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Stress and coping in caregivers of patients awaiting solid organ transplantation

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Abstract

Caregivers for patients undergoing solid organ transplantation play an essential role in the process of transplantation. However, little is known about stress and coping among these caregivers. Six hundred and twenty-one primary caregivers of potential candidates for lung (n = 317), liver (n = 147), heart (n = 115), and/or kidney (n = 42) transplantation completed a psychometric test battery at the time of the candidate's initial pre-transplant psychosocial evaluation. Caregivers were generally well adjusted, with only 17% exhibiting clinical symptoms of depression (Beck Depression Inventory-II score > 13) and 13% reporting clinical levels of anxiety (State Trait Anxiety Inventory score > 48). Greater caregiver burden and negative coping styles were associated with higher levels of depression. Greater objective burden and avoidant coping were associated with higher levels of anxiety. Caregivers evidenced a high degree of socially desirable (i.e., defensive) responding, which may reflect a deliberate effort to minimize fears or worries so as to not jeopardize patients' listing status.

Keywords

anxiety; caregiver burden; caregivers; coping; depression; solid organ transplantation; stress

Solid organ transplantation has become a sustainable and effective treatment intervention for patients with end-stage organ disease. The presence of one or more committed caregivers is an essential component of a patient's peri-operative well-being and postoperative success (1–3). Caregivers provide practical and emotional support to patients during various phases of the transplant process and play an integral part in facilitating successful transplant outcomes (4). Balancing patients' care needs and maintaining healthy lifestyle practices can be challenging for some caregivers; however, relatively few empirical studies have investigated the necessary psychological adjustment among transplant caregivers (5–7).

Caring for patients with chronic illnesses is regarded as demanding and stressful (8). Caregivers report more somatic complaints and greater affective distress when compared to

non-caregivers (9). Distressed caregivers commonly report feeling exhausted, overwhelmed, angry, resentful, depressed, and anxious (10–12). However, research on caregiver burden has tended to focus on certain specific patient populations, especially patients with Alzheimer's disease, other dementias, and various forms of cancer (13–15). Conversely, much less is known about how solid organ transplant caregivers cope with the stress of caring for a loved one, often a family member, who has end-stage organ disease and is being considered for transplantation.

Caregivers perform a variety of tasks throughout the transplant process. During the pre-transplant period, caregivers accompany patients to medical appointments, including pre-transplant evaluations to determine whether the patient is considered an appropriate candidate to be listed for an organ. Caregivers may need to arrange time off work, plan for family and other personal demands, raise funds to cover medical expenses, and potentially endure an unknown waiting period for a donor organ to become available (16). Perioperatively, caregivers await updates during the surgery and recovery periods, consult medical teams on any needed medical decisions, and often spend considerable amounts of time at the patient's bedside. Moreover, because major transplant centers are likely to be a distance from their homes, caregivers often relocate temporarily to be closer to the hospital, perhaps separating themselves from their local support systems and the comforts of home. Postoperative recovery time varies for patients, as does the amount and level of care required. Overall, care is viewed as a life-long process with patients requiring regular follow-up and adherence to complex medication regimens.

Prior to and during the transplant process, caregivers' health needs and psychological well-being may be overlooked because patient issues take precedence as the primary focus of attention among physicians and other healthcare professionals. Addressing patients' worsening health, increasing functional disability, and problems adjusting to stressors may become caregivers' top priority. Caregivers who disregard their own needs often experience high levels of burden and are more susceptible to burnout (17). Burnout occurs when a caregiver experiences physical or emotional exhaustion and loss of motivation, usually as a result of prolonged stress (18). Common symptoms of burnout include severe psychological distress, depression, interpersonal conflicts, and somatic symptoms (19).

How caregivers cope with stress is important for their own psychological and physical health and also impacts their ability to adequately fulfill caregiving responsibilities. The use of what are generally considered to be adaptive coping strategies, such as problem solving and seeking social support, potentially can buffer the negative effects of life and transplant-related stressors (20). In contrast, reliance upon maladaptive strategies, including avoidance, denial, and abusing substances such as tobacco products or alcohol, represent unhealthy lifestyle behaviors and have been associated with greater psychological distress (21).

