RESEARCH

Telephone-based intervention improves quality of life among family caregivers of persons with dementia in Malaysia: the mediating role of caregiver burden

Hashima E. Nasreen[1], Syarifah Amirah binti Syed Ahmad[1*], Marie Tyrrell[2,3], Nora Mat Zin[4], Karimah Hanim Abd Aziz[1], Mohd Aznan Md Aris[5] and Zarina Nahar Kabir[3]

Abstract

Background Family caregiver (FC) of persons with dementia (PWD) are increasingly affected by mental and physical health which leads to poor quality of life (QoL). Telephone-based interventions offer flexible solution to support caregivers of PWD but the effectiveness needs further evaluation. This study aimed to assess the effectiveness of a telephone-based intervention in improving QoL among FC of PWD and to examine the role of caregiver burden as a mediating factor.

Methods A randomized control trial study was conducted involving 121 FCs, divided into intervention ($n=60$) and control ($n=61$) groups. The intervention group received a 10-week intervention by the healthcare professionals via telephone. QoL were measured using the validated Malay version of Control, Autonomy, Self-Realization and Pleasure (CASP-19) at baseline (T0) and endline (T1). Intention-to-treat (ITT) analysis was performed to determine the independent effect of the intervention on QoL, and mediation analysis was conducted using the multiple linear regression and bootstrap analysis.

Results Participants in the intervention group showed a statistically significant improvement in QoL ($\beta=5.00$, 95% CI 2.21–7.78, $p=0.001$). Mediation analysis revealed that caregiver burden mediated the relationship between the telephone-based intervention and QoL. Additionally, reduction of caregiver burden was observed to mediate the relationship between telephone-based intervention and reduced anxiety symptoms.

Conclusion Telephone-based intervention was effective in improving the QoL among FCs of PWD. The findings also suggest that caregiver burden plays a mediating role in this process, underscoring the need for policymakers to integrate burden-reduction training into future programs.

Trial registration ISRCTN14565552.

Keywords Telephone-based intervention, Quality of life, Family caregiver, Dementia, Mediation analysis

*Correspondence:
Syarifah Amirah binti Syed Ahmad
syarifah.amirah@live.iium.edu.my
Full list of author information is available at the end of the article

Background

According to the World Health Organization (WHO), approximately 55 million people are living with dementia, a number that is projected triple to 139 million by 2050 [1]. In Asian countries, the prevalence of persons with dementia (PWD) above 65 years old reported ranging from 4 to 8% [2–4]. As Malaysia is projected to become an aging nation by 2030, with an estimated 15.3% of population aged 60 years and above, the number of PWD is predicted to increase by 312%. Of these persons, an estimated 8–11% will require 24-hour care and full dependency [5]. These raises concerns not only about the quality of life (QoL) of PWD and their daily functioning but may create substantial emotional and psychological strain on family caregiver (FC) particularly those in primary caregiving roles.

Numerous studies have found that FCs to PWD often face a range of caregiving related stressors including emotional distress [6], burden [7], social stigma [8], feelings of helplessness [9], and caregiver burnout [10]. This prolonged exposure to distress may result in clinically significant anxiety which affects their overall well-being and quality of life [11–13]. In a local Malaysian study, Nasreen et al. [14] reported prevalence of caregiver burden among FCs of PWD to be 69.4%, depressive symptoms to be 32.2% and anxiety symptoms 32.2%. Kai et al. [15] emphasise that FCs' QoL is a critical dimension representing how individuals perceive their life circumstances. Furthermore, studies in Malaysia indicate that the QoL of older adults is strongly influenced by social dimensions, particularly relationships with spouses, siblings, and adult children [16–18].

Despite increasing awareness of mental health issues in Malaysia, particularly following the COVID-19 pandemic, interventions have largely focused on PWD [19–23], while the mental health needs of their FCs have received insufficient attention. Although several support services for the FCs are available, such as focus group discussion [24, 25] and online education [26, 27], their effectiveness may be hindered by challenges such as logistical constraints, limited accessibility or unstable internet connections [28, 29] particularly in underserved areas. As a result, telephone-based intervention emerged as a potential approach to overcome these challenges [30, 31].

In some countries such as USA, Germany and Hong Kong [32–34], telephone-based interventions were found to effectively improve FC's well-being. Unfortunately, its role in supporting FCs of PWD remains limited, both in terms of availability and empirical validation especially in low- and middle-income countries in Asia. Additionally, research indicates that FCs' poor QoL, caregiver burden and anxiety often co-exist and influence one another [35, 36]. However, the pathways of the effect of an intervention on outcome variables is unclear [14, 34]. Therefore, the primary objective of this study was to measure the effectiveness of telephone-based intervention on improving QoL among FCs of PWD. The secondary objective aimed to analyze the mediating role of caregiver burden on the association between intervention and QoL as well as between intervention and anxiety symptoms.

Methods

Study design and setting

This was a randomized controlled trial (RCT) carried out among FCs of PWD. Participants were recruited from the list of PWD from the psychiatry and memory clinics of Sultan Ahmad Shah Medical Centre (SASMEC), and Hospital Tengku Ampuan Afzan (HTAA), Kuantan, Pahang, and the geriatric clinic at the University Kebangsaan Malaysia Medical Centre (UKMMC), Kuala Lumpur.

Participants

Participants were eligible for recruitment if they were primary FCs of a person who was diagnosed with dementia at any stage, aged 18 years and above, had been providing care for at least 4 h/day for >6 months, lived in the same household as the PWD, had access to a telephone, were able to read and understand Malay. FCs who reported having major acute medical illness or hearing-impairment were excluded from the study.

The sample size was estimated based on the main variables of interest according to the original study [14]. The sample size calculation was performed with an assumed current improvement rate of 30% in caregivers' burden and depressive symptoms, an expected net improvement of 25–30% with the intervention [37], a significant level of α = 0.05, and power of 0.80, resulting in a required sample size of 100 participants. Accounting for an anticipated 20% dropout rate, the final estimated sample size was 120 participants. With a sample size of 120, significance level of < 0.05, and median effect sizes of 0.06–0.148 (partial η^2) for QoL [38], the power analysis showed that power remained above 0.80 at post-intervention.

