Factors Associated with Home Care Outcomes among Community-Dwelling Older Adult Patients with Dementia

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Abstract

Background: With the increase in the proportion of people with dementia (PWD), it is necessary to address dementia-related issues among older adults who live at home; however, there is no integrative review on this issue. Objectives: To describe and analyze quantitative and qualitative studies from primary sources in order to identify the factors which impact home care outcomes among PWD. Methods: A computer search of PsycINFO, MEDLINE (PubMed), and the Cumulative Index of Nursing and Allied Health Literature (CINAHL) was performed. This study was guided by Whittemore and Knafl’s integrative review method. Results: This review of the literature identified 3 main factors related to home care outcomes among PWD. These factors are environmental factors, caregiver-related factors, and social network factors. Conclusions: Further research is required to investigate the impacts of multiple social and environmental factors on home care outcomes among PWD; which can eventually be used by nurses and family caregivers when providing care for older adult PWD.

Introduction

Across all cultures, up to 90\% of older adults prefer to remain in their own homes for as long as they can [1]. In 2011, a total of 22,400,000 households in the United States (US) were caring for a family member over the age of 50 [1]. However, one-third of the global population of people with dementia (PWD) are estimated to live alone [2]. Further, in the US, around one in 7 PWD live alone [3], and the number of PWD living alone is expected to increase [4]. With the increase in the proportion of PWD, it is necessary to address dementia-related issues among older adults who live at home. Caregivers across all cultures face challenges in managing PWD. These challenges may be exacerbated by several factors, which include caregivers’ lack of interest in caring for challenging patients, lack of standardized scales, and lack of necessary training [5].

Home care outcome in PWD can include physiological (e.g., behavior issues, cognitive and functional impairments, and the frequency and duration of caregiving) and psychological (e.g., anxiety, depression, and distress) outcomes. PWD gradually lose their ability to hold conversations and discuss events, information, or stimuli [6]. This lack of communication may hinder PWD from being able to voice their psychological needs to their caregivers [7].
Therefore, caregivers of PWD may become primarily focused on addressing patients’ physiological needs, such as their health, safety, shelter, and nourishment needs [6]. In turn, this may lead PWD with unmet psychological needs, therefore resulting in agitated behaviors and poor psychological health outcomes, such as depression. Agitated behavior among PWD is associated with multiple negative consequences.

Lawton [8] shed light on the importance of understanding the role of the social environment when investigating the impacts of social networks on agitation among older adults. In the case of PWD, who find it difficult to adapt to new environments, visitors, unfamiliar staff members, and new social networks may be overwhelming and may be a source of stress [9].

Limited studies in the literature have investigated the significance of environmental stressors and adaptation to these stressors among older adult PWD [8, 10, 11]. Understanding whether those factors have an association with outcomes for PWD may improve designing intervention of care, which may result in positive affect. This integrative review of the literature identified 3 main factors related to home care outcomes among PWD. These factors are environmental factors, caregiver-related factors, and social network factors. These factors are going to be addressed and highlighted as results of this integrative review of the literature.

Therefore, this review aims to describe and analyze quantitative and qualitative studies from primary sources in order to identify the factors mentioned above which may impact care outcomes among older adult PWD. Also, it aims, to examine the relative contributions of those identified factors such as environment, caregivers, and social interactions to home care outcomes among PWD.

