

PAPER

The impact of goal adjustment and caregiver burden on psychological distress among caregivers of cancer patients

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Abstract

Objectives: Research has demonstrated that serving in the caregiver role is often associated with increased symptoms of depression, stress, and anxiety, but some people fare better than others in managing the burden of caregiving. The goal of the present study was to examine the potential moderating role of goal adjustment (the ability to disengage from unattainable goals and reengage in alternative ones) on the relation between caregiver burden and distress in family caregivers of cancer patients.

Methods: Caregivers of adult family members diagnosed with cancer in the past 3 years participated (N = 102). Participants were consented and completed online questionnaires on psychological distress, caregiver burden, and goal adjustment.

Results: The ability to disengage from unattainable goals was associated with lower anxiety and stress in the face of increasing caregiver burden. By contrast, the ability to reengage in alternative goals was associated with lower depression as burden increased.

Conclusions: The present study suggests that goal adjustment may play an important moderating role in the relationship between caregiver burden and distress. Caregivers who are better able to disengage from unattainable goals may experience less stress and anxiety, and caregivers who are better able to reengage in alternative goals experience less depressed mood. This study provides preliminary evidence that learning different ways to approach and adjust goals may reduce depression, anxiety, and stress in family caregivers.

KEYWORDS

affect, anxiety, cancer, caregivers, depression, goals, motivation, oncology, personality, psychological stress

1 | BACKGROUND

People with serious physical health problems are more frequently being cared for at home, oftentimes receiving care from family members or close friends.¹ A recent report estimated that 39.8 million Americans are providing care for an adult family member.² Adopting the role of a family caregiver may constitute a negative life event and can disrupt many aspects of the caregiver's life.^{3,4} Not only do

family caregivers have to cope with the devastating news of a family members deteriorating health, but they also face changes to their own lifestyle and personal goals as they must manage new responsibilities.

Negative life events are associated with a range of psychological problems, including increased symptoms of depression and anxiety, a diminished ability to concentrate, and feeling nervous, restless, fearful, and distressed.^{5,6} However, while some individuals become

overwhelmed with the caregiver role, others find meaning and empowerment.⁷ A critical question is why some people transition more smoothly into the role of caregiver while others struggle.

Conceptual models of caregiving consistently suggest an influence of *caregiver burden* on a caregiver's experience of depression, anxiety, and stress.⁷⁻⁹ Also termed subjective burden, caregiver burden is often defined as an individual's negative emotional reactions to caregiver demands^{10,11} and tends to be associated with greater psychological distress.⁹⁻¹¹ However, inconsistencies exist regarding the magnitude of caregiver burden's impact on psychological distress, suggesting that it may be moderated by other individual differences.^{1,12,13}

While theoretical models within the caregiver literature provide some suggestions for moderating factors that may help explain variability in caregiver outcomes, few have considered the impact of caregiving on the pursuit of personal goals. Caregiving constitutes a major life event that may present obstacles to self-regulation, that is, the process of identifying and pursuing important personal goals. Theories of self-regulation help explain how people set and maintain personal goals and suggest that the attainment of personal goals contributes to positive emotional well-being.^{14,15} Effective goal pursuit provides individuals with a sense of purpose and meaning and is negatively associated with depression and negative affect.¹⁶

When faced with disruptions to personal goals, such as taking on the caregiver role, self-regulation can become ineffective,¹⁷ leading to greater psychological distress. Carver and Scheier suggest that such disruptions give individuals a chance to reevaluate their expectations for successful attainment of goals. For example, if an individual perceives disruptions to render goals temporarily or permanently unattainable, it may be adaptive to disengage from the current goals and reengage in new ones.^{18,19} In other words, those who can flexibly adjust their goals may have better outcomes.

