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Psychological Distress, Caregiver Burden, and Coping Methods Among Caregivers of Patients with cancer: A Study in a Nigerian Tertiary Institution

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Abstract

Caring for patients with cancer places significant emotional and physical burdens on caregivers, affecting their psychological well-being. This cross-sectional study investigated the psychological distress, caregiver burden, and coping strategies among caregivers of patients with cancer in a Nigerian tertiary institution.

Methods

The study involved 368 caregivers who completed questionnaires assessing their sociodemographic characteristics, psychological distress, caregiver burden, and coping methods.

Results

The results revealed that most caregivers were aged 31–50 years, predominantly female, and actively engaged in caregiving. Psychological distress was prevalent, with 57.1% of caregivers reporting high distress levels. The main stressors included transportation, work-related issues, fatigue, pain, worry, and fear. Caregiver burden was observed in 48.4% of the participants, with 14.7% experiencing severe burden. Coping strategies were diverse, with religious coping, planning, and active coping being the most employed. Substance use was the least favored coping method. Ineffective coping strategies were reported by 86.4% of caregivers. Caregivers aged ≤ 30 years, females with no formal education, and those lacking support experienced higher distress levels. Age, marital status, and support also influence caregiver burden.

Conclusions

This study identified significant associations between caregiver characteristics, psychological distress, and caregiver burden (P = < 0.001). Caregiving for patients with cancer in Nigeria is associated with psychological distress and caregiver burden. Understanding the factors contributing to distress and burdens is essential for developing targeted interventions and support systems. This study highlights the importance of addressing the unique challenges caregivers face.

INTRODUCTION

Caregivers are usually unpaid, untrained members of a person's social network, usually family members who help patients with cancer with activities of daily living[1]. Those who usually require the services of caregivers are those who have a malignant condition. Other areas of caregiving are old age, disability, chronic medical illness and mental illnesses. These conditions are often chronic with a long and deteriorating course extending for months or even years causing a negative joy balance and disruptive effect on the family unit[2]. Family members are fast becoming an integral part of the health care team, as family members are now carrying out many duties, which were usually performed by a trained nurse.

Cancer is one of the leading causes of adult deaths and it is second to heart disease[3]. The global cancer burden was estimated to be 18.1 million new cancer cases (17.0 million excluding non-melanoma skin cancer) and 9.6 million cancer deaths (9.5 million aside from non-melanoma skin cancer) in 2018[4]. The relative proportion of cancer is associated with a huge mortality and with the morbidity comes the huge burden of care from the caregivers.

The role of caregivers dates back in time as family members have stood in for the care of loved ones. Documented evidence reports that nursing and caring started in the late 18th century where the Nightingale influence and the Civil War in the United States birthed the caregiving industry. The central theme of both movements was the enlistment of women in the work of caring for others[5]. This was further elaborated by the American Civil War where women had to move out of the home and volunteered their services in such areas as sewing clothes for the soldiers; collecting necessary supplies, food, clothing, blankets in caring for the thousands of wounded soldiers. The women soon took up the act of caring for wounded soldiers and extended the same service to her children, husband, or aging parents[6].

Even though women are more related to the caregiver role, the female gender and caregiving almost synonymously and perfectly suit her. The primary caregiver invariably being the female spouse is more often than not, younger and healthier than the man and therefore, often experiences the caregiver burden. But literature shows that the role of the caregiver has evolved to involve both men and children and indeed the whole family of the one who is ill. Studies revealed that some men found care giving rather comforting. Men were found to provide the finance for the care and have been found to put in extra hours of work to generate more income[7]. Beyond taking care of their wife's health needs, they see the caregiving role as an extension of their authority within the family structure[8]. However, some other male caregivers experienced the caregiver distress in frustration, agitation and felt they were incompetent in the care of their spouses. Some because they were young in age and others because they felt they had not been properly tutored and oriented in the act before taking on the role of a caregiver[8,9]. Even though little work has been done by way of research to know the role of children, they obviously do form part of the care team in Africa.

