

End of Life Care for Clients with End Stage Dementia

Introduction

The World Health Organization (WHO) (1990) defined palliative care as: "The active total care of patients and families by a multiprofessional team when the patient's disease is no longer responsive to curative treatment."

This definition referred specifically to cancer patients, however, WHO (2004) has since stated that every person with a progressive illness has the right to palliative care. In a Sampson et al (2006) hospital-based study it was identified that dementia was not necessarily viewed as a terminal illness and patients with dementia may receive care which differs from that given to others who are terminally ill.

In the UK, the National Institute for Health and Clinical Excellence (NICE) guidance (2006) recommends that people with dementia receive palliative care from the time of diagnosis to the point of death. This approach aims to enhance the person's quality of life and enable the person to die with dignity in an appropriate environment. Care should include physical, psychological, social and spiritual needs.

Diseases such as cancer are widely recognized as being terminal diseases. Such conditions have clear lines of progression and it is usually clear when the focus of care moves to a palliative phase. Dementia is different: a person may live for years, and it can be difficult for staff and families to recognize when a person living with dementia begins to die (McCarthy et al, 1997; Schuster, 2000).

The Seniors Memory Disorders Unit (SMDU) at Ontario Shores is a 23 bed unit which provides specialized services to meet the mental health needs of seniors over 65 years of age with a diagnosis of dementia presenting with challenging behaviour. This patient population requires assessment, stabilization and treatment and management of challenging behaviours with the goal of reintegration into community or LTCHs so length of stay is expected to be for a limited period of time. SMDU is moving towards a formalized behavioural management mode utilizing abilities based programming. Staff includes a mix of RN, RPN, PCA, social workers, occupational therapists and recreational therapists, as well as psychiatrists, physicians, dietitian, physiotherapy and spiritual volunteer services. Referrals come from LTCHs and Schedule 1 hospitals.

Seniors who have come to the SMDU however have become palliative and end of life care planning for clients with ESD was not historically part of the careplan. Discussions about EOL need to start as early as possible in the disease process and must include clients, family and staff. This proactive approach will lead to improved communication and greater client/family focused care.

Sources: Nursing & Residential Care, August 2009, Vol. 11, No 8
NICE Guide 2006

Actions

- Identified all relevant internal and external stakeholders including Spiritual Services, OT, Social Work, Dietitian, Physicians, Registered Staff, Durham Hospice, Alzheimer Society, SMDU Unit Manager, Med Clinic, Professional Practice & Informatics, etc.
- Researched and reviewed the topic of *End of Life Care for Clients with ESD*
- Reviewed College of Nurses of Ontario Practice Guideline: Guiding Decisions About End-of-Life Care, 2009 & Alzheimer Society: Late Stage and End of Life Care
- Met with some stakeholders to discuss the project and ideas

Results

- Increased personal knowledge and awareness of the issues and challenges related to end of life care for clients with end stage dementia
- Identified relevant resources and literature which can be accessed



Challenges

- Changed jobs at the beginning of March 2010. This new role and location means no longer working on a Unit on the SMDU.
- I-CAP (Integrated Community Access Program) serves as a central point of access for all in and outpatient services at Ontario Shores Centre for Mental Health Sciences. Specialized recovery focused staff provide a range of triage, intake, system navigation and outpatient follow-up. Services include assessments, consultations, behavioural support, shared care and follow-up that can be provided in a traditional office based setting, in the community or via Telemedicine based on the unique needs of each individual.
- Time and multiple priorities are an ongoing challenge when balancing the demands of a new full time job, commuting and going to school on a part time basis.



Lessons Learned

- Change Happens...Constantly!
- Sharing information and collaboration with other healthcare providers is essential with all of the changes in organizations, roles, etc. to help provide for some continuity of care for a client
- Limited research about end of life care for clients with end stage dementia-the focus is more on easily recognizable terminal diseases such as cancer, etc.

New Evidence/Best Practices

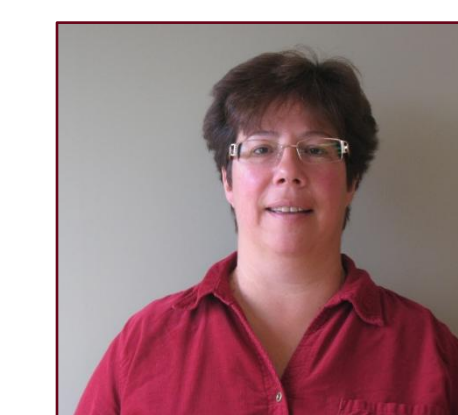
- Research findings show that the use of multidisciplinary guidelines can lead to improved palliative care for patients and suggest that when developed collaboratively they can contribute greatly to the improved care of patients dying from dementia. (International Journal of Palliative Nursing, 2002, Vol. 8, No. 8)
- Alzheimer Society: Late Stage and End of Life Care
- Durham Hospice offers a variety of resources including education, reference materials, volunteer program and grief and bereavement services.
- College of Nurses of Ontario Practice Guideline: Guiding Decisions About End-of-Life Care, 2009

Next Steps



Will explore the opportunity to continue working on this topic however this will be done within a different context being LTCHs. This will be assessed to determine the alignment with this new job and role.

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