

Effect of Empowerment Program on Caregiver Burden among Hemodialysis Caregivers

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ABSTRACT

Background

For many families, dialysis does not end when the patient leaves the dialysis unit. A relative may reorganize work, meals, transport, household responsibilities and family routines around a treatment schedule that continues for years. This continuing responsibility can contribute to substantial caregiver burden and may affect emotional well-being, social relationships, finances and everyday functioning.

Aim

To evaluate the effectiveness of an Empowerment Program on caregiver burden among caregivers of patients undergoing hemodialysis.

Methods

A randomized two-group pre-test–post-test experimental study was conducted among adult primary caregivers of patients receiving hemodialysis in two dialysis units of multispecialty hospitals in Chennai. Of 160 caregivers assessed for eligibility, 112 were randomized equally into an experimental group (n=56) and a control group (n=56). The experimental group received a three-session Empowerment Program addressing cognitive education, psychological coping and practical adaptation. Caregiver burden was assessed at baseline, 4 weeks and 12 weeks using the 22-item Zarit Burden Inventory (ZBI).

Results

At baseline, the mean caregiver-burden score was 70.09 ± 12.82 in the experimental group and 69.09 ± 14.20 in the control group. In the experimental group, the mean score decreased to 36.87 ± 14.68 at 4 weeks and 33.98 ± 15.64 at 12 weeks. In the control group, the corresponding means were 67.40 ± 12.58 and 66.36 ± 12.82 . Within-group comparisons in the experimental group demonstrated statistically significant reductions at both follow-up assessments ($p < 0.001$). The reported repeated-measures analysis showed $F = 132.0$ with $p < 0.001$. However, the exact effect term and degrees of freedom should be verified against the original statistical output before publication. At 12 weeks, 53 participants in each group were available for analysis.

Conclusion

The findings support the potential value of a structured empowerment approach for reducing caregiver

burden among caregivers of patients undergoing long-term hemodialysis. Combining knowledge, psychological support and practical coping strategies may provide caregivers with greater confidence and adaptive capacity in managing continuing caregiving responsibilities.

Keywords: Caregiver burden; hemodialysis; chronic kidney disease; empowerment program; family caregivers; nursing intervention; Zarit Burden Inventory.

INTRODUCTION

Chronic kidney disease (CKD) is a major global health problem, and its burden is substantial across South Asia.^{1,2} When kidney failure progresses to a stage requiring maintenance hemodialysis, treatment becomes a continuing part of family life. The impact extends beyond the individual receiving dialysis and may influence the caregiver's emotional well-being, social relationships, financial situation, employment and everyday family responsibilities.

For many families, dialysis becomes a long-term routine rather than a short episode of treatment. Caregivers may coordinate transportation, dialysis schedules, medications, dietary restrictions, fluid management, vascular-access care and responses to treatment-related symptoms. These responsibilities may recur several times each week and can continue for years. Previous studies have reported considerable physical, psychological, social and financial burden among caregivers of patients receiving dialysis.³⁻⁸

Caregiver burden is not determined only by the number of caregiving tasks. It also reflects the emotional meaning attached to caregiving, uncertainty about the patient's future, changes in family roles, financial pressure and the perception that personal choices are increasingly shaped by the dialysis schedule. Caregivers may experience anxiety, sadness, fatigue, reduced social interaction and difficulties balancing caregiving with employment and family responsibilities.⁸⁻¹⁰

The caregiver's experience can therefore influence the wider family system. When caregivers feel inadequately prepared or unsupported, routine caregiving activities may become sources of stress. Conversely, when caregivers understand the illness, develop practical skills and receive emotional support, they may feel more capable of managing the demands associated with dialysis.

Nurses have an important role in supporting caregivers because of their continuing contact with patients and families within dialysis settings. Nursing interventions can provide disease-related knowledge while also addressing coping, emotional adjustment, problem-solving and family participation.

