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Chidi Oguamanam*

Access to Palliative Care, Human Rights and Public Health: Diffusing ICT Innovations to Bridge
Global Pain Inequity for SDG #3

Introduction:

Owing to the general improvement in quality of life and advances in medical sciences and technology, life expectancy continues to rise in the developed and developing world. The combined effect of a technologically progressive health care system and higher life expectancy yields a corresponding increase globally of persons or candidates for care at the end of life spectrum. End of life care “designates a broad reference to circumstances and contexts for provision of care to all categories of patients [paediatric, geriatric, juvenile, etc.] at the terminal phase of life”.¹ Pain is a universally acknowledged common experience of virtually all patients at the end of life spectrum. Consequently, access to appropriate pain medication is pivotal to all other considerations or paraphernalia of palliative care as a specialized professional medical niche. However, beyond the issue of patient access to pain medication, palliative care involves “the combination of active and compassionate therapies intended to comfort and support persons and families who are living with, or dying from a progressive life-limiting illness or are bereaved”.² Palliative care focuses holistically on the patient in their social and cultural contexts, which involve family members, cultural and faith communities, and other affiliations in collaborative navigation with the care team toward the mitigation of complex and painful experiences at the end of life.

Until fairly recently, narratives of global health inequity focused on the misalignment of pharmaceutical R&D innovations and the patent system with health needs of 90% of the world’s population. Despite the flexibilities in the TRIPS Agreement and their elaborations in the Doha Declarations, more than twenty years after the TRIPS agreement, policy makers and scholars continue to bemoan the lack of attention to diseases that are endemic among the

¹ Chidi Oguamanam, “Cross-Cultural Tensions at the Intersection of Medical Futility and Palliative Care in Canada” (forthcoming 2016) at 2.

² “Definition of Palliative Care” World Health Organization (WHO), online: <<http://www.who.int/cancer/palliative/definition/en/>>.

world's most vulnerable. Ten million of the latter die annually from lack of access to medicines.³ Pharmaceutical R&D and the patent system remain aligned with those market forces which shun the interests of poor people's diseases while focusing on diseases that afflict the wealthy – those who can afford the high costs of patented drugs. In the last two decades more than 70% of new drugs introduced into the market have no associated new therapeutic benefit over pre-existing ones.⁴ However, in such cases where the disease or affliction at issue has no geopolitical, geographic, or class discrimination, where there is sufficient and comparatively affordable global drug supply for the affliction, global health inequity is even more evident. Such is the case with pain medications central to palliative care intervention. Pain is a universal disease albeit mainly opportunistic or dependent upon various forms of discriminating afflictions.

Access to pain medication and palliative care are concrete but long neglected sites of global health inequity. Binagwaho et al., observe that “[d]espite absorbing over 60% of the global cancer death and approximately 95% of death associated with HIV/AIDS worldwide, the developing world consumes only 6% of the global market of opioids for medical use”.⁵ The International Narcotic Control Board indicates that about 80% of the global population are inhabitants of countries having no or inadequate access to palliative care for moderate to severe pain.⁶ A study of 235 countries found that 115 (49%) of them have some form of hospice-palliative care presence, but only 35 (15%) of that number – most of them in the developed world – have achieved a measure of integration of palliative care as an essential part of their health care system.⁷ A similar study by the World Hospice and Palliative Care Alliance found that only 20 countries have actually integrated palliative care into their health care system. The study also found that 78% of people in need of palliative care are in the developing world, a region that contributes significantly to the 18 million people who die annually in

³ See World Health Organization, “The world medicines situation 2011: Access to essential medicines as part of the right to health” (Geneva: WHO, 2011) at 1; Paul Hunt, Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Human Rights Guidelines for Pharmaceutical Companies in Relation to the Access to Medicines, UN Doc. No. A/63/263 (2008), online: <http://www.who.int/medicines/areas/human_rights/A63_263.pdf> at 15.

⁴ P Chirac & E Torreele, “Global framework on essential health R&D” (2006) 367:9522 *Lancet* 1560-1561.

⁵ See Agnes Binagwaho et al, “Extending the Right to Health to the Moment of Death: End of Life Care and the Right to Palliation in Rwanda” (2015) 12 *Harvard Human Rights Journal*, online < <http://goo.gl/2vFjiO> > [Binagwaho et al].

