

Review Article

**Self-concept of Family Caregivers of Palliative Patients:
A scoping review**

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Abstract

Self-concept refers to how someone perceives themselves, and it is important for the psychological well-being of an individual. Taking on the role of family caregivers for patients with palliative care becomes a challenge for some caregivers in various aspects and could affect their individual self-concept. This scoping review aims to systematically identify the characteristics of all relevant individual studies relating to self-concept of family caregivers of palliative patients. Relevant studies published from 2010 to 2023 were sought by searching online databases, including PubMed, Embase, and Google Scholar. The Jonna Briggs Institute (JBI) scoping review protocol was applied for the methodological aspects of this study. A total of 643 references were identified, but only 14 studies were eligible to be included. The results reveal that when measuring self-concept among family caregivers of palliative patients, self-efficacy is the main major concern besides self-value, self-acceptance, and self-respect. Moreover, the result also shows factors that correlate to self-efficacy and supports the idea that self-efficacy contributes to the mental health of caregivers and the caregiver's and patient's quality of life.

Keywords: Self-concept; Family caregivers; Palliative care; Scoping review

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Introduction

Palliative care aims to relieve the suffering of patients suffering from life-threatening illnesses and their families by addressing physical, psychological, social, and spiritual components⁽¹⁾. Cancer, cardiac disease such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer's disease, Parkinson's disease, Amyotrophic Lateral Sclerosis (ALS), and many other illnesses are among those that frequently require palliative care and as currently palliative care is also essential for patients with COVID-19⁽²⁾. According to WHO⁽¹⁾, Forty million people worldwide require palliative care, with 78% of those in need living in low and middle-income countries. Globally, patients who got palliative care had cardiovascular disease (39%), with cancer coming in second (34%)⁽¹⁾. However, the statistics shows that most palliative patients in Thailand are those who have cancer (55.56%)⁽³⁾.

Family caregivers of palliative patients play an active role as an intermediate between palliative patients and other health professionals⁽⁴⁾ and take part in increasing the quality of life when palliative patients are discharged from the hospital and go back home⁽⁵⁾. Family caregivers or “informal caregivers” are described as individuals who care for their family member of origin who living with limitations and could be the congregation, neighbors, close friends, or those who has a significant personal relationship with patient⁽⁶⁾. Taking the role of family caregiver tends to be time-consuming and energy-consuming⁽⁷⁾ and caring for a patient with palliative care becomes a challenge for some caregivers in various aspects; physical, emotional, psychological, and social well-being^(8,9), especially for those who have no caregiver experience before.

Self-concept refers to how someone thinks about, evaluates, or perceives themselves⁽¹⁰⁾. Evidence from quantitative and qualitative studies support the idea that self-concept is relevant to the psychological well-being of individuals and has an association with the quality of care that family caregivers provide to palliative patients^(11,12), and the self-concept also illustrates family caregivers' adaptation in various aspects⁽¹³⁾.

Although many studies have shown that self-concept is related to adaptation and contributes to the quality of care and quality of life of family caregivers, there are lack of systematic reviews on the self-concept of family caregivers of palliative patients. It is important to understand caregivers' perspectives on self-concept and explore what shapes the self-concept of caregivers of dying relatives under hospice care at home and what contributes to it. Therefore, this scoping review aims to systematically identify characteristics of all relevant individual studies relating to the self-concept of palliative care family caregivers.

Objective

The purpose of this scoping review is to systematically identify characteristics of all relevant individual studies and factors relating to the self-concept of palliative care family caregivers and the review question of this study is “What are the characteristics of the self-concept of palliative care family caregivers?”.

Method

The Jonna Briggs Institute (JBI) scoping review protocol was applied for the methodological aspects of this study.

Eligibility Criteria

PCC” is a mnemonic used to guide the review question of scoping review type.

Participants (P): The inclusion criteria of participants are articles focusing on family caregivers or informal caregivers such as spouses, children, family members, or relatives of palliative patients. The articles which focus on formal caregivers or caregivers who are paid for care will be excluded.

