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The Marquette Palliative Care System

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Abstract

Worldwide, major clinical barriers to effective palliative care are the absence of a. current data on symptom type and intensity; b. immediately accessible information on practical, affordable, and effective interventions; and c. self-sustaining systems to facilitate physician engagement in continuing palliative care. Our adaptable system, developed for Bangladesh and Nepal, addresses these barriers. A tele-home palliative care program facilitates home care, minimizes expense, and encourages efficient professional practitioner involvement employing two information technology tools: a patient cell-phone "app" on the Android platform with a 15-item symptom questionnaire and an Internet website with health information sections for patients/families and for clinicians. The physician section contains a guide for patient symptom review, clinical practice palliative care guidelines, secured patient demographics, medical summaries, and current and past symptom reports along with prescription-writing capability. The system is managed by a local organization that registers patients and their physicians, instructs patients on the free downloadable application and completes their demographic and medical summaries, and arranges collection of a modest fee. The organization also ensures regular physician/clinic visits by the patient or by a family member with a patient phone check-in, at least every 2 weeks.

Keywords: palliative care, accessibility, symptom data, intervention information, efficiency, "app", tele-care, IT tools, home care, health

1. Introduction

1.1 Societal versus medical practice perspectives on improving palliative care

Reviews of country-by-country palliative care efforts, such as that provided by the Economist Quality of Death Index report, have identified broad area indicators of better palliative care, but such analyses ignore the weaknesses of prevailing clinical practice and health systems, which are poorly organized to provide patient-centered palliative care (**Table 1**) [1]. Ultimately, it is in clinical practice, the collective activities of health care providers, that the majority of critical activities bearing on actual patient palliative care experiences occur. To a great degree, the broad area indicators reviewed reflect community and political interest as well as financial investment. Unquestionably, such attention can, over time, lead to higher-quality palliative care, but throughout the world what governs the experience of individual patients needing palliation is primarily determined by the organization of medical

practice, the attention of clinicians, and the focus of health systems. In the United States, as Emanuel has suggested in identifying key directions for the future of medical practice, effective organizations are those that transform provider interactions in palliative care [2]. It is in this context that the goals of this communication are addressed: more immediately than can occur to address the broad national and community indicators, how can general clinical practice globally be favorably affected to provide efficient and more effective palliative care for all patients needing such service? We describe here an information technology tool-facilitated basic system we believe is easily implemented and widely adaptable to clinical practice circumstances in many countries. By addressing common major barriers to provision of palliative care, we can increase practitioner engagement in such care at significant patient-benefiting levels.

1.2 Challenges and barriers to high-quality palliative care in clinical practice

Three-quarters of patients with advanced cancer are reported to suffer from pain and "85% of patients (with pain) can be well palliated with the use of simple, inexpensive, 'low technology' oral analgesics" [3, 4]. Unfortunately, however, there is little evidence supporting the long-term benefit of these analgesics and other symptom-alleviating interventions [5]. What and where are the barriers to closing these gaps? (**Table 2**).

A primary barrier to provision of adequate symptom treatment for patients is a clinical practice failure sequence: under-appreciation from under-assessment by clinicians of the types and intensities of symptoms patients are experiencing, which then logically is associated with very limited or absence of interventions to address these or the consequent helplessness and hopelessness that are root causes of suffering [4–6]. To provide optimal care for patients with cancer and other life-threatening illnesses, practitioner-available accurate, complete, and timely information about symptoms, daily information if possible, is necessary. Specifically, repeated failure among physicians worldwide to use validated symptom assessment tools prevents communication between patients and health-caregivers that could bring attention to symptom issues [7]. The usual way such information is obtained is through direct questioning or information provided in completing paper instruments during patients' relatively infrequent (and typically very brief) office visits with medical practitioners. If symptomatic status information could be obtained regularly, for example on a daily basis, and brought to the attention of the caring practitioners, this would be expected to improve symptom management and decrease suffering. This kind of activity is what characterizes comprehensive hospice programs and contributes significantly to their effectiveness for patients and their positive image for family members. Additionally, the development of regularly obtained symptom data would provide the basis for measuring, reporting, and improving the quality of palliative care, all absent in general current practice [2].

