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**RATIONALE FOR MEDICAL LEGAL PARTNERSHIPS IN THE ADVANCEMENT OF PALLIATIVE CARE; A
UGANDAN CASE STUDY**

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RATIONALE FOR MEDICAL LEGAL PARTNERSHIPS IN THE ADVANCEMENT OF PALLIATIVE CARE; A UGANDAN CASE STUDY

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ABSTRACT

Palliative care worldwide is not a substantially novel concept let alone foreign. However despite its active practice mostly in European and American states, the same cannot be said of Uganda. This is troubling especially given the global increase in terminal illness. This article provides an insight into pathways that can be undertaken to improve provision of palliative care as an offshoot of the right to health, emphasizing the integration of medical legal partnerships. In so doing, it paints a picture of the human rights canvas upon which palliative care may be placed at the national and international level. It seeks to highlight that lawyers at various levels can play a key role in the realization of this end-goal.

1.0 INTRODUCTION

One might ordinarily overlook the need for an interdisciplinary approach to the provision of medical health, sticking to the treatment of physical ailments and in disregard of the psychological aspects that greatly affect patients. In this regard, research has been conducted and findings made to the effect that involvement of legal practitioners in the medical sphere can go a long way in healing the unseen “wounds” many of these patients carry, through the provision of legal aid.

In the words of Dame Cicely Saunders, one of the founders of palliative care, ‘*palliative care focuses on adding life to the days rather than days to the life.*’ ‘Patient care’ relates to the prevention, treatment and management of illnesses and the preservation of physical and mental well-being through services offered

* Law Student. I would like to express my profound gratitude to the PILAC organization for the extensive training and exposure. Through the CLE program, I was able to interface directly with various palliative care stakeholders in Uganda. It was these interactions that birthed this paper, in the hopes that the same might spur action towards advancing the right. My deepest gratitude also goes to Ms. Atim for the time and guidance provided throughout the process of writing the paper. Special thanks to the Makerere Law Journal Editorial Board for the insight provided in preparation. I also extend my thanks to the palliative care teams stationed at Mulago Hospital and Kawempe Home Care. Their work is a testament to what can be achieved by sheer grit. All errors and omissions remain my sole responsibility.

by medical and allied health professionals.¹ The provision of quality and appropriate health care is part of the right to the highest attainable standard of health.²

Palliative care has been defined as an approach to health care that improves the quality of life of patients (and their families) facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems- physical, psychosocial and spiritual.³

This article highlights the important role students undertaking the law course can play in improving accessibility of palliative care nationwide. It argues for the assertion that palliative care is a human right. In so doing, it traces its existence in legal instruments both at the national and international level. The role students can play is illustrated by the medical-legal approach, its history and the various models the approach entails. The author discusses the nature of obligations placed upon other actors in regards to the provision of palliative care and discusses recommendations for better service delivery of palliative care within Uganda.

2.0 PALLIATIVE CARE AS A HUMAN RIGHT

Human rights are entitlements that all human beings have by virtue of the fact that they are human beings. The United Nations human have defined them as the universal recognition that basic rights and fundamental freedoms are inherent to all human beings, inalienable and equally applicable to everyone, and that every one of us is born free and equal in dignity and rights

¹ Kenya Hospices and Palliative Care Association (KEHPCA), *Legal Aspects in Palliative Care Handbook*, 2013.

² CESR, UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, 11 August 2000, E/C.12/2000/4, available at: <https://www.refworld.org/docid/4538838d0.html> [accessed 4 July 2019]. Para, 36.

³ World Health Organization, "WHO Definition of Palliative Care," online: WHO. Accessed at; (www.who.int/cancer/palliative/definition/en/). Last Accessed [Feb 4, 2021]

irrespective of color, age, ethnicity, gender, nationality and many other considerations.⁴

Human rights encompass the full range of standards derived from the Universal Declaration of Human Rights (UDHR).⁵ These rights are formalized in many international legal instruments, including covenants to which Uganda is a signatory.⁶ However, Uganda is a dualist state and has to ratify international agreements in order for them to be binding. They have to be enshrined in domestic law either by statute or common law.⁷ Nevertheless, domestic law cannot be interpreted to violate international commitments unless the domestic law in issue when accorded its rightful interpretation expressly requires that consequence.