**Methods**

**Study Design**

An integrative review method was chosen for this study because it is the only method allowing for synthesis of different methodologies. The stages of this integrative review were data selection, data synthesis, data description, and data analysis. This integrative review was guided by the following questions: (a) what are the factors which impact care outcomes among older adult PWD? and (b) What is the relationship between environmental stressors, social factors, and caregiver factors and dementia-related issues among older adult PWD?
| Study author/year | Study design and level of evidence | Purpose of the study | Subjects | Interventions/controls | Validity and reliability | Outcomes/significant results |
|-------------------|----------------------------------|----------------------|----------|------------------------|-------------------------|-----------------------------|
| Zeisel et al. [19], 2003 | A descriptive study LOE level III | To examine the associations between environmental design features of nursing homes and the incidence of social withdrawal, agitation, aggression, psychotic problems, depression and among NH residents with dementia | 427 residents in 15 special care units | Sample included 308 women and 119 men | Not specifically addressed | There is an association between particular environmental design features and each behavioral health measure |
| Morgan and Stewart [17], 1997 | Qualitative study LOE III | To explore the perception of staff caregivers and family about the relationship between behavior and environment in PWD | A total of 18 (9 staff and 9 family members) | Semi-structured interview was conducted with open-ended questions. Ethnographic was used to facilitate coding, summary diagrams contact summary sheets, methodological notes, and analytic notes were also completed after each interview | The instruments have demonstrated validity and reliability | Social environment such as activity programming and staff-residents interaction was associated with behaviors exhibited by PWD |
| Nikmat et al. [18], 2015 | Cross-sectional survey/quasi-experimental study LOE III | To examine the quality of life (QoL) and its associated factors among PWD residing in NH or home | A total of 49 PWD | Consenting participants were assessed on cognitive severity, QoL, ADLs, MMSER, WHO-8, EUROHIS-QOL, AQoL-8, BI, CSDD, and FS | Instruments were tested for validity and reliability | Significant differences were found in HRQoLs, QoL, social connectedness, and ADLs among PWD in home care (n=419) and those in NHs (n=450) (p < 0.01) |
| Garre-Olmo et al. [14], 2012 | Cross-sectional, observational, analytical LOE III | To examine the association between environmental factors (e.g., noise, lighting, and temperature) and QoL in NH residents with severe dementia | 160 NH residents with severe dementia | Cognitive and functional impairments, pain, QoL, and neuropsychiatric disturbances were examined by standardized tools | Reliability and validity were tested | QoL of NH residents with severe dementia was associated with some environmental factors such as lighting, noise, and temperature. Low light, high noise, high temperature were associated with low behavioral signs of negative affective mood and social interactions |
| Cohen-Mansfield and Werner [31], 1998 | Cross-sectional, descriptive, observational, analytical LOE III | To assess the impacts of an improved environment on the mood and behavior, as well as on the symptoms of wandering and pacing behaviors, of NH residents | 27 NH residents | Observation: The duration of pacing demonstrated by residents was documented by a trained RA using the computer event recorder. Use of ambulatory device: Personal activity monitor (PAM) | Reliability and validity were tested | Enhanced environment had a positive impact on the mood and behavior of the NH residents |
| Griffin et al. [15], 2001 | Randomized controlled trial LOE I | To examine short-term impacts of home environmental interventions on upset and self-efficacy in ADLs of PWD and caregivers | Families (n = 175) of PWD | Participants were randomly assigned to either control or intervention group. The intervention was five 90-min home visits by occupational therapists who provided education sessions and environmental, social, physical adjustments | Reliability and validity were tested previously | The intervention had a positive effect on both the PWD and caregivers such as slowing the progression of IADL dependence of PWD and enhancing participants’ self-efficacy and minimizing the impact of PWD on caregivers |
| Koicka and Jachimowicz [16], 2010 | Cross-sectional study LOE III | To examine the association of health locus of control, self-efficacy, and dispositional optimism with QoL in older adults differing in level of institutionalization and disability | Age ≥65; n = 110 (healthy community-dwelling Older adults); n = 102 (independent Older adults living in veteran home); n = 112 (inhabitants of a long-term care home) | Multi-dimensional health locus of control, life orientation test revised, generalized self-efficacy scale, and a multidimensional assessment were conducted on the participants. QoL was measured, using the satisfaction with life scale, the Euroqol 5D questionnaire, and the Nottingham health profile | Reliability and validity were tested previously | QoL declined with increased levels of institutionalization and independence. Community-dwelling older adults had the highest MMSER scores and physical activity indices. Veterans home older adults had the highest external and internal locus of control |