The purpose of this study is to characterize the levels of burden and psychological adjustment among caregivers of persons awaiting solid organ transplant and examine relations among burden, styles of coping, and transplant caregivers' psychological adjustment.

Methods

Participants

Participants were 621 primary caregivers of potential candidates for lung (n = 317), liver (n = 147), heart (n = 115), or kidney (n = 42) transplantation at Duke University Medical Center (DUMC). A majority of caregivers were women, married, Caucasian, and the spouse of the transplant candidate (Table 1). Means and standard deviations for all study variables

by organ type are presented in Table 2. Because there were no differences between organ type and other study variables, data were combined for aggregate analyses.

Procedure

Caregivers accompanied transplant candidates during their routine pre-transplant psychosocial evaluation and participated in the clinical interview provided by the Clinical Behavioral Medicine program at DUMC. Between 2001 and 2008, a consecutive series of 845 candidates were referred for evaluation and also had their primary caregiver complete a psychometric test battery as part of their routine pre-transplant evaluation. Seventy-three percent of these caregivers agreed to participate in this research study and supplied written informed consent to have their responses de-identified and analyzed in aggregate form for research purposes. The institutional review board at Duke University Health System approved the research protocol. Participants were informed that their participation in this research study was voluntary and that their participation would not affect the candidate's transplant listing status.

Measures

1. Beck Depression Inventory (BDI-II). The BDI-II is a 21-item self-report instrument measuring cognitive, affective, and somatic symptoms associated with depression (22). For example, to assess sadness, participants can choose either: "I do not feel sad;" "I feel sad much of the time;" "I am sad all the time;" or "I am so sad or unhappy that I can't stand it." Scores range from 0 to 63, with higher scores indicating greater severity of depressive symptoms. In addition, scores can be used to classify symptoms of depression as minimal (0–13), mild (14–19), moderate (20–28), or severe (29–63).
2. Spielberger State Trait Anxiety Inventory-State Form (STAI). The STAI is a 20-item self-report instrument assessing state-related anxiety. Participants respond to statements, such as "I feel calm" and "I feel anxious," on a four-point scale ranging from 1 (not at all) to 4 (very much so) (23). Scores range from 20 to 80, with higher scores indicating elevated levels of anxiety. Normative data are available to categorize clinically elevated anxiety (STAI > 48).
3. Medical Coping Modes Questionnaire (MCMQ-R). The MCMQ-R is a 20-item self-report measure assessing medical coping among four categories: resignation, avoidance, social support seeking, and information seeking (24). Sample items include "I feel there is no hope for his/her recovery" (resignation); "When I think about his/her illness, I try to distract myself by doing something else" (avoidance); "I try to talk about his/her illness with my friends or relatives" (social support seeking); and "I have asked his/her doctor questions about his/her illness" (information seeking). Participants use a five-point rating scale ranging from "never" to "always" to indicate how often they use each strategy. Higher scores indicate greater use of each coping strategy.
4. Scale for Caregiver Burden (SCB-R). The SCB-R is a 20-item self-report instrument measuring two aspects of caregiver burden. The 10-item objective burden subscale measures the amount of practical caregiving support provided based on the severity of the patient's medical condition and functional needs. The 10-item subjective burden subscale assesses the caregiver's reported distress in response to the types and amount of caregiving activities provided (25). Sample items include "I am responsible for making sure that the patient takes all of his/her medications" and "I can't do the things I want to do because I'm taking care of the patient." For objective burden, participants rate how often they experience burden

concerns on a five-point scale ranging from “never” to “always,” and for subjective burden, participants rate how upsetting the problems are on a five-point scale from “not at all” to “a whole lot.” Scores range from 0 to 40 for the objective and subjective burden subscales, with higher scores indicating greater levels of burden.

5. Marlowe Crowne Social Desirability Scale–Short Form (MCSDS). The MCSDS consists of 13 dichotomously scored items assessing an individual’s level of socially acceptable and/or unrealistic responding (26). The scale measures the extent to which participants respond in a manner such that they would be viewed favorably by others, such as overreporting positive attributes or underreporting negative or unfavorable attributes. The scale is comprised of eight items that are keyed false (e.g., “It is sometimes hard for me to go on with my work if I am not encouraged”) and five items that are keyed true (e.g., “No matter who I’m talking to, I’m always a good listener”). A total score is computed by summing the number of true responses after reversing the negatively keyed items. Scores range from 0 to 13, with higher scores representing higher levels of socially desirable responding. Normative data are available to classify individuals who respond in an often unrealistic and socially desirable way ($\text{MCSDS} > 7$). Whereas the sample for this study is composed of 621 caregivers, MCSDS data were only available for 182 caregivers (1/3 of the total sample). The MCSDS was added as a psychometric measure to the pre-transplant questionnaire packet after initial data collection had begun, so MCSDS data were not available for caregivers who completed the questionnaire packet during the initial data collection period.

