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# Quality of life indicators in caregivers of older adults with dementia: A scoping review using Classification of functioning, Disability and Health on service and environmental support.



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#### Abstract

The quality of life of caregivers of persons with dementia greatly influences their health, physical, psychological, and emotional wellbeing. This in turn influences the quality of care they deliver to people with dementia. This scoping review aimed to map emerging evidence on the quality-of-life indicators using service and environmental support factors and a subsequent characterization using the WHO-ICF provides a platform for the understanding of these factors and how they influence the overall wellbeing of caregivers.

Using a systematic scoping review approach, we identified 14 studies on service and environmental support influencing quality of life of caregivers of persons with dementia. The search included EMBASE, CINAHL, the Cochrane Database of Systematic Reviews, JBI Evidence Synthesis, and Epistemonicos. A narrative synthesis of the data revealed that the quality of life of caregivers is greatly influenced by service and environmental support factors which in turn influences their activities of daily living and that of persons with dementia.

The service and environmental services factors include services from government, family, community, healthcare professionals, peer groups, and activities available, Attitudes from individuals especially family, spouse and others, environmental support and support relationships improving quality of life of caregivers of persons with dementia requires an understanding of the prevailing service and environmental support which drive their commitment to quality care for older adults with dementia especially in a pandemic environment.

Keywords: Caregiver; dementia; service; environmental support; quality of life

#### Introduction

According to the World Health Organization (2022), approximately 55 million people live with dementia worldwide, and about 10 million people are affected yearly. This adversely affects their ability to perform everyday activities and affects their independent living, thereby increasing their dependence and needs for personalized care [1]. This disease impacts caregivers' physical, biological, psychological, social, and economic conditions. Caregivers of persons with dementia may be among the first to notice these changes in quality of life. Nonetheless, while caregivers may report on signs of impairment from dementia, they may not be as well attuned to the quality-of-life issues for the aging population with dementia onset. Although several reviews have discussed factors that may influence the quality of life of persons with dementia, very few have focused on the role of

service and types of support environment on the quality of life of caregivers of persons with dementia.

Quality of life involves life situations, circumstances, placement, a sense of fulfillment, and satisfaction with work and personal relationships [2]. Among older adults with dementia, their interpersonal relationships, happiness, sense of satisfaction, family relationship, sense of fulfillment, housing, availability of food, and financial resources may suffer [3] Importantly, caregivers may report adverse physical health, energy, mood, memory, self, and ability to enjoy everyday activities from the objective and subjective demands of caregiving [4]. Caregiver quality of life can be described as the personal self-evaluation of the caregiving experience, which requires collecting and measuring patient-reported outcomes [5]. A good service and support environment

is correlated with the promotion and maintenance of good health and quality of life for caregivers of persons with dementia.

The WHO-ICF (2001) provides a framework for holistic understanding of health and wellbeing. According to the WHO-ICF, functioning is a term that comprises all body functions and structures, activities and participation, while disability refers to a broader term for impairments, activity limitations and participation restrictions. 'Impairments' can be described as issues in body function or structure. On the other hand, 'activity limitations' refer to difficulties a person may encounter while performing daily activities; and 'participation 'restrictions' are problems a person may face when involved in life situations [6]. An 'individual's functioning and disability, which comprises participation, are a function of interacting with health conditions and environmental factors.

This comprises environment accessibility, peer group relationships, service availability, etc.) and personal elements, including age, values, lifestyle and gender [7]. Regarding the health of caregivers of older adults with dementia, Factors such as the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and environmental support can influence the quality of life of an individual [8] Therefore, the factors enhancing 'caregivers' quality of life, such as service and support environments, should be further investigated. A vital step in monitoring and improving the quality of life of caregivers of persons with dementia is to determine what good determine a good quality of life and how this can be achieved in the context of service and support environment. Caregiver distress and burden indicate prolonged consequences of poor physical and emotional health [9]. suggest that caregiving is associated with more psychological complaints and poor involvement in social networks and having time for oneself, concern about the future, need for support, and engagement in enjoyable activities, which have also been identified as factors influencing carers' QOL [8].

The everyday caregiver, in most cases, could be the spouse, children, or other relatives and acquaintances. Despite inherent satisfaction derived from providing care, this task can also bring adverse physical, financial, behavioral, emotional, and financial effects on the care provider [10]. When this happens, the caregiver experiences burden from activities associated with care. Risk factors for caregiver burden include gender of the caregiver, low educational levels, residing with the care recipient, elevated hours of caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver [11]. The assessment, identification, and management of dementia are of important interest from care recipient point of view and from caregivers' perspective because dementia affects one's quality of life and psychological wellbeing [12]. This present review is aimed at scoping and synthesizing emerging evidence of the influence of services and support environment on the quality of life of caregivers of persons with dementia. We aimed to scope and synthesized emerging evidence

of quality of life of caregivers of persons with dementia based on types of services and environmental support they receive.

