

Impact of Long-Term Care Burden on Working Age Carers: A Scoping Review

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Abstract

Caregivers of chronically ill, disabled, or elderly family members encounter substantial physical, social, emotional, and financial difficulties. This study aims to identify how the stresses and strains associated with caregiving for family members impact caregivers' perceptions of health, well-being, and quality of life. Method: A systematic scoping review was done using PubMed, MEDLINE, CINAHL, JSTOR, EBSCO and Google Scholar, to search for primary research on caregiver burden, published between 2019 and 2023, and in English. Fifteen quantitative research studies were selected for the study. Results: Thematic analysis on characteristics that impact the health, well-being and quality of life of caregivers, most of whom are women, showed that women self-perceived the negative impact of care burden more than men did while increasing the range of type of care provided increase women's self-perceptions of their abilities. In developing country contexts, caregiving for elderly family members can begin earlier in the lifespan, thus increasing the care burden. Perception of lack of competence to provide care, doing more than 20 hours of unpaid caregiving per week, and caring for prolonged periods of time over years impacted the mental health of caregivers. Physical and mental health burden also depended on the level of physical, behavioural, and intellectual impairment of the care recipients. Providing low intensity unpaid care of less than ten hours per week appeared to boost carers' self-perception of physical well-being. The perceived quality of available social support and work supervisor support was significant in reducing depressive symptoms and improved perceptions of wellbeing. Conclusion: To improve the well-being of caregivers, it is essential to provide respite care, palliative care, and end of life care facilities to reduce the number of care work hours per week the family carers provide, to reduce the duration of care, and to alleviate significant care burden. Social insurance based paid leave, means-based financial support for caregivers, with capacity development, and social support networks, can be implemented to reduce the disproportionate health and wealth penalties on those caring for ill, disabled, and elderly family members.

Key words: informal unpaid care, long-term care, health, well-being, family, quality of life, burden

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Background

With an ageing population, and an increasing number of people living with long term physical and mental health conditions, the necessity to recognize and address the needs of care recipients and care givers is well recognized. People with long-term health conditions and the aged prefer to live in their own home, thus, home care is important. Informal care by family and friends is one way to meet this long-term care demand, while limiting the financial burden on the state (WHO, 2021). However, informal care comes at a cost. Additional to limiting the care givers' contribution to the labour market, social security, and taxes; research shows that caregiving can become overwhelming, go on for years, and can increase towards the second half of the life span.

As a community nurse with over 30 years of experience, working at a hospital in the Maldives, the impact of care burden on both the family care givers and care-recipients, have been a significant concern of the first author. At times, long-term-ill and end-of life care recipients have been left behind in hospitals by family members, as they could not cope with the care burden, meaning that beds needed by incoming patients were not available. Hospital policy is to reduce duration of hospital stay, and to promote out of hospital care, meaning that care burden on family caregivers is expected to increase.

Quality of Life (QoL) is the subjective perception of the person about their physical, emotional, social and or role wellbeing. Zarit et al. (1986) define caregiver burden as the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual wellbeing. Mobility limitations and specialized medical needs can cause severe physical strain, relationship changes, and significant financial burdens. Deterioration of family relationships, social isolation, changes to lifestyle, sleep disturbances, irregular eating habits and bad diet can all lead to negative health consequences for care givers. Age, gender, spirituality, education level, financial status, and social support available to the caregiver can contribute to how caregiver burden is perceived (Liu, Heffernan & Tan, 2020).

The aim of this scoping review is to synthesize existing current research evidence on the impact of unpaid, informal long-term caregiving on the health and well-being of care givers and to identify the factors associated with increased caregiver burden.

Method

Literature search was conducted utilizing six major databases: PubMed, MEDLINE, CINAHL, EBSCO, JSTOR and Google Scholar, with searches restricted to peer reviewed articles published between January 1, 2019, and December 31, 2023. The key words used were 'informal,' 'unpaid,' 'carer' 'caregiver burden' 'long-term,' 'impact' 'wellbeing' 'family' and 'quality of life.' Additionally, to refine the search, synonyms of the keywords are gathered in conjunction with the keywords. Articles focusing on caregiver burden are used, while articles focusing on care needs of care recipients were excluded, though dyad studies were included. Caring for own children without an illness, and paid care work were excluded.

The framework utilized for inclusion was the PEO format, which comprises the subsequent components as populations, exposure, and outcomes. The search was restricted to informal unpaid carers who were working age adults aged from 16 to 65, as the time pressures and financial burden of unpaid care could be self-perceived more by working aged people. The term 'exposure' refers to the emergence of several challenges, including mental health illnesses such as depression, anxiety, and inadequate self-care. Other difficulties include emotional and physical stress, problems in managing time, financial hardship, lack of privacy, and isolation. They were further refined to specifically encompass individuals encountering issues related to their mental well-being and overall quality of life. The last element of the PEO tool was referred to as the 'outcome', which was defined as the total enhancement in the well-being and quality of life of caregivers.

