

Original Article

The Impact of Dementia on Family Carers Using the ICF Framework

Stavroulla Grigoriou, PhD student

Department of Rehabilitation Sciences, Cyprus University of Technology, Limassol, Cyprus

Eliada Pampoulou

Assistant Professor, Department of Rehabilitation Sciences Cyprus University of Technology, Limassol, Cyprus

Maria Kambanaros

Professor, Department of Rehabilitation Sciences, Cyprus University of Technology, , Limassol, Cyprus

Correspondence: Stavroulla Grigoriou, Department of Rehabilitation Sciences, Cyprus University of Technology, 15 Vragadinou Street, ZT3 Building, 1st floor, 3041 Limassol, Cyprus. Email: ss.grigoriou@edu.cut.ac.cy

This work was carried out at the Department of Rehabilitation Sciences, Cyprus University of Technology, 15 Vragadinou Street, ZT3 Building, 1st floor, 3041 Limassol, Cyprus.

Abstract

Background and Objectives: The aim of the study was to explore the experiences of family carers of people with dementia (PWD) in Cyprus and to describe the impact of dementia on family carers using the International Classification of Functioning, Disability and Health (ICF) framework as a model to interpret the findings.

Research Design and Methods: A questionnaire with multiple choice responses was developed based on previous work published by the Netherlands Institute for Health Services Research (NIVEL). Eighty-four family carers of PWD completed the questionnaire and sixteen others completed the pencil-paper version. The data were analyzed based on descriptive statistics.

Results: The findings showed that family carers support PWD in several different life domains. The results from the questionnaire were mapped onto the ICF framework to determine the impact of dementia on carers' lives. The results, according to the ICF, revealed that, on the whole, dementia carers experience negative changes to body function, activities and participation as a result of caring for PWD. Furthermore, family carers attribute the detrimental effects on their health and well-being to the impact of continuous care resulting from the dementia.

Discussion and Implications: The findings provide valuable insight into the experiences of family carers of PWD in Cyprus, and the need for health professionals to support family carers. Taking into consideration the results of this study, dementia carers experience changes to their daily functioning because of the cared one's health condition. This has been described as carer's "third-party disability" in the literature.

Keywords: family carers, problems, ICF, third-party disability, impact

Background and Objectives

Five to eight percent of people who are over 60 years of age have dementia (WHO, 2021); a chronic, degenerative condition that affects cognition, behavior and communication (Banovic, Zunic and Sinanovic, 2018). The progressive course of dementia as well as its multilayered and demanding nature pose several challenges to family carers. Being a caregiver of a person with dementia has major physical and emotional burden, that can lead to various neuropsychiatric, behavioural and psychological problems (Cheng, 2017; Senturk, Akyol and Kucukguclu, 2018). Carers of PWD have higher levels of depression and anxiety than carers of older people without dementia (Papastavrou, Kalokerinou

Papacostas, Tsangari, and Sourtzi, 2007; Watson, Tatangelo and McCabe, 2019; Dimakopoulou, Vamvakari and Sakka, 2020). This is because carers of PWD receive limited support from other professionals or health services and have very little time for themselves (Queluz et al., 2019). Often apathy or aggression is demonstrated by PWD (Henskens et al., 2019) and carers may feel anxious, because they fear the loved one that they are caring for may leave the house and become involved in unsafe situations (Thoma-Lürken et al., 2018). Furthermore, the act of caring for PWD, is also associated with family conflict as well as reduced social support and interaction for the caregiver (Lucero et al., 2018). By devoting several hours to caring, carers often sacrifice pursuing their hobbies and engaging in social life (Zwaanswijk et al., 2013;

