The Role of Family Caregiver's Sense of Coherence and Family Adaptation Determinants in Predicting Distress and Caregiver Burden in Families of Cancer Patients

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Abstract

Background: Most cancer patients' families suffer from maladaptation which increases family distress and caregiving burden. This study was conducted to explore the relationship between these maladaptation indicators, and the sense of coherence (SOC) of family caregivers alongside other family resilience determines among family caregivers of cancer patients. **Methods:** A total of 104 family caregivers of cancer patients were included in this cross-sectional study. They answered three questionnaires to assess family resilience factors: Family Inventory of Resources for Management (FIRM), Family Crisis Oriented Personal Evaluation Scales (F-COPES), and SOC scale. In addition, family maladaptation factors were determined by two instruments, including Family Distress Index (FDI) and Caregiver Burden Inventory (CBI). **Results:** The results of this study showed that the FIRM and the SOC together were responsible for 35% and 43% of the variances in FDI and CBI scores, respectively ($P < 0.001$). "Reframing", the subscale of the F-COPES, significantly predicted the variances of FDI ($\beta = -0.26$, $P = 0.01$) and CBI scores ($\beta = -0.21$, $P = 0.04$). Moreover, "Mastery and health", the subscale of the FIRM, significantly predicted the variances of FDI ($\beta = -0.38$, $P < 0.01$) and CBI scores ($\beta = -0.21$, $P = 0.02$). **Conclusions:** Family caregiver's SOC alongside other family resilience determinants plays a significant role in alleviating family distress and caregiver burden. It is suggested that palliative care providers consider family caregivers' SOC in developing a psychological intervention plan to improve family resilience in families of cancer patients.

Keywords: Cancer, caregiver, family health, palliative care, psychological resilience, sense of coherence

INTRODUCTION

Cancer diagnosis and care provision for cancer patients have a significant physical and emotional impact on the lives of both patients and their families, especially on family caregivers who are not generally trained or prepared for this demanding task.[1,2] Family caregivers also have to adjust their families and their functions in response to overwhelming caregiving demands.[3] In other words, to react adaptively to such situations, families must mobilize their resources and show resilience.[4] Family resilience is defined as the successful coping of a family in the face of hardship, which enables its member to flourish with warmth, support, and cohesion.[5]

With respect to cancer patients' families, if they do not show resilience in the face of such crises, family distress will arise, exacerbating caregivers' burden.[6] The concept of family resilience was introduced by McCubbin and Patterson as an

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adaptation process, used by families, as a unit, to cope with a stressful situation.[4] Subsequently, McCubbin and McCubbin presented the Resiliency Model of Family Stress, Adjustment, and Adaptation in 1993.[7]

According to this model, the protective factors that buffer the effects of stressors on the family are family resources, such as financial well-being, and social support alongside with problem-solving and coping strategies.[8] On the other hand, sense of coherence (SOC) of each family member, as one of the internal resources, can also provide family members with the ability to choose an appropriate coping strategy toward stressors.[9] A review of literature showed that there were several studies based on the Resiliency Model of Family Stress, Adjustment, and Adaptation in different populations,[7,10] but there was no study on families of cancer patients to explore the effects of family caregiver's SOC alongside with problem-solving strategies and family resources. Inspired by the Resiliency Model of Family Stress, Adjustment and Adaptation, this study was conducted to assess the relationship between family caregivers' SOC alongside other family resilience determinants and family maladaptation among a sample of family caregivers of cancer patients.

METHODS

Study design and setting

This cross-sectional study was designed based on the Resiliency Model of Family Stress, Adjustment, and Adaptation,[7] assessing the relationship between family resilience factors as well as family caregivers' SOC and family maladaptation indicators, including family distress and caregiving burden, among the family caregivers of cancer patients attending the outpatient oncology clinics of five university hospitals affiliated with Shahid Beheshti University of Medical Sciences in Tehran during a 4-month period from Fall to Winter 2016.