It's important to note from the onset that there is no express protection for the right to palliative care in any UN treaty.⁸ However the World Health Organization (WHO) maintains that, “all people have a right to receive high-quality care during serious illness and to a dignified death free of overwhelming pain and in line with spiritual and religious needs.”⁹ The phrase, “All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood,” has increasingly become synonymous with the fight for human rights and this article borrows from that to make a case for the recognition of palliative care as one.¹⁰

⁴ UN, Human Rights Law. Accessed at: (<https://www.un.org/en/sections/universal-declaration/human-rights-law/>). Last Accessed [February 4, 2021]

Universal Declaration of Human Rights, GA Res 217(III), UN GAOR, 3d Sess, Supp No 13, UN Doc A/810 (1948) 71 [UDHR]

⁶ For example, Uganda ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR) on 21 January 1987

⁷ Shaw, Malcom N.2008. *International Law*. Cambridge, UK: Cambridge University Press

⁸ Liz Gwyther, Frank Brennan & Richard Harding, “Advancing Palliative Care as a Human Right” (2009) 38 *Journal of Pain and Symptom Management* at 769-770, pp767

⁹ World Health Organization, *The Solid Facts: Palliative Care* (Copenhagen: WHO Regional Office for Europe, 2004)

¹⁰ Article 1, UDHR

Additionally, the International Covenant on Economic, Social and Cultural Rights (ICESCR) recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and sets out standards for the state to follow as it houses state obligations to comply with the same.¹¹ The UN Committee on Economic, Social and Cultural Rights, a body responsible for supervising government compliance with the ICESCR, included palliative care as part of states' obligation to respect the right to health.¹²

The assertion of a positive right to palliative care under these international instruments, however, is highly problematic because of an overall lack of legal tools for enforcement. Many of the international treaties are based on review type remedies. They therefore fail to check ongoing violations of human rights by the state as it cannot be punished for the failure to carry out its well documented obligations. That is to say, they react to breaches rather than actively barring occurrences of the same, thus defeating their own purpose.

2.1.1 Palliative Care and the Right to Life

Uganda's constitution provides, by necessary implication, for the protection and enforcement of the right to palliative health care. However, the same is terribly lacking throughout the country. Article 20 of the constitution states that fundamental rights and freedoms of the individual are inherent and not granted by the state.

An argument in this regard is made for the relation between the right to life as protected under Article 22, and the quality of healthcare. Palliative care is intrinsically connected to the right to life. As earlier noted, palliative care focuses on adding life to the days. The importance of this right was

¹¹ UN General Assembly, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, United Nations, Treaty Series, vol. 993, p. 3, available at: (<https://www.refworld.org/docid/3ae6b36c0.html>) [accessed February 4, 2021]

¹² Committee on Economic, Social and Cultural Rights, General Comment 14: The right to the highest attainable standard of health, ESC, 22nd Session, UN Doc E/C.12/2000/4, (2000) at para 34

underscored by Justice Mishra Ragnat in *Paramanda Katara v. Union of India*, who asserted that; ‘preservation of life is of most importance, because if one’s life is lost, the status quo ante cannot be restored as resurrection is beyond the capacity of man’.¹³

2.1.2 Palliative Care and the Right to Dignity

The notion of “dignity,” a critically important and powerful cornerstone of palliative care, has also been asserted as the legal foundation establishing a human right to health care.¹⁴ The right to dignity is provided for under article 24 of the 1995 constitution of Uganda where it is stated that no person shall be subjected to any form of torture or cruel, inhuman or degrading treatment or punishment.

When formulated, the principle affirms the fundamental value of every human being. It enjoys general acceptance all around the globe as a basic ethical and legal principle because it draws upon the universal experience of the dynamics of recognition. It clearly is in everyone’s interest to be respected as having human dignity, that is to say, as having the highest value due to an inalienable humanity.¹⁵

This right is further supported by Article 1 of the UDHR which emphasizes equality in dignity and rights of all humans. The human rights call for equal dignity for all represents a transition from one normative universe to another, from the legitimate ranking of human worth and value, to de-legitimizing this very practice and labeling it a violation.¹⁶

¹³ Pt. Parmanand Katara vs Union Of India & Ors on 28 August, 1989, AIR 1989 SC 2039

¹⁴ Sebastian F Winter and Stefan F, Human Dignity as Leading Principle in Public Health Ethics: A Multi Case Analysis of 21st Century German Health Policy Decisions. International Journal of Health Policy and Management 2018, 7(3), 210-224. Accessed at: (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5890066/>) Last Accessed [February 4, 2021]

¹⁵ Mette Lebech, ‘What is Human Dignity?’

¹⁶ Evelin Gerda Lindner, ‘The Concept of Human Dignity’. In delegitimizing the concept of human ranking, there is a wide spread call for equal opportunity afforded to the masses at large to access various services.

What is sought isn't upfront equalitarianism but a certain amount of facilitating seems desirable society-wide to give patients a chance to protect their dignity through increased access to healthcare services within their respective communities. In this light, recourse has to be had to application of the said right to human dignity on the international scene so as to gain an insight on its applicability on the municipal scene as a legally enforceable right to palliative care in Uganda. ¹⁷

Every person has an inalienable right to live a dignified life without discrimination. It is one of the primary duties of each state to protect fundamental rights of human dignity and implement welfare schemes in order to improve the dignified life of the citizens.¹⁸ Patients with terminal illnesses endure the most de-humanizing conditions without access to palliative care. The onus of ensuring that the right to palliative care in Uganda is respected falls primarily on the shoulders of the government. It is mandated to do so even in the face of limited resources and should essentially be barred from citing this as an excuse when faced with shortcomings in areas of essential service delivery.