⁶ See, Report of the International Narcotics Control Board for 2004 (Vienna INCB, 2005), online: < <https://www.incb.org/incb/en/publications/annual-reports/annual-report-2004.html>>; See also Diederick Lohman & Joseph Amon, “Evaluating Human Rights-Based Advocacy Approach to Expanding Access to Pain Medicines and Palliative Care: Global Advocacy and Cases Studies of from India, Kenya, and Ukraine” (2015) 17:2 *Health and Human Rights J*, online: < <http://goo.gl/Qqbcr> > [Lohman & Amon].

⁷ See Michael Wright et al, “Mapping Levels of Palliative Care Development: A Global View” (2008) 35:5 *Journal of Pain and Symptom Management* 469-485

distress and pain without palliative care.⁸ The American Cancer Society initiative, “Treat the Pain”, maps on a global scale country-by-country access data or lack thereof to pain medication for people dying of HIV and Cancer.⁹ The result demonstrates an unconscionable asymmetrical access gap to pain medication between patients in developed and developing countries on an egregious or insidious scale of injustice.

The glaring crisis regarding access to pain medication and palliative care in general implicate a complex interface of issues. Given regard to the brevity of the present intervention, the issues engaged are limited, for the present purpose, to those at the intersection of human rights, public health, and access to targeted and innovative technologies to enhance capacity, and advance palliative care. Despite the lack of specificity or emphasis on palliative care in the 13 targets associated with the SDG #3, palliative care is critical to sustaining healthy lives and for promoting the well-being of all ages for a healthy, optimally productive and sustainable society.

Method

Building on the intervener’s work on medical futility and end of life care, the intervener undertook a guided critical review of recent scholarly studies (2011-2015) within the disciplines and sub-disciplines of health policy: public health, palliative care, human rights law and health informatics, and technology and innovation, with a view to evaluating the intersection of those themes and to identify gaps between them, the SDG #3, and its associated targets. The intervener also undertook a dedicated and close analysis on the Commission on Economic, Social and Cultural Right’s “General Comments No. 14”¹⁰ and several cognate secondary health and human rights instruments in order to ascertain the extent they accommodate palliative care and access to pain medication. These endeavours enabled the intervener to spot the gaps in SDG #3 in the areas of access to pain medication and palliative care, human rights and public health, as well as the opportunities in the potential diffusion of information communication technologies and other policy initiatives to address the gaps identified, toward the advancement of SDG #3.

Palliative Care as an Integral Aspect of the Right to Health

At the core of human rights is the dignity of the individual, which is a foundational element for human capacitation necessary for the optimal realization of a free, progressive, and sustainable

⁸ See WHPCA, “Global Atlas of Palliative Care at the End of Life” (2014) online: <http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf>; See also Richard Powell et al, “Putting Palliative Care on the Global Agenda” (2015) 16 *Lancet* 131-133.

⁹ See “Treat the Pain - Country Reports” A Program of the American Cancer Society, online <http://www.treatthepain.org/country_reports.html>.

¹⁰ *General Comment No. 14: The Right to the Highest Attainable Standard of Health*, ESC, 22nd Sess, UN Doc E/C 12/2000/4, (2000), online: <<http://www.refworld.org/docid/4538838d0.html>>.

society. The entire freedoms guaranteed under human rights norms, for example, freedoms from discrimination on the basis of conventional categories are designed to ensure that no one is inhibited from realizing their potential in the context of their self-worth and human dignity. The International Bill of Rights provides an unequivocal and affirmative guarantee of the right to life, liberty, and security of the person.¹¹ Specifically, the UDHRs provide that “Everyone has a right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services”.¹² The International Covenant on Economic Social and Cultural Rights (ICESCR) further strengthened the declaration by providing for the “right of everyone to enjoyment of highest attainable standard of physical and mental health”.¹³ While the ICESCR is the direct or primary source for normative understanding of the right to health, a corpus of several international human rights instruments, directly or indirectly, provide elaborate jurisprudence on the right to health. However, these bodies of instruments do not engage palliative care save as implicated in the diverse and detailed contexts for the realization of the right to health.

