on the daily basis. It is not ethical to deny patient care so long as you have it available, but where patients cannot come, then I don’t know who is infringing on their rights” (KI, medical officer).

5.5.4 Legal support to patients in palliative care

KIs comprised of legal and human rights experts indicated that the State had put in place legislation, policies, guidelines and monitoring mechanisms to ensure effective provision of palliative care to persons in need. They emphasised there was need to aim to implement these policies and guidelines. They further added that there might be some directive principles in the national objectives in the Constitution on the right to health. However, in a resource-constrained country like Uganda, where access to basic health care services (such as antenatal services or immunisation) still need to be met, the right to palliative could be lower down on the list of its priorities. One of the KI contended that:

State duties are not only implicated by the laws which are there but also the laws that are not there. Right now especially with palliative care, the state’s duties are not to promulgate laws that would trample upon those rights, because it is difficult in a resource-constrained country. It’s even not expressly there in the constitution (KI, human rights expert).

Respondents indicated that although under the Ugandan Constitution, the Government has a mandatory primary responsibility to protect, promote and enhance the right to health, other persons are also accountable. This is discernible in the Ugandan Constitution which states that: ‘The rights and freedoms of the individual and groups enshrined in this chapter shall be respected, upheld and promoted by all organs and agencies of Government and by all persons’.

Data further supports the need for core values that support palliative care, therefore recognising it as part of essential health care. One of the informants emphasised that:

“...the absence of the law in itself is a good thing in so far as there are no laws that seem to impeach the achievement of the right to palliative care. The law is more important for what it does not say – it is sometimes better not to have laws. We simply have to develop the minimum core contents that no person shall abuse the right to health or the rights of those terminally ill; that suffices (KI, legal expert).

The international treaties and instruments offer legal support in so far as they oblige the member states to enact laws and policies relating to health that are in conformity with their obligations under international human rights instruments. However, respondents further observed that there are no sound monitoring mechanisms on the ground to ensure states compliance with the international laws which reduce the impact of such legal support.

5.6 Preparation for death

Among the organisations that were studied, there were some facilities that had mechanisms to assist the patients learn how to make wills and encouraged them to make wills. Where necessary, health workers from these facilities prepared workshops for patient care providers

to address unanswered questions. There were also other facilities where the health providers did not actively provide services for will-making to their patients. In these facilities, health providers indicated that patients usually did not request these services from the doctors. Health workers reported that it was not common for them to ask whether patients have made a will. Doctors did not routinely ask the patient whether they have made a will.

However, will making was considered a personal issue that needed to be discussed by health providers who would have already established a personal relationship with the patient. When the patients have contact with the health providers over a long time, they develop a personal relationship which enables providers to be involved by the patients in such decisions.

Most of the respondents agreed that will-making was important.

Sincerely speaking life is terminal, you should know from the time you are born that at a certain point you are going to die. One issue that comes up is not so much of making of wills but it is an area of concern. While I have worked in the field of human rights we have been dealing with people living with HIV and AIDS. I have been training and working with them on their right to property especially with regard to property for widows. We have been mainly concerned with realising rights to health and dignity; and violations in that respect have not been so much because of will-making or not... Certainly testate succession is better than intestate succession, it minimises land wrangles, etc. You leave more confusion if you die intestate and the confusion is resolved against the weak, which in our cultural settings are mostly the women and children and I should say the terminally ill, because they are physically weak. (KI, Legal Officer)

However, making a will is not an assurance that it will be respected. Legal officers indicated that most wills are deviated from, due to deeper problems rooted in the socio-cultural settings. When it comes to HIV and AIDS, the relatives of the husband are always very angry, they chase the widow in the belief that it is only the woman who can infect a man or at least they are to blame for the death. They even deviate from the will.

Health workers expressed that patients could be ignorant on how to make a will. Some patients expressed the need, but health providers could find themselves in a position where they could not assist.

There are very few pro bono legal aid service providers who could intervene and assist such patients and their respective families firstly to appreciate the importance of making wills and ensuring wills are prepared to conform to legal requirements. Coupled with the customary attitude towards making of a will, majority die intestate.

We offer legal aid services to indigent patients, the poor who cannot afford legal services of the advocates; the legal services are generally expensive for many; it's a donor-funded project, we have partners who work with us. ..., we offer legal advice and services without limitation. We guide our patients on how to write wills... Recently we had a donor-funded project which ended in September, 2009 funded by the Australian Government. We prepared standard forms containing basic contents of a will. They were in English, Iteso, Luganda and Runyankore. The demand for these standard wills was so encouraging that the forms have since been finished... we can't force a client to follow a matter, we advise them on their legal rights. Some don't come back after reporting a case and majority are ignorant of their rights. Others view issues relating to inheritance as domestic and they fear to have them referred

to court which they view as an exposure of their family issues. (KI Legal officer)

When parents pass on when the children are still young, there is a problem of how the children would grow up. They need a guardian. It is important that before their death, patients plan ahead as to who is to take on the responsibilities of taking care of the children. Guardianship, however, had gender connotations. Females felt that death of women leaves children in worse situations than for men because the men were thought to be able to take on other wives if the women die. Alternatively due to the practice of polygamy, some men may have more than one wife, hence if one of the wives dies the man just keeps the other wives.

This is in consonance with deliberations from the FGD of women, who indicated that women are affected more than men. Even before the woman dies, the man is not taking care of the children.

Sometimes it is the clan members or even the children who should be the closest that chase away the mother. In cases when the husband had not made a will, it is difficult to take over the land as one woman narrated her experience thus:

I think the will helps a lot. We are four women so if the man can divide the land and leave every woman with a piece of land to stay on with the children, this helps a lot to avoid in avoiding disputes. (FGD Women)

Some other respondents indicated that men usually worry more about the children though with different worries from those of women. For men, the worry would be that the children would have no support at all, since the property would have been sold off and may be the wife would have also gone.

One FGD indicated that sickness sometimes impoverishes the men so that by the time they

die, there is nothing to inherit. This becomes even more of a challenge when some of the children are from other women. Moreover, the man may even distribute his property to other people and not to the woman and her children.

Health providers expressed challenges in discussing succession planning with the patients. As providers of health care, patients seemed not to expect health workers to discuss property. Some of the health workers thought that opening the discussion on property could lead to misunderstandings with the patients.

I think this is historical really that we regard that (succession planning) as being private; I mean, if you start asking about somebody's property you may be misunderstood and people may think you have an interest. So most of work has been around caring for patients unless the family brings it up, but we try not to. We may advise during the period of care but we do not go into details of who's to take what, where will children be. I think this is a good thing which we can include in our programme but it is quite sensitive and it is historical. (KI Medical Officer)

Some of the respondents suggested that succession planning could be addressed, but by a different member of the team and not the medical doctor or nurse. The suggestion was for the social worker in collaboration with a counsellor.

Patients felt that the law was weak in protecting them when the head of the family dies. In addition to having a succession plan, the law needs to be enforced. Cultural conceptions remain strong, some people holding the view that wills can be overridden by the relatives at home.

Making a will was given by patients as one of the ways of assisting the widow when the man dies.

If the couple could cooperate and be able to make a will, if a will is done all these disputes will be avoided because it will be well written that my wife should never be chased from here. My property will be given to so and so, you find that the relatives will respect such a thing and the woman won't be chased away. (FGD Women)

The respondents mentioned that they have less freedom of expression in cases of conflicts. In most cases their views are not respected, as in cases of settling debts, or inheritance of property. The political structures are not protective, and they cannot afford the legal expenses involved. In some instances there is lack of or little assistance from the relatives in cases of conflict; instead they also become part of the conflict.

We, as HIV positive people don't have freedom to do whatever we feel like doing. There are times for example, when the landlord can throw you out of his house due to rent arrears. He throws you out of the house with the help of the local council people. You can't take them to the courts of law. You can't even afford to take them to the human rights bodies because you are poor so you can't pay for the services. We can't afford our own houses due to the limited incomes. There are times when they tell you to even leave everything in the house since you hadn't paid rent for some months. This affects our rights as people a lot. (FGD Men)

It is discernable from the definition by the WHO that palliative care is not just about pain and symptom relief but a holistic approach that improves the quality of life of patients and their families, suffering not only from pain but also other problems; physical, psychological and spiritual problems associated with life-threatening illness, by means of early identification and impeccable assessment.