Demir and Platin, 2017). These issues can also have impact on the physical well-being of carers (Zwaanswijk et al., 2013; Cunningham, Cunningham, and Roberston, 2019) such as poorer immune response to vaccines, cardiovascular problems and higher levels of chronic diseases including diabetes, anemia and arthritis (Demir and Platin, 2017; Wang et al., 2018a). Dementia carers are found to present decreased engagement in drinking alcohol, smoking and poor sleep patterns (Kang, and Xiang, 2020), all of which have been linked to the above-mentioned physical conditions. Despite the fact that carers do not have a health condition, they show a high risk of developing impairments, having activity limitations and participation restrictions as a consequence of the health condition of the person that they care for. This can be related to the ICF's concept of third-party disability which describes the biopsychosocial perspective for health-related states. There are a number of studies that explore the experiences of third-party disability in other health conditions including family carers of people with aphasia after stroke (Grawburg et al., 2013; Grawburg, Howe et al., 2014; Wallace et al., 2017), spouses of older people with hearing loss (Scarinci et al., 2009), family carers of people with dysphagia (Nund et al., 2016), and family carers of people with Parkinson's disease (Mach et al., 2019). However, there is currently lack of research focusing on how the caring itself of a person with dementia impacts the family carers' Body systems, Participation levels, and Activities pursued, as influenced by personal and environmental factors. This study aimed to explore the experiences of family carers of PWD. The research questions were:

1. What kind of help do family carers provide for family members with dementia in Cyprus?
2. What problems do family carers experience in caring for their family member with dementia?
3. In accordance with the definitions of the ICF framework, how does caring for a person with dementia impact the family carer's body systems, participation and activities, as influenced by personal and environmental factors?

Research Design and Methods: Ethics approval was given by the Cyprus National Bioethics Committee (EEBK E11 2019.01.34). The methodology of this study was divided into two phases. Firstly, a questionnaire was distributed to dementia carers, to collect data about their problems and challenges they experience caring for a person with dementia. Secondly, the ICF linking rules (Stucki, 2005) were used, in order to map codes that describe the impact of dementia on family carers using the ICF framework.

Instruments: A questionnaire was used based on the work of the Netherlands Institute for Health Care Services Research (NIVEL) on behalf of the Dutch Alzheimer's Association (Peeters et al., 2010; Zwaanswijk et al., 2013). The original published Dutch questionnaire was translated from the English version into Greek by a professional translator. The second and third author, both bilingual academic SLTs reviewed the Greek translation and carried out a back translation. Agreement was high (97.9%) and the Greek

version was piloted on five carers of PWD to ensure that the wording of the questions and the responses provided could be easily understood by the respondents. A number of changes were made to the questionnaire as all pilot respondents indicated that the questionnaire was long, and they found it hard to concentrate in one go to complete it. Subsequently, it was modified.

The questionnaire was piloted again with three SLTs and two carers of PWD. The final version of the questionnaire can be found here: <https://forms.gle/MWE7Xf6eZtaMs7yQ7>. The first section comprises of general questions on the demographic profile of the family carer and the kind of care provided for the family member with dementia. The second part focuses on the demographic characteristics of PWD who the family carer takes care of. Most questions in both parts of section A, have multiple-choice answer options and the respondent can choose more than one option. Part B focuses on the problems and challenges that carers experience caring for a family member with dementia. Carers were asked to rate the importance of their problems, for twelve topic areas with a total of thirty-three questions using a Likert five-point scale to express how much they agree or disagree with a particular statement. Part C has twelve questions with multiple-choice options on the carers needs in terms of support across different the domains of care as reported above by different professionals.

Participants: An online survey in Google Forms was distributed via e-mail and social media (Facebook) to stakeholders supporting PWD seeking family carers to participate in the study. Eighty-four participants completed the online questionnaire. Additionally, 16 carers of PWD were purposively selected from care homes and rehabilitation centers to complete the paper and pencil version. In total, 100 carers of PWD were recruited. Due to the lack of information regarding the number of carers of PWD in the Republic of Cyprus, a collection of 100 questionnaires was considered adequate to gather information about the current situation, given that the island has a population of just over a million people. In contrast, the Netherlands with a population of around 17 million, the samples sizes for the two previous studies from which the survey was drawn, were approximately 1000 and 1500 respectively (Peeters et al., 2010; Zwaanswijk et al., 2013).

Data Collection Process: An information sheet on the very first page of the questionnaire informed all potential participants about the purpose of the research and what their participation entailed. Regarding those participants (n=16) selected via purposive sampling, they were initially informed both verbatim and in written form about the purpose of the research and their involvement. Those who completed the questionnaire online did so in their own space and time. The questionnaire took approximately 15-20 minutes for each version to be completed.