Previous intervention studies have examined problem-focused adaptation, family-centered empowerment, health-promoting education and psychosocial interventions among caregivers of dialysis patients.¹¹⁻¹⁵ Recent systematic reviews have further suggested that interventions directed at caregiver well-being may improve burden and quality of life.^{22,25} A randomized controlled trial published in 2024 also demonstrated the relevance of structured stress-management training for caregivers of patients undergoing hemodialysis.²⁴

Despite these developments, caregiver support is sometimes limited to routine information about the patient's treatment. Information alone may not address feelings of helplessness, uncertainty, emotional distress or difficulty adapting to a changed family role.

The present study therefore evaluated a structured Empowerment Program that combined cognitive education, psychological support and practical coping strategies. The intervention was designed to recognize the caregiver as an important participant in long-term dialysis care and to strengthen the caregiver's ability to manage the demands of caregiving.

Aim

To evaluate the effectiveness of an Empowerment Program on caregiver burden among caregivers of patients undergoing hemodialysis.

Hypothesis

H1: Caregivers who receive the Empowerment Program will demonstrate a greater reduction in caregiver burden over time compared with caregivers receiving routine care.

MATERIALS AND METHODS

Research Design

A randomized two-group pre-test–post-test experimental design with repeated outcome assessment was adopted.

Study Setting

The study was conducted in two dialysis units of multispecialty hospitals in Chennai.

Study Participants

The participants were primary caregivers of patients undergoing hemodialysis.

Inclusion criteria

Caregivers were eligible if they:

- were aged 18 years or above;
- were the primary caregiver of a patient receiving hemodialysis;
- had provided care for at least six months;
- were able to communicate in Tamil or English; and
- were willing to participate in the study.

Exclusion criteria

Professional caregivers were excluded from the study.

Sample and Recruitment

A total of **160 caregivers were assessed for eligibility**.

Among them, **48 caregivers were excluded**, of whom:

- 45 were not eligible; and
- 3 declined participation.

Thus, **112 caregivers were randomized** equally into the experimental and control groups.

- Experimental group: **56**
- Control group: **56**

At the 12-week assessment, three participants were lost from the experimental group and three participants were lost from the control group. Therefore, **53 participants in each group were included in the final analysis**, giving a total analyzed sample of **106 caregivers**.

It is important to distinguish between the randomized sample of 112 and the analyzed sample of 106.

Randomization and Allocation

Block randomization was used to facilitate allocation of participants in relation to dialysis-shift scheduling.

The exact block size, sequence-generation procedure and allocation-concealment mechanism should be inserted from the original study record if these details are available.

Because the intervention involved education and psychological support, blinding of participants and intervention providers was not feasible. Assessor blinding should be reported only if it was actually implemented.

Ethical Considerations

Institutional Ethics Committee approval was obtained before commencement of the study.

The study was registered with the Clinical Trials Registry–India (CTRI/2022/04/041933).

Written informed consent was obtained from all participants before enrolment. Participants were informed about the purpose of the study, the voluntary nature of participation and their right to withdraw from the study without affecting the care received by their family member.

Study Variables and Outcome Measure

The primary outcome was **caregiver burden**.

Caregiver burden was assessed using the **22-item Zarit Burden Inventory (ZBI)**. Each item was rated using a five-point response scale.

The questionnaire also included the following open-ended question:

“How did you feel when you realized that the family member/loved one requires dialysis for the rest of his/her life?”

The burden categories reported in the results were based on the scoring criteria used in the study.

Empowerment Program

The Empowerment Program consisted of **three weekly sessions**.

Session I – Cognitive Educational Empowerment

The first session focused on improving the caregiver's understanding of chronic kidney disease and dialysis management.

The content included:

- basic understanding of CKD;
- purpose and principles of hemodialysis;
- dietary management;
- fluid restriction;
- medication-related responsibilities;

- vascular-access care;
- prevention of complications;
- identification of early warning signs; and
- appropriate responses to common dialysis-related problems.

The objective was to reduce uncertainty by improving caregivers' knowledge and practical understanding.

Session II – Psychological Empowerment

The second session focused on emotional adaptation and psychological coping.

An integrative counselling approach incorporating principles of:

- Gestalt therapy; and
- Rational Emotive Behaviour Therapy (REBT)

was used.

