Information Technology Tools for Palliative Care for Populations

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> Imagination at scale is our only recourse. [1]

For most patients in the world needing end-of-life symptom-addressing palliative care, providers are not available or accessible, health systems are weak, and the quality and efficacy of the interventions received, if any, are likely to be low [2, 3]. Seventy to 80% of cancer 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 67% of patients dying of cardiovascular disease (CVD) and 67% of patients dying of chronic obstructive pulmonary disease (COPD), and experts opined that these figures may be low [6]. Thus, approaches to palliative care in the community focusing on cancer are clearly going to be relevant for larger numbers of patients suffering from more common CVD and COPD syndromes.

In the face of always-limited resources and perhaps less than compelling data regarding the favorable impact of palliative care, communities, caregivers, and certainly patients globally suffer [2, 3]. The Lancet Commission has highlighted the details of the problems and broad policy matters, and that in fact, relatively rather limited financial resources are projected to be necessary to have a major impact [2]. However, the Commission has offered rather sparse insight into the individual patient palliative care delivery challenges that follow from use of technologies, employed business models, and organization of medical care. The Commission does talk about the concept of competencies among needed health-care professionals, de-emphasizing specific professions, calls for expanded roles of general and community nurses in palliative care, and emphasizes the need for services linkages, but specific models for doing these things are not widely discussed or described, and the potentially major roles of information technology (IT) tools as enablers in these critical areas are not explored [2]. Perhaps, to a far-too-great extent, we believe that we understand what the problems of implementing such concepts are, and what the models for care should be, when in fact global challenges, broad loco-regional issues, and appropriate social change models are dominant determinants of any greater success in global palliative care [7]. Stepping back, as we have stated in our chapter opening sentence, we suggest that we should frame the central problems as weak primary health-care systems (provider-centered instead of patient-centered) in which patients have no or very limited access to providers (the major specific loco-regional issue) and limited

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ability to provide patient-specific/tailored (i.e., precision medicine), and critically, effective symptom interventions (the area where focus on social change models is much called for). Availability of morphine itself, while critical, as the Lancet Commission and the Economist analysis state, is not by itself enough [2, 3]. In the face of these, the major care "models" are firstly, dizzyingly academic and comprehensive (there are suggested to be eight domains for palliative care) with completely impractical, overwhelmingly complex, and lengthy patient care guidelines [5, 8] and secondly, community, in contrast to health system-organized, with an astonishing breadth of critical and needed activities [9, 10]. There appears to be a disconnect between these models and the two central problems in general palliative care identified above. Importantly, the first-line critical challenge is limiting the physical and mental suffering of all individual patients. Who can do this and what can they do? The focus for this chapter is on information technology (IT) tools, but context is everything, and so in part 1 of this communication, the focus is on palliative care barriers and metrics, patient-centered care models, details of current and ideal health service models, and elements of disruptive innovation, which set the stage for the exposition that follows in part 2, of the significant roles and promise of IT tools in delivering high-quality, affordable palliative care across all populations in alternative health-care delivery models.

Part 1: Palliative Care in the Context of Global Health Services

Current Framing of the Problem(S) in Delivering Palliative Care to all in Need

Two aforementioned major communications have sought to frame the challenges of better global palliative care—the Lancet Commission and The Economist Quality of Death Index project [2, 3]. Their major conclusions are important for what they say and do not say. The Lancet Commission takes a very global, international top-down, mostly policy approach in its analysis, highlighting six major issues, implying that addressing these might successfully improve palliative care (Table 1) [2].

Table 1 Barriers explaining neglect of palliative care globally (Lancet Commission, 2)

Opiophobia and focus on prevention of non-medical use of narcotics
Health outcome measures that ignore pain and suffering
Dearth of interventions
Medical focus on cure
Limited public advocacy
General neglect of non-communicable diseases in low- and middle-income countries

In the context of broad palliative care activities globally, these Table 1 points prompt the following take-home practical messages:

1. As noted above, availability of morphine is critical, but complex psychosocial and dysfunctional health systems issues often prevent its specific availability and use in practice. Getting our clinical practice houses in order for palliative care is critical if morphine is to be appropriately used.
2. Palliative care-focused health outcome measures are available; they are broadly underused. The use of tools for symptom assessment is an absolutely central issue in the development of high-quality care for all, and this subject will be majorly addressed later here.
3. The interventions concern is important; the major site of critical interventions however is the patient–provider interaction.
4. The fourth, fifth, and sixth listed barrier circumstances in Table 1 are not easily and rapidly addressable.

