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23 – When Chronic Care Becomes End-of-Life Care: Bridging the Gap

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Population ageing remains a global phenomenon and it is not only a triumph for society but a huge challenge for health care systems.

Advances in health care have transformed our society and as a result fewer people today die of infectious diseases, and more people live longer. In addition however, more people are living longer with serious and chronic illnesses characterised by fluctuations in trajectory, uncertainty in prognoses, extended disease timelines and stress.

Helping someone that is living with a chronic condition can be challenging and sometimes the transition to end-of-life care is introduced too late to be fully effective.

The Key Question Is “When Does End-of-life Care Begin?”

The point at which end-of-life care begins depends on patients’ needs. End-of-life care may last a few days, or for months, or years, beginning and ending when the patient needs it.

Often doctors focus on curing the disease but few have the time to explore all the wide-ranging solutions that can address symptoms and restore people to normal life as far as possible.

The current evidence suggests *various gaps in care, as reported by patients, their families, GPs and other health care providers.*

Identified gaps in the end-of-life care include problems in areas such as:

- patient’s quality of life
- quality of care
- physical or psychological distress of caregivers
- cost-effectiveness of care.

Quality of care incorporates a great variety of aspects related to structure and process of care such as:

- physical aspects of care which hide many underwater stones in the management of pain, other symptoms and side-effects of treatment
- psychological and psychiatric aspects of care which involve trained professionals working as a team and special attention given to delivering bad news
- social needs, spiritual, religious and existential aspects of care which are often underestimated
- not respecting cultural preferences of patients and family
- disregard for the end-of-life concerns, hopes, fears, and expectations of the imminently dying patients
- and finally, key ethical and legal issues for terminal patients

A great variety of initiatives are needed to bridge the gaps in the current practices of care and achieve a better quality of life. Providers who care for chronically ill patients should be supported with evidence-based guidelines, specialty expertise, and information systems.

This vast subject would require a much more comprehensive approach beyond the health care system as it concerns other areas such as employment and the environment - "health in all policies". Another consideration is "What are the patient's desires and wishes?"

There is a need for an approach that focuses on the individual who has specific needs related to provision of prolonged and continuous care. These needs can be:

- medical; with regard to pain control and prevention of complications, etc.
- psychological; associated with the need for information or emotional support
- social aid in patients' daily life and involvement in the community
- spiritual; searching for a meaning.

All these needs relate to the organisation of healthcare, accessibility of services, and coordination between care settings.

The key being "Patient gets the right care at the right time in the right setting by the right health care providers."

In the search for effective and efficient solutions for the management of long term care, scientists are developing different programs.

The Chronic Care Model by Ed Wagner describes the necessary components for a delivery system that encourages and sustains productive interactions between patients and providers.

Improving Chronic Illness Care's Chronic Care Model brings together the best in research and practice for chronic illness care interventions.

The KCE report from Belgium in 2012 proposed a draft of an optimal-idealised-system, with the characteristics for the optimal management of chronic diseases that is needs-based, personalized, goal-oriented, planned and services are provided in a high quality, efficient, sustainable, accessible, culturally competent and patient empowering manner in the least complex environment that is clinically appropriate.

Palliative care offers an alternative perspective. Palliative care is a new, supportive, compassionate and integrative 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. Palliative care can be provided in hospitals, nursing homes, outpatient palliative care clinics, other specialized clinics, or at home. Palliative care teams help patients manage their new circumstances and relieve some of the physical and mental stress of internal illness. Ultimately, palliative care helps individuals live as well as possible for as long as possible. It is focused on timely identification of patients in need of palliative and end-of life care, assessing and agreeing how to meet people's needs and preferences, timely referral to palliative care experts, collaboration between patients, family and the medical team, the use of guidelines and appropriate working procedures, and knowledge of palliative care and symptom management on the clinical wards using advanced care planning, and delivering high quality services.

The end of a person's life can be one of the most important moments in that life. Meeting end-of-life care gives rise to ethical issues. Voluntary euthanasia and physician-assisted suicide bring about many ethical issues regarding a patient's death and have been the focus of great controversy in recent years. Some physicians claim that euthanasia is a rational choice for competent patients who wish to die to escape unbearable suffering. Others feel that aiding in the patient's death goes against a physician's duty to preserve life that is morally unacceptable. Some forms of voluntary euthanasia are legal in Belgium, Luxembourg, the Netherlands, Switzerland, and some states in the USA.

Primary health care, provided by GPs, is to a great extent the cornerstone of eliminating some of the gaps previously mentioned. High quality training for family doctors is vital to ensure the delivery of quality chronic disease management and a smooth transition to palliative care.

Patient-centred care is an option to help patients and families in various ways. Good doctor-patient communication leads to various positive aspects both for patients as increased satisfaction, better health outcomes, improved understanding, increased adherence to treatment and for doctors - decreased job distress and less emotional stress and burnout.