Most of the legal officers argued that there is need for every citizen, especially those incapacitated, to have access to social benefits from the state.

The issue should be as long as you are a citizen, you should be able to afford basic needs like food. Persons who have HIV and AIDS may live even for over 40 years. I have interacted with most of them; those AIDS and cancer patients who are doing very well they even look healthier than me. However, there must be some guidelines for example to access social benefits, a certification by a licensed Doctor that your illness is terminal and requires social support, also as a licensing doctor, once you falsify a report for the sick to for the sake of accessing benefits, there should be a penalty for such certification (KI Legal officer).

Sometimes it is difficult to talk about making a will because once one talks about it, then the patients will think of impending death. Due to cultural issues patients sometimes need to initiate the discussion themselves.

We don't talk about it (making a will), because whenever people think about a will, they think about death. So we don't talk about it, like you know it is very important like even to myself, my dad was very ill, so when I went home I found that he was writing a will but that made me think a lot. Yet it is very important to these patients and we used to initiate it but we can't bring it up unless they have brought it up themselves (KI Nursing officer)

Among the health institutions where the survey took place, patients were asked whether they knew what a will was and 89.3 per cent (343/384) knew what it was. However, only 34.4 per cent (132/384) had completed any succession planning.

Most of the patients knew what a will was irrespective of gender, though the percentage of those who did not know about a will was higher in females (12.1 per cent) than in males

(7.6 per cent) a difference that was of no statistical significance (OR 1.60; 95 per cent CI 0.76 – 3.38, Chi square 1.78, p-value 0.182).

Table 9: Patients who knew what a will is according to marital status

		Marital status					Total
		Single	Married	Divorced / Separated	Widowed	Cohabiting	
Know what a will is	Yes	76 (88.2 per cent)	92 (88.5 per cent)	49 (87.5 per cent)	93 (91.2 per cent)	33 (91.7 per cent)	343 (89.3 per cent)
	No	10 (11.8 per cent)	12 (11.5 per cent)	7 (12.5 per cent)	9 (8.8 per cent)	3 (8.3 per cent)	41 (10.7 per cent)
Total		85 (100.0 per cent)	104 (100.0 per cent)	56 (100.0 per cent)	102 (100.0 per cent)	36 (100.0 per cent)	384 (100.0 per cent)

There was no significant difference between the respondents according to marital

status with respect to knowing what a will was (Chi square 1.08, p-value 0.956).

Table 10: Patients who knew what a will is according to education

		Highest level of education						Total
		None	Primary 1-4	Primary 5-7	Secondary 1-4	Secondary 5-6	Tertiary	
know what a will is	Yes	32 (80.0 per cent)	45 (81.8 per cent)	96 (87.3 per cent)	107 (93.9 per cent)	15 (100.0 per cent)	48 (96.0 per cent)	343 (89.3 per cent)
	No	8 (20.0 per cent)	10 (18.2 per cent)	14 (12.7 per cent)	7 (6.1 per cent)	0 (0.0 per cent)	2 (4.0 per cent)	41 (10.7 per cent)
Total		40 (100 per cent)	55 (100 per cent)	110 (100 per cent)	114 (100 per cent)	15 (100 per cent)	50 (100 per cent)	384 (100 per cent)

Twenty percent of the patients who did not have any education did not know what a will was yet all of those who had had secondary 5–6 as their highest education knew what a will was. Of those who had reached tertiary

education, only two of them (4.0 per cent) did not know what a will was. The people who had less education were less likely to know what a will was compared with those with higher education (Chi square 13.97, p-value 0.016).

Table 11: Patients who had received any advice on succession planning according to gender

		Sex		Total
		Male	Female	
Received any advice on succession planning	Yes	61 (38.4 per cent)	71 (31.6 per cent)	132 (34.4 per cent)
	No	98 (61.6 per cent)	154 (68.4 per cent)	252 (65.6 per cent)
Total		159 (100.0 per cent)	225 (100.0 per cent)	384 (100.0 per cent)

With respect to getting advice on succession planning, there were no significant differences between men and women (OR 1.35; 95 per cent CI 0.86 – 2.11, Chi square 1.91, p-value 0.166)

The patients were asked whether they had ever received any advice on succession planning. This was to assess the gap in what the patients receive as they are on palliative care.

Table 12: Patients who had received any advice on succession planning according to marital status

Received advice on succession planning	Marital status					Total
	Single	Married	Divorced / Separated	Widowed	Cohabiting	
Yes	14 (16.5 per cent)	42 (40.4 per cent)	14 (25.0 per cent)	48 (47.1 per cent)	14 (38.9 per cent)	132 (34.4 per cent)
No	71 (83.5 per cent)	62 (59.6 per cent)	42 (75.0 per cent)	54 (52.9 per cent)	23 (61.1 per cent)	252 (65.6 per cent)
Total	85 (100.0 per cent)	104 (100.0 per cent)	56 (100.0 per cent)	102 (100.0 per cent)	36 (100.0 per cent)	384 (100.0 per cent)

The majority of the respondents had not received advice on succession planning but this was greater among the single and the divorced.

The difference according to marital status was significant (Chi square 24.05, p-value 0.000).

Table 13: Patients who had received any advice on succession planning according to level of education

		Highest level of education						Total
		None	Primary 1-4	Primary 5-7	Secondary 1-4	Secondary 5-6	Tertiary	
Received any advice on succession planning	Yes	11 (27.5 per cent)	20 (36.4 per cent)	46 (41.8 per cent)	34 (29.8 per cent)	3 (20.0 per cent)	18 (36.0 per cent)	132 (34.4 per cent)
	No	29 (72.5 per cent)	35 (63.6 per cent)	64 (58.2 per cent)	80 (70.2 per cent)	12 (80.0 per cent)	32 (64.0 per cent)	252 (65.6 per cent)
Total		40 (100.0 per cent)	55 (100.0 per cent)	110 (100.0 per cent)	114 (100.0 per cent)	15 (100.0 per cent)	50 (100.0 per cent)	384 (100.0 per cent)

There was no significant difference in having been advised on succession

planning with respect to level of education (Chi square 6.12, p-value 0.295).

During KI, respondents were asked whether the patients attached a great deal of importance to will-making. Most health providers interviewed expressed that some patients do not see the necessity of making a will when the patients are still looking very healthy. They think they may be able to live much longer. Some respondents indicated that there were some who deliberately refused to make a will. One narrated his experience thus:

But I have also had one (patient) who insisted on not making the will; I don't know what happened when he died. One time he had to leave the bed and had to go to sign the cheque to withdraw money for his son who had been imprisoned because he had caused an accident, but I think two days later he died. But it was the kind of person he was; it was really hard to bring him to the point of 'you hand over all his things from the family side'. He was a man with many kids and wives and seemed to be a wealthy man the way he talked, because he was saying he built a church in his compound but he had control of his things until he died. (KI Medical officer)

5.7 Family participation in palliative care

The family as an institution is essential in health care, especially for those with life-threatening illnesses requiring palliative care. The family in the broader context includes the nucleus and immediate relatives as well as close friends. Participation in care can be physical, social as well as economic.

In most of the discussions, health workers mentioned that family members largely provided psychosocial support to the terminally ill. Information regarding illness was provided to both the patient and the family members. The health providers have been trained as part of the curriculum to involve the patients and family together in planning

for the care of the terminally ill. It was mainly in private institutions where a family based approach was taken. For HIV and AIDS for instance, if a mother comes with a child, spouse, or relative, they are encouraged to test and receive education on healthy living.

For public institutions, there is no clear protocol on how clinical staff routinely interact with family members as part of treatment. It seems the patients initiate the process of support and involvement of the family members when they notice that health has significantly declined and death might occur. This is done by the patient calling for a family meeting.