Study Results

The initial search yielded a total of 5,949 articles. After removing duplicated articles, and applying the inclusion and exclusion criteria, a total of thirty-eight articles were appraised by evaluating their titles, abstracts, and full text. A total of 15 articles were chosen for data extraction. The selection of these papers was based on their pertinence to the review's emphasis on the impact of caregiver burden on health and wellbeing of informal unpaid carers, and the evidence the authors had used to study the impact. While most of the studies were done in developed countries, research from other countries was chosen to ensure a wider perspective. The 15 papers selected had research from Belgium, Canada, Congo, Ecuador, Germany, Greece, France, Ireland, Italy, Malaysia, Netherlands, Norway, Sweden, UK, and USA. The additional literature obtained for this evaluation consisted of small scale qualitative studies from

Uganda which matched caregiver needs of vulnerable groups in the Maldives. Literature was sought from Asian countries with aged populations and comprehensive care policies such as China, Japan, and Taiwan.

Table 1: Study characteristics of selected studies

	First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
1	Achilike (2020), USA	A cross-sectional study aimed to examine caregiver burden and associated factors among a cohort of informal caregivers of stroke survivors	88 caregivers accompanying stroke survivors to an outpatient stroke clinic in the Texas Medical Center within 2 years of ischemic or intracerebral hemorrhagic stroke	Demographic questionnaire, the Zarit Burden Interview (ZBI), the Patient Health Questionnaire (PHQ-9), and the Barthel Index (BI)17 during clinic visits and afterwards by completing online surveys	Univariable analyses for variables that may be associated with caregiver burden. The χ^2 test was used for categorical variables. Variables with P values less than .10 in the univariable analyses were included in an ordinal logistic regression.	The odds of mild to moderate caregiver burden was 3.7 times higher for caregivers of stroke survivors with moderate to severe functional disability ($BI \leq 94$), compared to those caregivers of stroke survivors with no functional disability. The presence of depressive symptoms in the informal caregiver was highly correlated with caregiver burden ($\chi^2 = 41.341, P < .001$).

	First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
2	Barben (2023), France	A prospective observational study assessed health-related quality of life (HRQoL) in primary caregivers of patients aged 70 and older with cancer, 5 years after initial treatment	46 caregivers of patients 70 years and older who had a geriatric oncology consultation between 1 June 2014 and 18 March 2015 and were managed at the George Francois Leclerc Cancer Center or Dijon University Hospital, France	SF-12 and Zarit Burden Interview (ZBI) was used at baseline and final assessment 5 years after inclusion.	Descriptive statistics, Mann-Whitney test and Fisher's exact or chi2 tests. Wilcoxon signed-rank tests HRQoL and perceived burden scores were generated, described at baseline and at 5 years.	At 5 years with respect to baseline score, physical functioning (MD= -10, p=0.04), vitality (MD= -10.5, p=0.02), and role emotional (MD= -8.1, p=0.01) were statistically significant and clinically meaningful and all of 3 dimensions were deteriorated. Mental health dimension showed clinical improvement (MD=5.4, p=0.68) while role physical showed a clinical deterioration (MD= -7.2, p=0.17).
3	Henry (2020), USA	A cross-sectional study aimed to understand the needs of Caregivers for individuals with Parkinson's disease (PD)	Data from 181 caregiver/care recipient dyads at a multidisciplinary PD clinic in a public, academic medical center	Caregiver QOL (Parkinson's Disease Questionnaire for Caregivers (PDQ-Carer), and care recipient symptoms Parkinson's Disease Questionnaires (PDQ-39) and Non-Motor Symptoms Questionnaire (PD-NMS)	Multiple regression analysis to explore the relationships between PD symptoms and caregiver QOL	Female caregivers and those who provided care to male care recipients had worse QOL. Caregivers for male care-recipients had higher anxiety and depression. Female caregivers took less self-care than male care givers. Reduced mobility, emotional well-being, and non-motor symptoms of care recipients were unique predictors of reduced caregiver QOL.