National policies addressing palliative care
Higher levels of public spending
Extensive training of health professionals
Patient care subsidies
Availability of opiate drugs
Public awareness

Table 1.
National indicators of higher quality palliative care. From 2015 quality of death index of the Economist [1].

Practitioners lack current patient data on symptom presence and severity
Practitioners lack practical, quickly accessed information on palliative interventions
Lack of efficient local systems for providing palliative care, particularly at home
Insufficient numbers of health professionals
Higher level interventions with no practical effect in the short- or medium-term, including increasing numbers of hospices, specialists, or specialist training activities

Table 2.
Barriers to effective palliative care in clinical practice.

A second major palliative care practice barrier is the absence of immediately-accessible information on locally practical, affordable, and effective interventions. A generally useful approach to more widespread use of effective interventions across the board in medicine has been the development and promotion of clinical practice guidelines. Academic approaches to such palliative care guidelines have been comprehensive, but overwhelming in their dimension and their lengths, and thus impractical for over-scheduled clinicians everywhere. The American NCCN clinical practice guidelines for palliative care are 106 pages in length [8]. Increasingly, attempts are underway to create succinct and practical palliative care clinical practice guidelines specific to each country to address all of the common symptoms, and that are well-grounded in local conditions and circumstances. There has been, however, even more limited attention to facilitating access to such guidelines and employment of their recommendations.

A third major palliative care practice barrier worldwide is the absence of efficient systems and processes to facilitate physicians' engagement in successful palliative care. Components of this situation are the understandable interest of patients and families in home care over institution or medical facility care, a dearth of practitioners in low- and middle-income countries comfortable with palliative care problem-solving and practice, and general clinical practice circumstances in which physicians are overburdened. Further, even if physicians were to have patient symptom and applicable intervention information readily available, their practice systems are not organized to allow them to provide home care as part of the workload for which they can be appropriately compensated financially. Worldwide, the palliative care manpower shortage situation cannot be realistically addressed by scaling-up training of adequate numbers of palliative care specialists. The practical approach is to facilitate engagement of physicians across all practice specialties in basic palliative care, under cost-effective and efficient locally-acceptable systems. The Economist investigation recognizes this need in emphasizing that training for all doctors and nurses is essential [1].

In general, there is a lack of approaches that consider whole populations in a public health perspective that addresses clinical-practice systems to provide for palliative care needs. Calls for increasing manpower of palliative care specialists, residential hospices, or educational activities regarding palliative care, even if successful, can simply not be expected to address adequately the large numbers of patients needing palliative care. These calls stem from the usual starting point—a provider-centric model of health care that needs to be replaced by a more patient-centric model. Simplistically speaking, the evolution of our health systems, particularly in the United States, has been grounded in addressing how things can and should ideally work for providers fixing problems, not supporting patients. This has led to organizational functioning and operations that produce fragmented care oriented to a disease; patient goals, wishes, perspectives and, most importantly, needs are regularly ignored. Addressing palliative care better can logically start by

focusing on these patient-centered factors. In many ways, articulating an approach to palliative care is a tabula rasa, because, according to the Economist report documents, it is only in some high-income countries that apparently reasonable levels of palliative care for those in need are being provided [1]. Our personal experiences over the last 15 years in multiple health care settings across Asia, most particularly in Bangladesh (ranked 79 out of 80 countries in the Economist report), support the general conclusion that for the majority of global citizens, palliative care, at even the most basic levels, is nonexistent. It is within this broad perspective that the authors present the current innovations. Under the premise that information technology (IT) tools could contribute constructively to creation of patient-centered, effective, and cost-effective palliative care systems feasible within diverse health care systems in low- and middle-income countries (LMICs), we have been working for several years to develop practical, user-friendly, affordable IT tools and systems which address these afore-stated barriers [9–11].