The Economist project developed a methodology for assessing quality of palliative care across countries [3]. In its second analysis, it summarizes specific indicators of higher-quality palliative care by its measures, again by implication, suggesting that addressing these issues is critical to improving palliative care (Table 2).

Table 2 National indicators of higher-quality palliative care. (2015 Quality of death index of the Economist, 3)

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

Focus on these indicators prompts a different and second set of take-home practical messages:

1. Unquestionably, there are national policies that are critical to better public palliative care; those with respect to morphine are the prime example. This said, the practice of clinical medicine is a complex psychosocial activity, changes in which are remarkably difficult to achieve with "top-down" national policy approaches. Impactful social change models are field-practice-focused.
2. The spending and patient care subsidies needs are poorly justified when they are not associated with specific clinical practice interventions and systems.
3. The repeated calls for increased training of palliative care specialists and all primary care health providers is first an unrealistic approach to the growing population needs; no country will ever be able to train adequate numbers of such providers. Further, it is not at all clear that this is the most efficient way of making skilled providers more widely available.

As noted above, what is missing from these barrier and indicator summaries is discussion of the organization of medical care—which so powerfully impacts what happens to individual patients worldwide—and the role of information technology in palliative care.

Broad Perspectives: Doctor/Provider-Centered Versus Patient-Centered Care and Premises for Current and Ideal Health Service Models

The specific needs and wishes of patients needing palliative care at the end of life bring attention to the major differences between by far the most common doctor provider-centered systems globally and patient-centered systems. In Table 3, the first three of the eight principles of patient-centered medical care should lead to activities that tend to be far less emphasized in doctor-centered care.

Table 3 Eight principles of patient-centered medical care [11]

Access to care
Physical comfort
Coordination and integration of care
Respect for patient preferences
Information and education
Emotional support
Involvement of family and friends
Continuity and transition

In doctor-centered medical care, the expectation is that the patient will come to the practitioner for help—aka "solutions", while in patient-centered palliative care, because of the very circumstances of patients with high symptom burdens, patients and families need the care to come to them. The organization of medical care globally is dominantly doctor-centered in this respect. And this model prevails in the face of limited provider numbers and often distant-from-patients in sites of service provision.

While surprising and illogical, there is far too little focus in patient encounters on the details of physical symptoms; providers simply do not seek such data with regularity [12]. Considerable further evidence on this issue will be presented below.

Finally, specifically with respect to palliative care, model systems for coordination and integration of care are rare, again because the optimal and dominant site of care is the patient's home, not providers' offices or hospitals where the personnel resources (if there are any) for such activities are present.

While here we have started with the broad concept of patient-centered care and its application to palliative care, another perspective is to consider the basic premises of medical care as currently practiced globally, and those that might characterize an ideal medical system, because many issues in such a review are basic to getting to how we can better address palliative care. In his enlightening volume Turning the world upside down, Nigel Crisp highlights current common and ideal premises [13]. In Table 4, we have summarized his ideas in modified ways.

These premises touch on some issues already considered above: public health versus individual patient focus—another view of the access issues; Hospital-physician office-centered care; and National/Federal—“top” down—solutions. This table also highlights premises critical in developing better palliative care services. Specifically,

- The issue of professionalism. Unlike in many other businesses where the specific tasks have been carefully identified and technicians have been trained to carry out these tasks, in medical care, there has been considerable resistance to delegation of care tasks to non-professionals. As has been suggested above, this position simply cannot stand if we are to achieve better palliative care for populations.
- The issue of site of accountability. With the dominance of a business model for medicine globally, the place of basic medical and palliative care as a human right has been shoved aside.
- The issue of appropriate business models; while the unsustainability of current high-income country models is evident and recognized, a focus on public health-promoting business models is still lacking.
- Finally, the need for potentially disruptive change in our health-care models is accepted, but not happening rapidly, and when and where major changes occur, they are not widely noted [14].