Data Analysis: The descriptive data analysis was performed using Jamovi version 1.2.9.0 for Windows. From the analysis the results were recorded verbatim, to develop codes for what

problems and challenges carers were experiencing caring for a family member with dementia. The results from the questionnaire were analysed and later mapped onto the ICF. Implementing the results from the questionnaire, the identified categories and sub-categories were linked to the components of the ICF as proposed by the linking rules (Cieza et al., 2005; Stucki, 2005). According to the ICF linking rules, each category and sub-category are connected to the ICF codes (Cieza et al., 2005; Stucki, 2005).

Results

Characteristics of the family carer and the family member with dementia:

The first section of the questionnaire focused on the demographic profile of the participants and the nature of the care they provided for PWD (table 1). The majority of the respondents (84%) were females whereas 47% of them were daughters of the family member with dementia. The mean age of the family caregiver was 46.5 years. Almost one third of the participants (29%) had been caring for the family member with dementia for more than 6 years. The majority of the respondents (61%) cared for the family member with dementia on a daily basis. The majority of carers (70%) indicated that the PWD was female with a mean age of 78.5 years. Half of the PWD (52%) were widowed and 40% were married. The majority of PWD (78%) were living in their own home. Almost half of the responders (45%) indicated that the education level of the PWD was a primary school level of education (table 2).

Type of help that family carers provide to family members with dementia:

With regards to daily activities, the majority of the respondents (74%) indicated that they supported PWD by providing transport and driving (table 3). Also, more than half of the respondents aided family members with dementia for shopping (56%), with cooking and meal preparation (56%), and with household tasks (52%). In relation to physical care, most responders (65%) help with washing and dressing/undressing, followed by mealtime feeding (63%). Regarding communication, an overwhelming majority of the respondents (96%) indicated that they facilitate communication between themselves and the family member with dementia. Moreover, more than half of the respondents (54%) reported helping the PWD communicate with other relatives or friends. Finally, cognitive empowerment was an activity provided by more than half of the respondents (58%). Cronbach's alpha coefficient for this section was 0.979 revealing high internal consistency of survey questions.

Problems family carers experience when caring for a family member with dementia:

The second section of the questionnaire explored the problems faced by family carers caring for family members with dementia (table 4). The most common concerns reported were related to dealing with behavioral changes of the family member with dementia (89%), that the care was emotionally too demanding (84%) and the anxiety that carers experienced (82%). Furthermore, two-thirds of the participants (66%) indicated that health problems in PWD occurred because of their lack of awareness

regarding their physical state. More than half of the participants (59%) reported that health problems may occur for PWD due to communication breakdown and that caring was often too physically demanding. Family carers added that unsafe situations arising in or around the home, because of the PWD's behavior (57%), was also a worry. Finally, respondents experienced difficulties communicating with PWD (50%). Cronbach's alpha coefficient for this section was 0.878 revealing high internal consistency of survey questions. **Experiences of family carers of PWD based on ICF:** The analysis from the questionnaire identified 17 codes (7 for the body functions, 10 for activities and participation). Two of these codes were mapped as health conditions. The findings are reported in table 5.

Health conditions: Family carers in this study reported having high levels of depression and anxiety. One carer described her father's condition saying "I don't know what is happening with my dad. It is exceedingly difficult for someone to cope with this syndrome. I always feel anxious and I'm just waiting for the next attack from my father..." (participant 15, 34 years old, 2-3 years of caring). One daughter reported the development of depression following her mum's dementia (participant 93, 58 years old, 6 months – 1 year of caring). In addition, an 84-year-old wife reported that she has many health problems, because of caring for her loved one (participant 46, 84 years old, 4-5 years of caring). The majority of the respondents reported that providing care was emotionally too demanding (84%) and that they feel anxious all the time (82%). Furthermore, some of the participants reported that they cannot manage their sadness, which is related to observing the deterioration of their loved one because of the progression of the dementia (28%).

Body functions component: The findings, were linked to the ICF domains, in an attempt to have ICF specific codes for each descriptor. Carers' responses were divided into two domains of the ICF: mental functions and neuromusculoskeletal and movement-related functions.