<p>4</p>	<p>Hwang (2023), USA</p>	<p>A secondary data analysis aimed to examine the better caregiver mastery is associated with less anxiety in individuals with cognitive impairment over time</p>	<p>A total of 154 dyads from Healthy Patterns Clinical Trial (NCT03682185) dataset and guided by Factors Associated with Behavioral and Psychological Symptoms of Dementia conceptual framework</p>	<p>Secondary data analysis using data from Healthy Patterns Clinical Trial, a randomized control trial of a home-based 1-month program targeted individuals with cognitive impairment and their family caregivers and had an experimental group and an attention control group with pretest (T1) and posttest (T2) of the parent study. Caregiver mastery was measured with the Caregiving Mastery Index Anxiety of care recipients measured with Neuropsychiatric Inventory.</p>	<p>Multiple linear regression analyses</p>	<p>Improved caregiver mastery leads to decreased anxiety of the care-recipient, suggesting that psychoeducational programs and resources can help reduce anxiety in individuals with cognitive impairment, benefiting both caregivers and their loved ones, through improved psychological wellbeing of the caregiver.</p>
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<p>5</p>	<p>First Author (Year), Country</p> <p>Kazemi, (2021), Iran</p>	<p>Research Design</p> <p>A cross-sectional study aimed to determine the relationship between the severity of burden of care and coping strategies</p>	<p>Sample/Setting</p> <p>110 caregivers of older patients who previously had a stroke, used convenience sampling</p>	<p>Instrumentation</p> <p>The Zarit Burden Interview and Lazarus coping strategies questionnaires</p>	<p>Data Analysis/ tools</p> <p>Pearson's correlations and independent t-tests</p>	<p>Summary of findings</p> <p>Caregivers with higher burden of care used more negative coping strategies, such as escape-avoidance and distancing. Positive reappraisal (15.16±5.18) and seeking social support (8.58±2.90), were the most commonly used coping strategies and the least used were direct confronting (6.58±2.70) and escape-avoidance (14.37±4.98). The greatest caregiver burden was physical burden (15.49±5.06), and the least was social burden (4.68±3.56) Male caregivers used the positive reappraisal strategy (t (110) =2.76; p=0.007) and accepting responsibility (t (110) =2.26; p=0.026) significantly more than female caregivers.</p>
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	First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
6	Kavaalp, (2021), USA	A longitudinal study with 1007 unpaid caregivers aimed to explore the relationship between caregiver burden, work-family conflict, and mental health	The community sample consisted of 1,007 unpaid caregivers from block groups in the Chicago metropolitan area. Random digit dial used to recruit participants with Troidahl-Carter-Bryant method used to select who would participate from each household. A mailed self-report survey and resurveyed at 12-month intervals from when first questionnaire was received for three consecutive waves of data collection.	Caregiver burden using a modified Caregiver Burden Inventory (CBI Novak & Guest, 1989). Work-Family Conflict Scale (Kelloway et al., 1999); Center for Epidemiologic Studies Depression Scale (Radloff, 1977); and Profile of Mood States scale (McNair, Lorr, & Droppleman, 1981).	Structural equation modeling (SEM) was used to analyze the data	Strain-based work to family and family to work role conflict mediates the relationship between caregiver burden and mental health issues (depression and anxiety).

	First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
7	Kavga (2021), Greece	Cross-sectional, correlational study	Purposive sampling of dyads that consisted of 109 stroke survivors and their primary family caregivers, in Attica, Greece	The patients' and caregivers' demographic and clinical characteristics, the patient's functionality (Barthel Index), the caregiving outcome (revised Bakas Caregiving Outcomes Scale), the caregiver's mental state (Center for Epidemiological Studies-Depression, CES-D), and the level of social support (Personal Resource Questionnaire, PRQ 2000).	Multiple linear regression analysis was used with the BCOS scale as the dependent variable. The regression equation included terms for patients' characteristics and caregivers' characteristics, as well as the Barthel Index, CES-D and PRQ 2000 scores.	Patient's higher educational level, many family members living in the same house, the presence of equipment and facilities in the house (probably because of the patient's greater disability), and the number of months the patient needed care significantly increased caregiver burden, lowering the BCOS score. The caregivers' perception of burden was lower (higher BCOS score) for those caregivers in good health. The burden was higher (lower BCOS score) for those who provided many months and daily hours of care.

First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
8 Marsack-Topolewski, (2022), USA	A correlational study aimed to explore ongoing support for adult children with autism spectrum disorder (ASD) who have difficulty performing activities of daily living (ADLs) independently can increase caregiver burden	Snowball sampling with 320 parental caregivers of adult children with autism spectrum disorders	A web-based survey using Caregiver Burden Inventory (CBI; Novak & Guest, 1989) and Caregiver Reaction Assessment (CRA; Given et al., 1992)	Multivariate analysis of variance (MANOVA) to compare compound and noncompound caregivers. Bonferroni post hoc tests for differences in the individual subscales and one-way analysis of variance to examine differences on the individual items measuring the four dimensions of caregiver burden.	The study found significant differences in caregiver burden, between compound and noncompound caregivers, indicating that time, dependence, developmental and financial burden is more severely impacted by caring for an adult child with ASD whilst caring for another care-recipient with a disability, in comparison to caring for a child with ASD alone or caring for other children without ASD at the same time. It suggests caregivers' needs should be assessed as they coincide with specific needs of individual care-recipients.

	First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
9	McMillan (2021), Canada	A cross-sectional study aimed to find out the burden of Spinal Muscular Atrophy (SMA) by patients and caregivers, including disease and treatment impacts, indirect costs, and caregiver burden	962 caregivers of children with SMA. Two patient support groups (Cure SMA Canada and Muscular Dystrophy Canada) invited individuals with SMA and caregivers of individuals with SMA from their membership lists, via e-mail, to complete the survey.	EQ-5D-5L and Caregiver Strain Index (CSI)	Descriptive statistical analysis	46% of caregivers reported taking medications for anxiety and/or depression, had received counselling, and had received physiotherapy for an injury associated with lifting or transferring the patient, and 63% reported other health impacts. Changes to personal plans, sleep disturbances, and work adjustments, with a mean Caregiver Strain Index score of 7.5 [SD: 3.3] was reported.