Table 4 Critical premises for a twenty-first century health model for populations contrasted with those currently operative in many high-income countries[a]

Ideal model	Current high-income country models
Start by understanding society	Start with descriptive data on diseases
Public health-focused	Individual patient-focused
Community and outpatient-centered	Hospital or doctor’s office-centered
Non-professionalized approach	Deeply professionalized approach
Locally defined solutions, with reliance on local skills	National or federal solutions
Supportive of, complements, supplements, and strengthens primary health system	Primary health system is peripheral
Accountable to community	Accountable to business owners
Belief in co-dependence with other institutions globally as partners	Focus on independence
Deep beliefs in fairness, accountability, and transparency	Deepest focus on disease outcomes
Business models need to be defined	Business models are flawed
Constantly redesigning itself	Fixed models
Complementary central community issue activities are critical	Health care is an independent activity

[a] Summarized, supplemented, and modified from 13

Reframing Solutions: Disruptive Innovation

How can we become focused and pull out of this foregoing discussion a blueprint for taking concrete actions to develop better palliative care systems more rapidly? Christensen has provided the critical framework in his work on disruptive innovation [15]. The key elements are presented in Table 5.

Considering the first element, we need to standardize our processes, making them rule-based, simpler, affordable, and effective. Otherwise stated, we need to break down the “care” in palliative care into specific tasks, and crucially, bring to bear information “technological enablers” to make successful completion of tasks possible.

Table 5 The key elements of disruptive innovation solutions for health care [15]

Simplifying technology
Business model innovation
Value networks

These general premise statements beg formulation of premises, specifically for palliative care systems. In part 2 of this chapter to follow, we summarize the critical general premises and use Christensen's key elements for disruptive solutions, which well frame the crucial roles that information technology hardware and new software tools can play in definitions of more widely applicable and effective palliative care services.

Part 2: Information Technology Tools and Creation of Local High-Quality Palliatve Care Service Models

Practical Ground Rules for Achievable Progress

The foregoing discussion strongly suggests that we should approach improving palliative care service for populations by the following:

- Focusing first on specific measures to increase and improve patient–provider interactions.
- Acknowledging that financial resources and evidence for benefits are limited, and therefore taking local step-by-step experimental approaches.
- Designing whatever local innovations we develop, in light of the need to contribute to the gradual development of ideal health services models (Table 4).
- Focusing on symptom management, recognizing that physical comfort is the sine qua non of successful palliative care, whose key metric is pain.
- Developing business models which facilitate access for all, are patient-centered in providing home care, and are affordable.
- Organizing our services simply and in ways that encourage coordination and integration of component personnel.
- While making every effort in integration and liaisoning with existing local resources, limited as they may be, recognizing that we need to develop specific "solutions shops" for palliative care [15] (similar to specialty facilities in cataract surgery, cardiovascular disease, cancer, and other specialized surgery).

The unavoidable core conclusions is that the need is to develop capacity to take solutions to patients in their homes, and secondly, to have "centers," "solution shops," to process and act on patient cases [15]. Palliative end-of-life care of adequately high quality to make a difference is specialty care. The expectation that it is possible to have adequate specialists and all primary care providers available for the infrequently needed provision of such care at a given point in time in specific communities is unrealistic. What is new are information technology tools to address these challenges and needs efficiently and effectively.

Element #1: Simplifying Technology [15]

Following Christensen's framework, we need to first break down the components of the patient–provider palliative care process into specific routine tasks, and crucially, bring to bear on these information technology "enablers" to make successful completion of the tasks possible (Table 6).

What are the information technology "enablers" to allow operational efficiencies in accomplishing these tasks? The widespread availability and use of cell phones and the internet and worldwide web now provide the hardware infrastructure for software tools for efficient and precise conduct of these tasks (Table 7). The first part of the discussion then is how these tasks can be well completed; who and how these tasks can be done then follows.