The work by Wrosch and colleagues has shown that flexible goal adjustment, defined by the ability to disengage from current goals and reengage in new ones in the face of obstacles, is an adaptive aspect of self-regulation, and is associated with higher well-being.^{20,21}

Disengaging from unattainable goals is adaptive because it reduces an individuals' chance of experiencing the negative emotions associated with goal failure.^{19,20,22-25} An inability to disengage from unattainable goals has been found to be associated with greater psychological distress.¹⁶ Furthermore, the ability to reengage in meaningful alternative goals has been found to mitigate the negative impact of unattainable goals and to increase the experience of positive emotions.^{25,26}

The studies on goal adjustment discussed thus far involve primarily general community samples. What about caregivers? Few studies have focused on self-regulation in caregivers of cancer patients. However, in a study of family caregivers of mental health patients, Wrosch and Miller found that caregivers who reported high caregiver burden and poorer goal adjustment (both disengagement and reengagement) exhibited an increase in depressive symptoms.²⁶ Several studies have shown that an ability to reengage in new goals is associated with fewer symptoms of depression and anxiety among cancer patients themselves²⁷⁻³⁰; one small study (n = 40) that included partners

(who may or may not have been caregivers) found this relationship only among the patients but not partners.⁴

1.1 | Goals and hypotheses

While the empirical literature is sparse, there is theoretical justification for the notion that individual differences in self-regulation may help explain variation in psychological distress as it relates to the caregiving role. The primary aim of the current study was to examine the moderating role of goal adjustment in the relationship between caregiver burden and psychological distress in a sample of adults providing care to cancer patients. It was predicted that the ability to adjust personal goals moderates the relation between caregiver burden and psychological distress. More specifically, we hypothesized that flexibility in goal adjustment (ie, the ability to disengage from unattainable goals and to reengage in new goals) will moderate the relationship between caregiver burden and depression, anxiety, and stress.

2 | METHOD

2.1 | Participants

This study was approved by the University of North Carolina at Greensboro Internal Review Board (protocol 14-0292). Participants were recruited through social media, from community organizations, and by word of mouth; in-person recruitment also took place at a local hospital-based cancer treatment center. A sample of 102 adult caregivers (67.7% female, 75.5% White, average age of 52.81) who were currently caring for an adult family member diagnosed with cancer within the past 3 years were enrolled.

2.2 | Measures

2.2.1 | Demographics and health-related information

Participants reported on demographic information, disease stage, number of months providing care, and experience of prior mental health problems. Participants were asked four questions, two about social support and two about religious/spiritual involvement, based on a 5-point scale (1 = none of the time, 5 = all of the time): "Can you count on others to provide you with emotional support (ie, talk through difficult decisions, vent to, etc)?" and "Can you count on others help with daily demands?" "Do you consider yourself a religious or spiritual person?" and "does your religious or spiritual involvement bring you support?"

2.2.2 | Depression Anxiety Stress Scales-21

The Depression Anxiety Stress Scales-21 was used to measure caregiver psychological distress³¹ (symptoms of depression, anxiety, and stress). The 21-item measure assesses depression, anxiety, and stress with a 4-point scale (0 = did not apply to me at all to 3 = applied to

me very much, or most of the time). Items were summed and multiplied by two to obtain a total score in each subscale. Higher scores indicated greater distress. Results from this study indicated good internal consistency of the depression (Cronbach's $\alpha = .88$), anxiety (Cronbach's $\alpha = .81$), and stress (Cronbach's $\alpha = .88$) subscales.

2.2.3 | Zarit Burden Interview

The Zarit Burden Interview³² was used to measure caregiver (subjective) burden. The 22-item scale asked participants to describe how they feel as a result of the demands of caregiving, based on a 5-point scale (0 = never to 4 = nearly always). The questionnaire is intended to assess the perception of burden related to health, time, social, and financial well-being associated with being a caregiver. Items are summed to obtain a total score. Higher scores indicated greater burden. Consistent with previous research, the measure has high internal consistency in our sample (Cronbach's $\alpha = .94$).

2.2.4 | Goal Adjustment Scale

Participants were asked to complete the Goal Adjustment Scale,²¹ a commonly used self-report measure of individual differences in goal adjustment. Participants were asked to answer the questionnaire related to recent changes due to taking on the caregiver role. The 10-item scale has two subscales, and items are summed (negative items are reverse coded prior to summation) to obtain a total goal disengagement score and a total goal reengagement score. Participants are asked to indicate how they typically react when personal goals become unattainable, based on a 5-point scale (1 = strongly disagree to 5 = strongly agree). Examples of questions on this scale include the following: "I start working on other new goals" (reengagement) and "It is easy for me to reduce my effort towards the goal" (disengagement). Both subscales were internally consistent (Cronbach's $\alpha = .70$ and $.84$ for disengagement and reengagement, respectively).

