



Psychometric Properties of the Caregiver Inventory for Measuring Caregiving Self-Efficacy of Caregivers of Patients with Palliative Care Needs

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Abstract

Taking care of patients with palliative care needs could be a stressful event. While caregiving was associated with decreases in psychological health in caregivers, increased caregiving self-efficacy associated with reduced burden. Yet, there is no instrument available in Chinese for assessing caregiving self-efficacy in the palliative care setting. This study aimed to examine the psychometric properties of a Chinese version of Caregiver Inventory (CGI) in Chinese caregivers of patients with palliative care needs. The CGI was translated to the Chinese language, validated by an expert panel, and tested. A convenience sample of 232 patient-caregiver dyads recruited from three hospitals in Hong Kong was included in the analysis. A high completion rate of 95.5% in caregivers and no floor or ceiling effects were noted for the CGI. In contrast to the four-factor structure identified in the original 21-item CGI, our EFA produced an 18-item solution accounting for 57% of the total variation comprising three factors: (1) Care of the care recipient, (2) Managing information and self-care, and (3) Managing emotional interaction with care recipient (C-CGI-18). Separate dimensions for Managing information and Self-care were not supported. For the three domains of the C-CGI-18, Cronbach's alphas ranged from 0.84 to 0.90 and 2-week test-retest reliability ranged from 0.71 to 0.76. Correlations of the three domains with caregiver strain (r : -0.31 to -0.42, p -values < 0.01) and total scores in perceived social support (r : 0.24 to 0.36, p -values < 0.01). Correlation between the Care of the care recipient domain and patient's physical functioning (r =0.17, p -value < 0.05) indicated acceptable construct validity. In conclusion, the C-CGI-18 has suitable factor structure and psychometric properties for use in assessing caregiving self-efficacy among Chinese caregivers of patients with palliative care needs. It is simply and easy to use and can be recommended for clinical and research practice for the Hong Kong Chinese populations.

Keywords:

Caregivers, Self-efficacy, Caregiver Inventory, Palliative care, Caregiver burden, Chinese, Psychometric properties, Validation

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Introduction

Palliative care places an emphasis on meeting the needs of patients in order to improve quality of life of the patients and their family facing the problems associated with life-threatening illness [1], which should cover from the time of diagnosis, alongside potentially curative treatment, to disease progression and the end of life [2]. Palliative care became an important worldwide public health issue due to the ageing populations, the change in the disease pattern and the increasing complex needs of people with chronic diseases especially who are old [2]. Since many of these illnesses frequently exist concurrently among older people, many older people need some forms of help to meet their complex needs towards their end of life. Despite the different patterns of dying trajectory of these common serious illnesses, these patients may experience similar distressing symptoms including pain, breathlessness, and fatigue [3], hence the patients and their family may have similar palliative care needs regardless of the diagnosis. Previous studies reported palliative patients and their caregivers had needs in many aspects including social and psychological support, financial concerns; and the need for choice and information [4].

Informal caregivers play a pivotal role in the care of patients requiring palliative care. Providing care to patients can be stressful, and is expected to be worsening especially if the patients have palliative care need because of the chronic nature of the diseases and the lack of foresight when the care is no longer required [5]. Caregiving was associated with negative outcomes including decreases in both physical and psychological health in caregivers (i.e. caregiver burden), which in turn can also lead to undesirable patient outcomes, including premature institutionalization and mistreatment [5]. Conversely, caregiving could also be beneficial: caregivers who positively appraised the caregiving situation might become a stronger person and have better communication skills [6], which may also lead to a better quality of life (QoL) of the patient by providing better care. Consequently, it is important to gain a better understanding of the factors related to the positive aspects of caregiving despite the distressing situation, and some psychological constructs related to caregiver resources, in particular self-efficacy has been the focus in caregiving research recently.