The lack of institutionalized home for the elderly in Africa makes the children mandatory caregivers as most times children outlive their parents and as such, provide necessary care for them in the event of chronic medical illnesses such as cancer. Early studies found out that offspring playing the role of caregivers developed conflicts with their parents in carrying out daily routines. Also included were problems with social isolation, a decrease in their health status, family conflicts, and feelings of resentment and anger toward the parent[10]. Daughters mostly played the role of the caregiver while the son takes on the responsibility in the absence of an available female child.

The gender dynamics within caregiving roles are evolving, with daughters primarily assuming caregiving responsibilities and sons handling more administrative and financial aspects of care. Daughters often report higher stress levels, torn between caregiving and family responsibilities.

This study investigates the psychological distress experienced by caregivers and the associated burden of care when supporting family members diagnosed with cancer. This research seeks to correlate these experiences with the patients' social demographics, the disease stage, and tumor characteristics in patients with cancer undergoing treatment.

In Africa, caregiving is deeply embedded in communal life, where the community shares the responsibility for health and wellness and the associated burden. However, limited research has focused on caregiving, the psychological distress it generates, its long-term effects on caregivers, and the adaptive mechanisms caregivers employ to cope with the impact of caregiving.

This study's justification lies in examining the unique challenges posed by cancer, a chronic medical illness that places significant demands on caregivers. We emphasize the need for initial and ongoing psychological evaluation and counseling for caregivers and their family members at the onset and throughout illness and treatment to mitigate caregiver burden and distress. While caregiver burden has been extensively researched globally in other medical contexts, relatively few studies have investigated these issues locally, particularly in cancer treatment. This research seeks to contribute to the growing body of literature on caregiver burden in our environment, shedding light on caregivers' associated adaptive mechanisms and coping strategies.

MATERIALS AND METHODS

This research employs a cross-sectional descriptive design utilizing structured questionnaires, specifically the Zarit Burden Interview (ZBI)[11], COPE Inventory[12], and the NCCN Distress Thermometer[13]. The study was conducted at the NSIA LUTH CANCER CENTRE (NLCC) within Lagos University Teaching Hospital (LUTH) over six months. NLCC represents a pioneering public-private initiative by LUTH, aimed at optimizing the efficiency and effectiveness of cancer treatment. This initiative, designed to address the inefficiencies in cancer care within Nigeria, serves as a pilot program for potential replication across the country's geopolitical zones.

Lagos University Teaching Hospital (LUTH) serves as a referral center for both government-owned and private hospitals in the state. It boasts over 700 bed spaces across private and open wards and is situated in the densely populated Mainland area of Lagos, home to over 20 million inhabitants. NLCC conducts clinics five days a week, catering to both new and follow-up patients receiving various forms of cancer treatment, including chemotherapy and radiotherapy. On average, the clinic receives approximately 30 patients daily, encompassing both new and returning patients, many of whom are accompanied by caregivers, often spouses, adult children, or individuals actively involved in the patient care process.

The study was completed within a six-month timeframe from the time of ethical approval. Eligible caregivers who provided consent were enrolled in the study. Questionnaires were distributed to

caregivers, and a research assistant was available to provide assistance in completing the questionnaires, thereby assessing caregiver burden and the associated distress linked to patient care.

The study population consisted of caregivers of patients with histological verified diagnoses of primary cancer receiving various forms of care, such as radiotherapy, chemotherapy, at the NLCC of Lagos University Teaching Hospital.

Participants in the study included family members and friends of individuals with histological cancer diagnoses who had been receiving treatment for approximately six months and met the specified inclusion criteria. Informed consent was obtained from each participant.

The study included consented caregivers of histologically confirmed diagnosis of cancer who are on neo-adjuvant or adjuvant therapy (Chemotherapy or Radiotherapy). Other criteria include

- Caregivers who are 18 years and above;
- A family or paid caregiver who is the main caregiver as confirmed by the patient, and
- Healthy relatives of patients who are involved in the patient care and consent to the study.

Exclusion criteria consisted of family members not directly involved in patient care. Family members declining consent. Caregivers with known chronic medical illnesses.

The minimum sample size was determined using the Kish and Leslie formula[11], yielding a minimum of 332 participants, which was further increased to 365 to account for potential incomplete questionnaires or opt-outs.

