



Service Priorities and Programmes Electronic Presentations

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Submitting author: Ms Wai Kee LAU

Post title: Assistant Social Work Officer, Grantham Hospital

The unspoken concern behind palliative care referral: results of a community-based model for the intellectual disabilities

Lau VWK(1)

(1) Social worker, Grantham Hospital

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Introduction

Palliative care (PC) evolved from taking care of terminal cancer patients to modern concept of early integration into disease trajectories of patients with life limiting cancer and non-cancer diseases. However, palliative care for patients with moderate to severe developmental intellectual disabilities (ID) was seldom discussed in literature. Care of ID patients at end of life is often fragmented. Symptom management is difficult for unfamiliar doctors because of communication difficulty. Family carers often have been caring these dependent patients for long time and they are at increased risk of bereavement. Therefore ID patients represent a unique group for which PC is important and is best delivered via a collaborative model between PC team and community service.

Objectives

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Methodology

During the first visit, comprehensive review and explanation of overall medical condition is performed. The patient information is collected across different disciplines including nurse, social worker, physiotherapist and dietitian. In order to have mutual understanding of patient management, family conference is conducted together with patients, their main caregiver, residential home staff including nurses and case social worker. Possibility of maximizing patient autonomy is explored, depending on the level of mental capacity of the patient, by trying to explain and allowing the patient to express as much as possible with the help of the staff and family.

Advance care planning (ACP) is done, eliciting the preference of care, goal of care, place of care, and end of life care. Specific attention shall be paid to explore patient preference, character and habits. Symptom control shall be maximized to enhance patient comfort. Medical follow up and continuous update on patient condition with family and care team is provided.

Result

Case records of the ID patients referred for palliative care services from January 2008 to August 2014 were reviewed. Totally, 24 patients (54.2% male) were followed up for a median of 22 months (range 1 to 74 months). Mean age of patients was 50.3 (SD 11.7). Mean number of symptoms was 2.2 (SD 1.2), which included pain, constipation, weight loss, skin wound, spasticity and edema. 38% family main carer expressed sadness and helplessness on initial assessment. 38% of patients had advance care planning (ACP) discussed which included end of life issues, identification of goal of care and cardiopulmonary resuscitation preference. ACP discussion was associated with no cardiopulmonary resuscitation done before death ($p=0.046$) Half of the patients died during follow up. The main cause of death was infection (68%). Our preliminary result showed prior ACP discussion with family members and main caregivers was associated with less aggressive care at the end of life.