2. A patient-centric, generalizable palliative care system that addresses common clinical practice barriers

2.1 Acquiring real-time symptom data: development of the patient questionnaire tool

If, instead of seeking paper questionnaire data on symptoms at the times of office visits, symptomatic status information could be obtained regularly on the day's experience from home by use of patient cell phones and delivered to attentive and responding physicians and caregivers in real-time in a well-organized way that complements prevailing overburdened physician practice with appropriate financial compensation, we could expect to improve symptom management and decrease suffering. Changing the collection and recording of patient symptom data from a medical staff task, currently done inefficiently and irregularly, if at all, to a patient task and responsibility has multiple major consequences [7]. First, it obviously simplifies and eases the operations of often hectic and overburdened clinic staff. In circumstances where electronic medical records have been extensively implemented, a well-described scenario occurs: the addition of more and more features makes the software system progressively more frustrating to use, developing it into what is called a "Tar Pit". Second, it allows creation of a legible standardized record of symptoms, which can be permanently filed in some patient record system. Simple standardization of a rating system enhances clinical staff interpretation of those records and easily notices and responds to a (sudden) increase in any one symptom. Third, critically, it engages the patients and their family members in openly identifying in detail the breadth of common symptoms. Fourth, and perhaps even more critically, the process of recording and submitting symptom reports by cell phone sets the stage for increased patient and family expectations about attention to those very symptoms.

Experienced clinicians report that when they have provided such means for patients to report specific data, expectations are high that there will be a closing of the loop with a clinician's response. In the circumstances of serious symptom report, for example a high level of pain, particularly if sudden and/or new, such empowered patients and family members react strongly if there are not prompt clinician responses. The perception is that if clinicians allow such information submission, they should have the capacity to process and act on it. The kinds of unhappy conversations that follow when patient reports do not elicit health professional or system responses can easily be imagined. In fact, when a patient computer-submitted

report study that involved multiple practitioners did not train the practitioners beforehand in the creation of response systems, the clinicians experienced angry communications from patients and families in the absence of prompt responses to reports that demanded intervention. The practitioners quickly developed their own response systems to meet patient expectations, an example of a patient-driven change driven by enabling patients to communicate their needs.

We have first developed a basic cell phone symptom-status application, the reliability, feasibility, and validity of which we have established in studies in Bangladesh and Nepal [9–11]. The Marquette Symptom Assessment Survey (MSAS) is a 15-item questionnaire covering 12 symptoms; 4 items address pain dimensions. It is constructed using time-tested items from two well-validated and reliable instruments, the Edmonton Symptom Assessment Survey and the Brief Pain Inventory, and three additional items from prevailing palliative care practice: constipation, sleep quantity, and sleep quality [11–13] (**Table 3**). Current forms of this questionnaire in English, Bengali, or Nepali are presented on an Android cell-phone platform and display the questions in sequential fields in legible and audio-presented modes, allowing the patient, including those who are illiterate, to answer each question by moving a cursor along a Likert scale, which is a unidimensional 10-point visual analogue scale (**Figure 1**, top rating scale).

In a pilot study, 10 women with advanced breast cancer provided inter-rater and intra-rater reliabilities of >0.73, and patients or their caretakers were able to successfully submit reports despite progressive terminal illnesses [10]. These women and their families willingly and regularly submitted reports over several months. In <3 minutes, with minimal training, patients could and did answer the questions to indicate the presence and intensities of their symptoms. Subsequent extensive field testing and a large cross-sectional study of over 1000 patients with advanced cancers in Bangladesh and Nepal have established that this application is reliable, valid, and user-friendly, and can be employed by almost 100% of patients