A total of 121 FCs were enrolled for the study by the trained research assistant after screening of 380 eligible participants. The FCs were then randomly assigned (1:1 ratio) to either intervention or control group using a 4-block randomization. Participants in the intervention group received both the telephone-based intervention and standard care, and the control group received standard care only (Fig. 1). To minimize the risk of selection bias, the randomization sequence was generated by an independent statistician who was not involved in the study. The allocation was concealed using sealed opaque envelops and was sent to the head nurse who was responsible in issuing the envelopes to the trained healthcare professionals. The healthcare professional opened the sealed envelopes and subsequently initiated
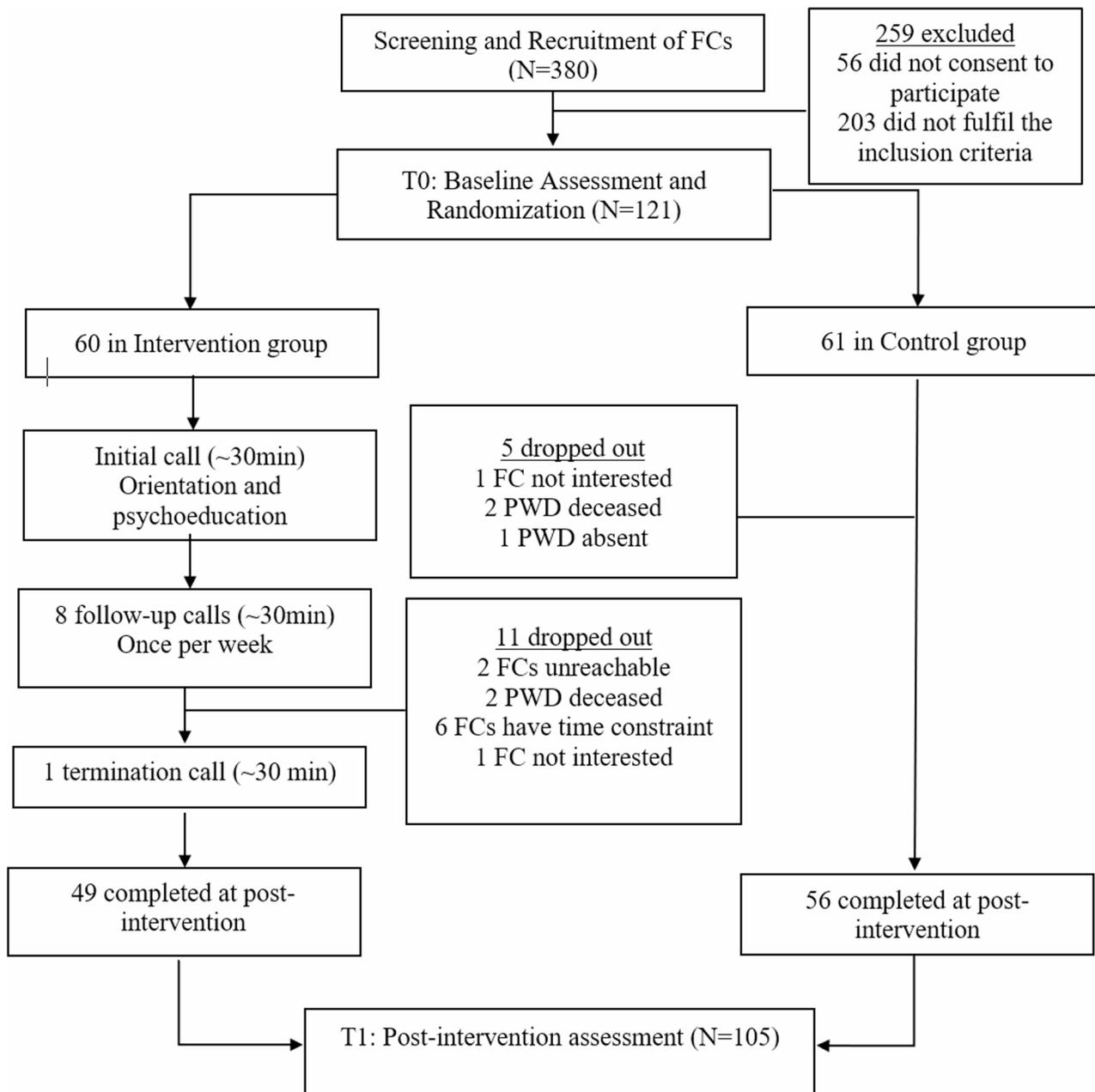
Fig. 1 Flowchart of the study procedures

the intervention. The allocation was concealed until the end of intervention to maintain blinding of the enrolled participants. These healthcare professionals were not involved in data acquisition.

Intervention

An intervention booklet called 'My Caregiver Booklet', inspired by WHO iSupport manual [39], was developed by the research team. iSupport was designed by WHO to support caregivers to PWD. It is a training and skills program aimed at improving the well-being of caregivers and enhancing the quality of care provided by FCs to

persons living with dementia. The booklet, which contained 10 main topics, as summarized in Supplementary Table 1, was provided exclusively to FCs in the intervention group. The FCs in the intervention group received the intervention through 10 weekly sessions, each lasting approximately 30 min, and delivered via telephone by a designated, trained healthcare professional (Fig. 1). The healthcare professionals who delivered the intervention consisting of 5 nurses and 2 occupational therapists. Each telephone call was scheduled at mutually agreed times for both FCs and healthcare staff. Each session began by addressing possible challenges faced by the caregivers

in their caregiving roles and concluded with a task to be completed before the next session.

In order to maintain fidelity and standardization, all healthcare professionals received a 3-day training on participant enrolment, psychoeducational intervention module and its implementation strategies, followed by a 1-day refresher training in the local language '*Bahasa Melayu*'. The training emphasized active learning by encouraging questions and using role playing extensively. Each nurse was given a file containing intervention guidelines, session log, My Caregiver Booklet in both English and Malay language, and a complete set of the WHO iSupport manual [39]. The healthcare professionals were monitored through session logs and were supervised by a psychiatrist consultant who was not involved in data collection. After each session, the nurses and occupational therapists recorded the session duration in their logbooks. The mean duration per session was 34.85 min, and 105 participants completed all sessions.

Data collection
The data was collected at two points of time; baseline i.e., prior to the intervention and end line, after the intervention period, which spanned from August 2022 to August 2024. Data collection was performed by trained research assistants (RAs) who were blinded to group allocation.

Background characteristics
Background characteristics were collected at baseline on demographic and socio-economic variables, caregiving information, information about PWD, social support and caregiving burden.

Demographic and socio-economic variables
Demographic and socio-economic characteristics of the FCs included age, sex, religion (Muslim, non-Muslim), education (primary, secondary or tertiary), marital status (unmarried, married, divorced/widowed), occupation (employed, homemaker/unemployed, retired), monthly household income (low income, middle income and high income) and FC's comorbidities. According to the Department of Statistics Malaysia (DOSM) (2019), households are classified into income group: low-income (B40: Bottom 40%), for households with a monthly income RM4850 and below; M40 (Middle 40%) for households with monthly income between RM 4851 and RM10,970; and T20 (Top 20%) for households with a monthly income of RM10,971 and above (1 USD = RM4.70 as of date of data collection).

Caregiving information
Caregiving information included length of caregiving period, hours of caregiving per day, whether caregiving is shared and number of family members involved, and caregiver's relationship with PWD.

Information about the PWD
Information about PWD included PWD's age, sex, and ability to self-care.

Social support
Perceived social support from family, friends and significant others was assessed using the validated Malay Version of the Multidimensional Scale of Perceived Social Support (MSPSS) [40]. The scale consists of 12 items, equally divided among the three support sources. The 7-point Likert scale were rated (1 = Very Strongly Disagree, 2 = Strongly Disagree, 3 = Mildly Disagree, 4 = Neutral, 5 = Mildly Agree, 6 = Strongly Agree, 7 = Very Strongly Agree), with the total score of 7–84, where higher score indicated higher social support. The Cronbach's alpha of MSPSS in this study was 0.93.

