

Chapter 7: Supportive and Palliative Care

Vignette with a vision of the future

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 prostatic 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 programme transferred his care to a colleague more skilled in dealing with polyopathy 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, Mr Yeo spoke into the speaker, but Im not feeling very well. This cough which started yesterday is not settling and I am having difficulty lying flat.

As she continued to speak to him, Kala looked at the readouts from the senses attached to Mr Yeos telehealth unit at his bedside. She asked Mr Yeo for assistance in applying the blood pressure cuff, the pulse oxymeter, thermometer and the stethoscope. She soon recognized that Mr Yeo was having 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 staying 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 review 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 onto 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 options of care, Dr Summers proceeded to speak to Mr Yeo to determine his understanding and to 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 Yeos 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 allowed palliation of his dyspnea at home and for him to remain comfortable. Video tele-monitoring by the programme 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 Yeos 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 rather 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 shorter intervals between the admissions. Without a clear primary physician to call upon, this often brought him into head-on assault of 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 laid gasping, desperate for attention, his family was told that he had a terminal condition and told 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, 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 stayed 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 the topic important?

Declining births and medical advances are leading to increased longevity such that of the world's estimated 9.3 billion people, 16% will be 65 years and older in 2050. Europe will be the greyest region, with 29% of its population projected to be 65 and older in 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, this number is expected to expand three-fold from a current 300,000 to 900,000 by 2030.

As described in detail in Chapter 1, global numbers of death in the world are 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, hypertension and chronic obstructive airway disease, with prevalence rates up to 20, 23, 26, 17 and 16% respectively (5). Consequently, more people will suffer and eventually die with complex chronic diseases (6).

Proximity to death is the major determinant of health care cost

The tragedy of unmet needs at the end of life

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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 (13). Palliative care (14):

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or 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 counselling, if indicated;
- Enhances quality of life, and may also positively influence the course of illness;

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(30, 31, 32), the majority of deaths from terminal illness still occur in hospital.

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%(33). 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(34).

Further analysis suggests that the opportunity for home death is disproportionately high among Caucasian people, and those with higher socioeconomic status(35,36), who are married(32, 33, 37, 38), who are suffering from cancer(32, 34)and living in a racially homogeneous area(39) in both the United States and other Western industrialized nations.

Observational studies have also shown that expressed preferences(40), poor functional status, intensive home care support, living with relatives and extended family support are associated with more frequent deaths at home(41).

On the other hand, lack of 24 hours home care services and poor coordination between health and social care services have been blamed for increase in hospital deaths in spite of patients preference for death at home(42, 43).

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

Having demonstrated its effectiveness in improving assessment, documentation and care of patients in the last 24 hours to last days, the Liverpool Care Pathway is now increasingly adopted in many parts of the world (44, 45). There is also good evidence that advance care planning led by skilled facilitators who engage key decision makers directly over multiple sessions lead to increased utilization of advanced directives(46, 47) and a better death experience at the end of life(48).

It is increasingly recognized that in the management of patients with heart failure, there is reduced re-admissions and improved continuity of care with multi-component

interventions(49). 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 (50, 51). 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 enlarging knowledge base, widespread adoption of the principles of palliative care and the dissemination of such knowledge is still lacking (52, 53, 54). Only in recent years have major organ- or disease-specific textbooks paid much attention to supportive and palliative care of end organ failure (55,56). Palliative care education is still not an essential component of many medical and nursing schools (57, 58). 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, still many health professionals find themselves standing by helplessly, as patients suffer and families fret.

Besides textbook revision and improving 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 programmes as venues for education and enhancing educational resources for end-of-life care(59, 60, 61).

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(62). 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* (63), which provided the beginnings of our understanding of the different trajectories of dying. These patterns of (1) sudden and abrupt death, (2) gradual decline followed by period of more rapid decline, such as seen in cancer, (3) the entry-reentry deaths on a background of steady decline of many chronic illnesses and (4) the progressive frailty followed by death, were subsequently illustrated in a study of Medicare beneficiaries (64) and by Lunney et al (65) 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 programmes were designed around 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 [\(66\)](#), brought forth 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 course of gradual decline followed by 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 (1) chronic disease management to reduce the likelihood of exacerbations and to sustain all possible function, (2) rapid intervention at the first sign of exacerbation, preferably in the home rather than the hospital and (3) good advance care planning directing 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 through the years, requiring assistance with activities of daily living 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.

Supportive and palliative care saves 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 [\(67\)](#).