In 2000, the CESCR issued “General Comment (GC) No. 14” that provides an interpretative and normative outlook on the scope and content of states’ negative and positive obligations over the right to the highest attainable standard of health. A targeted synthesis of General Comment No. 14 from the prism of palliative care implicates the obligation of the state to provide available health care facilities including “trained medical and professional personnel ... and essential drugs, as defined by the WHO Action Program on Essential Drugs”.¹⁴ Also, the GC emphasizes accessibility and affordability of health facilities and services without discrimination especially in regard to “the most vulnerable”, or “marginalized groups”, “persons with disabilities and persons with HIV/AIDS” through the use of information to enhance understanding of health issues¹⁵ in culturally appropriate and acceptable contexts.¹⁶ Throughout the text of GC 14, there are references to equal access to preventive, curative, and rehabilitative health services and the provision of essential drugs and the need for health education.¹⁷ While encouraging equal and non-discriminatory access to health facilities and services to all, the GC specifically encourages special attention to women, children and

¹¹ *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3d Sess, Supp No 13, UN Doc A/810 (1948) 71 at Article 3 [UDHR].

¹² *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, 993 UNTS 3, Can TS 1976 No 46 (entered into force 3 January 1976) at Article 25.1 [ICESCR].

¹³ *Ibid* at Article 12.1.

¹⁴ *Supra* note 10 at 12(a) [General Comment].

¹⁵ *Ibid* at 12(b); See also *Ibid* at 18 & 19 (for comments regarding non-discrimination).

¹⁶ *Supra* note 10 at 12(c) & (d).

¹⁷ *Supra* note 10 at 14, 17 & 25.

adolescents, and indigenous peoples' health consistent with cognate international human rights instruments.¹⁸

In paragraph 25, the GC pointedly addresses the realization of the right to health for older individuals and “reaffirms the importance of an integrated approach, combining elements of preventive, curative and rehabilitative health treatment ... aimed at maintaining the functionality of autonomy of older persons; and attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity”.¹⁹ Although the text of the GC is silent on palliative care; this paragraph has by far the most direct ramification for palliative care. In a similar vein, the GC cross-references and reaffirms para 12 of the 1990 General Comment No 3 (on the nature of obligations of parties to the ICESCR) to the effect that “in times of resource constraints, the vulnerable members of the society must be protected”.²⁰

The above guided textual scrutiny of the GC No. 14 provides ample accommodation for treating the health needs of all palliative care patients as a matter of human rights while it guarantees them access to essential medicines. Whether as children, adolescents, or older persons palliative care patients also double as the most vulnerable as they naturally engage the health care system in very disadvantaged and vulnerable positions. When pain is a critical experience of ill-health, especially at the end of life spectrum, patients are often no longer competent to make their own decision. Such a situation involves complex layers of ethical protocols between the caregiver and the patient's family, especially the substitute decision maker or other forms of intermediaries in applicable cases. In these and many other situations, the GC No. 14 appears to have pre-empted the human rights imperatives and susceptibility of palliative care candidates.

From the basic human rights instruments on the right to health, palliative care has an immanent prominence as an integral aspect of that right. At diverse policy levels, beginning from the WHO and its policy making organ, the World Health Assembly (WHA), cognate treaty instruments, (including the 1961 Single Convention on Narcotic Drugs), several actors within the UN human rights systems identify the link between the provision of palliative care, especially access to medical opioids to human rights, specifically the right to the highest standard of health. The WHO has developed a “pain relief ladder” which sanctions the prescription and administration of diverse pain medications in correlation to the nature or severity of pain. The WHO pain relief ladder is an influential manual for modern pain

¹⁸ *Supra* note 10 at 21, 22 & 27.

¹⁹ *Supra* note 10 at 25.

²⁰ *Supra* note 10 at 18.

treatment.²¹ As well, since 2013 the WHO “Model List of Essential Medicines” now includes candidate medicines for pain relief such as morphine. Because most of the medicines for pain relief or palliative intervention are classified as controlled substances pursuant to the UN “Single Convention on Narcotic Drugs”, they are strictly supervised by the International Narcotics Control Board which serves an implementation agency for UN Drug Conventions.²² Both the WHO and the International Narcotics Control Board continue to support the availability of narcotics as well as opiates for medical, including palliative, and scientific and other research, applications. However, the need to prevent illicit uses or abuses and trafficking of the substances account for complex regulatory control of these drugs that now constitute significant barriers to their access in legitimate palliative care contexts. One of the welcome consequences of this unfortunate state of affairs is that controlled medicine and the palliative care imperative have now entered into the agenda of the 2016 UN Assembly Special Session on Drugs scheduled for April 19-21 which is expected to engage in a review of global drug strategy.