10	<p>First Author (Year), Country</p> <p>Munyumu, (2023), Congo</p>	<p>Research Design</p> <p>A cross-sectional study aimed to investigate determinants of quality of life among caregivers of adolescent and young adult Ebola survivors in Democratic Republic of the Congo</p>	<p>Sample/Setting</p> <p>68 caregivers of adolescents and young adult Ebola virus survivors, using simple random sampling</p>	<p>Instrumentation</p> <p>WHO quality of life BREF (WHOQOL-BREF)</p>	<p>Data Analysis/ tools</p> <p>Descriptive analysis was used to determine the quality of life of caregivers</p>	<p>Summary of findings</p> <p>25% (17/68) reported fatigue; 24% (16/68) muscle pain; 18% (12/68) sleep problems and 13% (9/68) reported chest pain. Almost three quarter of the caregivers 85% (58/68) had experienced stress, 71% (48/68) had no social support. The majority of caregivers (79.41%) reported poor quality of life, with men being 3.17 times more likely to report good quality than women, and town dwellers having lower quality of life.</p>
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First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
11 Ruisoto (2020), Ecuador	Cross-sectional correlational study using face to face interviewing by a team of psychologists	Convenience sample of 688 informal primary caregivers and 688 elderly care recipients co-residing in eight regions of Ecuador	Burden (Zarit Burden Interview), competency (CUIDAR), coping (COPE-28), neuroticism (Eysenck Personality Questionnaire Revised-Abbreviated, EPQR-A), caregiver's general health (GHQ-12), and social support (modified Duke-UNC Functional Social Support Questionnaire, FSSQ11). For care recipients' cognitive function (short portable mental status questionnaire, SPMSQ), Pfeier's test, and functional dependency (Barthel scale/Index, BI).	Pearson's correlation, Student's t-test for gender variation, Levene's and Shapiro-Wilk's tests, Cohen's d. for effect size and independent multiple regression	Female caregivers reported higher degrees of burden and neuroticism than male caregivers. Females mostly cope through religion, and males through substance abuse. For men, burden was correlated to length of time providing care, the caregiver's neuroticism, and the degree of the elderly's functional dependency and cognitive impairment. For women burden predictors were length of time providing care, caregiver's competence, caregiver's neuroticism, and recipient's cognitive impairment.

	First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
12	Sevin (2022) US, Germany, UK, France, Belgium, and Norway	A cross-sectional study aimed to quantify caregiver-related impacts of Metachromatic leukodystrophy (MLD) across several key domains including symptoms, treatment burden, time investment, social and emotional well-being, and professional and financial impact	34 parents recruited through MLD Patient advocacy groups	Data was collected through a 60-minute quantitative telephone-assisted web survey and a 30-minute follow-up qualitative phone interview, during which the EQ-5D-5L questionnaire was administered	Fisher's exact test was used to compare country level results of the EQ-5D dimensions to the population norms. Wilcoxon signed rank test was used to compare country-level EQ-5D utility index and VAS scores to the population norms in each country. Mann-Whitney U test, Fisher-Freeman-Halton test and the Kruskal-Wallis test was used to compare the outcomes between the groups who had different treatments	A mean of 4.1 inpatient and 29.6 outpatient hospital visits in the previous 12-month period was observed. These commitments place stress on familial relationships with 50% of caregivers reporting their child's MLD diagnosis had negatively impacted their relationship with their spouse/partner. Professionally, 76.5% of caregivers stopped working or switched to part-time employment following their child's MLD diagnosis, and most acknowledged caring for their child had affected their potential for career progression or promotion. Differences are also observed based on late infantile versus juvenile onset MLD; time since diagnosis, and for transplanted patients versus those who received palliative care only.

	First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
13	Stratmann (2021), Sweden	A cross-sectional and longitudinal study aimed to determine associations between perceived limitation of informal caregiving and mental health of caregivers	9,346 participants aged 16 to 65	Questionnaire, Interview, and Swedish registers. Covariates included sex, age, social support and socio-economic position	Ordinal logistic regression and Cox regression	Caregivers experiencing limitations showed a significant association with short- and long-term anxiety and depression, compared to those carers with no limitations and to those not giving care
14	Tiehan (2021), Ireland	Secondary data analysis on a national cross-sectional data set to examine differences in carer burden among family carers of people with and without dementia	Original dataset of 2,311 family carers of older people in Ireland	Burden using Zarit Burden Interview. Care-recipient dependency was measured using the Activities for Daily Living Scale. Demographic and care context using self-report scales. Approximately one-fifth of this sample had a diagnosis of dementia.	Multivariable ordered logistic regression was used to analyze four levels of carer burden (low, mild, moderate, high)	Family carers of people with dementia were less likely to report low or mild carer burden and more likely to report moderate or high carer burden -

First Author (Year), Country	Research Design	Sample/Setting	Instrumentation	Data Analysis/ tools	Summary of findings
15 Zubaidi (2020), Malaysia	A cross-sectional study aimed to reveal the estimated proportion of caregiver burden, psychological manifestations and factors associated with caregiver burden among IC in the largest specialized Palliative Care Unit (PCU) in Malaysia	249 Malaysian informal caregivers of patients individually at different times in PCU using a non-probability, convenience sampling in a large palliative care unit	Zarit Burden Interview and DASS-21 questionnaires	Multiple logistic regression using stepwise regression. Variables with $p < 0.05$ were considered statistically significant. Multicollinearity was tested using Variance Inflation Factor (VIF). Model fitness was checked using Hosmer Lemeshow goodness of fit test.	Caregivers often experience mild to moderate burden, with anxiety, depression, and stress being the most common psychological manifestations. Women, highly educated caregivers and those with depression and anxiety are three times more likely to experience caregiver burden.

