Death and Dying in Young Adults: Reflections from a Surviving Parent
Andreya Stephenson, School of Social Work

Purpose
Dying is a process that all must face. No one is left untouched by death. Research reveals that preparation and using hope as a coping strategy can help make the process easier on the dying and bereaved. These strategies are more difficult to employ when the dying person is a young adult in what should be the prime of life. The purpose of this project is to gain a better understanding of how young adults with terminal illness prepare for death so that professionals can better serve that population.

Method
To explore how terminally ill young adults best prepare for death, I conducted a critical review of current literature, applied Erik Erikson’s Theory of Psychosocial Development and Elizabeth Kübler-Ross’ stages of grief, and interviewed a social worker with an end-of-life care organization and a mother of a young adult who died of cancer at age 25.

Unique Needs of Young Adults
When hospitalized, young adults often do not fit in. Their needs are not met because they are placed with kids or older adults. However, young adults may also feel uncomfortable with the care situation at home because it is difficult for them to “slip back into childhood dependency in the parental home in the face of life-threatening illness” (Grinyer and Thomas, 2004, p. 128). Young adults are at a stage where they are fighting for independence, but their illness strips them of it. It is a struggle to maintain individuality. It becomes important to garner that feeling from other aspects. Young adults did not anticipate having to face death yet so they have a harder time moving towards acceptance. Many times the caregiver of the patient is a parent or young spouse that is still working. This creates financial and practical burdens. Sometimes young children are involved. Certain provisions need to be made regarding the children before death occurs.

Preparation & Anxiety
When initially confronted with idea of one’s own death, patients respond with many different emotions. Fear, anxiety, depression, avoidance, anger, vulnerability, and dependency are all common reactions. Preparing for death can offset some of the anxiety associated with it. Honest straightforward information from professionals can help with preparation. However, some patients wish to have limited or no information regarding their illness and prognosis. Nevertheless, these patients still must face death.

Hope as a Coping Strategy
Patients feel that while others can have hope for them, maintaining hope is their own responsibility. Patients use two processes to preserve hope when close to death: 1) maintain life and 2) prepare for death. For patients, maintaining life and preparing death are not separate. In fact, these processes often run parallel.

Stages of Psychosocial Development
Erik Erikson asserted that humans go through designated life stages. Each stage has an accompanying psychosocial crisis. The crisis represents the tension that arises between an individual and their social environment. As individuals mature, they are better able to cope with the tension. Young adults face the psychosocial crisis of Intimacy vs. Isolation. When young adults are diagnosed with a terminal illness, their life stages are interrupted. As soon as they are given a prognosis, they are faced with the psychosocial crises of other generations – Generativity vs. Stagnation, and then Ego Integrity vs. Despair as their disease progresses. This causes discord because a time in their lives when they are supposed to be independent, they suddenly have to rely on others again.

Stages of Grief
The stages of grief include, 1) shock and denial, 2) anger, 3) bargaining, 4) depression, 5) acceptance. Ross noted that patients may not follow these stages consecutively. Oftentimes, stages overlap or patients may go back and forth between stages. Some patients may skip certain stages all together, while some get stuck in a stage and find it hard to move on. To accept death, one must grieve their own life. This is called preparatory grief. It helps patients reach the final stage of grief, acceptance.

Social Work Applications
- Remember that each patient is different and has a unique set of values, ideas, and needs regarding death. Customize care plans to meet their needs.
- Help patients make financial, legal, and funeral arrangements, including guardianship and trust funds for children.
- Work with patients to reach acceptance keeping in mind their life stage and coping mechanisms.
- Facilitate open expression of thoughts and feelings concerning death.

Address the concept of closure encouraging families to express love and forgiveness in their own way.
- Respect and fulfill the requests of the patient and family, when reasonable, so as to help the patient maintain hope.
- Be clear, straightforward, and honest about death and disease processes so the patient can understand and prepare for what is happening, if that meets the needs of the patient.

Advisor: Kim Rich-Rice, PhD, LMSW-IPR