Yet, significant attempts continue to be made to promote access to opioids, morphine, even ketamine and other medicines for pain relief among those in dire need. Thus, the global pain divide is now a catalyst for momentous coalition of “a broad range of organizations offering funds to initiate and support service provision particularly in resource poor settings”.²³ In 2008, the UN Special Rapporteur on the Right to Health and Special Rapporteur on Torture, Cruel, Inhuman and Degrading Treatment and Punishment made a joint representation to Commission on Narcotic Drugs. The two experts argued that failure to ensure access to pain treatment was a threat to fundamental human rights.²⁴ This joint position statement reflects a reinforcement of the official position of the two offices in other related contexts at the intersection of palliative care and right to health.²⁵ They are also consistent with various other stakeholders including the Work of Committee on the Rights of the Child (General Comment No. 15); the Committee on the Elimination of All forms of Discrimination against Women (General Recommendation No 27 on Older Women and Protection of their Human Rights, 2010).²⁶ Continued advocacy for the right to palliative care and access to pain medication by notable human rights advocates such as Human Rights Watch is credited for the change in attitude by the World Health Assembly. After a decade (2000-2010) of virtual silence on

²¹ “National Cancer Control Programme: Policies and Managerial Guidelines” (Geneva: World Health Organization, 2002); Diederik Lohman, Rebecca Schleifer & Joseph J Amon, “Access to Pain Treatment as a Human Right” (2010) 8:8 BMC Medicine, online: < <http://bmcmedicine.biomedcentral.com/articles/10.1186/1741-7015-8-8>> [Lohman, Schleifer & Amon].

²² *Ibid.*

²³ See Micheal Wright et al, “Mapping Levels of Palliative Care Development: A Global View” (2007) 35:5 J of Pain and Symptom Management 469-485 at 482.; Lohman, Schleifer & Amon, *supra* note 21.

²⁴ See Lohman & Amon *supra* note 6; Lohman, Schleifer & Amon, *supra* note 21.

²⁵ *Ibid.*

²⁶ *Ibid.*

palliative care, it is reported that “in May 2014 the World Health Assembly adopted a detailed Resolution on palliative care with 37 countries cosponsoring”.²⁷ The strategy for implementation of the resolution is presently under development.²⁸ The resolution of the human rights crisis associated with access deficit to pain medicines and palliative care would resonate positively on public health profile of resource-poor countries most endangered by the global pain divide.

The Public Health Ramification of Palliative Care Inequity

Public health focuses on protecting and improving the health of families, communities, and various categories of population groups through a combination of proactive and reactive measures, including promotion of healthy lifestyles and robust research among others.²⁹ Lack of access to pain medication and paucity of competent palliative care has negative ramifications for the public health of important social units critical for the health of the society. Palliative care is a crucial health care regime and expertise that is delivered in partnership, with a multidisciplinary team of health care workers (HCWs) in close collaboration with the family and community of the patient. Virtually all definitions of palliative care emphasize the provision of comfort and support for persons and families corresponding especially to those at the critical end of life spectrum and families faced with naked reality of imminent bereavement. At its core, palliative care aims to optimize the quality of life of patients and to address the needs of their families and close friends.³⁰ An “essential component of palliative care is pain relief. Freedom from pain allows the highest quality of life possible for as long as possible ... pain increases distress and anxiety not only in the patient but also in their friends and family”³¹ and, indeed, the patient’s closest cultural, social and even spiritual communities. At the end of life care spectrum when patients face progressive life limiting illness, physical, psychosocial, and spiritual trauma of the patient is often an experience jointly shared by all those at the frontline of providing care, including the patient family (especially women) and the care team operating at various scales of formal and informal continuum.

Coupled with inadequate access to pain relief medication, without a strong and professionally resourced palliative care competence, HCWs, families and communities who are forced to helplessly navigate end of life are exposed to harrowing and psychologically debilitating experiences arising from being at the frontlines of negotiating traumatic end of life experiences.

²⁷ Lohman & Amon, *supra* note 6.

²⁸ *Ibid.*

²⁹ See “What is Public Health”, CDC Foundation, online: <<http://www.cdcfoundation.org/content/what-public-health>>.

³⁰ Lohman & Amon, *supra* note 6 .

³¹ Help the Hospices (for the Worldwide Palliative Care Alliance), “Access to Pain Relief: An Essential Human Right – A Report for the World Hospice and Palliative Care Day 2007” (2008) *Journal of Pain and Palliative Care Pharmacotherapy*, online: <<http://www.howorthpress.com/web/JPPCP>>.