Quality Assessment and Critical Appraisal

In all of the studies selected, aims and objectives matched the research design and instrumentation and were appropriate for the research area. All of the studies were of medium to high quality, with a score of more than five out of eight, based on The Joanna Briggs Institute (JBI) critical appraisal tool. Lack of identification of confounding variables was the most commonly found bias in all of the studies.

Comparing research studies is difficult because of differences in the criteria used to choose participants, the definition of caregiver burden, the methods employed, and the length of the follow-up periods. Studies focused on different aspects of caregiving such as the caregiver's socio-demographic context and care-recipients' needs. Studies on personality traits, care proficiency, or coping strategies are only beginning to emerge. No studies were found in the local setting, which is another restriction. Restricting the choice to papers written in English may have led to the omission of significant contributions that could enhance the credibility of the evidence, hence diminishing its local applicability. The relationship between the research team and the care-giving burden was not clearly highlighted, which could have impacted on the research design.

Reliance on convenience sampling, of caregivers attending patients accessing medical care in formal settings and recruiting through patient advocacy groups may not accurately reflect the entire caregiver community, hence the level of burden measured may have been higher in the studies in these settings.

Narrative Analysis

Caregiver burden encompasses the perceptions of physical, emotional, and financial stress and strain endured by caregivers who provide care for family members with physical, mental and behavioural impairments. The strain on caregivers is impacted by the care recipients' age and level of need of the care recipient, and carer demographics and context of care. The thematic analysis on care giving and care burden was based on the following themes, namely (1) Type of care provided, (2) Impact of care-recipient dependency on care burden, (3) Impact of caregiving for children and young adults, (4) Impact of caregiver demographics and context on caregiver burden, (5) Work-family role conflict, professional and financial impact, (6) Health impact of caregiver burden, and (7) Coping Strategies used by caregivers.

1. Types of care provided

Research literature identifies three types of care provided by family caregivers — providing care and assistance with daily living, and instrumental activities of daily living (ADL/IADL); health management; and health systems logistics (Riffin et al., 2019; Sunde et al., 2023). IADL and ADL involves supporting with daily needs such as assistance with bathing, shampooing, daily body hygiene and grooming, organizing transportation and mobility facilities, arranging and overseeing social activities and respite care services, paying utility bills, managing financial and legal affairs, attending to household chores such as laundry, gardening, cooking, cleaning, repair and maintenance of home (Liu et al., 2020; Riffin et al., 2019; Thomas et al., 2021; Utz & Warner, 2022).

Riffin et al. (2019), and Hashemi et al. (2020) identified additional responsibilities that family caregivers fulfill as health management activities such as supporting with physical fitness and exercise routines; foot, skin, eyes, ears and teeth care; lifting, carrying and turning the bedridden; ensuring healthy diet and nutrition intake, assisting with feeding tubes; and maintaining effective communication with health care professionals and other family members.

Health systems logistics can involve monitoring for vital signs and for signs of worsening of existing symptoms, speaking with care recipient's health care providers and health insurance providers, keeping daily track of medication intake and collecting medication, scheduling medical appointments and treatments, and seeking and obtaining palliative care equipment and services.

Evidence showed that the range of care had no impact on carer burden while women reported higher perception of competence when doing a range of care giving tasks. The burden of caregiving increases depending on the number of hours per week, the duration of care across years, level of care needs of the patient, and perception of care competence (Riffin et al., 2019).

2. Impact of care-recipient dependency on care burden

Care-recipients with functional, cognitive, and behavioural impairments can increase the care burden of caring for elderly, disabled, and chronically ill family members. Reduced mobility and non-motor symptoms such as depression, anxiety and apathy of care-recipients can reduce the care giver's quality of life (Henry et al., 2020).

Long-term stress experienced by caregivers of chronically ill family members can differ during different periods of diagnosis, stability, remission, progressive

decline, palliative care, and end of life care (Pozet et al., 2023). Family members who have ongoing long-term complications from obesity, stroke, cardiovascular disease, terminal cancer, kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, schizophrenia, dementia, congenital disabilities, and drug-resistant infectious diseases, etc. can add to caregiver strain due to lack of knowledge and skills to support them (WHO, 2020; Spillman et al., 2020; Sunde et al., 2023). Ruisoto et al. (2020) showed that perception of lack of competence added to female caregivers' perception of burden more than male caregivers' perception.

Achilike et al. (2020) stated that caregivers who provide care for those with severe functional disability have 3.7 times higher odds of experiencing caregiver burden compared to those without functional disability. Where lifting and mobility equipment is not available, care giving burden may be more impacted by functional dependency. The highest level of care burden reported in the Iranian study by Kazemi et al. (2021) was physical burden. In the Ecuador study, men perceived higher burden due to functional dependency, while women perceived higher burden due to both mental impairment and physical dependency (Ruisoto et al., 2020).