2.3 | Procedures

To participate in the study, interested caregivers provided informed consent and either completed the questionnaires using an online survey platform or completed a paper questionnaire packet. Paper questionnaires were placed in a sealed envelope and returned directly to the principal investigator after completion. Upon completion of the study, participants were given the option to be entered into a raffle for a \$100 gift card.

2.4 | Data analytic strategy

Before data collection began, we conducted a power analysis to determine sample size. Results of this *a priori* analysis indicated that a sample size of 100 would yield sufficient power (.80) given a moderate effect size (R^2), .15, and an α of .05. Thus, our actual sample size of 102 is sufficient to detect moderate effects using linear regression analyses. Based on the results of the correlation analyses, tests for

multicollinearity among the predictor variables were examined prior to data analysis using the collinearity diagnostic test in SPSS 21. The results indicated low levels of multicollinearity (caregiver burden $VIF = 1.20$, goal adjustment $VIF = 1.09$). The PROCESS macro 1 was used to test moderation analyses; results were reported using unstandardized coefficients.³³

3 | RESULTS

3.1 | Participant characteristics

Participants (shown in Table 1) included 102 caregivers, 67.6% female, 75.5% identified as White or European American, mean age 52.81 years old ($SD = 15.17$), and most with at least some college education (67%). The majority of caregivers denied previous mental health care (69.6%) or a need for mental health care (70.6%). The number of months providing care in our sample ranged from 1 to 60 with an average of approximately 12 (1 year). The majority of participants were recruited from the Cone Cancer Centers in Greensboro, NC and Burlington, NC (67.7%); only seven participants (7%) enrolled in response to social media or online recruitment (geographic location undisclosed), so the sample is composed primarily of North Carolina residents. Bivariate correlations among all the included continuous study variables are available in a supplemental table upon request from the corresponding author.

3.2 | Correlations and group differences

We did not make predictions about sex effects or effects of other demographic variables, and our sample size limited our power to test for more complex interactions involving these variables. However, we did examine simple group differences and bivariate correlations with the primary study variables. Not surprisingly, female participants reported more anxiety ($t[94.41] = 2.86$, $P < .01$), depression ($t[82.21] = 2.72$, $P < .01$), stress ($t[69.40] = 2.33$, $P < .05$), and burden ($t[77.65] = 3.86$, $P < .001$); there were no significant sex differences on the GAS scales (P s $> .5$). Age was uncorrelated with GAS scales but was moderately correlated with anxiety ($r = -.38$), depression ($r = -.39$), stress ($r = -.37$), and burden ($r = -.28$).

Table 2 shows correlations among the primary study variables. Consistent with previous studies, there were strong positive correlations between caregiver burden and all three psychological distress subscales, which were also strongly intercorrelated. Additional correlations among the full set of study variables is available in Data S1.

3.3 | Goal disengagement

To examine whether goal disengagement moderated the impact of caregiver burden on symptoms of depressed mood, anxious mood, and stress, analyses were run. Table 3 shows the results of the interaction step for each model (full results including main effects are available in Data S1; note that in each model there was a significant main

TABLE 1 Caregiver demographics and health-related characteristics

Variable	Categories	Percentage or M (SD)
Sex	Male	31
	Female	68
	Did not answer	1
Age		52.81 (15.17)
Race	American Indian or Alaska Native	0
	Asian	0
	Black or African American	22
	Native Hawaiian or Other Pacific Islander	1
	White or European American Other	76
	Other	1
	Did not answer	1
Education	Did not complete high school	3
	High school or GED	26
	Some college	30
	Bachelor's degree	26
	Advanced graduate work	11
	Did not answer	5
Previous psychological services	Yes	28
	No	70
	Did not answer	28
Do you consider yourself religious?	Not at all	6
	Not really	6
	Somewhat	22
	Yes	8
	Very much so	57
Number of months providing care		12.11 (14.86)
Learned about study	Flyer from UNCG campus	4
	Flyer from hospital setting	64
	Flyer from health care provider	4
	Word of mouth	9
	Website or listserv	3
	Social media	4
	Other	13
Stage of diagnosis	Unknown	11
	Stage 1	7
	Stage 2	20
	Stage 3	11
	Stage 4	43
	Extensive	2
	Incurable	2
	Did not answer	6