Caregiver burden
Data on caregivers' burden were collected using the 22-item validated Malay version of the Zarit Burden Interview [41]. The instrument was rated on a 5-point Likert scale ranging from 0 (Never) to 4 (Nearly Always), with the total score ranging from 0 to 88. Higher score indicates higher level of burden, with a cut off value of > 21. Cronbach's alpha value of the scale in this study was reported as 0.92, indicating good internal consistency and reliability.

Outcome measures
The outcome measure in the study was QoL. However, we examined the mediating role of caregiver burden on both QoL and anxiety symptoms.

Caregiver's quality of life
Caregiver's QoL was assessed using the validated Malay version of Control, Autonomy, Self-Realization, and Pleasure (CASP-19) scale [42] which includes 19-items assessing 4 domains: control (4-items), autonomy (5-items), self-realization (5 items) and pleasure (5-items). Responses are rated on a 4-point Likert scale ranging from never to often (0–3), with a maximum total score of 57. Higher score represents greater QoL. Cronbach's alpha of the scale in this study was 0.88 and 0.91 at baseline and endline, respectively.

Caregiver's anxiety symptoms
Caregiver's anxiety symptoms were assessed using the anxiety subscale of the validated Malay version of the Hospital Anxiety and Depression Scale (HADS) [43]. The anxiety subscales consist of 7 items, scored from 0 to 3 on each item, the total score being 0 to 21. Higher score

indicates higher anxiety symptoms. In our study, the Cronbach`s alpha demonstrated good reliability of 0.84 at baseline and 0.83 at endline.

Data analysis
Data were analyzed using IBM SPSS version 28.0. Bivariate analyses, such as independent t-test, Chi-square test and Fisher's exact test were conducted to compare the baseline characteristics between intervention and control groups. Intention-to-treat (ITT) analysis using linear mixed-model for repeated measures and adjusted for all possible associated factors, was performed to determine the independent effect of the intervention on QoL. ITT included full samples regardless of whether they adhered to or withdrew from the assigned treatment. Assuming equal variance at all measurement points within the subject, the optimal covariance structure for the repeated measures model was determined by compound symmetry, based on best fit by Akaike Information Criterion (AIC) and Bayesian Information Criteria (BIC). We included fixed effects in the model because they represent the mean differences between the treatment groups and how the response changes over time.

To ensure the assumption whether caregiver burden mediated the relationship between intervention and, QoL and anxiety symptoms, a four-step method by Baron and Kenny [44] via a series of multiple regression analysis were used. The first step examined the relationship between the intervention (independent variable) and QoL or anxiety symptoms (dependent variables), which is known as Path C. In the second step, the intervention was regressed on the caregiver burden (mediator) (Path A). The third step is the relationship between the mediator, that is caregiver burden and (i) QoL or (ii) anxiety symptoms (Path B), and the final step examined the direct effect of telephone-based intervention on QoL or anxiety symptoms with the simultaneous entry of burden (Path C´). Four criteria must be met in order to establish mediation using the regression analysis: paths A, B and C must be significant, while path C´ should be either less significant (indicating partial mediation) or non-significant (indicating full mediation) compared to path C (Supplementary Fig. 1). Because of the high multicollinearity between the subscales of MPSS ($r > 0.80$, $p < 0.001$), separate multiple linear regression models were analyzed for each subscale of social support.

After the assumptions for mediation analysis were met, a Generalized Linear Model (GLM) mediation analysis was conducted using a bootstrapping procedure in the jAMM module of Jamovi (version 2.7.12) to enhance the robustness of the statistical inference [45]. Bootstrapping with 5000 replications was used, and percentile-based 95% confidence intervals (CI) were computed for each indirect effect. A significance level of $p < 0.05$ was applied for all statistical analyses.

Ethical consideration
This study was approved by the National Medical Research and Ethics Committee (NMRR ID-22-00137-BUY), IIUM Research and Ethics Committee (IREC 2022-007), Department of Psychiatry and Memory, Hospital Tengku Ampuan Afzan (HTAA) (00137-BUY(2)), and Department of Psychiatry Sultan Ahmad Shah Medical Centre (IIUM/413/013/14/11/2/IISR22-09), Research Ethics Committee of Universiti Kebangsaan Malaysia (UKMPPI/11/8/JEP-2022-328). Informed consent was obtained after providing detailed information about the purpose and type of the study, interventions, procedures and protocols, and risks as well as benefits for participating in the project. The participants were ensured anonymity and confidentiality of their data.

Results
Response rate and adherence to the intervention
A total of 121 FCs were enrolled in the study. Of these, 60 FCs were randomized to the intervention group and 61 FCs to the control group. During the course of the study, the attrition rate recorded was 13.2% (16 FCs) of which 9.1% (11 FCs) was from the intervention group, and 4.1% (5 FCs) from the control group. The primary reason for dropout was time constraints (38%), followed by the death of the PWD (25%), unreachable FCs (19%), FCs unwilling to continue (12%), and absence of PWDs (6%) during the study period (Fig. 1). As a result, 86.8% (105 FCs) completed both the baseline and endline assessments in the study.

Baseline characteristics of the participants
Baseline characteristics of participating FCs and PWD are presented in Table 1. More than half of the FCs were women (69%), Muslim (67%), married (74%), employed (54%) and had low household income (56%). Except for participants' gender and dyadic relationships, no significant differences on any other characteristics between the intervention and control groups were found. Significantly more women and adult children were found as primary caregiver in the intervention group compared to the control group. Regarding health-related conditions, a higher prevalence of chronic morbidities, such as hypertension, diabetes or arthritis, was observed among FCs in the intervention group compared to those in the control group. The two groups had similar mean scores on social support and QoL at baseline.

The mean age of the PWD between intervention and control group was comparable [M = 75 (SD 10) years in intervention group and M = 76 (SD 10) years in control group]. In terms of gender distribution, most of the PWD

