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**When people live with
multiple chronic diseases:**
a collaborative approach to an
emerging global challenge



Escuela Andaluza de Salud Pública
CONSEJERÍA DE SALUD

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Supportive and palliative care

This chapter is continuously evolving at www.opimec.org

Vignette: How it could be

Mr Yeo was an elderly widower who suffered from chronic obstructive pulmonary disease, ischemic heart disease, congestive heart failure and advanced prostate cancer. Despite the spread of cancer to the bones and the recurrent episodes of urinary tract infection, he suffered more from infective exacerbations of his chronic pulmonary disease and recurrent heart failure.

As he became frailer, his physician in the disease management program transferred his care to a colleague more skilled in dealing with poly pathology and palliative care. Having been educated about his own illness and the measures to take, Mr. Yeo knew what to do when he felt unwell one afternoon. He touched a special button on the screen of his home computer. An image of Kala, his home care nurse, appeared.

«Good afternoon, Kala, sorry to bother you», said Mr Yeo into the speaker, «but I'm not feeling very well. This cough which started yesterday is not settling down and I am having difficulty lying flat.»

As she continued to speak to him, Kala looked at the readouts from the sensors attached to Mr Yeo's telehealth unit at his bedside. She asked Mr Yeo for assistance in applying the blood pressure cuff, the pulse oxymeter, thermometer and stethoscope. She soon recognized that Mr Yeo was suffering an exacerbation of his chronic obstructive airway disease again. She quickly toggled onto the nurses-on-duty screen and noticed that advance practice nurse Sharon was on duty.

Sharon, can you swing by and check on Mr Yeo, he is the man living on Red Bridge Road.

Using her palm-top computer with wireless connection, Sharon was quickly able to access his medical records, check on the data from the telehealth unit and monitors and run an electrocardiogram. She was at his apartment within 30 minutes and quickly set about examining him. She checked his

medication and quickly called Dr Summers, his home palliative care physician. A course of steroids and antibiotics were ordered electronically. This was sent via courier service to his house within the hour by the neighborhood pharmacy.

Dr Summers took turns with Sharon to check up on Mr Yeo over the course of the next few days. In between, the easy interaction with the telehealth team by his bedside reassured Mr Yeo that there was constant attention. However, unlike previous episodes when his condition recovered well enough for him to get back on his feet, it became obvious that it was different this time around. His cough became more persistent and he was short of breath even when he was sitting up. Even as she was deciding on the care options, Dr Summers proceeded to speak to Mr Yeo to establish his understanding and elicit his views on his condition and management plans. Consistent with previously established advance care plans, a decision was made to withdraw the antibiotics and concentrate mainly on comfort measures. A family conference was also arranged between Dr Summers, Sharon, Jenny (the counselor), and Mr Yeo's daughters.

Yes, this is what he had anticipated, if he was facing an acute reversible condition, he would like everything possible to be done to help him recover. But if he crossed the line and had a severe exacerbation of his long-standing lung disease, he would prefer to be made comfortable and remain at home.

Home oxygen therapy and parenteral morphine infusion alleviated his dyspnea at home enough for him to remain comfortable. Video tele-monitoring by the program team gave his family a sense of security. He passed away peacefully about one week after the initial call, with his family by his side. Jenny called his daughter about one month after his death and she reported that Mr Yeo's family had settled back into their previous routine. His daughter was especially glad that he was able to remain at home and that he passed away quite peacefully.

How it is now

The following, instead, was the reality of the case.

Mr YKC had recurrent re-admissions to hospital of increasingly longer durations and with shorter intervals between the admissions. Without a clear primary physician to call upon, this often brought him into head-on collision with an unwieldy healthcare system, which often had doctors unfamiliar with his condition, unaware of the goals of his care and unable to provide the support and care he needed. During one such admission, as he lay gasping, desperate for attention, his family was told that he had a terminal condition and to accept his impending death. The family lodged a complaint: I knew he was going to die one day, but not in such a manner.

The hospital-based palliative care team was called upon and adjustments were made to his medication, which included bronchodilators, the addition of diuretics for heart failure and antibiotics for chest infection, the use of steroids, and low dose opioids. Advance care planning reached a decision against resuscitation in the event of cardiopulmonary collapse and the preference for care and death at home. Despite the initial pronouncement of doom, his symptoms improved enough for him to be discharged home.

