

## Suffering and Death Anxiety at the End of Life:

Toward a Comprehensive Model of Patient Adjustment

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Pablo Picasso  
*Ciencia y Caridad*

## Sin and Salvation

...You know, the older I get, what sounds better than anything I hear, is that good old Hymn number 123, *Amazing Grace*. I mean you could be the worst scoundrel in the world, and there have been times when I've been a big time sinner. I'm not proud of it. I wish I hadn't done it. But I've asked God's forgiveness for it. I really stepped off the path that I was brought up to walk. I committed adultery and some other things that don't fit with His teaching. But I believe there's not anything that He won't forgive if you're sincere. And I look forward to death. --Mr. P., 75 year old hospice patient

## Fetzer Foundation Grant



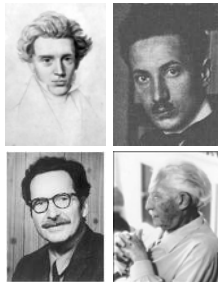
- Collaboration between Methodist Healthcare and University of Memphis
- Project team:
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  - Joe Currier, MA, UM
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## Research Goals

- **Problem statement:** Although over 4,000 studies of psychosocial issues at EOL, most are methodologically weak and poorly integrated
- **Purpose:** Test a comprehensive model of factors shaping attitudes toward death in the face of personal mortality
- **Analysis:** Identify direct and indirect effects of several relevant spiritual and psychological variables theoretically linked to patient well-being, including religiosity, self-esteem and past regrets

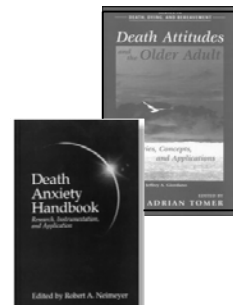
## Comprehensive Model: Philosophical Context

- Kierkegaard: Dread that has nothingness as its object.
- Heidegger: Acceptance of "being-toward-death" grants authenticity
- Becker: terror management through identification with cultural worldview, self-esteem as buffer against awareness of one's mortality
- Erikson: integrity vs. despair as final stage of identity development

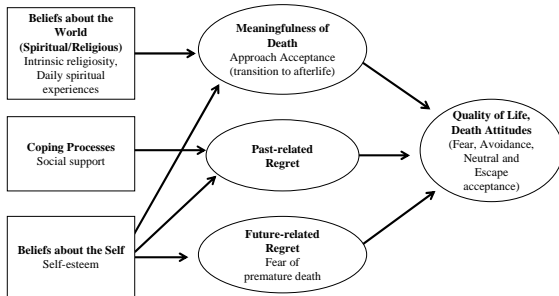


## Death Anxiety at the End of Life

- **Working definition:** negative emotional reaction to anticipation of state of death
- Trigger: Death salience
- 3 direct determinants
  - Past-related regret
  - Future-related regret
  - Meaningfulness of death
- 3 antecedents
  - Beliefs about self
  - Beliefs about world
  - Coping mechanisms



## Theoretical Model



## Primary Data Analysis

- SEM to provide powerful means of estimating direct and indirect effects of the various independent variables on death anxiety and quality of life
- Highest loading items from most psychometrically sound scales in the literature were used as indicators of each construct

## Spirituality (Allport)



- **Intrinsic religiosity:**
  - My religious beliefs are really what lie behind my whole approach to life.
  - I try hard to carry my religion over into all my other dealings in life.
  - It is important for me to spend time in private religious thought and contemplation.

## Spirituality (Underwood)



- **Daily Spiritual Experiences Scale**
- **Theistic factor**
  - I feel God's presence
  - I feel guided by God in the midst of daily activities
- **Transcendence factor**
  - I feel deep inner peace or harmony
  - I am spiritually touched by the beauty of creation

## Social Support (WHOQOL Group)

- Do you get the kind of support you need from others?
- How satisfied are you with your personal relationships?
- How satisfied are you with your friends?



## Self Esteem (Rosenberg)

- **Rosenberg Self Esteem Scale:**
  - I feel that I am a person of worth.
  - On the whole I am satisfied with myself.
  - I feel that I have a number of good qualities.



## Meaningfulness of Death (Wong)



### DAP Approach Acceptance:

- Death brings a promise of a new and glorious life
- I see death as a passage to an eternal and blessed place
- Death is a union with God and eternal bliss.

## Past Regrets (Tomer)

### ■ Past Related Regret Scale:

- I wish I could avoid many of the mistakes I made earlier in life.
- I regret that I wasted too much time on things that are unimportant.
- If I could turn back the clock, there are many things that I would do differently.



## Future Regrets (Hoelter, Tomer)

### ■ Multidimensional Fear of Death Scale: Fear of Premature Death

- I have a fear of not accomplishing my goals in life before dying
- I am afraid that I will not have time to experience everything I want to
- I am afraid that I will never see my loved ones grow up

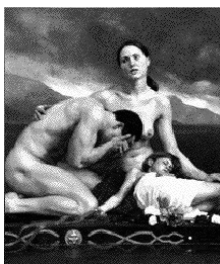


## Quality of Life (WHOQOL Group)



- How much do you experience positive feelings in your life?
- How well are you able to concentrate?
- How much do any feelings of sadness or depression interfere with your everyday functioning?