Mental functions: The most common concerns reported by the majority of the respondents were related to dealing with behavioural changes of the family member with dementia (89%). Also, they described changes to their confidence, reporting that the care was emotionally too demanding (84%) and that they were worried about unsafe situations arising in or around the home (57%), because of the behaviour of the person living with dementia. All of the above are classified as changes to emotions and energy. Also, a female carer reported the following: "I cannot continue caring my father, I cannot sleep, I am too tired and I don't know what to do with his behavior", (participant 15, 34 years old, 2-3 years of caring) which shows that carers have changes to energy functioning levels and sleep patterns. Also, a respondent told us that she felt stress related to caring for her father (participant 29, 45 years old, 4-5 years of caring).

Neuromusculoskeletal and movement-related functions: Many of the carers reported that caring for the person living with dementia is physically too demanding (59%). As

caregiving involves all daily activities, therefore the carers complain from physical tiredness and losing interest in doing anything else (Al-Zyoued et al., 2021).

Activities and Participation: *The linking of the findings to the ICF framework resulted in six domains regarding the activities and participation component. Namely, the six components are learning and applying knowledge, general tasks and demands, communication, domestic life, interpersonal interactions and relationships and major life areas.*

Learning and applying knowledge: Family carers (48%) experienced difficulties in making decisions for the person living with dementia. Similarly, carers (51%) reported that there was no health professional available to them to whom they could ask questions or express their concerns.

General tasks and demands: Family carers felt overwhelmed due to the demanding nature of caring for the person living with dementia. Some participants reported that they were unable to cope with caregiving (17%). Also, due to this situation, the symptoms of stress and anxiety were high as a result of caring for most carers (82%).

Communication: Family carers outlined how their relationship with the person living with dementia had changed in several ways. For example, they had difficulties communicating, and many times their conversations ended up in arguments (50%) because of communication breakdown. Moreover, carers indicated that PWD, due to their communication impairments, present with additional health problems (59%). Such an example, is PWD's inability to

express and define the source or type of pain (Cohen-Mansfield et al., 2013).

Interpersonal interactions and relationships: Family carers indicated that they felt they were alone in the caring of a person living with dementia (45%). This shows that taking care of a person living with dementia affects the relationship between carers and the person living with dementia, or between the carers and other family members, friends, or relatives. In this study, dementia carers reported there is communication difficulties with relatives and friends due to the caring that they offer (30%).

Major life areas: Family carers reported that community and health professionals do not provide adequate information about the nature of dementia and the role of different health professionals involved with dementia. Some participants (28%), reported that doctors did not inform them about the nature of the syndrome. In addition, the expenses of caring for a person living with dementia burden the carers, because community services and government agencies do not provide financial support for PWD.: Fourteen participants reported the following financial concerns. Some said: "I don't have any support from the government..." (participant 22, 47 years old, 6-7 years of caring and participant 79); "My parents get a small old-age pension, that is not enough to cover their medicines and therapies..." (participant 23, 41 years old, 6-7 years of caring). One woman carer reported "unfortunately with not so much help from the hospital and the government's negligence it is very difficult for someone to cope with this syndrome" (participant 85, 50 years old, 8-9 years of caring).

Table 1. Caregiver demographics

Caregiver demographics	N = 100
<i>Gender</i>	
Male	16
Female	84
<i>Age</i>	
≤30 years old	20
31-40 years old	11
41-50 years old	35
51-60 years old	19
61-70 years old	6
≥71 years old	9
<i>Relationship with person with dementia</i>	
Spouse	9
Daughter	47
Son	5
Relative	1
Neighbour	3
Professional caregiver	1
Grandchild	16
Other	18
<i>Duration of caregiving</i>	
Less than half a year	8
6 months to 1 year	18

2 to 3 years	23
4 to 5 years	22
6 to 7 years	23
8 to 9 years	4
More than 10 years	2
<i>Frequency of caregiving</i>	
Daily	61
3 to 6 times per week	28
1 to 2 times per week	5
Less than once per week	6
Total number of respondents	100

Table 2. Demographics of PWD

People with dementia demographics	N = 100
<i>Gender</i>	
Male	30
Female	70
<i>Age</i>	
50-60 years old	10
61-70 years old	7
71-80 years old	37
81-90 years old	44
91-100 years old	1
≥101 years old	1
<i>Place of residence</i>	
Living at home	78
Living at a son or daughter's home	8
Living in a nursing home	8
Living at a daily care centre for people with Alzheimer's	1
Living in a care institution	1
Other	4
<i>Education level</i>	
No schooling	7
Primary school	45
Lower secondary school	4
Higher secondary school	10
Middle vocational education	3
Third level vocational education	13
University education	15
Not known	3
<i>Duration of dementia symptoms</i>	
Less than half a year	4
6 months to 1 year	25
2 to 3 years	20
4 to 5 years	14
6 to 7 years	24
8 to 9 years	7