Even in societies with no significant resource problem both in access to pain medication and palliative care competence or personnel, formal and informal care providers are often faced with anxiety and psychological crisis long after the patient has died. Caregivers are highly susceptible to depression, deterioration in physical health and financial health, overall quality of life, and consequently premature death in some cases.³² This scenario is worse when palliative care resources are lacking especially in resource poor countries. Escalation of trauma and stress among HCWs, families, and direct community categories involved in end of life with limited palliative care support is disruptive of public health among a crucial population group. Such a situation has negative ramifications for the group's healthy life style and well-being, and by extension, across chains of complex relations in the public health demographic in the long run. In most developing countries, families especially women are primary caregivers in end of life and palliative care situations. Women continue to bear an overwhelming weight of the public health burden as they often outlive their spouses. In many other cases, they are the sole or most active care providers for their children and, indeed, for other members of the family. As crucial agents of public health, and frontline partners in end of life and palliative care situations, the disruptive effect of non-existent or poorly resourced and mismanaged end of life on women has negative public health consequences for society as a whole.

Palliative care is less about end of life as it is about optimizing the quality of life of patients and, by extension, ensuring that immediate families, social groups, and the cultural and spiritual communities to which the patient is a part of, have the best possible experience in the often hyper-stressful circumstance of the patient. It is not unusual that in societies with inadequate professionally developed palliative care specialities, such care is associated with end of life or hospices care, one that is synonymous, albeit erroneously, with giving up on the patient and resigning to fate. On the contrary, in specific contexts, there could still be a healthy and functional space between palliative care on a curative or functional pain management scale and when palliative care is elevated to the exclusive treatment plan resulting in abandonment of any commitment to a curative outcome. Under the latter, palliative care converges with end of life and hospices care. However, in the first scenario, adequate pain management and professional palliative care intervention ensure that patients, whether as paediatric, adolescent, adult or other age categories are still able to operate in their social and economic space in the community, contributing to the sustainability of society's public health ecosystem. There is no dearth of case studies that demonstrate that effective pain management and

³² See George Demiris, Debara P Oliver & Elaine Wittenberg-Lyles, "Technologies to Support End of Life" (2011) 27:3 Semin Oncol Nurs 211-217.

professional palliative care regime put people back on their feet as it optimizes the quality of life of patients even when they are saddled with ongoing chronic pain.³³

A well-resourced palliative care system through adequate and functional access to pain medication, professional palliative care delivery services, and infrastructure are crucial for realizing the SDG #3. Embedding palliative care in a health care system has positive instrumental relationships to public health, first in relation to HCWs, on the one hand and, second, in relation to family, community and various categories of patient's social group. As its complement, an adequate supply of pain medication and their professional utilization in palliative care settings provides mitigating, in some cases curative or at least a managed outcome from pain relief for patients in a manner that optimizes their quality of life and restores their roles as social and economic members of the community. Given the ubiquity of pain as an inescapable experience of all age groups in the health and life chain, palliative care relief is instrumental for the realization of SDG #3. Even though the latter makes no direct mention of palliative care despite failed attempts to ensure that palliative care became an integral part of SDGs as an "era-defining agenda",³⁴ ensuring healthy lives and promoting well-being for all ages is an impossible goal without a viable palliative care.

While recognizing the interconnectedness of all the thirteen targets of SDG #3 and the relevance to palliative care in each space, targets eleven and thirteen provide a strong and direct corollary for palliative care. Among other things, target eleven invokes the use of TRIPS flexibilities by developing countries to provide access to essential medicines and vaccines for all. Opioid analgesics and other forms of pain relief medications are now part of the WHO Essential Medicines List. But unlike the case with patented drugs, price is not the prime barrier to access for most of these drugs; regulatory interventions are. Target thirteen sanctions improved capacity of all countries especially developing countries "for early warning, risk reduction and management of national and global health risks".³⁵ There has been a progressive increase in global life expectancies in both the developed and developing world and a rise in the prevalence of communicable and non-communicable diseases. Candidate diseases that cause significant pain include cancer, (chemotherapy) HIV/AIDS, Parkinson's, Crohn's, muscular degenerative diseases, diabetes, cardiovascular diseases, tuberculosis, malaria, epilepsy and some occasional and unpredictable public health crisis flashpoint as symbolized by incessant

³³ See eg A Kim, P Fall & D Wang "Palliative Care: Optimizing Quality of Life" (2005) 105:(11 Suppl 5) J Am Osteopath Assoc S9-14; MJ Desai et al, "Optimizing Quality of Life Through Palliative Care" (2007) 107:(12 Suppl 7) J Am Osteopath Assoc ES9-14; Hrachya Nerseyan & Konstantin V Slavin "Current Approaches to Cancer Pain Management: Availability and Implications of Different Treatment Options" (2007) 3:3 Ther Clin Risk Manag 381-400; Russell K Portenoy & Pauline Lesage "Management of Cancer Pain" (1999) 353:9156 Lancet 1695-1700.