Self-efficacy refers to the perceived confidence

in one's ability to perform a behavior in a given situation, and it is a central psychological construct in the social cognitive theory that is amenable to change [7]. In regard to caregiving, the theory postulates that individuals with higher self-efficacy for performing the tasks of caregiving would be more successful in completing these tasks with lesser burden and more positive gains. Previous studies in Chinese showed that increased self-efficacy was associated with both increased positive aspects of caregiving and reduced burden [8,9]. Moreover, self-efficacy was a mediating factor of the relationship of social support with QoL and depression in caregivers of patients with dementia [10,11]. Caregiving self-efficacy has been the target variable for some interventions aim to reduce health risk behaviors in caregivers and behavioral problems in dementia patients [12]. These findings underscore the importance of caregiver's self-efficacy in enhancing quality of life of the patients. Assessing caregivers' self-efficacy may help planning and implementing effective interventions in palliative care. Yet, such an instrument for self-efficacy for caregiving for patients with palliative care needs is lacking in Hong Kong.

Recently, a number of instruments have been specifically developed to measure caregiving self-efficacy in palliative care including Caregiver Inventory (CGI) [13], Revised Scale for Caregiving Self-Efficacy (RSCSE) [14], and Caregiver Self-Efficacy Scale (CaSES) [15]. Among them, the last two (RSCSE and CaSES) were disease-specific instruments with RSCSE assessing self-efficacy of caregivers of dementia patients and CaSES for caregivers of advanced cancer patients while CGI is a non-disease specific/generic instrument for caregivers of patients with palliative care. The CGI has good psychometric properties including acceptable internal consistency and good factorial and construct validity in samples of caregivers of palliative patients with cancer, advanced chronic obstructive pulmonary disorder, chronic heart failure, stroke and dementia [13]. Currently, the CGI has been administered to caregivers of colorectal cancer patients [16], and a Spanish version of the scale has been used in a randomized controlled trial in improving QoL of Latina cancer survivors and caregivers [17]. Yet, its applicability to Chinese caregivers of persons with palliative care needs remains unclear, precluding the confidence use of the instrument in this large population. This study aims to test the reliability and validity of a Chinese version

of CGI in primary caregivers of patients with palliative care needs in Hong Kong.

Method

■ Study design, sample and participants

This was a methodological study consisting of a cross-sectional survey and follow-up survey with a subsample conducted in Hong Kong between Sept 2016 and May 2017. A convenience sample of patient-caregiver dyads was recruited in a hospice and palliative day care ward, a geriatric ward and an emergency medicine ward from three different hospitals. Eligible patients were those who satisfied the criteria: (1) 18 years or older, (2) classified in need for palliative care with NECPAL CCOMS-ICO[®] Tool (Version 1.0) [18], (3) medically stable; (4) communicable in Chinese; and (5) primarily living at home, (6) mentally competent at the time of recruitment, (7) able to nominate a family member or friend to join the study and (8) had Mini-Mental State Examination (MMSE) score >10 [19]. The NECPAL CCOMS-ICO tool, developed by a research team in WHO Collaborating Centre for Public Health Palliative Care Programmes in Spain, has four sections: (1) surprise question; (2) choice/demand or need of palliative care approach; (3) general clinical indicators of severity and progression; and (4) disease-specific indicators. A patient with an answer “NO” to the Surprise question in Section 1 and an answer ‘YES’ to at least one question in Sections 2-4 was classified as in need of palliative care. Their caregivers were eligible if they were: (1) 18 years or older, (2) taking care for the patient over the past three months, (3) a non-paid caregiver as suggested by the patient and (4) who were Chinese. Written consents were obtained from eligible patient-caregiver dyads before the administration of the questionnaire.

For sample size calculation, using a case-to-variable ratio of 10:1, a minimum sample size of 210 (21 items x 10 subjects) is required for exploratory factor analysis (EFA). Allowing a small percentage of incomplete or problematic questionnaires, a total 230 patient-caregiver dyads was considered as sufficient. For the assessment of the 2-week test-retest reliability of the translated CGI, assuming the true reliability is 0.8 and the observed reliability is 0.7, a total of 66 caregivers are needed to achieve a power of 0.95.