Statistical analysis

Descriptive statistics were used to characterize the severity of caregivers’ psychological distress. Two separate standard hierarchical regression analyses were used to examine the relation of stress and coping with respect to caregivers’ levels of depression and anxiety. Assumptions of multiple regression, including univariate and multivariate normality, linearity, and homoscedasticity of residuals, were examined and met (27).

Results

Caregivers’ psychological adjustment

The average BDI-II score was $7.32 (\pm 6.99)$, suggesting that caregivers of transplant candidates generally report minimal depressive symptoms. When caregivers were categorized by severity of depression using an established cutoff of 13 on the BDI-II (22), 17% of the sample could be characterized as clinically depressed, based upon their BDI scores > 13 . Among those caregivers with clinically elevated symptoms of depression, 10% ($n = 63$) were classified as having mild, 5% ($n = 28$) moderate, and 2% ($n = 11$) severe depressive symptoms. Similarly, caregivers’ mean STAI score was $37.40 (\pm 11.18)$, suggesting that caregivers generally do not report clinically elevated levels of anxiety. Using a cutoff of 48 on the STAI (23), 13% of caregivers reported anxiety scores in the clinically elevated range.

Associations between burden and coping with caregivers’ psychological adjustment

Bivariate correlations among all study variables are presented in Table 3. On average, caregivers reported significantly higher levels of objective burden associated with the provision of practical caregiving support (8.21 ± 6.44) compared to subjective burden or appraised distress attributed to those activities (4.32 ± 5.38), paired $t(542) = 25.52$, $p < 0.001$.

In the first hierarchical regression, predicting depression, age and sex were entered first as control variables, followed by objective burden, subjective burden, and coping variables entered on separate steps (Table 4). Objective burden accounted for 18% of the variance in caregivers' depression scores. Greater objective burden ($b = 0.43$, $p < 0.001$) was associated with higher levels of depression, such that a 2-unit increase in the objective burden associated with the severity of a patient's medical condition and functional needs (i.e., score on the SCB-R objective burden sub-scale) was associated with a 1-unit increase in caregivers' BDI scores. Subjective burden accounted for an additional 4% of variance in depression scores. Thus, after accounting for burden associated with actual caregiving demands, caregivers' subjective appraisal of emotional burden ($b = 0.32$, $p < 0.001$) also was associated with higher levels of depressive symptoms. The four coping variables accounted for a combined 4% of variance. Among the coping variables, only resignation ($b = 0.12$, $p = 0.002$) and avoidance ($b = 0.16$, $p < 0.001$) were statistically significant predictors, such that greater use of these negative coping strategies was related to elevated depressive symptoms. The two positive coping styles, information and social support seeking, were not associated with depression.

The second hierarchical regression investigated the relationships of burden and coping with state anxiety (Table 4). Objective burden accounted for 15% of the variance in state anxiety, and subjective burden accounted for an additional 1% of variance. The four coping variables accounted for an additional 4% of variance. Objective burden ($b = 0.38$, $p < 0.001$) and avoidant ($b = 0.17$, $p = 0.002$) coping were statistically significant predictors of anxiety. Subjective burden, resignation, information seeking, and social support seeking were not statistically associated with anxiety.