Before the week was up, he was back in hospital again. His complaints were similar breathlessness. The home oxygen concentrator and nebulizer had not provided sufficient relief. He had not mobilized the home hospice team that he was referred to upon discharge, as he had not found them responsive or familiar enough with his condition to call upon. In his opinion, the emergency ambulance service was by far more reliable. In any case, his family also preferred him to be admitted into the security of a hospital as he lived alone with a live-in domestic helper to assist him.

Proposals for admission to a hospice were not taken up by his family. They kept saying, «The hospice is not the place for my father». Finally, after six admissions in the last six months of his life, Mr YKC passed away in the familiarity of the hospital.

In most parts of the world, the patient would not have fared any better.

Why is this topic important?

Of the world's estimated 9.3 billion people, 16% will be 65 years and older in 2050. Europe will be the «grayest» region, with 29% of its population forecast to be 65 and older by 2050. Currently, Japan, Germany, Italy and Monaco have the most senior citizens aged 65 and older, with Japan leading at 20.8% (1). China, one of the most rapidly emerging economies in the world, has a current ratio of 16 elderly persons per 100 workers. This is set to quadruple to 61 by the year 2050. In Singapore, another rapidly emerging economy, the number is expected to rise three-fold from the current figure of 300,000 to 900,000 by 2030.

As described in detail in Chapter 1, the global tally of deaths is expected to rise to 74 million per year by 2030 (2). Whereas people died mainly from infectious diseases about a century ago, for many decades now chronic diseases, in particular heart disease, cancer and stroke, have predominated as causes of death (3). This is especially so in high-income countries where as many as 25% of those aged 60-65 years old and 50% of those aged 80-84 years old are affected by two or more chronic health conditions simultaneously (4). A population-based study in the Netherlands reported that of patients above the age

of 65 diagnosed with cancer between 1995 and 2002, 60% suffered from at least one other serious illness. The most frequent concomitant diseases were previous cancers, heart disease, hypertension, chronic obstructive airway disease and hypertension, with prevalence rates up to 20, 23, 26, 17 and 16% respectively (5). Consequently, more people will suffer from and eventually die with complex chronic diseases (6).

The tragedy of unmet needs at the end of life

Since 1990, when the World Health Organization first recognized and underscored its importance as a component of cancer care, and amended its definition to include non-cancer conditions in 2002 (7), palliative care has entered into mainstream medicine in many places in the world (8). It is now widely acknowledged that palliative care involves both the patients and their loved ones, and that it should not only deal with the relief of suffering in the physical, psychosocial and spiritual domains of patients with life-threatening illnesses, but also with the need to prevent needless suffering, stressing the importance of support systems and a team approach.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (9).

Palliative care (10):

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten nor postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if appropriate.
- Enhances quality of life, and may also positively influence the course of the illness.

- Is applicable early in the course of an illness, in conjunction with other therapies intended to prolong life, such as antibiotics, chemotherapy or radiation therapy, or surgery, and includes the exploration needed to better understand and manage distressing clinical complications.

Supportive care, a closely related term to palliative care, refers to the provision of the necessary services as defined by those living with or affected by chronic diseases, to meet their physical, social, emotional, informational, psychological, spiritual and practical needs during the pre-diagnostic, diagnostic, treatment and follow-up phases of care, encompassing issues of survivorship, palliation and bereavement. Supportive care refers not only to those living with the diseases, but also to carers and health professionals, and must take into account their preferences and values (11).

Despite this strong rhetoric, studies of patients with chronic diseases still show significant suffering amongst patients and needs of families and loved ones remain unmet even in countries reported to have a measure of integration of palliative and supportive care with mainstream service providers. Reviews have consistently shown high prevalence for almost all considered symptoms across all end-stage chronic disease groups (12-14). There is significant psychosocial and emotional and spiritual morbidity at the end of life (15-17). Although there is a dearth of knowledge in relation to multiple chronic diseases, the picture is likely to be grimmer, as a result of poorer coordination of resources and even fewer opportunities for patients and loved ones to ensure that the services they receive meet their needs.