2.1.3 Status Of Palliative Care As A Health Right In Uganda

Through a medical-legal approach,¹⁹ palliative care providers have long led the health profession in challenging and pushing the boundaries of holistic care.²⁰ In 1993, Uganda was only the third country in Sub-Saharan Africa (SSA) to

¹⁷ Shodhanga, Right to Life with Human Dignity: Constitutional Jurisprudence .Accessed at : (<<https://www.shodhanga.inflibnet.ac.in/bitstream>>) Last Accessed [February 4, 2021]

¹⁸ Ibid

¹⁹ The medical-legal partnership (MLP) approach to health was formulated as a way of promoting the use of law to remedy societal and institutional pathologies that lead to individual and population illness and to health inequalities. *For more see* Joel Teitelbaum & Ellen Lawton, □ Also see The Roots and Branches of the Medical-Legal Partnership Approach to Health: From Collegiality to Civil Rights to Health Equity, 17 Yale J. Health Pol'y L. & Ethics(2017). Available at: (<https://digitalcommons.law.yale.edu/yjhple/vol17/iss2/5>) [accessed February 4, 2021]

²⁰ Tamar Ezer, Naomi Burke-Shyne and Kiera Hepford, "Legal Support for Palliative Care Patients," *Journal of Pain and Symptom Management*, Vol 55 No. 2S February 2018: 157

have modern palliative care (PC) including pain and symptom control according to the modern methods researched by Dame Cicely Saunders.²¹ Examples of these included treating nausea related to chemotherapy, or something as simple as morphine to treat the pain suffered by the terminally ill. Though non curative, they provide a level of comfort to the patients.

It therefore is a relatively new area of medical consideration in the country. However, there has been implementation and incorporation of these methods in some leading medical health centers countrywide, a leading example being the Palliative Care Unit at Mulago.²² In Uganda, nurses are the backbone of palliative care given their continued access to patients in various medical establishments and health centers country-wide.

A leading agency in 1998, Mildmay International, opened a center of excellence in collaboration with the Ministry of Health, under the patronage of the President. This center was to manage patients in their clinics and train health professionals not only from Uganda but also from other African countries.²³ In this way, health workers would be equipped with the necessary skills for pain and symptom control which are central to their ability to provide patients with relief and better living conditions overall.

Fast forward to the present situation, the issue of palliative care is still being grappled with country wide. A leading consideration here is the apparent lack of knowledge of end-of-life care and critical care among health professionals.²⁴ This is rather surprising given the fact that many of our students in the medical practice are taught issues relating to the same. Undergraduate doctors at both Makerere University and and Mbarara University of Science and

²¹ Dr Karen Frame, Meeting Palliative Care Challenges: The experience of Hospice Africa Uganda (HAU)

²² Anne Merriman, MBE, FRCP , “Uganda: Current Status of Palliative Care,” Journal of Pain and Symptom Management, Vol.24 No. 2 August 2002: 252

²³ Ibid

²⁴ Ibid

Technology (MUST) are receiving palliative care training as part of the undergraduate curriculum.

Palliative care is also part of the specialist Master of Medicine degree curriculum in Mbarara University of Science and Technology. Undergraduate pharmacists and Bachelor of Science in Nursing are also taught palliative medicine, and student nurses at the Government Referral hospital are trained both in didactic and experience with hospice. In addition, updates (CME) in palliative care are held quarterly and a publication twice a year is circulated to members of the Palliative Care Association of Uganda.²⁵

The appalling lack of availability of drugs for pain and symptom control is another major factor hindering the realization of effective care offered countrywide. The inadequacy has been attributed to various factors like these drugs being “relatively expensive.” It is a pressing issue especially considering the fact that over 57% of persons in Uganda never have access to a health worker.²⁶ Government has attempted to tackle this by increasing supply of morphine in various districts which has tried to improve their conditions. However, as is common in government hospitals, there is a shortage of medication meaning that people are forced to purchase medicines at relatively higher prices that many cannot afford.

Additionally, there is lack of hospital space in many medical institutions. Patients outnumber the available “bed space” and they are either not immediately attended to or not attended to at all yet they may be in dire need of medical assistance.²⁷

²⁵ Ibid

²⁶ Nyakato Viola, Pelupessy Wim, Not by Money Alone: The Health Trap in Rural Uganda. Accessed at: (https://www.academia.edu/5426648/Not_by_money_alone_the_health_poverty_trap_in_rural_Uganda) Last Accessed [Feb 4, 2021]

²⁷ Flavia Nassaka, Mulago’s Referral System Failure. The Independent. November 21, 2018 Accessed at: (<https://www.independent.co.ug/mulagos-referral-system-failure/>). Last Accessed [Feb 4, 2021]

From the fore stated, one can assert that the healthcare system in Uganda requires urgent reform to remedy the numerous flaws in a bid to improve on the living conditions of patients throughout the country, with specific reference to palliative care and the special considerations it entails.