IT Software Tool #1: Messaging and Social Media

Tasks 1, 2, and 3 in Table 6 concern "awareness" or making sure that all patients and families in need in communities know how to access local resources for help in palliative care situations. While computer access and thus worldwide web access using search engines may be limited for many citizens in low- and middle-income countries, cell phones are now available almost universally. In Nepal, there are as many cell phones

Table 6 The patient-level provider/health system task list

1. Make patients and family members aware of specific contact people/resources locally they can call on for palliative care assistance
2. Reach out to seek local community members in need of palliative care
3. Inform patients and families in need of palliative care of a process for their getting such help through local resources
4. Provide patients with a symptom questionnaire to describe repeatedly their physical discomforts and their intensities
5. Work with patients and families to create moderately detailed summaries of patients' active medical conditions
6. Create palliative care center capacity to provide services in circumstances when patients and families cannot be physically present in the center
7. Create palliative care center capacity to provide affordable, symptom-targeted, high-quality interventions to patients and families based on symptom reports and medical summaries
8. Create palliative care centers with expandable front-line palliative care clinical specialist capacity to receive, analyze, clarify, and better specify symptom reports and medical summaries
9. Establish business practices and mechanisms for payment for the local- and center-specific services and share this information with families in need

Table 7 Information technology software tools for completing major patient–provider palliative care tasks

Cell phone and internet social media materials and messages
Cell phone and web-based platform symptom questionnaires
Web-based basic medical summary electronic health record
Cell phone or internet-facilitated virtual caregiver–patient visits and sharing of personal patient and family educational materials (telemedicine)
Web-based automated decision-making algorithms for symptom management and machine learning refinements of these based on clinical management symptom report data

as there are people. While the fraction of cell phones that are smartphones varies widely across countries, many phones have multiple features. Broadly, messaging systems such as SMS (short message services) are widely available and provide a basic mechanism for addressing tasks 1–3 in local communities. Such mechanisms are low cost and direct and engage recipients effectively; they can reach large and geographically distant populations. Text messaging generally has been favorably impactful in health activities and in effecting specific behavioral change [16, 17]. While the greater experience has to date been in high-income country settings, digital tools have been effective in improving treatment for tuberculosis in Africa [18].

When social media sources are accessible, often among adult children of older adults in need of palliative care, internet websites, Twitter, Facebook, and Instagram can provide podcasts, links, videos, and photos. An in-country system we are developing in Nepal provides such an example and will be further discussed below (homepalliativecare Nepal.net). Increasing data, again admittedly from high-income country settings, suggest that social media tools can be significantly and favorably impactful in health [19, 20].

IT Software Tool #2: Symptom Questionnaires

The absolute central focus of palliative care has to be on patient symptoms and their minimization. Our major metric for palliative care is pain [2]. Thus, Task 4 in Table 6 is a, if not the major issue in palliative care, for we cannot manage impactful symptoms whose nature and intensities are not clearly defined.

Assessment of symptoms has been increasingly accomplished by use of symptom questionnaires. As the scope of outcomes from patient interventions is obviously greater than that of only symptoms, including more global measures such as "quality of life," disability-adjusted life-years of survival, and of course overall survival, the term patient reported outcomes (PROs) has been used, particularly by palliative care specialists, to describe all such measures [21]. Here we have chosen to use the more understandable basic term—symptom questionnaires—because for major clinical purposes, we wish to focus on management of patients' symptoms, and not on additional outcomes measures, and the instruments we believe are critical deal only with symptoms.

For a long time, the use of symptom questionnaires has been seen by clinicians as a burden, whose time-consuming and impractical applications were poorly justified by any obvious benefit. It has been assumed by clinicians that they can more efficiently acquire such critical data directly from questioning patients, when this is simply not the case. The situation has very much changed over the last decade, such that symptom questionnaires are now seen as a key tool in patient-centered care, and nowhere is this tool more central than in palliative care, particularly that component focusing on physical symptoms. An additional issue for some clinicians has been uncertainty regarding the validity of data from symptom questionnaires. Three general developments have put these validity concerns to rest. First, the use of multiple instruments has been shown to provide the same picture—thus providing external validity. Second, careful analyses of clusters of answers in symptom questionnaires have shown internally consistent results, providing internal validity data. Third, and really the most compelling development, has been new results of clinical trials demonstrating clear improvements in "hard" patient outcomes associated with symptom questionnaire use (emergency room visits, hospitalizations, survival) [22, 23]. The now-documented benefits are outlined in Table 8.