TABLE 2 Correlation matrix of primary study variables

Variables	1	2	3	4	5	6
1. Caregiver burden	1.00					
2. Goal disengagement	-.17	1.00				
3. Goal reengagement	.01	.11	1.00			
4. Depression	.75**	-.09	-.04	1.00		
5. Anxiety	.62**	-.20*	-.10	.70**	1.00	
6. Stress	.75**	-.20	-.03	.82**	.74**	1.00

* $P < .05$.** $P < .01$.

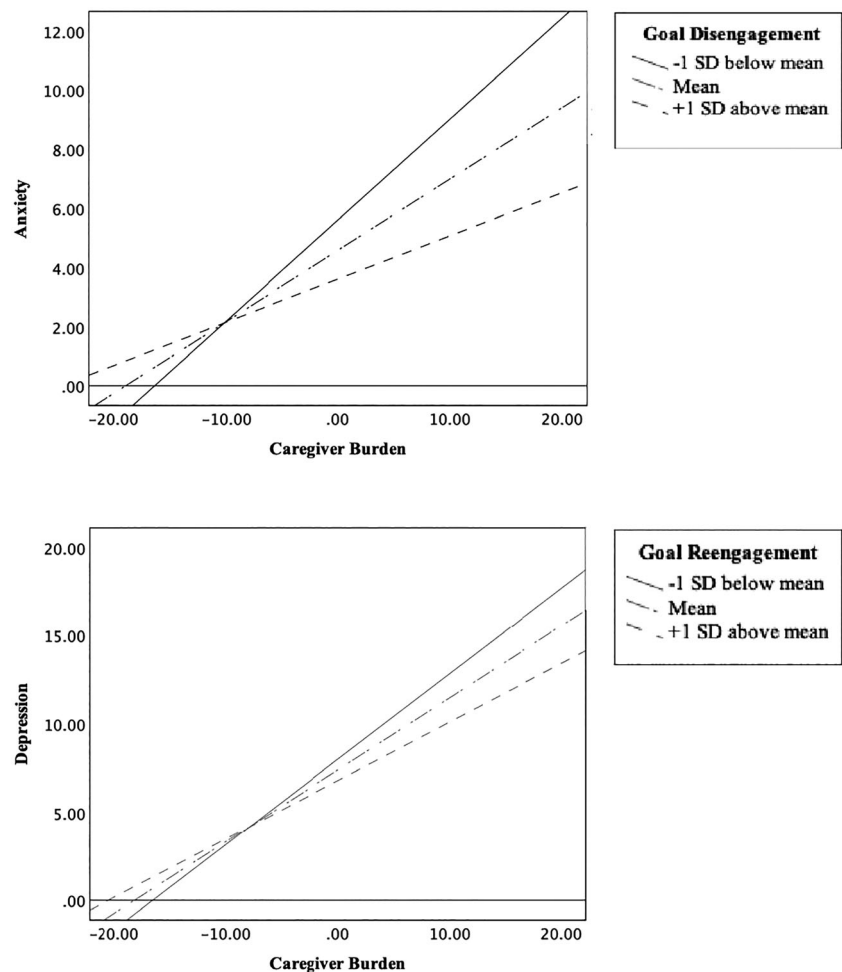
TABLE 3 Goal adjustment X caregiver burden regressed on depression, anxiety, and stress