³⁴ Richard A. Powell et al, "Putting Palliative Care on the Global Agenda" (2015) 2 Lancet 131-13 at 131, online: <<http://www.lancet.com/oncology>>.

³⁵ "Sustainable Development Goal 3: Health" World Health Organization, online: <<http://www.who.int/topics/sustainable-development-goals/targets/en/>>.

outbreaks of epidemics of communicable diseases such as the recent Ebola occurrence. Coupled with advances in medical technologies, collectively the consequential effect of these trends is an upsurge in the number of people in need of palliative care, which it is argued constitutes a national health risk warranting the need for palliative care as risk reduction and management strategy under target 13 of SDG #3

Innovative Technology for Palliative Care: Of Opportunity and Low Hanging Fruit

Most of the studies that focus on global palliative care inequity, including the so-called pain divide recognize the important role of formal and informal education of HCWs, families and members of society for building palliative care capacity and core end of life and pain management competences.³⁶ Only a few things highlight the asymmetrical disparity between countries and regions with developed palliative care and elsewhere than the recent interest in the use of information and communication technology to support clinical practice in hospice and pediatric setting.³⁷ Lindley et al., found that in pediatric oncology setting, patients encounter variety of clinicians ranging from primary physicians, nurse practitioners, oncologists and neurologists, most of whom serve as “gate-keepers” in need of qualitative information (which they often do not have) to enable them make informed referral decisions to suitable hospices as well as engage in meaningful conversations with parents over most suitable and available facilities to support patients.³⁸ Under the present state of poor clinician hospice referral practice, the researchers observe that very few children are able to access hospice and palliative care at the end of their short-lived sojourn. To that end, without discounting the need for continued clinician education and training, the researchers, comprising an interdisciplinary professional team including a nurse, an information system engineer, physician and a Big Data Analyst from Knoxville, Tennessee in the United States have designed a mobile application (app) as a technological tool to assist clinicians in “understanding, experiencing pediatric hospice care in the palm of their hands”³⁹ which can be easily accessed when needed in exam rooms, physicians’ offices, while doing test reviews or engaging in clinical conferences with care teams or with the patient’s family. The study acknowledges the fledgling nature of this technological initiative. However, the authors remark that “the cutting-edge technology associated with smart phones and tablet (e.g. ipads) may have the potential to significantly influence health care. By providing powerful platforms, mobile applications (apps) may increase awareness of pediatric hospice care, assist clinicians’ discussions with families about it, and create referrals to hospice that would ultimately improve access to pediatric hospice and

³⁶ See eg, Binagwaho et al, *supra* note 5; Lohman & Amon, *supra* note 6; *Supra* note 32.

³⁷ See LC Lindley, et al “Pediatric and Palliative Care: Designing a Mobile App for Clinical Practice” (2014) 32:7 *Comput Inform Nurs* 299-302.

³⁸ *Ibid* at 299.

³⁹ *Ibid*.

palliative care”.⁴⁰ The app has easily navigable features and is resourced with up-to-date information on pediatric hospice care experts and facilities from the US National Hospice and Palliative Care Organization. The device enhances clinicians’ ability to share information orally with families. In the alternative “with a click, they can send the information to the families’ computer or mobile device”.⁴¹

In another study, Demiris, Oliver and Wittenberg-Lyles observe that there is a limited use of informatics (electronic-driven information generating and management system) in the specific context of palliative and hospice care. After examining the current level of utilization of informatics system technologies in hospice and palliative care setting, the authors conclude that there is a strong potential for the use of information technology to enhance the experience of informal home care givers including family, spouses, friends and other informal stakeholders who may have the burden of a primary and unpaid caregiver.⁴² In the US one of every four deaths results from cancer. While the majority of these deaths happen in formal institutional care settings requiring palliative care, the rest happen at home with care provided by informal caregivers. It is widely recognized that non-professional caregiving is important for the provision of palliative care at the end of life. Information and communication technologies of various kinds, from basic telecommunication to web-based interactive resources to creative uses of video platforms can be used to provide support to informal caregivers and build capacity.