3.0 RATIONALE FOR A MEDICAL-LEGAL APPROACH TO PALLIATIVE CARE

Inspiration for the integration of legal support in palliative care came from the medical-legal partnerships in the US in the late 90's.²⁸ They pioneered the integration of legal services into healthcare, advancing the idea that lawyers and doctors could be partners in addressing health and its underlying determinants.²⁹

Research has shown that factors related to low socioeconomic status can adversely affect health outcomes.³⁰ Poverty increases exposure to a variety of conditions that negatively affect health.³¹ Poverty has a correlation to increased rates of domestic violence, lack of access to services like health treatment and overall lack of financial support coupled with emotional distress for various individuals.

This is fortified by the fact that the lower economic class is generally not greatly considered when cutting the proverbial 'national cake' as policy considerations are a preserve for the higher social classes.³² A majority of palliative care patients are poor and adversely affected by illnesses that cause not only a great

²⁸ Joel Teitelbaum & Ellen Lawton, *The Roots and Branches of the Medical-Legal Partnership Approach to Health: From Collegiality to Civil Rights to Health Equity*, 17 *Yale J. Health Pol'y L. & Ethics* (2017). Available at: <https://digitalcommons.law.yale.edu/yjhple/vol17/iss2/5>

²⁹ Justice Programs For Public Health: A Good Practice Guide. Accessed at: <https://irgt.org/library/justice-programs-for-public-health-a-good-practice-guide/>

³⁰ Ibid

³¹ Evans GW. The environment of childhood poverty. *Am Psychol.* 2004;59(2):77-92

³² Mick Foster, Adrian Fozzard, Felix Naschold and Tim Conway, *How, When and Why Does Poverty Get Budget Priority? Poverty Reduction Strategy and Public Expenditure Reform in Five African Countries*, Working Paper 168.

physical but also an emotional toll on the mind and body, conditions which do not bode well with additional external pressures.

It should be noted that such conditions carry with them certain associated legal issues that need to be addressed and this cannot be done by medical practitioners. Low socioeconomic conditions affect not only the patients but also their families that depend entirely on the health care system for their well-being because of the inherently chronic/ long term illnesses which palliative care seeks to address. Inevitably, increasing medication costs are a direct consequence of such chronic illnesses. It is in this light that there has come into existence the advent of medical-legal partnerships (MLP's) as a way of addressing additional needs of these patients and their caretakers and families.³³

These partnerships are a collaboration between a legal entity, such as a law school, and a medical entity such as a hospital or clinic formed to address the multiple determinants of health, including legal issues that might present barriers to the patient's health and overall well-being.³⁴ The role of lawyers in this setting is to address the complex legal issues that may ordinarily arise in the course of their interactions with the patients and their family members or caretakers.

Examples of these situations are patients desperate to make arrangements for their children's care, anxious about the disposal of their property and their family's future, inability to access pain medication, falling into debt and struggling to secure social benefits, grappling with discrimination and violence, and laboring to navigate complex application procedures for identity

³³ Zuckerman B, Sandel M, Smith L, Lawton E. Why pediatricians need lawyers to keep children healthy. *Pediatrics*. 2004;114(1): 224–228

³⁴ Robert Pettignano, Sylvia B. Caley, and Lisa R. Bliss, Medical Legal Partnership: Impact on Patients With Sickle Cell Disease. *PEDIATRICS* Volume 128, Number 6, December 2011: e1482. Accessed at: (<https://www.academia.edu>). Last Accessed [Feb 4, 2021]

documents and death certificates.³⁵ Evidently, the expertise of lawyers is essential to handle such issues.

i. Efforts Underway

In furtherance of this objective, Uganda Network on Law Ethics and HIV/AIDS (UGANET), in partnership with the Palliative Care Association of Uganda (PCAU), have set out to address legal and human rights issues faced by these patients through partnerships with law schools as well as non-governmental organizations (NGOs) and pro bono attorneys. They have organized workshops and training clinics for palliative care-givers and nurses. They have also published a manual, *An Introduction to Palliative Care Course for Legal Practitioners*, as an aid to enhance understanding of palliative care for legal practitioners in the country.

