Measuring self-efficacy for caregiving of caregivers of patients with palliative care need: Validation of the Caregiver Inventory

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Funded by Health and Medical Research Fund (#1314124)
Palliative Care

- WHO (under Cancer category): An approach that improves QoL of patients and their family facing the problem associated with life-threatening illness, ...’
  (http://www.who.int/cancer/palliative/definition/en/)

- WHO (2011): A more appropriate concept – Offered from the time of diagnosis, alongside potentially curative treatment, to disease progression and the end of life. (Hall et al., 2011)
The Challenge

• A worldwide public health issue (WHO, 2002)
  – Ageing populations
  – Change of pattern of diseases: chronic diseases
  – Complex needs of older people

• Hong Kong
  – > 1.2 million adults age ≥ 65 by 2018 (Planning Dept, 2009)
  – Topic 5 causes of death in 2013
    • Cancer, Pneumonia, Heart, Cerebrovascular, Chronic lower respiratory
    • Similar distressing symptoms regardless diagnosis (Lo & Woo, 2000)

Similar Palliative care needs
Informal Caregivers

- Legal: ‘Informal caregiver is a family member or a natural person who aids and supervises the daily cares of a disabled person’.
- Caregiving of patients is a very stressful event
- Expected to be more serious for patients with palliative care needs
  - Chronic nature of the diseases
  - Don’t know when can stop

(Zarit, 2002; Carreetero et al., 2009)
Caregiving: Two sides of a coin

– Negative aspects
  • Caregiver burden: decrease in both physical and psychological health associated with caregiving
  • In turn, can lead to undesirable consequences to the patient

– Positive aspects
  • Fulfilment, become a stronger person, better communication skills (among ‘positive caregiver’)
  • In turn, may lead to a better QoL of the patient by providing better care and support

(Carretero et al., 2009; Semiatin et al., 2012)
Self-efficacy for Caregiving

• Social Cognitive Theory: Self-efficacy
  – Perceived confidence in one’s ability to perform a behavior in a given situation
  – amenable to change
  – Postulate: SE for caregiving
    – more successful in caregiving
      • then lesser burden and more positive aspects

(Bandura, 2001)
SE for Caregiving

• Supporting evidence
  – Associated with increased positive aspects of caregiving and lesser burden
  – Mediating factor (dementia):
    • Social support and QoL
    • Social support and depression

  (Cheng et al., 2012; Uei et al., 2013; Au et al., 2009; Zhang et al., 2014)

• Interventions for caregivers of dementia

  (Savundranaygam & Brintnall-Peterson, 2010)
Tools measuring SE for Caregiving

• Previous studies: Either disease-specific or non-specific for caregiving

• Two HK studies on dementia patients: (Revised Scale for Caregiving Self-Efficacy)
  – Disease-specific: patients with palliative care needs?
  – Negative aspects of caregiving. Positive?

(Cheng et al., 2012; Au et al., 2009)
The Caregiver Inventory (CGI)

- A valid instrument with a better coverage of caregiving, in particular targeting caregivers of patients with palliative care need is lacking in Hong Kong

- CGI for patients with palliative care needs:
  - 21 items on 4 domains:
    - Managing medical information (3 items)
    - Caring for the care recipient (7 items)
    - Caring for oneself (caregiver) (5 items)
    - Managing difficult interaction and emotions (6 items)

(Merluzzi et al., 2011)
Current Study

Aims:
• Translate and adapt CGI into Chinese (C-CGI)
• Examine psychometric properties of C-CGI
  – Reliability
  – Construct Validity
Subjects

• Dyads of patient-caregiver
  • Patient:
    Inclusion:
    • age 18 or above
    • Classified as in need for palliative care with NECPAL CCOMS-ICO© Tool (Version 1.0)
    • Communicable
    • Primarily living at home
    Exclusion:
    • Severe cognitively impaired (MMSE ≤10)
  • Caregiver
    • Age 18 or above
    • Primary caregiver as suggested by the patient
    • Taking care of the patient over the past three months
    • Communicable
Design and Setting

Study Design: A cross-sectional survey

Study sites:
- Shatin Hospital: Palliative care ward
- Grantham Hospital: Geriatric medical ward
- Alice Ho Miu Ling Hospital: Emergency ward
Procedure

RA approach Patients in the Ward

Screening

Eligible patients recommend caregivers

Data collection

RA administer patient questionnaire

Caregiver arrive during visiting hours

Data collection

RA administer caregiver questionnaire
# Main Measures

<table>
<thead>
<tr>
<th>Construct</th>
<th>Instrument</th>
<th>Score</th>
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</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
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<tr>
<td>Self-efficacy for caregiving</td>
<td>Caregiver Inventory (21 items): 4 dimensions</td>
<td>Higher score, higher self-efficacy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global Burden in caregiving</td>
<td>Caregivers Strain Index (C-CSI)</td>
<td>Higher score, higher burden</td>
</tr>
<tr>
<td>Perceived social support</td>
<td>Multi-dimensional scale of perceived social support (C-MSPSS)</td>
<td>Higher score, higher support</td>
</tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td>Modified Barthel Index</td>
<td>Higher score, more independency</td>
</tr>
<tr>
<td>Quality of life</td>
<td>McGill Quality of Life Questionnaire</td>
<td>Higher score, higher QoL</td>
</tr>
</tbody>
</table>
Result