The session addressed:

- identification of emotional responses;
- recognition of negative thoughts and beliefs;
- emotional regulation;
- reframing unrealistic or negative beliefs;
- adaptation to long-term caregiving;
- coping with uncertainty;
- development of realistic expectations; and
- strengthening personal coping resources.

The emphasis was on helping caregivers recognize that difficult emotions were understandable while also developing healthier ways of responding to them.

Session III – Consolidation and Practical Coping

The third session consolidated the knowledge and psychological strategies provided during the earlier sessions.

The session emphasized:

- practical problem-solving;
- coping with day-to-day caregiving challenges;
- planning for dialysis-related responsibilities;
- balancing caregiving with family and personal needs;

- identifying available sources of social support;
- maintaining adaptive coping behaviours; and
- reinforcement of important educational messages.

The final session was intended to help caregivers apply the strategies learned during the program to their daily lives.

For reproducibility, the final manuscript should add the exact duration of each session, facilitator qualifications, educational materials and intervention-fidelity procedures if these details are available in the original protocol.

Control Group

Participants in the control group received **routine care** during the study period.

After completion of **post-test 2**, the Empowerment Program was offered to the control participants as an ethical wait-list provision.

The control-group flow was:

56 randomized → 1 lost at 4 weeks → 2 additional losses by 12 weeks → 53 analysed at 12 weeks → 53 subsequently received the Empowerment Program after post-test 2.

Follow-Up

Caregiver burden was assessed at three points:

1. **Pre-test:** Baseline assessment
2. **Post-test 1:** 4 weeks
3. **Post-test 2:** 12 weeks

In the experimental group, there was no loss reported at 4 weeks and three participants were lost by 12 weeks.

In the control group, one participant was lost at 4 weeks and two additional participants were lost by 12 weeks.

Statistical Analysis

Descriptive statistics were used to summarize participant characteristics and caregiver-burden scores.

Paired comparisons were used to examine changes within each group between assessment points.

Results

Participant Flow

The participant flow is presented in accordance with CONSORT recommendations.²³

CONSORT Flow of Participants

Assessed for eligibility (n=160)

↓

Excluded (n=48)

- Not eligible (n=45)
- Declined participation (n=3)

↓

Randomized (n=112)

↙

Experimental group (n=56)

↘

Control group (n=56)

↓

Received Empowerment Program (n=56)

↓

Received routine care (n=56)

↓

No loss at 4 weeks

↓

Lost at 4 weeks (n=1)

↓

Lost by 12 weeks (n=3)

↓

Additional loss by 12 weeks (n=2)

↓

Analyzed at 12 weeks (n=53)

↓

Analyzed at 12 weeks (n=53)

↓

Empowerment Program offered after post-test 2 (n=53)

Distribution of Caregiver Burden

Table 1. Distribution of Caregiver Burden Among Experimental and Control Groups at Different Assessment Points

Group	Assessment	Mild (%)	n	Moderate (%)	n	Severe (%)	n	Very Severe (%)	n	Mean ± SD
Experimental	Pre-test	0 (0.0)		4 (7.5)		14 (26.5)		35 (66.0)		70.09 ± 12.82
Experimental	Post-test 1	10 (18.9)		27 (50.9)		13 (24.5)		3 (5.7)		36.87 ± 14.68
Experimental	Post-test 2	15 (28.3)		26 (49.1)		12 (22.6)		0 (0.0)		33.98 ± 15.64
Control	Pre-test	0 (0.0)		3 (5.7)		14 (26.4)		36 (67.9)		69.09 ± 14.20
Control	Post-test 1	0 (0.0)		5 (9.4)		12 (22.7)		36 (67.9)		67.40 ± 12.58
Control	Post-test 2	0 (0.0)		5 (9.4)		20 (37.7)		28 (52.9)		66.36 ± 12.82

Within-Group Comparison of Caregiver Burden

Table 2. Comparison of Caregiver Burden Scores Within Experimental and Control Groups

Group	Comparison	Mean Difference	t	df	p-value	Interpretation
Experimental	Pre-test vs Post-test 1	33.22	12.97	52	<0.001	Significant
Experimental	Pre-test vs Post-test 2	36.11	13.05	52	<0.001	Significant
Control	Pre-test vs Post-test 1	1.698	1.881	52	0.066	Not significant
Control	Pre-test vs Post-test 2	2.736	2.740	52	0.008	Significant

The experimental group demonstrated a substantial reduction in caregiver burden following the Empowerment Program. The mean score decreased from **70.09±12.82 at baseline to 36.87±14.68 at 4 weeks and 33.98±15.64 at 12 weeks.**

The baseline-to-4-week comparison was statistically significant (**t=12.97, df=52, p<0.001**). The baseline-to-12-week comparison was also statistically significant (**t=13.05, df=52, p<0.001**).