Given the vulnerability of informal givers and their limited mobility, technology comes to the rescue and assists in the delivery of care that specifically focuses on issues peculiar to the caregivers while helping to improve their education and competence in care giving. A theoretical model of this form of intervention is designed to elicit objective and subjective information on ongoing basis that maps the caregiver’s backgrounds including “primary, secondary and intrapsychic stressors as well as outcomes of caregiving experience”⁴³ to inform the design of right kind of intervention to be provided by the hospices team. The resulting framework is called ACT (Assessing Care Giver for Team Intervention). The ACT model can be implemented by the use of a videophone unit linking the caregiver/patient home location and the institutional site of the care team (hospice) through standard telephone lines under a framework called Assessing Caregivers for Team Interventions through Videophone Encounters (ACTIVE) with the interdisciplinary team. ACTIVE enables for virtual interaction between the hospice Interdisciplinary Team (IDT) and the care provider permitting for confidence building, improved outcome, enhanced pain management, and diminished anxiety.

⁴⁰ *Ibid.*

⁴¹ *Supra* note 37 at 300.

⁴² *Supra* note 32.

⁴³ *Supra* note 32.

Similar to the use of videophone technology to facilitate meeting between IDTs and caregivers, the technology has also been identified as feasible for the extension of Problem-Solving Therapy (PST) to informal caregiver by the hospice team as opposed to an audio-only mechanism. In their pilot study, Dimiris, Oliver and Wittenberg-Lyle used commercially available low cost videophone technology to deliver researcher-initiated PST.⁴⁴ They found that not only was the technical quality of the video-call very good, caregivers' level of anxiety and problem solving skill reflected marked improvement from the baseline.⁴⁵

As an outcome, both the ACTIVE study and the videophone-supported PST pilot program demonstrate that technology and innovation have a crucial role to play in advancing palliative care and in bridging the global pain divide. This is very much so for resource poor, low-income and middle income countries. Under the World Hospices and Palliative Care Association's level of Palliative Care, they include countries with no known activity, with identifiable capacity building, with isolated provision and those with generalized provision of palliative care. For such countries, there is certainly no need to reinvent the wheel. They can take advantage of the latecomer effect, and leapfrog into the fledgling technology-driven palliative care intervention.

The use of technology intervention to enhance palliative care delivery has two major appeals for resource poor lower and middle income countries. First, from the above sample of preliminary introduction of these technologies in palliative care contexts, it is clear that there is a leveraging of existing technologies with minimum proprietary protection. In many developing countries, including African countries the development of mobile application algorithms is increasingly an area of competence with significant local factor endowment. African youths are active actors and stakeholders in information technology innovation. Quite unlike in the area of pharmaceutical research and innovation where there is asymmetry in access to technology which accounts for high cost of patented drugs, in the area of information communication technology, especially at the base level of app designs, resource poor, low or middle income countries are less likely to be constrained in terms of access to complementary technologies and innovation to advance access to palliative care. Finally, the use of information and communication technology in the palliative context would potentially benefit from the malleability of those technologies for collaborative and open access innovation. In the palliative care contexts, such technologies easily lend themselves to all forms of shared and innovative adaptation under the open access framework unlike the hard-edged patent-induced proprietary control of innovation that undergird R&D in new drugs.

Also, taking the example of Lindley et al's use of mobile app to promote clinicians' referrals and to enhance access to palliative care for pediatric patients, it is easy to see how such initiative

⁴⁴ *Supra* note 32.

⁴⁵ *Supra* note 32.

could be scaled up in various other contexts. In terms of their features, most mobile apps are context and local specific. For example, outside the specific pediatric oncology context in which the app was developed, the idea can be used on a nationwide basis to assist clinicians and families to access limited palliative care resources. As well, it can be adapted for use to obtain valuable information on availability and location of hard-to-come-by pain medications.