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 [\(68\)](#).

In hospitals, matched patients who received palliative care resulted in highly significant reduction in costs for the hospital compared with those who did not (69). 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 (70).

What do we need to know?

What would it take to design a health system that meets the needs of patients with complex chronic diseases? This can be addressed at four levels, described by Donald Berwick, that characterize a high-quality health system (71): 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.

One of the key challenges in the management of patients with complex chronic diseases is the need to keep the fine balance between disease modifying or restorative 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 comorbidities 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.

There is already a significant body of information on what constitutes good supportive and palliative care at the end of life. What remain unclear are the reasons for inadequate application of existing knowledge for provision of care. How can we best incorporate the knowledge available into systems of care such that health professionals have such information when they need it? How do we ensure that patients and their loved ones get the care that they need?

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

Currently, there are very little 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 of value-added services such as family conferences, care liaison, counseling and healthcare worker-patient communication via new media in a changing world? In Kansas, 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 is being tested (74).

Can social systems and policies also ensure that families needs are addressed? In Canada (75) 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 in-patient 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?

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 [\(76\)](#):

- 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. In Catalonia, Spain, an integrated net of palliative care services includes home care teams, acute hospital teams and beds in long-term care facilities. This integrated net of services helped to resolve the problems of coordination and continuity of patient care across settings [\(77\)](#) and is the envy of many in Europe and the rest of the world.

Going a step further, service development should take into account the need for customization and development of systems for different group of patients as suggested by Joanne Lynn [\(78\)](#).

By separating patients who are near the end of life based on functional trajectories,

we are able to have groups of population with sufficiently similar health care needs, rhythms of needs, and priorities to make the segment useful for planning. In view 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 it 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, in-patient hospice facilities and hospital based palliative care services, Australia (79) and UK (80) have found it fit to develop end-of-life programs catering to the frail elderly in nursing homes as conventional model of palliative care does not serve this population well. Similarly, the Program of All-inclusive Care (PACE) project (81) 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 (82).

Though not labeled as such, all these microsystems have, or aspire to have, elements of the advanced medical home' (83). The concept of a medical home was first introduced by the American Academy of Pediatrics and has been described to provide care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (84). The key attributes of an advanced medical home include:

- A personal physician, which 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 patients healthcare needs 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, expanded 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 (85). In the many countries, policies have largely led to palliative care being embedded into the fabric of healthcare delivery (86, 87, 88) Hence, advocacy with policy makers will be a key aspect for sustained gains.

The small picture the nuts and bolts

The use of new technology [\(89\)](#) 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 programs headquarters. Various sensing devices connected to a monitor by a patients 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 similar make use of video conferencing devices to assess and address identified psychosocial, emotional or spiritual needs.
- Point-of-care computing wireless or broadband grids on portable computers at the patients home and other sites of care allows for rapid, timely and accurate access of information and medical records * [\(90, 91, 92, 93\)](#), rescheduling of visits, help to retrieve essential contact information, guide systematic assessment of patients and document care provided. This can also include links to evidence-based practices and decision making tools and prompts to guidelines in patient management, prevent drug-related errors.
- Microdiagnostics technologies such as glucose monitoring and electrocardiography already exist. More can be done and made available to staff on the field as diagnostic equipment becomes cheaper, smaller and easier to use. Such technologies allow for rapid assessments, which may especially pertinent in patients in the entry-reentry trajectory.

Technology is also revolutionizing education and the decision making process, particularly through Web-enabled tools [\(94\)](#). 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, change the culture of health care institutions, change 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 has funded through the years. Many of these innovations [\(95\)](#) are still relevant to this day. In the past decade, patient and family education has gone beyond paper and person-to-person interactions. The new age belongs to interactive technologies and on-line resources [\(96,97,98\)](#).

The popular media, such as movies, television, theatre, press and literature, can also be used effectively to help change perception of death and dying [\(99\)](#) and expectations of healthcare at the end of life.

New media communication tools such as social networks, video chat and instant messaging platforms will shape the way patients and their healthcare workers interact to increase accessibility and produce a more responsive healthcare system with personalization of care. Building these forms of communication into palliative care system development with its appropriate reimbursement incentives will be necessary to deal with a new generation of patients. OPIMEC could play a key role in making this possible.