There is also a small, but growing, body of literature on the burden that individuals feel they are creating for others as a consequence of their illness (18-19). The pressure for families is in fact significant. Caregivers are often middle-aged or older, and often become prone to ill health and financial difficulties as a result of looking after a loved one (20). Many are also not prepared for the care-giving process (21) and the amount of emotional energy that needs to be invested (22), and suffer from anxiety over the suffering of their loved ones and may consequently become depressed. They also face isolation and disruption of their social life and are known to suffer sleep deprivation (23).

Even though they have a similarly high symptom burden compared with patients with advanced cancer, they tend not to receive the same attention and level of symptomatic relief (24). The problem is frequently compounded by the fact that in such cases death

and dying are often regarded by health professionals as a failure; education on supportive and palliative care tends to be deficient; awareness of policymakers and managers about the need for resource allocation is usually low; and resources to enable the patients and their loved ones to adjust to the realities of incurable diseases (particularly when they are multiple) are almost always lacking.

What do we know? So what?

Most patients are dying in institutions

There is concern that inpatient facilities will not be able to cope with the large increase in deaths in the years to come. Despite documented preferences for home death (25-27), the majority of deaths from terminal illness still occur in hospital. This happens mostly when there is no guarantee of 24-hour support at home or back-up from specialized personnel (28).

In the United Kingdom, often considered the birthplace of modern hospice and palliative care, the percentage of home deaths fell from 31.1% in 1974 to 18.1% in 2003. If the trend continues, it is anticipated that less than one in 10 (9.6%) will die at home in 2030. Such a decline in home deaths would correspond to an increase in institutional deaths of 20.3% (29). In the United States, of the more than 1.4 million deaths in 1997 available for complete analysis, 52.8% occurred in hospital, 23.6% occurred in nursing homes and only 23.6% occurred at home (30).

Further analysis suggests that the opportunity for home death is disproportionately high among Caucasian people, and those with higher socioeconomic status (31, 32), who are married (27, 29, 33-34), who are suffering from cancer (27, 30) and living in a racially homogeneous area (35) in both the United States and other Western industrialized nations.

Observational studies have also shown that expressed preferences (36), poor functional status, intensive home care support, living with relatives and extended family support are associated with more frequent deaths at home (37).

Meanwhile, a lack of 24-hour home care services and poor coordination between health and social care services have been blamed for an increase in hospital deaths in spite of patients' preferences for death at home (38-39).

Care at the end of life is improving slowly

Over the past 25 years, the field of palliative medicine has developed in response to the needs of dying patients and their families such that in many countries it is recognized as a specialty or a sub-specialty.

In the management of non-cancer chronic diseases near the end of life, there is clear evidence that the management of symptoms often has to go hand in hand with the continued management of the underlying illness.

Having demonstrated its effectiveness in improving assessment, documentation and care for patients in the last 24 hours to the final days, the Liverpool Care Pathway is now increasingly adopted in many parts of the world (40, 41). There is also good evidence that advance care planning led by skilled facilitators who engage key decision-makers directly over multiple sessions leads to increased utilization of advance directives (42, 43) and a better death experience at the end of life (44, 45).

It is increasingly recognized that in the management of patients with heart failure, there are reduced re-admissions and improved continuity of care with multi-component interventions (46). Although effect sizes are small, there is weak to moderate evidence suggesting that comprehensive and individually targeted interventions can relieve caregiver burden and improve satisfaction mainly in patients with dementia (47, 48). These interventions involve multi-disciplinary collaboration, address needs across care settings and over time, and facilitate communication by personal and technological means.

Despite pockets of excellence and the growing knowledge base, widespread adoption of the principles of palliative care and the dissemination of such knowledge is still lacking (49, 51). Only in recent years have major organ- or disease-specific textbooks paid much attention to supportive and palliative care of end organ failure (52, 53). Palliative care education is still not an essential component of many medical and nursing schools (54, 55). When offered, teaching tends to be fragmented, ad hoc and lacking in coordination. Most teaching is hospital-based and little attention is given to home care, hospice and nursing home care. As a result, many health professionals still find themselves standing by helplessly as patients suffer and families fret.

Besides textbook revision and improvements in health care curricula, the way forward should include the development of palliative care leaders and faculty, creating standards

of care and certification, and promoting clinical programs as venues for education and enhanced educational resources for end-of-life care (56, 57, 58).

People die differently

Knowledge and skills alone are inadequate in the provision of good palliative and supportive care.