## Death Attitudes (Wong)



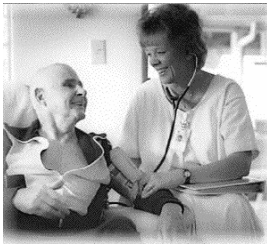
- Death Fear
  - I have an intense fear of death.
- Death Avoidance
  - I try not to think about death.
- Escape Acceptance
  - I see death as an escape from the burden of life.
- Neutral Acceptance
  - Death is simply part of the process of life.

## Procedure



- Initial contact by hospice nurse or chaplain, followed by scheduling by social worker for consenting patients
- Subsequent 1 hour interview by hospice social worker or university psychology staff
- Structured questions followed by open ended interview

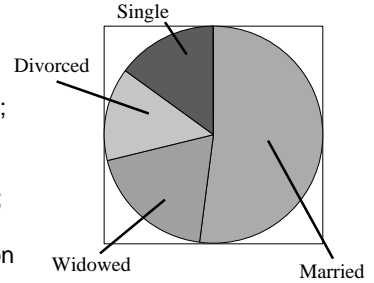
### Participants



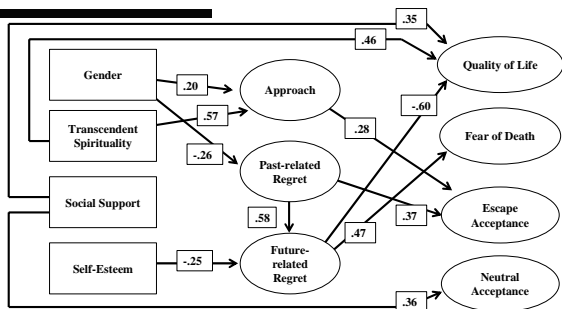
- 153 patients in Methodist Hospice
- Hospice participation for > 3 weeks
- Life expectancy > 3 months
- Ability to consent
- Participation of family ideal, but not required

### Patient Characteristics

- 46% men; 54% women
- 65% Caucasian; 35% African American
- 71% Protestant; 7% Catholic; 22% no affiliation
- Mean age: 75; Range 39-99

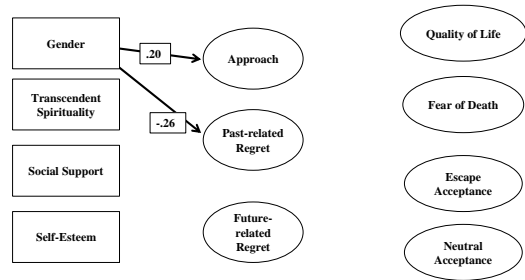


### Estimated Model

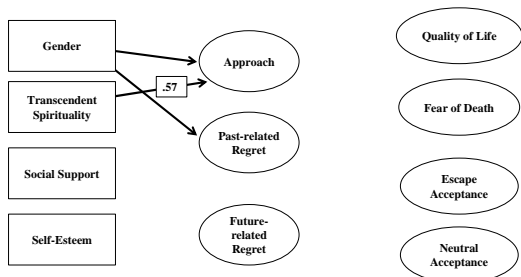


Chi-Sq. = 799.45, df = 614, RMSEA=.046, NNFI=.93 CFI=.94

### Estimated Model



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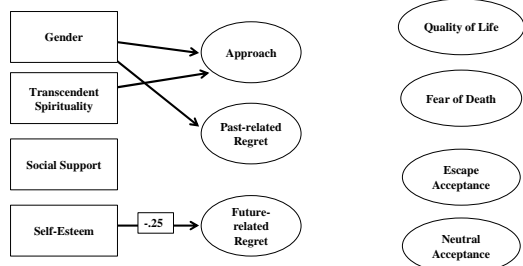


### Varieties of Religious Experience

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- I give myself a high score on that, cause if – even though I may not get down on my knees and pray and go to a quiet place, my mind – my mind is kind of there. Thinking on spiritual things. God things.
- It's not really [very helpful]. You have [religion] rammed down your throat for the first – from the [age of] ten, had it so much rammed down your throat that it's enough for the rest of your life.

### Estimated Model

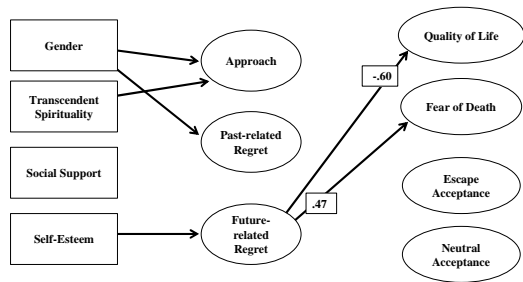


### Self Esteem

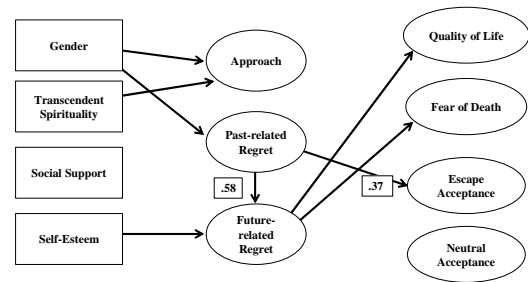
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- I'm – in most cases, I'm at peace with myself. Except I'm not entirely sure that I've been good enough.
- ...because I'm always doubtful that I have achieved [that much] – that my confession has achieved peace of mind.