Moderator; Outcome	Coefficient	SE	t	P	ΔR^2
Goal disengagement; depression	0.00	0.01	.35	ns	.00
Goal disengagement; anxiety	-0.03	0.01	-2.35	<.05	.04
Goal disengagement; stress	-0.03	0.01	-2.43	<.05	.03
Goal reengagement; depression	-0.02	0.01	-1.89	.05	.02
Goal reengagement; anxiety	0.00	0.01	.53	ns	.00
Goal reengagement; stress	-0.01	0.01	-1.22	ns	.01

effect of caregiver burden on psychological symptoms but no main effects of goal disengagement). Results showed a significant interaction effect for the model that included goal disengagement and anxiety, $R^2 = .42$, $F(3, 90) = 22.17$, $P < .001$, and also for stress, $R^2 = .60$, $F(3, 90) = 44.78$, $P < .001$; caregivers who reported a greater ability to disengage from goals when caregiver burden was high reported lower anxiety and lower stress. Simple slopes tests indicated that caregiver burden was more strongly related to greater anxiety for

low levels of goal disengagement, $b = 0.34$, $t(90) = 6.98$, $P < .001$, than for moderate levels, $b = 0.24$, $t(90) = 6.59$, $P < .001$, and high levels, $b = 0.15$, $t(90) = 2.40$, $P < .05$.

Similarly, the experience of caregiver burden was more strongly related to greater stress for low levels of goal disengagement, $b = 0.52$, $t(90) = 9.59$, $P < .001$, than for moderate levels, $b = 0.41$, $t(90) = 10.00$, $P < .001$, and high levels, $b = 0.30$, $t(90) = 4.38$, $P < .01$. These findings suggest that caregivers with high levels of

**FIGURE 1** Interactive effect of goal adjustment and caregiver burden on psychological symptoms

caregiver burden who report a poorer ability to disengage from goals experience greater anxiety and stress than those with a greater ability to disengage from goals (illustrated in Figure 1).

3.4 | Goal reengagement

For reengagement, results indicated a significant interaction effect for depression, $R^2 = .58$, $F(3, 89) = 40.26$, $P < .001$, but not for anxiety or stress. Table 3 shows the results of the interaction step for each model (again, there was a significant main effect of caregiver burden on psychological symptoms but no main effects of goal reengagement). Simple slopes analyses indicated that the experience of caregiver burden was more strongly related to greater depression for low levels of goal reengagement, $b = 0.48$, $t(89) = 8.46$, $P < .001$, than for moderate levels, $b = 0.41$, $t(89) = 10.94$, $P < .001$, or high levels, $b = 0.33$, $t(89) = 6.30$, $P < .001$. This suggests that caregivers who reported a poorer ability to reengage in goals, at high levels of caregiver burden, are more likely to experience greater depression than caregivers who report a greater ability to reengage in goals (as illustrated in Figure 1).

4 | CONCLUSIONS

Because of recent medical advances that reduce dependence on hospitals and medical centers, more people are caring for physically ill family members, potentially disrupting many aspects of the caregiver's life^{3,4} and resulting in a range of psychological problems, including symptoms of depression and anxiety.^{5,6} However, inconsistencies exist in the caregiver literature about the impact of caregiver burden on psychological distress, with some caregivers faring better than others. In an attempt to explain these inconsistencies, we proposed that the ability to flexibly adjust one's personal goals may be an important factor in how well people adjust to the caregiver role. The findings from the current study provide support for our prediction; we found that goal disengagement moderated the relationship between caregiver burden and anxiety and stress, and goal reengagement moderated the relationship between caregiver burdens on depression.

Research suggests that having multiple roles (ie, working and parenting) in addition to the caregiving role can increase psychological distress³⁴; juggling the demands from multiple roles may mean that fewer resources (eg, time, energy, and money) are available to devote to important personal goals. Our findings suggest that the ability to flexibly adjust one's goals (goal disengagement and goal reengagement) may be an important factor in how well caregivers adjust to these changes in their roles and responsibilities. In particular, we found that at high levels of caregiver burden, caregivers with a greater ability to disengage from unattainable goals report fewer symptoms of stress and anxiety. Additionally, at high levels of caregiver burden, caregivers with greater ability to reengage in new goals report fewer symptoms of depression.