LOE, level of evidence; PWD, people with dementia; NH, nursing home; QoL, quality of life; MMSE, Mini-Mental State Examination; IADL, instrumental activity of daily living; ADL, activity of daily living; HRQOL, health-related quality of life.
### Table 2. Study results and characteristics of selected research investigating caregiver factors in home care and outcomes

| Study: author/year | Study design and level of evidence | Purpose of the study | Subjects | Interventions/control groups | Validity and reliability | Outcomes/significant results |
|--------------------|-----------------------------------|----------------------|----------|------------------------------|--------------------------|----------------------------|
| Alvira et al. [20], 2015 | Association study based on cross-sectional data LOE: level III | To examine the associations between negative and positive reactions of PWD informal caregivers and health outcomes across 8 European countries | 2014 PWD and their informal caregivers | Data were collected using the caregiver reaction assessment | The instruments have previously demonstrated validity and reliability | Lack of family and self-esteem support correlated with psychological well-being and caregiver burden Associations were found between caregiver burden and disrupted schedule, QOL and psychological well-being |
| Jaglal et al. [21], 2007 | Multiple comparative case study design LOE: level III | To examine whether sociodemographic characteristics, amount of service use, and type of support network in PWD and caregivers were associated with care experiences | PWD and caregivers (n = 267 dyads) | Health status for PWD and their caregivers were measured based on core healthy days measures Personal support network was measured by network assessment tool | The instruments have previously demonstrated validity and reliability | PWD and their caregivers were satisfied with their experiences with healthcare professionals when PWD received emotional support and caregivers received home support |
| Karlsson et al. [22], 2015 | Qualitative research (focus groups) LOE: level III | To examine PWD and their caregivers’ perception of intersectoral information, collaboration, and communication throughout the course of dementia care in 8 European countries | PWD and their informal caregivers (n = 137) | Focus group interviews Content analysis generated a tentative model of information, collaboration and communication for PWD and their caregivers, which was then tested | The Categories and sub-categories were formed by the first author, and categorization was thereafter validated by the last author | Establishing a trust relationship with caregivers and healthcare providers, commitment and professional knowledge, care adapted to needs and variation in service were identified as important factors for dementia care |
| Stephan et al. [49], 2015 | Cross-sectional survey LOE: level III | To examine the perceptions of healthcare professionals and informal caregivers regarding potential causes of PWD institutionalization in 8 European countries | 1,160 PWD | Answers were openly categorized and coded Differences between healthcare professionals and informal caregivers were examined (agreement on at least 1 potential reason per case/proportion of maximum attainable kappa) | Two validation procedures were used 1. Quality and reliability of translations from the native language to English 2. Final coding scheme tested in terms of inter-coder agreement between the 2 researchers | Agreement that caregiver burden, care dependency, caregiver unable to provide care, overall deterioration, and neuropsychiatric symptoms were potential causes of institutionalization of PWD |
| Wang et al. [24], 2014 | Double hermeneutic approach LOE: level III | To examine culturally, socially, and politically constructed factors impacting family caregiver practice in dementia care | 23 family caregivers of PWD | Semi-structured interviews were audi ta ped, transcribed and analyzed | Not specifically addressed | Relying on family caregivers to care for PWD without the provision of dementia care leads to poor health outcomes for both PWD and caregivers |
| Qadir et al. [23], 2013 | Qualitative research LOE: level III | To explore caregiver awareness, attitudes, and experience of caring for PWD | 12 caregivers of PWD | In-depth interviews | Not specifically addressed | Financial and social burden of dementia on Pakistani caregivers may be exacerbated when there is no support |