Before enrolling eligible participants, written informed consent was obtained from each caregiver. The instruments used for data collection were a Researcher-Developed Structured Questionnaire, Adopted 22-Item Standardized Validated Zarit Burden Interview (ZBI)[11] and 60-item adapted modified Coping Orientation to Problems Experienced (COPE) Inventory.[12] The ZBI scale is a 22-item questionnaire with each item rated from 0–88 (higher score denotes higher burden for a particular item). The total burden for a subject is the sum of the scores in all the items endorsed. The total score for the scale ranges from 0 to 88 on a five-point Likert Scale (0–4). To measure the burden level of caregivers, the following scale was used:

- 0–20 represented trivial or no burden;
- 21–30 signified mild burden;
- 31–40 denoted moderate burden and
- 41–88 represented severe burden level.

The modified COPE Inventory was adopted to analyse the coping mechanism used by caregivers when confronted with the burden of caregiving. The inventory was designed using a four-point Likert scale (1–4).

Data was analyzed using Statistical Package for Social Sciences (SPSS) version 24.0. Descriptive data was entered into SPSS for validation and analysis. Findings were presented using frequency tables and charts, and bivariate associations were determined using the chi-square test, with statistical significance set at p-value ≤ 0.05.

RESULTS

Out of the 400 questionnaires distributed, 368 were filled and returned for analysis, resulting in a response rate of 92%.

In Table 1, caregiver roles in the management of care receivers are highlighted. Parent (25.3%) and spouse/partner (23.9%) were the most common caregiver relationships reported. The majority (78.8%) of caregivers lived with the patient, and only 25.3% provided more than 48 hours of care per week. Additionally, 87.0% of caregivers received support from other people in the care of the patient.

Table 1
Caregiver Role in the Management of Care Receiver

Variable	Frequency (%)
Relationship to care receiver	
Friend	4.9
Offspring	20.4
Parent	25.3
Sibling	16.8
Spouse/partner	23.9
Others (Paid caregiver, church member, work colleague)	8.7
Residing with care receiver	
Yes	78.8
No	21.2
Duration of being the caregiver	
< 6 months	32.3
6–12 months	31.5
12–24 months	18.8
> 24 months	1.4
Hours of care provided per week	
< 24 hours	45.1
24–48 hours	29.6
> 48 hours	25.3
Other people support in care of patient	
Yes	87
No	13

Psychological Distress Among the Respondents

Table 2 presents an overview of the problems and concerns causing psychological distress among caregivers. Transportation problems (27.4%) and work/school problems (26.4%) were the most common

practical concerns. Fatigue (63.9%) and pain (62.5%) were the predominant physical problems, while worry (66.3%) and fear (62.5%) were the most common emotional challenges.

Table 2
Mean score and standard deviation of coping strategies among cancer caregivers

Coping Strategies Scales	Mean (Standard deviation)
Positive reinterpretation and growth	12.5 (2.2)
Mental disengagement	9.3 (2.6)
Focus on and venting of emotions	8.7 (2.6)
Use of instrumental social support	11.8 (2.8)
Active coping	13.1 (2.7)
Denial	8.2 (2.8)
Religious coping	14.6 (2.3)
Humor	6.8 (2.7)
Behavioral disengagement	5.9 (2.3)
Restraint	11.8 (3.2)
Use of emotional social support	10.3 (2.6)
Substance use	5.1 (2.1)
Acceptance	11.4 (2.6)
Suppression of competing activities	12.2 (2.9)
Planning	13.2 (2.7)

Coping Methods Adopted by Caregivers

Table 3 displays the mean scores and standard deviations of 15 coping styles among the study caregivers. The three leading coping strategies utilized were Religious coping (14.6 ± 2.3), Planning (13.2 ± 2.7), and Active coping (13.1 ± 2.2). Substance use was the least utilized coping strategy (5.1 ± 2.1).