Sampling and data collection

Among university hospitals, all five hospitals with an outpatient oncology clinic were included in this study. Based on the purposive sampling, eligible main caregivers were identified and invited to participate in the study. Inclusion criteria were age >18, being an immediate family member, his or her patient receiving adjuvant chemotherapy, and no more than 1 year past the initial cancer digenesis. A total of 120 questionnaires were distributed in five hospitals, of which 16 were excluded due to incompleteness.

Instruments

Six self-report instruments were used in this study.

Family Inventory of Resources for Management

The Family Inventory of Resources for Management (FIRM) was designed to assess family resources in areas of personal resources, family system, internal resources, and also social support. The FIRM is comprised four subscales: Family Strengths I (esteem and communication), Family Strengths II (mastery and health), Extended Family Social Support, and

Financial Well-being.[11] In this study, the Persian version of this instrument was used, which has desirable psychometrics properties.[12] In the present study, Cronbach's alpha coefficient of the FIRM was 0.71.

Family Crisis Oriented Personal Evaluation Scales

This instrument measures problem-solving and behavioral coping strategies of a family in crises or challenging situations, including five subscales: acquiring social support, reframing, which refers to redefining stressful situations, seeking spiritual support, mobilizing to acquire and accept others' help, and finally, passive appraisal, indicating willingness to accept the crisis.[11] The Persian version of this instrument has acceptable validity and reliability.[13] In the present study, Cronbach's alpha coefficient of the Family Crisis Oriented Personal Evaluation Scales (F-COPES) was estimated 0.87.

Sense of Coherence scale

The short version of this scale (SOC-13) has 13 items. Validity and reliability of the Persian version of the scale were previously investigated in Iran.[14] In the present study, Cronbach's alpha coefficient of the scale was calculated 0.70.

Family Distress Index

This instrument is used to obtain family challenges and problems, showing distress or lack of balance and instability in the family.[11] In the present study, a valid and reliable Persian version of this index was used.[6] Cronbach's alpha coefficient of the instrument was 0.82 in our study.

Caregiver Burden Inventory

This instrument consists of five subscales: time-dependent burden, developmental burden, physical burden, emotional burden, and social burden.[15] The validity and reliability of the Persian version of this instrument have been confirmed.[16] In the present study, Cronbach's alpha coefficient of the instrument was evaluated 0.92.

Demographic clinical information questionnaire

Demographic and clinical data were collected by a short 8-item questionnaire.

Data analysis

Data were analyzed by the SPSS version 1 9 (SPSS Inc. Chicago, IL, USA), using descriptive and analytical statistical tests. Outcome variables were assessed by Kolmogorov–Smirnov tests for the normal distribution of the data. The results showed that there were normal distributions for all the outcome variables; thus, parametric tests were used. Before conducting hierarchical multiple linear regression analyses, a series of univariate linear regression analyses were conducted to select significant demographic and clinical variables for six main regression models.

Prior to conducting the regression analyses, all of the necessary assumptions were assessed, showing satisfactory results. These assumptions included linearity, normality, multicollinearity, and homoscedasticity.[17] For hierarchical multiple linear regressions, the variables were inserted into

two blocks: significant demographic and clinical variables and family resilience determinants (FIRM, F-COPES, and SOC). The Family Distress Index (FDI) and the Caregiver Burden Inventory (CBI) were considered as dependent variables. The significance level was set at $P < 0.05$. Missing data were <5% in our study.

Overall, in this study, six relationships were tested: (1) the FIRM, the F-COPES, and the SOC are predictors of the FDI score, (2) the FIRM, the F-COPES, and the SOC are predictors of the CBI score, (3) the FIRM subscales are predictors of the FDI score, (4) the FIRM subscales are predictors of the CBI score, (5) the F-COPES subscales are predictors of FDI score, and (6) the F-COPES subscales are predictors of CBI score.