LOE, level of evidence; PWD, people with dementia; QOL, quality of life.
### Table 3. Study results and characteristics of selected research investigating social factors in home care and outcomes

| Study: author/year | Study design and level of evidence | Purpose of the study | Subjects | Interventions/ control groups | Validity and reliability | Significant results |
|--------------------|-----------------------------------|----------------------|----------|--------------------------------|--------------------------|---------------------|
| Burgio et al. [25], 2000 | Descriptive study LOE: Level III | To investigate the association between residents’ gender and agitation, and staff social interaction | 46 (15 female and 31 male) NH residents with dementia | Direct observations using computer-assisted, real-time observational system | Previously tested tool, Not specifically addressed in this study | Verbal interaction and staff touch significantly elicit agitation in NH residents |
| Carpentier et al. [26], 2008 | Exploratory study LOE: Level III | To investigate the interface between nurses and caregivers of PWD living in the community | 20 nurses recruited from seven urban groups | The authors interviewed the subjects and analyzed contacts between nurses and caregivers at the beginning of the care course | Previously tested tool Not specifically addressed in this study | The establishment of contacts in the early stages of dementia was beneficial among informal and formal service networks |
| Giles et al. [28], 2004 | Longitudinal study LOE: Level III | To examine the impacts of specific social networks with relatives, friends, children, and total social networks on Nagi functional tasks and confidants on disability in mobility in older adults | 1,477 participants aged 70 years or older | Big data from the Australian Longitudinal Study of Ageing were used | Not specifically addressed in this study | After controlling for health, personal, and environmental factors, social networks with relatives protected against mobility disability and Nagi tasks |
| Nay et al. [29], 2015 | Exploratory study LOE: Level III | To examine the PWD family caregivers’ perception about social participation means | 33 family caregivers (17 spouses and 16 adult children) | Semi-structured face-to-face and/or telephone interviews were employed to collect data | Not specifically addressed in this study | Caregivers went through a process whereby the ways in which they had previously participated socially were compromised, which often prompted an exploration of new ways in which to remain socially engaged |
| Nicholls et al. [30], 2013 | Mixed methods approach implementing the “high touch” intervention and evaluating results with pre/post-measurements: Level I | To improve delivery of palliative care to PWD, increase the health professionals’ knowledge and skills of dementia care and enhance communication between PWD, health professionals, and their families | 7 focus groups consisting of 31 participants | Data were derived from focus groups conducted at three nursing homes located in metropolitan and regional areas of NSW, Australia | Not specifically addressed in this study | Social relations contributed to provide life meaning and role satisfaction to care providers and PWD |
| de Vocht et al. [27], 2015 | Pre-/post-test study LOE: Level III | To assess the impact of a one-to-one 30-min individualized interaction/day | 15 PWD, 13 health care professionals and 4 family relatives were included | PWD behavior was recorded by videotapes and their QOL was measured by Qualidem | Not specifically addressed in this study | Individualized interaction/day significantly improved positive interactive behavior of PWD during the intervention |

LOE, level of evidence; PWD, people with dementia; NH, nursing home; QOL, quality of life.
Data Selection

In order to find relevant articles, searches of electronic databases, including PsycINFO, MEDLINE (PubMed), and the Cumulative Index of Nursing and Allied Health Literature (CINAHL), were conducted by entering combinations of the terms “older adults,” “dementia,” “environment,” “factors,” “caregiver,” and “social.” More than 11,399 articles were retrieved, some of which had been published before the 1970s. Therefore, the search was further refined by entering more specific keywords such as “dementia,” “environmental factors,” “social factors,” and “caregiver factors.” Out of the 238 articles retrieved, a total of 19 articles were relevant to the topic of this study and thus relevant for review. Articles were included in this study if they had been published in English between 1997 and 2019 and if they focused on PWD exclusively. Articles which were relevant but from fields of study other than nursing, such as medicine and psychology, were included. The Preferred Reporting Items for Meta-Analysis (PRISMA) checklist and flow chart were utilized in the current review, as shown in Figure 1.

Data Synthesis

The synthesis of findings is the final step of the integrative review [12]. In order to synthesize the data retrieved, the articles were categorized into evidence tables based on the different identified factors related to care outcomes among PWD. The authors analyzed the articles in the sample, and the following 3 categories emerged: environmental factors, caregiver-related factors, and social network factors. Articles which described environmental factors were included in the first evidence table (Table 1) [13–19]. Meanwhile, articles which described caregiver-related factors were included in the second evidence table (Table 2) [20–24]. Finally, articles which described social network factors were included in the third evidence table (Table 3) [25–30].