# Health Related Quality of life and the ICF framework

Health related quality of life has been defined by the WHO-ICF as a measure of the value assigned to the duration of life modified by impairments, functional states, perceptions, and opportunities, as influenced by disease, injury, treatment, and policy. It is described as a multidimensional ensemble that encircles the aspects of Quality of life (QoL) impacting health, thereby referring to how an individual's daily function is influenced by their physical, mental health and perceptions of their ability to having a fulfilling life [12]. The ICF is a systematic framework developed by the WHO-ICF that closely adopts this definition. Components included in the ICF are body functions and structure, activities and participation, and contextual factors (personal and environmental factors). Because the health and functioning dimensions covered by HRQL measurements are compatible with the health and health-related domains within the scope of the ICF [13], it is suggested that the ICF can be used as a conceptual platform to classify and select the appropriate HRQL measurement according to the relevant purpose of interest. Therefore, the ICF model will be applied as a framework to discuss the appropriate health related quality of life measures in this review.

## **Caregivers Quality of Life**

The WHO-1CF has defined caregivers as anyone who is involved in the provision of services to support individuals in their daily activities and maintenance of performance at work, education or other life circumstances, provided either through public or private funds, or else on a voluntary basis, such as providers of support for homemaking and maintenance, personal assistants, transport assistant, paid help, nannies and others. Caregivers of persons with dementia are often challenged to manage the long-term symptoms of dementia without adequate knowledge of the disease or support from others [13]. As a result, caregivers are at increased risk of negative mental and physical health outcomes, such as depression and high blood pressure [14]. Due to the chronic, intensive, and time-consuming nature of caring for patients with dementia, physical and mental erosion are often observed in caregivers, which might also impact their quality of life (QOL) [15].

Caregivers of persons with dementia do not provide care in isolation from the other roles and responsibilities in their lives. They incorporate their personal lives which includes their spouse, parent, employee, business owner, community member. Under normal circumstances, the caregiver can balance the responsibilities and rewards of competing roles such as caring for the family or working to earn and their caregiving responsibilities. Nevertheless, unavoidable caregiving demands, and the costs of long-term services and support (LTSS) can overwhelm and

undermine other dimensions of one's life [15]. Additional complexity in direction occurs when family members disagree about the type of care needed and how it should be provided [16], or when family roles and responsibilities shift over time.

Studies by Domico, 1997 reported that caregivers' age, physical health, purpose in life and financial status were predictors of good quality of life [17]. Other studies reported that the presence of a good social support network can lead to improved mental and physical health and spiritual well-being [18,19]. Some studies investigating the impact that education and professional health care support has on caregivers' quality of life reported that improved quality of life is achievable when caregivers receive in-home occupational therapy sessions to help them modify their home to support the daily function of persons with dementia [20,21]

This includes environmental modifications to ease patients taking medications, the use of mobile devices and restrooms, caregiver approaches to the patient (i.e., daily living tasks), and community-based assistance provided (i.e., referrals to the resources available). Interdisciplinary psychoeducational family group intervention has been reported to reduce caregivers' burden thereby improving their quality of life [22]. Additionally, visits to memory clinics have been shown to increase caregivers' psychosocial health-related quality of life [15].

# Services and quality of life in caregivers of persons with dementia

Services in caregiving refers to aiding with the activities of daily living and this can include more skilled services such as medication assistance and prompts, or medication administration or nursing services depending on the educational level of the caregiver. The WHO-ICF describes services as processes or systems that help with provision of benefits, structured programs, and operations, in different aspects of the community and designed to meet the needs of individuals. Further included in services are the people who provide them. Services could be public, private, or voluntary, and may be established at various levels by individuals, associations, organizations, agencies, or governments. However, the reality of issues and challenges for caregivers of people with dementia is complex. Various studies have emphasized the need for mediations, techniques, facilities, as well as staff training that can help improve the quality of life for caregivers in all settings and stages of dementia as the ailment is progressive [23,24].

Another study reported that caregivers experience different levels of negative physical and psychosocial health outcomes depending on the quality and duration of the relationship between the caregiver and care-recipient [25]. The consequences of dementia on caregivers can include both psychological ailments, such as anxiety and depression [26], and physical challenges, such as bodily pain and elevated blood pressure [27].

Hence there is also a need to focus on caregivers' needs and expectations so they can enjoy quality of life while delivering care to persons with dementia. According to a study by [28] focusing on the needs and expectations of caregivers involves two important aspects of care: information about the disease and learning of skills for improving the management of everyday life of the patient. The authors suggest that among the available support programs, programs that provide information, education, and practical guidance for enhancing activities of daily life should be of great importance.