Concept (C): The core concept of this study is self-esteem. According to the concept analysis of self-esteem, the attributes are self-value, self-acceptance, self-efficacy, and self-respect. Therefore, inclusion criteria regarding concept are articles related to the attributes of self-concept mentioned above. Although articles consist of one attribute of self-esteem, they are eligible to be included in this scoping review.

Context (C): The context of included articles focusses on palliative care or hospice care.

Study Types & Search Strategy:

The study types that were included in this scoping review were descriptive quantitative studies qualitative studies, and reviews published in English between 2010 and 2023. PubMed, Embase, and Google Scholar were used to find the papers. The kinds of studies included were descriptive quantitative studies, qualitative studies, and reviews. Systematic Reviews were not included in this study. A three-step search strategy recommended by JBI is utilized for the search strategy in this study.

Study Selection & Data Extraction

All identified citations from data-based and Google Scholar were collated and uploaded into EndNote X9 then duplicate articles were removed. The titles and abstracts of identified articles were screened by two independent reviewers for assessment against the inclusion criteria for the review. The full texts of selected citations were assessed in detail against the inclusion

criteria by two independent reviewers. If a consensus was not reached at any stage of the selection procedure, a third reviewer was necessary to determine the choice. However, a third reviewer was not required because two reviewers reached agreement.

Data Synthesis

The extracted data were presented in a table with accompanying narrative, describing how the results relate to the review objectives and research question. The data were discussed in terms of aim, study design, underpin theory, and main finding relevant to self-concept of family caregivers.

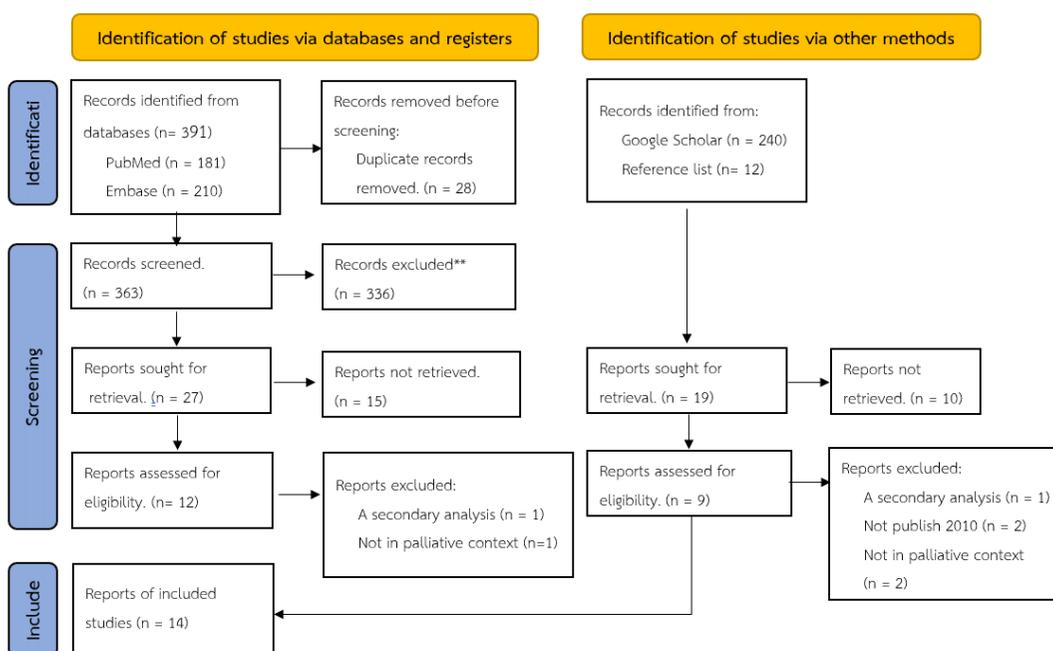


Figure 1 PRISMA Flow Diagram

Results

1. **Study characteristics:** A total of 643 references were identified, of which 28 duplicate records were removed and 594 were excluded by screening the title and abstract. Of the remaining 21 references, the full text was sought and 14 were retained. Characteristics of all included studies in this review were shown in Table 1.