The current review will discuss the groups of articles in terms of (a) their levels of evidence, (b) their targeted populations and health care issues addressed, (c) the types of interventions implemented, and (d) the study results. Then, an analysis of the article groups will be carried out according to the articles’ generalizability, strengths and weaknesses, relevance to nursing practice, and influence on future nursing research.

Quality of Evidence Appraisal Assessment

The quality the selected articles was assessed according to the 2011 guidelines of Melnyk and Fineout-Overholt. Two of these studies were Level I; one was a randomized control trial [15] and one was a Level I study with a mixed-methods approach [30], whilst the remaining were Level III cross-sectional studies [13–21, 26, 28, 29]. One was a comparative case study [21], 8 were descriptive cross-sectional studies [13–20], 2 were qualitative studies which used focus groups [22, 23], one study adopted the double hermeneutic methodology [24], 2 were exploratory studies, [26, 29] one descriptive cross-sectional [25], one longitudinal [28], and one pretest/posttest [27].

Results and Discussion

Environmental Factors Impacting Care Outcomes

Seven of the retrieved studies had investigated the impact of environmental factors on home care outcomes. A detailed description of the relevant studies is summarized in Table 1. The strength of the selected articles lies in their exploration of the relationship between different care outcomes and environmental factors among PWD. For example, different factors were identified in the study of Kolano [31] as being associated with behavioral symptoms among PWD. These factors included proximal precipitating factors, including “qualities of the physical and social environment, and physiological and psychological need states,” and background risk factors, including “neuropathology, cognitive deficits, physical function, and premorbid personality,” (p. 1,032) [31]. Meanwhile, in the study of Garre-Olmo et al. [14] physical environmental factors such as noise, lighting, and temperature were found to have an association with the quality of life (QoL) of nursing home residents with severe dementia. These findings supported the findings of the study of Cohen-Mansfield and Werner [13] which found that making modifications to the corridors of nursing homes, such as adding pictures of nature, flower smells, and bird sounds, increased satisfaction levels among PWD. After the modifications were made, the observed residents were found to smile more often, appear calmer, and show fewer signs of regression or agitation [13].

Increasing attention is being placed on physical environment design when making care plans for PWD [15]. The environment plays an important role in the way that an individual interacts with other people and understands their surroundings [19]. Too often or too much stimulation can lead PWD to exhibit disruptive behaviors, including agitation [32]. Nikmat et al. [18] found that in comparison to PWD residing in long-term care facilities, older adult PWD residing in their own homes had higher QoL and took part in more ADLs, including socialization. PWD who are institutionalized face overwhelming stimulation from new environments such as nursing homes [33]. Zeisel et al. [19] also highlighted the fact that conventional environments are designed for cognitively intact residents and may not always be suited to the needs of residents with Alzheimer’s disease or other forms of dementia.

In their literature review, Volkers and Scherder [34] found that the studies of Winocur and Moscovitch [35] and Wang et al. [24] both of which had conducted experiments on animals, had revealed that older rats are more greatly impacted by environmental conditions than younger rats. This was found to be particularly true in environments that had limited opportunities for social interaction and physical activity. Likewise, in the study of Angevaren et al. [36] sedentary and lonely older adults...
were found to experience a faster decline in physical and cognitive function than did physically and socially active older adults. It has also been reported that institutionalization, which is an environmental factor, exacerbates the decline in cognitive functioning among older adults [35]. Egerton and Brauer [37] suggested that although physical exercise is encouraged in nursing homes, these homes reflect a passive environment. The study reported that ambulatory residents may spend only 137 min/day, on average, standing or walking, whilst they may spend the rest of the day sitting down or lying in bed.