■ Instruments

The CGI consists of 21 items to measure

confidence in performing the caregiving behaviors in four domains: Managing Medical Information (3 items), Caring for the Care Recipient (7 items), Caring for Oneself (5 items) and Managing Difficult Interactions and Emotions (6 items) [13]. Caregivers were asked to respond to the items using a 9-point Likert scale: 1-not at all confident to 9-totally confident.

The Chinese version of the Multidimensional Scale of Perceived Social Support (C-MPSS) assessed the self-perceived social support from family, friends and significant others [20]. The C-MPSS consists of 12 items which are rated on a 7-point Likert scale: 1-strongly disagrees to 7-strongly agree. A higher score indicates a higher level of perceived social support. Good validity and reliability of the Chinese version has been demonstrated in a previous study [20]. The Chinese version of the 13-item Caregiver Strain Index (CSI) measured the global burden of the caregivers [21]. It has been widely used in studies on burden of caregivers of patients with chronic illness. Items were rated by caregivers on a yes (1) or no (0) response, with the total score ranging 0-13 and a higher score indicating a greater level of burden [22]. The 20-item Modified Barthel Index (MBI) evaluated patients' physical functioning in terms of personal hygiene, bathing, feeding, toileting, stair climbing, dressing, bowel control, bladder control, ambulation or wheelchair, and chair-bed transfer [23]. The MBI total score can range 0-100, with higher scores indicating higher independence. Demographic data were also collected from both patients and caregivers respectively.

■ Procedure

The CGI was translated into Chinese using the 4-step guideline by World Health Organization on instrument translation and adaptation [24]. The CGI was first forward translated by a nurse in palliative care and the translation draft was assessed by an expert panel. Then, another nurse who was blinded to the original version of CGI backward translated the derived version of the instrument. The back-translated CGI was then assessed by the expert panel, with discrepancies were identified and resolved by discussion or translation procedure reiterated until a satisfactory conceptual and semantic equivalence was found. The translated instrument was then pre-tested with 10 primary caregivers with cognitive interviews to achieve idiomatic and experiential equivalence. The final version of the Chinese version of CGI (C-CGI) has a good

content validity with content validity index at item level ≥ 0.9 [25].

Trained research assistants (RAs) approached and patients in the ward before visiting hours for eligibility screening. During visiting hours, the RA further screened the eligibility of the caregivers. If the caregivers did not present in the ward during the visiting hours, the RAs contacted them via phone and scheduled a time for meeting. After obtaining written consents from both patients and their caregivers, the RAs administered the questionnaires to both the patients and the caregivers, but some of the caregivers completed the questionnaires by themselves. At 2 months, a convenience subsample of 70 caregivers was selected and RA administered the C-CGI again via telephone. It took about 5 minutes for the caregivers to complete the CGI in the study. Ethical approval for the study was obtained from the hospital ethical committees.

■ Data analysis

The Chinese version of CGI was evaluated for factor validity by EFA using maximum likelihood with oblique rotation of factors with eigenvalues ≥ 1.0 , scree plot, interpretability of factors and items with loadings above 0.40. Appropriateness for factor analysis was examined using Bartlett's test of sphericity and the KMO index of sampling adequacy. Cronbach's alpha values were calculated for internal consistency. Test-retest reliability of the scale scores at 2-month was assessed using intra-class correlation coefficient (ICC). For each item, if more than 30% of the caregivers obtaining the highest (9) or lowest (0) score then ceiling or floor effects were inferred respectively [26].

Construct validity of the scale was examined by correlations with the C-MPSS subscale scores, the CSI and the MBI. We hypothesized that CGI scores would correlate positively with the C-MPSS and the MBI, and negatively with the CSI. All statistical analyses were performed using SPSS22.0 with the significance level set at 0.05.