Ethical consideration

After obtaining ethical permission from the Ethical Research Committee of the Shahid Beheshti University of Medical Sciences (Code: IR. SBMU.PHNM.1394.209), necessary permits were received. Oral and written consent forms were obtained from the participants, and afterward, the questionnaires were given to them. Participants were informed about their right to withdraw at any time during the study.

RESULTS

The results showed that 56% of family caregivers were women and 44% of men. The mean ages of family caregivers and cancer patients were 40.29 ± 13.47 and 51.67 ± 15.33 years, respectively. Most patients were diagnosed with breast cancer (61.5%). Other demographic and clinical information of caregivers and patients is shown in Table 1. Descriptive statistics for all instruments; the FIRM, the F-COPES, the SOC, the FDI, and the CBI are represented in Table 2.

The results of correlation analysis between total scores of four outcome variables: FIRM, F-COPES, FDI, and CBI are depicted in a correlation matrix in Table 3. As shown in Table 3, the total score of the FDI had a significant inverse correlation with a total score of the F-COPES ($r = -0.30$, $P < 0.001$). The total score of the FIRM ($r = 0.51$, $P < 0.001$) also had inverse correlations with the FDI.

The total score of the CBI did not show a significant inverse correlation with the F-COPES ($r = -0.16$, $P = 0.33$). However, the total score of the FIRM ($r = -0.50$, $P < 0.001$) had significant inverse correlations with the CBI.

Finally, the total score of the SOC showed a significant inverse correlation with the FDI ($r = -0.48$, $P < 0.001$) and the CBI ($r = -0.49$, $P < 0.001$).

To investigate the predictors of the FDI and the CBI, six main regression analyses were done. First, according to the univariate regression analyses, significant demographic and clinical variables ($P < 0.05$) were found (patient's gender, family income, and relationship between the patient and time

Table 1: Demographic and clinical characteristics of family caregivers and patients (*n*=104)

Variable	*n* (%)
Caregiver relationship with the patient	
Spouse	25 (24.0)
Daughter/son	50 (48.1)
Mother/father	7 (6.7)
Sister/brother	22 (21.2)
Caregiver gender	
Male	38 (36.5)
Female	66 (63.5)
Caregiver education	
Primary school	27 (25.9)
Secondary school	49 (47.1)
College/university	28 (27.0)
Sufficient monthly family income	
Yes	28 (26.9)
No	76 (73.1)
Having chronic disease	
Yes	32 (30.8)
No	72 (69.2)
Patient gender	
Male	33 (31.7)
Female	71 (68.3)
Cancer type	
Breast	64 (61.5)
Prostate	5 (4.8)
Lung	9 (8.7)
Colorectal	17 (16.3)
Other	9 (8.7)
Time since diagnosis (month)	
<3	20 (19.2)
3-6	32 (30.8)
>6 months	52 (50.0)

since diagnosis), and then, they were entered into the six hierarchical multiple regression models.

As shown in Table 4, after controlling demographic and clinical variables, two resilience factors: the FIRM ($\beta = -0.32$, $P < 0.001$) and the SOC ($\beta = -0.26$, $P < 0.001$), respectively, explained 35% of variances in the FDI score. However, The F-COPES could not predict the FDI score ($\beta = -0.03$, $P = 0.69$).

As shown in Table 4, after controlling the demographic and clinical variables, two resilience factors; the SOC ($\beta = -0.30$, $P < 0.001$) and the FIRM ($\beta = -0.28$, $P < 0.001$), respectively, explained 43% of variances in the CBI score. However, The F-COPES could not predict the CBI score ($\beta = -0.21$, $P = 0.10$).

After these analyses, we decided to run two new hierarchical multiple linear regression analyses with FDI and CBI scores as dependent variables and assess all subscales of the FIRM [Table 5] and the F-COPES [Table 6] separately.