Subject recruitment: 1 Sept 2016 – 3 Jan 2017

746 patients screened

240 patients eligible

167 (69.6%) patients consented

157 (94.0%) caregivers approached

136 (86.6%) caregivers consented
<table>
<thead>
<tr>
<th>Sample Characteristics of Patients</th>
<th>Mean±SD / Freq (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>76.8±10.5</td>
</tr>
<tr>
<td>Male</td>
<td>56 (41.2%)</td>
</tr>
<tr>
<td>Married</td>
<td>53 (38.7%)</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>53 (39.0%)</td>
</tr>
<tr>
<td>Primary education</td>
<td>49 (36.0%)</td>
</tr>
<tr>
<td>Secondary education or above</td>
<td>34 (25.0%)</td>
</tr>
<tr>
<td>Perceived poor financial status</td>
<td>29 (16.2%)</td>
</tr>
</tbody>
</table>
## Sample Characteristics of Caregivers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean±SD / Freq (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>57.3±14.5</td>
</tr>
<tr>
<td>Male</td>
<td>48 (35.0%)</td>
</tr>
<tr>
<td>Married</td>
<td>116 (84.7%)</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>13 (20.6%)</td>
</tr>
<tr>
<td>Primary education</td>
<td>33 (24.3%)</td>
</tr>
<tr>
<td>Secondary education or above</td>
<td>90 (66.2%)</td>
</tr>
<tr>
<td><strong>Relationship with the patient</strong></td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>77 (56.2%)</td>
</tr>
<tr>
<td>Spouse</td>
<td>50 (36.8%)</td>
</tr>
<tr>
<td>Others</td>
<td>9 (6.6%)</td>
</tr>
<tr>
<td>Perceived poor financial status</td>
<td>44 (38.2%)</td>
</tr>
<tr>
<td>Perceived poor health status</td>
<td>23 (16.9%)</td>
</tr>
<tr>
<td>Have maid to help</td>
<td>98 (71.5%)</td>
</tr>
<tr>
<td>Patient received long-term care service</td>
<td>20 (14.7%)</td>
</tr>
</tbody>
</table>
**Responsiveness**

- One subject missed Items 19 and 20
- Item 21 (maintain a close relationship): 35.3% reported ‘10’

**Reliability (n = 135)**

<table>
<thead>
<tr>
<th>Subscales in CGI (range: 1-9)</th>
<th>Mean±SD</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing Medical Information</td>
<td>6.4±1.4</td>
<td>0.748</td>
</tr>
<tr>
<td>Caring for the Care Recipient</td>
<td>6.7±1.3</td>
<td>0.871</td>
</tr>
<tr>
<td>Caring for Oneself</td>
<td>6.2±1.4</td>
<td>0.805</td>
</tr>
<tr>
<td>Managing Difficult interactions and emotions</td>
<td>6.3±1.3</td>
<td>0.824</td>
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</tbody>
</table>
## Construct Validity: Caregiver data

<table>
<thead>
<tr>
<th>Subscales in CGI</th>
<th>Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Social Support</td>
</tr>
<tr>
<td></td>
<td>(+ve)</td>
</tr>
<tr>
<td>Managing Medical Information</td>
<td>0.362**</td>
</tr>
<tr>
<td>Caring for the Care Recipient</td>
<td>0.251**</td>
</tr>
<tr>
<td>Caring for Oneself</td>
<td>0.390**</td>
</tr>
<tr>
<td>Managing Difficult interactions and emotions</td>
<td>0.277**</td>
</tr>
</tbody>
</table>

**p < 0.01
## Construct Validity: Patient data

<table>
<thead>
<tr>
<th>Subscales in CGI</th>
<th>Correlation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MBI (+ve)</td>
<td>QoL (+ve)</td>
</tr>
<tr>
<td>Managing Medical Information</td>
<td>0.159</td>
<td>0.091</td>
</tr>
<tr>
<td>Caring for the Care Recipient</td>
<td>0.175*</td>
<td>0.217*</td>
</tr>
<tr>
<td>Caring for Oneself</td>
<td>0.249**</td>
<td>0.188*</td>
</tr>
<tr>
<td>Managing Difficult interactions and emotions</td>
<td>0.287**</td>
<td>0.182*</td>
</tr>
</tbody>
</table>

* p < 0.05, ** p < 0.01
Discussion

**Caring for Oneself** related the strongest with
- Caregiving burden
- Perceived social support
- Patient’s physical functioning

**Caring for the Care Recipient** related the strongest with
- Patient’s QoL
Discussion

Data is in progress: 230 dyads

• Preliminary support to the psychometric properties of C-CGI

Further Analysis

• Factorial validity: Exploratory and Confirmatory Factor Analysis
• Test-Retest Reliability
• Effects of having a maid to help in caregiving