Results

■ Participant characteristics

Overall, 72.4% (330/456) of eligible patients and 95.1% (233/245) of eligible caregivers provided full informed consent and participated in the study. At 2 months, a subsample of 70 caregivers completed the Chinese version of the CGI again.

Among the 233 patients, their mean age was 76.8 years (SD=10.3), 41.2% were male, and 41.6% did not have any formal education. All of them have more than two chronic diseases, with 49.8% had leading diagnosis of heart diseases (including hypertension, stroke, heart failure) and 18.9% had cancer. For the caregivers, their mean age was 57.2 years (SD=14.7), 34.3% were male, had secondary education or above, and 50.6% were children of the patients. **Table 1** shows the characteristics of the patients and the caregivers.

■ Missing data of CGI

The rate of missing data for the CGI was extremely low, with only one caregiver did not respond Items 19 and 20 and another caregiver did not respond Item 19. Thus, data from 232 (99.6%) patient-caregiver dyads at baseline and 69 caregivers at 2-week were used in the analysis.

■ Factor analysis

Bartlett's test statistics was 3158.277 ($p < 0.001$) and KMO statistic was 0.948, indicating appropriateness and sampling adequacy for factor analysis. Results of the EFA revealed a 3-factor structure accounting for 57.3% of the variance. The factor loadings of the 3-factor solution are presented in **Table 2**. Factor 1 closely resembled the original version, comprising seven items focusing on the positive aspects of caregiving in providing good care to the recipient and the caregivers' expectations regarding their ability to provide support in maintaining a close relationship and noticing good moments of caregiving, was labelled *Care of the Care Recipient*. Factor 2, labelled *Managing information and Self-Care*, contained seven items covering predominantly on the interface with the medical community and understanding the medical information as well as items on self-care practices of actively seeking help and dealing with negative aspects of caregiving on oneself. Factor 3 comprising four items reflecting the ability to interact actively with the patients in dealing emotional situations was labelled *Managing Emotional Interaction with Care Recipient*. Two items have cross-loadings on 2 factors. Item 5 (Maintaining hope) was loaded on both factor 1 (loading, 0.551) and factor 2 (loading, 0.417). The item was retained in factor 1 because of the substantial differences in the 2 factor loadings (>0.1). Item 10 (Talking openly and honestly with the person) was loaded on both factor 1 (loading, 0.528) and factor 3 (loading, 0.552).

Table 1: Characteristics of patients and primary caregivers (n=233).

Characteristics	Patients	Caregivers
Age, mean ± SD	76.8 ± 10.3	57.2 ± 14.7
Male, n (%)	96 (41.2%)	80 (34.3%)
Married/Cohabitation, n (%)	144 (61.8%)	193 (82.8%)
Educational level, n (%)		
No formal education	97 (41.6%)	22 (9.4%)
Primary education	75 (32.2%)	53 (22.7%)
Secondary education or above	61 (26.2%)	158 (67.8%)
Perceived poor financial status, n (%)	61 (26.2%)	59 (25.3%)
Leading class of diagnosis, n (%)		
Diabetes	42 (18%)	
Heart diseases	116 (49.8%)	
Neurological diseases	7 (3.0%)	
Kidney diseases	8 (3.4%)	
Cancer	44 (18.9%)	
Lung diseases	13 (5.6%)	
Bone diseases	3 (1.3%)	
MBI, mean ± SD	85.3 ± 19.5	
Relationship with the patient, n (%)		
Child	-	118 (50.6%)
Spouse	-	87 (37.3%)
Others	-	28 (12.0%)
Perceived poor health status, n (%)	-	49 (21.0%)
Has a maid to help, n (%)	-	58 (24.9%)
Patient is receiving long-term care service, n (%)	-	24 (10.3%)

MBI, Modified Barthel Index.

Table 2: Results of exploratory factor analysis with oblique rotation (n=232).