Table 3
Association between socio-demographic characteristics and psychological distress of caregivers

Characteristics	Distress (%)		Chi-square	p-value
	Low	High		
Age (years)			4.621	0.099
≤ 30	54 (39.4)	83 (60.6)		
31–50	66 (41.0)	95 (59.0)		
51–70	38 (54.3)	32 (45.7)		
Gender			3.299	0.069
Female	86 (39.1)	134 (60.9)		
Male	72 (48.6)	76 (51.4)		
Marital status			2.237	0.327
Married	93 (45.8)	110 (54.2)		
Divorced/widow	3 (27.3)	8 (72.7)		
Single	62 (40.3)	92 (59.7)		
Level of education			1.136	0.768
No formal education	1 (25.0)	3 (75.0)		
Primary	6 (54.5)	5 (45.5)		
Secondary	43 (42.6)	58 (57.4)		
Tertiary	108 (42.9)	144 (57.1)		
Religion			2.304	0.129
Christianity	134 (44.8)	165 (55.2)		
Islam	24 (34.8)	45 (65.2)		
Employment status			2.384	0.304
Employed	46 (48.4)	49 (51.6)		
Self employed	92 (42.4)	125 (57.6)		
Unemployed	20 (35.7)	36 (64.3)		
Residing with care receiver			2.017	0.156
Yes	119 (41.0)	171 (59.0)		

Characteristics	Distress (%)		Chi-square	p-value
	Low	High		
No	39 (50.0)	39 (50.0)		
Other people support in care of patient			5.342	**0.021***
Yes	130 (40.6)	190 (59.4)		
No	28 (58.3)	20 (41.7)		

Relationship Between Caregivers' Characteristics, Psychological Distress, Caregiver Burden, and Coping Strategies

Table 4 examines the association between socio-demographic characteristics and psychological distress among caregivers. Caregivers under 30 years of age, females, and those with no formal education expressed the highest distress levels. Despite receiving support in the care of patients from other people, a significant 59.4% of caregivers had high stress levels (p = 0.021).

Table 4
Association between socio-demographic characteristics and caregivers' burden

Characteristics	Caregiver burden (%)	Chi-square	p-value
	Trivial/no burden	Mild	Moderate
Age (years)			
≤ 30	64 (46.7)	30 (21.9)	17 (12.4)
31–50	76 (47.2)	46 (28.6)	18 (11.2)
51–70	50 (71.4)	8 (11.4)	5 (7.1)
Gender			
Female	110 (50.0)	51 (23.2)	26 (11.8)
Male	80 (54.1)	33 (22.3)	14 (9.5)
Marital status			
Married	117 (57.6)	48 (23.6)	15 (7.4)
Divorced/widow	5 (45.4)	1 (9.1)	3 (27.3)
Single	68 (44.2)	35 (22.7)	22 (14.3)
Level of education			
No formal education	2 (50.0)	1 (25.0)	0 (0.0)
Primary	5 (45.4)	2 (18.2)	3 (27.3)
Secondary	50 (49.6)	26 (25.7)	8 (7.9)
Tertiary	133 (52.8)	55 (21.8)	29 (11.5)
Religion			
Christianity	162 (54.2)	68 (22.7)	29 (9.7)
Islam	28 (40.6)	16 (23.2)	11 (15.9)
Employment status			
Employed	50 (52.6)	20 (21.1)	13 (13.7)
Self-employed	117 (53.9)	51 (23.5)	17 (7.8)
Unemployed	23 (41.1)	13 (23.1)	10 (17.9)
Residing with care receiver			
Yes	109 (37.6)	46 (15.9)	28 (9.7)
No	81 (51.9)	38 (24.4)	12 (7.7)

Characteristics	Caregiver burden (%)	Chi-square	p-value
	Trivial/no burden	Mild	Moderate
Other people support in care of patient			
Yes	121 (37.8)	47 (14.7)	25 (7.8)
No	69 (51.9)	37 (27.8)	15 (11.3)

Table 5 shows the association between socio-demographic characteristics and caregiver burden. A significant association was observed in age (p = 0.009), marital status (p = 0.027), receiving support in the care of the patient (p = 0.011), and caregiver's burden. As age increased, there was a decreasing prevalence of the severe form of caregiver burden. Single caregivers (18.8%) and those who did not receive any support in the care of the patient (16.7%) were observed to have the severe form of burden.

Table 5
Association between psychological distress and caregiver burden

Caregiver burden	Distress (%)	Chi-square	p-value
	Low	High	
Trivial/no burden	100 (61.0)	64 (39.0)	
Mild	15 (68.2)	7 (31.8)	
Moderate	10 (76.9)	3 (23.1)	
Severe	8 (53.3)	7 (46.7)	
Total	133 (57.1)	100 (42.9)	< 0.001*

Table 6 presents the relationship between psychological distress and caregiver burden. A statistically significant association (p < 0.001) was observed between the two variables. Caregivers with high distress levels were more likely to experience a severe burden.