In their 1965 book, *Awareness of Dying*, Glaser and Strauss first described the different types of interaction that occur between the dying and those around them (59). They described the contexts of interaction based on the different degree of awareness of the dying phase: closed awareness, suspected awareness, mutual pretense awareness and open awareness. The impact of each type of awareness context upon the interplay between patients and personnel is profound, for people guide their discourse and actions according to who knows what and with what certainty.

The authors subsequently went on to describe the various patterns of dying in a book, *Time for Dying* (60), which provided the beginnings of our understanding of the different trajectories of dying. These patterns of (a) sudden and abrupt death, (b) gradual decline followed by period of more rapid decline, such as seen in cancer, (c) the entry-reentry deaths against a background of steady decline of many chronic illnesses and (d) the progressive frailty followed by death, were subsequently illustrated in a study of Medicare beneficiaries (61) and by Lunney et al (62) in their cohort study of four US regions.

One of the challenges faced by those interested in supportive and palliative care for people living with multiple chronic diseases is that the majority of hospice and palliative care programs were designed to support a cancer trajectory. In cancer, there is usually a period of overall slow decline until anti-cancer treatments are stopped, followed by a relatively rapid decline in function towards the end of life. These expected deaths are likely to have a fairly predictable terminal phase, where there is time to anticipate palliative needs and plan for end-of-life care. It may also largely match public expectation of dying. However, this does not necessarily serve the needs of those dying with other trajectories.

With the recognition of different terminal trajectories, Joanne Lynn, in a Hastings Centre Report (63), raised the notion of mass customization, in order to meet the needs of the terminally ill. Mass customization aims to define manageable populations with

similar needs to then engineer services that match the size of the population and its predictable needs.

It is estimated that about 20% of Americans will die following a course of gradual decline followed by a more rapid period of deterioration. This course, followed by most major cancers, requires excellent medical care during the long period of good function, followed by supportive and palliative care for patient and family during the period of rapid decline.

Other conditions, such as chronic heart failure and chronic obstructive lung disease, tend to follow a course of slow decline punctuated by serious exacerbations, with death occurring rather suddenly (the entry-reentry trajectory). It is estimated that about 25% of Americans follow this course. Those living with this trajectory usually benefit from (a) chronic disease management to reduce the likelihood of exacerbations and to sustain all possible function, (b) rapid intervention at the first sign of exacerbation, preferably in the home rather than the hospital and (c) good advance care planning to direct care in the event of overwhelming exacerbations.

Approximately 40% of Americans are estimated to follow the trajectory of long-term dwindling of function with death following physiological challenges such as those triggered by influenza, urinary tract infection, pneumonia or a broken hip. Half of these patients lose cognitive function. Those following this trajectory tend to benefit from supportive care over the years, requiring assistance with everyday activities and long-term interventions to promote optimal levels of comfort for patients and family caregivers.

One of the main drawbacks of this approach is its foundation on the assumption that the vast majority of patients will have the right things done for them at the right time because it is built into the system and part of the expected pattern, while downplaying the fact that good care could arise from prudent choices by individual patients, and their health professionals and caregivers.

Dying is a multidimensional experience

Dying is not just a physical demise, and health professionals must strive to identify and meet the multidimensional needs of people with progressive disease. Centuries ago, spiritual care dominated end of life care. Although palliative care set out 40 years ago to

address the suffering of total pain, including lack of personal integrity and inner peace, spiritual distress at the end of life has remained relatively unexplored (64), although it is accepted that quality of life is modified by all dimensions of personhood (65).

Defining and assessing spiritual needs, however, is problematic. A useful definition is that proposed by the US Institute of Medicine, which states: spiritual needs are the needs and expectations that human beings have to find meaning and purpose in life; such needs may be specifically religious but even people who have no religious faith or who are not members of an organized religion have belief systems relating to meaning and purpose (66).

Spiritual issues are frequently very significant for people living and dying with lung cancer and heart failure (67). A secondary analysis of in-depth serial interviews suggests that there might be typical patterns of social, psychological and spiritual needs towards the end of life (68-70). In lung cancer, the social trajectory mirrored physical decline while the psychological and spiritual wellbeing decreased together at four key transitions: at diagnosis, after getting home after initial treatment, during disease progression, and in the terminal stage. In advanced heart failure, social and psychological decline both tended to track the physical decline while spiritual distress exhibited background fluctuations.

