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Nasreen, H.E.^a, Tyrrell, M.^{b,c}, Vikström, S.^c, Craftman, Å.^c, Syed Ahmad, S.A.B.^a, Zin, N.M.^d, Aziz, K.H.A.^a, Mohd Tohit, N.B.^e, Md Aris, M.A.^f, Kabir, Z.N.^c

Caregiver burden, mental health, quality of life and self-efficacy of family caregivers of persons with dementia in Malaysia: baseline results of a psychoeducational intervention study
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^a Department of Community Medicine, Faculty of Medicine, International Islamic University Malaysia, Jalan Sultan Ahmad Shah, Pahang, Kuantan, 25200, Malaysia

^b Sophiahemmet Högskola, Valhallavägen 91, Stockholm, 114 86, Sweden

^c Department of Neurobiology, Care Sciences and Society, Karolinska Institute, Huddinge, Stockholm, SE-141 83, Sweden

^d Department of Psychiatry, Faculty of Medicine, International Islamic University Malaysia, Jalan Sultan Ahmad Shah, Pahang, Kuantan, 25200, Malaysia

^e Department of Family Medicine, Universiti Kebangsaan Malaysia, Bandar Tun Razak, Kuala Lumpur, Cheras, 56000, Malaysia

^f Department of Family Medicine, Faculty of Medicine, International Islamic University Malaysia, Pahang, Kuantan, 25200, Malaysia

Abstract

Background: The majority of persons with dementia (PWD) are mainly cared for by their family members in the home. Evidence is however scarce on family caregivers' psychosocial burden and quality of life in Asian countries including Malaysia. This study describes the baseline data of a telephone-delivered psychoeducational intervention study and examines the determinants of outcome measures (caregiver burden, depressive and anxiety symptoms, quality of life and caregiving self-efficacy) among Malaysian family caregivers to PWD. **Methods:** This was a cross-sectional study originated from the baseline survey of a randomized control trial of 121 family caregivers recruited from lists of PWD who were registered at memory and psychiatry clinics in three tertiary care hospitals in Malaysia. The participants were assessed for caregiver burden by the Zarit Burden Interview, depressive and anxiety symptoms by the Hospital Anxiety and Depression Scale, quality of life by the Control, Autonomy, Self-Realization, and Pleasure Scale, and caregiving self-efficacy by the Revised Scale for Caregiving Self-Efficacy. **Results:** Prevalence of caregiver burden was 69.4%, depressive symptoms 32.2% and anxiety symptoms 32.2%. Family caregivers to PWD having perceived peer support e.g., social/family/friend/significant other supports were less likely to report caregiver burden, depressive and anxiety symptoms, and more likely to report higher levels of quality of life and caregiving self-efficacy. Being married and PWD's ability to self-care were associated with lesser likelihood of experiencing caregiver burden, depressive and anxiety symptoms. The other determinants of greater probability of reporting better quality of life were caregivers' employment and having Islamic faith. Marital status (married), PWD's ability to self-care, spousal relationship with PWD and shared caregiving process were associated with higher likelihood of reporting caregiving self-efficacy. **Conclusion:** Caregiver burden, depressive and anxiety symptoms are prevalent in family caregivers to PWD in Malaysia. Social support and caregiving related factors influence family caregivers' quality of life and caregiving self-efficacy. Implementing psychoeducational intervention and support in the psychiatry and memory clinics may help improve the psychosocial burden, quality of life and caregiving self-efficacy in family caregivers of PWD. Trial registration: ISRCTN14565552 (retrospectively registered). © The Author(s) 2024.