Another major factor associated with quality of life of caregivers is the understanding and awareness of how society functions [29]. Most people do not have correct information about dementia, hence, do not understand the difficulties of caregivers and their families, do not offer any help and deny them services. This makes them feel isolated and lonely. Limited or no access and use of the official services, scar of dementia, lack of or limited information and awareness, financial barriers, especially in underdeveloped areas, leads to diminishing quality of life [29].

# **Environmental support and Caregivers quality of** life

The World Health Organization has predicted that approximately 34 million people will be diagnosed with dementia by the year 2025 and much of their care will be provided by family members. Support involves provision of empirical physical or emotional support, fostering, providing defense, assistance and relationships to other persons either in their home, place of work, school or at play or in other aspects of their daily activities (WHO-ICF, 2001).

The WHO- ICF has described environmental support to involve the contextual factors and can serve as barriers of facilitators. For facilitators, it involves accessibility of needed resources, whether dependable or variable, or of good or poor quality. In the case of barriers, it might be relevant how often a factor hinders the caregiver, either small or great, avoidable, or unavoidable. However, environmental factor or supports can be a barrier either because of its presence (for example, negative attitudes towards the caregiver or care recipient) or its absence (for example, the unavailability of a needed service by either the caregiver or persons with dementia). Environmental support has varying influences on the quality of life of people with dementia and their caregivers which depends on a lot of factors.

Though very little research has focused on quality of life of family caregivers of persons with dementia. A common factor in defining quality of life is the individual's perception of general wellbeing which included physical, psychological, and financial well-being [27] In a phenomenological study of 32 family caregivers of persons with Alzheimer's disease (AD) identifying the meaning of quality of life, factors affecting quality of life of

caregivers include the health condition of the person they were caring for, independence of the care recipient, assistance with caregiving, and anxiety about the future [30] Other studies on quality of life of caregivers of persons with dementia reported that demographic variables such as relationship to family member, length of the time care giving, and hours of care provision were significantly associated with quality of life [31].

Globally, factors predicting caregiver availability for older adults with functional difficulties in formal aged care institutions have been investigated. These include advanced age in older adults', difficulty with self-care activities, without a partner, wealth, and those with dementia, advanced tumor or post-stroke [27]. Other factors include being a woman, availability of family member, infrastructural investment, and insurance for long-term care. Similarly, other evidence suggests a weakening desire of caregivers availing themselves for the care of community-dwelling older adults. For instance, a study reported a significant association existing between advanced age, functional ability and caregiver availability [30]

Hence, identifying factors influencing QoL in each stage of dementia will provide a better understanding of the relationship between Quality of life of caregiver, recipient, and dementia progression. Changes in environment, from a familiar environment to an unfamiliar one, could have an adverse or pragmatic impact on the quality of life of persons with dementia and their caregivers [32]. Moreover, many care facilities provide professional care for persons with dementia. However, studies which compared the quality of life of persons with dementia and their caregivers in the community and those living in care facilities showed that living in the community influenced a better quality of life in persons with dementia and their caregivers [33,34].

## Research questions

Studies have shown that when compared to non-caregivers, stress and psychological morbidity are higher among caregivers of persons with dementia. Behavioral symptoms and impairment in instrumental activities of daily living are also reported to be correlated with caregiver stress. Gonzalez-salvador et al., 1999). Our specific research question will be.

- i. 1.How does service and environmental support enhance and sustain quality of life of caregivers of persons with dementia? and
- ii. 2.what services and environmental support factors help enhance activities of daily living in caregivers of persons with dementia?

The findings would inform the design, implementation and application of services and environmental support for the enhancement of quality of life of caregivers of persons with dementia. Moreover, the findings would provide a basis for further empirical studies on quality-of-life resourcing and maintenance of activities of daily living among caregivers of persons with

dementia in a community-spread pandemic.

#### **Methods**

#### **Research Design**

A systematic scoping review summarizes the emerging evidence on a newer and under-studied phenomenon for mapping the trends to guide future related studies with the benefit of clarification of perceptions and study procedures [35]. It is widely accepted as a form of research synthesis with the aim of mapping the literature on a particular topic, it provides an opportunity to identify important theories, themes, gaps in knowledge, and types and sources of evidence to inform practice, policymaking, and research efforts [36]. Therefore, a scoping review was appropriate to this study for aggregating and the emerging research evidence on the impact of service and environmental supports in carrying out activities of daily living among caregivers of persons with dementia and ensuring the enhancement and maintenance of good quality of life. This systematic scoping review is guided by the [37] five-step process, including (1) identifying and establishing the research question; (2) sorting and identifying relevant studies; (3) selecting relevant studies; (4) mapping the data; and (5) arranging, summarizing, and communicating outcomes. This scoping review was also guided by the PRISMA guidelines for scoping reviews [38].

#### **Search Procedure**

A primary search was conducted using the following electronic databases: (EMBASE), CINAHL, Cochrane Database of Systematic Reviews, JBI Evidence Synthesis, and Epistemonicos for studies on quality of life among caregivers of persons with dementia.