Knowledge about these patterns can improve the ability of health professionals to anticipate and share with patients when they are likely to be distressed. Explanations for patients and their carers about when practical, emotional and existential issues might be expected to occur, and the services available, can empower them and their carers, and this can be very reassuring for all.

This holistic view, considering each dimension of need, may lessen the multi-specialist approach, and moderate the current technological imperative with care focused on interventions to prolong life, with sometimes overzealous and futile treatment. Considering these different trajectories would bring spiritual assessment and care into focus, highlighting that many patients have spiritual issues from diagnosis of cancer or chronic life threatening illness, not just at the very end of life.

The implication of this is that spiritual support should be available for patients from diagnosis, sooner rather than later. A patient-centered approach that supports people in their own worldview while allowing for expression of fear, doubt and anxiety may help patients in their search for meaning and purpose, and prevent spiritual concerns

amounting to disabling spiritual distress. Some questions that could be asked of people living with multiple chronic diseases, and of their loved ones, in order to facilitate such an approach are [71]:

- What is the most important issue in your life right now?
- What helps you keep going?
- How do you see the future?
- What is your greatest worry or concern?
- Are there ever times when you feel down?
- If things got worse, where would you like to be cared for?

Allowing patients to raise spiritual and religious issues may be therapeutic, as may the use of a gentle prompt, such as: You seem fine today, but do you ever feel down or a bit low? This may allow them to reveal their personally felt narrative, rather than the public account they may tend to offer, as patients often have competing narratives in their minds. Patients may sometimes ask us about our own beliefs. In such cases, it might be useful to acknowledge the question, reflecting it back to the patients to ask them about their beliefs. This is because they may just be looking for an opportunity to express their own feelings and needs.

Supportive and palliative care save money

There is evidence that enrollment into hospice and palliative care services saves money. In the US there has been an increase in Medicare dependents choosing hospice benefits, from 27% in 2000 to 40% in 2005. An independent study from Duke University in 2007 showed that hospices provide compassionate care for those reaching the end of life and save Medicare an average of \$2,300 per patient, amounting to savings of more than \$2 billion last year [72].

A 2008 paper also reported that hospice enrollment results in substantial savings in government expenditures (22 percent) among all short-stay (< or = 90 days) dying residents of nursing homes. For long-stay (> 90 days) dying residents, hospice care led to some savings (8%) among cancer residents while it was cost-neutral among dementia residents, while adding some cost (10%) for residents with a diagnosis other than cancer or dementia [73].

In hospitals, matched patients who received palliative care resulted in highly significant cost savings for the hospital compared with those who did not (74). The savings were primarily through reduced hospital stay, an increase in the death-at-home option, and a lower use of hospital emergency rooms by complex cases. In Spain, palliative care led to significant cost savings with greater efficiency and no compromise of patient care (75).

What do we need to know?

The extent to which the illness trajectories identified in Scotland reflect what happens in other contexts and groups needs to be assessed. If they do, they could provide the foundation for the transformation of the lived experience of dying. Similar efforts are required to gain a better understanding of the social, psychological and spiritual issues faced by loved ones and caregivers in particular.

A much larger and more complex question is: What would it take to design a health system that meets the needs of patients with complex chronic diseases and their loved ones? This could be addressed at four levels, described by Donald Berwick, that characterize a high-quality health system (76): the experience of patients and their families (Level A); the functioning of small units of care delivery (microsystems, Level B); the functioning of the organizations that house or support microsystems (Level C); and the environment of policy, payment, regulation (Level D) that influences Levels B and C.

Level A: Restorative care versus palliative treatment

One of the key challenges in the management of patients with complex chronic diseases is the need to maintain the fine balance between a disease modifying or restorative approach and the use of interventions that are mainly designed for symptom control. However, little research has been carried out on the timing of withdrawal of disease-modifying therapies in patients nearing the end of life. When would the risk-benefit ratio of aspirin given for stroke prophylaxis be considered too high for a patient who is deteriorating from cancer? Similarly, is it still reasonable to consider sympatholytic agents in a patient with cardiac failure who is also suffering from renal failure? There is even less evidence on the interaction between illnesses in a patient with multiple co-morbidities and its implication on prognoses. Research in such circumstances will be challenging but the resulting improved decision aids could certainly enable health professionals to make better judgments, and advise patients and their loved ones.

