RESEARCH SHOWS THAT DISTINCT PATTERNS OF FUNCTIONAL DECLINE IN THE LAST YEAR OF LIFE INDICATE THE NEED FOR DIFFERENT APPROACHES TO PALLIATIVE CARE

New scientific evidence shows consistent patterns of decline of functioning for four different types of dying. These findings suggest that different pathways to death require more flexibility of healthcare and hospice services to meet the needs of critically ill patients whose time until death is unpredictable.

Led by investigator Dr. June Lunney, the research team analyzed data from 4,190 participants 65 years of age and older in the Established Populations for Epidemiologic Studies of the Elderly (EPESE). The article on the study, Patterns of Functional Decline at the End of Life, appears in the May 14 issue of JAMA. The study was funded by the National Institute of Nursing Research and conducted in the Laboratory of Epidemiology, Demography and Biometry of the National Institute on Aging. Both institutes are part of the NIH, Department of Health and Human Services.

In discussing the study, Dr. Lunney stated, “A ‘one size fits all’ model for end-of-life palliative care doesn’t work. People usually assume a terminal illness when thinking about the end of life. Yet only 23% of Americans die of cancer, the most common illness with a distinct terminal phase. Most, particularly those who are chronically ill, are not diagnosed as ‘terminal,’” she added, “yet they may also need palliative care.” Palliative care offered mainly by hospice emphasizes compassionate therapies focused on physical, psychological, social and spiritual needs of the patient, family and caregiver. Currently, those services may not be available, because reimbursement for hospice requires a diagnosis that predicts a life expectancy of six months or less if the terminal illness runs its normal course.

The four pathways to death used in the study and their patterns of decline during a one-year period were:

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• **Sudden death.** There was no functional decline for this group.

• **Expected death** in the short term from cancer. The cancer patients had good functional status early in their final year that degenerated markedly three months prior to death.

• **Entry-reentry deaths,** where people slowly get worse but go home between hospital stays. These patients have a serious chronic illness that presents an ongoing threat of sudden exacerbation and death caused by organ failure.

• **Lingering, expected deaths,** associated with frailty in old age. Patients have no reserve defenses, and either die when an unpredicted medical challenge occurs or decline so gradually that signs of the end cannot be clearly identified. Twenty percent were classified as frail in the study, and they were relatively disabled throughout the year before death. These patients typically resided in nursing homes.

According to Dr. Patricia A. Grady, Director of the NINR, “Clearly end-of-life palliative care needs to have a more extensive focus. This study shows that because of the different ways people die, palliative care should start earlier for those who need it, and should involve health and social services that are adjusted to fit the anticipated patterns of illness and death.”

The data used in the study were based on interviews of participants, who were asked about common activities of daily living, such as bathing, dressing, using the toilet, or walking across a small room. The study found that while dependency increased at older ages, the level of dependence followed similar declines within each age group. Females were more disabled than males, but their slope of decline a year prior to death was the same. There were no differences in functional decline according to level of education or race.