There are a number of well-validated symptom questionnaires tailored to different clinical situations. Recent authors have emphasized the easy usability of symptom questionnaires. It should be noted that adding or possibly subtracting a question or two to an established, validated instrument should hardly be challenged. Our own symptom questionnaire is presented here in Table 9 [35]. This instrument was created to serve cancer patients in low- and middle-income countries where symptoms consequent to treatment toxicities are uncommon.

What is key now is that the benefits of symptom questionnaires have been demonstrated and magnified by placing these instruments on cell phone and web-based platforms [22–24, 27, 29, 30, 32–34]. The use of these software IT tools clearly provides multiple benefits, specifically for both patients and providers (Table 8). For patients, what is really important is engaging them in the central issues of their medical conditions. Patient hopelessness and suffering are in part addressed by this engagement per se [38]. For providers, the previous excess burdens associated with the use of these questionnaires as paper tools have been removed; it is possible to make comprehensive and specific repeated patient symptom data easily accessible for both

Table 8 Benefits of use of symptom questionnaires [6, 12, 21–34]

Provide data justifying palliative care service needs
Facilitate accessibility of patients to care providers
Prompt clinicians to increase attention to symptom management
Improvement in symptom control with increased adherence to interventions
Provide richer, multiple metric data than those for only pain and its intensity
Enhancement of patient–clinician communication
Increased patient satisfaction
Empowerment of patients and families with increased participation in care
Suggested improved quality of life and increased survival
Suggested more effective in particular in lower socio-economic groups with less computer literacy
Essentially technology enablers, allowing precision medicine

Table 9 The Marquette Symptom Assessment Survey (MarqueSAS) [35]

Nausea[a]
Tiredness[a]
Depression[a]
Anxiety[a]
Drowsiness[a]
Appetite[a]
Well-being[a]
Shortness of breath[a]
Current pain[a]
In the last 24 hours: Worst level of pain[b]
Lowest level of pain[b]
Usual level of pain[b]
Constipation
Quantity of sleep
Quality of sleep

[a] From the Edmonton Symptom Assessment Survey [36]
[b] From the Brief Pain Inventory [37]

providers and patients. While a review of all of the new data justifying the statements in Table 8 is beyond the practical scope of this chapter, the work reported over the last 15 years in the listed references provides strong support for these summary conclusions. Clearly, we need more data, particularly data on application of these symptom data tools in low-resource settings. In this context, we can share our own experience.

We developed a cell phone (android and IOS) platform-based visual and audible instructional "app" for our MarqueSAS (Table 9). We have used this in preliminary longitudinal patient populations in Bangladesh, and in a one-time assessment cross sectional study in over 1000 patients with advanced cancers presenting to tertiary care centers in Bangladesh and Nepal [24, 35]. What was remarkable was that all of the patients were able to easily and quickly answer the questionnaire items, even patients who were illiterate; they all essentially said they would be comfortable using this "app" to report repeatedly on their symptoms. We have now moved on to developing a Nepalese website and physician web-app to receive and organize patient symptom reports and provide a menu of written and video interventions, which can be sent to patients' cell phones or patient or family email sites (homepalliativecareNepal.net). Our cell phone symptom questionnaire "app" named NAPCare is available for free at https://play.google.com/store/search?q=napcare.

As the last bullet point in Table 8 states, the use of symptom questionnaires with IT tools allows higher-quality "precision" symptom management medicine, and this technology enabler can be made available to essentially everyone.

IT Software Tool #3: Basic Medical Summary Electronic Health Record

Besides having past and current broad patient symptom data, central to providing adequately high-quality palliative care to make a difference is having a sufficiently detailed summary of major relevant and active individual patient medical diagnoses and problems (Task 5 in Table 6). In Table 10, we suggest what such a summary should cover. The challenge here is to get in one place for patients, and local and sometimes distant center providers to see, the information critical to making, together with symptom data, patient-tailored palliative care management recommendations. All-too-frequently, clinicians are either working with inadequate basic patient status information or are spending excess time searching (again and again) for key information. Creating this summary is too often seen as an overwhelming burden, when in fact paraprofessional medical technicians can be trained to do this task remarkably well. Putting such a summary into some kind of web-based system associated with a center (as discussed below) creates essentially an electronic medical record summary, which can be easily amended, but most importantly easily accessed and used.