Case Study

“UGANET in partnership with PCAU intervened to uphold the property rights of a female hospice patient in Western Uganda. The patient had been threatened with violence by her estranged husband and told to move off the family property, notwithstanding her extremely weak health. The UGANET lawyer initiated a meeting of the husband’s family and guided the elders of the family in mediating and monitoring an agreement to allow the patient to continue living on the family land. UGANET reported that the patient found it easier to look after her health and adhere to treatment when not threatened with violence and homelessness.”³⁶

ii. Lessons from PILAC, UGANET and PCAU Uganda

³⁵ Ezer T. The start of a new movement: Access to justice for palliative care patients. Accessed at: (<https://www.opensocietyfoundations.org/voices/start-new-movement-access-justice-palliative-care-patients>). Last Accessed [Feb 4, 2021]

³⁶ Robert Pettignano, SylviaB. Caley, and LisaR. Bliss , op..cit

➤ *Legal Support Models*

In a bid to address these various considerations, cognizance has to be given to the medical-legal partnership methodology applied elsewhere across the globe to counteract this common problem and here we'll indicate that the same can be applied in Uganda's context to achieve similar results.

➤ *Collaborations with Various Law Schools*

In Uganda, UGANET in partnership with PCAU and the Public Interest Law Clinic (PILAC) at Makerere University initiated a student centered program that involves a hands-on approach to provision of legal services to palliative care patients across various institutions. This involved consultations at various health centres like Mulago and Kawempe Home Care. Weekly sessions were held to educate the patients and their care takers on key aspects of the law such as making of wills, land law and succession principles, patient rights and other legal issues. Sessions were conducted in concert with the medical and other staff members at the various institutes. Also, legal aid consultation was offered and clients were profiled and referred to the fore stated organizations with teams of advocates ready and capable of undertaking the necessary steps to provide a comprehensive remedy to the various legal issues.

➤ *Developing Paralegal Skills*

The term paralegal is used in its broad sense to refer to a person with basic knowledge of the law and skills to address legal issues or human rights, gained either through formal training or by gaining experience on the job.³⁷ They in turn, having more access to patients at their respective work places, can offer whatever services might be within their knowledge should the need arise. Paralegals are better placed and can refer other matters to legal aid service providers who offer more technical legal support.

³⁷ National Federation of Paralegal Associations, Paralegal Responsibilities Accessed at: (https://www.paralegals.org/files/Paralegal_Responsibilities.pdf) last accessed February 4, 2021

Various training sessions where staff is taken through courses on various legal aspects to equip them with the necessary skills are conducted.³⁸ Topics are chosen through identification of the frequently occurring legal issues amongst patients. In documenting these issues, paralegals are sensitive to patient concerns and do not record information without the patient's consent. Paralegals find relevance in the fact that they are more readily available than legal practitioners who usually only provide pro bono services as an additional service to their mainstay occupations.

➤ *Accessing Skilled Legal Advice*

The epitome of the medical-legal partnership (MLPs) is the direct relationship between lawyers and clients where the latter is accorded an avenue for access to legal aid services through consultation. In order to achieve this, UGANET in partnership with PILAC have formed working relations with various health centers where they offer the said services.

Additionally, measures have been taken to interest other pro bono giving legal organizations in providing legal services in order to expand access to legal services for palliative care patients. UGANET provides legal aid services in 10 districts across Uganda and has memoranda of understanding with 15 hospitals, hospices, and HIV care centres in which UGANET legal aid lawyers conduct free monthly legal aid clinics for palliative care patients.³⁹

This model in all of its variations integrates legal service into the palliative care setting and takes the law out of private offices and into communities, thus increasing access to justice and contributes to a better quality of life and better health outcomes for palliative care patients.

➤ *Empowering Patients and Families*

³⁸ Ibid

³⁹ Palliative Care Association of Uganda, Newsletter, may 2016. Accessed at: (<http://pcauganda.org>) Last Accessed [6thFeb 4, 2021]

Patient and family legal empowerment is a critical component and outcome of legal support in palliative care. It is done through information sharing and exchange of knowledge with an aim of creating legal literacy. This has been done through legal information sessions, learning materials and guides. Information about rights catalyzes patients' claims and triggers requests for legal and paralegal support.

The Medical Legal Partnership that UGANET has established seeks to develop legal information materials and translated text into the relevant local languages. During ward rounds, patients and their caretakers are accorded opportunity to discuss their queries about the law and rights. Additionally, brochures or guides on patients' rights and technical procedures like the drafting of wills have been made available in multiple languages and at various health care facilities. Empowering many of these patients has turned them into advocates for patient rights in their various communities and into a beacon of hope for others suffering from similar dilemmas.