More than 10 years	6
Total number of respondents	100

Table 3. The type of help that informal carers provide to family members with dementia

Type of help that carers provide	n	%
<i>Daily activities</i>		
Household tasks	46	52%
Cooking, food preparation	50	56%
Transport, driving	66	74%
Shopping	53	56%
Administration of personal effects	65	73%
Total number of respondents	89	
<i>Physical care</i>		
Showering	46	58%
Eating meals	50	63%
Washing and/or dressing/undressing	51	65%
Walking, standing	47	60%
Total number of respondents	79	
<i>Communication</i>		
Communication with caregiver	92	96%
Communication with relatives/friends	52	54%
Cognitive empowerment	56	58%
Total number of respondents	96	

Table 4. Problems informal carers experience in caring for a family member with dementia

Problems carers experience	N = 100 (%)
Changes in the person's behavior trouble caregiver	89%
Caring person with dementia is emotionally too demanding	84%
Anxiety because of the caring	82%
Thinks that health problems may occur because the person with dementia has difficulty indicating physical ailments	66%
Thinks that health problems may occur because the person with dementia has communication difficulties	59%
The care for person with dementia is often too much of a physical burden for the caregiver	59%
Worried that unsafe situations might occur in or around the house because of the person's behaviour	57%
Feels lonely in person's care	52%
Communication difficulties with person with dementia	50%

Thinking that person with dementia might leave the house because of the difficulties that they have 50%

Table 5. Results mapped onto ICF

ICF component	ICF domain	ICF code	ICF code name
Body functions	Mental functions	b1263	Psychic stability
		b1265	Optimism
		b1266	Confidence
		b130	Energy and drive functions
		b134	Sleep functions
		b152	Emotional functions
		b740	Muscle endurance functions
Activities and Participation	Learning and applying knowledge	d177	Making decisions
	General tasks and demands	d240	Handling stress and other psychological demands
	Communication	d3503	Conversing with one person
		d3550	Discussion with one person
	Domestic life	d660	Assisting others
	Interpersonal interactions and relationships	d7500	Informal relationships with friend
		d760	Family relationships
	Major life areas	d810	Informal education
		d8700	Personal economic resources
		d8701	Public economic entitlements

Discussion

The aim of the current study was to explore the experiences of family carers of PWD and to apply the ICF framework to evaluate the impact of dementia on carers. The majority of respondents as well as the PWD in this study were females, a similar finding to other research (Peeters, et al., 2010; Zwaanswijk, et al. 2013; Demir and Platin, 2017). In line with previous reports (Beama et al., 2018) this might be because women survive longer than men and therefore the higher incidence of dementia in females. Most of the respondents were daughters of PWD, whereas in the Dutch study (Peeters et al., 2010) half of those surveyed were spouses and only 38% were children. It might be the case that the spouses of the PWD in this study were not alive or were unable to care for their partner. Furthermore, there is an expectation in the Cypriot culture that children will look after their parents in

their later years and usually daughters are more involved than sons (Papa et al., 2019). In Cyprus, PWD remain at home as there are no other options of full-time specialized residential care for dementia sufferers. In addition, carers indicated that they assisted PWD with transport, in administration of their personal affairs and/or personal care needs, findings like those described by Martindale-Adams et al. (2015) and Dimakopoulou, Vamvakari and Sakka (2020). With regards to physical care, respondents reported helping with washing, and/or dressing as previously found (Martolf et al., 2019). Almost all respondents assisted PWD with communication activities, revealing that there are barriers to participation for family members with dementia in communication (Hennings and Froggatt, 2019; Smith, and Newbury, 2019). The most prevalent problem was dealing with behavioral changes of the person with dementia. In fact, behavioural change is one of