... of course family support is needed. Some say, let me call my brother and my uncle. So in that way they are involved. 'My brother has decided to take on my son'. I remember one who called his wife, children and uncles. The kids came from school and came to greet their dad, and they seem to have had a chance to repair relationships. I think he felt like 'now I have done my part' and I think he died a happy man (KI, nurse).

The other tasks involve encouraging the patient to take medicines, and to look for the side-effects of the drugs. This is done through identification of the family members by the palliative care teams, providing them with knowledge and skills on how to look after the terminally ill. Health workers noted that it was not an easy task to communicate to the family facts of the illness about their patients. Health workers indicated that providing information about the patients to the family was emotionally demanding. They agreed that one has to be knowledgeable to deliver the right information.

Barriers to family involvement, as mentioned by some respondents, included mis-information by the health providers about the situation of the patients. Besides, keeping the patient in suspense that 'you will be alright' until the

last minute, was also thought to be counter-productive. The other barriers included time constraint, lack of private space to counsel the family and heavy workload to the medical staff.

The communities supported by international NGOs like Mildmay have trained community volunteers who are in majority of cases reported to be women helping patients who are terminally ill. Some of the activities being done as mentioned by the respondents include community sensitisation, drug provision, counselling and identification of the very sick people in the villages. However, some of the challenges mentioned include lack of the spirit of volunteering, limited support from the community leaders, limited involvement of the men and difficulties in mobilising the communities.

5.8 The provider and the health care system

Training of health workers is essential in ensuring that quality health care is delivered. The broad areas of training include communication to the family with a client, patient care and management, drug prescription, safety and procurement. Training can be offered during medical training and on-the-job continuous medical training.

5.8.1 Training

Service providers, mainly from private institutions, mentioned that continuing medical education sessions were a useful channel to train them in pain control for the terminally ill in their facilities. This in most cases was reported as being done on a weekly basis and rotational in some health facilities. The facility training committee identifies training needs and a schedule is prepared. Some of the topics covered include communication, impact of HIV on the life of an individual, basic hygiene

practices and generally how to care for the terminally ill. However, it was mentioned that Hospice Africa, Uganda is training many health providers country-wide in palliative care.

... nurses apply for different courses according to their need. Of recent, there is a doctor who made a presentation at the IDT (Interdisciplinary Team). There are different IDT meetings where nurses, doctors, counsellors and all those working in the clinic meet to discuss different issues concerning patients. They can also present some cases, if someone comes across a patient who is interesting, has failed to be managed, has so many social problems or feels should be discussed and knowledge shared with others (KI, medical officer).

For the public facilities, health workers largely attended training in palliative care from medical schools. Most of the support seems to be delegated to Hospice Africa Uganda to take care of patients who need palliative care. However, the health workers expressed the desire for continuous medical education programmes on palliative care and support.

I for one I got training when I was at Medical School but I don't think there is like an organised sort of programme to orient doctors for palliative care. But at Makerere Medical School every graduate has palliative care training. It would be great to have continuous medical education to remind ourselves. (KI, medical officer).

5.8.2 Prescription practices

KIs show that the commonly prescribed drugs are opioids, such as morphine and codeine, which were principally reported to be prescribed by specially trained palliative care registered nurses and/or doctors in many of the health facilities. The other drugs mentioned included propylene, diclofenac and paracetamol. The challenges expressed by some of the prescribers were that sometimes the patients are in pain but there is no one to prescribe and release the medicine and take stock of key drugs like morphine, particularly in the public health facilities.

In some cases it was reported that there are clinic days for particular programmes involved in palliative care. This is the only time when the drugs are available to the patients even if the patient is in need of the drugs outside the clinic days. Some of the patients who are not enrolled in such programmes are denied the chance to access the medicines due to policy guidelines concerning that particular programme. Some of the respondents mentioned that patients, for one reason or the other, delay coming to the clinics to seek medical advice and treatment. This delays access to the drugs when they are needed. Some patients were believed to be reacting to the medicines, and at times the patients themselves are not aware of the reactions.

In terms of accessing drugs and supplies other than the painkillers the NGOs (such as Mildmay Uganda and Kitovu Mobile) reported having enough stocks. Patients seemed to be comfortable with the procedures for getting the medicines, in terms of the quantity and types of drugs prescribed.

The most important thing here is that they don't segregate the patients in any way. Be it when you are rich or poor you will all be treated the same. They follow a first come first serve basis. I've never been told that 'we don't have medicines' and besides the health workers are very gentle to us. The services offered to us are really good and they keep us going without worrying a lot (FGD, men).

Even for other illnesses we are treated as long as you tell the health worker what the problem is. We even get ARVs from here. Even if you came and said that you had ulcers, they give you the medicines. Even headaches, they give us the medicines as long as you tell them so (FGD, women).

5.8.3 Drug safety

Drugs were mainly stored under lock-and-key and only released on the request of a legitimate person (registered nurse/medical officer/specialists). It was mentioned that there are stock cards used in the monitoring of drugs released from the pharmacy.

Strictly they must be kept under lock and key. Nurses in the treatment room are accountable, that's why I said it has to be documented. So I don't think that just anyone can come and collect medicines. There is no way those in the treatment room can order without bringing it here for countersigning. So it is not that anybody in the treatment room can just order these medicines. (KI, nursing officer).

... and then again also where drugs are kept, the keys are kept by particular people. Not anyone can open even when I want morphine. Now I can't just get in – even the director does not have the keys (KI, medical officer).

However, there were concerns regarding the use of opioids by the patients. Some of the informants mentioned that the drugs are given to the patients who are at times negligent about their control due to inadequate information, sharing or patient transfers without information to the health providers.

Yes, there may be worries because we don't know what happens at home. At times some of these patients are given a bottle of morphine to go home with ... we don't know what takes place there. (KI, medical officer).

Some of the suggested solutions included providing information to patients on drug storage since most of them are discharged with the drugs; close community follow up where necessary, and proper record keeping.

The interviews with health care managers indicated that there are guidelines and policy documents developed by the Ministry of Health that govern the use of opioids and narcotic drugs. As part of safety, it was reported that the National Medical Stores (NMS) delivers these drugs to the institutions that require them. The drugs are signed for by the person in charge of the health facility or the stores managers. This ensures that there is no potential loss whatsoever. Respondents reported that there has not been any reported abuse of drugs by the service providers. One of the challenges raised was lack of coordination among the agencies which use opioids, as mentioned by the different partners.

5.8.4 Drug procurement and distribution

The NMS is mandated under law to procure all drugs into the country but procurement of certain narcotics – i.e. morphine is not done by NMS but by the Joint Medical Stores (JMS). There are other organisations, including Mildmay Uganda and Hospice Africa Uganda that procure their own. They have their own procurement policies and they do not procure through NMS unless specific drugs are earmarked for them through NMS. The demand for strong pain drugs and their procurement through NMS is erratic and more reliable statistics can be obtained from the respective health providers.

As a matter of law, NMS is allowed to procure everything including opioid drugs. Key informants noted that there is inadequate coordination. Whereas NMS is mandated to procure drugs for the country, other health service providers like Mildmay or Hospice procure individually. This in the end causes drugs to sometimes expire in stores due to limited demand.

a) Procurement-related problems

KIs pointed out that procurement-related problems were mainly financial and managerial in nature. Lack of funds, lack of coordination due to individual procurement, and distance that escalates transport and other costs were listed as the challenges.

