

Meeting the Global Abyss: A Framework for Local Patient Centered Palliative Care

Richard R Love*, and Sheikh I Ahamed

Professor, Department of Computer Science, Marquette University, Milwaukee, USA

Abstract

The majority of global deaths are characterized by misery and limited palliation and occur in low- and middle-income countries (LMICs). Strategies for addressing the growing challenges of end-of-life palliative care, particularly those concerned with physical aspects of care, have been defined based on high-income country models of health care services and research. In LMICs, access to adequate quality primary care practitioners and oncologists is limited, and calls for training these specialists and palliative care physician specialists, even if heeded, cannot be expected to meet the growing palliative care population needs.

An applicable general framework for addressing this patient-centred abyss however, is now apparent, grounded in emerging favourable data about three components: new kinds of health paraprofessionals; information technology (IT) tools; and innovative health system approaches.

Routinizing palliative care can allow development of paraprofessional palliative care specialists. IT tools of importance include cell phone-based symptom questionnaires; internet facilitated virtual caregiver-patient visits and sharing of personal patient and family educational materials, and automated decision-making algorithms for symptom management. Health system approaches with these foregoing operational efficiencies and improved productivity can allow more and higher-quality care for more patients in need.

New local approaches are needed to address the right questions about public health palliative care.

Keywords: Palliative Care; Health System; Symptoms

Description

“Imagination at scale is our only recourse.” Jonathan Ledgard [1]. The majority of global deaths are characterized by misery and limited palliation and occur in low- and middle-income countries (LMICs) [2, 3]. Two thirds of patients with cancers in these countries die of these malignancies; 70-80% of these deaths are accompanied by severe pain [4]. Pain is also a major symptom in patients dying of other common non-communicable diseases [5]. As an example, in Nepal estimates for 2012 based on mortality data, are that pain at the end of life was an issue for 84% of 13,724 patients dying of cancer, 67% of 31,714 patients dying of cardiovascular disease (CVD), and 67% of 17,049 patients dying of chronic obstructive pulmonary disease (COPD), and experts opined that these figures may be low [6]. While the pain syndromes associated with malignancies are usually directly related to the pathophysiology of the disease processes, those associated with CVD and COPD often appear more associated with general functional disability. In Globocan, cancer estimates for 2018, among many data items for examples, some striking numbers are that of all cancer deaths 57.3% were in Asia; China has the highest age-specific death rate for lung cancer; South Central Asia (meaning India and Pakistan) with 26% of the global population, has the highest global incidence rates for oral cancer in men, and mortality incidence ratios of 63% for cervical cancer and 53% for breast cancer, compared with ratios of 30% and 15 % respectively for North America [7]. These data for cancer suggest what the most frequent diseases needing palliation are in Asia, where the majority of the underserved case burden occurs.

Strategies for addressing the growing challenges of end-of-life palliative care, particularly in LMICs, have been defined based on high-income country models of health care services and research, and despite efforts to apply these in resource-constrained settings; the assumptions inherent in recommendations of even multi-national groups are astonishingly insensitive to the realities of health systems' operations in many LMICs. For example, the ASCO Resource-Stratified

Practice Guideline starts with a discussion of palliative care models in which “needs of patients and families are identified and met at all levels, in collaboration with the team providing oncology care” [8]. The basic care recommendation which follows states that “Palliative care needs should be addressed in the community or at the primary health care centre.” Later discussion in this guideline refers to apparently successful models in Africa, Malaysia and Kerala, India, which reflect this recommendation. The difficulty with this start to a discussion of models is that globally primary health care facilities are often scarce, painfully understaffed, and operationally dysfunctional, offering low quality care; and for the vast majority of patients, the quality of cancer care is poor, cancer specialists are never seen, and teams for oncology care don't exist. The guideline goes on to advocate that “all health professionals should be trained in basic palliative care”. Again, is this a realistic goal to raise when there is a paucity of palliative care trainers world-wide, the efficacy and impact of such efforts compared with other public health interventions (such as those now for coronavirus), may be very low, and the systems in which the majority of practitioners work, are so weak and dysfunctional?

When more specific models from India and Africa are offered, their emphasis is on community engagement models, which in the case of Kerala, India have been enormously impressive, with an astonishing breadth of critical and needed activities [9-11]. What is not commented on in detail in these reviews is any rigorous evidence that patient symptom management efforts are observably impactful. Further, as

***Corresponding author:** Love RR, Professor, Department of Computer Science, Marquette University, Milwaukee, USA, Tel: + 1 6086987881; E-mail: debpratim008@gmail.com

Received June 03, 2020; **Accepted** July 22, 2020; **Published** July 31, 2020

Citation: Love RR, Ahamed SI (2020) Meeting the Global Abyss: A Framework for Local Patient Centered Palliative Care. J Palliat Care Med 10: 370.