➤ *Creating Awareness of Rights among Health Care Workers*

Due to the fact that these workers interact more often with the patients, it is only desirable that they are afforded an opportunity to acquire legal knowledge with which they can help patients in need of such services. They are therefore the cornerstones of legal support for palliative care patients and families. This can be achieved through workshops and seminars which promote maximum access to learning about legal and human rights issues for the staff. Health care workers therefore participate in these to enable them to identify the fore stated issues and to furnish them with basic legal knowledge which they will use to assist patients in need of legal advice.⁴⁰

⁴⁰ Heleen Soeters, Daniella Mark, Agnes Ronan, Damiolla Walker, Wole Ameyan and Luann Hatane, Sensitizing Health Workers To Providing Responsive Care for Adolescents and Young People Living With HIV. Accessed at: (<https://www.who.int/hiv/pub/paediatric/sensitizing-heal-worker-care-hiv/en/>) [Last accessed February 4, 2021.]

In Uganda, PCAU and UGANET partnered with the Ministry of Health to publish a guide and implement training on legal and human rights issues into introductory palliative care training for health professionals. The guidelines are not only used to support and train the palliative care practitioners to update their knowledge but also by health facilities to provide guidance for service provision.⁴¹

iii. The Law School Clinic as a Legal Partner

In today's complex and interconnected society, lawyers undeniably must possess the ability to solve problems in an interdisciplinary context. The development of this cross-disciplinary problem-solving ability has increasingly become part of clinical legal education.⁴² The medical –legal partnership model has developed to offer legal services to low income clients while at the same time providing students with an invaluable opportunity to interface with society and apply legal principles to live-case scenarios in a bid to provide legal solutions to patients.

This model is highly beneficial due to the fact that students do not only offer the much needed manpower but also learn a great deal from their interactions in such settings. Given their close interactions with patients, medical practitioners are well placed to understand the need for legal aid as many clients are adversely affected health-wise due to external social and economic considerations.

In light of the above, medical institutions become a focal point for client referrals which are necessary for clinics to function due to connections by doctors of patients to legal practitioners. These practitioners are well equipped with the necessary skills to solve underlying legal issues that may inadvertently

⁴¹ Luyirika E, Kiyange F. Development of legal and human rights guidelines for palliative care in Uganda. Accessed at: (https://ehospice.com/africa_posts/development-of-legal-and-human-rights-guidelines-for-palliative-care-in-uganda/). Last Accessed [7th May, 2019]

⁴² Jane R. Wetach, The Law School Clinic As A Partner In A Medical-Legal Partnership, Tennessee Law Review, Vol. 75: 304

be affecting the patient's health and well-being. Such partnerships also act as a platform for law students to practice advocacy with various community health concerns prevalent in different areas.

iv. Benefit to Law Students

Medical-legal partnerships carry a number of benefits for students of law. First, there is great improvement on the communication skills of law students due to the fact that their interactions with doctors and medical staff familiarize them with medical jargon as opposed to the usual legal jargon.⁴³ This builds rapport with the medical team and enhances effective communication making tasks and objectives that much easier to achieve. These skills, once cultivated, can apply to different areas of practice and also enhance one's ability to interact with clients. The same is especially true when one considers that students are tasked with interviewing clients as a part of their daily interactions.

Secondly, the students are always tasked with distinguishing between a legal standard and a medical standard. In doing so, the student acquires the skill of gathering medical evidence on one end and using the same to prove that the legal criteria exists and is satisfied on the other. An example of this may be found in application for bail proceedings under which a certain degree of illness will accord one the opportunity to be granted bail where the court deems it fit.

An advocate can employ medical evidence to persuade court for the need of his client to be granted bail to have access to his healthcare. Where such evidence is being compiled, students can provide guidance to medical staff as to what particular aspects have to be taken note of hence making their work much easier.

The essence of the skill of translation cannot be underscored because it is relevant to many other fields of practice. Those who find themselves embroiled in negligence or malpractice claims against medical practitioners will greatly

⁴³ Ibid

benefit from such experiences. Moreover, attorneys who practice in other areas, particularly those involving scientific or technical evidence, will apply the same principles in another milieu.⁴⁴

Presentation skills are improved as a result of interaction with the various patients at the various places offering palliative care. Students carry out legal awareness sessions, public dialogues and also involve clinical staff through engagement during training sessions to equip them with legal knowledge that they could in turn use to assist some of their patients.

In creating a training session for the medical team in the partnership, law students must fully understand the subject matter and determine the most efficient and powerful method of presentation, given the characteristics of the audience.⁴⁵ Various considerations inform their overall presentation like the use of illustrative charts, visual aids, audience centered discussions and keen choice of language in order to effectively communicate to the masses. In so doing, they are better equipped with skills that they make use of throughout their careers.

Last is the advent of learning to engage with other professions so distinct from the legal one and yet as essential to the whole program in achieving the common goal. This occurs because it is not only the lawyers who advocate for the wellbeing of these patients because the concern is shared by various groups like doctors, social workers and even volunteers for various projects who all chip in to support the entire endeavor in their respective fields and capacity.