Table 1 Baseline characteristics of family caregivers and persons with dementia

	Total n = 121	Intervention n = 60	Control n = 61	p value
Background Variables				
Family caregivers' socioeconomic characteristics				
Age (years), Mean (SD)	51.6 (12.7)	50.1 (12.4)	53.1 (12.9)	0.185
Gender (%)				
Male	30.6	18.3	42.6	0.004
Female	69.4	81.7	57.4	
Religion (%)				
Muslim	66.9	75.0	59.0	0.057
Non-Muslim	33.1	25.0	41.7	
Education (%)				
Primary	13.2	15.0	11.5	0.365
Secondary	39.7	33.3	45.9	
Tertiary	47.1	51.7	42.6	
Marital status (%)				
Unmarried	18.2	18.3	18.0	0.553
Married	73.6	71.7	75.4	
Divorced/widowed	8.3	10.0	6.6	
Occupation (%)				
Employed	54.5	45.0	63.9	0.111
Homemaker/unemployed	35.5	43.3	27.9	
Retired	10.0	11.7	8.2	
Monthly HH income (RM)*, (%)				
low income (< RM4581)	56.2	60	52.5	0.667
middle income (RM4581-RM10959)	35.5	31.7	39.3	
high income (> RM10959)	8.3	8.3	8.2	
Comorbidities (%)				
Yes	55.2	67.3	44.6	0.020
No	44.8	32.7	55.4	
Caregiving information				
Length of caregiving (months), Mean (SD)	47.9 (42.8)	40.7 (34.3)	55.1 (49.0)	0.064
Hours of caregiving/day, Mean (SD)	18.6 (6.9)	18.8 (6.9)	18.4 (7.1)	0.800
Shared caregiving by other family members (%)	60.3	56.7	63.9	0.414
Relationship with person with dementia (%)				
Spouse	27.3	21.7	32.8	0.041
Adult child	62.8	73.3	52.5	
In-laws	9.9	5.0	14.8	
Social support, Mean (SD)				
Total Social Support	59.3 (17.1)	58.6 (16.8)	59.9 (17.6)	0.682
Family support	21.4 (6.4)	21.3 (6.0)	21.5 (6.7)	0.891
Friend support	16.1 (7.3)	16.0 (7.5)	16.3 (7.2)	0.844
Significant other support	21.7 (6.5)	21.3 (6.9)	22.2 (6.1)	0.466
Outcome Variables				
Caregiver Burden, Mean (SD)	11.7 (8.2)	12.6 (8.1)	10.8 (8.2)	0.227
Quality of Life (QoL), Mean (SD)	40.6 (10.4)	39.4 (10.5)	41.7 (10.3)	0.237
Anxiety Symptoms, Mean (SD)	6.2 (4.6)	6.9 (4.3)	5.5 (4.9)	0.090

*USD 1 = RM4.70 (based on 2022 exchange rate at time of data collection)

in this study were women (63%). The proportion of PWD who were able to perform self-care was similar across both groups. No significant difference was observed on demographic characteristics of PWD between intervention and control groups (data not shown).

Intervention effects

An intention-to-treat analysis using a linear mixed model for repeated measures was conducted to evaluate the independent effect of intervention on QoL over time while controlling the covariates, such as FC's gender,

Table 2 Linear mixed model showing the effect of intervention on caregiver's quality of life ($N=121$)

	Unadjusted				Adjusted			
	β	Std. error	95% CI	*p* value	β	Std. error	95% CI	*p* value
QoL								
IG (ref: CG)	-2.24	1.91	-6.02–1.54	0.244	-0.95	1.76	-4.43–2.52	0.590
T1 (ref: T0)	-1.44	0.96	-3.35–0.47	0.137	-1.40	0.96	-3.31–0.51	0.149
IG × T1 (ref: CG × T0)	4.87	1.40	2.09–7.66	0.001	5.00	1.40	2.21–7.78	0.001

IG Intervention group, *CG* Control group, *T0* Baseline, *T1* Post-intervention
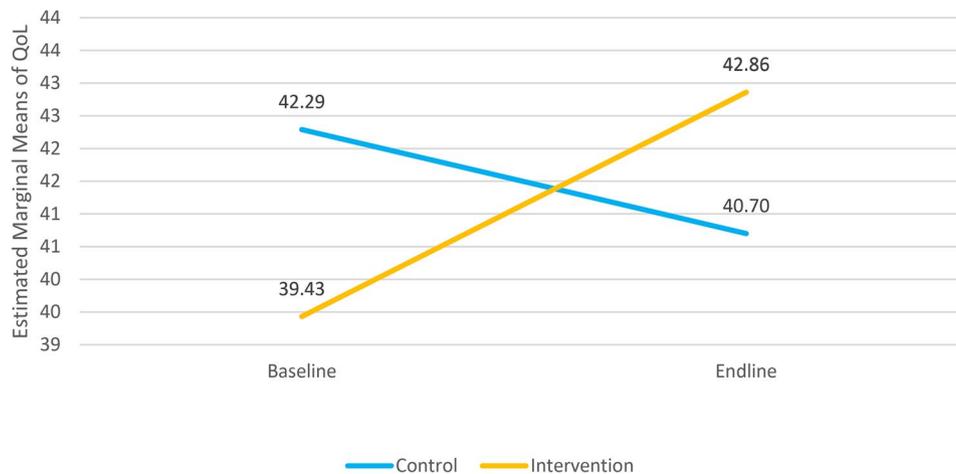

Fig. 2 Effect of interaction between time and intervention on quality of life

religion, comorbidity, household income and their relationship with the PWD (Table 2). Neither the intervention nor the time had any effect on QoL independently. However, interaction between intervention and time showed a significant effect revealed that the score of QoL among FCs in the intervention group (IG) increased by 5.00 units from T0 (baseline) to T1 (post-intervention) (β = 5.00, 95% CI 2.21–7.78, *p* = 0.001) compared to the difference in the control group (CG). As illustrated in Fig. 2, the mean QoL score in the intervention group increased from M = 39.43 (SD 10.98) at baseline to M = 42.86 (SD 10.11) at endline, whereas in the control group it decreased from M = 42.29 (SD 10.01) to M = 40.70 (SD 11.34).

For repeated measures, a compound symmetry (CS) covariance structure was specified, yielding the best fit according to the Akaike Information Criterion (AIC = 1605.03, BIC = 1611.83). Restricted Maximum Likelihood (REML) was used to estimate the parameters. All available observations were included without imputation, and the analysis was carried out using the intention-to-treat principle, assuming that data were missing at random (MAR). Both the ITT ($N=121$) and per protocol ($N=105$) analyses showed similar effects of the intervention on the outcome (Supplementary Table 4).

Mediation analysis

A series of linear regression analyses were conducted to examine the mediating role of caregiver burden on the association between the telephone-based intervention and QoL. Results showed that path C was significant, (B = 3.794, SE = 1.410, *p* = 0.008), indicating that the telephone-based intervention had a positive association with QoL before considering the mediator. In the second step (path A), the telephone-based intervention was negatively associated with caregiver burden (B = - 7.090, SE = 1.848, *p* < 0.001), indicating reduction in caregiver burden. In the third step, caregiver burden was negatively associated with QoL (B = - 0.203, SE = 0.042, *p* < 0.001) (Path B). In the final step, when the caregiver burden was controlled for in the linear regression model, direct effect of telephone-based intervention on QoL (Path C') was reduced and lost statistical significance (B = 2.330, SE = 1.341, *p* = 0.085) (Supplementary Fig. 1). The reduction and non-significant effect of the telephone-based intervention on QoL suggested that caregiver burden mediated the effect of the intervention on QoL (Table 3).

Mediation analysis further revealed that caregiver burden also mediated the relationship between the telephone-based intervention and anxiety symptoms. In line with the first criterion, the intervention demonstrated a significant effect on FCs' anxiety symptoms (B = - 1.801, SE = 0.640, *p* = 0.006) (Path C). Similarly, in path B, FCs' burden also showed a significant direct association

Table 3 Multiple linear regression models with and without caregiver burden as mediator in the association between telephone-based intervention and the outcome variables (Caregiver's QoL and anxiety symptoms)

Outcome	Model without Caregiver Burden as mediator			Model with Caregiver Burden as mediator		
	B (SE)	β	p	B (SE)	β	p
Quality of life[a]	3.794	0.176	0.008	2.330	0.108	0.085
Anxiety Symptoms[a]	-1.801	-0.203	0.006	-1.021	-0.115	0.106

[a] Regression analyses were adjusted for caregiver's religion, household income, comorbidity, social support and QoL at baseline

[a] Regression analyses were adjusted for caregiver's religion, marital status, social support and anxiety symptoms at baseline

with anxiety symptoms (B = 0.095, SE = 0.020, $p < 0.001$). When caregiver burden was included as mediator in the regression model (Path C'), the direct effect of the telephone-based intervention on anxiety symptoms became non-significant (B = -1.021, SE = 0.626, p = 106) (Table 3, Supplementary Fig. 1).