Caring for family members with mental illnesses such as schizophrenia, Parkinson's disease, and dementia, can add to perceptions of social isolation, and loneliness, due to stigma attached to these illnesses. The time constraints attached to these illnesses can also reduce time available for self-care. Women caregivers caring for male care recipients can experience higher care burden, as male carers are able to take time for self-care more than women carers do (Teahan, et al., 2021; Henry et al., 2020).

3. Impact of caregiving for children and young adults

The demands of caregiving are different when caring for offspring with life threatening and life-limiting conditions. Marsack-Topolewski (2021) demonstrated that parental caregivers can anticipate an augmented level of duty and demand in supporting their adult children with autism spectrum disorder (ASD) throughout their entire lives. Offering continuous assistance to adult children with ASD who struggle to do everyday tasks independently might amplify the load on caregivers. Compound caregivers, who are responsible for caring for both an adult child with ASD and another person in need of care, may find this task particularly difficult.

Sevin et al. (2022) showed that caregivers who provide care for children with both functional disability and mental impairment face significant burden, leading to 76.5% resigning or adjusting to part-time employment. The financial hardship can extend long term, with limited resources and opportunities to attend to their own well-being. Consequently, this leads to a decline in their overall quality of life long-term (Ferrell & Kravitz, 2017).

Often, caregivers who are responsible for children with life threatening functional and neurological illnesses have to significantly alter their routines, which can have adverse effects on their familial, physical, mental, social, and financial well-being. Significant changes to lifestyles, with fewer social and leisure activities, dissatisfaction with personal lives, dissatisfaction with ability to communicate with care professionals, to share information, feelings of guilt, feelings of inadequacy of parenting skills were reported in Sevin et al.'s (2022) study, with 75% of caregivers resigning or adjusting their work schedules to remote work.

McMillan et al. (2021) reported that parents caring for children with spinal muscular atrophy reported taking medications for anxiety and/or depression, had received counselling, and had received physiotherapy for an injury associated with lifting or transferring the patient, work adjustments, sleep disturbances, changes to personal plans with a mean Caregiver Strain Index score of 7.5.

In the study in Congo, conducted by Munyumu et al. (2023), the researchers found that the quality of life and related factors among caregivers of adolescent and young adult Ebola survivors are affected by the fear of infection and the possibility of death. This can lead to hypervigilance, exhaustion, and profoundly affect both survivors' and caregivers' psychological wellbeing which consequently impacts their quality of life. They found that 75% of caregivers of Ebola victims reported poor quality of life compared to a similar study of QOL in Uganda with caregivers of cancer patients where less than 50% reported poor quality of life. Managing children's incontinence, catheterization, feeding, communication, and mobility training without additional support can be overwhelming for parents in developing country contexts (Nanyunja et al., 2022).

In a study of grandmothers providing primary care for ill grandchildren, additional to physical and psychological burden, financial burden was the most salient challenge (Matovu et al., 2019).

4. Impact of caregiver demographics and context on caregiver burden

Additional to care recipient's age, ethnicity and co-morbidities of care recipients, caregiver burden is shaped by caregiver characteristics such as age, sex, level of education, marital status, residence, co-residence, socio-economic status, and perceived support available (Riffin et al. 2019; Stratmann et al., 2021; Teahan et al. 2021).

In the Irish study (Teahan et al., 2021), while there were fewer care recipients living in rural areas, the number of care recipients cared for by a family member was higher in the rural context. Social isolation, limited transportation, reduced accessibility to services and gaps in service provision in the rural contexts can increase the care giver burden in rural communities.

The mean age of carers in developed countries is about 56. This data is similar to a Europe wide study by Elayan et al. (2024), by Kavga et al. (2021), by Teahan et al. (2021) and by Zubaidi et al. (2020), in Malaysia. In the Iranian study, and the Ecuador study, care givers for the elderly were in their early forties, which indicates duration of caregiving can be longer in developing countries. There is some evidence that younger adults perceive care burden more, as they may be balancing work, and caring for own children, while caregiving, with role conflict adding to the care-burden (Kayaalp, et al., 2021). However, there is not sufficient evidence to show how the age of caregiver and care-recipient impacts different aspects of care burden such as unmet physical, social, emotional, educational, employment and spiritual needs of young adult carers, and of child carers of parents (Reuvers, et al., 2023).

Higher level of education is positively associated with perceived care burden, with 58% of those with higher education demonstrating care giver burden in the Irish study (Teahan et al., 2021). These findings are similar to the findings by Kavga et al (2021) and by Zubaidi et al. (2020). It is possible that higher levels of education are associated with higher levels of opportunity cost for the carer (Mudrazijah, 2019).

In Teahan et al. (2021)'s study, 53% of care was provided by adult children, and 73% of carers co-resided with the care recipient. Co-residing with a family care recipient and caring for a parent were associated with increased care burden in the Irish study. Psychological abuse, physical abuse variables and poor relationships between family carer and care recipients were positively associated with care burden. Mental illness in care recipients may be causing the abuse and breakdown of relationships (Teahan et al., 2021).

Co-living with the care recipient in a large household also indirectly increases the caregiver burden (Ruisoto et al. 2020). In Zubaidi et al. (2021)'s study in Malaysia, 31% of the carers had an existing underlying medical condition at the time of the study, while only 9% had paid to utilize respite care.