the key characteristics of the dementia profile (Henskens et al., 2019; Monfared et al., 2019). Carers reported that supporting the person with dementia was emotionally and physically demanding, findings that align with the recent literature (Hennings and Froggatt, 2019; Queluz et al., 2019; Watson, Tatangelo and McCabe, 2019). These group of researchers, among others, elicited the presence of emotions like deep sadness, distress, burden, and regret (Demir, 2018). Participants also reported worrying about the person with dementia wandering and finding themselves in an unsafe situation (Thoma-Lürken et al., 2018). Respondents indicated that the health problems of PWD are heightened, because of their difficulty in recognizing physical ailments or because of communication difficulties corroborating earlier findings (Zwaanswijk et al., 2013). Respondents indicated that they want to know from SLTs how they could communicate with a PWD, and what is achievable with the appropriate intervention (Swan et al., 2018). However, when participants were asked to indicate whether they had previously collaborated with an SLT, most of them expressed that this was not the case. In addressing the third research question, the results showed that dementia affects the health, functioning and ability of carers to carry out their caring role. This study illustrates the presence of third-party disability in carers dealing with chronic conditions. Even though there are a number of studies that explore the experiences of third-party disability in other health conditions (Scarinci et al., 2009; Grawburg et al., 2013; Grawburg et al., 2014; Nund et al., 2016; Wallace et al., 2017; Mach et al., 2019), they do not specifically focus on the impact on family members of PWD. The Activity, Limitations, and Participation Restrictions identified in this study are divided into six domains: learning and applying knowledge, general tasks and demands, communication, domestic life, interpersonal interactions and relationships and major life areas. One example of third-party disability is increased demands on the participants to take on more communication-related roles and responsibilities in the household (Mach et al., 2019; Grawburg et al., 2014). In addition, third-party disability includes the social isolation and perceived loneliness that carers encounter as they are incapable of communicating with the person that they are caring for (Kovaleva et al., 2018). The above findings, provide a preliminary description of third-party disability in dementia carers and reveals how dementia impacts upon a carer's Functioning and Disability from the perspective of the ICF framework. The mapping of the questionnaire outcomes to the ICF framework, demonstrates how dementia may impact the carer's health condition, activities, and participation. Moreover, the ICF framework, reflects the constant interaction between Functioning and Disability, Contextual Factors, and the health condition. Finally, the outcomes from this study emphasize the significance of offering support to dementia carers. This study reveals that dementia carers experience of caring has a negative impact on their functioning in relation to the body functions, activities, and participation components of the ICF.

The mapping of the outcomes of the questionnaire onto the ICF, not only demonstrated how dementia impacts upon a carer's health condition, activities, and participation, but also highlighted plausible interactions for reducing the development of a health condition, or lessening its effects, e.g., depression. The ICF framework provides a starting point for investigating 'third-party disability' in dementia carers. Understanding the results for dementia carers as changes in Functioning and Disability, gives them the opportunity to address their experience of third-party disability. Further research into third-party disability in dementia carers is required.

Conclusions: The current study is the first in Cyprus that focused exclusively on the experiences of family carers of family members with dementia and using the ICF framework. Family carers reported a series of problems and outlined what additional professional help is required. Future research is needed focusing on a larger sample of PWD in order for the findings to be generalised. Additionally, the experiences of carers could be investigated as part of a qualitative approach to collect in-depth information, which would allow researchers to capture the essence of those experiences. Research should also be guided by the need to identify the most effective intervention approaches that would eventually support carers in overcoming the problems/challenges raised by receiving appropriate and adequate support from allied health professionals, such as speech-language therapists.