Level B: Operationalizing knowledge

There is already a significant body of information on what constitutes good supportive and palliative care at the end of life. It is unclear, however, how these two terms complement or overlap each other, or how should they be used when communicating with patients and loved ones. The term palliative care, for instance, is fraught with negative connotations particularly for patients and family members who equate it with impending death.

Other key questions are: How can we best incorporate the knowledge available into systems of care such that health professionals have the necessary support when they need it? How do we ensure that patients and their loved ones get the care that they need?

Regarding the latter, it is important to recognize that it may be challenging for patients to express their supportive care needs to health care providers, particularly if they feel that by discussing symptoms or side effects they may: a) be viewed as bad patients or complainers, b) distract the physician from treating the underlying disease. Moreover, it is often challenging for patients to describe subjective symptoms (e.g., pain, dyspnea, fatigue) and side effects, and this task is made much more difficult for those dealing with multiple conditions. In fact, research suggests that formulating and articulating questions about symptoms such as pain is a context-dependent, time-intensive process that requires reflection, knowledge, and a good use of language (77).

Level C: How can we build an enduring system of care?

Supportive care and palliative care service delivery is a disjointed and fragmented enterprise in most parts of the world, involving a variety of people (e.g. primary physician, nurse practitioner, disease specialist, symptom specialist, psychosocial specialist, allied health professionals, family, friends and community networks) and locations (e.g. community clinics, acute care hospitals, long-term care centers, rehabilitation programs/centers, community support organizations, hospices and the home). As a result, patients continue to be cared for in an episodic, illness-orientated, complaint- and transaction-based system. Patients who live with multiple chronic illnesses fare particularly poorly in this environment of single-organ specialty and single-setting care. Transitions across care settings are also fraught with challenging attempts to establish continuity. How do we best align our services and systems with an increasingly complex and chronically ill population?

Will the isolated family physician still have a role in the management of such patients? If so, where do they figure in the increasingly complex system of care required to manage this group of patients?

Silos of care are increasingly giving way to integrated and comprehensive systems that span care settings and disease states. We know that in many chronic illnesses, even near the end of life, it is not possible to distinguish between restorative and palliative care and such patients do not simply transit from one modality to another (78-79). How then should our healthcare system develop such that transitions between professionals with the requisite specialist skills are smooth?

Level D: What reimbursement model will best serve the system?

Currently there are very few financial incentives for institutions and physicians to facilitate the smooth transition between care settings in most cases, let alone in those in which multiple chronic conditions co-exist. What funding mechanism will provide the most cost-effective supportive and palliative care system and yet ensure reimbursement for value-added services such as family conferences, care liaison, counseling and healthcare worker-patient communication via new media in a changing world? In Kansas they are testing a model of financial reimbursement, drawn up as an interdisciplinary service agreement between the hospital and the palliative care team, and based on achievement of quality standards with defined staffing ratios (80).

Can social systems and policies also ensure that families' needs are addressed? In Canada (81) and other enlightened countries, there is compassionate care benefit in the form of paid leave for caregivers. Can more be done to help families?

What patients need may not be what they want. Right-siting of care, a catch term in healthcare management, is often lost on patients and their families. The best and most affordable place of care for a patient may not be in the acute hospital but in an inpatient hospice facility. Patients and their families may not concur. In planning services, how do patients' preferences and knowledge about end-of-life care options interact with healthcare providers and public attitudes and knowledge about end-of-life care?

Lastly, it is important to emphasize that efforts to answer any of the above questions must take into account the special needs of children, adolescents and multi-cultural communities.

What innovative strategies could fill the gap?

A systematic review identified the following domains and themes that conceptualize satisfaction with end-of-life care and the effectiveness of palliative care interventions (82):

- Accessibility: taking as much time as needed, non-abandonment, maintaining contact, availability, timeliness, focusing on the patient, providing needed services.
- Coordination: using other members of the team effectively and efficiently, providing coverage, maintaining consistency, helping with navigation of the healthcare system.
- Competence: knowledge and skills, symptom management, comfort with death and dying, knowing when to stop.
- Communication and relationships: personal interaction, caring, understanding, reassurance.
- Education: providing information in a way that others could understand on all relevant topics, including what to expect, financial issues, advance care planning.
- Emotional support: compassion, responsiveness to emotional needs, maintaining hope and a positive attitude, physical touch.
- Personalization: treating the whole person, not just the disease, treating the patient as unique, respecting values and lifestyles, considering the social situation, including the family.
- Support of patients' decision-making: maintaining a sense of control, avoiding inappropriate prolongation of dying.