The mediation analysis indicated a significant indirect effect of the intervention on QoL through caregiver burden (intervention → caregiver burden → QoL) (B = 1.46, 95% CI: 0.18–3.13, p = 0.022), whereas the direct effect was not significant (B = 2.33, 95% CI: −0.11–5.32, p = 0.071) (Fig. 3A). Similarly, the intervention was associated with anxiety symptoms via caregiver burden (B = − 0.78, 95% CI: −1.45 to − 0.25, p = 0.009), but not directly associated (B = − 1.02, 95% CI: −2.12 to 0.28, p = 0.091) (Fig. 3B). Consistent findings from both the Baron and Kenny approach and the bootstrap method support the robustness of the mediating effect (Fig. 3).

Discussion

The findings of this study demonstrated that the telephone-based intervention had a significant effect in improving QoL among FCs of PWD. The effectiveness in reducing caregiver burden, anxiety symptoms and psychological distress was reported in a previous study [46]. Additionally, the results of the current study showed that caregiver burden mediates the effect of the telephone-based intervention on QoL and anxiety symptoms, suggesting that the intervention reduces anxiety and improves QoL directly and indirectly through the reduction of caregiver burden.

These findings are consistent with previous studies conducted in Germany [34] which showed a 24% overall improvement in FC's QoL. A randomized controlled trial in Italy [47], found that a telephone-based psychological intervention had a positive effect on caregiver burden and post-traumatic stress symptoms after 4-weeks' intervention period, however QoL outcomes were not reported. In contrast, the telephone-based intervention in the current study in Malaysia was shown to be effective in improving other outcomes such as anxiety, caregiver burden and psychological distress after the 14-weeks intervention [46].

Compared to the smaller effect size on QoL reported by Risch et al. [48], this study shows a moderate effect size, which might be attributed to variations in both the type and duration of the intervention. Risch et al. [48] employed psychotherapeutic intervention over a period of 8-weeks, which may have limited the intervention's impact on QoL. However, the study shows a significant improvement on caregiver's QoL in physical health but not mental health. In relation to the delivery method of the intervention, Topfler and Meishcner [34, 49] have shown that telephone-based cognitive behavioural therapy (TEL-CBT) had positive impact on caregivers` QoL and their ability to cope with caregiving situations. The results enhance flexibility benefits for telephone-based intervention with reduction of facility usage and costs in terms of transportation for both FCs and healthcare providers.

Previous literature indicates that caregivers` mental health is associated with increased emotional and physical burden [17, 50]. By targeting caregiver burden through telephone-based intervention, FCs may regain emotional stability and develop internal resilience, which in turn enhance their capacity to provide sustained care and improve their QoL and anxiety symptoms. As reported by López-Martínez et al. [51], caregiver burden shows mediating effect of the association between coping responses and caregiver's anxiety symptoms. Although the intervention in the present study was delivered via telephone, it also included several coping components, such as problem-solving engagements, building a positive mindset and emotional regulation strategies. In a cross-sectional study in China, social support was found as the mediating role between caregiver burden and QoL in FCs of PWD. These findings show that social support can influence how caregiver burden impacts FCs of PWD's overall well-being [35, 36]. Other research by Srivastava et al. [52], identified a negative association between caregiver burden and QoL, suggesting that burden may moderate the effectiveness of psychotherapy interventions aimed at enhancing QoL. However, this moderating effect was not empirically tested within the study.

In Malaysia, where mental health services for PWD and their caregivers are still evolving in terms of accessibility and cultural acceptance, this study contributes to the local evidence base by highlighting a community-centered approach to mental healthcare. Furthermore, it aligns with the government's Health Research Priorities
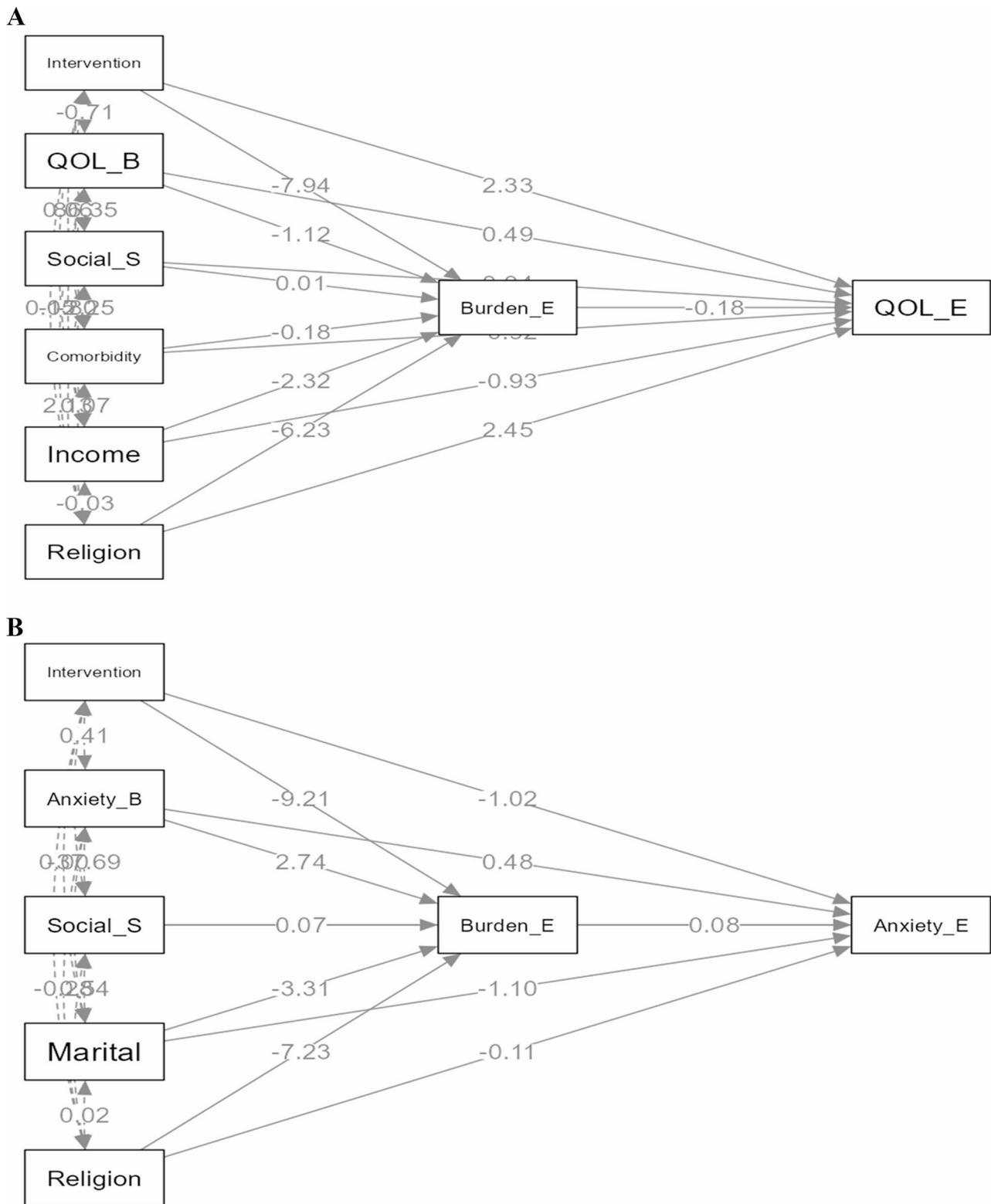
Fig. 3 A Bootstrapped indirect effect for the mediation pathway. NB. QOL_B= Caregiver's quality of line at baseline; Social_S= Social support; Burden_E= Caregiver burden at endline, QOL_E= Quality of life at endline. Significant Paths: • Intervention ➜ Burden; B= -7.94, *p*= 0.008. • QOL_B ➜ Burden; B= -1.12, p<0.001. • QOL_B ➜ QOL_E; B= 0.49, *p*<0.001. • Burden ➜ QOL_E; B= -0.18, *p*<0.001. • All other paths are not significant. **B** Bootstrapped indirect effect for the mediation pathway. NB. Anxiety_B= Anxiety symptoms at baseline; Social_S= Social support; Burden_E= Caregiver burden at endline, Anxiety_E= Anxiety symptoms at endline. Significant Paths: • Religion ➜ Burden; B= -7.23, *p*=0.017. • Anxiety_B ➜ Burden; B= 2.74, *p*<0.001. • Intervention ➜ Burden; B= -9.21, *p*<0.001. • Burden ➜ Anxiety_E; B= 0.08, *p*<0.001. • Anxiety_B ➜ Anxiety_E; B= 0.48, *p*<0.001. • All other paths are not significant