Nausea[1]
Tiredness[1]
Depression[1]
Anxiety[1]
Drowsiness[1]
Appetite[1]
Well-being[1]
Shortness of breath[1]
Current pain[1]
In last 24 hours: worst level of pain[2]
lowest level of pain[2]
usual level of pain[2]
Constipation
Quantity of sleep
Quality of sleep

[1]*From the Edmonton Symptom Assessment Survey [12].*
[2]*From the Brief Pain Inventory [13].*

Table 3.
The Marquette Symptom Assessment Survey (MSAS).
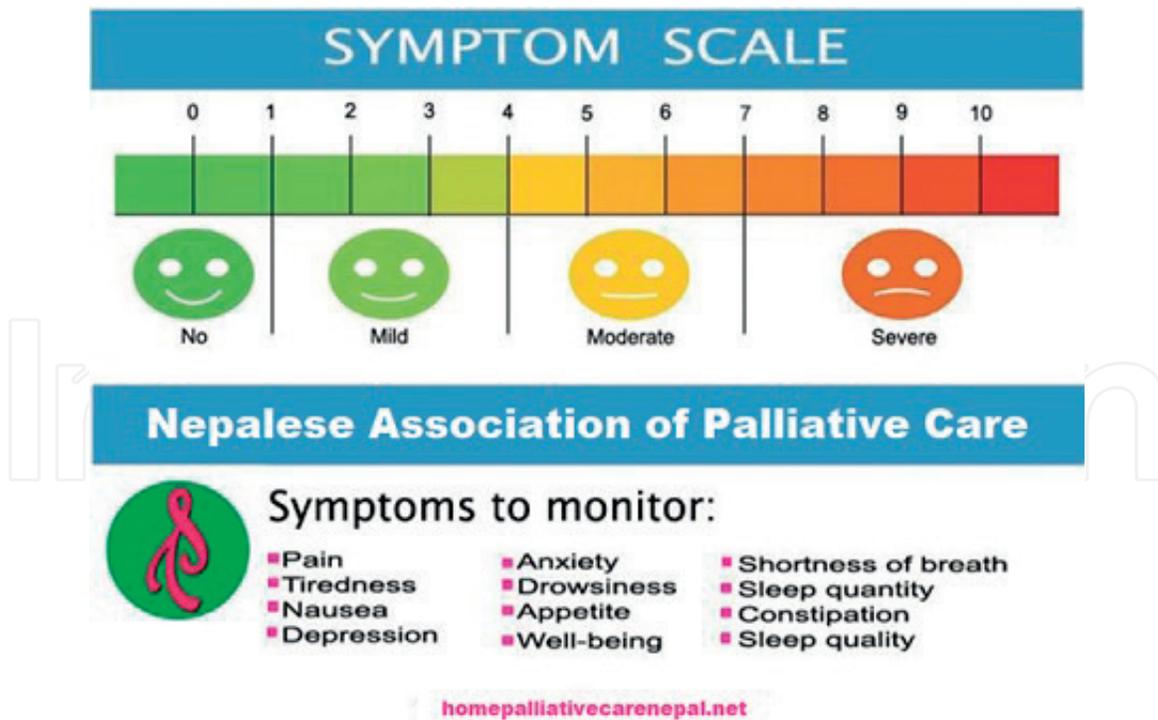
Figure 1.
Laminated symptom scale and symptoms-to monitor pocket ruler.

from a broad spectrum of socioeconomic circumstances. Specifically, in 640 adult Bangladeshi patients with advanced cancers under regular care in tertiary level institutions, all but two patients recruited agreed to study participation; all of these 638 patients had no trouble completing the questionnaire, despite the fact that some of the patients did not personally possess their own Android/smart phone [11, 14]. Only 2 patients out of the 640 said they would not choose to provide future monitoring data using this application [11]. Among 383 similarly recruited patients with advanced malignancies in Nepal, no patients refused study participation, all were able to complete the questionnaire rapidly, and none said they would refuse to provide future monitoring data with this questionnaire. Cell phone penetrance in Bangladesh is >90%; our Bangladeshi colleagues estimate that perhaps 50% of Dhaka residents have Android phones. In Nepal, more than 90% of families have access to cell phones, 2/3rds of which are estimated to be Android phones.