2. **Participant characteristics:** Of the included articles, sample sizes ranged from 10 to 284, with the total sample of family caregivers in the studies being 1,530. The caregiver’s age

ranged from 20 to 90 years old. As expected, there were more females (992; 64.84%) than males (528; 34.51%). Ten participants (0.65%) cannot indicate gender. There were fewer spousal/partner kinships (41.76%) than intergenerational kinships (56.67%) and there was no information about the relationship with palliative patients of 24 participants (1.57%).

3. Study measures: Of the 12 quantitative studies included in this review, there were several different self-concept measures adopted. Most studies measure self-efficacy (n=11) and one study measured self-esteem. The number of items ranges from 1-27 items. The most popular measure of domain-specific self-efficacy was the Revised Scale for Caregiving Self-efficacy scale (n=2)^(14,15) and the Caregivers' General Perceived Self-Efficacy Scale (GSE) (n=2)^(16,17). Seven research assessed task-specific aspects of self-efficacy^(11-15,17-19). Self-efficacy-obtaining respite (SE-OR) (measures caregivers' confidence to ask for assistance), self-efficacy-managing patients' disturbing behaviors (SE-DB) (caregivers' confidence to respond to the patient's behaviors effectively), and self-efficacy-controlling upsetting thoughts (SE-CU) (confidence of caregiver to get rid of the negative thinking associated with caregiving) are the task-specific domains most measured in studies^(14,15,17).

4. Relationships within and between studies: The findings also show that there are numerous elements that influence self-efficacy.

4.1 Self-efficacy and caregiver burden

Six of twelve quantitative studies investigated the relationship between self-efficacy and caregiver burden, and the findings support the notion that family caregiver self-efficacy has a negative significant connection with caregiver burden. However, only one of these six studies assessed specific self-efficacy in pain management.

4.2 Self-efficacy and caregiver anxiety

Four of twelve quantitative studies examined the correlation between self-efficacy and caregiver anxiety and the results of them are similar, self-efficacy of family caregivers has a negative significant correlation with caregiver anxiety.

4.3 Self-efficacy and caregiver depression

Three studies examined the correlation between self-efficacy and caregiver depression and the results of them are similar, self-efficacy of family caregivers has a negative significant correlation with caregiver depression.

Table 1 Studies included in this review

Authors (year)/ Country	Objectives	Population and Sample Size	Design/Analysis	Measurements Related Self-concept	Results/Conclusion
1. Leung et al. (2020) Hong Kong	To test the associations of two sources of social support (family and friends) and the mediating role of caregiving self-efficacy on caregiver burden and patient's quality of life	223 family caregivers Female=79 Male=144 Spouse=83 Others=140	A cross-sectional study/Structural equation modeling or Path Analysis	Chinese version of the Caregiving self-efficacy (C-CGI-18) (18 items) Cronbach's alpha range 0.85-0.90	Family support had a significant negative indirect effect on caregiver burden and a significant positive indirect effect on patient quality of life, whereas friend support had a significant positive direct effect on caregiver burden but a minimal effect on patient quality of life ⁽¹³⁾
2. Kizza & Mulira (2020) Uganda	To explore determinants of QoL among FCGs of adult cancer patients	284 family caregivers of adult cancer patients Female=208 Male=76 Spouse=57 Others=227	A cross-sectional study/Binary logistic regression	The modified Chronic Pain Self-Efficacy Scale (22 items) Cronbach's alpha 0.94	FCGs' knowledge and self-efficacy for cancer pain management were the most important drivers of overall QoL ⁽²⁰⁾
3. Duggleby et al. (2014) Canada	To determine factors influencing the hope of rural women caring for persons with advanced cancer, by examining relationship of hope with demographic variables, self-efficacy, guilt, and caregiver physical and mental health.	122 carers of persons with advanced cancer Female=122 Male=0 Spouse=80 Others=42	A cross-sectional/ Generalized linear modeling (GLM)	General Self-Efficacy Scale (GSES) (10 items) Reliability $r=0.76$ 0.90 and criterion related reliability $r=0.80$, $p<0.05$ ¹⁹ Cronbach's alpha $r=0.88$	Participants with greater hope ratings had better mental health, reduced perceptions of loss and grief, and stronger self-efficacy (confidence in one's ability to deal with tough situations) ⁽¹¹⁾

