

CAREGIVING END-OF-LIFE EXPERIENCES AND WELLBEING OF CAREGIVERS OF CARDIAC PATIENTS: MEDIATING ROLE OF CAREGIVING SELF EFFICACY

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Contribution

SS conceived the idea and designed the study. Data collection and manuscript writing was done by FK and SK. All the authors contributed equally to the submitted manuscript.

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ABSTRACT

Objectives: To investigate the role of caregiving self-efficacy as mediator between the relationship of experiences of caregivers of dying heart patients with caregivers' wellbeing.

Methodology: Participants of this study were 211 caregivers of heart patients at Institute of Cardiology Multan. Caregivers aged 26-57 years provided data on three scales measuring End-of-Life experiences, caregiving wellbeing and caregiving self-efficacy.

Results: Mediating effect of caregiving self-efficacy was supported through the path analysis on AMOS-21 between end-of-life care experiences and wellbeing of caregivers. Findings indicated that caregivers confronted high negative experiences and low well-being among caregivers of cardiac patients. Results also showed that caregivers' negative end-of-life care experiences such as physical suffering and burden significantly negatively affect their level of wellbeing; and positive and neutral experiences have positive impression on wellbeing. However, caregiving self-efficacy reported by caregivers mediate the effects of these experiences on their wellbeing.

Conclusion: Assumed paths in model between the study variables supported the claim that caregivers' self-efficacy intervened as mediator between caregiving experiences while giving during terminal period of dying patients and caregiver's own wellbeing. Findings suggested that if caregiving self-efficacy is high among caregivers, they may undergo negative experience less and may have high wellbeing during end-of-life care.

Keywords: End-of-life care, end-of-life experiences, caregiver' self-efficacy, well-being, cardiac patients

INTRODUCTION

Extended and unsure period of discomfort and difficulty is called as “end of life”. Most of the people suffering from critical illness today die of chronic conditions because circumstances become worsen and serious; and then eventually result in death. Consequently it causes difficulty and discomfort for dying patients to maintain dignity during the end-of-life stage of illness such as cancer, liver failure, chronic heart disease, renal failure, lung infection, stroke, and dementia.¹⁻²

Providing support and care to dying patients is referred as end-of-life (EOL) care. Effective EOL care can improve the Quality of life of dying patients and wellbeing of their caregivers and family members can be improved through effective EOL care during terminal stage and critical situations of illness including forthcoming medical treatment or even bereavement.³⁻⁴ Recent studies conducted on EOL care provided to terminal patients suggested that caregiving experiences of patients in intensive care unit (ICU),⁵⁻¹⁰ and the EOL care experiences for congestive heart failure patients¹¹ can affect the physical and mental health of caregivers of such patients. These investigations were primarily focused on exploring more effective coping ways and developing more efficient interventions for family caregivers and dying patients.

EOL care experiences are always complex for family members and caregivers. Critical and chronic illness involved patients in irreversible certain situations and life damages wherein patients need help, care, support, maintenance of activity, and removal of illness.¹² EOL care for chronic ailments related to heart diseases such as coronary artery disease, congestive heart failure, angina, heart attacks (Myocardial Infarction), heart failure, and arrhythmia can be painful and critical for caregivers due to physical suffering and fear of expected loss of dying patient. Caregivers who are providing EOL care to the terminal stage patients can cope with these circumstances.¹³⁻¹⁴

Lazarus and Folkman’ theory of coping process¹⁵ elaborated the concept of “caregiving appraisal” that is involved in all potential cognitive and affective appraisals, one individual’s ways of coping during EOL care experiences and, reappraisals of the stressor. The expression of subjective reaction to potential stressing situation whether it is negative experience such as burden, positive experience such as satisfaction, or neutral experience such as need for help were defined. Neutral appraisal included social life of caregivers perceived by one individual, work and activities, and whether providing care affect caregivers’ own perception and actions.¹⁶

Caregivers’ physical, mental and financial status has also been influenced by caregiving appraisal.¹⁷ Several

researches have been conducted on EOL experiences of caregivers of stroke patients¹⁸ and dementia patients^{16,19} EOL caregivers and family members anticipate dear and must all confront death. However, this phase can differ among caregivers depending on their individual circumstances and personal characteristics. Hence EOL care is absolutely unexpected, uncertain, and unpredictable, therefore EOL caregivers and significant members of family generally remain in uncertainty. Thus, such EOL caregivers very often look for information and seek suggestions regarding spiritual care, provision of help and support, and decision making from healthcare physicians.²⁰