References

- Al-Zyoud, E., Maharmeh, M. and Ahmad, M., (2021). Family experiences of caregiving to patients with Alzheimer. *Working with Older People*.
- Banovic, S., Zunic, L.J. and Sinanovic, O., 2018. Communication difficulties as a result of dementia. *Mater.Socio Med.*, 30,3, 221.
- Beam, C.R., Kaneshiro, C., Jang, J.Y., Reynolds, C.A., Pedersen, N.L. and Gatz, M., 2018. Differences between women and men in incidence rates of dementia and Alzheimer's disease. *Journal of Alzheimer's Disease*, 64(4), pp.1077-1083.
- Cheng, S.T., 2017. Dementia caregiver burden: a research update and critical analysis. *Current psychiatry reports*, 19(9), pp.1-8.
- Cunningham, N.A., Cunningham, T.R. and Roberston, J.M., 2019. Understanding and measuring the wellbeing of carers of people with dementia. *The Gerontologist*, 59(5), pp.e552-e564.
- Demir, G. and Platin, N., 2017. Impact of Neuman Systems Model in reducing care burden primary caregivers of patients with dementia. *Int. J. Caring Sci*, 10(1), p.393.
- Demir, G., 2018. The impact of Neuman systems model in reducing the care burden on primary caregivers of dementia patients. *Int. J. Caring Sci*, 11(3), pp.1849-1858.
- Dimakopoulou, E., Vamvakari, E. and Paraskevi Sakka, M.D., 2020. A Profile of Paid Caregivers who Assist Older Adults with Dementia: A Descriptive Study. *Int. J. Caring Sci*, 13(3), pp.1582-1588.
- Efthymiou, A., Papastavrou, E., Middleton, N., Markatou, A. and Sakka, P., 2020. How caregivers of people with dementia search for dementia-specific information on the internet: Survey study. *JMIR aging*, 3(1), p.e15480.