Copyright: © 2020 Love RR, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

the Kerala authors themselves comment, the efforts there are markedly different than those which characterize palliative care elsewhere in that country [10].

In summary, for most patients in the world needing end-of-life symptom-addressing palliative care, providers are not available, health systems are weak, and the quality of the interventions received, if any, is likely to be low. An applicable general framework for addressing this abyss however, is now apparent, grounded in emerging favourable data about three components: new kinds of health paraprofessionals; information technology tools; and innovative health system approaches.

Palliative care para-professional specialists

Because the chokepoint for provision of palliative care to the majority of global citizens-in-need is lack of access to providers, the creation of new types of palliative care specialist providers is essential [2,12,13]. As an example, routinizing components of specialty care which can be carried out by paraprofessionals has been dramatically successful for cataract treatment. The specific steps in evaluating patients, preparing for and doing cataract surgery were broken down, and responsibility for each step was given to single individuals who became very expert with specific activities. High volume with such care became possible and such volume begets lower costs and high quality. For palliative care visits, the necessary assemblage and recording of previous and current relevant data are significantly time-consuming, usually of the most-costly staff individuals in the system-physician practitioners. However, particularly the medical summary, details of patients' most intense symptoms, and elicitation of the patient's current major health concerns, can be Para-professional interview and documentation tasks. Critical to efficient and high-quality paraprofessional care is the development of rigorous and evidenced-based diagnostic pathways and treatment guidelines to direct clinical practice, addressed below.

Information technology tools

In high-income countries, the use of tools for patient reported outcomes (PROs)-generally paper symptom questionnaires are associated with as follows:

- Improved detection and recognition of symptoms and their intensities
- Increased management interventions
- Better control of symptoms
- iv Increased patient-provider communications
- Increased patient satisfaction with care [14].

But whether symptoms like pain (by far the most common and intense symptom) and some measures of overall quality of life are significantly improved and survival are impacted by use of PROs and subsequent interventions, have only been suggested from complex and expensive intervention studies conducted by tertiary care centres in high-income countries [14,15]. What is new however, is that PROs tools can be placed on cell phone platforms, and feasibility of their use with this technology has been demonstrated even with illiterate populations in LMICs [16]. Cell phone availability is high in many low- and middle-income countries and large fractions of these populations are facile in the use of the medium.

Secondly, virtual visits with a health care provider, using video engagement, are becoming more common in high-income countries, particularly in the face of the current coronavirus pandemic, and the payment models and quality issues are being successfully addressed [17]. Tele-care works. Tele-palliative care should be also very feasible.

Thirdly, effective automated, patient-tailored, artificial intelligence-facilitated decision-making systems for patient symptom management are increasingly available [18-23]. Such systems can bring Para-professionals into front line roles in patient care [24].

Innovative health systems

To address the gap between population needs and available services in palliative care we need, world-wide, major scaled-up changes in operational efficiencies and productivity [12, 19]. We need what Christensen calls disruptive innovation [12]. The foregoing two sections of this communication identify how these efficiency and productivity challenges can be successfully and economically addressed. Markman and the late Jonathan Mann have pointed to a central issue applicable to how we approach the global palliative care challenges: the critical matter is how we define the problems [25]. We have been talking about how we train more palliative care physician specialists and primary care providers, when we might better be asking how we can describe the specific work tasks for rapidly trainable paraprofessional palliative care specialists, transforming or increasing the activity portfolios for example of primary care nursing professionals and linking these practitioners to palliative care centres using information technology tools We have been talking about increasing provision of face-to-face provider encounters, when we have the means to, and should be striving to offer tele-palliative care. We have been struggling to develop palliative care treatment guidelines and get providers to use these, when we have the skills to create automated patient-tailored intervention recommendations. We have the opportunity now to scale up effective palliative care systems. Developing local experiments implementation research exploring these alternative approaches to do this is the way forward [26].

The broad framework for addressing global end-of-life palliative care dictates a need for disruptive local approaches characterized by more imagination about defining the central issues and how to address them. We need more of Jonathan Ledgard's spirit [1].

Conclusion

The global health community has the responsibility and the opportunity to close the access abyss in the relief of pain and other types of suffering at end-of-life and throughout the life course, caused by life-limiting and life-threatening health conditions

The global health community has the responsibility and the opportunity to close the access abyss in the relief of pain and other types of suffering at end-of-life and throughout the life course, caused by life-limiting and life-threatening health conditions

The Global Health Community has the responsibility and the opportunity to close the access abyss in the relief of pain and other types of suffering at end of life and throughout the life course, caused by Life-limiting and Life-threatening health conditions.