In this holistic approach to problem solving, students are able to witness their own niche or curve out for themselves as advocates in the making, and a better

⁴⁴ Ibid

⁴⁵ Ibid

understanding of their role will ensure that they perform more proficiently to strengthen the whole eco-system within which they find themselves.⁴⁶

4.0 A HANDS ON APPROACH

Despite efforts undertaken to make palliative care more accessible, there is still a long way to go to realize the right more effectively. Improving on the standard of living of persons is a goal common to medicine and human rights hence the concept of social justice. The global community has been expressly seeking to identify palliative care as a human right for many years but it still remains largely unenforceable.

The overarching reasons for this failure are numerous and include, among other things: the difficulty in allocating scarce resources; disparities in health care delivery systems; the conceptual separation of end-of-life care from health care; a historic lack of consensus and training in the medical community regarding the core framework of end-of-life care; the complexity in translating scientific evidence into policy and action; the absence of political will; and finally, the absence of binding domestic legislation which results from the lack of a political will to legislate on the said subject matter which would greatly enhance implementation standards and procedure in so far as palliative care is concerned across our health institutions.⁴⁷

Access to palliative care is primarily a legal obligation of States. This has already been recognized by the Committee on Economic, Social and Cultural Rights in general comment No. 14 and by the Committee on the Elimination of Discrimination against Women in general recommendation No. 27.⁴⁸ Consistent

⁴⁶ Ibid

⁴⁷ Mary J Shariff, Palliative Care: 'An Enforceable Canadian Human Right' Accessed at (https://www.researchgate.net/publication/236146393_Palliative_Care_An_Enforceable_Canadian_Human_Right?) McGill Journal of Law and Health, Vol 5 No.1:109. Last Accessed [May 5, 2019]

⁴⁸ Contribution From Un-Eclac, The Right To End-Of-Life Palliative Care And A Dignified Death. CESCR General Comment No. 14 Para, 36: "*In particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons.....to palliative health services.*"

with this, the Special Rapporteur on torture in 2013 established that denying pain relief could constitute inhuman and degrading treatment, according to the definition of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.⁴⁹ It is important to highlight the obligations of various stakeholders in a bid to make palliative care a reality.

4.1 NATURE OF OBLIGATIONS

4.1.1 The State

The state has an obligation to respect, protect and fulfill the right to health. This encompasses the duty not to violate and the duty to uphold or implement. Chapman asserts that the obligation also requires the state to remove obstacles or barriers to access, a kind of affirmative action applied to the health sector.⁵⁰ According to the ICESCR, the obligation to respect also includes the obligation to refrain from marketing unsafe drugs and applying coercive medical treatments.⁵¹

Professor Ben Twinomugisha further asserts that among the state's numerous obligations, is the fact that it should ensure that privatization of the health care sector doesn't water-down service delivery of the persons in need of the same.⁵² With reference to these guidelines, the government can henceforth set out to design programs and ensure implementation of these guidelines in order to ensure that the rights of palliative care patients are given due cognizance within the state of Uganda. This will enhance their widespread acknowledgement and practice.

⁴⁹ United Nations (2013), Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez (A/HRC/22/53), Human Rights Council. (A/RES/34/180), New York.

⁵⁰ Chapman, A. (1993), *Exploring a Human Rights Approach to Health Care*. New York: American Association for the Advancement of Science

⁵¹ Para.24 General Comment 14, 'The Right to the Highest Attainable Standard of Health', Twenty Second Session, 25th April-12th May 2000, Geneva, EC. 12/2000/4

⁵² Ben Twinomugisha, Protection of the Right to Health Care of Women in Uganda Living with HIV/AIDS (WLA) in Uganda; The Case of Mbarara Hospital. HURIPEC Working Paper No.5 April, 2007

Recourse must be had to the fact that jurisprudence in the area has developed what is referred to as the “principle of minimum core content.” This principle espouses the fact that states are mandated to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights stipulated in the ICESR, including essential primary health care.⁵³ The state must demonstrably assert that it has used all resources at its disposition in an effort to satisfy its bare obligations.⁵⁴

4.1.2 Non-State Actors

Historically, the responsibility of protecting, respecting and fulfilling human rights obligations laid solely with the state. Professor Ben Twinomugisha however asserts that due to the advent of globalization, the protections once offered by sovereignty of a state have blurred to offer an avenue for external interference. This is manifesting through institutions such as the World Bank, International Monetary Fund (IMF) and World Trade Organization (WTO) which are increasingly asserting high levels of influence over policy considerations within the state. Considering the fact that the World Bank is the primary source of development funding and compliance with the IMF conditionalities is usually a pre-requisite to other sources of funding. In this way, they are able to indirectly influence policy considerations as they have the resources.⁵⁵

According to the ICESR, international organizations should co-operate effectively with states in relation to the right to health at the national level in respect to their individual mandates.⁵⁶ Being informed by the fore stated, any resultant legislation and policy would cover a wider scope of application, inevitably satisfying salient health needs. In this way these various organizations would effectively influence positive changes that will improve the living conditions of palliative care patients in Uganda.