Assuming that patients can understand the symptom-intensity Likert scale and that there are no major cultural factors which influence specific patient reports such as language interpretations of the end-points, for example, or beliefs that there are "right" answers, which might lead to mid-scale scores, it is important to ask how we should define mild, moderate, and severe scores, and what unit changes in scores might be truly meaningful for patients. We have explored some of these cultural issues in our data from Bangladesh and have concluded that our data present a true picture of patients' symptoms [14]. With respect to word definitions in English for describing symptom intensity, we have chosen to consider as "mild" symptom scores of 3–4; otherwise our definitions are similar to those widely used. It is important to note that the scales are graphically as well as verbally defined. Regarding clinically significant score changes, for pain, it is reported that changes of 1–2 units, or down from moderate (5–6 score) to mild 1–4 scores, are, for patients, clinically significant [15].

In summary, we have developed a reliable and validated symptom assessment tool, specifically tailored to palliative care by adding questions about constipation and sleep because these issues are frequently of importance for such patients. This

tool has been easily and rapidly used by essentially all studied patients (together over 1000) in two low-middle income countries. Importantly, ongoing repeated use was favorably perceived by patients and family members, even in the face of suboptimal patient symptom relief. After the deaths of relatives, family members repeatedly told staff members receiving the symptom reports how grateful they were for the opportunities to regularly engage the staff in assisting their loved ones. To them, often the most important matter was that everyone was paying attention to their relatives' symptoms. Thus, requesting and recording patient experience can be validated even when no intervention is possible—the opposite of clinician abandonment.

2.2 Using the MSAS to develop palliative care data on specific population symptoms to direct interventions

While the foregoing barrier considerations are all valid and should be the focus of interventions, successful palliative care management must begin with some understanding of the numbers, levels, and types of symptoms experienced by patients with limited life expectancy and the implications of that experience. Thus, we began as Cleeland did some 25 years ago in the United States, investigating the symptom picture for patients with advanced malignancy in two low- and middle-income country (LMIC) sites [11, 16]. The cross-sectional study described above allowed such evaluation for populations in Bangladesh and Nepal [11, 14, 17].

In Bangladesh, usual pain scores were ≥ 5 in two thirds of patients, but few patients had very high or minimal scores [11, 14]. Majorities of patients reported moderate scores for tiredness, nausea, depression, anxiety, drowsiness, poor appetite, and poor sleep [14]. The reported high intensity levels of these symptoms were not surprising to our Bangladeshi clinician colleagues. Collectively these symptoms contributed significantly to the suffering of these patients. For example, pain scores were correlated significantly with scores for nausea, anxiety, and poor sleep [14]. The patient population studied here might be expected to have a lesser symptom burden than that of the broad population of palliative care-needing patients in the country, because these patients were able to travel and seek care in tertiary care institutions. Overall, we interpret these data to suggest that there is high level and multi-symptom suffering among patients needing palliative care in Bangladesh, despite access to tertiary level care. The moderate pain scores for the majority of patients studied, along with minimal frequencies of high-score levels, suggest partial- and under-treatment. These conclusions are consistent with the Economist report assessment for the country, and with, for pain, the low level of narcotic consumption per capita [1, 18]. More important for the current communication is the practical usefulness of the tool used and these data in developing and targeting interventions [14]. Specifically, it is reasonable to suggest that under-treatment might be partially addressed by physicians having more symptom information in real time, the very issue our cell phone system seeks to address.

