Families Confronting the End-of-Life: Promoting Peaceful Acceptance of Death

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Overview

Conceptual Model: Predictors, correlates & outcomes of peaceful acceptance at the end-of-life (EOL)

Defining terms:
1. Acceptance – cognitive; emotional
2. Grief – normal; Prolonged Grief Disorder
3. States of Grief – changes over time

Preliminary Test of PEACE Model

Promoting acceptance in family members
Promoting End-of-Life Acceptance in the Cancer Experience (PEACE):

The PEACE Model

preliminary results from our Coping with Cancer data (MH63892; CA10637)
The PEACE Model

Medical Environment
- Academic vs. community
- Therapeutic alliance
- EOL communication

Family
- Acceptance
- Dependency
- # Dependents
- Ethnicity

Patient
- Psychological Status
  - spirituality; coping style; cognitive status; integrity-despair
- Medical Status

Cognitive Acceptance

Emotional Acceptance

EOL Outcomes
- Quality of life
- EOL Care
- Goal attainment

Family Bereavement Adjustment

Prigerson 2007
The PEACE Model

Medical Environment
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Prigerson 2007
End of Life Acceptance

- **Cognitive acceptance**: awareness that patient is terminally ill (< 6 mos life-expectancy)

- **Emotional acceptance (peacefulness)**: the ability to be at peace with, rather than struggle against, the terminal prognosis
Peace, Equanimity and Acceptance in the Cancer Experience (PEACE) Scale (Cronbach’s α = .86)

1. To what extent are you able to accept your diagnosis of cancer?
2. To what extent would you say you have a sense of inner peace and harmony?
3. To what extent do you feel that you have made peace with your illness?
4. Do you feel well-loved now?
5. To what extent do you feel a sense of inner calm and tranquility?
6. To what extent do changes in your physical appearance upset you?
7. To what extent does worry about your illness make it difficult for you to live from day to day?
8. To what extent do you feel that it is unfair for you to get cancer now?
9. To what extent do you feel that your life, as you know it, is now over?
10. To what extent do you feel angry because of your illness?
11. To what extent do you think your illness has beaten you down?
12. To what extent do you feel ashamed of, or embarrassed by your current condition?

Mack et al. Cancer 2008
# Cognitive & Emotional Acceptance

<table>
<thead>
<tr>
<th></th>
<th>Cognitive Acceptance</th>
<th>Cognitive Acceptance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>(32%)</td>
<td>(68%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional Acceptance:</th>
<th>94</th>
<th>228</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel peaceful</td>
<td>19.75% of total</td>
<td>47.9% of total</td>
</tr>
<tr>
<td></td>
<td><strong>61% of “aware” are at peace</strong></td>
<td><strong>71% of “unaware” are at peace</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional Acceptance:</th>
<th>60</th>
<th>94</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t feel peaceful</td>
<td>12.6% of total</td>
<td>19.75% of total</td>
</tr>
</tbody>
</table>

~Ray et al. *J Palliative Medicine, 2006*
## Cognitive & Emotional Acceptance (Peace Item)

<table>
<thead>
<tr>
<th>Patient Mental Health &amp; Spirituality</th>
<th>Cognitive Acceptance (p-value)</th>
<th>Emotional Acceptance (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MDD dx (OR)</td>
<td>1.28 (0.50)</td>
<td>0.88 (0.03)</td>
</tr>
<tr>
<td>GAD dx (OR)</td>
<td>0.46 (0.32)</td>
<td>0.62 (0.29)</td>
</tr>
<tr>
<td>Terrified (β)</td>
<td>0.13 (0.003)</td>
<td>-0.65 (&lt;0.0001)</td>
</tr>
<tr>
<td>Sad (β)</td>
<td>0.11 (0.02)</td>
<td>-0.55 (&lt;0.0001)</td>
</tr>
<tr>
<td>Life as gift (β)</td>
<td>-0.10 (0.03)</td>
<td>0.48 (&lt;0.0001)</td>
</tr>
<tr>
<td>Death anxiety (β)</td>
<td>0.05 (0.66)</td>
<td>--</td>
</tr>
<tr>
<td>Spirituality (β)</td>
<td>-0.11 (0.06)</td>
<td>0.43 (0.02)</td>
</tr>
</tbody>
</table>
Grief & Acceptance: Opposite Sides of the Same Coin