Author Keywords

Anxiety symptoms; Caregiver burden; Caregiving self-efficacy; Depressive symptoms; Family caregivers; Persons with dementia; Quality of life

Index Keywords

adult, aged, caregiver, caregiver burden, clinical trial, controlled study, cost of illness, cross-sectional study, dementia, epidemiology, female, human, Malaysia, male, mental health, middle aged, multicenter study, psychology, quality of life, randomized controlled trial, self concept, very elderly; Adult, Aged, Aged, 80 and over, Caregiver Burden, Caregivers, Cost of Illness, Cross-Sectional Studies, Dementia, Female, Humans, Malaysia, Male, Mental Health, Middle Aged, Quality of Life, Self Efficacy

References

- Hazzan, A.A., Dauenhauer, J., Follansbee, P., Hazzan, J.O., Allen, K., Omobepade, I.
Family caregiver quality of life and the care provided to older people living with dementia: qualitative analyses of caregiver interviews
(2022) *BMC Geriatr*, 22 (1), p. 86.
35101000, 8802743

- Ganapathy, S.S., Sooryanarayana, R., Ahmad, N.A., Jamaluddin, R., Abd Razak, M.A., Tan, M.P., Ibrahim, N.
Prevalence of dementia and quality of life of caregivers of people living with dementia in Malaysia
(2020) *Geriatr Gerontol Int*, 20, pp. 16-20.
33370858
- Hsin-Yi, L., Lian-Hua, H.
The relationship between family functioning and caregiving appraisal of dementia family caregivers: caregiving self-efficacy as a mediator
(2018) *Aging Ment Health*, 22 (4), pp. 558-567.
- Bin, S.A., Sayampanathan, A.A., Cuttilan, A., Chun-Man Ho, R.
(2015). Prevalence of mental health disorders among caregivers of patients with Alzheimer disease
(2015) *J am Med Dir Assoc*, 16 (12), pp. 1034-1041.
- Abdollahpour, I., Nedjat, S., Salimi, Y.
Positive aspects of Caregiving and Caregiver Burden: a study of caregivers of patients with dementia
(2018) *J Geriatr Psychiatry Neurol*, 31 (1), pp. 34-38.
29187025
- Tulek, Z., Baykal, D., Erturk, S., Bilgic, B., Hanagasi, H., Gurvit, I.H., Caregiver, Burden
Quality of life and related factors in Family caregivers of Dementia patients in Turkey
(2020) *Issues Ment Health Nurs*, 41 (8), pp. 741-749.
32286096
- Wawrziczny, E., Berna, G., Ducharme, F., Kergoat, M.J., Pasquier, F., Antoine, P.
Modeling the distress of spousal caregivers of people with dementia
(2017) *J Alzheimers Dis*, 55 (2), pp. 703-716.
27716667
- Wulff, J., Malmgren Fänge, A., Lethin, C., Chiatti, C.
Self-reported symptoms of depression and anxiety among informal caregivers of persons with dementia: a cross-sectional comparative study between Sweden and Italy
(2020) *BMC Health Serv Res*, 20, p. 1114.
33267856, 7709414
- Mahoney, R., Regan, C., Katona, C., Livingston, G.
Anxiety and depression in family caregivers of people with Alzheimer disease: the LASER-AD study
(2005) *Am J Geriatr Psychiatry*, 13, pp. 795-801.
16166409
- Tu, J.Y., Jin, G., Chen, J.H., Chen, Y.C.
Caregiver Burden and Dementia: a systematic review of Self-Report instruments
(2022) *J Alzheimers Dis*, 86 (4), pp. 1527-1543.
35253744
- Delpinocasado, R., Priegocubero, E., Lopezmartinez, C., Orgeta, V.
Subjective caregiver burden and anxiety in informal caregivers: A systematic review and meta-analysis
(2021) *Plos ONE.*, 16 (3).
2021
- **Global status report on the public health response to dementia**
(2021) *Geneva: World Health Organization*,
License: CC BY-NC-SA 3.0 IGO