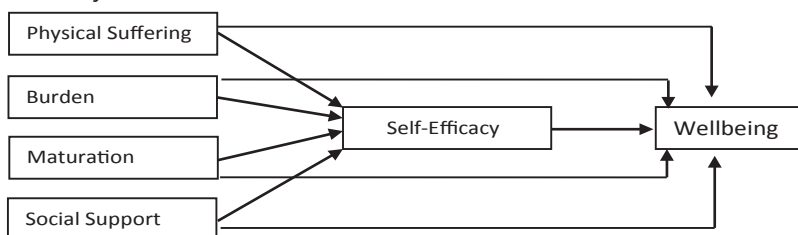
Caregivers’ self-efficacy has been conceptualized as their belief about their ability to care of patients, manage the situation, and handle the stress during the EOL period.²¹ Self efficacy beliefs have significant several influences on psychosocial activities and behaviors. They (a) ascertain whether behaviors of coping ways will be originated, how many attempts will be exerted, and how long these attempts will be retained in the critical situation and worsen experiences and (b) have impact on tendency towards psychological discomfort, stress, and depression.²¹ In spite of the notion that several studies have frequently used the self-efficacy model in exploring the chronic distress and coping. Recently this concept has only been employed to describe the EOL care experiences of family caregivers of dying patients.²²⁻²³ These latest findings proposed that theory model explaining self-efficacy construct keeps absolutely clear direction for describing the differences in coping skills of family members for chronic needs and demands of EOL care.

Studies from recent past conducted on development of stress proposed that one’s self efficacy beliefs and sense of control take part diverse significant roles in wellbeing of caregivers. Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch²⁴ reported in their 3-year longitudinal study conducted on EOL care and outcomes that personal control and self-efficacy had significant outcome of decreasing depression and increasing health over time. No mediating or moderating effects of mastery beliefs were found between burden or care-related stressors and depression or mental health. However, the enhanced self-efficacy over time also had mediating or indirect effects through reducing a sense of mastery and increasing perceived competence as a caregiver, both of which were associated with depression.

Provided literature on caregivers’ experiences during terminal phase of patients led us to devise the path model for the present study. Consequently, the main objective of this study was to explore the caregivers’ wellbeing resulting from the influences of caregivers’ experiences during the end-of-life care of cardiac patients. In addition to this objective, the mediating effect of caregiving self-efficacy was also the focus of this study.

The path diagrams for the hypothesized model of caregivers' experiences and wellbeing are depicted in Figure 1 below.

Figure 1. The Path Diagram of the Hypothesized Model of Work Family Conflict



CAREGIVING SELF EFFICACY SCALE

To measure the self-efficacy of caregivers, the Caregiving Self Efficacy Scale was used.²⁷ This is a 15-item scale with three subscales; Self-Efficacy for Obtaining Respite,

METHODOLOGY

The participants of this study were the caregivers of 221 male patients of congestive heart failure with age of 23 to 57 years (M=36.71, SD=13.77). Demographic information for consecutively approached sample were related to age, education, relationship to the patient (e.g., wife, daughter, other), and length of time as a caregiver.

The instruments used to evaluate EOL was End-of-life Caregiving Experience Appraisal Scale (EOLCAS). The scale²⁵ comprised of 32 items with four subscales: two negative appraisals (physical suffering and burden), one positive appraisal (maturation), and one neutral appraisal (social support pursuit). The Cronbach's alpha for the entire scale was 0.84 indicating adequate reliability. A Likert type response format was presented to the participants for responses ranging from 1 to 5 (1 = strongly disagree, 5= strongly agree).

A shorter version of Caregiver Wellbeing Scale²⁶ was used to measure the caregivers' wellbeing. It is composed of two subscales named basic human needs and daily life activities measured with eight items each rated on 5-point likert scale. The internal consistency of overall scale and its two subscales were found high and satisfactory indicated as alpha coefficients 0.94, 0.86, and 0.82 respectively.

Self-Efficacy for Responding to Disruptive Patient Behaviors, Self-Efficacy for Controlling Upsetting Thoughts about Caregiving rated on 5-point rating response options. The overall internal reliability of the scale as indicated by alpha coefficient was 0.91.

Participants were approached through consecutive sampling technique at the Institute of Cardiology Multan. Sample participation was volunteer and with informed consents. They were fully assured about the confidentiality of their identity and responses to be provided on questionnaires. Three questionnaires altogether along with demographic sheet were then administered to the participants of this study. They were guided about the response options given for items of questionnaires. Results were then analyzed using SPSS-21.

RESULTS

Correlation analyses was performed on SPSS-21 (Table 1) to see the direct relationships among caregiving experiences (independent), wellbeing (dependent), and caregiving self-efficacy (mediating variable). The goodness of fit indices for hypothesized model was checked on AMOS-21 by using structure equation model (Table 2), and then main analysis was performed for assessing the hypothesized paths (Table 3 & 4).