## Eligibility Criteria

This systematic scoping review adopted the inclusion criteria which consisted of peer-reviewed empirical studies across the continuum of qualitative randomized controlled trials to that of quantitative. To be included for review, we considered studies from the past 22 years (January 2020 to October 2022) on service and environmental support factors influencing activities of daily living among caregivers of persons with dementia for a better quality of life. Only studies reported in English were considered. Gray literature and other information from sources which were not confirmed as empirical studies were excluded in our review. Table 2 shows a summary of the eligibility criteria of potential studies for the present scoping review.

# **Data Extraction**

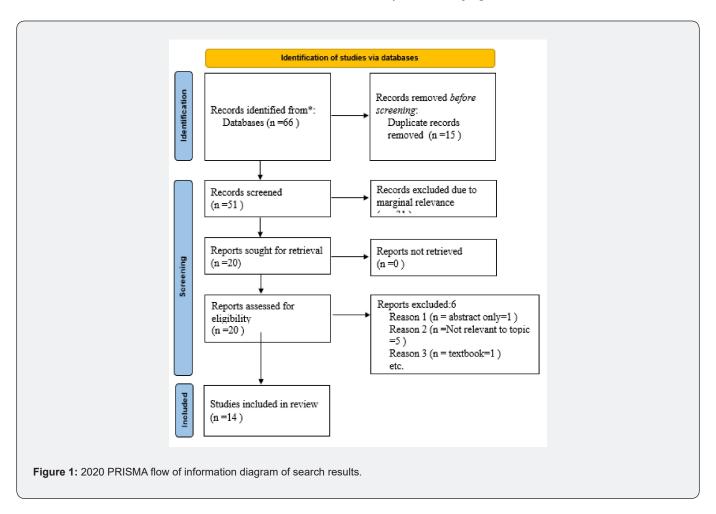
Essential data qualities of study design (i.e., qualitative randomized controlled trials quantitative), participant characteristics (i.e., caregivers of persons with dementia), interventions (i.e., types of services and environmental supports), and outcomes (quality of health sustenance, restoration, or enhancement) were given priority. Articles were individually examined for their relevance to the topic and possible link to

the inclusion criteria, resolving emerging disagreements by concurrence.

#### **Study Selection**

Figure 1 shows a flow chart of the studies' selection process. The initial database search resulted in 66 applicable studies,

of which fifteen were duplicates. Further screening of the remaining 51 studies led to excluding 31 publications due to marginal relevance and the retention of 20 documents for further screening. That process led to the rejection of six studies due to inclusion criteria issues. The outcome yielded 14 studies used in this systematic scoping review.



#### Data Organization.

Data was organized from the articles for review based on source, location, study aims, quality of life indicators, method, participant characteristics, and outcome, quality of life sustenance outcomes Table 3. For each study, we considered whether it identifies a gap in the literature to be addressed.

## Participants' Characteristics

To briefly summarize the study characteristics, four studies were conducted by researchers in the United States, two studies were from Taiwan, others were from Spain, United Kingdom, Poland, Russia, Australia, Portugal, Germany and the Netherlands. Across studies, most participants identified as close family members living with and providing care to persons with dementia. However, some studies included people with dementia in their studies. Nearly two-thirds of included studies sampled

individuals who reported caregiver burden because of providing care to persons with dementia.

Additionally, approximately one third of the studies admitted to having knowledge about dementia, what it entails and diminished quality of life. More than 80% reported improvements in quality of life when provided with appropriate and timely services and environmental support. Two studies discussed unmet needs of caregivers and reduction in activities of daily living by the caregivers. Participants in most of the studies lived in their homes and communities. Studies were conducted based on interviews, semi structured diagnostic interviews, on-site interviews, questionnaires, telephone interviews, cognitive behavioral therapy, and individually tailored intervention programs. Some studies interviewed both caregivers of persons with dementia and their care recipient especially in instances where care recipients could not speak for themselves. while others were based off self-

report, or it was not made clear. Most of the studies of non-clinical populations sampled university students or adults/adolescents from the general population. These studies used samples of convenience by relying on information and responses received and reported by the participants in the study. We note, however, that

detailed descriptions of the recruitment strategy were generally lacking across included studies. We refer readers to Tables 1 & 2 for a more detailed description of the samples, methods, designs, and key findings.

Table 1: presents an overview of search procedures, including key topics and searched terms.

Topic	Basic search term
Caregivers or carers	Caregivers OR Carer OR seniors AND dementia AND service OR environmental support OR quality of life OR activities of daily living
Caregivers, dementia, service, environmental support	Caregivers AND Dementia AND quality of life OR services
Caregivers, dementia, service, environmental support, quality of life	Caregivers AND dementia OR coronavirus OR Alzheimer's disease, AND services AND environmental support
Caregivers, dementia, quality of life, activities of daily living	Caregivers AND dementia OR coronavirus OR Alzheimer's disease, AND services AND environmental support AND activities of daily living

Table 2: shows a summary of the eligibility criteria of potential studies for the present scoping review.