Those who are working to improve supportive and palliative care should understand how to frame their efforts in relation to a larger context of the problem and gauge it against the domains of satisfaction with care as described above.

The big picture-system building and customization

Innovations will have no impact if they are not incorporated into systems of care. It has been shown, for instance, that an integrated network of palliative care services including home care teams, acute hospital teams and beds in long-term care facilities can resolve many of the problems of coordination and continuity of patient care across settings (83).

Going a step further, service development should take into account the need for customization and development of systems for different groups of patients (84).

By separating patients who are near the end of life based on functional trajectories, it is possible to identify and serve population groups with sufficiently similar health care needs, rhythms of needs and priorities to make the segment useful in planning. In light of more common needs, planners are able to structure the supports, service arrays and care delivery arrangements so that they will meet the needs of anyone in that segment reasonably well, even though they may be mismatched to other segments. As is usually the case, one size does not fit all and even for patients with complex chronic diseases the trajectory may well be different and follow that of the predominant illness.

In many parts of the world this has already taken place. Palliative care services are increasingly customized to meet population needs. Though a full range of services are already present in terms of home hospice services, inpatient hospice facilities and hospital-based palliative care services, Australia (85) and the UK (86) have opted to develop end-of-life programs catering for the frail elderly in nursing homes as the conventional model of palliative care does not serve this population well. Similarly, the Program of All-inclusive Care (PACE) project (87) provides comprehensive care for the frail elderly at home in San Francisco, allowing them to spend their days, up till the last if possible, at home. This program has now been adopted in many parts of America. Other chronic disease management programs incorporating palliative care practices and expertise have shown promising results (88).

Though not labeled as such, all these microsystems have, or aspire to have, elements of the «advanced medical home» (89). The concept of a medical home was first introduced by the American Academy of Pediatrics and has been described as providing care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (90). The key attributes of an advanced medical home include:

- A personal physician, who has an ongoing relationship with the patient and is trained to provide first-contact, continuous and comprehensive care. This physician can either be a trained family physician or a specialist.
- A multidisciplinary team, led by the physician, which collectively takes responsibility for the ongoing care of patients.
- Holistic care, which provides for all the healthcare needs of patients and their loved ones, and arranges referral to other qualified professionals if necessary.

- Coordinated and integrated care across specialty and care settings.
- Emphasis on quality and safety, which is assured by a care planning process, evidence-based medicine, clinical decision-support tools, performance measurement, active participation of patients in decision-making, information technology, quality improvement activities.
- Enhanced access availability through open scheduling, extended hours and new options for communication.
- Payment models that are appropriate for the added value provided to patients, which falls outside the face-to-face visit and supports the use of health information technology for quality improvement.

This must be supported by policies laying the groundwork for an effective healthcare system and society (91). In the many countries, policies have largely led to palliative care being embedded into the fabric of healthcare delivery (92-94). Advocacy with policy makers will thus be a key aspect in sustained gains.

The small picture; the nuts and bolts

The use of new technology (95) has allowed for a greater attention to quality and safety through closer monitoring of patients without their needing to leave the comfort of their own homes, a very important consideration in frail individuals at the end of their lives. This can be accomplished through:

- Telehealth services-using remote telecommunications equipment for consultations and to monitor the condition of a patient, and relay information over a telephone line or wireless connection back to individual health professionals or a program's headquarters. Various sensing devices connected to a monitor by a patient's bedside can transmit pulse, blood pressure, respiratory and pulse oxymetry readings. This not only reduces travel costs and improves accessibility, but also provides a sense of reassurance to patients and their families. Use need not necessarily be restricted to the medical and nursing members of the team. The counselor or social worker can similarly make use of video conferencing devices to assess and address identified psychosocial, emotional or spiritual needs.
- Point-of-care computing with wireless or broadband grids on portable computers at the patient's home and other sites of care allows for rapid, timely and accurate

access to information and medical records (96-99), rescheduling of visits, help in retrieving essential contact information, guides the systematic assessment of patients and documents the care provided. This can also include links to evidence-based practices and decision-making tools and prompts to guidelines in patient management, preventing drug-related errors.

