

Home Care Services: Palliative Care Program Evaluation

Note: Collaborative study with the Community Services Department of JHL and Beth Israel's Department of Pain Medicine and Palliative Care

Overview

Palliative care services are focused on helping patients and their families maintain a satisfactory quality of life, manage the burden of illness and reduce the source of suffering throughout the course of a disease. Palliative care often intensifies as death approaches to ensure patients and families that comfort will be a priority, values and decisions will be respected, psychosocial and spiritual needs will be addressed, and practical assistance will be available. While a vast number of community based elderly have chronic, debilitating and progressive incurable illnesses and could greatly benefit from palliative care, providing adequate palliative care to the chronically ill and frail elderly in home and community based care settings is quite challenging. Lack of appropriate education of front line caregivers, failure to incorporate palliative care within routine home visits and insufficient numbers of trained palliative care specialists are all barriers to effective palliative care.

Jewish Home Lifecare's (JHL) Home Care Department along with Beth Israel's Department of Pain Medicine and Palliative Care (DPMPC) developed a palliative care program to bring comprehensive palliative care services into the Bronx and Manhattan home care communities. This program consisted of three components: (1) A palliative care educational training program for home care nurses, social workers, escort-translators, and home health aides. (2) The use of tele-health "Health Buddies" to assist in palliative care case identification and palliative care monitoring¹. (3) The addition of a palliative care specialist dedicated to JHL's Home Care Department.

Study Purpose

The purpose of this study was to examine the impact of the palliative care program described above on (1) nurses, social workers, escort-translators, and home health aides knowledge and attitudes about palliative care; (2) clients' physical and emotional well-being, pain, anxiety, and depression; (3) family caregivers' caregiving related experience, satisfaction with care planning, and perceived physical and psychological symptoms of the elder relative; and (4)

¹ The "Health Buddy" is a small interactive unit placed in patients' homes with a text based monitor that is used to collect information on a daily basis regarding patient symptoms, vital signs, and behaviors by having the patient respond to a series of simple questions that display on the monitor. A palliative care dialogue has been created and added to the "Health Buddies" that are currently being used by JHHLS Home Care clients. Additionally, 70 more "Health Buddies" will be placed in client homes over the next two years with preference given to clients in need of palliative care services.

overall number of programmatic palliative care and hospice referrals, hospital and ER visits, advance directives, and prescription treatments for pain.

Study Measures

Nurses, social workers, escort-translators, and home health aides completed pre and post test instruments to assess the impact of a palliative care training program on their knowledge and attitudes about palliative care. Nurses and social workers received a 32 hour training program while escort-translators and home health aides completed a 4-hour training session.

The pre-test data were collected at the beginning of the first educational session and the post-test was completed at the end of the last educational session (for escort-translators and home health aides the pre and post tests and educational program occurred during one session). For nurses and social workers a second post test survey was completed three months after training.

To explore the impact of the palliative care program on home care clients a chart review examining clients' physical and emotional well-being, pain, anxiety, and depression was conducted at six month intervals. Additionally, the number of community services palliative care and hospice referrals, hospital and ER visits, advance directives, and prescription treatments for pain were tracked.

To examine the impact of the program on family caregivers, caregivers were asked to complete a brief telephone survey about their caregiving experience, satisfaction with care planning, and their relatives' physical and psychological symptoms. These interviews were conducted at baseline and again three months later.

Selected Findings

Staff

1. Nurses and social workers scored significantly higher on the palliative care knowledge post-test than on the pre-test. This significant improvement however was not maintained on the three-month follow-up test.
2. No significant differences in social workers and nurses scores were found across the three time points on any of the attitudinal items. One possible explanation for the lack of change was that subjects' attitudes were supportive of palliative care principles even before the educational sessions.
3. Escort-translators performed significantly better on the palliative care post-test than on the pre-test.

Client Symptoms as Reported by Family Caregiver

1. The most frequently reported physical symptoms of clients were difficulty sleeping, lack of energy and pain. All three symptoms were reported by more than 70% of family caregivers. Lack of appetite and difficulty

concentrating were displayed by at least 50% of clients. The least frequently indicated symptom was nausea reported in a third of the cases.

2. In addition to being the most frequently reported symptoms, pain and lack of energy were also reported as the most distressing symptoms.
3. The most frequently reported psychological symptom displayed by clients was sadness which was reported in 44% of cases.

Health Buddy Usage

In addition to improved palliative care treatment via the palliative care specialist and enhanced team education, one of the goals of this program was to place "Health Buddies" in the homes of clients with potential palliative care needs to better monitor their condition and flag when a palliative care referral is needed. By the end of the study 52% of the clients referred for palliative care had a "Health Buddy" in the home. Of the remaining clients who were referred for palliative care 28% died or were discharged from JHL Home Care Services, 9% refused a "Health Buddy", 7% were deemed inappropriate candidates for a "Health Buddy", and 3% were awaiting assessment to determine if they would be appropriate candidates.

An additional outcome of the study has been the current very successful use of the "Health Buddy" as a source of palliative care referrals.

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