Our assumptions in defining the specific items in this list are the following. First, our major patient population is that of patients with malignancies. Here then the primary cancer site, the state of clinically evident and potentially symptom-causing regional and metastatic disease needs to be clarified. The later Table 10 item on details of common symptoms is listed because disease involvement at specific anatomic sites

Table 10 Components of basic palliative care patient medical summary

Primary cancer site
Dominant or potentially life-threatening loco-regional or distant cancer metastatic site
Secondary loco-regional or distant cancer metastatic site
Cardiac disease
Ischemic heart disease
Congestive heart failure
Other cardiac disease
Chronic obstructive pulmonary disease
Diabetes mellitus
Cerebrovascular disease
Other major health problem
Any medication causing allergic or major adverse reaction
Details of common symptoms
Patient's major health concern

needs to be stated if the pathophysiology of patient's symptoms is to be appropriately understood. An example: Writing the word bone under "Dominant…. distant cancer metastatic site," can only be helpful if the particular anatomic sites known to be affected are identified. Having to make assumptions that metastatic cancer lesions cause particular symptoms, without some specific objective symptom data, leads to interventions that are too often ineffective.

Other common non-communicable diseases are listed in this medical summary table only to acknowledge their active presence (often existing because the general population of patients with major malignancies is older and therefore likely to be so afflicted), and because in advanced stages, these common conditions and their management must temper optimal symptom management.

Finally, this table lists "Patient's major health concern" because far too often providers make assumptions about what bothers patients most (even in the face of good symptom questionnaire data), when an uncommon physical or a mental or other domain issue is in fact most important to an individual patient (Table 3).

In summary, after a symptom questionnaire, the second critical mini-database necessary for high-quality palliative care is an electronic summary medical record. Here we are not asking for a complete re-creation of a patient's medical history and listing of all of his/her problems; rather, we are insisting that good care cannot be given without an adequately detailed summary of current major active medical problems. Use of these two basic instruments with IT facilitated means is central to the development of affordable, widely available, and as stated high-quality effective, palliative care. Their regular use essentially "standardizes the process" [15].

IT Software Tool #4: Cell Phone or Internet-Facilitated Virtual Caregiver–Patient Visit Programs

Task 6 in Table 6 is the provision of virtual palliative care center service capacity. The concept and necessity of palliative care centers will be approached below as a business model matter, together with the payment model challenges of non-visit care. Here, we wish to highlight the powerful capacity of new cell phone and internet systems to allow "virtual" (i.e., not face to face physically) patient and family visits with providers. Historically, the organization of medical care has not placed major value on patients' time and the indirect costs of provider office- and hospital-based care. With palliative care, the "site of care" issue comes very much to the fore. The downsides of office/hospital-based care have been too long ignored. One example from our own data illustrates how our current systems sadly contribute to patient suffering. In our cross sectional study in outpatient tertiary care facility clinics in Dhaka, Bangladesh and Kathmandu, Nepal, patients reported that their current pain levels were higher than their usual pain levels, presumably because of the discomforts and symptom-alleviating disruptions associated with getting to a tertiary care facility [24].

Duffy and Lee have recently well described why in-person health care should be "option B" [39]. They emphasize, and this is particularly applicable to palliative care, that development of virtual care systems should be an explicit goal, and we agree. Further, as they write, the burden should be on the providers to develop such systems.

Cell phone and internet-based conferencing capacities are now multiple: for the former WhatsApp and I-phone Facetime, and for the latter Skype, Zoom, and Gotomeeting. Telemedicine programs are increasing and remarkably successful [40]. In the two general component services model we have been alluding to heretofore (and will expand upon below) i.e., local community palliative care specialists and palliative care centers, the experience with telemedicine services has not unexpectedly been that over time the skills and capacities of the local providers increase with decreased dependence on the centers [41]. There is a desperate need to develop such local country and community prototypes in palliative care—the basic IT tools are available.

IT Software Tool #5: Web-Based Automated Decision-Making Algorithms

The central critical activity in palliative care is providing appropriate patient-symptom-tailored effective interventions. The major emphasis in better addressing this task for populations has been on training of all health-care providers and on increasing the numbers of palliative care specialists [3]. As has been suggested at the beginning of this chapter, creation of different kinds of palliative care specialists/technicians may offer an alternative and more realistic approach; the nature of these specialists will be further discussed below. Our current patient–provider care loops are woefully “black box” (from symptoms to interventions), and adequately high-quality care is so dependent on high levels of training for the providers. The purpose of Table 6 has been to spell out the specific tasks to make the processes of individual patient care transparent and thus more effectively addressable.