- Microdiagnostic technologies such as glucose monitoring and electrocardiography already exist. More can be done and made available to staff in the field as diagnostic equipment becomes cheaper, smaller and easier to use. Such technologies allow for rapid assessments, which may be especially pertinent in patients in the entry-reentry trajectory.

Technology is also revolutionizing education and the decision-making process, particularly through Web-enabled tools (100). Last Acts, a national communications campaign sponsored by the Robert Wood Johnson Foundation is a case in point. It began in 1995 and ended in 2005, and was a coalition of more than 800 national health and consumer groups that worked together to improve communication and decision-making for consumers about their own death, to change the culture of health care institutions, to change our culture and attitudes toward death. Though this highly acclaimed program has come to a close, it has left as its legacy a wealth of web content from the various projects it funded over the years. Many of these innovations (101) are still relevant to this day. In the past decade, patient and family education has gone beyond paper and person-to-person interactions. The popular media, such as movies, television, theatre, press and literature, can also be used effectively to help change perceptions of death and dying (102) and expectations of healthcare at the end of life.

The new age, however, belongs to interactive technologies and online resources (103-105). Social networks, video chat and instant messaging platforms are already shaping the way patients and their healthcare workers interact, increasing accessibility to services and nurturing a more responsive healthcare system with personalization of care. Peer-to-peer interactions through social media are in particular playing an increasingly important role, as support from people in similar circumstances is highly valued by patients (106), even for those who report high levels of support from family members (107). Such interactions can yield a unique sense of community, reassurance and practical information that cannot be gained from other supportive relationships and can improve relations with family and friends by relieving their burden of care (108).

Building these forms of communication into supportive and palliative care system development, coupled with the appropriate reimbursement incentives, will be essential in dealing with a new generation of patients in the 21st century. OPIMEC could play a key role in making this possible.



Contributors

Angel Lee and Ong Yew Jin wrote the first draft of this chapter in English. Alejandro Jadad approved it before it was translated into Spanish. The English and Spanish versions were uploaded onto the OPIMEC platform, where they received important contributions from Maria Nabal (in Spanish), Scott A. Murray (in English) and Jackie Bender (in English). Alejandro Jadad incorporated these contributions into a revised version of the chapter, which was approved by Angel Lee and Ong Yew Jin, and the other contributors.

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Abbreviations

AAL: Ambient Assisted Living

BMJ: British Medical Journal

CAM: Complementary And Alternative Medicine

CCD: Complex Chronic Disease

CCM: Chronic Care Model

CIRS: Chronic Illness Resources Survey

CMPs: Case Management Programs

CVD: Cardiovascular Disease

DMPs: Disease Management Programs

EASP: *Escuela Andaluza de Salud Pública*

EPP CIC: Expert Patients Programme Community Interest Company

GRIN: Genomics, Robotics, Informatics and Nanotechnologies

ICCC: Innovative Care for Chronic Conditions

ICD: International Classification of Diseases

ICED: Index of Coexisting Disease

IDS: Individual Disease Severity

MCCs: Multiple Chronic Conditions

MD team: Medical Doctor

MeSH: Medicines Medical Subject Headings

MI: Motivational interviewing

MPOWER: Monitor (tobacco use and prevention policies), Protect (people from tobacco smoke), Offer (help to quit tobacco use), Warn (about the dangers of tobacco), Enforce (bans on tobacco advertising, promotion and sponsorship), Raise (taxes on tobacco)

NHIS: National Health Interview Survey

NHS: National Health Service

OECD: Organization for Economic Co-operation and Development

OPIMEC: *Observatorio de Prácticas Innovadoras en el Manejo de Enfermedades Crónicas Complejas*

PACE: Program of All-inclusive Care

QALY: Quality-Adjusted Life Year

QRISK: Cardiovascular disease risk score

RE-AIM: Reach, Effectiveness, Adoption, Implementation and Maintenance

SNOMED CT: Systematized Nomenclature of Medicine-Clinical Terms

SSPA: *Sistema Sanitario Público de Andalucía*

TCAM: Traditional Complementary And Alternative Medicine

TPE: Therapeutic patient education

VHA: Veterans Health Administration

WHO: World Health Organization

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When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge

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