The second appeal of the use of information technology to enhance palliative care delivery in resource poor low or middle income countries is based on the fact that there is acute shortage of pain management specialists and core professional competence in end of life care in those countries. And for the most part, majority of palliative caregivers at the end of life spectrum in many of those countries are informal providers – spouses, families, and other immediate relatives of the patient. Aside from lack of professional skill sets in palliative care in those countries, culturally family is perhaps more proactive and involved than is the case in many industrialized Western countries with integrated palliative care system. Under the prevailing state of affairs, resource poor countries with little or non-existent palliative care system are likely to benefit immensely with a technology model that supports focusing on the needs of informal care providers. For these countries, the model represented by use of videophone technology to facilitate IDT's interaction with care providers and patient the ACTIVE module and the pilot model for exposing caregiver to problem-solving therapy (PST) potentially represent revolutionary strategies to leapfrog palliative care in societies where the majority of care providers are home-based informal family members. Aside from being suited to the cultural and pragmatic exigencies in many countries, when appropriately adapted the ACTIVE and PST modules can potentially ensure that even the limited number of palliative care expertise that exist at institutional levels could be optimally exploited for bigger impact than where there is no application of technologies. In sum, the emerging prospects for diffusion of information and communication technology in the domain of hospice and palliative represent, in a counterintuitive way, are a strong opportunity akin to a low-hanging fruit to be harvested with little or no strings attached for the advancement of palliative care in parts of the world with chronic shortage of expertise in that medical speciality.

Local diffusion of information and communication technology for the advancement of palliative care especially in regions of the world where there is acute shortage would be tested by infrastructural deficit pursuant to the digital divide. Access to computer, the internet and other digital resources and supportive infrastructure such as electricity by many in resource poor countries with little or no palliative care expertise and capacity, is limited in relation to other highly resourced countries with fairly integrated palliative care. Despite the problem of the digital divide, the adaptive nature of these technologies and the continuous evolution and elasticity of information and communication technologies hold strong hope for their ability as

important factors to leapfrog those countries toward development of technology-enhanced capacity in palliative care.

Palliative Care: Re-Rethinking Global Drug Strategy and Advancing SDG #3

Most narcotic drugs, opioids and several other controlled substances that are clinically efficacious for pain control are in adequate supply globally. Their lack of access to over 80% of the world population in need of pain medication is less a factor of their cost or proprietary barrier to access than it is a factor of drug regulatory control gone ugly. Throughout the texts of policy instruments for the control of these substances there is an overarching need to ensure that these drugs do not get into the illicit drug chain through recreational users, organized criminal rings or even those who are determined to not apply the drugs to lawful purposes. The present global state of pain divide, which is reflected in the availability of integrated palliative care in only 15% of countries of the world point in part to a counterproductive outcome of global narcotic drug policy.

The phobia over illicit use of controlled substances by wrong parties manifests in the apparent lack of trust in the health institutional infrastructures in many lower income countries and their ability to responsibly dispense controlled substances. This state of affair is further aggravated by a glaring lack of professional and core expertise or capacity in palliative and end of life care in those countries. Such lack of expertise can hardly be disentangled from other competences of the cognate public administrative skills required to meet the stringent international reporting and accountability standard essential for dealing in controlled substances. For many years global public health policy neglected investment in building public institutional and professional capacity and trust in countries and regions especially in the developing world. For as long as this gap which has as its consequences annual deaths of over 10 million people without access to palliative care and pain medication – an egregious and insidious form of injustice, one that leaps up to the scale of cruel, inhuman and degrading treatment is not closed, it would not be feasible to secure healthy lives and promote well-being of *all* for as espoused under the SDG #3.

Access to palliative care and to pain medication central to its delivery is a human right integral to the right to highest standard of health. A poor or non-existent standard of meaningful palliative care to the majority of the world's population in need of it poses a fundamental threat not only to their human rights but to public health. In order to truly realize the broader goal espoused under the SDG #3 namely to ensure healthy lives and promote well-being for *all* ages, palliative care crises and the global pain divide must assume a preeminent place on the agenda of global health and drug policy. In this regard, the ongoing initiative of the WHO pursuant to the 2014 WHA Resolution on palliative care and the upcoming 2016 UN General

Assembly Special Session on Drugs provide an opportunity for constructive and coherent implementation strategy to address access to pain medications. Already, the moribund drug law barriers continue to be pulled down in many developed countries through legalization of hitherto criminalized substances (especially cannabis or marijuana) under more progressive national regimes. There are lessons to be learned from those national systems for application to the issue of pain medication at global level. In addition to progressive legal and policy framework, current public private partnerships (PPP) and various forms of public interest advocacy around improvement of palliative care and access to pain medication to needy people can shift their focus toward the development of local institutional and professional manpower in the field. Constructive and strategic diffusion of information and communication technology in the field of palliative care potentially presents an interesting opportunity to fast-track any attempt to address the challenge that the palliative care deficit and the pain divide pose for the realization of SDG #3.

*Professor of Law in the Centre for Health Law, Policy and Ethics and the Centre for Law, Technology and Society, University of Ottawa, Canada coguaman@uottawa.ca
(UNACCESSMEDS, Feb 2015)