What has been missing from the discussions however has been the role that creation of patient symptom management automated artificial intelligence-facilitated decision-making systems can play in efficiently and productively meeting this care demand, and this is critical Task 7 (Table 6 above).

Bell has summarized the significant potential of such software systems, and Kamdar and Mooney have provided recent detailed examples of these in palliative care [27, 29]. Asch et al. have described how such systems can meaningfully contribute to the creation of better health system operations [42].

The breadth of symptoms and the basic evidence about useful interventions are well summarized by Kelley (5, suppl). Mooney et al. demonstrated how such multi-symptom-addressing applications might work, while Kamdar et al. focused on pain management [27, 29]. In addressing the development of algorithms for malignancies, it is clear that definition of optimal baseline interventions for the same symptom might differ by cancer type, and symptom site, and thus, key input data for individual patients will be that from his/her basic medical summary in addition to her symptom questionnaire information. For example, lumbo-sacral vertebral bone pain associated with multiple myeloma might be approached differently than similar site pain associated with metastatic lung cancer. Decision trees, which allow recognition of very treatable symptom causes such as infection or bronchospasm in the case of lung cancer, are important. What needs to happen now is to create and share initial patient symptom management dynamic algorithms and accumulate significant experience with these and their impacts on symptom intensities to use machine learning to refine algorithm specifics. This kind of software tool then can be used by palliative care specialists first at centers to define quickly a selection of potential interventions, which can then, based on “exception” individual patient information, be directed to the patient.

This type of symptom management tool capacity will be critical to extending high-quality palliative care to greater number of patients through paraprofessional providers. The essentials of the model we are proposing are presented in Fig. 1.

Element #2: Business Model/Health System innovation to Routinize Critical Elements of Palliative Care [15]

As has been stated in earlier discussions, we propose that instead of emphasizing palliative care expertise and training throughout health-care systems, the central activities of palliative care should be carried out in centers for palliative care (Task 8, Table 6). Such a model for high-quality palliative care services is no different than those successfully developed and promoted for eye cataract care [43]. The core argument is that such centers can deliver high-quality, cost-effective care because in essence, in employing Christensen’s simplification technology model and standardized processes, they can care for larger numbers of patients [15, 42]. What we have proposed above in the discussion of such centers as tele-medicine operations is that they

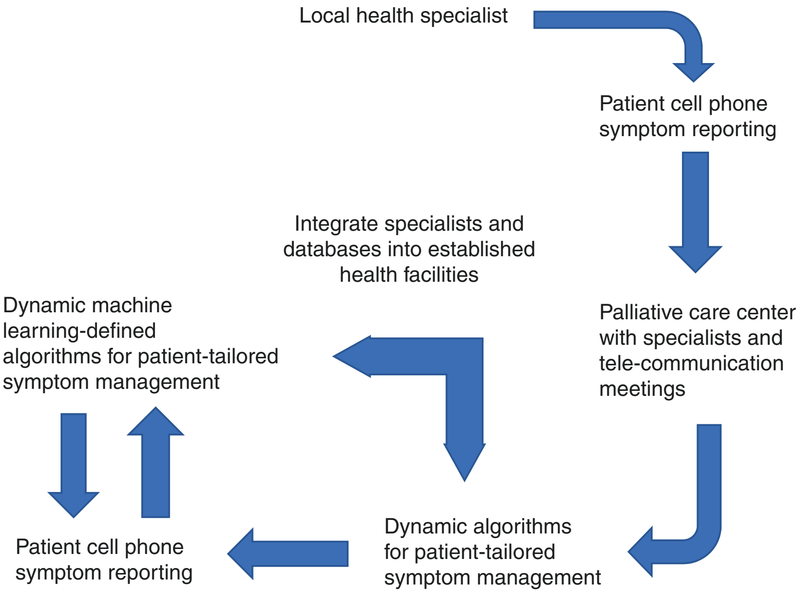

Fig. 1 Putting IT all together: Health system changes with increased palliative care paraprofessionals and IT tools

are planned as true centers, that is providers of regional, not just local use, expertise.