(Prigerson & Maciejewski, Br J Psychiatry, 2008)

- Emotional acceptance of loss = letting go of wanting; ceasing to struggle against approaching death

- Grief = wanting what you can’t have
As family members process the loss, an inability to resolve grief creates instability in the family system...

How does the course of normal grief differ from that of prolonged grief?

- **Normal grief** resolves over time from loss (80-90%)

- Untreated, **Prolonged Grief Disorder** symptoms persist (10-20%)
Maciejewski, Zhang, Block, Prigerson, *JAMA* 2007
Maciejewski, Zhang, Block, Prigerson, *JAMA* 2007
Criteria for **Prolonged Grief Disorder** Proposed for DSM-V and ICD-11

**Criterion A.** Loss of a significant other

**Criterion B.** Separation Distress: yearning (e.g., craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired but unfulfilled reunion with the deceased) daily or to a disabling degree

**Criterion C.** Cognitive, Emotional, and Behavioral Symptoms: The bereaved person must have ≥5 below symptoms experienced daily or to a disabling degree.

1. Confusion about one’s role in life or diminished sense of self (i.e., feeling that a part of oneself has died)
2. Difficulty accepting the loss
3. Avoidance of reminders of the reality of the loss
4. Inability to trust others since the loss
5. Bitterness or anger related to the loss
6. Difficulty moving on with life (e.g., making new friends, pursuing interests)
7. Numbness (absence of emotion) since the loss
8. Feeling that life is unfulfilling, empty, and meaningless since the loss
9. Feeling stunned, dazed or shocked by the loss

**Criterion D.** Timing: Diagnosis should not be made until at least 6 months have elapsed since the death

**Criterion E.** Impairment: The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)
Grief Resolution for those meeting criteria for PGD

Grief Score over Time Stratified by Grief Diagnosis Criteria
Therapeutic Alliance:

The Human Connection Scale (Cronbach’s $\alpha = 0.90$)

- 16 items measuring: mutual understanding; caring; trust
  - How much do you feel your doctor cares about you?
  - How much do you trust your doctor?
  - How open-minded do you feel your doctor is?

- Emotional acceptance ($r = 0.31$, $p < 0.0001$)

- Cognitive acceptance n.s.

- Less time in ICU in last week ($p = 0.002$)
EOL Discussions & Acceptance

- EOL discussions associated with patient’s cognitive acceptance of terminal illness?
  - AOR=2.24, [95% CI 1.45-3.44]
  - (1/3 cog accept; 2/3 don’t – so much room for improvement)

- EOL discussions not shown to “take away hope” or adversely affect emotional acceptance/peace?
  - EOL discussions (months before death) were NOT associated with psychological harm
## Dependent children and patient mental health

<table>
<thead>
<tr>
<th>Mental Health Disorder</th>
<th>with dep child</th>
<th>without dep child</th>
<th>adjusted p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generalized Anxiety Disorder (GAD)</td>
<td>4%</td>
<td>2%</td>
<td>0.20</td>
</tr>
<tr>
<td>Major Depressive Disorder (MDD)</td>
<td>11%</td>
<td>7%</td>
<td>0.07</td>
</tr>
<tr>
<td>Panic Disorder</td>
<td>9%</td>
<td>2%</td>
<td>0.0004</td>
</tr>
<tr>
<td>Worried</td>
<td>3.7 (3.3)</td>
<td>2.9 (3.1)</td>
<td>0.006</td>
</tr>
<tr>
<td>Peaceful</td>
<td>60%</td>
<td>70%</td>
<td>0.01</td>
</tr>
</tbody>
</table>
## Dependent children and caregiver mental health

