The meaning of Hope in Chinese terminally ill patients

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Hope in the end-of-life context

- Possible and important (Herth 1990, Hall 1990)
- Therapeutic (Felder, 2004, Chochinov et al., 1998)
- Dynamic and transforming (Dufault & Martocchio 1985, Benzein et al. 2001)
- Part of spirituality, closely related to meaning and peace (Vachon et al. 2009)
Research niche

- Existing research are predominately Western cultural belief system
- May not adequately reflect the experience of hope for people from non-European cultures

Aim

To understand the meaning of hope and some cultural consideration of hope as experienced by Chinese terminally ill patients in Hong Kong
Method

- Design: Qualitative
- Participants: 17 patients received palliative care services from a local hospital
- Data collection: Face-to-face, individual, semi-structured interview
- Data analysis: Content analysis

Sample

<table>
<thead>
<tr>
<th>Sex (n)</th>
<th>F</th>
<th>M</th>
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<tr>
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<td>8</td>
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<thead>
<tr>
<th>Marital status (n)</th>
<th>Single</th>
<th>Married</th>
<th>Widowed</th>
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<td>2</td>
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<tr>
<th>Age</th>
<th>Range</th>
<th>Median</th>
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<td>49 - 84</td>
<td>71</td>
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Findings

Concept of Hope
- General Hope
- Disease – Specific Hope

Cultural Consideration of Hope
- Time orientation
- Truth–telling
- Control

General Hope

- **Common things people want to achieve in life**
  Fulfilling family responsibility

- **Elderly** expressed that they are not the one in control but rather “let nature takes its course” and *contented*, which transcends illness and death

- **Younger** group do not fulfill this hope, this *unfinished business* may induce distress if not resolved
Disease-specific Hope

- **Hope for recovery**
  did not imply distress that need intervention medicated by professional support and social support

- **Symptom control**
  less physical suffering

- **Others**
  things patients wanted to do that were limited by their physical ability and longevity

Time orientation

- **Present-focused in general**
  did not make plans, nor concerned about life after death

- **Exceptional ones looked into the future**
  manifested as worries about suffering of the self and well-being of significant others

- **Two broad focuses of life**
  focusing on living vs. focusing on the disease and death

- **Those who focused on living**
  more hopeful than those who focused on the disease and death
Truth-telling

- Preferred to know incurable status in general
  prepared for death both practically and psychologically

- Exceptional ones preferred not to know
  blamed the doctor for telling the truth in no uncertain terms

- All participants knew the truth and did not deny
  wanted to know their condition, but in a gentle and supportive manner

Beliefs about control

- Death was part of life
- Did not express a desire to control it
- Two forms of letting go of control

| Gave away control actively | Able to retain control
Believed the one in control would do them good
Able to live in peace & look for something good to happen |
|---------------------------|-------------------------------------------------------------|
| Gave up control passively  | Experienced a loss of control helplessly
Attributed bad things happened to the one in control
Lived in helplessness and did not expect good things to happen |
Discussion

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<tr>
<th></th>
<th>General Hope</th>
<th>Disease Specific Hope</th>
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<tbody>
<tr>
<td><strong>Western Study</strong></td>
<td>Age related: Elderly: sense of fulfillment Young: unfinished business</td>
<td>Recovery Symptom control Others</td>
</tr>
<tr>
<td><strong>This Study</strong></td>
<td>Similar</td>
<td>Similar</td>
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Discussion

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<tr>
<th></th>
<th>Time orientation</th>
<th>Truth-telling</th>
<th>Control</th>
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<tbody>
<tr>
<td><strong>Euro-American</strong></td>
<td>Future-focused</td>
<td>Full disclosure</td>
<td>Desire for &amp; believe in personal control</td>
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<td>(Ersek, 2006)</td>
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<tr>
<td><strong>Chinese</strong></td>
<td>Present-focused</td>
<td>Disclose with support</td>
<td>Let go of personal control</td>
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<td>(This study)</td>
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**Limitations**

- **Convenience sampling**
- **Participants** were vulnerable, we were unable to receive comments on our findings from them that will otherwise enhance trustworthiness.
- Sample was predominantly older in age and made up of **in-patients**. Participants with diverse backgrounds are needed to verify our findings.
- The data are **cross-sectional**. Longitudinal change of hope, if any, across the illness trajectory cannot be observed.

**Summary**

- Themes of hope in Chinese are in line with those found in Western literature.
- Impact of time orientation, truth-telling, and beliefs about control, on hope in the Chinese context depends on how control is let go, the focus of the present life, and how truth is told.
Summary

- If the process of letting go of control is an active one, the focus of the present life is on living instead of dying, and the truth is told gently and supportively, Chinese patients are able to remain hopeful.

Implications

- While hope is related to the well-being of patients in the end-of-life context, successful palliative care partly depends on an understanding of the importance of hope and cultural sensitivity to the meanings behind it from the perspective of patients with terminal illness.
Implications

- It is possible for healthcare professionals to foster or impede hope in terminally ill patients as well as their families by what they do and say.

- Specific hope interventions are suggested to meet the needs of specific group of terminally ill patients.

References


Thank you