Nasreen *et al. BMC Geriatrics*   (2026) 26:307

Page 10 of 12

for 12th Malaysia Plan 2021–2025 on mental health promotion and supports the SDG 3, highlighting good health and well-being by focusing on both preventive and responsive care.

[32 In Italy, De Stefeno et al. [47] found that the benefits of a four-week telephone-based psychological intervention had disappeared by the six-month follow-up. To enhance the sustainability of such interventions, researchers and clinicians should continuously include flexible adaptations, such as ad-hoc counselling options and periodic booster sessions, to maintain long-term effectiveness [34, 53]. Future research should consider the long-term impact of interventions and how the intervention can be sustained over time. Although concern remain about long-term sustainability of interventions, some studies reported encouraging outcome after 6-month treatment where FCs who received telephone-based intervention were found to have lower overall pre-death grief, fewer physical symptoms such as less rheumatic pain and higher acceptance of loss of their loved one with dementia [48].

A key strength of this study lies in its contribution to understanding the psychological mechanisms through which telephone-based interventions influence outcomes. All measurement instruments used for data collection were locally validated, enhancing the cultural relevance and the validity of the results. However, it is important to acknowledge several possible limitations. A key limitation of this study is the lack of long-term follow-up period. Future research should include at least a 3- to 6-month follow-up and consider incorporating booster sessions to determine whether the intervention effects are sustained over time [34, 53]. In addition, participants were recruited from tertiary urban hospitals, which limits the generalisability of the findings to rural or under-resourced settings. The specific stages of dementia of the PWD were not classified as FCs of persons across all stages of dementia, mild, moderate and severe, were included in the study. FCs who care for PWD with moderate to severe stages experienced greater physical and psychological burden due to behavioral changes and higher dependency on daily routines [54–56]. Additionally, both healthcare providers and FCs might have faced challenges in scheduling intervention sessions, which could have led to delays, increased stress and inconsistencies in the delivery of the intervention.

Conclusion

In conclusion, this research demonstrates that the telephone-based interventions can effectively improve QoL among FCs of PWD, with caregiver burden playing a significant mediating role in the relationship between the intervention and anxiety symptoms as well as QoL. By understanding the underlying mechanisms, it not only

strengthens theoretical clarity, but also facilitates the development of more effective interventions to address the comprehensive needs of FCs to PWDs. Although the intervention proved effective in tertiary hospital setting, its scalability and adaptation in community and rural contexts should be evaluated in future studies. This includes exploring integration with existing primary care or mHealth systems to enhance accessibility and sustainability among FCs of PWD in Malaysia.

Abbreviations

PWD	Persons with dementia
RCT	Randomized control trial
FC	Family caregiver
QoL	Quality of life
IG	Intervention group
CG	Control group
CASP	Control, Autonomy, Self-Realization and Pleasure
ITT	Intention-to-treat
WHO	World Health Organization
RA	Research Assistant
DOSM	Department of Statistics Malaysia
MPSS	Multidimensional Scale of Perceived Social Support
TEL-CBT	Telephone-based cognitive behavioural therapy
SDG	Sustainable development goal

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12877-026-07066-w.

Supplementary Material 1.

Supplementary Material 2.

Authors' contributions

Hashima E Nasreen (HEN), Zarina Nahar Kabir (ZNK), Mohd Aznan Md Aris (MAMA), and Karimah Hanim Abd Aziz (KHAA) participated in conceptualization and study planning. Syarifah Amirah binti Syed Ahmad (SABSA) and Nora Mat Zin (NMZ) involved in data collection of the study. HEN and SABSA conducted the data analysis. SABSA drafted the manuscript, while HEN, ZNK, Marie Tyrell (MT) contributed to review and editing. HEN, SABSA, ZNK, MT critically revised the manuscript for important intellectual content. All authors read and approved the final version of the manuscript.

Data availability

The dataset generated and analysed during the current study are not publicly available due to confidentiality issues but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the Malaysia Medical Research and Ethics Committee [NMRR-22-00137-BUY(IRR)], the IIUM Research Ethics committee [IREC 2022-007] and the Research Ethics committee of Universiti Kebangsaan Malaysia [UKM PPI/111/8/JEP-2022-328]. All participants were explained in detail about the study and provided informed consent prior participation.

