

Version 2.0



Abstract

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PI Title:

Project Title: ADVANCE DIRECTIVES IN AIDS: A GROUNDED THEORY STUDY

Abstract: *In this research, a grounded theory (GT) method will be used to explicate the process of how persons with AIDS make their advance directives (ADS) for end-of-life health care. ADS are the federally legislated means of documenting a patient's wishes. Fundamentally, ADS are based on the ethical construct of respect for persons, also referred to as autonomy or self-determination. Preserving autonomy can become problematic because of the discontinuity between the time when one contemplates an AD and when one's wishes are carried out. Invoking ADS indicates that the patient no longer has the capacity for self-determination, and thus others are required to carry out the patient's wishes. Interventions to improve the process of making ADS have been found to be only modestly successful (in terms of increasing the frequency of completed documents in medical records) or, more distressingly, have actually had no effect on care and outcomes at the end of life (as documented by the outcomes of the SUPPORT study intervention). As there seems to be no theoretically based model of understanding this process, research should now be directed at generating such a model. Developing a theory, generated by using a grounded theory method, should allow researchers to formulate interventions that have positive effects on outcomes at the end of life for people with AIDS-people forced to consider a foreshortened life expectancy.*

Thesaurus Terms:

AIDS, decision making, health behavior, health related legal, human mortality health care service utilization

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