Table 5 shows that among the F-COPES subscales scores, only the subscale of the "reframing" was the significant predictor of the FDI ($\beta = -0.26$, $P = 0.01$) and also the CBI ($\beta = -0.21$,

Table 2: Mean and standard deviation of the Family Inventory of Resources for Management, the Family Crisis Oriented Personal Evaluation Scales, the Sense of Coherence scale, the Family Distress Index, and the Caregiver Burden Inventory and their subscales

Variables (range)	Mean±SD	Range (in the study)
FIRM (0-207)	112.15±28.20	41-184
Esteem and communication (0-45)	31.42±7.21	14-44
Mastery and health (0-60)	29.30±11.11	2-57
Extended family social support (0-12)	8.00±4.15	1-42
Financial well-being (0-45)	19.97±8.16	4-41
F-COPES (30-150)	99.54±15.71	53-127
Acquiring social support (9-45)	26.73±7.98	9-43
Reframing (8-40)	31.29±5.59	12-40
Seeking spiritual support (5-25)	14.39±3.53	7-20
Mobilizing family to acquire and accept help (4-20)	14.38±4.03	4-20
Passive appraisal (4-20)	9.56±3.01	4-16
SOC scale (13-91)	55.40±14.17	19-87
Comprehensibility (5-35)	20.49±5.92	5-35
Manageability (4-28)	15.72±5.56	4-28
Meaningfulness (4-28)	19.19±5.27	4-28
CBI (0-96)	36.92±19.00	2-96
Developmental burden (0-20)	11.64±5.23	1-20
Time dependence burden (0-20)	9.49±5.58	0-20
Physical burden (0-16)	7.89±5.75	0-16
Social burden (0-20)	3.44±3.82	0-20
Emotional burden (0-20)	6.02±5.05	0-20
FDI (0-24)	9.76±5.40	0-24

FIRM: Family Inventory of Resources for Management, F-COPES: Family Crisis Oriented Personal Evaluation Scale, SOC: Sense of Coherence, CBI: Caregiver Burden Inventory, FDI: Family Distress Index

$P < 0.05$). Table 6 shows that among the FIRM subscales scores, only the subscale of the "mastery and health" was a significantly inverse predictor of the FDI ($\beta = -0.38, P < 0.001$) and also the CBI ($\beta = -0.21, P < 0.05$).

DISCUSSION

Inspired by the Resiliency Model of Family Stress, Adjustment, and Adaptation, this study was conducted to explore the family resilience mechanism to manage a demanding cancer care provision to prevent family distress and overwhelming caregiving burden as the sings of family maladaptation. Accordingly, this study aimed to assess the relationship between family resilience factors (FIRM, F-COPES, and SOC) and family maladaptation factors (FDI and CBI) in a sample of cancer patients' family caregivers.

The result of this study showed that the degree of SOC of family caregiver is a strong significant predictor of caregiver burden and family distress. In a study conducted by Stensletten *et al*., SOC as a protective psychological factor was one of the important factors in predicting caregiving burden in caregivers of dementia

patients.[18] Studies have shown that SOC is a defining variable in successful adaptation to stressful situations. In fact, strong SOC, as an internal resource, can be a modulator of better adaptation.[19] It can be said that caregivers with stronger SOC, despite facing serious challenges, could find a meaning for life in stressful situations.[18] SOC has a role in finding and using resources. Three factors that comprise SOC (comprehensibility, manageability, and meaningfulness) are pathways that can help people to deal with stressful events in life and ultimately overcome them.[20,21] Overall, caregivers' SOC as one of the internal resources of families facilitates the successful adaptation of the families and also alleviates caregiving burden.