Variable	Inclusion criteria	Exclusion criteria
Study design	Qualitative, randomized controlled trials, quantitative, and peer reviewed.	Single case studies, literature reviews, non-peer-reviewed studies, and gray literature
	Reported on caregivers of persons with dementia	Did not report on caregivers of persons with dementia
Participants	caregivers of persons with dementia and quality of life	No report on caregivers of persons with dementia and their quality of life
Intervention	Impact of services and environmental support systems and/or effect on activities of daily living	No mention of information on the impact of services and environmental support. Impact of services and environmental support systems and/or effect on activities of daily living
Analysis	Data analysis by care provision to persons with dementia and their quality of life	Analysis did not care provision to persons with dementia and their quality of life
Outcomes	Quality of life from services and environ- mental support systems	No information on mental health wellbeing and use of information and communication support systems

Of the fourteen published articles being reviewed, only one assessed quality of life indicators based on activities of daily living using the Barthel index [39]. The Barthel index is an ordinal scale that measures functional independence in the domains of personal care and mobility in patients with chronic, disabling conditions, especially in rehabilitation settings. Quality of life indicators includes financial security, employment, the environment, physical and mental health, education, recreation and leisure time, social belonging, religious beliefs, safety, security and freedom. These were classified as service and environmental support on the ICF framework.

## **Summary of findings**

Health related quality of life indicators refers to an individual's perceived physical and mental health over time. All the published articles included an assessment of health-related quality of life in different dimensions. Framed on the ICF, quality of life indicators

was represented by four phenotypes: Products and Technology, Natural environment & human made changes to the environment, Attitudes, Services, systems and policies. The phenotypes: Natural environment & human made changes to the environment and the services, systems and policies made use of the Barthex index [39], studies utilizing the product and technology phenotype in the form of telephone and structured interviews includes [40-46] attitudes included [47,48] and services, systems and policies included [49 50 &45]

**Services:** includes provision of benefits, structured programs, and operations, in various sectors of society, designed to meet the needs of individuals. (Included in services are the people who provide them. It could be public, private or voluntary, and can also be at a local, community, regional, state, provincial, national or international level by individuals, associations, organizations, agencies or governments and activities.

Table 3: summary of key findings.

No	Source	Location	Study aim(s)	Quality of life indicators	Method	Participant characteristics	Outcome
1	Quinn et al., 2020	United states	To identify the potential impact of the caregiver's perception of the caregiving experience on how people with mild to moderate dementia self-rate their QoL, well-being and satisfaction with life.	Caregiver stress (–1.98; 95% CI: –2.89, –1.07), high perceived social restric- tions (–2.04; 95% CI: –2.94, –1.14) and low caregiving competence	Cross sec- tional study	N= 1283 persons with dementia & their caregivers. Participants were people with dementia and their respective informal caregivers. People with dementia were eligible to join the study if they were residing in the community, had a clinical diagnosis of dementia (any sub-type), and a Mini-Mental State Examination score (MMSE; Folstein, Folstein, & McHugh, 1975) of 15 or above, indicating that they were in the mild to moderate stages of dementia	I-HARP group showed favorable effects across most outcomes at short-term (4 months) and longer-term (12 months) assessments. However, wide Confidence Intervals (CIs) point to the degree of uncertainty around interpretation of these results.
2	Rodri- guez-Perez et al., 2017	Spain	To analyze the relationship between coping strategies and quality of life dimensions in primary caregivers of dependent elderly relatives.	Dysfunctional coping was related to worse quality of life in the psychological dimension, while emotion-focused and socially supported coping were related to superior psychological and environmental dimensions of quality of life. The physical and relational dimensions of quality of life were not related to coping strategies	Cross- sec- tional study	Being a primary caregiver, age >18 yrs, caregiver for > 3 months, no receipt of remuneration for the care, the ability to read and write, and care of a dependent elderly relative aged > 65 yrs dependent in at least one basic activity of daily living (BADL) according to the Barthel Index.	
3	Hlaban- gana& Hearn, 2019	United Kingdom	To investigate depression and quality of life in partner caregivers of people with a long-term or neurological condition (e.g. dementia or spinal cord injury) and explored the extent to which QoL and self-compassion are predictive of depression.	supportive interventions for informal partner caregivers and developing self-compassion in these.	Qualitative study	Participants were recruited from charities and support groups. Partner caregivers (N = 57) completed assessments of depression, QoL, and self-compassion.	Over half (61.8%) of caregivers experienced at least mild symptoms of depression, illustrating high prevalence among caregivers compared with the general population. Overall QoL was poor compared with noncaregivers. QoL was poorest in the physical domain (M = 51.9, SD = 10.1) and highest in the environmental domain (M = 64.9, SD = 15.8). Both self-compassion and QoL were significant predictors of depression (p < 0.05), explaining 48.8% of the variance. Hours spent providing care was also significantly predictive of depression (p < 0.05)
4	Mazurek et al., 2019	Poland	To investigate whether the Meeting Centres Support Programme (MCSP) is effective in meeting the needs of older people with dementia.	Activities of daily living, psychological distress, and the need for company	Cross sec- tional study	N= 47 people diagnosed with mild-to-moderate dementia (n=24, MCSP group; n=23, UC control group) and 42 informal carers (n=22, MCSP group; n=20, UC control group), all living in Wroclaw in Poland and involved in the European JPND-MEETINGDEM project	Compared to the UC group the unmet needs were reduced considerably in the Meeting center support program) MCSP group providing convincing evidence that MCSP is effective in reducing unmet needs over a 6-month period.

