MARQUECare: Information Technology Tools and a System for Palliative Care for Everyone

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"The big question of human life is how do we limit suffering?"
- Yuval Noah Harari

Introduction

- The majority of global deaths are characterized by misery and limited palliation and occur among citizens in low- and middle-income countries [1, 2].

Palliative-end-of-life care is a PUBLIC HEALTH issue.

- The action place everywhere in the world, where the DOING of palliative care happens however, is the patient-health care provider encounter (Figure 1).
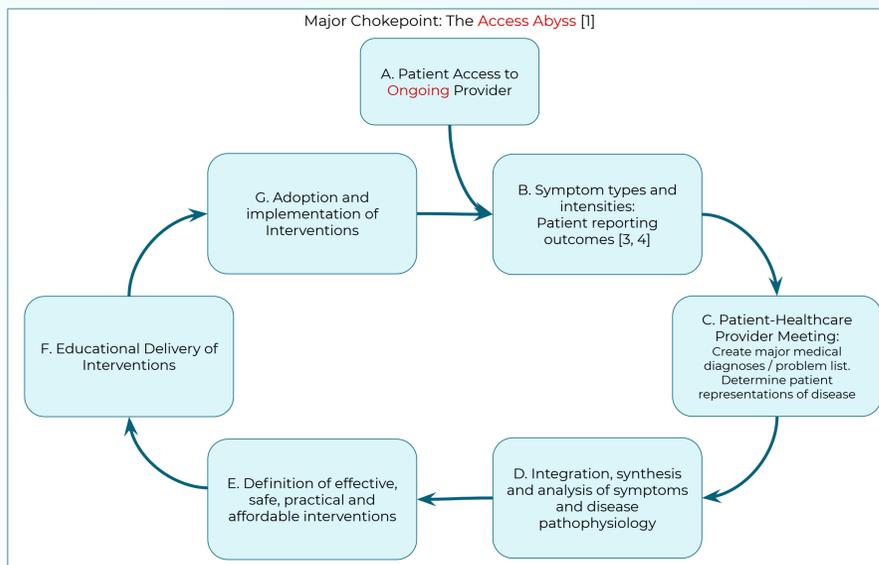

Figure 1: The MARQUECare Patient-Healthcare Provider Palliative Care Loop

Rationale for Approach

- Desires and needs for home care because of rural locations, inconveniences of travel, expenses.

- To meet these challenges, we need:
  - better organizational mechanisms,
  - facilitation for involvement of all health care providers, and
  - better functioning and efficiency of activities in the patient-provider palliative care loop.

- Information technology tools offer means for doing these activities effectively and inexpensively.
  - Cell phone availability in Nepal is high—there are as many cell phones as people. Half of these phones are Smartphones.

Methods

Our goal is to create an artificial intelligence-facilitated palliative care symptom management system, to bring more healthcare providers into effective palliative care.

Based on our MARQUECare model, we have developed a patient-centered home palliative care system (NAPCare) with the Nepalese Association of Palliative Care. We require a patient or family member-provider clinical meeting at least once every two weeks, giving provider remuneration.

Our software system consists of three components:
- **Public website:** Patient, family, healthcare provider and guest information about the system. (Web Address: homepalliativecarenepal.net)

Figure 2: Public website homepage

- **Patients' Mobile App:** the Marquette Symptom Assessment Survey (MSAS) (a PRO, or EMA [6] - a 15 item questionnaire on Android and iOS cellphones. Cross-sectional data in 383 Nepali patients have demonstrated easy usability [5].
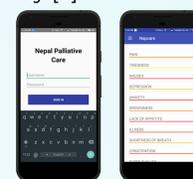

Figure 3: Patients' Mobile App

- **Doctors'/ providers' web-app:** Palliative care news and notices; individual and organised doctor-registered patient MSAS, demographic and medical summary data; submenus of written and video interventions for patients (8), families (7) and providers (4); prescription writing capacity; palliative care clinical practice guidelines.
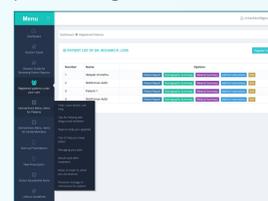

Figure 4: Doctors' Web App menu

Future Steps

- Development and structure of an A.I. model for pain

- Deployment of tools in 3 Nepali clinical settings → Data collection Fall 2019 → troubleshoot operational problems (patient information delivery). Development of evaluation strategy for system impact.

- Development of alert messages to patients to submit MSAS reports and providers for increased/ high patient symptom levels and mismatch between pain level and prescribed medication

- Nepalese audio instructions for patient mobile app

- Nepalese versions of all menu items

Take Home Points

- The chokepoint for provision of palliative care to the majority of global patients is lack of access to health care providers.

- A public IT tools-rich system - *a "bottoms'-up" approach* - may encourage a major increase in impactful providers, particularly local and centralized para-professional providers in a tele-care system.

- Cell phone availability is high in many low- and middle-income countries, and large fractions of these populations are facile in use of this media.

- Cell phone PROs can be an efficient and high- quality promoting IT tool for facilitating targeted provider care. [5]

- Comprehensive provider web-apps offer significant promise for delivery of efficient, home-based symptom-managing palliative care, easily integratable into established healthcare systems.

References

1. Knaul, F.M., Farmer, P.E., Krakauer, E.L. et al.: Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: The Lancet Commission report. Lancet 2018; 391: 1391–1454. http://dx.doi.org/10.1016/S0140-6736(17)32513-8.
2. The Economist Intelligence Unit: The 2015 Quality of Death Index:Ranking palliative care across the world. The Economist, 2015.
3. Au, E., Loprinzi, C.L., Dhodaptkar, M. et al.: Regular use of verbal pain scale improves the understanding of oncology inpatient pain intensity. J Clin Oncol 1994; 12:2751-2755.
4. Basch, E., Deal, A.M., Kris, M.G., et al.: Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. J Clin Oncol 2015. 34:557-565.
5. Love, R. R., Ferdousy, T., Paudel, B. D., Nahar, S., Dowla, R., Adibuzzaman, M., ... & Ahamed, S. I. (2016). Symptom levels in care-seeking Bangladeshi and Nepalese adults with advanced cancer. Journal of global oncology, 3(3), 257-260.
6. May,M., Junghaenel,D.U.,Ono,M.: Ecological Momentary Assessment Methodology in Chronic Pain Research: A Systematic Review. J Pain 2018.19(7):699-716.

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