- Vikström, S., Josephsson, S., Stigsdotter-Neely, A., Nygård, L.
Engagement in activities: experiences of persons with dementia and their caregiving spouses
(2008) *Dementia*, 7 (2), pp. 251-270.
- Chiao, C.Y., Wu, H.S., Hsiao, C.Y.
Caregiver burden for informal caregivers of patients with dementia: a systematic review
(2015) *Int Nurs Rev*, 62 (3), pp. 340-350.
26058542
- Liu, Z., Sun, W., Chen, H.
Caregiver burden and its associated factors among family caregivers of persons with dementia in Shanghai, China: a cross-sectional study
(2022) *BMJ Open*, 12, p. e057817.
35613751, 9174806
- Putri, Y.S.E., Putra, I.G.N.E., Falahaini, A., Wardani, I.Y.
Factors Associated with Caregiver Burden in caregivers of older patients with dementia in Indonesia
(2022) *Int J Environ Res Public Health*, 19 (19), p. 12437.
36231732, 9566301
- Cheng, S.T.
Dementia caregiver Burden: a Research Update and critical analysis
(2017) *Curr Psychiatry Rep*, 19 (9), p. 64.
28795386, 5550537
- Kim, H., Chang, M., Rose, K., Kim, S.
Predictors of caregiver burden in caregivers of individuals with dementia
(2012) *J Adv Nurs*, 68, pp. 846-855.
21793872
- Tyrrell, M., Hillerås, P., Skovdahl, K., Fossum, B., Religa, D.
(2019). Voices of spouses living with partners with neuropsychiatric symptoms related to dementia
(2019) *Dementia*, 18 (3), pp. 903-919.
- Connors, M.H., Seeher, K., Teixeira-Pinto, A., Woodward, M., Ames, D., Brodaty, H.
Dementia and caregiver burden: a three-year longitudinal study
(2020) *Int J Geriatr Psychiatry*, 35 (2), pp. 250-258.
31821606
- Bandura, A.
(2005) *Guide for Constructing Self-Efficacy Scales (Chap. 14)*, p. 307.
Self-efficacy beliefs of adolescents, Charlotte, North Carolina, Information Age Publishing,
Retrieved from
- Merrilees, J.J., Bernstein, A., Dulaney, S., Heunis, J., Walker, R., Rah, E., Choi, J., Possin, K.L.
The Care Ecosystem: promoting self-efficacy among dementia family caregivers
(2018) *Dementia*, 19, p. 6.
- van der Lee, J., Bakker, T.J., Duivenvoorden, H.J., Droes, R.M.
Multivariate models of subjective caregiver burden in dementia: a systematic review
(2014) *Ageing Res Rev*, 15, pp. 76-93.
24675045
- Samia, L.W., O'Sullivan, A., Fallon, K.C., Aboueissa, A., Hepburn, K.W.
Building on self-efficacy for experienced family caregivers: the Savvy Advanced

Program(2018) *Gerontologist*, pp. 1-11.

1:CAS:528:DC%2BC1cXovFeksw%3D%3D

- Tremont, G., Davis, J.D., Papandonatos, G.D., Ott, B.R., Fortinsky, R.H., Gozalo, P., Yue, M.S.
Psychosocial telephone intervention for dementia caregivers: a randomized, controlled trial
(2015) *Alzheimer's Dement*, 11, pp. 541-548.
- Jackson, D., Roberts, G., Wu, M.L., Ford, R., Doyle, C.
A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer's, vascular or mixed dementia in the community
(2016) *Arch Gerontol Geriatr*, 66, pp. 218-236.
27372903
- (2014) *Dementia 2014: Opportunity for Change*. UK, Alzheimer's Society, Retrieved from
- Hinton, L., Tran, D., Nguyen, T.N., Ho, J., Gitlin, L.
Interventions to support family caregivers of people living with dementia in high, middle and low-income countries in Asia: a scoping review
(2019) *BMJ Global Health*, 4, p. e001830.
31798992, 6861057
- 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
(2013) *Clin Interv Aging*, 8, pp. 1191-1197.
24072965, 3783504
- Tremont, G., Davis, J.D., Bishop, D.S., Fortinsky, R.H.
Telephone-delivered psychosocial intervention reduces burden in dementia caregivers
(2008) *Dementia*, 7 (4), pp. 503-520.
20228893, 2836858
- **2015: The global impact of dementia, an analysis of prevalence, incidence cost and trend**
(2015) *World Alzheimer's Report*,
- Mutalib, A.S.A., Dahlan, A., Danis, A., Masuri, M.G.
Independency and quality of life amongst malay older people in the community: an interpretative phenomenological analysis
(2016) *Procedia Soc Behav Sci*, 234, pp. 90-97.
- NurFatimah, O.A., Rahman, M.A., Rosnah, S., Ismail, D., Khadijah, S., ShEzat, S.P.
Quality of life among caregivers of elderly with dementia and its associated factors
(2013) *IOSR J Nurs Health Sci*, 1, pp. 7-13.
- Tremont, G., Davis, J., Papandonatos, G.D., Grover, C., Ott, B.R., Fortinsky, R.H., Gozalo, P.
A telephone intervention for dementia caregivers: background, design, and baseline characteristics
(2013) *Contemp Clin Trials*, 36 (2), pp. 338-347.
23916916
- Meichsner, F., Theurer, C., Wilz, G.
Acceptance and treatment effects of an internet-delivered cognitive-behavioral intervention for family caregivers of people with dementia: A randomized-controlled trial

