Original Article

Changes in Relatives' Perspectives on Quality of Death, Quality of Care, Pain Relief, and Caregiving Burden Before and After a Region-Based Palliative Care Intervention

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Abstract

Context. A region-based palliative care intervention (Outreach Palliative Care Trial of Integrated Regional Model Study) increased home death, access to specialist palliative care, quality of care, and quality of death and dying.

Objectives. The objective of this study was to examine changes in palliative care outcomes in different care settings (hospitals, palliative care units, and home) and obtain insights into how to improve region-level palliative care.

Methods. The intervention program was implemented from April 2008 to March 2011. Two bereavement surveys were conducted before and after intervention involving 4228 family caregivers of deceased cancer patients. Family-perceived quality of care (range 1–6), quality of death and dying (1–7), pain relief (1–7), and caregiver burden (1–7) were measured.

Results. Response rates were 69% (preintervention) and 66% (postintervention), respectively. Family-perceived quality of care (adjusted mean 4.89, 95% CI 4.54–5.23) and quality of death and dying (4.96, 4.72–5.20) at home were the highest and sustained throughout the study. Palliative care units were at the intermediate level between home and hospitals. In hospitals, both quality of care and quality of death and dying were low at baseline but significantly improved after intervention (quality of care: 4.24, 4.13–4.34 to 4.43, 4.31–4.54, $P = 0.002$; quality of death and dying: 4.22, 4.09–4.36 to 4.36, 4.22–4.50, $P = 0.012$). Caregiver burden did not significantly increase after intervention, regardless of place of death.

Conclusions. The dual strategies of transition of place of death to home and improving quality of care in hospitals should be recognized as important targets for improving region-level palliative care. J Pain Symptom Manage 2016;■:■–■. © *2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Regional palliative care, quality of care, quality of death and dying, caregiver burden, bereavement survey

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Introduction

Improving palliative care at the regional level is of great importance.[1,2] The goal of palliative care for terminally ill patients is not only reducing the symptom burden but also achieving holistic well-being and a good death.[2] A good death for terminally ill patients is multidimensional, including aspects of physical and psychological comfort, staying at a preferred place, sharing time with family and close friends, maintaining hope and joy, and preparedness to die.[3,4] Region-wide cooperation and coordination between multiple medical professionals are needed to achieve these goals.

Several region-based palliative care interventions have been implemented and found to improve various palliative care outcomes, including home death rate, availability of specialized palliative care, symptom control, and medical costs.[5–9] The Japan Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) Study,[10–13] a region-based palliative care intervention trial, indicated a 1.5-fold increase in home death rate and specialized palliative care access, and an improvement in patient- and family-reported quality of care in the regions included in the study.[10]

Previous studies indicated that there have been changes at the regional level; however, little information is available about changes in palliative care outcomes in each place of care, such as hospitals and the home. Examining the impact of the OPTIM intervention on palliative care outcomes in different care settings will give us valuable insight into how best to improve palliative care at the regional level.

In this report, we aimed to clarify changes in family-perceived quality of care, quality of death and dying, pain relief, and caregiver burden in hospitals, palliative care units, and the home after the implementation of region-based palliative care interventions. The overarching aim of the study was to obtain insight into ways to improve region-level palliative care.

Methods

Overview of the OPTIM Study

The OPTIM study was a mixed-method region-based palliative care intervention trial conducted in four regions of Japan from April 2008 to March 2011. Ethical approval and confirmation of scientific validity were obtained from the institutional review board and all participating hospitals. The study methodology has been described in detail previously;[14] however, in brief, it was used to explore whether region-wide palliative care outcomes were improved by the OPTIMize strategy. All OPTIM interventions were designed to optimize existing health care resources within the region without requiring fundamental changes and included a comprehensive program with the following four goals: 1) to improve regional medical professionals' knowledge and skills of palliative care (i.e., dissemination of manuals and assessment tools with interactive workshops about palliative care), 2) to increase the availability of specialized palliative care services for community patients (i.e., establishment of a new community palliative care team, and educational outreach visits), 3) to coordinate community palliative care resources (i.e., regional palliative care centers, whole-region interdisciplinary conferences, patient-held records, and discharge-planning systems), and 4) to provide appropriate information about palliative care to the general public, patients, and families (i.e., dissemination of leaflets, posters, and DVDs and setting up workshops).

Postintervention, significant increases were observed in home death rate in the study regions (6.8%–10.5%, $P < 0.0001$; national average in the same period, 6.7%–7.8%), the proportion of cancer patients who received specialized palliative care before their death (31%–50%, $P < 0.0001$), and the quality of care (patient-reported quality of care: 4.43–4.57, effect size 0.14, $P = 0.0055$; family-reported quality of care: 4.31–4.56, effect size 0.23, $P < 0.0001$).[10] Significant improvements were also observed, as secondary outcomes, in quality of death and dying (patient-reported measures: 4.43–4.57, effect size 0.14, $P = 0.006$; family-reported measures: 4.41–4.63, effect size 0.22, $P < 0.0001$), whereas no significant increase was observed in caregiver burden (3.97–4.03, $P = 0.35$) at the regional level.[10] Qualitative analysis revealed that the participating medical professionals greatly emphasized improved communication and cooperation among regional medical professionals.[15]

Settings and Procedures

This study was a secondary analysis of bereavement surveys conducted before and after the regional intervention. Participating medical institutions were 23 of 34 hospitals (covering 81% hospital beds in the regions) and all home care clinics in the study regions that have expertise in caring for terminally ill cancer patients. Cancer patients who died during the preintervention (April 1, 2007, to March 31, 2008) and postintervention (April 1, 2010, to March 31, 2011) phases were listed, and one primary caregiver was detected for each patient. A mail survey was sent in October 2008 (preintervention) and October 2011 (postintervention), after the patient's principal physician judged the eligibility of the family caregiver according to inclusion and exclusion criteria based on the information in the medical records. The time interval between the patient's death