5	Cho et al., 2019	United States	To evaluate the impact of REACH-TX, a translation of the REACH II intervention for community-based organizations, and to show its sustainability.	Safety Self-care, Social sup- port Social support, Stress management, Emotional well-being, Pleasant events, Problem behaviors, Healthy living, Understanding feelings Skillful communi- cation ,Memory problems and behaviors, legal and medical information	Qualitative study	N= 1,592 caregivers, resident in Tarrant County, Texas, and provision of at least 8 hr of care a week for a loved one with dementia living at home	significant improvement in burden and social support scores.
6	Golim- bet & Trubnikov, 2001	Russia	To assess the situation of carers in Russia and to determine predictors of their quality of life and psychological morbidity.	low level of service input, Aids to daily living from social service	Structured question-naire, Quality of Life Questionnaire (WHOQOL BREF), and General Health Questionnaire.	N= 83, 15 males and 68 females, aged from 19 to 72 years. The relationships to the demented person were: daughters (52%); spouses (8%), sons (12%) and others (28%).	Female carers were found to report lower QOL mean scores in health and physical domains) than other rela- tives.
7	Chen et al., 2000	Taiwan	To explore the caregiving experiences for older Atayal PWDS and their families in Taiwan.	"Low dementia awareness, high family-like ambience in the community, envi- ronmental challenges, e.g., environmental constraints and barriers to transporta- tion access.	In-depth interviews to explore the perspectives of older PWDS (n = 4), their family members (n = 3), and key persons (n = 10) in an Atayal community in northern Taiwan. Data were analyzed using constant comparative analysis	N= 17. Persons with dementia (n = 4), their family members (n = 3), and key persons (n = 10) in an Atayal community in northern Taiwan	Low dementia awareness suggests that services introduced must be culturally appropriate and nondisruptive to existing supportive helping systems
8	Jeon et al., 2020	Australia	To test feasibility and potential effects of the interdisciplinary HomebAsed Reablement Program (I-HARP) that integrates evidence-based strategies and cognitive rehabilitation techniques into a dementia-specific, bio-behavioral-environmental intervention.	need for better carer and allied health support	Randomized controlled study	N= 18. parallel-group randomized controlled pilot trial was conducted in Sydney, Australia, targeting community-dwelling people with amnestic mild cognitive impairment or mild/moderate stages of dementia and their carer. I-HARP comprised: up to 12 home visits by registered nurse, occupational therapist, and psychologist, tailored to the individual client's needs; <a\$1000 all="" and="" assistive="" carer="" devices;="" for="" four="" home="" individual="" modification="" months<="" over="" provided="" support,="" td=""><td>Improved quality of life</td></a\$1000>	Improved quality of life
9	Teles et al., 2022	Portugal	To examine the feasibility of the protocol for a main effectiveness trial of iSupport-Portugal and explores how the intervention and control arms compare over time on well-being outcomes.	Significant group-by-time interaction effects favoring the intervention were found for anxiety (Wald $\chi 2 = 6.17$ , p = .046) and for environmental QoL (Wald $\chi 2 = 7.06$ , p = .029)	Mixed meth- ods study	N= 42 were allocated to the intervention (N = 21) and control (N = 21) arms. Participation (78.1%) and retention rates (73.8%) were fair. More carers in the control arm completed the study (N = 20, 95.2%) than in the intervention arm (N = 11; 52.4%) (\chi_2 = 9.98, p = .002)	caregiver burden, depression, anxiety, QoL, positive aspects of caregiving, and self-efficacy