Table 6
Association between caregiver coping strategies and caregiver burden

Coping Strategies Scales	Caregiver burden (%)	Chi-square	p-value
	Trivial/no burden	Mild	Moderate
Positive reinterpretation and growth	9 (69.2)	3 (23.1)	1 (7.7)
Mental disengagement	1 (7.7)	4 (30.8)	3 (23.1)
Focus on and venting of emotions	2 (10.5)	4 (21.1)	3 (15.8)
Use of instrumental social support	16 (57.1)	7 (25.0)	4 (14.3)
Active coping	25 (57.1)	12 (27.3)	4 (9.1)
Denial	2 (18.2)	4 (36.4)	3 (27.3)
Religious coping	16 (58.8)	9 (33.3)	2 (7.4)
Humor	3 (42.9)	2 (28.6)	1 (14.3)
Behavioral disengagement	1 (7.7)	0 (0.0)	0 (0.0)
Restraint	6 (54.5)	2 (18.2)	2 (18.2)
Use of emotional social support	6 (35.3)	6 (35.3)	3 (17.6)
Substance use	0 (0.0)	1 (12.5)	3 (37.5)
Acceptance	7 (63.6)	2 (18.2)	2 (18.2)
Suppression of competing activities	8 (66.7)	1 (8.3)	1 (8.3)
Planning	17 (53.1)	10 (31.3)	2 (6.3)

Table 7 explores the relationship between caregiver coping strategies and caregiver burden. Active coping, positive reinterpretation and growth, and use of instrumental social support were significantly associated with lower caregiver burden ($p < 0.001$).

Table 7
Association between psychological distress and stage of cancer

Cancer stage	Distress (%)		Chi-square	p-value
	Low	High		
			16.564	**0.001***
I	36 (62.1)	22 (37.9)		
II	68 (45.0)	83 (55.0)		
III	44 (37.6)	73 (62.4)		
IV	10 (23.8)	32 (76.2)		

Relationship Between Caregivers' Characteristics, Coping Strategies, and Psychological Distress

Table 8 illustrates the relationship between socio-demographic characteristics, coping strategies, and psychological distress. Caregivers with no formal education ($p = 0.004$) and those who did not receive support in the care of the patient ($p = 0.012$) were significantly associated with higher psychological distress levels. Active coping ($p < 0.001$), planning ($p < 0.001$), and acceptance ($p = 0.027$) were significantly associated with lower psychological distress levels.

Table 8
Relationship Between Caregivers' Characteristics, Coping Strategies, and Psychological Distress

Variable	Psychological Distress (p-value)
Education Level	
No Formal Education	0.004
Support in Caregiving	
No Support	0.012
Coping Strategies	
Active Coping	< 0.001
Planning	< 0.001
Acceptance	0.027

DISCUSSION

This cross-sectional descriptive study investigated the psychological distress and burden experienced by caregivers of patients with cancer and examined how caregivers navigate this process to prevent becoming overwhelmed. Our findings revealed that the most active age group in caregiving was individuals aged 31–50, followed by those under 30 years old. These two groups comprised over three-quarters of the caregiver population, with the majority being women within their active years of life. This aligns with previous research by Rosemary L. Hoffman, which also identified females in their active age as the ideal caregivers[14]. Our study further corroborates earlier findings by Adedoyin O[15], which suggested that women experience more distress and burden in caregiving due to their higher engagement in personal caregiving roles and greater exposure to caregiving risks.

Interestingly, our study did not find a statistically significant difference in distress levels between divorced or widowed caregivers and married or single caregivers. However, the fact that many of our study subjects were gainfully employed highlighted the burden associated with balancing caregiving responsibilities and employment.

Our study identified a high prevalence of psychological distress among caregivers, particularly in cases where the cancer was in advanced stages. This trend is consistent with a study conducted by Ricardo J. T. et al. in Portugal, which also observed a high prevalence of caregiver burden in advanced cancer cases[16]. Furthermore, we found a significant relationship between caregiver burden and psychological distress, indicating a direct association between these variables. Low burden levels were associated with lower distress levels.