Caregivers' responses to the Marlowe Crowne Social Desirability Scale (MCSDS), among the 182 caregivers for which these data were available, were examined in post hoc analyses. The distribution of scores on the MCSDS, in which scores range from 0 to 13 (higher scores indicating more defensiveness), was negatively skewed with a median score of 10.0 and mean score of 9.68 (± 2.74). Using an established cutoff score of MCSDS > 7 based on normative comparisons (24), 80% ($n = 146$) of caregivers were considered to display defensive responding. In addition, independent t -tests comparing low vs. highly defensive caregivers (MCSDS scores in the bottom vs. top third) showed that the group of highly defensive caregivers reported significantly lower levels of objective burden ($p = 0.001$), subjective burden ($p = 0.001$), depression ($p < 0.001$), anxiety ($p = 0.008$), and avoidance coping ($p = 0.004$), compared to the low defensive caregiver group. Highly defensive caregivers also reported greater use of positive coping strategies, including information seeking ($p = 0.047$) and social support seeking ($p = 0.013$).

Discussion

Our findings suggest that a relatively small percentage of solid organ transplant caregivers report experiencing clinically elevated symptoms of depression (17%) or anxiety (13%) during their pre-transplant evaluations. Comparatively, the prevalence of mood and anxiety disorders in the general population in a given year is approximately 10% and 18%, respectively (28). Based on their self-report, these caregivers present as being psychologically well adjusted during the pre-transplant phase and presumably would be capable of managing stress and caring for themselves and the patient before and following transplant.

The results also demonstrate that objective burden (i.e., practical demands associated with the provision of care) is negatively associated with caregivers' psychological adjustment. For example, as patients' practical needs increase (i.e., they become more ill and physically

decompensated requiring more care), caregivers report experiencing significantly more psychological distress. This result is consistent with previous research. In caregivers of patients with end-stage renal disease, greater caregiver burden has been linked to poorer perceived quality of life (29) and self-rated health (30).

Following transplant, caregivers continue providing emotional and practical care to patients, suggesting that objective burden is expected to continue. Evidence also suggests that distress and psychological adjustment concerns may persist among transplant caregivers, particularly during the early postoperative period. Canning et al. (31) found that caregiver burden was associated with increased distress in the early post-transplant period among a sample of heart transplant caregivers. However, caregivers in this study appeared to recover in the months following transplant, and at one-yr post-transplant they reported having improved adjustment and feeling less stressed.

In terms of clinical relevance, early detection of caregiver distress and adjustment challenges may be helpful for patients and caregivers. Clinicians could identify and provide or refer distressed caregivers to support or mental health services early on in the process. Often times, the transplant team has social workers and/or psychologists on staff who are specifically trained and available to address the needs of transplant patients and their families. Caregivers could potentially access support services while patients await transplant and may even have access to these resources during the patients' regularly scheduled clinic visits. Results also highlight the importance of having transplant patients develop a backup care plan. A backup caregiver can be available to assist the primary caregiver or could relieve the primary caregiver for a short time so that they can rest, seek needed respite, and attend to personal needs.

Our findings also indicate that negative coping strategies are associated with elevated symptoms of distress. Use of resignation (e.g., giving up or perceiving recovery as hopeless) and avoidance (e.g., avoiding problem solving or distracting oneself with other activities) was associated with greater depressive symptomology, while use of avoidance was related to greater anxiety. If caregivers use negative coping strategies, such as resigning to the fact that they have a problem that is out of their control or avoiding problems altogether, they are more likely to feel emotionally distressed and could become clinically depressed and/or anxious. Assisting caregivers in learning more adaptive coping strategies could help them build feelings of self-efficacy, confidence, and personal control, which may reduce their reliance on negative coping strategies. Improved coping during the transplant process could also assist caregivers as they transition from their caregiving role post-transplant and resume their normal activities.

It is important to note that caregiver stability and commitment typically are considered by most transplant programs during the listing process (32). However, the extent to which that message is communicated to caregivers is not clear. The majority of caregivers in our study, for which data were available, exhibited a high level of socially desirable responding. Socially desirable responding reflects a response bias characterized by the tendency to respond in a manner that makes the respondent look good. In this context, this finding could suggest that caregivers may tend to minimize their problems and/or distress during the pre-transplant evaluation. Caregivers could be concerned that the patient might not be listed for transplant as a result of their admitting to problems or concerns. In addition, they may perceive the assessment more as an opportunity to demonstrate their competence and mental health rather than an opportunity to seek out support services and resources to address challenges.