10	Zimmer- man et al., 2005	United States	To determine 1-year medical outcomes, nursing home transfer, and functional change of assisted living (AL) residents and their relationship to care.	Supports diversity to accommodate individual preferences.	Mixed meth- od study	N= carers of 2,078 residents in 193 facilities across four states were conducted; follow-up was by telephone interview with care providers	probability of hospitalization and new/worsening mor- bidities over a standardized quarter per 100 residents was 12.7 and 22.7. Standard- ized change in function was notable
11	Bruce et al., 2005	United States	To determine whether physical disability, as deter- mined by the SF-12 survey that provides information on both physical and mental health problems, contributes to care- giver stress	Physical disability, caregiver stress	Mixed meth- od study	N= 91 primary caregivers	Presence of medical prob- lems were independently associated with caregiver stress. reducing the impact of physical disability could ameliorate caregiver stress.
12	Hsieh et al., 2022	Taiwan	To develop a program for providing support and empowerment to older adult caregivers of spouses with mild and moderate dementia in the community	Connects the home situation and effective dialogue as a bridge to the researcher, to confirm the daily needs or expectations of the caregiver and the patient, and to enhance the interactions and quality of life of family members with resources and network	Semi-struc- tured, in- depth	N= 19 dementia care dyads	
13	de Boer et al., 2021	Nether- lands	To purposefully redesign the building to facilitate care provision according to the new care model, based on principles of green care farms and other innovative residential care models	physical, social and organi- zational environment	Case study design	N=7 core development group led the development process and managed the co-creation by deciding on the overall planning	The needs and requirements of older citizens were well addressed and their care- givers
14	Soellner et al., 2015	Germany	To evaluate whether telephone-based cognitive-behavioral therapy, which is implemented in established care provision structures improves outcomes compared to usual care and whether it is as effective as face-to-face cognitive-behavioral therapy.	care provision structures	Data collected at baseline, post-intervention, and at a 6-month follow-up.	Participants live in one of the study centers (Jena, Berlin, Munich) and indicate that attendance of a face-to-face therapy is possible, they will be assigned to the face-to-face group. The other participants will be randomized to receive either telephone-based cognitive-behavioral therapy or usual care	The primary outcomes were depressiveness, burden of care, health complaints, and problem-solving ability. The secondary outcomes will be anxiety, quality of life, violence in caregiving, utilization of professional assistance, and cost effectiveness. Care provision structures.

Ten of the published articles addressed the influence of services on quality of life of caregivers of persons with dementia [44, 50, 47& 45] [48, 46 &39] [42,40] This included provision of housing, transportation, systems and policies, Association and organizational services, general social support services, systems and policies, Health services and Education and training services.

**Support relationships:** Nine studies addressed the influence of environmental support on quality of life of caregivers of persons with dementia. [40 50,43], [51 44], [43, 51,48] This involved

support relationship from family, health professionals, friends, and peer groups.

**Environmental Support:** involves the provision of practical physical or emotional support, nurturing, protection, assistance, and relationships to other people, in their home, place of work, school or at play or in other aspects of their daily activities. Ten studies also addressed the influence of environmental support on quality of life of caregivers of persons with dementia. [39,42,44-46,48,50,51]. This involves products and technology for

communication, time related changes, Natural environment and human made changes to environment.

**Attitudes:** Five studies also addressed the influence of environmental support on quality of life of caregivers of persons with dementia [39,42,47,51]. This involved individual attitudes of family members, peers, societal attitudes, neighbors, and communities.

#### **Discussion**

Activities of daily living, which are ultimately affected by quality of life, can be described essential skills needed to independently

care for oneself, such as eating, bathing, and mobility. The term activities of daily living were first coined by Sidney Katz,1950. It can serve as an indicator of a person's functional status and any inability to accomplish these essential activities of daily living can lead to precarious conditions and poor quality of life [52] Table 4 Caregivers of persons with dementia are continuously faced with the challenges of providing assistance with activities of daily living and having to manage behavioral and psychological. Symptoms of dementia Additionally, with the elevated need for providing care to persons with dementia, there is need for a clear understanding about the experiences and perceptions of the early stages of caregiving [53].

Table 4: Summary of service and environmental support factors categorized using the WHO-ICF.

Environmental factors	<u>Studies</u>			
Services				
e525- Housing services, systems and policies	Zimmerman et al., 2005, de Boer et al., 2021			
e530 - Utilities services, systems ad policies	Zimmerman et al,2005, Mazurek et al, Jeon et al., 2020			
e535 - communication services, systems and policies	Zimmerman et al,2005, Quinn et al., 2020			
e540 - transportation services, systems and policies	Chen et al., 2000			
e545 - civil protection services, systems and policies				
e550 - legal services, systems and policies				
e555 - Association and organizational services, systems and policies	de Boer et al.,2021			
e565 - economic services, systems and policies				
e575 - General social support services, systems and policies	Teles et al.,2022, Rodriguez et a., 2017, Mazurek et al., 2019 Cho et al., 201			
e580 - Health services, systems and policies	de Boer et al., 2021, Bruce et al.,2005 Jeon et al., 2020			
e585 - Education and training services, systems and policies	Teles et al.,2022, Jeon et al.,2020			
e599 - Services, systems and policies unspecified				
Envi	ronmental Support			
Products and Technology				
e125 - Products and Technology for communication	Rodriguez Perez et al.,2017, zimmerman et al.,2005, Teles et al., 2022			