Our study confirmed previous reports of caregivers experiencing physical problems, including fatigue, pain, and sleep impairment. These physical issues were consistent with the effects of caregiver burden reported in earlier studies.

Approximately half of our study population experienced some degree of caregiver burden, with 30% reporting severe burden, which was linked to lower patient functionality. This burden was more pronounced among female caregivers in the productive age group, single or widowed/divorced caregivers, and those without additional support.

Interestingly, our study revealed that social support received by caregivers was associated with some degree of distress. This finding aligns with research by Tilden and Galyen, who noted that social support may not always be beneficial and can be a source of stress for caregivers[17]. Kuei-Ru Chou also found that caregivers occasionally viewed visits by other relatives as intrusive and burdensome[18]. Therefore, it may be important to regulate and tailor social support to the caregiver's preferences.

Caregivers employ various coping mechanisms to manage their burden. Our study found that religious coping and extended social support were the top external coping strategies, consistent with Kuei-Ru Chou's findings[19]. Internal coping strategies included active coping, positive reframing, and acceptance. Substance use was the least utilized coping mechanism.

Our study established a significant relationship between psychological distress, cancer stage, and caregiver burden. As cancer advanced and the caregiving burden increased, psychological distress also heightened. These findings align with the works of Youngmee Kim and Serge Dumont et al., which reported increasing psychological distress with advancing cancer stages and increasing caregiving demands[19,20]. Understanding these factors can inform the development of targeted interventions to support caregivers and mitigate their distress in cancer care.

CONCLUSION

In conclusion, our study sheds light on the challenges faced by caregivers of patients with cancer and highlights several important findings. Approximately half of the caregivers in our study experienced varying degrees of distress and caregiving burden, with one-third reporting severe burden. Prominent factors contributing to psychological distress among caregivers included worry, fatigue, and pain.

Religious coping mechanisms were widely embraced to address the distress associated with caregiving, underscoring the significance of spirituality in the coping strategies of caregivers. Conversely, substance use emerged as the least utilized coping method, emphasizing the importance of healthier alternatives.

Our findings revealed statistically significant associations between the caregiver's age, marital status, presence of additional support, and the level of caregiving burden experienced. Additionally, we identified statistically significant relationships between psychological distress, caregiving burden, and the stage of the disease.

These findings underscore the complexity of the caregiver's role in cancer care and the need for targeted support and interventions. As the caregiver population continues to grow, understanding the specific factors contributing to distress and burden is crucial for developing effective support systems and interventions to improve the overall well-being of caregivers and, by extension, the quality of care provided to patients with cancer. Further research is warranted to explore these relationships in more depth and develop tailored interventions to alleviate distress and burden among caregivers.

Abbreviations

COPE Inventory
A questionnaire assessing coping strategies
LUTH
Lagos University Teaching Hospital
NCCN
National Comprehensive Cancer Network
NLCC
NSIA LUTH CANCER CENTRE
SPSS

Statistical Package for Social Sciences
ZBI
Zarit Burden Interview

Declarations

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Approval

Ethical approval was obtained from the Health Research and Ethics committee (HREC) of Lagos University Teaching HospitalWritten informed consent was obtained from each respondent before administering the questionnaire. The nature of the study was properly communicated to the participants and their right to withdraw from the study at any point in time was made voluntary. The participants were assured of confidentiality, as their names were not required for the study.

Conflict of Interest

We declare that there was no conflict of interest regarding this study.

Ethical Declaration

This study was conducted in accordance with the Declaration of Helsinki. Ethical approval was obtained from the Health Research and Ethics Committee (HREC) of Lagos University Teaching Hospital (LUTH).

Author Contribution

- Eben A. Aje conceptualized the topic, made the first draft, data collection, analyzed data, and wrote the final draft.
- Anthonia Sowunmi contributed to the first draft and the final draft.
- Adewumi Alabi assisted with the journal editing and final draft.
- Chidi Agbakwuru assisted with data collection and analysis.
- Maryam Bashir assisted with data collection and analysis.
- Muhammad Habeebu contributed to the final editing and final draft.
- Bukola Oshikanlu contributed to the final editing and final draft.
- Ola Isaac assisted with compilation, data analysis, editing, and final draft.

Data Availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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