References

1. Ledgard J, Taub B (2019) Jonathan Ledgard believes imagination could save the world. *The New Yorker*.
2. Knaul FM, Farmer PE, Krakauer EL, Lima LD and Bhadelia A, et al. (2018) Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: The Lancet Commission report. *Lancet* 391: 1391-1454.

3. The Economist (2015) The Economist Intelligence Unit: The 2015 Quality of Death Index: Ranking palliative care across the world.
4. Cleary J, Gelband H, Wagner J (2015) Cancer pain relief. *Disease Control Priorities* 3: 165-173.
5. Kelley AS, Morrison RS (2015) Palliative care for the seriously ill. *New Engl J Med* 373: 747-755.
6. Swarbrick EM, Pietroni MAC, Munday DM (2019) The Need for Palliative Care in Adults in Nepal: Projections Based on Modeling Mortality Data. *Indian J Palliat Care* 25: 41-45.
7. Bray F, Ferlay J, Soerjomataram I, Siegel RL and Torre LA, et al. (2018) Global Cancer Statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries: *Global Cancer Statistics 2018. CA A Cancer Journal for Clinicians* 0: 1-31.
8. Osman H, Shrestha S, Temin S, Ali ZV and Cleary JF, et al. (2018) Palliative care in the global setting: ASCO Resource-Stratified Practice Guideline. *J Global Oncology* 14: 431-436.
9. Rajagopol MR and Palat Gm (2002) Kerala, India: Status of Cancer Pain Relief and Palliative Care. *J Pain Symptom Manage* 24: 191-3.
10. Kumar S (2013) Models of delivering palliative and end-of-life care in India. *Curr Opin Support Palliat Care* 7: 216-222.
11. Downing J, Grant L, Leng M, Namukwaya E (2015) Understanding Models of Palliative Care Delivery in Sub-Saharan Africa: Learning from Programs in Kenya and Malawi. *J Pain Symptom Manage* 50: 362-370.
12. Christensen CM, Grossman JH, Hwang J (2009) *The innovator's prescription. A disruptive solution for health care* New York: McGraw-Hill.
13. Emanuel EJ (2017) *Prescription for the future: The twelve transformational practices of highly effective medical organizations.* New York: Perseus Books.
14. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, et al. (2015) Symptom Monitoring with Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *J Clin Oncol* 34: 557-565.
15. Denis F, Basch E, Stephans AL, Bennounna J, Urbam T, et al. (2019) Two-Year Survival Comparing Web-Based Symptom Monitoring vs Routine Surveillance Following Treatment for Lung Cancer. *JAMA* 321: 306-307.
16. Love RR, Ferdousy T, Paudel BD, et al. (2016) Symptom levels in care-seeking Bangladeshi and Nepalese adults with advanced cancer. *Journal of Global Oncology* 3: 257-260.
17. Duffy S, Lee TH (2018) In-person health care as option B. *New Engl J Med* 378: 104-106.
18. Asch DA, Nicholson S, Berger ML (2019) Towards facilitated self-service in health care. *New Engl J Med* 380: 1891-1893.
19. Cleeland CS, Portenoy RK, Rue M, Mendoza TR, Eeller E, et al. (2005) Does an oral analgesic protocol improve pain control for patients with cancer? An intergroup study coordinated by the Eastern Cooperative Oncology Group. *Annals of Oncology* 16: 972-980.
20. LG Pérez, Libertova R, Olivera RM, Anguiler PS, Rosario MAB, et al. (2009) A systematic review of specialized palliative care for terminal patients: which model is better? *Palliative Medicine* 23: 17-22.
21. Bell D, Gachuhi N, Fischer N, (2018) Dynamic clinical algorithms: Digital technology can transform healthcare decision-making. *Am J Trop Med Hyg* 98: 9-14.
22. Kamdar M, Centi AJ, Agboda S, Jethwani K (2019) A randomized controlled trial of a novel artificial intelligence-based Smartphone application to optimize management of cancer-related pain. *J Clin Oncol* 37.
23. Mooney K, Beck SL, Wong B, Dunson W and Wujcik D, et al. (2017) Automated home monitoring and management of patient-reported symptoms during chemotherapy: results of the symptom care at home RCT. *Cancer Med* 6: 537-546.
24. Mehta MC, Katz IT, Jha AK (2020) Transforming global health with AI. *New Engl J Med* 382: 791-793.
25. Markman A (2019) How you define the problem determines whether you solve it. *Harvard Business Review*. Spring 29-30.
26. Love RR (2019) Improving cancer outcomes in low and middle income countries. *J Global Oncology* 5.