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The palliative care in assisted living (PCAL) pilot study: Successes, shortfalls, and methodological implications ☆

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Abstract

Troubling deficits exist in palliative care (PC) of older adults under the prevailing ''terminal care''-oriented model. We previously described a PC model—*TLC*—that provides a blueprint for remedying these shortfalls. In this model, PC is envisioned as *T*imely and *T*eam-oriented, *L*ongitudinal, and *C*ollaborative and *C*omprehensive. We present results of the Palliative Care in Assisted Living pilot, comparing two TLC model-based, facility delivered interventions for improving the PC of elderly assisted living residents in Sacramento, California, a growing and under-researched population. The less intensive intervention involved one assessment followed by a PC improvement recommendation letter to the resident, family member, primary provider, and facility staff, while the more intensive intervention involved assessments and letters every three months. Primary outcomes were SF-36 Physical (PCS) and Mental (MCS) Component scores and recommendation adherence. Eighty-one subjects enrolled (mean age 85), 58 in the more and 23 in the less intensive group. A loved one attended 56% of baseline assessments. Most subjects expressed a preference for maintaining current quality of life over prolonging life at reduced quality. None were eligible for hospice care. A total of 418 recommendations (mean 5.1 per subject) were generated concerning symptoms, mood, functional impairments, and advance directives. We found no significant differences in recommendation adherence between more (42%) and less (44%) intensive groups, and no significant changes in PCS and MCS scores within or between groups. However, a loved one's attendance of the baseline assessment was associated with improved PCS scores ($p = 0.04$). Our pilot study had methodological limitations that could account for the lack of significant outcome effects. In this context, and given the

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myriad unmet PC needs we detected, interventions based on the TLC model might allow delivery of timely PC to assisted living residents not eligible for hospice care. Further studies exploring the TLC model appear warranted.

Keywords: Palliative care; Residential facilities; Aged; 80 and over; House calls; Hospice care; Evaluation studies; USA

Introduction

Older people nearing the end of life often experience unnecessary suffering due to uncontrolled symptoms (Fox, Raina, & Jadad, 1999; SUPPORT Investigators, 1995) and depression (Beekman et al., 2002). These shortfalls exist across a variety of care settings despite palliative care (PC) research initiatives (SUPPORT Investigators, 1995), process improvement efforts (Jacobs, Bonuck, & Burton, 2002), and education programs (Education for Physicians on End-of-Life Care (EPEC), 1999).

There is increasing recognition that these deficits exist primarily because the conceptual framework for PC applied to older people may be fundamentally flawed (Committee on Care at the End of Life & Institute of Medicine, 1997). We recently described a new model for PC of the elderly—the TLC model—that provides one potential blueprint for remedying this situation (Table 1) (Jerant, Azari, Nesbitt, & Meyers, 2004). In this model, a key assumption is that PC should be conceptualized as care aimed at improving the quality of life of people nearing but not necessarily at the end of life. This increasingly endorsed definition (World Health Organization (WHO), 2003), which contrasts with common usage of the term PC as a synonym for "terminal care," does not arbitrarily extend the period before anticipated death. Rather, it acknowledges the prolonged, unpredictable process of "nearing death" faced by many older people (Fox et al., 1999). It also accounts for the wide variation in the point in time when patients, families, and doctors agree death is approaching (Slomka, 1992). Both issues may delay or even completely preclude older patients' enrollment in hospice programs. While hospice programs typically provide excellent PC, the "six months or less" prognosis requirement for enrollment excludes many older patients with ongoing PC needs but less certain prognoses. New models of PC such as TLC may help to fill this important gap in PC for the elderly.

The TLC model was informed by the research literature related to PC (Center for Gerontology and Health Care Research, Brown University, 2004) chronic illness care (Improving Chronic Illness Care, 2004), shared decision making (O'Connor et al., 2003), and comprehensive geriatric assessment (Reuben, 1999). Despite its high face validity, no studies have examined the effectiveness of PC interventions based on the TLC model. To begin to fill this research gap, we conducted the Palliative Care in Assisted Living (PCAL) pilot study, in which two interventions for improving PC in older people based on the model were compared.

Assisted living facilities (ALFs)—congregate residential settings that provide or coordinate personal services, supervision, activities, and health-related services (National Center for Assisted Living (NCAL), 2001)—represented an ideal setting in which to evaluate the TLC model. There are about 1.5 million ALF beds in the US, and demand is expected to grow significantly over the next 20 years as the population with the expanding aged population (Allen, 1999). Such facilities (with some variations compared with their US counterparts) have also proliferated recently in Scandinavia, Europe, Australia, and Japan. Regardless of the geographical location, the ALF population is functionally

Table 1
Comparison of attributes of the TLC model of palliative care with the prevailing approach to palliative care (PC) in the United States (US)

TLC model		Prevailing model
T	PC is *timely*	PC measures are often initiated far too late in the illness trajectory (Christakis, 1999)
	PC is *team-oriented*	PC is viewed by many as care delivered exclusively by palliative medicine specialists and/or hospice programs
L	PC is *longitudinal*	A sporadic approach to PC triggered by periodic chronic illness exacerbations is common (Christakis, 1999)
C	PC is *collaborative*	PC decision making is often not shared among physicians, patients, and loved ones (Hiltunen et al., 1999)
	PC is *comprehensive*	In the prevailing US model, a minority of patients have their PC needs comprehensively assessed, so some important aspects of healing such as preserving dignity (Chochinov, 2002) are often neglected