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Comments to the whole document

- 29 Apr 2010 03:24 **Liliana De Lima** commented, on

El capítulo me parece que está bueno, pero la primera impresión que tengo es que esto es para países en desarrollo. Se asume que existen los equipos y los medicamentos y que lo que falta es integración de los niveles en el sistema sanitario. Es cierto que en muchos países desarrollados esto sucede así, pero la situación en países en desarrollo es bastante diferente, como sabes y aunque intento buscarle el lado por donde podría meterse algo de eso, no lo encuentro.

Si tomas como marco conceptual el triángulo de la OMS, ninguno de los componentes (educación, políticas sanitarias y educación) se dan en los países en desarrollo...mi opinión es que esto debería ser enseñado en las carreras de salud desde pregrado, y sobretodo en los casos de enfermedades crónicas, que son las que están en aumento a nivel mundial. El caso de la disponibilidad y uso de opioides es patético: después de 20 años de la escalera analgésica, la foto no ha cambiado: el 80% de la morfina se consume en 6 países. El resto utiliza niveles absurdos o no reporta consumo. En fin, los ejemplos son muchos y no quiero aburrir. El caso es que no encuentro bien el "fit" de esto dentro del marco del capítulo de paliativos.

Comments by section

[Vignette with a vision of the future](#)

- 24 Jan 2010 20:25 [Maria Nabal](#) commented, on

Resulta chocante este inicio del capítulo, suena un poco a ciencia ficción pero refleja bien todo lo que se podría lograr aplicando la tecnología a las necesidades de las

personas.

Es reseñable que esta alta tecnología parece no aplicable en muchos países de África, Medio Oriente, Asia y América del Sur

How it is now

- 24 Jan 2010 20:26 [Maria Nabal](#) commented, on

Refleja claramente la situación de escasa previsión, comunicación deficiente entre paciente-familia y equipo asistencial y falta de coordinación entre niveles de atención.

Why is the topic important?

- 24 Jan 2010 20:31 [Maria Nabal](#) commented, on

La proximidad de la muerte es el principal factor determinante de los costes sanitarios:

Este capítulo ilustra bien la magnitud del gasto al final de la vida pero profundiza poco en los factores que lo determinan.

Establecer las causas que condicionan ese gasto puede facilitar un análisis más profundo de los datos ya que creo que se presentan datos relativos tanto a procesos agudos como crónicos. La posibilidad de encontrar y poner en marcha soluciones para los casos de gastos poco justificables dependerá de ese análisis más profundo

Una tragedia: cuando hay necesidades que no están cubiertas al final de la vida

Este apartado promete en su título el análisis de los daños producidos por las necesidades no cubiertas al final de la vida pero es demasiado escueto para ello.

No se hace referencia a la inequidad en el acceso a los recursos entre países y entre regiones dentro de cada país. No profundiza en las dificultades de acceso a ciertos medicamentos. Tampoco se hace referencia a que en el caso de las situaciones de pluripatología o insuficiencia de órgano el paciente, en nuestro medio, recibe poca información y por ello es muy difícil realizar una planificación anticipada de cuidados que responda a los deseos y posibilidades de cada paciente.

Cuidado de apoyo y paliativo

En este capítulo quedan bien definidos los principios y filosofía de los cuidados paliativos pero no se profundiza mucho sobre las razones que dificultan su

implantación en las enfermedades diferentes al cáncer:

la muerte como fracaso del profesional

falta de formación

curso fluctuante de la enfermedad de base

falta de información del paciente sobre su realidad y expectativas a corto y medio plazo

déficit en la gestión de las emociones del propio profesional y del paciente y su familia

problemas relacionados con la gestión sanitaria y la asignación de recursos

etc.

- 24 Jan 2010 20:26 [Maria Nabal](#) commented, on

Constituye un apartado muy interesante para poder valorar la magnitud del problema

[What do we know? So what?](#)

- 31 Jan 2010 18:43 **carlos alvarez-dardet** commented, on

revisad como empieza el capitulo la longevidad no se afecta por el numero de nacimientos, es independiente, ni incluso la esperanza de vida al nacer que tambien incluye las muertes infantiles se afecta por el numero de nacimientos es un error grave que debeis corregir para mantener la credibilidad del libro

- 24 Jan 2010 20:34 [Maria Nabal](#) commented, on

La mayoría de los pacientes mueren en instituciones

Tampoco en este capitulo se ofrecen las razones que motivan que los pacientes fallezcan en las instituciones prefiriendo fallecer en el domicilio.

La frase *“Este descenso en el número de fallecimientos en el hogar sería paralelo a un incremento del 20,3% (33)”* parece incompleta y no se entiende.