### Estimated Model



### Estimated Model

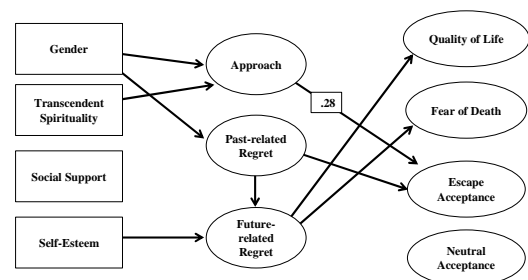


### Past Regrets

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- Well, you know, we always feel inadequate, I know I do. No matter what you've done. You – you think you could have done more.
- I used to drink too much. And of course I was in the Army. Four – four and a half years. And you know, I did a lot of bad things there. And – well, I've done a lot of regretful things. I'm so thankful that I finally saw the light.

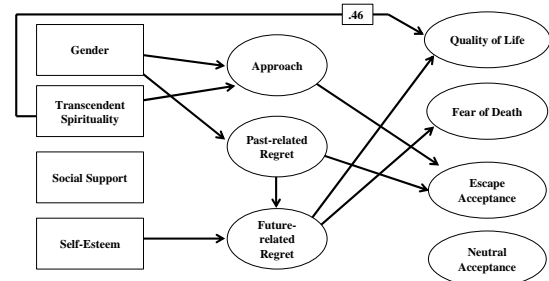
### Estimated Model



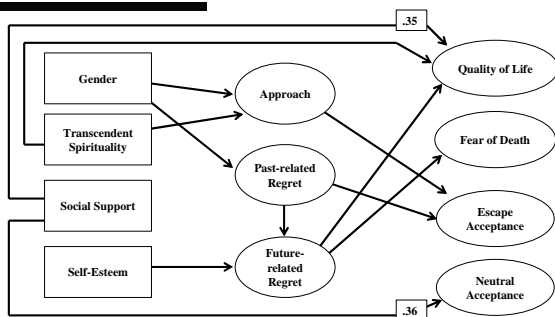
## Escape Acceptance

- Well, yeah, I see the wonderful hope and future of being resurrected--sickness, sorrow, pain and death are eradicated, [when that happens].

## Estimated Model



## Estimated Model

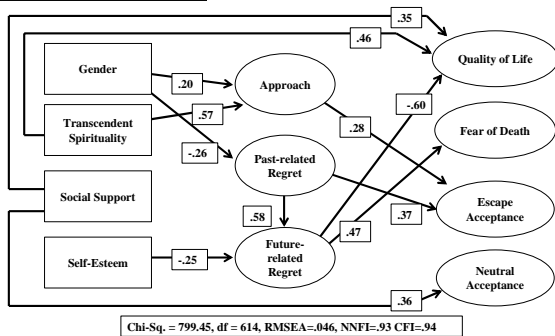


## Social Support



- I lost part of my manhood. But my daughter and my son and my wife take me to [the bathroom]. And then my church members come by and pray for me. My [elders] come pray for me. It makes me feel good.

## Estimated Model



## Research Implications

- Use multivariate models to clarify the determinants of death attitudes, integrate literature
- Treat spirituality as a complex variable
- Assess multiple dimensions of death attitudes, not merely death anxiety
- Evaluate regret, in both its past and future aspects
- Build bridges between worlds of science and practice

## Clinical Implications

QuickTime/and a  
TIFF (uncompressed) decompressor  
are needed to see this picture.

- Assess relevant determinants of QOL, not simply its presence or absence.
  - *Include life regrets; spiritual resources and issues; social support; self-esteem and death fear and acceptance*
- Join patient's quest for spiritual or existential meaning and self-determined life closure
  - *Meaning oriented therapy at EOL, rituals of connection*
- Affirm life integrity, promote (self-) forgiveness
  - *Dignity-enhancing therapy, life review, ethical will, narrative and biographical procedures*

## Open Questions

- Past related regret exercised only an indirect effect (through future-related regret) on fear of death.
- Future related regret was measured here as fear of premature death. Future related regret defined as lack of ability to achieve goals was not found to affect fear of death
- We need to understand better approach acceptance that was found to be impacted by cosmic/gero-transcendence and gender.
- There is a need to develop better tools to measure meaningfulness of death that are not based exclusively on acceptance of an after-life.

## Limitations

- Relatively small sample for SEM
- Variables with excessive positive or negative skewness and kurtosis (nonnormality)
- Use of simple items as indicators