Due to limited funds, the opioids are not a priority when it comes to procurement. In the international market there is a limited scope. The people or organisations that can supply high quality opioid drugs are very few. Distance is also a problem, those narcotics drugs are sourced

from different stores in Europe and America. The imported drugs have to be registered with National Drug Authority upon payment of a retention fee which depends on the quantity but this escalates the costs and eventual market price. (KI, drug procurement)

However, to minimise procurement-related problems as well as the shortage of drugs, and to improve its efficiency, NMS works hand in hand with JMS which is an NGO. Sometimes the NMS purchases drugs from JMS when its stocks are down and generally shares information to improve the processes.

a) Distribution

The NMS uses two systems to distribute drugs to different parts of the country: there is the pull system, where the health centres request the drugs and NMS responds by supplying them. The NMS also uses the push system, where they identify the needs and take drugs to those services without being requested to do so. In such cases, NMS intervenes by taking the required services to the population

However, with opioids, because of the strong fear of addiction, the NMS cannot just push them. NMS, being a signatory is also bound by a quota system on the opioids prescribed by the International Narcotic Control Board (INCB) which obliges every country to procure a certain quota. It follows that whatever is distributed must be accounted for, which calls for close monitoring. One of the KIs affirmed that supply of drugs to different health service providers is done by the NMS according to the budget allocation and requisition. Every requisition for drugs comes with allocation from the

report prepared by the Ministry of Health prescribing the quantity of drugs required. The NMS receives the report and distributes drugs accordingly.

tion of the procured drugs, including opioids, to different health centres is in some cases done by NMS but in some instances the patients collect the drugs by themselves from the stores. Respondents observed that NMS takes 3.5 days to deliver drugs to the furthest health facility

With regard to supply chain mechanisms, respondents indicated that the opioids procured and supplied are codeine phosphates, morphine oral solution/tablets and Bernadine. They further pointed out that before the NMS supplies any opioid, it considers the level of performance of the clinic, health centres or hospital and observes whether it can supply them with what class of drugs. Further still, it was pointed out that the NMS establishes the level and type of staffing as well quantity of drug consumption. Meanwhile in the stores opioids are kept under lock and key. When a request is received the NMS looks at the requisitions. Sales of those drugs to various health facilities are also regularly reviewed. From the quality assurance department, it was pointed out that, “supply of opioids are strictly on order”; it is only hospitals and other authorised health facilities that are allowed to order opioids. No clinic or health centre can order for opioids. The opioids are issued to referral hospitals or where NMS is satisfied the facilities have the required personnel for instance to effect surgical operations or those that have terminally ill patients who

require the opioids.

Morphine, codeine and Bernadine are the only narcotics procured and supplied to the patients. It should be noted that NMS has a responsibility to have the opioids/narcotic drugs available in its stores whether or not the demand is there, so that the public can be served in case of emergency.

c) Restrictions

KIs in the drug procurement chain affirmed that the restrictions are necessary because the opioid drugs are very dangerous to people who do not need them. The NMS argues that most of these narcotics are addictive and can easily be abused. Thus only institutions that need the drugs receive them. If not restricted, they would instead go in the hands of the addicts and those who genuinely need them would miss out.

During interviews, it was revealed that restrictions were justified by the Drug Inspectorate, NDA as indicated below:

Opioids such as morphine are recognised by NDA as essential drugs. Although nationally controlled, we also subscribe to the international and regional instruments that allow opioid use for medical purpose. The restrictions we enforce are for safety reasons. All those strong pain-relieving drugs are available and allowed to be dispensed but are only restricted. As NDA we are drug regulatory agents of the Government and that includes regulation of all classified drugs. Although certain drugs are strictly controlled by NDA, we ensure they are available but they are only dispensed by registered and authorised institutions and personnel (KI, drugs inspector).

6: DISCUSSION

6.1 Access to palliative care

Findings from the study indicate that both government and NGOs offer palliative care. Many of the patients were disadvantaged in terms of physical access, incurred costs on transport and costs on drugs. Availability of comprehensive services and hence utilisation of these services would have been curtailed by the extra costs incurred. It is worth noting, however, that more people incurred costs on transport than on drugs. The less educated went to facilities less often than the more educated. There was lack of raw materials to make morphine in some facilities, which made the supply of morphine irregular. Patients in some organisations failed to get opioids because opioids were provided through other organisations and not directly by the organisation they visited. In addition, palliative care organisations concentrated more on medical care and to a lesser extent, offer the social dimensions of palliative care.

These results are similar to results from other studies with respect to non-comprehensive care offered in some areas (Billings and Pantilat, 2001), where some facilities offer consultation alone and patients are referred to higher level institutions (Goldsmith, Dietrich et al. 2008). In Uganda, as in some other countries, palliative care is offered by both the government and NGO facilities (Morrison, Maroney-Galin et al. 2005). However there are differences, especially on the levels at which palliative care is provided. While some countries, like Chile, have put it at the primary health care level and by so doing increased access, this is not yet the case in Uganda.

It is, therefore, imperative that to increase access and reduce the costs that patients have to incur in transport it would be important to integrate these services at the primary level. These facilities will be closer to the patients who even at this time are unable to travel

long distances. Secondly, it is important to secure the support of the NGOs as this would increase the coverage of services.

For the fulfilment of this objective, amendments, judicial activism, public litigation or expansive application of human rights could provide the legal basis for the expansion of access to palliative services.

6.2 Ethical issues

The study identified ethical issues of autonomy and confidentiality as some of the key dilemmas confronting palliative care provision. The illnesses that the patients suffered from would be handled more easily in a family atmosphere yet health workers found themselves in a dilemma over whether to divulge information to the family or to depend on the patient to inform the family. Another dilemma was when the patients refused to take certain medicines, which would be very helpful to them, yet the principle of autonomy meant the patients had the right to refuse. The providers also have to ensure that whatever they are doing is for the good of the patient. This highlights the principle of beneficence.

Issues of decision-making have been highlighted even in other studies in high income countries (Kinlaw 2005). Patients have to keep their autonomy. The challenge is compounded when the providers would need to keep confidentiality, and yet would need to involve the family (Plu, Purssell-Francois et al. 2008).

Despite the observance of ethical principles by the providers, ethical dilemmas remain. The providers will keep debating within themselves how to balance confidentiality and autonomy. It requires a disciplined health workforce and this is supported by a strong code of conduct, enforced regulatory policies and strong observance of human rights.

6.3 Awareness of laws and rights of patients

Palliative care patients as well as health providers were largely aware of the laws, legal services and rights affecting patients in need of palliative care. Although there were high levels of knowledge, in most cases implementing these rights did not always happen due to environmental and circumstantial reasons. For instance, privacy is almost always affected by the physical infrastructure. There was a low level of knowledge of international laws and conventions among health workers. Other studies concur that most patients for example are aware of their rights or have adequate information on their illness. An Italian study on illness awareness in terminal cancer patients revealed that in the case of information, 67 per cent of patients reported they were previously informed about their diagnosis, but only 58 per cent seemed to be aware of their terminal condition. The comparison between the caregivers' opinions about the level of information provided to the patients and their present awareness, and what the patients really know about their own, disease, shows a high degree of correspondence. Some variables, such as age and the education level of patients were associated with patient awareness (Corli, Apolone et al. 2009).

It should be observed that infrastructure for health care, especially palliative services, is essential since patients tend to stay in care longer, turning these facilities into 'their homes'. Knowledge gaps in international laws and conventions among health workers call for systematic training and making available relevant materials not only to health workers but also patients. In a resource-constrained country, such as Uganda, an awareness campaign of relevant laws and rights of patients would be critical in the mass media and ongoing medical training.

6.4 Preparation for death

The study highlighted issues of will-making, succession planning and social security. Whereas many respondents agreed that will-making was important, it was also noted that having a will was not an assurance it would be respected. This was complicated by the many hurdles the people who would be wronged have to go through if they are to seek redress in court. Many people did not even know how to make a will in such a way that it would comply with legal requirements. The patients who had less education were less likely to know what a will was. The patients who were single were also less likely to have received advice on succession planning. Some respondents also indicated that some of the patients were not willing to make a will. Family involvement was sometimes detrimental to the patients as even the children who would be closest to the patient would sometimes turn against the patient.

Studies from elsewhere have highlighted the importance of preparation for death immediately the symptoms are difficult to control (Sekelja, Butow et al. 2009). This is unlike the practice among our respondents who could even refuse to make a will up to their death. Whereas family involvement was expected to benefit the patient (Terry, Olson et al. 2006), respondents in the study found the family sometimes not supportive. It is important that not only should people make wills, but that once a will is made the government institute a mechanism, even at the grass roots level where sometimes traditions are so strong, to protect those to whom property has been bequeathed.