“Diferentes formas de morir”

Ofrece una reflexión muy interesante

- 30 Dec 2009 16:25 [scott Murray](#) commented, on

I wonder if this would make a useful section after "people die differently" to bring out the fact that death is 4dimensional, and not simply a physical activity, a la classic trajectories of physical decline

the basic ref is no9 Could be edited.

Other dimensions of need

But what is going on with the other dimensions of need? Dying is a multidimensional experience. It is not just a physical demise, and as doctors we 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 been relatively unexplored.¹ But it is accepted that quality of life is modified by all dimensions of personhood.²

Spiritual issues are frequently very significant for people living and dying with lung cancer and heart failure.⁵ Might there be typical patterns of social, psychological and spiritual needs towards the end of life? A secondary analysis of in-depth serial interviews suggests there might be.^{6,7}

Defining and assessing spiritual needs is problematic. We used a definition relevant for a secular health service: *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 organised religion have belief systems relating to meaning and purpose.*⁸

We found characteristic social, psychological and spiritual end of life patterns as we read and re-read the in-depth serial interviews which were conducted every three months in the last year of life, with participants talking about their main worries and concerns.⁹ 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 (see Figures 2 and 3).

Figures 2 and 3

'4D' care planning

The extent to which these findings⁹ from Scotland are generalisable to different national, social, ethnic and religious groups is unknown. Individual patients will die,

some unexpectedly, at different stages in these trajectories and rates of progression vary. However, I have found that mapping out these patterns to medical students and doctors has allowed them to understand that care planning must be four dimensional, or '4D'. In complex co-morbidities, we can consider the total impact on each dimension of need, with a view to relieving that.

We can anticipate and share with patients when they are likely to be distressed. Explanation to 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 mapping thus helps build a big picture, a wide perspective to help us understand and anticipate the likely needs of individuals. This holistic approach, considering each dimension of need, may lessen the multi-specialist approach, and moderate the current 'technological imperative' when care is focused on interventions to prolong life, with sometimes overzealous and futile treatment. Considering these different trajectories brings spiritual assessment and care into focus, and highlights that many patients have spiritual issues from *diagnosis* of cancer or chronic life threatening illness, not just at the very end of life.

What is 'spiritual support'?

The implication of this is that spiritual support should be available for patients from diagnosis, sooner rather than later. But what is spiritual support? We asked a number of patients with advanced illness in the community how they got 'spiritual support', and they tended to reflect and respond as follows: 'It was the nurse who sat down and listened and...' A patient-centred 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.

BOX

Adopting patient-centred supportive care: possible questions¹⁰

What's 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. When asked about my own faith I've often found it useful to acknowledge the question and say that I will explain, but first I tend to reflect the question back to the patient to ask them about their beliefs. This is because they may just be looking for an opportunity

to express where they are on this issue.

A welcome innovation

The concept of illness trajectories, not only physical, but also those of social, psychological and spiritual wellbeing or distress, is a welcome innovation to help understand the lived experience of dying. Carers may also have social, psychological and spiritual issues simultaneously with their loved one. We must now use this understanding to plan services which respond to patients' needs, which will include holistic care from the diagnosis of a life-threatening illness. Lessons learnt in caring for patients who die of cancer must also be extended to embrace patients in general – the majority of whom die from other conditions.¹¹

Scott A Murray is St Columba's Professor of Primary Palliative Care in the University of Edinburgh. references

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What do we need to know?

- 31 Jan 2010 19:04 **carlos alvarez-dardet** commented, on

en este parrafo:

En el Reino Unido, considerado a menudo el país donde aparecieron las primeras residencias modernas para enfermos terminales y donde se desarrolló en primer lugar el cuidado paliativo, el porcentaje de muertes en los hogares cayó del 31,1% en el año 1974 al 18,1% en el año 2003. Si continúa esta tendencia, se prevé que en el año 2030 menos de una de cada diez personas (9,6%) morirá en casa. Este descenso en el número de fallecimientos en el hogar sería paralelo a un incremento del 20,3% (33) falta algo debe ser una errata al final no se dice de que es el aumento del 20,3%

- 24 Jan 2010 20:35 [Maria Nabal](#) commented, on

Este capítulo no es claro. Ofrece más interrogantes que respuestas cuando el título parece querer enseñar algo.

Bajo cada uno de los niveles no se explica como desarrollarlo

[What innovative strategies could fill the gap?](#)

- 23 Feb 2010 23:58 [Jackie Bender](#) commented, on

With respect to 'What do we need to know' sub-theme A) experience of patients and families...