Table 1 (cont.) Studies included in this review

Authors (year)/ Country	Objectives	Population and Sample Size	Design/Analysis	Measurements Related Self-concept	Results/Conclusion
4. Mroz et al. (2018) United States	To investigate whether caregiver self-esteem moderates the association between relationship satisfaction and patient health outcomes	24 caregivers & 24 patients in a hospice home care program Female= 21 Male= 3 Spouse= NA Others= NA	A longitudinal study/ Multiple regression design	Single-Item Self Esteem (SISE) Scale: "I have high self-esteem." Cronbach's alpha r=NA	Patient relationship satisfaction reduced significantly when the patient's physical health declined in patients with low self-esteem carers, but patient relationship satisfaction increased modestly in patients with high self-esteem caregivers ⁽²¹⁾
5. Mystakidou et al. (2013) Greek	1) to determine correlation between anxiety levels, self-efficacy and socio-demographic characteristics of caregivers of advanced cancer patients 2) to evaluate the effect of the various socio-demographic characteristics of caregivers and their self-efficacy on their state and trait anxiety	107 family caregivers of patients with advanced cancer Female=69 Male=38 Spouse=31 Others=76	A cross sectional, correlational design. /A multiple regression	The Caregivers' General Perceived Self-Efficacy Scale (GSE) (10 items) Cronbach's alpha of the Greek version=0.927	Self efficacy is the most powerful predictor of trait anxiety (p=0.0005). Carers with poor self-efficacy are more likely to have greater anxiety levels than caregivers with high self-efficacy ⁽¹⁶⁾
6. Durmaz & Okanli (2014) Turkey	To determine the burden of care and the effect of self-efficacy on the burden of care	62 schizophrenia and their family caregivers Female=28 Male=34 Spouse=0 Others=62	A cross-sectional/ Pearson's correlation	The Self-efficacy Scale (17 items) Cronbach's alpha of the Turkish version=0.84 Reliability= 0.92	The burden of care decreases with the increasing level of self-efficacy in caregiver family members ⁽²²⁾

Table 1 (cont.) Studies included in this review

Authors (year)/ Country	Objectives	Population and Sample Size	Design/Analysis	Measurements Related Self-concept	Results/Conclusion
7. Cheng et al. (2013) Hong Kong	To test the effects of different self-efficacy beliefs on caregiver appraisals and depressive symptoms	99 family caregivers of Alzheimer patients Female=70 Male=29 Spouse=36 Others=63	A cross-sectional/ multiple regression	9 items from 15-item Revised Scale for Caring Self-Efficacy Cronbach's alpha range 0.75-0.92	When presented with more behavioral difficulties, family caregivers who had stronger self-efficacy in controlling upsetting thoughts experienced more positive gains and less strain. Self-efficacy in seeking respite had direct effects on burden and sadness, while self-efficacy in responding to disruptive behaviors had direct effects on positive gains but no moderating effects. ⁽¹⁴⁾
8. Zhang et al. (2014) China	To compare the level of HRQoL between caregivers and the general population and to assess the role of caregiver self-efficacy in the relationship between social support and Health related Quality of Life (HRQoL)	205 family caregivers of dementia patients Female=123 Male=82 Spouse=137 Others=68	A cross-sectional/ multiple regression	The Self-Efficacy Questionnaire for Chinese Family Caregivers (SEQCFC) (27 items) Cronbach's alpha r=0.80	When matched for age and gender, caregivers' HRQoL was lower than that of the general population. Caregiver self-efficacy is a partial mediator between social support and HRQoL, as well as a partial mediator between BPSD and caregiver mental health. ⁽¹²⁾
9. Yang et al. (2019) China	To test that caregiver self-efficacy and social support were two chaining mediator variables on the paths for patient factors affecting caregiver burden,	112 family caregivers of PD patients Female=66 Male=46 Spouse=60 Others=52	A cross-sectional/ Partial Least Squares Structural Equation Modeling (PLS-SEM)	The Generalized Self-Efficacy Scale (GSE) (15 items); Cronbach's alpha SE OR=0.89,	Caregiver self-efficacy was found to be a partial mediator of the effects of patient motor function on caregiver burden, anxiety, and sadness. Social support for carers was found to be a partial mediator