In all of the studies majority of the caregivers were female. Zubaidi's study also showed that most of the spousal carers in their study were women. Studies show that caregiver burden is experienced more by women (Henry et al., 2020; Ruisoto et al. 2020). The higher number of female carers shows gender disparity in informal care provision and the ensuing significant physical, emotional, and financial burden for women as they age. Since the number of female care recipients are higher than males, the future care burden, as populations age, with women living longer than men, can become significant, unless policy is implemented to ensure gender equality in care horizontally and vertically across generations (Rodrigues, et al., 2023).

5. Work-family role conflict, professional and financial impact

The financial burden is financial demands put on families because of caregiving responsibilities. Research indicates that care-giver burden can be less for those who remain employed while caregiving (Longacre et al., 2021). Caregivers who may be the primary providers for the family may continue to work despite the severe caregiver burden. Even if the caregiver was the secondary income earner, continuing to stay on the job can become more significant, if the care recipient is the primary income earner for the household.

Out of pocket costs for medical expenditures, paying for respite care, nutritional supplements, transportation to hospital costs, accommodation and meals in hospitals can add to the financial burden, with reports of caregivers begging on the streets and borrowing from family and community members to stay alive in low-income contexts (Montgomery et al. 2023). In one study, parents abandoned their ill child, when there was no means of paying for out-of-pocket costs of caregiving (Atwiine et al., 2021).

Many employed care givers take time off work, either paid or unpaid, to care for family members. Taking time off to care may require changing work schedules to attend hospital visits, foregoing promotions, change to lower paid or more flexible work, to work remotely, or to give up work altogether. Many struggle to go back to the same work after providing care for long periods of time and continue to work in care roles (Gardiner et al. 2020). In Sevin et al.'s (2022) study of parents with children with a severely deteriorating condition, parents reported they had accomplished less than they would have liked,

had missed about 4 days of work in the previous month and the number of workdays ranged between 0 to 29 days in a month, and that on average 50% of the missed days were unpaid.

In some companies, approximately six weeks of paid leave is given to care for an immediate family member, though this level of paid leave is not common. Globally, the majority of countries do not have any policy for paid leave to care for aging relatives or to care for adult children (Heymann et al., 2022). Different countries have different levels of public spending for unpaid long-term care, including cash payments for specific respite care, carer allowance payments, and holiday payments, using either pooled insurance funds or tax-based funds. Taking unpaid leave can have detrimental effects when social insurance pay is extremely low or unavailable (Hastert et al., 2020).

In the Malaysian study by Zubaidi et al. (2020), only half of the carers were employed though the age range of the participants was under 65. 55% of carers were giving care for more than 14 hours per day, which is comparable to the Irish study of about 12 hours a day. About a third of the carers had other caregiving responsibilities whilst providing palliative care.

6. Health impact of caregiver burden

Emotional burdens experienced by caregivers can be feelings of sadness, anxiety, loneliness, despair, frustration, and depression. Studies by both Zubaidi et al. (2020) in Malaysia and by Stratmann et al. (2021) in Sweden showed that caregivers who experience severe to moderate burden, demonstrated associated anxiety and depression, with the longitudinal evaluation in Stratmann et al.'s study showing the increased likelihood for clinical diagnosis of depression among informal, unpaid caregivers. The study by Kazemi et al. (2021) in Iran also highlights strain-based conflict mediating the relationship between mild to moderate level of strain, which often leads to psychological manifestations such as worry, melancholy, and stress among caregivers.

When caregiving is perceived as a demanding activity, this leads to psychological and physical repercussions (Bom & Stöckel, 2019). The context specificness of the perceived care burden is demonstrated by Stockel & Bom (2021)'s study comparing caregiving in UK and Netherlands which showed a strong correlation on mental health issues with increasing number of hours per week, spent in caregiving, in Netherlands, more so than in UK. In both countries mental health deteriorated with a than 20 hours of care per week. Riffin et al.'s study in USA (2019) also showed a similar pattern while showing the type of care given did not impact the carer burden except for dementia care (Riffin et

al., 2019). 47% of carers in Teahan et al.'s study (2021) provided more than 80 hours of care per week, and in this study, it was the length of the time the carer has been providing care significantly which increased the care burden while the number of hours per week did not. Kavga et al.'s (2021) study in Greece showed that both longer duration of time and increased number of hours were correlated with increased care burden.

Sevin et al.'s (2022) international study on caregiver-reported burden and quality of life in metachromatic leukodystrophy revealed that the prevalence of caregivers encountering difficulties in carrying out routine tasks and experiencing pain, discomfort, anxiety, worry, or sadness exceeded the average for the general population in the United States, United Kingdom, and in France. Caregivers exhibited elevated rates of challenges in regard to self-care and typical activities as compared to the established norms of the general population. Fifty percent of caregivers stated that their relationship with their spouse was negatively affected by their caregiving burden, which could be due to the length of time spent caring, changes to professional status, family income, reduced social and leisure activities, physical and mental health impact of the caregiving.

The findings of Cheng et al. (2022) examined the mediating influences of self-esteem and psychological distress. The study found that families that had lower self-esteem, higher depression levels, and a greater burden of care experienced a lower quality of life.