Author details
[1]Department of Community Medicine, Faculty of Medicine, International Islamic University Malaysia, Jalan Sultan Ahmad Shah, Kuantan 25200, Pahang, Malaysia

[2]Sophiahemmet Högskola, Valhallavägen 91, Stockholm 114 86, Sweden
[3]Department of Neurobiology, Care Sciences and Society, Karolinska Institute, Huddinge, Stockholm SE-141 83, Sweden

[4]Department of Psychiatry, Faculty of Medicine, International Islamic University Malaysia, Jalan Sultan Ahmad Shah, Kuantan 25200, Pahang, Malaysia

[5]Department of Family Medicine, Faculty of Medicine, International Islamic University Malaysia, Jalan Sultan Ahmad Shah, Kuantan 25200, Pahang, Malaysia

References

1. World Health Organization. Global status report on the public health response to dementia. Geneva: World Health Organization; 2021. p. 251. Available from: https://digitalcommons.fiu.edu/cgi/viewcontent.cgi?article=1962&context=srhreports.
2. Qi S, Yin P, Zhang H, Zhang Q, Xiao Y, Deng Y, et al. Prevalence of dementia in China in 2015: a nationwide community-based study. Front Public Health. 2021;9:733314. .
3. Yin Y, Tam HL, Quint J, Chen M, Ding R, Zhang X. Epidemiology of dementia in China in 2010–2020: a systematic review and meta-analysis. Healthc (Switzerland). 2024;12(3):334.
4. Lee J, Meijer E, Langa KM, Ganguli M, Varghese M, Banerjee J, et al. Prevalence of dementia in India: National and state estimates from a nationwide study. Alzheimer's Dement. 2023;19(7):2898–912.
5. Alzheimer Disease Foundation. Dementia cases set to rise 312 per cent by 2050: Is Malaysia prepared?>. 2022 June 8. Available from: https://www.adfm.org.my/dementia-cases-set-to-rise-312-per-cent-by-2050-is-malaysia-prepared/
6. Caputo A. The emotional experience of caregiving in dementia: feelings of guilt and ambivalence underlying narratives of family caregivers. Dementia. 2021;20(7):2248–60.
7. Tu JY, Jin G, Chen JH, Chen YC. Caregiver burden and dementia: a systematic review of self-report instruments. J Alzheimer's Disease. 2022;86(4):1527–43. https://doi.org/10.3233/JAD-215082.
8. Duangjina T, Hershberger PE, Gruss V, Fritschi C. Resilience in family caregivers of Asian older people with dementia: an integrative review. J Adv Nurs. 2024;81(1):156–70. https://doi.org/10.1111/jan.16272.
9. Ng CKM, Leung DKY, Cai X, Wong GHY. Perceived help-seeking difficulty, barriers, delay, and burden in carers of people with suspected dementia. Int J Environ Res Public Health. 2021;18(6):2956.
10. Chan CY, Cheung G, Martinez-Ruiz A, Chau PYK, Wang K, Yeoh EK, et al. Caregiving burnout of community-dwelling people with dementia in Hong Kong and new zealand: a cross-sectional study. BMC Geriatr. 2021;21(1):1–15. https://doi.org/10.1186/s12877-021-02153-6.
11. Hwang Y, Kim J. Influence of caregivers' psychological well-being on the anxiety and depression of care recipients with dementia. Geriatr Nurs. 2024;55:44–51.
12. Wang S, Huang Y, Fan AYN, Ho MH, Davidson PM. Factors influencing the psychosocial well-being of people with dementia and their informal caregivers: A systematic review of dyadic studies. Int J Ment Health Nurs. 2024;33(3):560–81. https://doi.org/10.1111/inm.13279.
13. Ang JPK, Koh EBY, Pang NTP, Mat Saher Z, Pin Tan K, Kiat Ang J, et al. Relationship of psychological flexibility and mindfulness to caregiver burden, and depressive and anxiety symptoms in caregivers of people with dementia. Int J Environ Res Public Health. 2023;20(5):4232. Available from: https://www.mdpi.com/1660-4601/20/5/4232/htm.
14. Nasreen HE, Tyrrell M, Vikström S, Craftman Å, Syed Ahmad SAB, Zin NM, et al. Caregiver burden, mental health, quality of life and self-efficacy of family caregivers of persons with dementia in Malaysia: baseline results of a psycho-educational intervention study. BMC Geriatr. 2024;24(1):1–12. https://doi.org/10.1186/s12877-024-05221-9.
15. Kai I, Ohi G, Kobayashi Y, Ishizaki T, Hisata M, Kiuchi M. Quality of life: a possible health index for the elderly. Asia Pac J Public Health Asia Pac Acad Consortium Public Health. 1991;5(3):221–7.
16. Rizal Abdul Manaf M, Helma Firdaus M, Fairuz Md Teridi N. Introduction quality of life and its associated factors among patient with dementia caregivers: A Cross-Sectional study in geriatric clinic. Malaysia: Hospital Kuala Lumpur; 2024.
17. Hu YL, Chang CC, Lee CH, Liu CH, Chen YJ, Su JA, et al. Associations between affiliate stigma and quality of life among caregivers of individuals with dementia: mediated roles of caregiving burden and psychological distress. Asian J Social Health Behav. 2023;6(2):64–71.
18. Contreras ML, Mioshi E, Kishita N. Factors related to the quality of life in family carers of people with dementia: a meta-analysis. J Geriatr Psychiatry Neurol. 2021;34(5):482–500. Available from: https://pubmed.ncbi.nlm.nih.gov/32394770/.
19. Canevelli M, Bruno G, Cesari M. Providing simultaneous COVID-19–sensitive and Dementia-Sensitive care as we transition from crisis care to ongoing care. J Am Med Dir Assoc. 2020;21(7):968.
20. Cuffaro L, Di Lorenzo F, Bonavita S, Tedeschi G, Leocani L, Lavorgna L. Dementia care and COVID-19 pandemic: a necessary digital revolution. Neurol Sci. 2020;41(8):1977–9.
21. Farkhondeh V, Decarli C. White matter hyperintensities in diverse populations: a systematic review of literature in the united States. Cereb Circ Cogn Behav. 2024;6:100204. https://doi.org/10.1016/j.cccb.2024.100204.
22. Paplikar A, Rajagopalan J, Alladi S. Care for dementia patients and caregivers amid COVID-19 pandemic. Cereb Circ Cogn Behav. 2022;3:100040.
23. Quail Z, Bolton L, Massey K. Digital delivery of non-pharmacological intervention programmes for people living with dementia during the COVID-19 pandemic. BMJ Case Rep CP. 2021;14(6):e242550.
24. Dombestein H, Norheim A, Aase K. How to stay motivated: a focus group study of Norwegian caregivers' experiences with community healthcare services to their parents with dementia. Health Soc Care Community. 2022;30(1):235–43. https://doi.org/10.1111/hsc.13396.
25. Sadavoy J, Sajedinejad S, Chiu M. A quasi-experimental study of the effectiveness of the Reitman centre CARERS group intervention on family caregivers of persons with dementia. Int J Geriatr Psychiatry. 2021;36(6):811–21. https://doi.org/10.1002/gps.5481.
26. Fossey J, Charlesworth G, Fowler JA, Frangou E, Pimm TJ, Dent J, et al. Online education and cognitive behavior therapy improve dementia caregivers' mental health: a randomized trial. J Am Med Dir Assoc. 2021;22(7):1403–9. Cited 2025.
27. Baruah U, Loganathan S, Shivakumar P, Pot AM, Mehta KM, Gallagher-Thompson D, et al. Adaptation of an online training and support program for caregivers of people with dementia to Indian cultural setting. Asian J Psychiatr. 2021;59:102624.
28. Ramirez M, Duran MC, Pabiniak CJ, Hansen KE, Kelley A, Ralston JD, et al. Family caregiver needs and preferences for virtual training to manage behavioral and psychological symptoms of dementia: interview study. JMIR Aging. 2021;4(1):e24965.
29. Wen Y, Xing Y, Ding Y, Xu W, Wang X. Challenges of conducting of online educational programs for family caregivers of people with dementia living at home: an integrative review. Int J Nurs Sci. 2023;10(1):121–8.
30. Possin KL, Sideman AB, Dulaney S, Lee K, Merrilees J, Bonasera S, et al. The care ecosystem: the effectiveness and implementation of Telephone-Based collaborative dementia care. Alzheimer's Dement. 2022;18(S9):e063938. https://doi.org/10.1002/alz.063938.
31. Wang Y, Xiao LD, Yu Y, Huang R, You H, Liu M. An individualized telephone-based care support program for rural family caregivers of people with dementia: study protocol for a cluster randomized controlled trial. BMC Geriatr. 2021;21(1):1–11. https://doi.org/10.1186/s12877-021-02575-2.
32. Kwok T, Wong B, Ip I, Chui K, Young D, Ho F. Telephone-delivered psychoeducational intervention for Hong Kong Chinese dementia caregivers: A single-blinded randomized controlled trial. Clin Interv Aging. 2013;8:1191–7. https://doi.org/10.2147/CIA.S48264.
33. Tremont G, Davis JD, Papandonatos GD, Ott BR, Fortinsky RH, Gozalo P, et al. Psychosocial telephone intervention for dementia caregivers: A randomized, controlled trial. Alzheimer's Dement. 2015;11(5):541–8.