Why was disengagement associated with anxiety and stress but not depression? While the ability to disengage from unattainable goals may be associated with less psychological distress^{18,19,25}, it may also

have negative consequences such as increasing a sense of failure.²¹ Furthermore, "unattainability" is in the eye of the beholder, and while some people may be reluctant to accept that a goal is unattainable, others (ie, those with depression) may be much too quick to do so. Researchers have suggested that disengagement in the context of clinical depression may be maladaptive and reflect goal abandonment or premature "giving up."³⁵ This notion is consistent with prior research showing that depressed individuals disengage more quickly from difficult tasks³⁶ and fail to appropriately calibrate mobilization of effort according to task difficulty.³⁷

Thus, researchers have suggested that successful goal adjustment, in the face of unattainable goals, also requires goal reengagement.^{20,21} Specifically, individuals who are able to reengage in new goals experience more positive emotions^{27,38} and fewer depressive symptoms.^{4,26} Indeed, we found a significant interactive effect of goal reengagement and caregiver burden on depression, suggesting that at high levels of caregiver burden, caregivers who report a greater ability to reengage in new goals experience fewer depressive symptoms than caregivers who report a weaker ability to reengage in new goals. Although our results require replication, and are cross-sectional in nature, they lend support to the notion that reengagement may be particularly important in depression. Goal reengagement did not moderate the relationship between caregiver burden and stress or anxiety, which is an unexpected finding. The extant literature offers no theoretical explanation for this finding, but we might speculate the goal reengagement can involve taking on new responsibilities and facing new challenges that may not serve to reduce stress or anxiety. Replication is certainly warranted in this area.

4.1 | Clinical implications

These results suggest that both goal disengagement and goal reengagement are important for family caregivers' psychological distress but in different ways. Caregivers' ability to disengage from unattainable goals may help to reduce stress and anxiety, but caregivers' ability to reengage in a new goal may work to reduce their experience of depressed mood. Taking on the caregiver role tends to come with increased emotional, physical, and temporal demands that can conflict with prior personal goals. The ability to temporarily shift goals may provide a sense of relief, reducing stress and anxiety associated with goal pursuit. However, these caregivers may still feel a sense of disappointment, sadness, and failure over not being able to maintain all goals. Thus, the ability to reengage in new goals may buffer against this by promoting a sense of success and accomplishment, decreasing depressed mood.

Psychological interventions geared toward increasing self-regulation skills and enhancing flexibility may reduce psychological distress in family caregivers, although we acknowledge that a causal relationship between goal adjustment and distress has not yet been established. Additionally, psychological interventions such as self-system therapy,³⁹ which targets self-regulatory processes, have been shown to be effective in alleviating depression, particularly among

patients with poor goal reengagement. Similar interventions may prove to be beneficial for family caregivers as well.

4.2 | Study limitations

Self-selection bias may have yielded a nonrepresentative sample. Caregivers who felt too overwhelmed by the caregiving role may have opted out of the research study entirely. While caregivers in our sample reported a range in symptom severity, the majority of caregivers reported mild symptoms of depression, anxiety, and stress. Although we aimed to keep our study as brief as possible for this reason, the time commitment associated with the present study may have deterred more overwhelmed caregivers.

Future research may benefit from examining the causality of goal disengagement and reengagement on caregiver psychological functioning across disease progression. Researchers have suggested that caregivers who have been providing care longer may experience fewer symptoms of depression because they have had more time to adjust their personal goals and expectations.¹³ Longitudinal research that follows caregivers from time of diagnosis to end of treatment may provide a unique opportunity to examine the causal relationship between individual differences in goal pursuit and psychological distress.

Given the limited research on self-regulatory processes within the caregiver literature, this study is a first step in understanding of how these constructs influence the experience of psychological distress in family caregivers of cancer patients. We therefore did not limit participation based on cancer diagnosis or stage of diagnosis. Thus, study results provided a foundational understanding of the impact of goal pursuit on the cancer caregiver experience. Future research would benefit from examining these strategies by specific types of cancer or stage of cancer to gain a more complete understanding of individual differences in the experience of cancer caregiving, as cancer type or stage may impact goal processes in important ways.

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CONFLICTS OF INTEREST

The authors have no conflicts to disclose

DATA AVAILABILITY

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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