Table 1: Correlations Matrix among End-of-life Experiences, Caregiving Self Efficacy, and Caregiver well-being

Caregiver Variables	M	SD	1	2	3	4	5
Independent variable							
End-of-life Experiences							
1 Physical suffering	31.2	3.50	1				
2 Burden	34.5	4.12	.32**	1			
3 Maturation	26.1	6.37	-0.07	-0.05	1		
4 Social Support	27.3	4.68	-0.09	-0.08	0.37**	1	
Mediator							
5 Self Efficacy	53.4	9.19	-0.27**	-0.21**	0.35**	0.24**	1
Dependent variable							
6 Caregiver wellbeing	19.46	7.89	-0.31**	-0.19*	0.42**	0.23**	0.44**

*p>.05, **p>.01

Table 1 shows the means, standard deviations, and correlation coefficients of the study variables. Findings demonstrate the high levels of negative experiences; physical suffering and burden among caregivers of congestive heart failure patients. Results also indicate that caregivers report the self-efficacy and wellbeing as well. Correlation analyses show the significant negative relationships of physical suffering and burden with maturation, social support, self-efficacy, and wellbeing of caregivers, while caregivers' self-efficacy and wellbeing are found positively connected with each other.

TESTING THE STRUCTURAL MODEL

Adequacy of model fitness was checked through SEM that is presented in Table 2. The model fitness was found significantly satisfactory.

indices for assumed paths in model. Results show the significant Bollen-Stine bootstrap chi-square; satisfactory normed chi-square ranging between 2-3; CFI greater than 0.90; and RMSEA less than 0.05. All these findings absolutely confirms the data normality fit for path analysis.

Table 3 presents the direct effects of caregivers' end-of-life care experiences on wellbeing and self-efficacy. Findings reveal that physical suffering and burden have significant negative direct impact on caregivers' self-efficacy and wellbeing. Positive experience of maturation has significant positive influence on wellbeing and self-efficacy. The neutral experience of social support also indicates the significant positive effect on wellbeing and caregiving self-efficacy.

Table 2: The Summary of Fit Indices Statistics for the Full Structural Equation Model (SEM) Analyses

Overall χ^2	ML p	Normed χ^2	BSB p	CFI	SRMR	RMSEA with 95% CI and P Close
77.42	0.003	2.13	0.002	0.907	0.022	0.043

Table 3: Direct Effects from Path Analysis of the Trans-contextual Model

Hypothesized Paths	Path Coefficients	
	Un-standardized	Standardized
Physical Suffering → Wellbeing	-0.23**	-0.20
Physical Suffering → Self efficacy	-0.15*	-0.14
Burden → Wellbeing	-0.38**	-0.29
Burden → Self efficacy	-0.18*	-0.19
Maturation → Wellbeing	0.31**	0.25
Maturation → Self efficacy	0.12*	0.13
Social support → Wellbeing	0.24**	0.21
Social support → Self efficacy	0.28**	0.24

*p<0.01, **p< 0.001

Table 2 demonstrates the adequacy of hypothesized model.

Table 4 submit the indirect effects of independent variables

Table 4: Indirect Effects from Path Analysis of the Trans-contextual Model

Hypothesized Paths	Path Coefficients	
	Un-standardized	Standardized
Physical Suffering → SE → Wellbeing	-0.41**	-0.33
Burden → SE → Wellbeing	-0.46**	-0.38
Maturation → SE → Wellbeing	0.49**	0.40
Social support → SE → Wellbeing	0.36**	0.27

*p<0.01, **p< 0.001

Data fulfills all the assumptions that show the goodness of fit

on dependent variables through mediating variable. Results

demonstrate that physical suffering negatively predicted the wellbeing and this relationship was further found mediated by caregiving self-efficacy. Similarly negative experience of burden also negatively affects the wellbeing which is mediated by self-efficacy. Findings also present the significant mediated effect of self-efficacy between the relationship of maturation and social support with caregivers' wellbeing.

DISCUSSION

The hypothesized model of current study was examined through SEM on AMOS-21. For calculation of direct effects and mediated effects, bootstrapping was applied. All indices of goodness of fit for data were found satisfactory (Table 2) and data were considered for further analyses of assumed paths in model. Assumed paths suggested that end-of-life care experiences of caregivers will likely to have impact on their self-efficacy and wellbeing (direct effects); caregiving self-efficacy will predict wellbeing (direct effect); self-efficacy will mediate the effects of end-of-life care experiences on wellbeing.