34. Meichsner F, Töpfer NF, Reder M, Soellner R, Wilz G. Telephone-Based cognitive behavioral intervention improves dementia caregivers' quality of life. Am J Alzheimers Dis Other Demen. 2019;34(4):236–46.

35. del-Pino-Casado R, Priego-Cubero E, López-Martínez C, Orgeta V. Subjective caregiver burden and anxiety in informal caregivers: A systematic review and meta-analysis. PLoS ONE. 2021;16(3):e0247143.

36. Han A. Effects of Mindfulness-Based interventions on depressive Symptoms, Anxiety, Stress, and quality of life in family caregivers of persons living with dementia: a systematic review and Meta-analysis. Res Aging. 2022;44(7–8):494–509. https://doi.org/10.1177/01640275211043486.

37. Tremont G, Davis J, Papandonatos GD, Grover C, Ott BR, Fortinsky RH, et al. A telephone intervention for dementia caregivers: Background, design, and baseline characteristics. Contemp Clin Trials. 2013;36(2):338–47.

38. Richardson JT. Eta squared and partial Eta squared as measures of effect size in educational research. Educational Res Rev. 2011;6(2):135–47.

39. World Health Organization. iSupport for dementia: training and support manual for carers of people with dementia. 2018.

40. Ng CG, Nurasikin MS, Loh HS, Anne Yee HA, Zainal NZ. Factorial validation of the Malay version of multidimensional scale of perceived social support among a group of psychiatric patients. Malaysian J Psychiatry. 2012;21(2):17–26.

41. Shim VK, Ng CG, Drahman I. Validation of the Malay version of Zarit burden interview (MZBI). Malaysian J Psychiatry. 2017;26(2):3–18.

42. Nalathamby N, Morgan K, Mat S, Tan PJ, Kamaruzzaman SB, Tan MP. Validation of the CASP-19 quality of life measure in three languages in Malaysia. J Trop Psychol. 2017;7:e4.

43. Yahya F, Zoim J. 2015 undefined. Validation of the Malay version of hospital anxiety and depression scale (HADS) in Hospital Universiti Sains Malaysia. Int Med J. 2015;22(2):80–2.

44. Baron RM, Kenny DA. The Moderator-Mediator variable distinction in social psychological Research. Conceptual, Strategic, and statistical considerations. J Pers Soc Psychol. 1986;51(6):1173–82.

45. Gallucci M. jAMM: jamovi advanced mediation models. 2020. Retrieved from https://jamovi-amm.github.io/.

46. Ahmad SABS, Kabir ZN, Tyrrell M, Craftman Å, Nasreen HE. Efficacy of a Telephone-Intervention on caregiving burden and mental health among family caregivers of persons with dementia in malaysia: A randomized controlled trial. Int J Environ Res Public Health. 2024;21(10):1354.

47. De Stefano M, Esposito S, Iavarone A, Carpinelli Mazzi M, Siciliano M, Buonanno D, et al. Effects of Phone-Based psychological intervention on caregivers of patients with Early-Onset alzheimer's disease: A Six-Months study during the COVID-19 emergency in Italy. Brain Sci. 2022;12(3):310.

48. Risch AK, Lechner-Meichsner F, Wilz G. Telephone-based acceptance and commitment therapy for caregivers of persons with dementia: results of a randomized controlled trial. Clin Gerontol. 2024. Available from: https://www.tandfonline.com/doi/pdf/10.1080/07317115.2024.2393307. Cited 2025 Jun 28.

49. Töpfer NF, Wrede N, Theurer C, Wilz G. Face-to-face versus telephone-based cognitive-behavioral therapy for family caregivers of people with dementia. J Clin Psychol. 2023;79(10):2270–87. https://doi.org/10.1002/jclp.23538.

50. Vrettos I, Anagnostopoulos F, Voukelatou P, Panayiotou S, Kyvetos A, Nikas A, et al. Factors associated with health-related quality of life of informal caregivers of older patients and the mediating role of subjective caregivers' burden. Psychogeriatrics. 2023;23(2):286–97. https://doi.org/10.1111/psyg.12930.

51. López-Martínez C, Orgeta V, Frías-Osuna A, del-Pino-Casado R. Coping and anxiety symptoms in family carers of dependent older people: mediation and moderation effects of subjective caregiver burden. J Nurs Scholarsh. 2024;56(3):371–81. https://doi.org/10.1111/jnu.12957.

52. Srivastava G, Tripathi RK, Tiwari SC, Singh B, Tripathi SM. Caregiver burden and quality of life of key caregivers of patients with dementia. Indian J Psychol Med. 2016;38(2):133–6.

53. Bartels SL, van Knippenberg RJM, Köhler S, Ponds RW, Myin-Germeys I, Verhey FRJ, et al. The necessity for sustainable intervention effects: lessons-learned from an experience sampling intervention for spousal carers of people with dementia. Aging Ment Health. 2020;24(12):2082–93. https://doi.org/10.1080/13607863.2019.1647130.

54. Tay RY, Tan JYS, Hum AYM. Factors associated with family caregiver burden of Home-Dwelling patients with advanced dementia. J Am Med Dir Assoc. 2022;23(7):1248–56.

55. García-Martín V, de Hoyos-Alonso MC, Delgado-Puebla R, Ariza-Cardiel G, del Cura-González I. Burden in caregivers of primary care patients with dementia: influence of neuropsychiatric symptoms according to disease stage (NeDEM project). BMC Geriatr. 2023;23(1):1–12. https://doi.org/10.1186/s12877-023-04234-0.

56. Ozcan M, Akyar İ. Caregivers' experiences of patients with moderate-stage alzheimer's disease: a qualitative study. Psychogeriatrics. 2021;21(5):763–72. https://doi.org/10.1111/psyg.12736.

Publisher's note