The present study has several limitations. First, caregivers consenting to this study were self-selected and likely may have underreported symptoms of psychological distress because of concerns about transplant patients' listing status. In addition, 26% of caregivers who completed the pre-transplant assessment packet did not provide consent to use their responses for research purposes, so comparisons between consenting and non-consenting caregivers could not be performed. Examining the impact that social desirability had on caregivers' responding also was limited, owing to the fact that MCSDS scores were only available for a subset of the total sample. It is also possible that our sample may not have included those caregivers who are experiencing higher levels of distress, who may be less likely to consent to this study. Second, sample size varied by organ type with some groups, particularly with kidney being underrepresented in the total sample, which may influence the generalizability of results. Third, the design was cross-sectional and did not allow for analysis of changes in stress and coping throughout the entire transplant experience. Longitudinal follow-up of transplant caregivers is needed to determine whether and how burden and adjustment may change over time (i.e., during the pre-, peri-, and post-transplant periods). In addition, patients' level of adjustment and other relationship factors (e.g., satisfaction, communication, and cohesion) was not assessed. Investigation of related patient and relationship variables could be an important area for further study. Finally, this study primarily investigated the potentially negative consequences of caregiving. It is important to note that transplant caregivers also may experience benefits from the caregiving experience, such as feeling useful and needed, discovering inner strength, and developing a new life perspective (5). Future research examining the extent to which positive effects of caregiving may serve to buffer stress associated with transplant could be an important avenue for future research.

In summary, findings from this study highlight the need to carefully assess transplant caregivers' psychological adjustment. For those caregivers who acknowledge a high level of burden and/or psychological distress, it would be helpful to develop effective interventions to reduce caregiver burden and improve their coping and psychological adjustment. Identifying sources of objective burden (i.e., the activities that are most closely linked to distress) can be applied to the development and implementation of support services and interventions made available to caregivers. Moreover, encouraging caregivers to find a balance between attending to their personal needs and also meeting the demands of a high level of needed care is important. A multidimensional approach that provides some respite care, encourages participation in support groups, and promotes the acquisition and use of more adaptive coping skills could be most helpful in reducing psychological distress among transplant caregivers. This study also highlights limitations in interpreting self-reported data from caregivers of transplant patients provided during the pre-transplant evaluation period. Because caregivers may tend to underreport burden and emotional distress, their needs may not be identified and they are less likely to be referred for appropriate support services. Clinicians could aim to reduce caregivers' defensive response set by clearly explaining the purpose of the pre-transplant evaluation, displaying empathy and support, discussing common challenges reported by caregivers as a way of normalizing their experience, and welcoming caregivers' input during the pre-transplant interview.

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Table 1

Characteristics of caregiver sample by organ type^a

Variable	Lung n = 317 (51%)	Liver n = 147 (24%)	Heart n = 115 (18%)	Kidney n = 42 (7%)	Total N = 621 (100%)
Age ^b	51.70 (±11.40)	50.76 (±10.58)	51.19 (±11.02)	49.71 (±14.88)	51.24 (±11.40)
Gender ^c					
Female	231 (73%)	113 (77%)	103 (90%)	33 (79%)	481 (78%)
Male	84 (27%)	34 (23%)	12 (10%)	9 (21%)	140 (22%)
Ethnicity ^c					
Caucasian	272 (87%)	121 (83%)	86 (77%)	22 (54%)	503 (82%)
African American	31 (10%)	12 (8%)	21 (19%)	17 (42%)	81 (13%)
Other	13 (3%)	14 (9%)	8 (4%)	3 (4%)	37 (5%)
Relationship to candidate ^c					
Spouse	205 (65%)	99 (67%)	82 (71%)	19 (45%)	405 (65%)
Work status ^c					
Full time	161 (56%)	93 (65%)	68 (59%)	24 (57%)	348 (56%)
Part time	31 (9%)	10 (7%)	9 (8%)	4 (10%)	54 (9%)
Not working	124 (35%)	44 (28%)	37 (67%)	14 (33%)	219 (35%)

^aNo differences were found across transplant types for the reported variables.

^bMean (±standard deviation).

^cFrequency count (% by organ type).