The timing of legal aspects in palliative care is generally designed as last-card interventions. In Uganda, like any other African community, it is a taboo to even mention the word 'will' because it is believed that doing so attracts an immediate death. Consequently, not so many know about a will and if they do, they nevertheless appreciate

its importance. It is the men who are supposed to make decisions on all matters including matters of inheritance. The cultural practice is so strong that it renders the written law a mere paper tiger whose impact is practically not felt.

Even before death, some of the respondents especially from the FGDs indicated that men would already be very poor and would have nothing to pass on to the children and wives left behind. In Uganda, the legal regime compels employees/persons not entitled to earn pensions to make compulsory savings. Accordingly, the National Social Security Fund Act is a compulsory saving scheme that covers all employees in the private sector, including the NGOs and parastatal bodies that are not covered by the Government pension scheme.

Under the NSSF Pension Scheme, every eligible employee is entitled to subscribe to the fund which collects and invests the funds and pays qualified contributing persons any of the following benefits: old-age benefit, invalidity benefit, survivors benefit, emigration grant and withdrawal benefit.

Currently as a policy, the NSSF identifies people with HIV and AIDS as physically or mentally incapacitated and as potential beneficiaries of the invalidity benefit upon providing a certificate from a medical doctor that they have HIV and AIDS, which the NSSF can then verify. This stems from the acknowledgement by NSSF of the financial constraints caused by HIV-AIDS-related hospital admissions, treatments and transport to health facilities. Patients at this stage desperately need their savings to meet their needs and also to allow them to adequately plan for the future for their families.

Meanwhile, survivor's benefit is a benefit paid after the death of the contributing employee by NSSF to his or her dependant relatives who may include the spouse, children or other dependant relatives who were wholly or substantially dependent on the deceased.

However, the stringent procedure, bureaucracy and limitation in the law, which does not extend to those in public service, and NSSF policies make it difficult for patients or dependants to claim for their benefits from the Fund.

The social security is also governed by the Police Act Cap 303 for the police forces, the Municipalities and Public Authorities Provident Fund Cap 285, the Provident Fund (Local Governments Act Cap 287) which caters for employees in the local Governments and the Armed Forces Act cap 298 which provides for the pension requirement for soldiers and other armed personnel. These laws, however, remain fragmented and not comprehensive enough to address the social security needs of all Ugandans. Even then the ranges of benefits offered under the schemes do not cater for immediate social needs like sickness, medical care, and education. These contravene the international standards stipulated in the Social Security (Minimum Standards) Convention, which in effect do not guarantee the required social security.

6.5 Family participation in palliative care

Largely there is adequate participation in patient care by the family, both physically and psychologically. This is in terms of physical and psychosocial support. However, in some instances there is still the 'blame game' in cases of HIV terminally-ill patients, and cases of abandonment were echoed in this study. There is, therefore, need for legal support and continuous counselling for the family. In terms of legal support, this is highly needed, especially when the head of the family dies, to help deal with the many legal disputes and property inheritance wrangles. Participation in patient care was desired in other studies (Henriksson and Andershed 2007; Feuerwerker and Merhy

2008; Wolff, Robert et al. 2010). The demise of the head of the family affects the family not only economically but also socially and psychologically. The scar or vacuum created by the death is even greater when the family has been deprived of its breadwinner. To ensure effective management and survival of the estate of the deceased member, there should be in place a humane legal framework that not only enables the family to survive economically, but also enables them to deal with all other associated problems that surface with the death of the leading member of the family, such as property and inheritance disputes.

Inheritance disputes are basically associated with cultural practices that lean in favour of men more than women and children. The following legal support mechanisms could be useful if made available to a family post death:

- Enactment of strict laws against interference with the deceased's estate. There should be a severe penalty for deviation from the will of the deceased where the deceased dies testate and against those who interfere with the estate on a cultural basis.
- Empowerment of the Administrator General's Office. This could be so that by operation of law the Administrator General takes over the management of the estate of the deceased upon death of a person who dies intestate. However, the Administrator General's office, which falls under Ministry of Justice and Constitutional affairs, does not have capacity to prosecute the interferers.
- Home care services: orphans and the elderly should be treated as marginalised groups. This is so where the death leaves the family without anyone to provide for the surviving family members.

- Social security to the families: there should be a law that enables citizens including the terminally ill with no sources of gainful employment to seek social benefits from the State upon proper certification.

6.6 The provider and the health care system

Our results indicated that health workers recognise the need for continuous education when they begin to work for a palliative care institution. This possibility enables them to get oriented and/or updated on prescription practices and dispensing, and safety procedures, especially for addictive medicines. It ought to be noted that safety of opioids needs to remain balanced within the distribution chain. There is need to enhance drug safety, especially at the household level, where health workers are not in absolute control.

In circumstances of cancers and other diseases requires palliation, a critical mass of health workforce needs to be trained in the diagnosis and management diseases that lead to palliative care. This is particularly important at the lower levels of health care (HC IVs and district hospitals). The challenge would be the cost of diagnostics and other logistics involved.

7: Conclusions and Recommendations

7.1 Conclusions

Many people still lack easy access to palliative care services. This is more pronounced in the less educated who go to the palliative health facilities less often than the more educated. There are fewer facilities that offer comprehensive palliative care. This goes against the patients' rights to care. It is incumbent upon the government to see that these rights are respected.

Ethical dilemmas still confront the health care providers in the management of palliative care. HIV and AIDS patients would benefit from revealing their HIV status but some do not do so quickly. Despite the providers' wish that the patients receive the best support possible, they have to respect the patients' autonomy and not reveal their HIV status. HIV and AIDS patients should be encouraged to disclose their status. Sensitisation to reduce stigma among people should also be carried out, so that the HIV patients could comfortably disclose their status.

Palliative care patients and health providers were largely aware of some of the laws, legal services and rights affecting patients in need of palliative care. There was, however, inadequate knowledge of international laws and conventions among health workers, as well as palliative care patients.

Despite the importance of making a will and succession planning, many people still do not do it partly because they do not want to, but also partly because they are not aware or do not or have the technical knowledge to write a will. The less educated were more likely not to know what a will is and the single patients were more likely not to have received advice on succession planning.

There is adequate family participation and support in patient care, both

physically and psychologically.

Health workers recognise the need for continuous education when they begin to work for a palliative care institution. This possibility enables them get oriented and/or updated on prescription practices and dispensing and safety procedure especially for addictive medicines.

7.2 Recommendations

Judicial officers can play an important role in addressing human rights issues of palliative care patients and courts of law must speak clearly and strongly in support of fundamental human rights of disadvantaged and vulnerable individuals and groups. To achieve these, courts need to move away from formalism and embrace judicial activism/creativity in the administration of justice. There is consequently a need for a judicial transformation that absorbs international human rights norms as part of a broader transformation of Ugandan human rights culture.

The courts need to apply international and regional instruments directly, recognising the rights of palliative care patients especially where they are void in the national law. With a creative mind, courts can utilise the recognised rights under the 1995 constitution to protect, respect and promote palliative care patients against discrimination and stigma and other egregious violations of their dignity.

Because of their vulnerability, the majority of persons may not afford the legal recourses required for court intervention when their human rights are violated. Some may not be aware of the legal responsibilities to challenge the discriminatory laws, policies and practices. More sensitisation among the communities should be done to make people aware of the legal recourse but also local government officials should be obliged to support the vulnerable.

Human rights activists, individuals and organisations need to take palliative care issues to court for declarations or adjudication. Advocacy for palliative care by existing organisations may be advantageous since they already have the resources and human power, as well as the legal platform. The constitutional framework offers an accommodating legal atmosphere under which such cases can be taken up by human rights activists, for instance, through public interest litigation. However, judicial protection may not be sufficient. What is required is an inter-disciplinary approach involving judicial officers, lawyers, health professionals, legislators (Parliament) and policy makers (Executive). The executive, for example, should spearhead the sensitisation and awareness-raising programmes.

Regarding social security reforms, there is need for the relevant laws (the NSSF Act and the Pensions Act) to be amended to make it easier for patients with life-threatening illnesses to access their social benefits with minimal difficulty, to enable them to plan sufficiently for their families. This reduces the psychological fatigue of the patient. This in our view will lead to realisation of palliative care in its full application.