- Grawburg, M., Howe, T., Worrall, L. and Scarinci, N., 2013. Third-party disability in family members of people with aphasia: A systematic review. *Disabil. Rehabil.*, 35(16), 1324-1341.
- Grawburg, M., Howe, T., Worrall, L. and Scarinci, N., 2014. Describing the impact of aphasia on close family members using the ICF framework. *Disabil. Rehabil.*, 36(14), pp.1184-1195.
- Hennings, J. and Froggatt, K., 2019. The experiences of family caregivers of people with advanced dementia living in nursing homes, with a specific focus on spouses: A narrative literature review. *Dementia*, 18(1), pp.303-322.
- Henskens, M., Nauta, I.M., Vrijkotte, S., Drost, K.T., Milders, M.V. and Scherder, E.J., 2019. Mood and behavioral problems are important predictors of quality of life of nursing home residents with moderate to severe dementia: A cross-sectional study. *Plos one*, 14(12), p.e0223704.
- Kang, S.W. and Xiang, X., 2020. The influence of cognitive impairment on health behaviors among older adults. *American Journal of Health Behavior*, 44(2), pp.159-168.
- Kovaleva, M., Spangler, S., Clevenger, C. and Hepburn, K., 2018. Chronic stress, social isolation, and perceived loneliness in dementia caregivers. *S J Psychosoc Nurs Ment Health Serv*, 56(10), pp.36-43.
- Lucero, R.J., Fehlberg, E.A., Patel, A.G., Bjarnardottir, R.I., Williams, R., Lee, K., Ansell, M., Bakken, S., Luchsinger, J.A. and Mittelman, M., 2019. The effects of information and communication technologies on informal caregivers of persons living with dementia: a systematic review. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 5, pp.1-12.
- Mach, H., Baylor, C., Pompon, R.H. and Yorkston, K., 2019. Third-party disability in family members of people with communication disorders associated with Parkinson's disease. *Topics in Language Disorders*, 39(1), pp.71-88.
- Martolf, G.R., Kandrack, R., Rodakowski, J., Friedman, E.M., Beach, S., Folb, B. and James III, A.E., 2020. Work performance among informal caregivers: a review of the literature. *Journal of Aging and Health*, 32(9), pp.1017-1028.
- Nund, R.L., Scarinci, N.A., Cartmill, B., Ward, E.C., Kuipers, P. and Porceddu, S.V., 2016. Third-party disability in carers of people with dysphagia following non-surgical management for head and neck cancer. *Disability and Rehabilitation*, 38(5)462-471.
- Papa, R., Efthymiou, A., Lamura, G., Piccinini, F., Onorati, G., Papastavrou, E., Tsitsi, T., Casu, G., Boccaletti, L., Manattini, A. and Seneca, R., 2020. Review and selection of online resources for carers of frail adults or older people in five European countries: Mixed-methods study. *JMIR mHealth and uHealth*, 8(6), p.e14618.
- Papastavrou, E., Kalokerinou, A., Papacostas, S.S., Tsangari, H. and Sourtzi, P., 2007. Caring for a relative with dementia: family caregiver burden. *Journal of advanced nursing*, 58(5)446-457.
- Paraskevi Sakka, M.D. and Nomiki Karpathiou BSc, P., 2015. Evaluating the needs of dementia patients' caregivers in Greece: A questionnaire survey. *Int. J. Caring Sci*, 8(2), p.274.
- Peeters, J.M., Van Beek, A., Meerveld, J.H., Spreuwenberg, P.M. and Francke, A.L., 2010. Informal caregivers of persons with dementia, their use of and needs for specific professional support: a survey of the Nation Demen Progr. *BMC nursing*, 9(1), pp.1-8. Quéluz, F.N., Kervin, E., Wozney, L., Fancey, P., McGrath, P.J. and Keefe, J., 2020. Understanding the needs of caregivers of persons with dementia: a scoping review. *International psychogeriatrics*, 32(1), pp.35-52.
- Scarinci, N., Worrall, L. and Hickson, L., 2009. The ICF and third-party disability: Its application to spouses of older people with hearing impairment. *Disabil. Rehabil.*, 31(25), pp.2088-2100.
- Senturk, S.G., Akyol, M.A. and Kucukguclu, O., 2018. The relationship between caregiver burden and psychological resilience in caregivers of individuals with dementia. *Int J Caring Sci*, 11(2), pp.1223-1230.
- Smith, C. and Newbury, G., 2019. Palliative care for community patients diagnosed with dementia: a systematic review. *British Journal of Community Nursing*, 24(12), pp.570-575.
- Stucki, G., 2005. ICF linking rules: an update based on lessons learned. *J Rehabil med*, 37(4), pp.212-8.
- Swan, K., Hopper, M., Wenke, R., Jackson, C., Till, T. and Conway, E., 2018. Speech-language pathologist interventions for communication in moderate-severe dementia: A systematic review. *Am J Speech Lang Pathol*, 27(2), 836-852.
- Swartz, K. and Collins, L.G., 2019. Caregiver care. *American family physician*, 99(11), pp.699-706.
- Tahami Monfared, A.A., Meier, G., Perry, R. and Joe, D., 2019. Burden of disease and current management of dementia with Lewy bodies: a literature review. *Neurol Ther*, 8(2), pp.289-305.
- Thoma-Lürken, T., Bleijlevens, M.H., Lexis, M.A., de Witte, L.P. and Hamers, J.P., 2018. Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home. *Geriatric Nursing*, 39(1), pp.29-38.
- Udoh, E.E., Omorere, D.E., Sunday, O., Osasu, O.S. and Amoo, B.A., 2021. Psychological distress and burden of care among family caregivers of patients with mental illness in a neuropsychiatric outpatient clinic in Nigeria. *PLoS One*, 16(5), p.e0250309.
- Wallace, S.J., Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., Kong, A.P.H., Simmons-Mackie, N., Scarinci, N. and Gauvreau, C.A., 2017. Which outcomes are most important to people with aphasia and their families? An international nominal group technique study framed within the ICF. *Disabil. Rehabil.*, 39(14), pp.1364-1379.
- Wang, M., Shao, S., Li, J., Liu, Y., Xu, X. and Du, J., 2018. The needs of informal caregivers and barriers of primary care workers toward dementia management in primary care: a qualitative study in Beijing. *BMC Family Practice*, 19(1), 1-9.
- Wang, Y.N., Hsu, W.C., Yang, P.S., Yao, G., Chiu, Y.C., Chen, S.T., Huang, T.H. and Shyu, Y.I.L., 2018. Caregiving demands, job demands, and health outcomes for employed family caregivers of older adults with dementia: Structural equation modeling. *Geriatric Nursing*, 39(6), pp.676-682.
- Watson, B., Tatangelo, G. and McCabe, M., 2019. Depression and anxiety among partner and offspring carers of people with dementia: a systematic review. *The Gerontologist*, 59(5), pp.e597-e610.
- World Health Organization, 2001. ICF: International Classification of Functioning, Disability and Health.
- World Health Organization, 2021. Available at: <https://www.who.int/news-room/fact-sheets/detail/dementia>
- Zwaanswijk, M., Peeters, J.M., van Beek, A., Meerveld, J.H. and Francke, A.L., 2013. Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a question survey. *The open nursing journal*, 7(1).