e145 - Products and Technology for the practice of religion and Spirituality	
Natural environment & human made changes to the environment	
e245 - time related changes	Zimmerman et al., 2005, Teles et al., 2022
e298 - Natural environment and human made changes to envi- ronment specified	de Boer et al., 2021
support relationships	
e310 - immediate family	Chen et al.,2000 Hseich et al.,2022 Golimbet & trunnikov,2001, Quinn et al.,2020
e315 - Extended family	Chen et al.,2000 Hseich et al.,2022 Golimbet et al.,2001 Quinn et al.,2020
e320 - friends	
e325 - Acquaintances, peers, colleagues, neighbors, and community members	Zimmerman et al.,2005, de Boer et al.,2021, Jeon et al., 2020
e340 - Personal care providers and personal assistants	de Boer et al.2021, Hlabagana &Heam, 2019
e345 - Health professionals	Bruce et al., 2005, de Boer et al.2021, Hseich et al.,2022, Golimbet et al.2001, Zimmerman et al., 2005
e398 - Support and relationships, other specified	Cho et al.,2019, de Boer et al.,2021, Golimbet et al.,2001, Rodriguez-Perez et al.,2017, Quinn et al., 2020
Attitudes	
e410 - individual attitudes of family members	Quinn et al.,2020, Mazurek et al., 2019
e415 - individual attitudes of extended family members	Quinn et al.,2020, Mazurek et al.,2019
e420 - individual attitudes of friends	Mazurek et al., 2019
e425 - individual attitudes of acquaintances, peers, colleagues, neighbors and community members	
e440 - individual attitudes of personal care providers and personal assistants	
e450 - individual attitudes of health professionals	Zimmerman et al., 2005
e460 - societal attitudes	Cho et al.,2019, Golimbet et al.,2001, Rodriguez-Perez et al.2017
t	

This can lead to a better understanding of the inevitable challenges a caregiver encounters. Additionally, this can help direct health psychologists, care commissioners, and policy makers in determining measures in which caregivers can be provided with support [54,55] Improvements in caregivers' quality of life, health, and wellbeing would eventually lead to better care for the care recipients [56] and could likely delay the necessity of carerecipients becoming institutionalized [55] A meta-synthesis study by Yong and Price (2014) reported that occupational therapists were well positioned to support families where the person with dementia could be supported to remain living at home.

In a mixed methods systematic review by [57] to identify the factors associated with quality of life in family caregivers of people with dementia, 10 modifiable and non-modifiable factors that may harm or enhance the quality of life of family caregivers of people with dementia were reported which includes demographics, the caregiver and patient relationship, dementia characteristics, the demands of providing care, health, emotional well-being, level of support received, and caregiver independence.

With an aim to guide the development and implementation of policy, treatment, care, and support packages, and ensuring good quality of life for family caregivers, it was reported that Psychological and emotional support during various stages of dementia progression and transitions such as changes in relationship, or worsening symptoms can lead to improvements in caregiver quality of life. Moreover, interventions or caregiver support groups can be of immense help to caregivers with poorer quality of life, enhance their resilience, perceptions of their caregiving role, better appraisals of dementia and that of the carerecipient, leading to improvement in their quality of life. This is consistent with previous studies by Oliveira et al., 2017.

Another major factor associated with quality of life of caregivers is the understanding and awareness on how society functions [59] Majority of people do not have correct information about dementia, hence, do not understand the difficulties of caregivers and their families, do not offer any help, and deny them services. This makes them feel isolated and lonely. Limited or no access and use of the official services, scar of dementia, lack of or limited information and awareness, non-pharmacological interventions financial barriers, especially in underdeveloped areas, leads to diminishing quality of life [60-67].

#### **Conclusion**

One of the most important aspects of the ICF relative to dementia is that it recognizes that caregivers are important potential supports and environmental support. The WHO-ICF compels researchers and gerontologists to consider caregivers within the wider context of communication that has always been the norm. It is important to note that support within the environmental factor considers the quality and quantity of support caregivers do and do not provide.

Thus, family caregivers are considered to the extent that they support or hinder individuals with AD. In the ICF manual, the WHO authors identify possible areas for future development and application of the framework including studying the disability and functioning of family members that can result from the health condition of their relatives. Evidence from scoping review strengthens the fact that adequate and appropriate services and support environment will strengthen and add to the quality of life of caregivers through the implementation of enhancement programs for caregivers of individuals with dementia. Also, effective usage of the ICF framework can provide a framework on how significant others experience activity limitations and participation restrictions because of ineffective support and service environments.

Therefore, it is important that researchers and gerontologist consider the abilities of caregivers of older adults with dementia to ensure that language and communication education and training programs are not restricted only to their clients (persons with dementia) but includes programs that harnesses the strengths of the caregivers and reduces burnout thereby enabling them deliver efficiently on their caregiving duties.

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