- (2019) *J Clin Psychol*, 75 (4), pp. 594-613.
2019
- Polit, D.F., Beck, C.T.
(2017) *Nursing research: Generating and assessing evidence for nursing practice*, Wolters Kluwer Health, Liincott Williams & Wilkins
 - Ng, C.G., Nurasikin, M.S., Loh, H.S., Anne Yee, H.A., Zainal, N.Z.
Factorial validation of the malay version of multidimensional scale of perceived social support among a group of psychiatric patients
(2012) *Malaysian J Psychiatry*, 21.
 - Zimet, G.D., Dahlem, N.W., Zimet, S.G., Farley, G.K.
The multidimensional scale of perceived social support
(1988) *J Pers Assess*, 52, pp. 30-41.
 - Zarit, S.H., Reever, K.E., Bach-Peterson, J.
Relatives of the impaired elderly: correlates of feelings of burden
(1980) *Gerontologist*, 20, pp. 649-655.
1:STN:280:DyaL3M7jvFOhtw%3D%3D, 7203086
 - Shim, V.K., Ng, C.G., Drahman, I.
Validation of malay version of Zarit Burden interview (MZBI)
(2018) *Malaysian J Psychiatry*, 26 (2), pp. 3-18.
 - Yahya, F., Othman, Z.
Validation of the malay version of hospital anxiety and Depression Scale (HADS) in hospital university sains Malaysia
(2015) *Int Med J*, 22, pp. 80-82.
 - Nalathamby, N., Morgan, K., Mat, S., Tan, P.J., Kamaruzzaman, S.B., Tan, M.P.
Validation of the CASP-19 quality of life measure in three languages in Malaysia
(2017) *J Trop Psychol*, 7, pp. 1-8.
 - Steffen, A.M., McKibbin, C., Zeiss, A.M., Gallagher-Thompson, D., Bandura, A.
The revised scale for caregiving self-efficacy: reliability and validity studies
(2002) *J Gerontol B Psychol*, 57 (1), pp. P74-P86.
 - Sinha, P., Desai, N.G., Prakash, O., Kushwaha, S., Tripathi, C.B.
Caregiver burden in Alzheimer-type dementia and psychosis: a comparative study from India
(2017) *Asian J Psychiatry*, 26, pp. 86-91.
1:STN:280:DC%2BC1crltFKqsQ%3D%3D
 - Panyavin, I., Trujillo, M., Peralta, S.V., Stolfi, M.E., Morelli, E., Perrin, P.B., Peña, J., Arango-Lasprilla, J.C.
Examining the influence of family dynamics on quality of care by informal caregivers of patients with Alzheimer's dementia in Argentina
(2015) *Am J Alzheimers Disease Other Dement*, 30, pp. 613-621.
 - Pillemer, S., Davis, J., Tremont, G.
(2018). Gender effects on components of burden and depression among dementia caregivers
(2018) *Aging Ment Health*, 22 (9), pp. 1156-1161.
 - Jutkowitz, E., Mitchell, L.L., Bardenheier, B.H., Gaugler, J.E.
Profiles of caregiving arrangements of community-dwelling people living with probable dementia
(2022) *J Aging Soc Policy*, 34 (6), pp. 860-875.
34003081