Table 1 (cont.) Studies included in this review

Authors (year)/ Country	Objectives	Population and Sample Size	Design/Analysis	Measurements Related Self-concept	Results/Conclusion
	caregiver anxiety, and depression			SE-DB=0.91 and SE-CU=0.90.	of the effects of patient motor function on caregiver self-efficacy. Two chaining mediator factors on the pathway for patient motor function impacts on caregiver load and caregiver depression were caregiver social support and self-efficacy. ⁽¹⁷⁾
10. Liu & Huang (2018) Taiwan	To explore caregiving self-efficacy as a mediator for the association between family functioning and caregiving appraisal of dementia family caregivers in Taiwan	115 family caregivers of people with dementia Female=76 Male=39 Spouse=30 Others=85	a cross-sectional correlational design/ Pearson's correlation, and Spearman correlation	The Revised Scale for Caregiving Self-Efficacy (RS-CSE) (15 items): Cronbach's alpha SE OR=0.94, SE-DB=0.96 and SE CU=0.96	The caregiver burden was substantially associated with family functioning, patients' activities of daily living score, Neuropsychiatric Inventory caregiver distress, and three dimensions of self-efficacy. ⁽¹⁵⁾
11. Ugalde et al. (2014) Australia	To describe the prevalence of anxiety and distress in a sample of caregivers of people with advanced cancer and explore the relationship with self efficacy	94 family caregivers of people with advanced cancer Female= 76 Male=18 Spouse= 70 Others=24	a cross-sectional / Pearson's r correlation	Caregiver Self Efficacy Scale (CaSES) (21-items) Reliability=0.73-0.85 and Cronbach's alpha = 0.81 to 0.94	Caregivers had high anxiety and distress. Females had more distress and state anxiety than males. Only one self-efficacy scale, self-maintenance, correlated with distress. All STAI scores correlated with self-efficacy and self-maintenance had the strongest relationship. Caregivers with higher anxiety reported lower self-efficacy. ⁽¹⁸⁾

Table 1 (cont.) Studies included in this review.

Authors (year)/ Country	Objectives	Population and Sample Size	Design/Analysis	Measurements Related Self-concept	Results/Conclusion
12. Semiatin & O'Connor (2012) United States	To investigate the extent to which caregiver self-efficacy is related to positive aspects of caregiving among Alzheimer's disease caregivers.	57 family members caring for a loved one with Alzheimer's disease. Female=43 Male=14 Spouse=39 Others=18	a cross-sectional correlational design/ Pearson's correlations and multiple regression analysis	The RIS Eldercare Self Efficacy scale (RIS) (10-items) Cronbach's alpha=0.89	Self-efficacy accounted for a significant percentage of the variance in positive aspects of caregiving after controlling for other factors commonly associated with positive aspects of caregiving including caregiver demographics, care recipient neuropsychiatric symptoms, and caregiver depression ⁽¹⁹⁾
13.Soroka et al. (2018) United States	To elicit the views, feelings, and experiences of primary caregivers who provide unpaid care to dying family members in the home setting	16 family caregivers of palliative patients Female=11 Male=5 Spouse=10 Others=6	A cross-sectional, semi-structured, in-depth interviews with a narrative analysis	—	Caregivers' confidence is shaped by the terminal illness of the person for whom they care and caregivers' values and relationships. It is also influenced by their needs and the sources and strength of support they receive ⁽²³⁾
14. Carlander et al. (2011) Sweden	To explore situations in daily life that challenge caregivers' self image when caring for a dying family member at home	10 family caregivers who cared for a dying family member at home. Female=NA Male=NA Spouse=6 Others=4	Qualitative study. Interviews with interpretive description analysis	—	Caregivers' daily life in caring for a dying family member at home were characterized by three patterns: challenged ideals, stretched limits, and interdependence. Situations that questioned the caregivers' self-image were associated with 'forbidden thoughts,' closeness, and shrinking personal space ⁽²⁴⁾

4.4 Self-efficacy and caregiver’s quality of life

Three of twelve quantitative studies examined the correlation between self-efficacy and caregiver quality of life and the results of them are similar, self-efficacy of family caregivers has a positive significant correlation with the quality of life.