In Nepal, among the 383 studied patients, 37% reported maximal pain scores of 7 or greater [17]. Disturbingly, 5% of patients reported maximal pain scores of 10 [17]. A total of 59% of subjects however reported minimal pain. Again, the majority of patients reported moderate or greater levels of tiredness, depression, anxiety, poor appetite, and poor sleep. Alarmingly, 15% and 19%, respectively, reported severe depression and anxiety scores [17]. Our interpretation of these data is that again the cell phone questionnaire tool was very useful in developing reliable and informative data. Here, in contrast to Bangladesh, it appeared that a major fraction of the population had no pain management intervention at all.

In summary, in two LMIC settings, we have been able to demonstrate that our cell phone questionnaire tool can be used to develop important, clinically-useful patient symptom data.

2.3 Creating access to clinical practice guidelines

As discussed above, a practical barrier for clinicians to effectual palliative care is having easy and quick access to information about evidenced-based interventions. For LMIC settings, the first issue is creating such guidelines. Ideally, such guidelines would involve, as they have in high-income countries, comprehensive, rigorous, and transparent local processes involving a large cross section of local stake-holders and experts. The challenge, of course, is that such activities are expensive. Recognizing that the perfect is the enemy of the good, and that having some credible palliative care clinical practice guidelines in each of our pilot LMIC sites would be better than having none, we have created local guidelines in each country. Using the limited resources and experts available, we grounded these documents on local and international sources [8]. The 7-page document for Bangladesh is available at ag-palliativecare.net and the 13-page version for Nepal is available at HomepalliativecareNepal.net. Both were based on the outline presented in **Table 4**. Palliative care goals were informed by the understanding that "Survival is linked to symptom control, and pain management contributes to broad quality of life improvement [8]." Specific targets are to have as many as possible of the 12 common symptom scores in the mild range (4 or less) of the 10-point Likert scales and to lower moderate pain scores of 5 or 6 to at least a 4.

2.4 Coordinating information flow through a multi-user website

To integrate the cell phone questionnaire patient data and the clinical practice guidelines for practitioners in a system that will facilitate provision of palliative care interventions, we have created websites in Bangladesh and Nepal (ag-palliativecare.net and HomepalliativecareNepal.net). Patients submit their symptom questionnaire data to the website over the usual telephone systems. Each of these websites has six sections. There is an introductory home page that explains the system and a health information section for patients and their families. For all

• Palliative care goals
• General approach-psychological support
• Patient education
• Adult pain
• Sleep
• Poor appetite/constipation/feelings of unwellness/nausea
• Anxiety
• Depression
• Disclaimers
• Authors
• Accessible resources

Table 4.
Clinical Practice Palliative Care Guidelines.

participants, an "About us" section describes the operating organization and a contact information section provides a "hotline" telephone number. For health professionals, there is a general background informational section and a secure physician's section accessed using user name and password, with further authorization for prescribing.

Entering this section, physicians can access the following:

- The Clinical Practice Palliative Care Guidelines.

- Basic descriptive instructions for patient symptom report review.

- A menu of types of the different reports that can be generated with one click.

- A list of specific patients registered to each clinician.

- Current or most recent MSAS reports for their patients.

- An historical graph of any score for last 14 or 28 days.

- Individual demographic and medical summary data for their patients, as outlined in **Tables 5** and **6**.

- A link to specific Clinical Practice Guideline intervention suggestions if any moderate or greater symptom score is reported.

- Twice-weekly alerts by text and/or email, by physician's preference, if any patient reports symptoms with an increase in the level of an individual item score by more than 2 units, or a pain score of level 7 or greater results.

- A follow-up alert after a phone call has prompted a patient to send a confirmatory duplicate report to correct for patient entry errors.

- A prescription-writing field, with links to specific Clinical Practice Guideline intervention suggestions, and a menu of commonly prescribed drugs, standard indications, recommended doses, and standard use instructions. When an individual menu item is selected, drug, dose, and usage instructions automatically fill the individual patient's prescription field. When the patients' field is clicked on, their name and the date and other data required for prescriptions, as well as the physician's name, are also automatically entered into the prescription field. A prescription cannot be completed without independent physician identity confirmation digital delivery is available.