Item	Factor loading		
	Factor 1	Factor 2	Factor 3
1. Coping with information overload		0.753	
2. Listening and learning from the person as to how to care better for him/her	0.578		
3. Letting go of things I can't control		0.480	
4. Expressing negative feelings about the illness		0.527	
5. Maintaining hope	0.551	0.417	
6. Being able to notice the "good moments" in caregiving when they occur	0.687		
7. Allowing the person to have and express his or her own feelings	0.759		
8. Assisting the person with activities such as feeding, washing, dressing, or toileting			0.468
9. Continuing to take care of myself (for example: exercise, diet, sleep)	0.416		
10. Talking openly and honestly with the person	0.528		0.552
11. Continuing to engage in personal activities that I like to do			
12. Talking about death and dying			
13. Providing emotional support for the person I'm caring for			0.763
14. Understanding medical information from doctors, nurses, or other sources		0.710	
15. Seeking support for myself		0.608	
16. Dealing with feelings of helplessness		0.675	
17. Dealing with the person expressing negative feelings toward me when they occur			0.768
18. Assisting and encouraging the person in following through with all treatments	0.588		
19. Asking physician and nurses questions		0.458	
20. Dealing with criticism from others			
21. Maintaining a close relationship with the person I'm caring for	0.764		
Eigenvalues	10.690	1.392	1.109
Percentage of variance explained	48.91	4.79	3.61

The item was retained in factor 3 because of the interpretability of the factors. In addition, three items, item 11 (Continuing to engage in personal activities that I like to do), item 12 (Talking about death and dying), and item 20 (Dealing with criticism from others), did not load onto any factor.

■ **Internal consistency**

The resulting C-CGI-18 demonstrated good internal consistency and test-retest reliability, with Cronbach’s alpha > 0.70 and ICC values over a 2-week interval for the subsample of 69 caregivers >0.7 respectively (Table 3). For all the three domains, only small proportions of the caregivers (< 9%) obtained either the highest (9) or lowest score (0), showing the absence of ceiling and floor effects.

■ **Construct validity**

Table 4 presents correlations of the three dimensions of CGI with caregiver’s CSI and C-MPSS scores and patient’s MBI score. As hypothesized, higher scores on the three domains of C-CGI-18 associated significantly with lower scores on CSI and higher scores on the total scores of C-MPSS respectively. Regarding the subscales of C-MPSS, the two subscales of significant others and family have small to moderate positive associations with the CGI domains however, the subscale of friend in C-MPSS was significantly associated with the domain managing information and self-care only. Regarding patient’s physical functioning, MBI showed a significant positive correlation with the Care of the Care Recipient domain, but did not correlate significantly with the other two domains of C-CGI-18.

Discussion

In this paper, we provide robust evidence of the validity and reliability of the Chinese version of the CGI. The completion rate for the CGI was very high and the caregivers completed the instrument within a few minutes with no difficulty, suggesting that it is easy to administer and puts little burden on caregivers and hence the instrument could be used to measure caregiving self-efficacy of caregivers even in a busy clinical setting. By identifying the domains of caregiving self-efficacy in which the caregivers have low scores, healthcare professionals could be able to provide appropriate support or intervention to enhance their caregiving self-efficacy.

In contrast to the four-factor structure of the CGI derived from the original American sample, our EFA revealed a three-factor structure from 18 items (C-CGI-18): Care of the care recipient, Managing information and self-care, and managing emotional interaction with care recipient. Our results suggested there might be a substantial overlapping between items on caring for themselves and items on managing medical information in our sample of caregivers of patients with palliative care needs. A previous study examining the factor structure of a supportive care needs questionnaire among breast cancer patients also has a similar finding that items of patient support and information needs might be substantial overlapping [27]. This needs further investigation. Alternatively, the discrepancy in the factor structure of CGI between the original study and our study might be due to the specific characteristics of the patients in the two studies. Compared to our sample, the original sample of patients were in a more severe condition as all of them were receiving palliative care [13], and their caregivers should have more chances to reflect on their needs and ability of performing caregiving-related tasks. This might also be the reason why three items on continuing to engage in personal activities, talking about death and dying, and dealing with criticism from others showed low factor loadings in EFA.