According to the results of this study, the FIRM alongside other family resilience factors (SOC and F-COPES) was able to significantly predict the intensity of caregiving burden as well as family distress; however, closer examination revealed that "mastery and health"-one of the FIRM subscales played the greatest role. Studies have shown that families with more resources have more chance to manage stress and restore balance in the family compared to other families.[22] The findings of Khamis's study (2016) showed that among war-torn Palestinian families, "sense of mastery and health" can inversely predict mental distress and neurological disorders.[23] "Sense of mastery" in a family points to the peoples' ability to control their family life. Compelling evidence shows that sense of mastery could implicitly and explicitly protect people when they encounter stressful experiences. For instance, families with a sense of mastery might believe that they are able to solve all of their problems and control all impending problems. On the other hand, health improvement is also another critical issue to increase family capacity to provide necessary care for family members.[24] Therefore, according to our results, although cancer diagnosis and its treatments as the stressful factors can affect the family, family resilience resources, especially a sense of mastery and health, can modulate and buffer the effects of such devastating factors.

According to our findings, the total score of F-COPES alongside with other studied family resilience factors (SOC and FIRM) had no significant effect in predicting the caregiving burden and family distress, yet among five subscales of this questionnaire, reframing subscale as an adaptation skill in the family could alleviate family distress and caregiving burden. In a study conducted by Minnes *et al*., "reframing," as a subscale of F-COPES inversely correlated with the intensity of reported stress by caregivers of patients suffering from brain disorders.[25] In another study by Ostwald *et al*. among families of stroke survivors, there was also a negative correlation between "reframing" and the intensity of stress in patients' spouses as the main caregivers.[26] "Reframing" refers to the family ability to redefine the stressful incidents in the way that it would be more manageable.[11] Consequently, according to the results, it can be said that for palliative care providers, it is advisable to promote appropriate problem-solving and coping behaviors, especially reframing to facilitate coping with difficulties of cancer diagnosis and its treatment process.

Table 3: Correlation matrix between scores of the Family Inventory of Resources for Management, Family Crisis Oriented Personal Evaluation, Sense of Coherence Scale, Family Distress Index, and Caregiver Burden Inventory and their subscales scores

Variables		1	2	3	4	5	6	7	8	9	10	11	12	13	14
FDI	FDI	1	0.76**	−0.30**	−0.10	−0.37**	−0.15	−0.25*	0.03	−0.51**	−0.27**	−0.52**	−0.26**	−0.28**	−0.48**
CBI	CBI		1	−0.16	0.00	−0.31**	0.01	−0.07	−0.15	−0.50**	−0.38**	−0.44**	−0.30**	−0.33**	−0.49**
F-COPES	F-COPES			1	0.79**	0.65**	0.68**	0.70**	0.16	0.43**	0.53**	0.28**	0.33**	0.30**	0.35**
	Acquired social support				1	0.24*	0.46**	0.42**	−0.29**	0.12	0.26**	0.00	0.30**	0.07	0.09
	Reframing					1	0.33**	0.38**	−0.22**	0.56**	0.58**	0.44**	0.25*	0.36**	0.46*
	Seeking spiritual support						1	0.44**	−0.28**	0.16	0.24*	0.05	0.07	0.14	0.32**
	Mobilizing to acquire and accept help							1	−0.23*	0.37**	0.43**	0.26**	0.22*	0.29**	0.26**
	Passive appraisal								1	0.02	−0.11	0.08	−0.02	0.04	−0.10
FIRM	FIRM									1	0.74**	0.80*	0.48**	0.79**	0.47**
	Esteem and communication										1	0.39**	0.43**	0.50**	0.52**
	Mastery and health											1	0.27**	0.44**	0.38**
	Extended family social support												1	0.25**	0.14
	Financial wellbeing													1	0.29**
SOC	SOC														1

FIRM: Family Inventory of Resources for Management, F-COPES: Family Crisis Oriented Personal Evaluation Scale, SOC: Sense of Coherence, CBI: Caregiver Burden Inventory, FDI: Family Distress Index. *Correlation is significant at the 0.01 level (2-tailed), **Correlation is significant at the level 0.05 level (2-tailed)

