

The Needs of Families Caring for Relatives Facing the End of Life



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The past decade has produced growing advocacy for improved care for dying individuals, yet little is known about the experiences of family members providing care to those near the end of life. Families are an essential source of support for most individuals facing death, but the end of life confronts families with some of the most emotionally challenging transitions they may ever have to face. How the family members respond can have profound consequences for their grief and interpersonal relationships, as well as a major impact on the dying individual's quality of life and interactions with service providers.

One service model designed to improve care to the dying and their families is hospice, a program of palliative and supportive services providing physical, psychological, social, and spiritual care for dying individuals, their families, and other loved ones. According to the National Hospice and Palliative Care Organization, hospice programs in the U.S. served an estimated 950,000 patients in 2003.

That same year, a research partnership began between Case's Mandel School of Applied Social Sciences and Hospice of the Western Reserve, the third largest non-profit hospice in the United States. **Aloen L. Townsend, Ph.D.**, associate professor of social work, led a multidisciplinary team composed of a psychologist, social workers, and nurses (including a hospice administrator) in a project called the "Family Assessment Collaboration to Enhance End-of-Life Support." The goal was to enhance end-of-life care through improved assessment of family caregivers' needs and resources. To that end, the research team developed an interview tool to assess the social, financial, physical, emotional, and spiritual strains of family caregivers, as well as their internal and external resources. Social workers at Hospice of the Western Reserve used the tool to interview 162 family members providing care to an adult age 65 or older receiving home hospice services.

With interview results in hand, Dr. Townsend's team is currently working with hospice social workers to identify ways in which the assessment tool and study findings can be used to improve end-of-life care. For example, by more quickly identifying family caregivers with high levels of strain and limited resources, service providers can immediately begin to address their problems. "If issues resulting from the stress of caring for dying relatives aren't identified early on, they can lead to bigger problems beyond this final care-giving period," notes Dr. Townsend.



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