A social environment, which includes social support at home, is exhibited by functional and structural components [38]. Among the structural elements are relational bonds and network size, which include social integration, assistance, and attachment [39]. Morgan and Stewart [17] conducted a qualitative study in order to assess the perceptions of family members and nursing staff towards the impacts of physical and social environments on PWD. The study findings indicated that the social environment has a greater effect than the physical environment on functional ability and QoL among PWD. Further, the elements of the social environment that were identified as being important were human contact, stimulation, supervision, flexibility, and meaningful activity [17].

Older adults may experience feelings of loneliness as a result of moving from one environment to another, such as moving from their own homes to long-term care facilities. Kostka and Jachimowicz [16] suggested that institutions for older adults are often impoverished environments which provide limited opportunities for residents to maintain social relationships with their loved ones. Therefore, it is often the case that residents of long-term care facilities experience more social isolation than do community-dwelling older adults. Consistent with these findings, Scocco et al. [40] reported that loneliness is experienced by about 50% of nursing home residents.

Out of the studies reviewed in this article, 5 had an adequate sample size and therefore generalizable results. Meanwhile, the study of Morgan and Stewart [17] was conducted on a small sample of 18 nurses and caregivers, and the study of Cohen-Mansfield and Werner [13] on a sample of 27 nursing home residents. Further, whilst the study of Nikmat et al. [18] explored the home care setting, the results of the remaining 5 articles shed light on the association of several environmental factors with care outcomes among PWD. Researchers and healthcare professionals may expand their knowledge by examining the impacts of these factors on home care outcomes among PWD (Table 1).

### Caregiver-Related Factors Impacting Home Care Outcomes

Whilst many studies have been conducted on caregivers of PWD, the current review was limited to studies which have explored the associations of caregiver-related factors with care outcomes among PWD. Of the studies selected, 6 had examined the impact of the caregiver on care outcomes. A detailed description of the relevant studies is summarized in Table 2.

In the present review, 6 studies investigating the caregiver-related factors impacting care outcomes among PWD were reviewed. In all of the 6 studies, caregiver burden and stress were found to be factors influencing quality of care [20–24]. In addition to caregiver burden, caregivers’ poor psychological well-being resulting from lack of family support and low self-esteem was found to lead to negative outcomes, including disrupted schedules and reduced QoL among PWD [20]. A positive correlation has been reported between family support and caregivers’ psychological well-being, whereby the more support that caregivers receive whilst caring for PWD, the more likely their psychological well-being is to increase [20]. Other caregiver-related factors include the establishment of trusting relationships, collaboration, and communication between family caregivers and professionals [22]. Caregiver-related factors also include the provision of services by the public health care system [24], type of support network and sociodemographic and health characteristics [21], and financial and social burdens [23]. Qadir et al. [23] also shed light on the fact that in developing countries, many people do not have sufficient understanding of dementia and the continuous care it requires, which therefore hinders them from effectively coping with dementia. Moreover, in the study of Jaglal et al. [21], it was concluded that when caregivers of PWD received sufficient emotional support from their social support networks, the quality of their provided care was likely to increase. According to Egdell [41], caregivers often highlight their need to receive proper information regarding the support services available and emphasize that healthcare professionals also need to make these services available not only to PWD but also to their informal caregivers. Karlsson et al. [22] and Stephan et al. [49] supported the findings of Jaglal et al. [21] and highlighted the importance of caregivers establishing trust relationships with professionals, having commitment and professional knowledge, and offering care services which are varied and suited to patients’ needs. In turn, these caregiver-related factors lead to positive outcomes among PWD and increase patients’ trust in their caregiv-
ers, therefore increasing their satisfaction with the care experience [22].

Meanwhile, Wang et al. [24] highlighted the significant role that social changes have played in undermining the traditional family care model and how this has resulted in several challenges for PWD and their caregivers. Other caregiver-related factors which have been found to negatively impact health outcomes among PWD and their caregivers and to result in increased institutionalization of PWD include the immediate caregiver’s inability to provide care for the patient or increased caregiver burden, financial and social burdens, and lack of supervision by the public health care system [22–24]. In the study of Wang et al. [24], PWD were described as living in “empty nests,” as the majority relied on their spouses, rather than their children, for care. When family caregivers have insufficient resources or support, older adult PWD are more likely to be placed in nursing homes [24]. Making the decision to permanently institutionalize an older adult family member in a long-term care facility is among the most difficult decisions that family caregivers must make and is a decision which is often followed by feelings of sadness and guilt [42].