There is need to consolidate and harmonise the various laws related to the practice of medicine to eliminate the fragmentation which adversely affects implementation. The professional codes ought to be strengthened, and inspection and monitoring need to be improved.

Intervivos disposition should also be encouraged, whereby a person disposes of their property while alive. This, of course, takes effect upon death. But this is tricky in itself because the beneficiary will know that he or she has been given property and it will only take effect only after the donor's death.

The terminally ill should be encouraged to invest in ventures which do not require their physical presence, like shares. The investment in shares which is now gaining ground in Uganda, is an opportune area for the terminally ill to venture in so far as it requires no supervision, neither does it require one's presence.

Advocacy groups are the voice of the very many who are not only uninformed but also lack the means to raise their concerns. Advocacy groups therefore have a significant part to perform if palliative care is to be promoted in Uganda. There is need to fill the policy gaps by making palliative care a priority.

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Appendices

Appendix 1: Consent form for patients

Information Sheet for the patients participating in the study on assessment of legal needs for patients and palliative care providers
(English Version)

Introduction and what we are doing:

I am -----, and I work with African Palliative Care Association (APCA). We are assessing the legal needs for patients and palliative care providers in accessing the palliative care patients need which is physical like for drugs, spiritual, and psycho-social.

Purpose of the research:

Access to palliative care that is total is very important in the management of patients with excessive pain like those with cancer or AIDS. In order to find ways of having this total care to the patients who need it, we need a better understanding of what the patients in these organisations know about these medicines and palliative care in general and what they think are challenges that affect provision of palliative care. This will help in identifying the legal needs of patients and the providers in these organisations that provide palliative care.

Procedures:

To find answers to some of these questions, we invite you to take part in this study. If you accept, you will be required to answer questions which will be administered by [..... name of research assistant].

You are being invited to take part in this interview because we feel that your experience in this organisation as a client

can contribute much to this research.

If you do not wish to answer any of the questions included in the survey, you may skip them and we move on to the next question. The survey will be by interviewer-administered questionnaires. The information recorded is considered confidential, and no one else except the research team will have access to the survey.

The expected duration of the survey is about 40 minutes.

Risks and Discomforts:

There is a slight risk that you may share some personal or confidential information by chance or that you may feel uncomfortable about talking about some of the topics. However, we do not wish this to happen, and you may refuse to answer any question or not take part in a portion of the survey if you feel the question(s) are personal or if talking about them makes you uncomfortable.

Benefits:

There will be no immediate benefit to you, but your participation is likely to help us find out more about the legal needs for patients like you who need these powerful drugs that work on pain. Your participation will help us to know more about these legal needs and hopefully by addressing them, you and other patients like you will also get more access to palliative care that takes care of your physical needs, psychosocial needs and spiritual needs.

Confidentiality:

The information that we collect from this research will be kept confidential. Information about you that will be collected from the study will be stored in a file that will not have your name on it, but a number assigned to it instead. The name associated with the

number assigned to each file will be kept under lock and key and will not be divulged to anyone except the research team.

Right to refuse or withdraw:

You do not have to take part in this research if you do not wish to do so, and refusing to participate will not affect your future treatment at this facility here in any way. You will still have all the benefits that you would otherwise have at this health facility. You may stop participating in the interview at any time that you wish without losing any of your rights as a patient here. Your treatment at this centre will not be affected in any way.

Who to contact:

If you have any questions you may ask those now or later. If you wish to ask questions later, you may contact any of the following:

Dr. Henry Ddungu, Advocacy Manager,
African Palliative Care Association

Tel: +256-772-426 806, e-mail:
henry.ddungu@apca.co.ug

Abby Baguma, Partnerships Manager,
African Palliative Care Association

Tel: +256-772 821 070, e-mail:
abby.baguma@apca.co.ug

Dr. Lynn Atuyambe, Lead Investigator

Tel: +256-772 467 504, e-mail:
atuyambe@musph.ac.ug

This proposal has been reviewed and approved by the Uganda National Council for Science and Technology, which is a team whose task it is to make sure that research participants are protected from harm.

Certificate of Consent for the Survey

I have been invited to take part in the research on assessment of legal needs for patients and palliative care providers. I have been told the purpose of this research study is identifying the legal needs of patients and the providers in these organisations that provide palliative care. There may be some discomforts on questions that I may not feel comfortable with. However I am free not to answer and my action will not affect my benefits from this organisation.

As an individual, I may not immediately benefit from this research but the findings will help in responding to the legal needs that patients and health providers face in accessing medicines that work on pain.

The information that I will give is going to be kept confidential. Nobody except the research team will have access to it. The names will not be recorded. Numbers will replace the names.

I have been given the contact person in case I have something to ask namely Dr. Henry Ddungu, Abby Baguma and Dr. Lynn Atuyambe.

I have read the foregoing information, [or it has been read to me]. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study and understand that I have the right to withdraw from the interview at any time without in any way affecting my medical care.

Name of Subject

Date and Signature of Subject

___/___/___ (dd/mm/yy)

If illiterate

Name of Independent Literate Witness

Date and Signature of Witness/RA

(this person will be selected by the participant and will have no connection to the research team)

___/___/___ (dd/mm/yy)

Name of Researcher/Moderator

Date and Signature of

Researcher/Moderator

___/___/___ (dd/mm/yy)

Appendix 2: Assessment of Legal Needs for Patients and Palliative care providers

General introductions

Survey questionnaire for patients

The interview is done in a place where the client feels comfortable. First an informed consent is sought from the in-charge of the organisation but also the client or the attendant if the client is a child. The sheet containing information about the study and seeking the client's consent is given to the client.

Respondent no:

Organisation:

Date:

Interviewer's name:

Section A: Background characteristics of the respondents:

1. Sex: a Male b) Female
2. How old are you: _____
3. Which is your current home district? _____
4. Marital status: a) Single b) Married
c) Divorced / Separated
d) Widowed e) Cohabiting
5. What is your highest level of education?
a) None b) Primary 1 – 4
c) Primary 5 – 7 d) Secondary 1 – 4
e) Secondary 5 – 6 f) Tertiary
6. Have you ever been told by a doctor or any health worker what illness you have?
a) Yes b) No (Go to No 8)
7. Would you be willing to tell me what your illness is?
a) Cancer of any kind b) HIV/AIDS
c) Any other condition, specify.

d) Not willing to disclose
8. How long have you had this illness? _____
9. How long have you been part of this programme under this facility?
_____. Probe the relationship between the length of illness and time in programme – referral, symptoms etc

Section B: Access to health care

10. How much does it cost you to come from your home to this place to get treatment?
_____ (transport, lunch etc)
11. How often do you come to the facility?
12. How much do you spend on medicines in a week? _____
13. Would you say pain is or has been one of your major complaints that has brought you to this centre? a) Yes b) No
14. Did you/ do you receive medicines
 - i) To control severe pain?
a) Yes – where did the medicines come from or where did you receive it?
b) No (Go to No 15)
 - ii) For other symptoms?
a) Yes – where did the medicines come from or where did you receive it
b) No (Go to No 15)
15. Why don't you get the medicines that you need for your pain? (The respondent can give more than one response. Mention the reason and ask whether that is the one or it is not the one)
 - a) Medicines are very expensive
 - b) Medicines not available even when one has the money to buy them
 - c) I do not know the medicines to buy
 - d) Any other; Specify _____
16. Apart from medicines, what other services are you given in this organisation? (The respondent can give more than one response)
 - a) Counselling/ psycho-social support
 - b) Legal advice e.g. to make a will
 - c) Spiritual talks from religious leaders
 - d) Others, (Specify) _____

Section C: Ethical Issues

17. Are you given information about side effects of the medicines you are given?

- a) Yes (Go to No 19)
- b) No

18. Why do you think you have not been given that information? (The respondent can give more than one response)

Section D: Legal Issues

19. Do you know what a will is?

- a) Yes
- b) No

20. Have you received any advice on succession planning?

- a) Yes
- b) No

Thank you for your time!