Table 2Caregivers' means and standard deviations for psychosocial variables by organ type^a

Variable	Lung	Liver	Heart	Kidney	Total
SCB-R – objective burden	7.88 (±6.38)	8.47 (±6.65)	8.42 (±6.12)	8.98 (±7.09)	8.20 (±6.44)
SCB-R – subjective burden	4.01 (±5.44)	4.63 (±5.36)	4.26 (±5.20)	5.69 (±5.54)	4.32 (±5.38)
MCMI – information seeking	14.22 (±5.54)	14.21 (±4.63)	14.75 (±4.68)	14.26 (±5.60)	14.32 (±5.16)
MCMI – social support	10.33 (±3.35)	9.95 (±3.23)	10.86 (±2.98)	9.86 (±3.86)	10.31 (±3.30)
MCMI – resignation	9.81 (±3.03)	9.20 (±3.15)	9.45 (±2.48)	9.60 (±2.72)	9.57 (±2.94)
MCMI – avoidance	4.28 (±3.54)	4.00 (±3.22)	4.39 (±2.92)	3.45 (±3.05)	4.18 (±3.32)
BDI-II – depression	7.78 (±7.39)	7.23 (±6.92)	7.17 (±6.51)	4.50 (±4.44)	7.32 (±6.99)
STAI – anxiety	38.21 (±11.12)	35.99 (±11.03)	39.05 (±11.48)	33.00 (±10.21)	37.40 (±11.18)
MCSDS – social desirability	9.52 (±2.79)	10.00 (±2.48)	9.52 (±3.07)	9.57 (±2.87)	9.68 (±2.74)

^aNo differences were found across transplant types for the reported variables.

Table 3

Correlations among study variables

	Burden			Coping			Psychological adjustment		
	1	2	3	4	5	6	7	8	
1	SCB-R – objective burden	0.82							
2	SCB-R – subjective burden	0.79**	0.85						
3	MCMI – information seeking	0.01	-0.04	0.80					
4	MCMI – social support	-0.02	-0.06	0.47	0.75				
5	MCMI – resignation	0.22**	0.20**	-0.01	0.10*	0.44			
6	MCMI – avoidance	0.31**	0.33**	0.03	0.08	0.24**	0.75		
7	BDI-II	0.42**	0.46**	-0.02	-0.01	0.24**	0.31**	0.90	
8	STAI	0.37**	0.37**	0.00	0.09	0.19**	0.30**	0.61**	
9	MCSDS	-0.22**	-0.24**	0.17*	0.13	-0.12	-0.23**	-0.41**	
								-0.24**	

Cronbach's alpha reliability coefficients for this sample displayed on the diagonal in bold.

^{**} p < 0.001,^{*} p < 0.01.

Table 4

Hierarchical regression analyses predicting caregivers' depression and anxiety

		Depression (BDI-II)			Anxiety (STAI)				
Block	Predictors	Beta ^a	b (SE) ^b	95% confidence Interval	Δ R ² block	Beta ^a	b (SE) ^b	95% confidence interval	Δ R ² block
1.	Covariates				0.01				0.01
	Age	−0.07	−0.04 (0.03)	−0.10, 0.01		−0.09	−0.09 (0.05)	−0.20, 0.01	
	Female	0.04	0.70 (0.75)	−0.78, 2.18		0.03	0.80 (1.47)	−2.09, 3.68	
2.	Objective burden				0.18**				0.15**
	SCB-R – objective burden	0.43**	0.48 (0.04)	0.39, 0.56		0.38**	0.67 (0.09)	0.50, 0.84	
3.	Subjective burden				0.04**				0.01
	SCB-R – subjective burden	0.32**	0.42 (0.08)	0.25, 0.58		0.16	0.32 (0.16)	−0.01, 0.64	
4.	Coping				0.04**				0.04*
	MCMI – information seeking	−0.03	−0.05 (0.06)	−0.016, 0.07		−0.05	−0.12 (0.12)	−0.35, 0.12	
	MCMI – Social support	−0.02	−0.03 (0.09)	−0.22, 0.15		0.03	0.10 (0.20)	0.29, 0.48	
	MCMI – resignation	0.12*	0.31 (0.10)	0.11, 0.50		0.09	0.34 (0.21)	−0.07, 0.74	
	MCMI – avoidance	0.16**	0.33 (0.09)	0.16, 0.51		0.17*	0.54 (0.18)	0.19, 0.89	

All regression coefficients from final model.

^aStandardized regression coefficient.^bUnstandardized regression coefficient (standard error).**
p < 0.001,*
p < 0.01.