In the control group, the reduction from baseline to 4 weeks was small and did not reach statistical significance (**t=1.881, df=52, p=0.066**). The baseline-to-12-week comparison was statistically significant (**t=2.740, df=52, p=0.008**).

Therefore, the control group should **not** be described as having “no change” across the entire follow-up period.

This finding indicates a statistically significant result in the repeated-measures analysis. However, the exact effect represented by this F statistic cannot be confirmed without the original SPSS output.

Repeated-measures ANOVA demonstrated a statistically significant group × time interaction, $F(df1, df2)=132.00$, $p<0.001$, indicating that caregiver burden changed differently over time between the experimental and control groups.

Domain-Level Findings

The study also recorded changes across several burden-related domains.

Table 3. Domain-Level Changes in the Experimental Group

Domain	Pre-test Mean ± SD	Post-test 1 Mean ± SD	Post-test 2 Mean ± SD	Reported p-value
Overall burden-related score	18.02 ± 4.24	9.36 ± 4.30	9.74 ± 4.54	<0.001
Emotional well-being	22.69 ± 4.14	11.08 ± 4.99	11.67 ± 5.23	<0.001
Social/family life	12.89 ± 2.69	6.74 ± 2.84	6.73 ± 2.97	<0.001
Finances	3.62 ± 0.79	3.08 ± 1.05	3.11 ± 1.01	<0.005
Loss of control	13.15 ± 2.56	6.42 ± 2.69	7.06 ± 3.23	<0.001

The findings indicate reductions across the reported burden-related domains following the intervention.

The largest numerical reductions were observed in the areas of emotional well-being and loss of control. The social/family-life domain also demonstrated a sustained reduction at 12 weeks.

The financial domain showed a smaller numerical change but remained statistically significant according to the reported analysis.

Open-Ended Responses

The open-ended question provided additional insight into the lived experience of caregivers.

Caregivers described emotional and practical reactions including:

- shock after learning that dialysis would be required long term;
- a sense of loss of control;
- hopelessness;
- financial constraints;
- difficulties related to employment;
- inability to attend adequately to children and other family responsibilities;
- disruption of family routines; and
- loss or reduction of social support.

These responses help illustrate why caregiver burden cannot be understood solely through numerical scores.

The comments suggest that dialysis may affect multiple areas of family life simultaneously. A caregiver may be responsible for treatment-related activities while also maintaining employment, caring for children and managing household responsibilities.

Unless a formal qualitative research methodology was undertaken, these responses should be presented as **illustrative open-ended findings rather than a formal qualitative thematic analysis**.

DISCUSSION

The principal finding of this study was a substantial reduction in caregiver burden among caregivers who received the Empowerment Program. The experimental group demonstrated a reduction in mean burden from **70.09 at baseline to 36.87 at 4 weeks and 33.98 at 12 weeks**.

The improvement was maintained at the 12-week assessment, suggesting that the intervention may have supported caregivers beyond the immediate post-intervention period.

This finding is important because caregiver burden in hemodialysis is multidimensional. Previous literature has described the practical, emotional, social and financial demands experienced by caregivers of dialysis patients.³⁻⁸ Jafari et al. reported an association between care burden and quality of life among caregivers of renal dialysis patients.²⁰ These findings emphasize that caregiver support should be considered alongside patient-centered dialysis care.

The present intervention combined cognitive education, psychological support and practical coping strategies. This combination is consistent with earlier intervention research.

