*Original Article*

# Trajectories of the Multidimensional Dying Experience for Terminally Ill Cancer Patients

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## Abstract

**Context.** Studies exploring the trajectories of physical-psychological-social-spiritual dying experiences frequently treat changes in these experiences as consistent across different domains and over time.

**Objective.** This prospective, longitudinal investigation was designed to characterize trajectories of the multidimensional dying experience for cancer patients in their last year of life.

**Methods.** Trajectories of physical-psychological-social-spiritual/existential dimensions and overall quality of life (QOL) were identified among 313 cancer patients using mixed-effects models to test for linear, quadratic, or cubic changes. Changes in each variable were evaluated for clinical significance using minimal important difference.

**Results.** When patients transitioned to their end of life, symptom distress, functional dependence, anxiety, and depressive symptoms slightly increased, followed by a stable status for approximately four to six months, and accelerated dramatically to the first clinically significant changes at three to four months before death. Perceived social support and post-traumatic growth declined gradually to clinically significant changes at one and four months before death, respectively. Perceived sense of burden to others increased steadily in the last year of life, with no clinically significant changes identified. Overall QOL deteriorated gradually in the last year but did not reach a clinically significant change until 2.5 months before death.

**Conclusion.** All dimensions deteriorated in the last year of life but with distinctive physical-psychological-social-spiritual/existential and overall QOL trajectories. Recognizing trajectory patterns and tipping points of accelerating deterioration in each dimension can help clinicians anticipate times of increased distress, initiate timely, effective interventions to relieve patient suffering, and facilitate high-quality end-of-life care tailored to patients' needs and

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**Key Words**
*Trajectory, quality of life, symptom distress, functional dependence, psychological distress, sense of burden to others, post-traumatic growth*

## Introduction

Death because of cancer is inevitable for terminally ill cancer patients. Such patients' dying experience is multidimensional,[1] with well-documented changes: progressive functional decline,[2–8] symptom acceleration,[4,5,7,9,10] and deteriorating quality of life (QOL).[2–4,11–15] As the disease progresses and death approaches, patients experience more stressful circumstances such as multiple losses, an uncertain future, and anticipatory grief. However, relatively few studies investigated trajectories of psychological distress,[5,7,9,10,16] social plight,[2,4,5,17] and spiritual/existential suffering[18] as death approaches.

The few studies exploring trajectories of physical-psychological-social-spiritual dimensions of the dying experience were predominantly based on small samples ($n$ = 23–88)[3,4,11,12,14,15] with a limited time frame (weeks to months)[2,4,11,12,19,20] before death. More importantly, changes in dying experiences are commonly recognized as consistent across different domains[2,14,19] and over time,[2,11,13,19] requiring validation because evidence supports a "terminal drop"[3] in patient well-being. Therefore, the purpose of this prospective, longitudinal study was to characterize trajectories of the physical-psychological-social-spiritual/existential dimensions of the dying experience for a large sample of terminally ill cancer patients in their last year of life.

## Methods

### Study Design and Sample

For this prospective, longitudinal study, a convenience sample of cancer patients was recruited from March 2009 to December 2012 from the general medical inpatient units of a medical center in northwest Taiwan and followed until June 30, 2013. Eligible patients were 1) diagnosed with a terminal-stage disease continuing to progress and judged by their oncologists as unresponsive to current curative cancer treatment, 2) cognitively competent, 3) able to communicate coherently with data collectors, and 4) 20 years or older.

### Procedures

Patients recognized by their primary physicians as terminally ill were referred to data collectors who approached patients, explained the study, and invited them to participate. Patients who agreed to participate were interviewed in person, whereas they were hospitalized approximately every two weeks thereafter (when they returned for outpatient visits or were rehospitalized) until they declined to participate or died. Patients who did not return to hospital were interviewed by telephone. The research ethics committee of the study site approved the research protocol. All subjects provided written informed consent.

### Measures

The physical dimension was represented by physical symptom distress and functional dependence. Physical symptom distress was measured by the 13-item Symptom Distress Scale,[21] including common symptoms of terminally ill cancer patients, that is, pain, dyspnea, nausea/vomiting, anorexia, constipation, and insomnia. Scores range from 13 to 65; higher scores indicate greater distress. Functional dependence was measured by the 10-item Enforced Social Dependency Scale (ESDS).[22] Total ESDS scores range from 10 to 51; higher scores reflect greater dependence on help for personal and social functioning.

Psychological distress included anxiety and depressive symptoms, as measured by the Hospital Anxiety and Depression Scale (HADS).[23] The HADS contains 14 items: seven measure anxiety (HADS-A) and seven measure depression (HADS-D). The HADS assesses no