⁵³ Para.43, General Comment 14

⁵⁴ Ibid

⁵⁵ Ben Twinomugisha, op.cit

⁵⁶ Para . 64, General Comment 14

4.1.3 Non-Governmental Organizations

Non-Governmental Organizations (NGOs) have long played a significant role in the realization of policy changes throughout the world due to their underlying influence being backed by major international organizations especially in third world countries.

One of their major contributions has been through research. Several NGOs have had impressive track records in global health research. Other NGOs have expressed an interest in becoming more involved in global health research.⁵⁷ Their contribution to more equitable, ethical, relevant and effective research is crucial and needs to be strengthened. This is particularly critical for palliative care research whose primary goal should be to improve health and its determinants in low and middle income countries. This could result in improved drugs and various medical technologies that would greatly improve the living conditions of palliative care patients country wide.

Additionally, various NGOs undertake advocacy campaigns for various health concerns and this can go a long way in raising awareness of the plight of palliative care patients. With increased awareness and sensitization, the society at large will be more accommodative of future initiatives to improve the well-being of these patients where communal support is sought in various means.

4.2 GENERAL RECOMMENDATIONS

➤ *Legal Policy Framework*

There is need for a legal policy framework with special reference to palliative care needs. Parliament should enact laws to protect the rights of palliative care patients. Legislation will go a long way in ensuring that implementation of set guidelines are followed conscientiously by concerned sections of the public like health care centers, clinics and hospitals.

⁵⁷ Nathan S, Rotem A, Ritchie J: Closing the gap: building the capacity of non-government organizations as advocates for health equity. *Health Promotion Inter.* 2002, 17: 69-78. 10.1093/heapro/17.1.69.

This can be achieved through state, private insurance and health care delivery programs integrating the financing of medical and social services to support the provision of quality care consistent with the values, goals, and informed preferences of people with advanced serious illness. To the extent that additional legislation is necessary to implement this recommendation, the parliament must enact the same. In addition, the government should require public reporting on quality measures, outcomes, and costs regarding care near the end of life (e.g., in the last year of life) for programs it funds or administers.⁵⁸

➤ *Capacity Building*

Institutions providing medical care to palliative patients should provide nurses employed in generalist settings who provide care for seriously ill or medically complex individuals with regular continuing education based on the components of new and advanced palliative care technologies as they emerge.⁵⁹ Additionally, those already serving can be equipped with the same through workshops to skill them and enable them to perform various tasks related to service of palliative care to the populace at large.

This can also be achieved by incentivizing participation in continuing education with palliative care content in concert with the recently developed requirement for continuing education as a condition for continued licensure of medical practitioners. This should cover all health workers to improve service delivery at various institutions especially regarding the provision of palliative care where it is needed.⁶⁰

➤ *Sensitization*

⁵⁸ Institute Of Medicine, *Dying In America: Improving Quality and Honoring Individual Preferences Near the End of Life*

⁵⁹ New York State Palliative Care Education and Training Council, *Need, Approaches and Resources to Provide Palliative Care Education and Training in State Certified Schools of Nursing and Social Work, and in Practice Settings at the Health Care Provider Facility or Agency Level*, April 2018.

⁶⁰ Ibid

Civic leaders, public health and other governmental agencies, community-based organizations, faith based organizations, consumer groups, health care delivery organizations, payers, employers, and professional societies should engage their constituents and provide fact-based information about the care of people with advanced serious illness to encourage advanced care planning and informed choices based on the needs and values of individuals.⁶¹

➤ *Education*

Importantly, educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and licensure requirements to strengthen palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness and are nearing the end of life.⁶² This is due to the fact that despite being part of the curriculum in institutions of higher learning, doctors country-wide have little regard for the whole aspect of providing palliative care support to those in need of it. It should be made a major building block of the medical practitioner's curriculum.

5.0 CONCLUSION

Considerable progress has been realized in the medical research to do with palliative care as pioneered by Dame Sicely. There has also been increased acknowledgement of the important role played by the legal profession. The Hospice movement is a wholesome treatment module and recognizes that psychosocial and socio-economic issues can hinder the effectiveness of medical care. The diversity of approaches in integrating legal support into palliative care is evidenced by articles, books and handbooks on legal support in palliative care.

⁶¹ Institute Of Medicine, op.cit

⁶² Ibid

All these sources speak to the feasibility and successful implementation of the same that all began with the Boston medical-legal partnership. With this in mind, it is argued that solving of legal issues can go a long way in promoting health alongside improving the living conditions of palliative care patients. Thomas Carlyle once remarked, 'He who has health has hope; and he who has hope, has everything.' Provision of legal support can extend this hope to the patients and assist in their continued treatment if implemented in what has come to be known as holistic care.

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