4.5 Self-efficacy and family & social support

Two of twelve quantitative studies examined the correlation between self-efficacy and family support and the results of them are similar, family support has a positive impact on the self-efficacy of family caregivers. One of the two studies also indicates that family support had a significant positive indirect effect on patient’s quality of life through caregiving self-efficacy.

Regarding social support, 2 of 12 quantitative studies examined the correlation between self-efficacy and social support, and the results of them are similar, social support has a positive impact on the self-efficacy of family caregivers and add more than self-efficacy was a partial mediator between social support and quality of life of family caregivers.

One of the two included qualitative studies also suggests that carers' self-efficacy is influenced by the level of assistance they receive.

There was just one study that revealed a correlation between self-esteem and relationship satisfaction and one qualitative study that showed self-image related to "forbidden thoughts," which was pertinent to the sub-domain of self-efficacy. Table 2 summarizes the data on the relationship between self-efficacy and other components.

Table 2 Summary of studies that examined correlations with self-efficacy

Correlates	Relationship with Self-efficacy*	
	Negative (–)	Positive (+)
Caregiver burden	1, 2, 6, 7, 9, 10	
Anxiety	6, 8, 9, 11	
Depression	7, 8, 9	
Quality of life		3, 8
Social Support		8, 9
Family Support		1, 2
Self-esteem		10
Positive aspect of caring		12

*Numbers in table indicate article shown in Table 1

Discussion

The primary finding of this scoping study highlights that self-efficacy is the main component that influences and affects the caregiver's quality of life among family carers of palliative care patients. According to the findings of this scoping review, self-efficacy has a considerable negative direct effect on caregiver burden and mental health issues such as depression and anxiety, which will ultimately contribute to caregiver quality of life. Aside from that, self-efficacy has a substantial positive effect on the quality of life of caregivers. Furthermore, family and social support contribute to the self-efficacy of palliative patient carers.

The result of this study also shows a similar direction to Roy Adaptation Model (RAM). The RAM mentioned that ineffective response in four adaptive modes contributes to the quality of life. The self-concept of family caregivers, one mode under the RAM, then effects their quality of life⁽¹⁰⁾. The result of this scoping review supports that self-efficacy, an element of self-concept, has a significant positive relationship with the quality of life of family caregivers of palliative patients. This means that for those family caregivers of palliative patients who have high self-efficacy, we can predict that they will have a higher level of quality of life, compared to those who have lower self-efficacy.

The result of this study shows that family support and social support have positive effects on self-efficacy which means that those family caregivers who have a high level of support of family or social, will have higher levels of self-efficacy as well. This result supports the Self-Concept Theory. Self-concept theory mentions that developing self-concept can be done in various ways: positive thoughts about yourself and others, improving the quality of interpersonal relationships, being proactive, maintaining the balance of life, and changing the way we communicate⁽²⁵⁾. Therefore, when creating interventions supporting adaptive responses in self-concept mode and quality of life in family caregivers of palliative patient groups, nurses should take these factors into account especially in terms of family and social support since these two factors have a significantly positive effect on self-efficacy and self-concept.

Limitation and future direction

There are limitations in the characteristics charting regarding the education level of family caregivers because some primary studies did not provide this information. The differences in study statistics used also lead to limitations to synthesis in statistics, so we cannot extend the result to meta-analysis. A greater number of primary research are required to be able to conclude the correlations between self-esteem and relationship satisfaction, as well as to support a

correlation with the positive aspect of caring, therefore, if there is more primary research related to these, the systematic review should be conducted again to support the finding.

Conclusion

This scoping review systematically identifies characteristics of all relevant individual studies relating to the self-concept of palliative care family caregivers. 14 studies were included and revealed that when measuring related to self-concept among family caregivers of palliative patients, self-efficacy is the major concern, besides self-value, self-acceptance, and self-respect. In addition, there are many factors that have correlated to self-efficacy, as well as the contribution of self-efficacy to the mental health of caregivers and caregivers and patients' quality of life. The review highlights the status of self-concept research in family caregivers in a palliative context and the methodological challenges concerning measurement in this area. This review might have clinical implications for intervention in supporting quality of life of both palliative patients and their caregivers.

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