Table 4: Results of hierarchical multiple linear regression analysis with predictor variables (Family Crisis Oriented Personal Evaluation Scale (F-COPES), Family Inventory of Resources for Management, and Sense of Coherence) of Family Distress and Caregiver Burden*

Variables	FDI			CBI		
	β	P	Adjusted R^2	β	P	Adjusted R^2
Patient gender	-	-	0.35	−0.18	0.02	0.43
Family financial situation	-	-		0.08	0.32	
Being a spouse	0.16	0.05		0.14	0.07	
Duration of diagnosis	0.16	0.04		0.25	0.00	
FIRM	−0.32	0.00		−0.28	0.00	
F-COPES	−0.03	0.69		0.10	0.21	
SOC	−0.26	0.00		−0.30	0.00	

*Dependent variables: FDI and CBI score. FIRM: Family Inventory of Resources for Management, F-COPES: Family Crisis Oriented Personal Evaluation Scale, SOC: Sense of Coherence, CBI: Caregiver Burden Inventory, FDI: Family Distress Index

Based on our findings, it is recommended that palliative care nurses develop special plans for investigating and improving families' reframing coping skill and also to increase their sense of power and health to manage their resources effectively and by doing so reduce the intensity of distress as well as caregiving burden in these families. Palliative care providers should also consider family caregivers' SOC as a key factor in family resilience.

The main strength of this study was its scientific framework which was based on the Resiliency Model of Family Stress, Adjustment, and Adaptation. This study also involved an acceptable number of cancer patients' caregivers and conducted comprehensive analyses about families' resilience resources. Nevertheless, due to the cross-sectional design of this study, we were unable to reveal some details about family resilience as a process, which materializes over time.

CONCLUSIONS

The effects of cancer as a major stressor could be managed by

Table 5: Results of hierarchical multiple linear regression analysis with predictor variables (Family Crisis Oriented Personal Evaluation subscales) of Family Distress and Caregiver Burden*

Variables	FDI			CBI		
	β	P	Adjusted R^2	β	P	Adjusted R^2
Patient gender	-	-	0.18	−0.19	0.03	0.28
Family financial situation	-	-		0.16	0.07	
Being a spouse	0.23	0.01		0.23	0.00	
Duration of diagnosis	0.17	0.06		0.28	0.00	
Acquired social support	−0.01	0.89		−0.04	0.62	
Reframing	−0.26	0.01		−0.21	0.04	
Seeking spiritual support	0.00	0.93		0.05	0.57	
Mobilizing to acquire and accept help	−0.11	0.29		0.01	0.89	
Passive appraisal	−0.06	0.52		−0.14	0.12	

*Dependent variable: FDI and CBI score. CBI: Caregiver Burden Inventory, FDI: Family Distress Index

Table 6: Result of hierarchical multiple linear regression analysis with predictor variables (Family Inventory of Resources for Management subscales) of Family Distress and Caregiver Burden*

Variables	FDI			CBI		
	β	P	Adjusted R^2	B	P	Adjusted R^2
Patient gender	-	-	0.33	−0.19	0.02	0.42
Family income situation	-	-		0.15	0.09	
Being a spouse	0.20	0.01		0.19	0.01	
Duration of diagnosis	0.14	0.08		0.25	0.00	
Esteem and communication	−0.17	0.09		−0.18	0.07	
Mastery and health	−0.38	0.00		−0.21	0.02	
Extended family social support	−0.06	0.50		−0.09	0.27	
Financial well-being	0.03	0.76		0.01	0.90	

*Dependent variable: FDI and CBI scores. CBI: Caregiver Burden Inventory, FDI: Family Distress Index

family resilience resources. Most notable resilience resources include caregivers' SOC, families' ability to reframe, and also a sense of mastery and health, which can facilitate family adaptation and reduce caregiving burden. It is suggested that palliative care providers consider family caregivers' SOC alongside other family resilience determinants in developing a psychological plan to improve family resilience of cancer-affected families.

Conflicts of interest
There are no conflicts of interest.

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