- Kokorelias, K.M., Nguyen, L., Elane, G., Wasilewski, M.B., Rittenberg, N., Cameron, J.I.
Daughters' experiences of shared caregiving to a parent with dementia
(2021) *Scand J Caring Sci*, 35 (3), pp. 853-859.
32781486
- Haro, J.M., Kahle-Wroblewski, K., Bruno, G., Belger, M., Dell'Agnello, G., Dodel, R.
Analysis of burden in caregivers of people with Alzheimer's disease using self-report and supervision hours
(2014) *J Nutr Health Aging*, 18 (7), pp. 677-684.
1:STN:280:DC%2BC2M7itVKjtjg%3D%3D, 25226106
- Tan, K.P., Ang, J.K., Koh, E.B.Y., Pang, N.T.P., Mat Saher, Z.
Relationship of psychological flexibility and mindfulness to Caregiver Burden, and depressive and anxiety symptoms in caregivers of people with dementia
(2023) *Int J Environ Res Public Health*, 20, p. 5.
- Krutter, S., Schaffler-Schaden, D., Essl-Maurer, R., Wurm, L., Seymer, A., Kriechmayr, C.
Comparing perspectives of family caregivers and healthcare professionals regarding caregiver burden in dementia care: results of a mixed methods study in a rural setting
(2020) *Age Ageing*, 49 (2), pp. 199-207.
31875879
- Collins, R.N., Kishita, N.
Prevalence of depression and burden among informal care-givers of people with dementia: a meta-analysis
(2020) *Ageing Soc*, 40 (11), pp. 2355-2392.
- Khanal, B., Chalise, H.
Caregiver Burden among Informal caregivers of Rural Older persons in Nepal
(2020) *J Health Care Res*, 1 (3), pp. 149-156.
- Kaddour, L., Kishita, N.
Anxiety in Informal Dementia carers: a Meta-analysis of prevalence
(2020) *J Geriatr Psychiatry Neurol*, 33 (3), pp. 161-172.
31409196
- Chan, E.Y., Glass, G., Chua, K.C., Ali, N., Lim, W.S.
Relationship between mastery and caregiving competence in protecting against Burden, anxiety and depression among caregivers of Frail older adults
(2018) *J Nutr Health Aging*, 22 (10), pp. 1238-1245.
30498832, 6302747
- Nemcikova, M., Katreniakova, Z., Nagyova, I.
Social support, positive caregiving experience, and caregiver burden in informal caregivers of older adults with dementia
(2023) *Front Public Health*, 11, p. 1104250.
36761127, 9905841
- Wang, Q., Xiao, X., Zhang, J., Jiang, D., Wilson, A., Qian, B.
The experiences of east Asian dementia caregivers in filial culture: a systematic review and meta-analysis
(2023) *Front Psychiatry*, 14, p. 1173755.
37151975, 10160681
- Tan, G.T.H., Yuan, Q., Devi, F., Wang, P., Ng, L.L., Goveas, R.
Factors associated with caregiving self-efficacy among primary informal caregivers of persons with dementia in Singapore
(2021) *BMC Geriatr*, 21, p. 13.
33407201, 7789728

- Colloby, S., Whiting, S., Warren, A.
Supporting the couple relationship following dementia diagnosis: a scoping review
(2022) *Health Soc Care Community*, 30 (6), pp. e3643-e3655.
36124618, 10087355
- Tew, C.W., Tan, L.F., Luo, N., Ng, W.Y., Yap, P.
Why family caregivers choose to institutionalize a loved one with dementia: a Singapore perspective
(2010) *Dement Geriatr Cogn Disord*, 30 (6), pp. 509-516.
21252545

Correspondence Address

Nasreen H.E.; Department of Community Medicine, Jalan Sultan Ahmad Shah, Pahang, Malaysia; email: drnasreen@iiium.edu.my

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