Appendix 3: Key Informant interview guide for health providers

ID: _____

Gender (male/female): _____

Job Title: _____

Organisation/Health facility: _____

Date of Interview: _____

Name of interviewer: _____

Time started-Ended: _____

Transcribed by: _____

General introduction – ask questions such as length of time in job, specific role etc

A). Introductory question

1. What services do you offer at this facility? (probe for legal support, spiritual support, palliative care etc)
2. At what stage do most patients come to this facility (probe whether they come early enough or if they come when they are really sick. Is there a difference between when men and women come?).
3. What is the catchment area for your patients/ where do you patients come from?
Probe into differences for men and women in how far they travel.

B) Rights

4. Are you aware of human rights related to the patients you serve? What are they? Would you say that patients are aware of their rights? How do you address these rights?

C) Laws and conventions

5. Are you aware of International laws and conventions in relation to the patients you serve? Do you find them applicable or even necessary in your setting? Explain your response. (probe with examples)
6. In your experience, are there legal issues that affect the patients you serve? In which way do they affect the patients? Give detailed explanation.
Probe into gender differences for legal issues

D) Death, dying and the law

7. Have any of your patients ever sought guidance from you or your staff on:
 - a) How to make a will
 - b) Guidance on how to prepare for their end of life
 - c) Worries about life after their death?*Probe into whether men or women seek guidance more*
8. How do you involve families in the care of the patients and do you think the families are usually more or less prepared to handle bereavement and after life issues such as ownership of property, care of orphans etc?
Have you been involved in the discussion of any of the above issues with any of your patients? Give detailed explanation.

E) Ethical issues

9. As a practitioner, what are some of the ethical considerations you take into account while providing care for patients?

F) Access issues

10. What palliative care medicines do you have at this facility? How accessible (in terms of availability and affordability) are the medicines you use in providing palliative care? (Probe for availability of opioids)
11. In general, how do health providers (doctors, clinical officers, nurses, midwives) in this facility and generally in country get training or education in pain control medication and methods?
12. What control measures are in place at this facility to ensure that palliative care drugs such as Opioids do not get into hands of unlawful/illicit/illegal users?
Probe into legal requirements for opioids
13. Which staff cadres prescribe opioids at this facility? Are opioids prescribed effectively for all patients or are there any recommendations you would make for change? Explain
14. What do you consider the biggest barrier to prescribing and/or dispensing opioid medications to persons under palliative care? (Probe: whether it is the lack of training of health workers, the legal system, the drug policy in the country, the cost of the drugs, and the fear of using the drugs by the patients. Are the barriers for men different from those of women?)
15. Do you have any questions on what we have discussed

Thanks very much for your time!

Appendix 4: Key informant interview for legal officer

ID: _____

Gender (male/female): _____

Job Title: _____

Organisation/Health facility: _____

Date of Interview: _____

Name of interviewer: _____

Time started-Ended: _____

Transcribed by: _____

Note the interviewer will introduce to the officer what palliative care is and the role Opioids in life-threatening illnesses

A) Medical Regulations

1. Tell me about how laws, policies and regulations concerning clinical use of opioid drugs are enforced?

Prompts: Elicit details of the day to day practice of enforcement

2. Do laws, regulations and policies relating to clinicians create any additional restrictions for prescribing opioids? Tell me about them...

Prompts

- Elicit each barrier, for example, do regulations ...
- Limit the length of prescription validity or refill
- Require record keeping of prescriptions?
- Require that a patient be “terminal” for pain relief?
- Require a particular diagnosis?
- Limits on dosage or type of drug?

- Limits dispensing authority
- Probe for differences by drug type or dose

B) Dispensing Regulations

3. Tell me about how laws, policies and regulations concerning health providers who dispense opioid drugs are enforced?
Prompts: Elicit details of the day to day practice of enforcement
4. Are health workers subject to inspection, review, or additional scrutiny for, or related to, prescriptions of opiates or opiate substitutes?
5. Do licensing and disciplinary bodies review patterns and “legitimacy” of pharmacist’s dispensing of opioids?

C) Palliative care in general

6. What do you consider to be the legal needs of the family and those left behind which should be taken care of before the person dies?
7. What are the legal issues we need to consider when caring for people with life-threatening illnesses?

Thank you for the time!

Appendix 5: Key Informant interview guide for Human Rights law expert(s)

ID: _____

Gender (male/female): _____

Job Title: _____

Organisation/Health facility: _____

Date of Interview: _____

Name of interviewer: _____

Time started-Ended: _____

Transcribed by: _____

Note the interviewer will introduce to the officer what palliative care is and the role of Opioids in life-threatening illnesses.

A) Adequacy of the human rights to palliative care in the laws

1. For how long have you been in practice as a human rights defender/advocate?
Probe time and what he/she has mainly been doing for the past 5 years
2. In your opinion and experience, do you feel there is an adequate guarantee of human right to health specifically to palliative care in the laws?
 - a) Which are these laws you are referring to?
 - b) If yes (No.2), briefly state the reasons for your answer
3. What would you describe as the legal needs of persons receiving palliative care? What legal support do they have currently?

4. In your view, does the law sufficiently address the legal needs of the various interest groups including the children, the elderly, disabled, prisoners, refugees with life-threatening illnesses? Specify the needs under each group? Explain in details
5. Do you feel the current laws adequately protect the rights of persons with life-threatening illnesses?
 - a) If not give reasons?
 - b) What changes would you recommend?

B) Succession, guardianship and other legal issues associated with end of life

6. Do you help people in writing/drafting of wills?
 - a) Has any person with a life-threatening illness ever instructed you to write a will?
 - b) What was his or her basic motivation/reason for a will?
 - c) In your opinion, do you think people with life-threatening illnesses should make wills?
 - d) Why? Give reasons for your answer
7. Would you or your organisation provide pro-bono services to people with life-threatening illnesses?
8. In your experience as a legal practitioner, are there any problems a family may face when its influential member dies without making a will?
 - a) If yes, state the problems such a family may face?

D) Estate/property management during illness

9. In your view, what other available avenues do you feel persons under palliative care can use to manage their properties, debt management, family or plan for the life ahead of them?
(probe for powers of attorney if not mentioned)

E) Social security/benefits etc as an aspect of palliative care

10. Are people with life-threatening illnesses entitled to any form social benefits from the Government under the Constitution or any other law that you know?
a) If not what do you propose should be done?
b) What would you propose to be done to address the various interests groups; the children, elderly, prisoners, etc under palliative care?
11. What other legal reforms do you propose to ensure realisation of a fully fledged palliative care in Uganda?

F) Ethics and palliative care, examine the relationship

12. In your view, do feel there are adequate laws to regulate the practice of medicine, pharmacy and Nursing in Uganda?
a) How does that impact on the rights of people with life-threatening illnesses?
13. Do you have any questions for us?

Thank you for your time

Appendix 6: Key Informant interview guide for Human Rights law expert(s)

ID: _____
Gender (male/female): _____
Job Title: _____
Organisation/Health facility: _____
Date of Interview: _____
Name of interviewer: _____
Time started-Ended: _____
Transcribed by: _____

Note the interviewer will introduce to the officer what palliative care is and the role of Opioids in life-threatening illnesses.

B) Adequacy of the human rights to palliative care in the laws

14. For how long have you been in practice as a human rights defender/advocate?
Probe time and what he/she has mainly been doing for the past 5 years
15. In your opinion and experience, do you feel there is an adequate guarantee of human right to health specifically to palliative care in the laws?
a) Which are these laws you are referring to?
b) If yes (No.2), briefly state the reasons for your answer
16. What would you describe as the legal needs of persons receiving palliative care? What legal support do they have currently?

17. In your view, does the law sufficiently address the legal needs of the various interest groups including the children, the elderly, disabled, prisoners, refugees with life-threatening illnesses? Specify the needs under each group? Explain in details
18. Do you feel the current laws adequately protect the rights of persons with life-threatening illnesses?
 - a) If not give reasons?
 - b) What changes would you recommend?