In our study, Cronbach alpha values of the C-CGI-18 exceeding 0.80 and hence was considered as good, showing the internal consistency of the instrument. In addition, the high values of the ICCs in this study for assessing the test-retest reliability of the instrument indicate excellent stability. This finding extends the previous study on showing the good psychometric properties of the modified version of the CGI.

Furthermore, there were significant correlations and in the expected directions between most dimensions, showing the C-CGI-18 has good construct validity. Consistent with the previous validation study [13], we also found that patient’s physical functioning correlated significantly with the Care of care recipient domain only. In addition, we further observed that the perceived social support received from friends correlated significantly with the Managing information and self-care domain in C-CGI-18. Both observations suggest that the conceptually distinction of the three domains in the C-CGI-18. Moreover, previous research in Chinese has been focused on caregiving for dementia patients [8-11], our

Table 3: Descriptive statistics, Cronbach’s alpha and ICC for each C-CGI18 domain.

Domain of C-CGI-18	Number of items	Mean (0-9)	SD	Median (IQR)	Lowest score (floor)	Highest score (ceiling)	Cronbach’s alpha	ICC (95% CI)
Care of the Care Recipient	7	7.07	1.39	7.1 (1.8)	0 (0%)	19 (8.2%)	0.903	0.735 (0.573-0.835)
Managing information and Self-Care	7	6.38	1.51	6.4 (2.0)	1 (0.4%)	9 (3.9%)	0.879	0.762 (0.617-0.850)
Managing Emotional Interaction with Care Recipient	4	6.46	1.72	6.5 (2.3)	1 (0.4%)	16 (6.9%)	0.844	0.706 (0.525-0.818)

ICC, Intra-class correlation coefficient.

Table 4: Correlations matrix for construct validity.

	Care of the Care Recipient	Managing information and Self-Care	Managing Emotional Interaction with Care Recipient
CSI	-0.415**	-0.338**	-0.310**
CMPSS			
Significant others	0.343**	0.334**	0.280**
Family	0.383**	0.401**	0.322**
Friend	0.044	0.160*	0.035
Total	0.302**	0.360**	0.247**
MBI	0.167*	0.119	0.087

CSI, Caregiver Strain Index; CMPSS, Multidimensional Scale of Perceived Social Support; MBI, Modified Barthel Index; **p-value <0.01, *p-value <0.05.

current findings extend these previous studies on the negative association between caregiving self-efficacy and caregiver burden among a boarder group of caregivers who are taking care of patients with palliative care needs.

There are several limitations of the current study that worth noting. First, the three-factor solution for the C-CGI-18 was generated using one single sample, and cross-validation using new samples with a confirmatory approach will be necessary to confirm its factor structure further. Second, we investigated only the factor structure, concurrent validity and stability of the scale, further studies on the predictive validity of the scale over time will be needed. Third, the use of convenience sample in this study certainly limits its generalizability. Lastly, although our patients were in needs of palliative care, they were rather independent as shown by their high MBI scores. Furthermore, this research focused primarily on caregivers of patients with heart diseases and cancer. It would be important to investigate the external validity of these findings with respect to caregivers of people who have diagnoses other than heart diseases and higher

level of dependency.

Conclusion

In conclusion, the results of the study with a Chinese sample of patient-caregiver dyads gave preliminary evidence of a three-factor structure and good reliability and validity of the CGI after deletion of three items. The abbreviated 18-item version of the CGI appears to be a practical instrument for measuring caregiving self-efficacy in Chinese caregivers who are taking care of patients with palliative care needs. This offers healthcare professionals in palliative care with a practical and usable instrument.

Conflict of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper.

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