The second critical component of our disruptive innovation model is paraprofessional palliative care specialists locally and in centers. They may come from different health-care backgrounds—nursing or pharmacy primarily—and maybe attached to different local health-care organizations. The principle tasks for these specialists were defined in #s 1–6 in Table 6, and it is primarily for these tasks that their training should be targeted. Their work now can productively be carried out with the five software tools we have discussed in detail above. In some sense, we are talking about local navigators for patients and families in need of palliative care. First, they are the point people for awareness about palliative care resources and systems (Tasks 1–3, Table 6). Next, they become experts in facilitating patient access to a cell phone-based symptom questionnaire and teaching patients how to use this tool (Task 4), Finally, they work with the patient and family to establish the necessary medical summary (Task 5). Heretofore, training in palliative care has been majorly about biology, physiology, and interventions, when such information can only be well used by providers who are engaged in this kind of care every day. Training for these five tasks is completely different and absolutely manageable to create a new type of health-care specialist. The concept of local community health-care workers with specialty focus has been of course broadly applied in maternal and child health with enormous success. Over time, the local specialists will become more involved in Task 6—interaction with palliative care centers—and tele-medicine conferencing and then logically with implementation of intervention recommendations.

Paraprofessional palliative care specialists at palliative care centers can have focused capacity to receive, analyze, clarify, and better specify symptom reports and medical summaries (Task 8). These specialists are the front-line professionals for face to face or virtual patient/family visits (Task 6) and use of software management algorithms to define and work to implement appropriate interventions (Task 7). Discussions of use of "technicians" in such capacities often get bogged down over concerns about the nuances and details of patients' specific circumstances, which appropriately define better targeting of interventions, and the need for "super specialists" to therefore provide such care. We believe that we can build into the initial algorithms necessary "exception management" flags, and that in fact over time, nursing paraprofessional palliative care specialists in centers can become experts in carrying out these tasks.

With palliative care centers, and local and in-center paraprofessional palliative care specialists, the third essential component of such a model system is, of course, finances (Task 9, Table 6). While payment systems have been in high-income country settings the perceived major barrier to implementation of such a disruptive model of care with tele-medicine service at its core, in fact these are becoming increasingly manageable and accepted by patients and families, particularly when the specifics of the care system are engaged in and transparent to these consumers—the repeated use of a symptom questionnaire; the creation of a medical summary; the convenience of telemedicine virtual visits; the focus on patient's major health concerns and physical symptoms [39]. Efficient, patient-symptom-tailored care using the software tools we have emphasized here can be inexpensive for patients and families, even when they are paying the direct costs completely themselves. Electronic payment systems can be facilitating; in-person visits by family members to palliative care centers (as for prescriptions) can allow use of the usual outpatient visit charging mechanisms; and over time, governmental and non-governmental organizational support for local paraprofessionals and palliative care centers can be expected with demonstration of operational efficacy and patient outcome data.

Element #3: Value Networks [15]

While it is implicit in the foregoing discussion of the two health system components—palliative care centers and local palliative care specialists—that these must work well together for a successful palliative care model, Christensen emphasizes that in such innovated systems, it is vital for all stake-holders to recognize coherent value in each component.

We need to convince providers of the value of all parts of the system:

- Ease of administration.
- Ease of access.
- Ease of understanding.
- Guidance to action.
- Confidence of quality and security.

in order to promote a strong widespread desire to use the system.

Summary

We have proposed a theory and general medical system practice-grounded approach to accelerating improvement of palliative care for patients in widely different health systems. Our approach is "bottoms up" focusing on innovation that needs to happen at the local patient–provider encounter level. We envision potential for leap-frogging the challenges that prevent many systems now from developing better palliative care efforts. Almost universal cell phone and web-internet capacities now provide the hardware infrastructure for use of information technology software tools in five critical areas for palliative care: increasing local patient and family awareness, symptom questionnaires, basic medical summary, virtual patient visits, and algorithms for tailored symptom management. Employment of these tools within a palliative care-niche model with local paraprofessional specialists and palliative care centers can offer "public health palliative care." Imagining at scale and experimenting with such software tools and palliative care organizational models is the way forward [1, 7]. Models will evolve over time.

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