2.5 Integrating the system with clinician and clinic practice

At least every 2 weeks, there will be a visit to the responsible physician. In recognition that repeated clinic visits may be a burden to family or patients, may worsen the very symptoms that are the target of care, and may even not be possible, the clinician will see either the patient or a family member. If the patient is not physically present at the clinic, the physician will call him or her during the visit, and confirm the information shared by a family member. This will also discreetly serve to avoid opioid theft and diversion, as well as to confirm that the patient is alive and receiving medication. Further benefit of the clinic visits

Name
Date of birth
National identity number
Home address
Patient mobile phone
Patient email address
Patient facial photograph
Family or closest friend contact information:
1. Name
Contact information
2. Name
Contact information
Notes:

Table 5.
Patient demographic dashboard.

Name
Major medical problems and diagnoses
Current major symptoms (most recent MSAS report)
Symptom MSAS score Date
Current medications (most recent prescription)
Notes:

Table 6.
Patient medical summary dashboard.

is continuity of record keeping, so that the palliative care website can remain auxiliary and does not need to match or duplicate any one facility's medical record system. These visits will also coordinate palliative care with the facility billing procedure, ensuring that physicians will be compensated at their usual rates for their time and expertise and encouraging their participation in the palliative care program. Palliative care is therefore insulated from the economic, administrative, and political concerns of a facility and does not interfere with the compensatory concerns of the physicians.

2.6 Engaging the Marquette Palliative Care System

Use of the cell phone symptom questionnaire "app" described in Section 2.1 and the website described in section 2.4 by physicians and patients is managed under the following system: patients or physicians contact the local system operating organization to learn about and register for system use. In Bangladesh, this is a nongovernmental organization, Amader Gram, and in Nepal, this organization is The Nepal Association for Palliative Care (NAPCare).

The local organization:

- Educates patients and families (and physicians) about the system. An essential requirement is that ongoing use of the system requires a clinic visit to the responsible physician at a maximum of every 14 days by the patient or a family member.

- Registers the patient and doctor in the website system so that cell-phone submitted patient symptom reports will be accepted and filed, associated with the responsible physician.

- Provides the physician with a website doctor's password and obtains a finger-print for prescription writing verification/security.

- Provides the physician with a pocket-sized paper copy of the local Palliative Care Clinical Practice Guidelines as described in Section 2.3 and a laminated symptom-scale and symptoms-to-monitor pocket ruler (**Figure 1**).

- Encourages conduct of a baseline palliative care assessment clinical visit to clarify and codify breadth of patient medical diagnoses, specific symptoms and their likely pathophysiology, patient and family goals, and an overall palliative care plan (**Table 7**).

- Completes, along with the patient, the demographic "dashboard" database for that patient (**Table 5**) and identifies the responsible physician who agrees to provide care for that patient using the system.

- Works with the responsible physician using the baseline assessment data to create the medical summary "dashboard" database, and posts this database on the website.

- Assists patients in obtaining the cell-phone patient symptom questionnaire application from the Google store.

- Trains the patient and family in making symptom assessments, and then recording, and submitting them to the website.

- Arranges for payment (or waiving) of modest monthly fee to the local organization for submission of the reports and their availability on the system website. Use of an online payment system like PayPal can facilitate these transactions. Note that this fee can remain small because it covers the administration of the efficient palliative care system, not medical care compensation.

- Provides a text and telephone trouble-shooting "hotline" for patients and physicians and insures coverage.

- Maintains smooth operation, security, and accuracy of the website system. Reviews and updates the clinical practice guidelines periodically.

- Acts as an intermediary with responsible physicians for patient crises.