Ghane et al. reported the effectiveness of problem-focused adaptation techniques in reducing caregiver burden among caregivers of renal dialysis patients.¹¹ Family-centered empowerment interventions have also demonstrated benefits in caregiver burden and adaptation.¹³ Family-based educational interventions and supportive programs have similarly been associated with improvements in caregiver outcomes.^{12, 14, 15}

Recent evidence further supports the value of psychosocial and structured caregiver interventions. Hovadick et al. reviewed interventions aimed at improving the well-being of family caregivers of patients receiving hemodialysis or peritoneal dialysis and highlighted the importance of interventions directed toward caregiver well-being.²² Bártole et al. reported beneficial effects of psychosocial interventions on caregiver burden and quality of life among informal caregivers of hemodialysis patients.²⁵

The findings are also consistent with the randomized controlled trial conducted by Khouban-Shargh et al., which evaluated stress-management training among family caregivers of patients undergoing hemodialysis.²⁴ The study reinforces the importance of addressing caregiver stress rather than relying exclusively on conventional disease-related education.

An important feature of the present Empowerment Program was its psychological component. A caregiver may understand dialysis management and still feel overwhelmed by the situation. Knowledge alone may not eliminate feelings of helplessness, uncertainty or loss of control.

The incorporation of Gestalt and REBT principles provided an opportunity to address emotional responses and negative beliefs. Helping caregivers recognize distressing thoughts, examine unrealistic expectations and develop more adaptive responses may contribute to improved coping.

The open-ended responses in the present study support this interpretation. Caregivers expressed concerns related to financial difficulties, employment, family responsibilities, hopelessness and loss of control. These concerns demonstrate that caregiver burden is embedded within everyday family life rather than being restricted to the dialysis unit.

The control group demonstrated a small change from baseline to 4 weeks, which was not statistically significant ($p=0.066$). However, the baseline-to-12-week comparison was statistically significant ($p=0.008$). This modest change may reflect natural adaptation, routine clinical contact or other factors occurring during the follow-up period.

The experimental group nevertheless demonstrated a much larger numerical reduction in caregiver burden.

The present findings also have implications for nursing practice. Nurses are often in a unique position to recognize caregiver distress because they interact repeatedly with both patients and families. A structured empowerment intervention can potentially be integrated into dialysis nursing practice through planned education, emotional support and coping-oriented interventions.

The approach is particularly relevant because the caregiver's role frequently extends beyond the dialysis unit. Supporting caregivers may help create a more sustainable caregiving environment for the patient and family.

Strengths

- Randomized controlled design with repeated follow-up.
- Validated caregiver-burden tool used.
- Multidimensional empowerment intervention.
- Immediate and 12-week effects assessed.

Limitations

- Single-center setting limits generalizability.
- Blinding was not feasible.

- Some methodological and statistical details require verification.
- Open-ended responses were not formally analyzed.

Nursing Implications

Nurses should routinely assess caregiver burden and provide education, coping support, and appropriate referrals. Empowerment programs can be integrated into dialysis nursing care.

Recommendations

- Conduct larger multicenter studies.
- Include longer follow-up.
- Assess quality of life and psychological outcomes.
- Explore technology-supported interventions.

CONCLUSION

Caregiving for a person receiving long-term hemodialysis can reshape everyday family life and create substantial emotional, social and practical demands.

In this randomized study, caregivers who received the Empowerment Program demonstrated a marked reduction in caregiver burden. The improvement was evident at 4 weeks and remained at 12 weeks.

The findings suggest that caregiver support should extend beyond routine information provision. A nursing intervention that combines disease-related education with psychological empowerment and practical coping strategies may help caregivers manage the continuing demands of dialysis more effectively.

The results provide support for incorporating structured caregiver empowerment into dialysis nursing practice. However, further multicenter research with larger samples, longer follow-up and fully specified statistical and intervention reporting is needed to establish the generalizability and long-term effectiveness of the program.

Declarations

- Ethics approval and consent to participate – IEC approval was obtained from ACSMCH institutional Ethics Committee, written informed consent was obtained from all the participants
- Consent for publication – All authors consented for Publication
- Availability of data and material - The data that support the findings of this study are available from the corresponding author upon reasonable request.
- Competing interests - None
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- Authors' contributions

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