B) Succession, guardianship and other legal issues associated with end of life

19. Do you help people in writing/drafting of wills?
 - a) Has any person with a life-threatening illness ever instructed you to write a will?
 - b) What was his or her basic motivation/reason for a will?
 - c) In your opinion, do you think people with life-threatening illnesses should make wills?
 - d) Why? Give reasons for your answer
20. Would you or your organisation provide pro-bono services to people with life-threatening illnesses?
21. In your experience as a legal practitioner, are there any problems a family may face when its influential member dies without making a will?
 - a) If yes, state the problems such a family may face?

D) Estate/property management during illness

22. In your view, what other available avenues do you feel persons under palliative care can use to manage their properties, debt management, family or plan for the life ahead of them? (probe for powers of attorney if not mentioned)

E) Social security/benefits etc as an aspect of palliative care

23. Are people with life-threatening illnesses entitled to any form social benefits from the Government under the Constitution or any other law that you know?
 - a) If not what do you propose should be done?
 - b) What would you propose to be done to address the various interests groups; the children, elderly, prisoners, etc under palliative care?
24. What other legal reforms do you propose to ensure realisation of a fully fledged palliative care in Uganda?

F) Ethics and palliative care, examine the relationship

25. In your view, do you feel there are adequate laws to regulate the practice of medicine, pharmacy and Nursing in Uganda?
 - a) How does that impact on the rights of people with life-threatening illnesses?
26. Do you have any questions for us?

Thank you for your time

Appendix 7: Focus Group Discussions with HIV/AIDS and Cancer patients

Good-morning /afternoon / evening participants,

You are welcome to this discussion. We are a team from the Makerere University School of Public Health (MUIPH) and the African Palliative Care Association (APCA). We would like to discuss with you the issues that concern your health and the services you require.

Feel free to discuss /participate and ask for clarification where necessary. All the information is strictly confidential and nothing you will say will make us unhappy. You do not have to reveal any personal information if you do not want to, but if you are willing to share your experiences; it will be very helpful to us in understanding issues relating to the care and support provided to you at this clinic. I would request that you be audible and speak one at a time so that all your important views are understood and written down.

I also have a tape recorder that will help me to capture the discussion to ensure that I do not miss anything. May I use it? [Moderator seeks consent]. In case some participants do not wish to be audio taped, the moderator should thank them for their interest and request them to leave.

Thank you very much.

Date

District

Facility

Moderator

Recorder

Language(s)

Time began

Time ended

Description of participants:

Type of contact group (males or females)

Number of participant's

Age range

Other relevant characteristics/description

Group introductions

The discussions questions

A) Introduction

1. What are the main problems faced by patients like you? Brain storm of key issues affecting the patients such as pain, physical, psychosocial, spiritual – what are the legal implications here?
2. What legal services are you entitled to as patients on palliative care? Explain.

B) Rights

3. Have you heard the about human rights and what do you understand by this?
4. What are the issues you face in terms of human rights?: Probe for the following if not mentioned.
 - Limited awareness of the fundamental rights or freedoms e.g. right to health
 - Limited awareness of legal services
 - Legal Services are costly if one seeks redress for the violated rights.
 - The law is difficult to understand including the language used
 - Access to the legal services;
 - Corruption in the process of redress.
 - Attitude to legal rights – hopelessness/ belief in the system
 - Ignorance of enforcement procedure

C) Issues of access: medicines and information

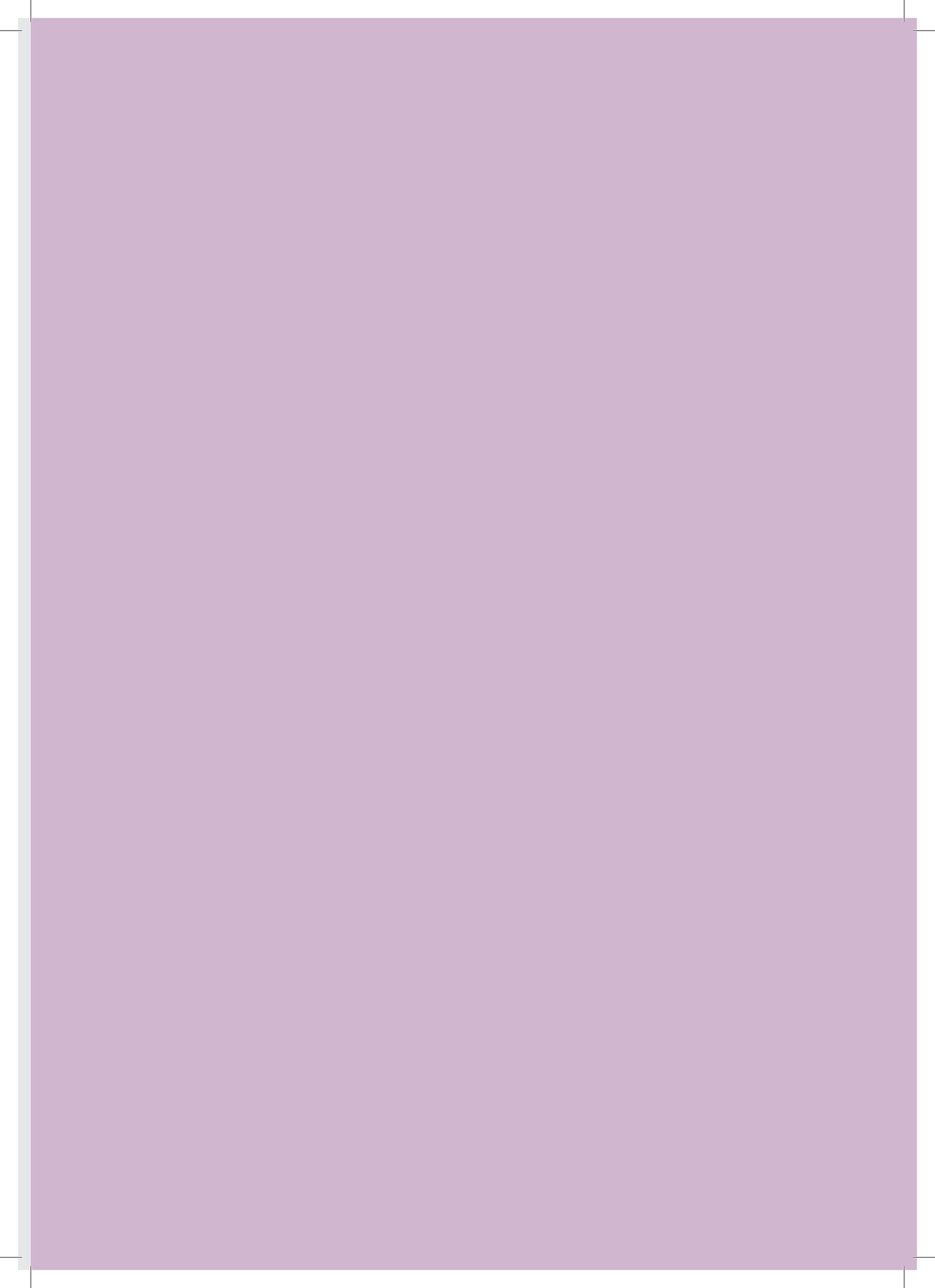
5. How are your families/communities involved in your current sickness in a caring role? Would you say females are involved in your current sickness differently from males?
6. Would you say from your experience that there is restriction to palliative care medicines? Explain?

D) The community and legal issues

7. Would you say there are family disputes upon the death of head of the family who owns property and what are the likely causes of these disputes? Probe into issues of succession planning, making of wills, and conflict resolution upon death. Probe for other issues such as debts
8. 8. What would one do to ensure that these disputes do not occur after passing on (e.g. free from disputes) regarding your children (guardianship), property/assets, and the management of your family? Probe into male and female differences
9. Do you think the law is good enough to protect the land, children/dependents and property rights upon the death of the head of a household? Probe into male and female differences.

Do you have any questions for us?

Thank you for your time



African Palliative Care Association
PO Box 72518
Plot 850 Dr Gibbons Road
Kampala, Uganda

Tel: +256 414 266251
Fax: +256 414 266217
Email: info@apca.org.ug
Website: www.apca.org.ug

NGO Registration Number 4251



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