- Seeks feedback from the patient, families, and physicians regularly on system operations and problems and vigorously seeks to extend the use of the system, by marketing, to as large a patient population as possible.

- Seeks peer review of anonymized patient data and management for quality assurance to evaluate quality of care.

- Seeks to develop and conduct a rigorous evaluation of the entire system to determine the impact of the system on patients' symptoms, quality of life, and survival.

- Seeks, from the start-up phases on, to develop an operational business model that secures local system sustainability.

Date of evaluation:
All major medical diagnoses
(For cancer, list primary site of origin and sites of known clinical metastases)
1.
2.
3.
Performance status (ECOG scale 1–4)
Vital signs: Blood pressure, pulse, respiratory rate, temperature
Weight BMI
Height
Results of the most recent examination showing disease status:
Physical examination (+findings)
Imaging tests:
Hemoglobin
Current symptoms by Marquette Symptom Assessment Survey
Pain: Maximal pain score
Minimal pain score
Usual pain score
Current pain score
Major site(s) of pain and presumed causes (Inflammation, neuropathic, diffuse or focal bone, other)
MSAS score
Tiredness
Nausea
Depression
Anxiety
Drowsiness
Anorexia
Illness
Shortness of breath
Constipation
Sleep quantity
Sleep quality
Patient major goals
Family concerns and goals
Management plan
Problem/symptom Intervention/treatment

Table 7.
Palliative care baseline assessment checklist.

2.7 Piloting the Marquette Palliative Care System in Bangladesh and Nepal

In 2013–2014, the cross-sectional study described above was done in both Bangladesh and Nepal [11]. As detailed earlier in this chapter, considerable developmental work with the tools and on the system described here has been done in Bangladesh. By the end of 2017, the website and software had been developed

and we were ready to launch the system as a business with Amader Gram. Unfortunately, various Amader Gram personnel and broad political uncertainty in the country have subsequently prevented further activities as of the end of 2018.

During the last half of 2018, we have been setting up the website and the operational system for this palliative care service model in Nepal. During the first 6 months of 2019, major clinical piloting experience with this system will be underway at a major cancer hospital outside of Kathmandu.

3. Implications and ideas for better global palliative care going forward

How to respond meaningfully to the data from reports like those of the Economist and to general calls for addressing palliative care globally is challenging [1, 19]. In this chapter, we argue that there can be a constructive way forward with immediate impact by taking a patient-centric, bottom-up approach to clinical practice systems, their barriers to palliative care, and the potential of IT tools and software. The system we present can in part and wholly be adapted to other country's circumstances, through a relatively minor investment of resources. High-income countries are beginning to develop and use such tools and systems in palliative care, and integration of such systems into established electronic medical record systems is achievable when the control issues can be worked out [2]. Until then, this system can economically function as a program auxiliary to facilities with medical records and those without. The system we present is particularly important in being directed at engaging clinicians/physicians who might otherwise avoid, refer, or somehow abandon their patients who now need palliative care. It can also be employed in noncancer specialties other than oncology that deal with chronic pain, and even be a resource for clinicians with less frequent need for palliation, or those in rural areas with fewer resources. Because our system is patient-centric and relies on and facilitates greater patient and family engagement and control, it also encourages stronger family support.

The entire system focus on palliative care might be expected to generally lower the total care costs, with minimal patient family expenses for submission of symptom reports and clinical office visits. In general, while limited, the available data suggest that facilitating home palliative care is effective for symptomatic relief of patients and is grief-limiting for families, while the overall cost efficacy remains to be well-understood [20]. We believe that after being extensively piloted, our system in Nepal and Bangladesh should be rigorously evaluated in a randomized clinical trial to document the impact on symptoms over time and overall patient survival.

The increasing use of IT technologies in patient care, including the use of video images and consultations, offer many ways of adding to the capacities of the system we describe. It would very much seem that affordable, efficient, and effective home care/palliative care should be within the reach of many more countries and global citizens.

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