As hypothesized, the findings demonstrated the significant direct effects of EOL experiences on caregivers' wellbeing (Table 3). Generally caregivers experience discomfort during broaching the topic of death with physicians of their patients. Results revealed that negative emotions of physical suffering and burden have significant negative impression on wellbeing (-0.23, $p < 0.001$, -0.38, $p < 0.001$ respectively). These findings implied that when caregivers experience high levels of physical suffering and burden they experience low level of wellbeing. Negative experiences of caregivers during end-of-life care phase have reversal relationships with caregivers' mental health or wellbeing.

Physical suffering and burden reported by caregivers were also found negatively connected with self-efficacy (-0.15, $p < 0.01$, -0.18, $p < 0.01$ respectively) as hypothesized in model. Negative experiences have significant negative impression on self-efficacy. These results postulated that when caregivers experience negative emotions more they found themselves with low self-efficacy and believed that they cannot cope with this situation of terminal phase of patient who is gradually being lost from them.

These findings are in line with the work of Hofmann, Wenger, and Davis⁷ who reported that for the most part, caregivers interpret the death of their patients as the ultimate enemy. Until now, however, medical education process lacks the guidelines generally for physicians and particularly for caregivers of how to care for patients who could not be cured. Family members when are expected to provide patient-centered palliative care, are found ill-prepared. Negative experiences such as physical discomfort and psychological burden may result. Several empirical investi-

gations proposed that communication between dying persons and their families, and the physician must be improved and caregivers should understand the needs of dying patients.²⁸⁻³⁰

However one of the most important paths assumed in model tested on SEM was to see the mediating effect of self-efficacy between negative experiences and wellbeing (Table 4). Results showed that self-efficacy significantly mediated the impression of negative experiences of physical suffering and burden on wellbeing (-0.41, $p < 0.001$, -0.46, $p < 0.001$ respectively). These findings entailed that caregivers' self-efficacy was found as a strong factor that could serve as significant mediator between the negative experiences of terminal care and wellbeing.

Other findings from hypothesized mode tested on SEM pertaining to positive and neutral experiences during end-of-life care of heart patients revealed the positive impression on self-efficacy and wellbeing. Results indicated that positive experience of maturation that includes positive caregiving appraisal such as caregivers' appreciation, growth, and better relationships have significant positive effect on self-efficacy and wellbeing of caregivers (0.12, $p < 0.01$, 0.31, $p < 0.01$ respectively). Caregivers when receive the appreciation from others during the critical phase of dying patients' care feel satisfied and experience personal growth that have direct positive impact on their self-efficacy and wellbeing. Similarly, neutral experiences of caregiving appraisal such as need of spiritual support, need of resources, information and help also have positive impact on self-efficacy and wellbeing (0.28, $p < 0.001$, 0.24, $p < 0.001$ respectively).

One another significant contribution from the path analyses was the mediating role of self-efficacy between the relationships of maturation and neutral experiences of need for social support. Results supported the hypothesized path and demonstrated that self-efficacy significantly mediated the positive and neutral effect of end-of-life care experiences on wellbeing (0.49, $p < 0.001$, 0.36, $p < 0.001$ respectively). Findings suggested that when caregivers experience positive appraisal and feel need for support may experience wellbeing that is further mediated by their caregiving self-efficacy tasks during care of end-of-life patients.

CONCLUSION

The study contributed the significant findings in terms of caregivers' end-of-life experiences and its effects on their wellbeing. Findings suggested that caregivers' negative experiences of physical suffering and burden have negative impact on wellbeing while positive experiences of maturation and neutral experience of social support affected the wellbeing positively. However findings further suggested that caregiving self-efficacy mediated the effect of positive

and negative experiences on wellbeing. Self-efficacy of caregivers positively strengthened the impact of positive experiences on wellbeing; and negative experiences of end-of-life care weakened the impact of negative experiences on caregivers' wellbeing.

LIMITATIONS AND SUGGESTIONS

Hence the study findings are significant to add in literature on caregivers' end-of-life care experiences and their wellbeing, however some limitations are also important to highlight here for future research line. This study has been conducted on male caregivers and the gender of caregivers could present the different findings. Gender differences should be studied in future research. The participants of the study were only the caregivers of heart disease, the caregivers of many other terminal illnesses such as cancer and renal failure could report their experiences differently compared to caregivers of heart patients. So study could be replicated with other sample as well. The characteristics of caregivers such as personality types, coping ways, and self-esteem should also be studied as mediators between caregivers' end-of-life care experiences and their wellbeing. On the basis of these findings it is suggested that caregivers should be provided interventions for enhancing their self-efficacy because their beliefs about completing the tasks during end-of-life care of dying patients may lessen the effects of physical suffering and burden, and their wellbeing could be maintained during the whole process of care of seriously ill heart patients.

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