The psychological strain can culminate in caregiver burnout, which is identified by feelings of overwhelming fatigue, emotional detachment, and a reduced sense of achievement. This state of burnout can have several adverse effects, including weakened cognitive functions (like memory issues, concentration difficulties, and trouble handling elaborate tasks), feelings of detachment from others, a decline in work performance, increased likelihood of missing workdays, lowered productivity, and potential negative impacts on the safety of the person receiving care (Blom, Reis, & Lencastre, 2023).

While low intensity care improved the physical health of unemployed or retired people, this improvement was not seen with full-time employed and high intensity care givers (Bom & Stöckel, 2019).

7. Coping strategies used by caregivers

Coping strategies used by men and women are different (Kazemi et al., 2021). Women tend to turn to religion and denial as coping strategies while men tend

to turn to substance misuse and self-distraction as coping strategies (Ruisoto et al., 2020). Emerging evidence indicates that men who are primary caregivers can have different unmet needs compared to women (Fisher et al., 2021).

While hiring foreign caregivers is an increasing trend globally, safety, security, and quality of care remain a concern. Research indicates that adequate rest, information, and training to provide care are needed by these caregivers (Heng, Fan & Chan, 2019).

Having perceptions of positive social relationships reduced perceptions of care giver burden (Kavga et al., 2021; Teahan et al., 2021, Kazemi et al., 2021). In a study by Chung et al. (2022), the caregiver's perceived social support availability mediated the association between optimism and depressive symptoms in stroke survivors. Chung et al. (2022) recommended interventions to promote optimism and social support in chronic illness management. This highlights the need to provide opportunities for caregivers to socialize with other caregivers, as well as with good friends, and close relatives, either face to face or using audiovisual technology.

Work supervisor support is linked to work to family enrichment for working caregivers (Morimoto & Takebayashi, 2021). Supervisors can inform employees of paid leave, and other resources available such as counselling and communication skills training through work-based insurance schemes. In developed countries, charitable grant funding can be sought for extreme hardship.

Summary of Findings and Recommendations

The fifteen studies included in this review show quantitative evidence that the responsibility of caring for the elderly, disabled and chronically ill family members results in a significant amount of care burden, which negatively impacts the caregiver's health, overall well-being, and quality of life. Unmet caregiver needs can cause long-term ill health for the caregiver and can necessitate the need for long-term institutional care for the care recipient.

The results of the primary studies included in the review suggest that caregiving burden can be multi-dimensional. For family caregivers, loss of employment, pressures to remain at work, the perceived lack of knowledge, and caring capability, combined with financial and time burden of care giving can be exhaustive. For those without employment, caregiving can involve moving home, going without food, and going into debt.

The requirements of providing care can differ depending on an individual's socio-demographic factors, and on the level of demand of care expected. Depending on the resources available, the same obligations can be more difficult for the poor, including level of physical exertion, psychological pressure, and impact on health, well-being, and the overall quality of life (QoL). Care giving thus raises issues of inequity as care work is related to gender, migration and cultural biases (Gardiner et al. 2020).

Research shows that responsive government policies, a welfare state with generous allowances for carers and care recipients, supportive cultural norms, and socially supportive work environments can positively impact the well-being of caregivers (Bom & Stöckel, 2019; Morimoto & Takebayashi, 2021).

WHO recommends that support such as training, respite care, information services need to be tailored to improve carers' knowledge, caring skills, coping strategies to meet challenging behaviours, reduce stress, burden, and health problems (WHO, 2017). Support systems, resource accessibility, and respite opportunities are crucial elements for sustaining the well-being of caregivers. Enhanced caregiver proficiency can result in reduced anxiety, indicating that psychoeducational programs, and nursing education programs might be advantageous for both caregivers and care users, as well as door to door community-based services (Ren et al., 2022). For example, The Taiwanese LTC 2.0 system is one of the most comprehensive ageing at home systems, with eligibility determined by assessment of ADL, IADL, cognition, behavioural changes, rehabilitation, home situation and care giver stress. Government subsidies are given for rural areas and family caregiver support centres. A local government's care manager assesses the disability level and benefit amounts and connects the care recipient with service providers in what is called an ABC Framework with a long-term care services hotline (Chen & Fu, 2020).

Recommendations for Research

The findings indicate a requirement for additional studies to establish effective strategies to support working age caregivers, so that their careers and future financial status will not be compromised by providing long term care. Since social relationships and psychological wellbeing are significant to reduce care burden, additional studies on the level of social support required and which type of support works best need to be investigated using comparison studies, and control groups. While carer demographics impact the carer burden, how this impact caregiving in diverse cultural contexts needs to be investigated qualitatively, so that effective interventions can be implemented.

From a clinical perspective, the results emphasize the importance of healthcare professionals evaluating caregiver load in a structured manner and integrating the training requirements of caregivers into high-quality patient care. To deescalate the burden, it is necessary to assess the caregiver's well-being on all follow-up visits, and to promote counselling, psychotherapy, physiotherapy, access to respite care, and social support networks for caregivers (McMillan et al., 2021). Professional care providers must prioritize the needs of both patients and their family caregivers, as well as other family members, so that the care burden is minimized.

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