<table>
<thead>
<tr>
<th></th>
<th>Caregivers with dep child</th>
<th>Caregivers without dep child</th>
<th>Adjusted p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>MDD</td>
<td>10%</td>
<td>3%</td>
<td>0.01</td>
</tr>
<tr>
<td>GAD</td>
<td>11%</td>
<td>3%</td>
<td>0.02</td>
</tr>
<tr>
<td>Panic Disorder</td>
<td>10%</td>
<td>3%</td>
<td>0.05</td>
</tr>
</tbody>
</table>
## Location of Patient Death

<table>
<thead>
<tr>
<th></th>
<th>with dep child</th>
<th>without dep child</th>
<th>Adjusted p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>54%</td>
<td>54%</td>
<td>0.75</td>
</tr>
<tr>
<td>Hospital</td>
<td>26%</td>
<td>23%</td>
<td>0.14</td>
</tr>
<tr>
<td>ICU</td>
<td>12%</td>
<td>6%</td>
<td>0.74</td>
</tr>
<tr>
<td>Inpatient Hospice</td>
<td>1%</td>
<td>14%</td>
<td>0.02</td>
</tr>
</tbody>
</table>
Quality of Death

- Worse quality of death/last week of life: 5.51 ($\sigma=3.21$) vs. 6.54 ($\sigma=2.87$) $p$-value: 0.04
Caregiver’s Relationship to Dying Patient and Risk for PGD versus MDD

<table>
<thead>
<tr>
<th>Marital Quality</th>
<th>PGD</th>
<th>MDD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r</td>
<td>p</td>
</tr>
<tr>
<td>feelings of security</td>
<td>.47</td>
<td>.005</td>
</tr>
<tr>
<td>dependency on partner</td>
<td>.43</td>
<td>.001</td>
</tr>
<tr>
<td>confiding in partner</td>
<td>.43</td>
<td>.001</td>
</tr>
<tr>
<td>active emotional support</td>
<td>.60</td>
<td>.0001</td>
</tr>
<tr>
<td>combo security, confiding, support</td>
<td>.69</td>
<td>.0001</td>
</tr>
<tr>
<td>Overall Quality of Marriage</td>
<td>.39</td>
<td>.01</td>
</tr>
</tbody>
</table>

The risk for PGD is positively associated with feelings of security, dependency on partner, confiding in partner, and overall quality of marriage. The risk for MDD is positively associated with dependency on partner and overall quality of marriage.
Effects of Cognitive & Emotional Acceptance on EOL Care

- **Cognitive Acceptance** resulted in 2.12 times greater likelihood of using **inpatient hospice**, **goal attainment**, and less time in the **ICU** at EOL (p=0.05)

- **Emotional Acceptance** resulted in significantly less use of aggressive measures (**feeding tubes**) and higher rates of **goal attainment** in the last week of life (p=0.05)
Cognitive & Emotional Acceptance, “Peaceful Awareness”, associated with...

- Lower rates of psych distress
- Higher rates of ACP
- Better quality of life in last week
- Bereaved caregivers better physical and mental health 6 months post-loss
Conclusions

How to promote PEACE?

Medical Environment
- EOL communication (curability, prognosis, goals of care)
- Therapeutic alliance

Family
- Promote independence and acceptance
- Ensure safety and security of dependents

Patient
- Ensure symptom management (pain)
- Spirituality
- Resolve grief
  - spiritual support (pastoral care visits)
  - Social and personal support in confronting death (grief therapy)
Future Research: The PEACE Study

- Prospective, longitudinal cohort study of oncology provider, patient, caregivers
- Documentation (validated with audio-taping) to assess the EOL discussion more accurately
- Assess acceptance pre-post EOL discussions and over time to determine effect of EOL discussions on acceptance, change in acceptance, and outcomes of acceptance for patients and their family members