We may want to include some research that describes the nature and extent of supportive care needs of individuals with complex, confluent conditions.

It may be challenging for patients to adequately 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 adequately describe subjective symptoms and side effects, and this task is made much more difficult for those dealing with multiple, confluent conditions.

A study I conducted with women experiencing pain related to breast cancer revealed that formulating and articulating questions about pain is a context-dependent, time-intensive process that requires reflection, knowledge, and a good use of language. This qualitative study identified that breast cancer patients have questions about (1) understanding cancer pain, (2) knowing what to expect, (3) options for pain control, (4) coping with cancer pain, (5) talking with others with cancer pain, (6) finding help managing cancer pain, and (7) describing pain to health professionals. It also revealed that they lacked awareness regarding what to expect in terms of pain relief, the health services available, and how to access these services.

Bender JL, Hohenadel J, Wong J, et al. What patients with cancer want to know about pain: a qualitative study. *J Pain Symptom Manage* 2008;35:177–87.

Strategies need to be developed to enable patients to raise and describe their supportive care needs, and supportive care interventions/ programs should be developed based on patients' expressed needs.

- 23 Feb 2010 23:32 [Jackie Bender](#) commented, on

To emphasize the disjointed and fractured nature of supportive care delivery and services, I think it is important to articulate the variety of people (e.g. primary physician, nurse practitioner, disease specialist, symptom specialist, psychosocial specialist, allied health professionals, family, friends and community networks) and places (e.g. community clinics, acute care hospitals, long-term care centres, rehabilitation programs/centres, community support organizations, hospices and the home) either potentially or typically involved in supportive care.

It would also be great if we could discuss or reference any good examples, models or case studies of successful supportive care coordination across the different providers and places.

- 23 Feb 2010 23:21 [Jackie Bender](#) commented, on

Jackie Bender

Since this section is titled Supportive and palliative care, I think this chapter needs a definition or history of both terms and areas of overlap... as well as suggestions for appropriate use of terms with patients and families. The term palliative care is fraught with negative connotations particularly for patients and family members who equate it with impending death.

A useful definition of supportive care in the context of cancer has been advanced by Marg Fitch (1994):

"the provision of the necessary services as defined by those living with cancer to meet their physical, social, emotional, informational, psychological, spiritual, and practical needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases of cancer care, encompassing issues of survivorship, palliation and bereavement"

- 24 Jan 2010 20:36 [Maria Nabal](#) commented, on

Parece que el título no refleja el contenido de la sección ya que dentro del capítulo no se habla de estrategias innovadoras sino de factores valorados como de calidad por los usuarios

[References \(click here to access\)](#)

- 24 Feb 2010 00:20 [Jackie Bender](#) commented, on

In terms of innovative strategies for supportive care and the practical 'nuts and bolts'

of meeting patients supportive care needs, I think peers supported by social media could play a big role here.

Support from people in similar circumstances is highly valued by breast cancer survivors (Rosmovits & Ziebland, 2004), even for some who report high levels of support from family members (Arora et al., 2007). Research has demonstrated that support from peers can provide 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 (Ussher, Kirsten, Butow & Sandoval, 2006). Moreover, people with chronic illness often become experts in the management of their illness, and many patients prefer to seek advice from other patients rather than health care professionals for certain types of supportive information and support.

In recognition of the important role of the 'expert patient' several programs and chronic disease models have developed with them in mind:

-UK NHS Expert Patient Program

-Stanford Peer-Led chronic disease self-management programs

Social medial and mobile social networking technologies could provide an ideal opportunity to extend the reach of the 'expert patient' module. Online communities provide a rich database of experiential knowledge and support from peer experts. In their examination of the Brain Talk community for neurological conditions, physicians Hoch and Ferguson described online communities as:

Illness support communities are invaluable resources for clinicians; ... smarter, or at least more comprehensive, than many physicians—even medical specialists.
— Hoch & Ferguson, 2005

[Creative commons license Supportive and Palliative](#)

24 Jan 2010 20:40 [Maria Nabal](#) commented, on

En su conjunto el capítulo 7 resulta muy interesante en tanto que aporta reflexiones e interrogantes que invitan a profundizar en el análisis. Como lectora me aporta más interrogantes que respuestas a esos interrogantes y a las necesidades de pacientes y familias al final de la vida.

No existe ninguna referencia al final de la vida de niños o adolescentes, que por sus peculiaridades y el alto impacto que generan merecerían una mención.