









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

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## **Palliative Care**

- WHO (under Cancer category): An approach that improves QoL of patients and their family facing the problem associated with lifethreatening 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  $\geq 65$  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









<sup>(</sup>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

(Carreetero 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

(Bandura, 2001)

- Postulate: SE for caregiving
  - more successful in caregiving
  - then lesser burden and more positive aspects









# 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 <u>a better coverage of caregiving</u>, 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<sup>©</sup> Tool (Version 1.0)
- Communicable
- Primarily living at home

Exclusion:

- Severe cognitively impaired (MMSE ≤10)
- Caregiver

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- Age 18 or above
- Primary caregiver as suggested by the patient
- Taking care of the patient over the past three months
- Communicable

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## **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

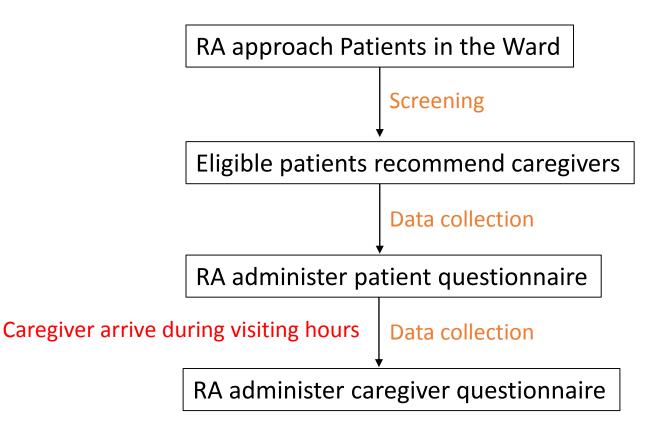








### Procedure











## **Main Measures**

Construct	Instrument	Score
Caregiver		
Self-efficacy for caregiving	Caregiver Inventory (21 items): 4 dimensions	Higher score, higher self- efficacy
Global Burden in caregiving	Caregivers Strain Index (C- CSI)	Higher score, higher burden
Perceived social support	Multi-dmensional scale of perceived social support (C-MSPSS)	Higher score, higher support
Patient		
Physical functioning	Modfied Barthel Index	Higher score, more independency
Quality of life	McGill Quality of Life Questionnaire	Higher score, higher QoL



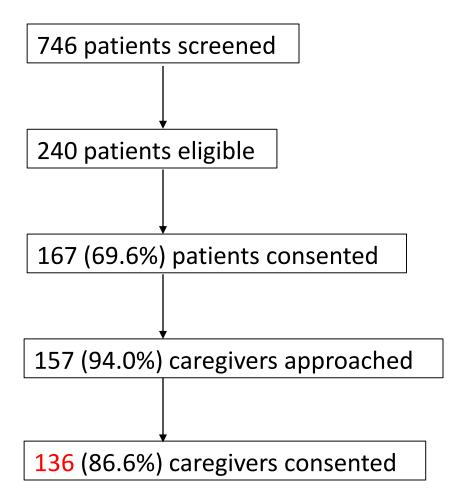




25

### Result

#### Subject recruitment: 1 Sept 2016 – 3 Jan 2017







#### **Sample Characteristics of Patients**

	Mean±SD / Freq (%)
Age	76.8±10.5
Male	56 (41.2%)
Married	53 (38.7%)
Educational level	
No formal education	53 (39.0%)
Primary education	49 (36.0%)
Secondary education or above	34 (25.0%)
Perceived poor financial status	29 (16.2%)







#### **Sample Characteristics of Caregivers**

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



#### Responsiveness

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

#### Reliability (n = 135)

Subscales in CGI (range: 1-9)	<b>Mean±SD</b>	α	
Managing Medical Information	6.4±1.4	0.748	
Caring for the Care Recipient	6.7±1.3	0.871	
Caring for Oneself	6.2±1.4	0.805	
Managing Difficult interactions and	6.3±1.3	0.824	
emotions			





## **Construct Validity: Caregiver data**

	Correlation	
Subscales in CGI	Social Support ( <mark>+ve</mark> )	Caregiving burden (-ve)
Managing Medical Information	0.362**	-0.081
Caring for the Care Recipient	0.251**	-0.273**
Caring for Oneself	0.390**	-0.341**
Managing Difficult interactions and emotions	0.277**	-0.286**

\*\* p < 0.01





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## **Construct Validity: Patient data**

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

\* 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



