Schedule disruptions and caregiver burden have also been reported to have negative impacts on QoL and psychological well-being [20]. Factors related to unstable emotional status among both PWD and their caregivers and which include busy periods, excess conversation, and disturbed social routine have also been identified [20, 39]. Further, it has been reported that receiving care from multiple caregivers can be stressful for PWD and can have negative impacts on their cognitive abilities [19, 24]. Further, when PWD have multiple caregivers who are not part of their immediate core networks, this can be overwhelming, increase agitation and poor health outcomes, and eventually interfere with the delivery of care.

As shown in Table 2, two of the reviewed studies had relied on small samples [23, 24], which may limit the generalizability of the findings of these studies. Further, in 4 of the reviewed studies, it is possible that language transfer bias may have occurred during the process of translating participants’ responses into English [22, 23]. Finally, none of the 6 studies reviewed were found to address the home care setting component. The findings of the reviewed studies shed light on the caregiver-related factors associated with care outcomes among PWD.

Social Network-Related Factors Impacting Home Care Outcomes

The present study reviews 6 studies which have examined social networks as a factor in care outcomes. A detailed description of the relevant studies is summarized in Table 3. One strength of the 6 studies reviewed above was that 4 of these studies were based on theoretical models [26, 28–30]. Further, all of the selected studies reported statistically significant results, revealing significant associations between “social networks” or “social interaction” and QoL, meaning, and positive interactions among PWD and their caregivers.

Due to their impaired communication abilities, PWD may show decreased cognitive insight into their symptoms and needs [43]. However, positive associations have been reported in several studies between active social interactions, positive affect, and improved physical function among PWD [28, 30, 44]. Active participation in social networks contributes towards general well-being and secure, comfortable, and productive aging among older adults. In Australia, Giles et al. [28] revealed that social networks with home caregivers from a core network, such as children, significantly delayed the onset of disability and improved recovery among older adults.

In the study of de Vocht et al. [27] one-on-one interaction that was tailored to the patients’ individual needs and preferences led to significant improvements in positive interactive behaviors among care-dependent PWD. Such form of interaction can easily be implemented in home care settings [27]. Social interaction has also been reported to have a significant association with caregivers’ satisfaction [29]. Vocht et al. [27] highlighted that caregivers of PWD highly value social participation and social networks, as socializing strengthens their identities as active community members and enables them to maintain their sense of identity throughout the process of providing care. Meaningful social interaction has also been associated with improved health outcomes [45].

In the case of PWD who live at home, social interaction is not always facilitated, and patients may often feel isolated and neglected as a result of them being separated from their friends and society [25]. Social support and ongoing friendships have been shown to decrease agitation among PWD [30, 46]. In their study, Cohen-Mansfield et al. [11] observed 5 older adults with a history of disruptive and/or agitated behaviors, such as screaming, and found that residents often exhibited such behaviors when they were alone. Consistent with these findings, Burgio et al. [25] found that residents were more likely to exhibit aggressive behaviors when
left alone or when their significant caregivers were more than 3 feet away.

Burgio et al. [25] greatly emphasized the role of the social environment in the behaviors of older adult residents with dementia. Older adults were found to experience significantly fewer episodes of agitation when they had physical and verbal interactions with their caregivers. The study also found that as patients’ privacy personalization scores increased, their Psychotic Problem Scale scores decreased.

Furthermore, Mark [38] reported that the increase in social participation and social network size reduces the impacts of psychological and physical stressors, hence reducing mortality of PWD. However, Moniz-Cook and Clarke [39] showed that having too many social networks may lead to disappointment and conflict and therefore negatively impact well-being. There may be other factors which have not been identified in the current study, including use of psychotic medications and frequency of social contact, but which may be associated with care outcomes among PWD. The core network size and number of caregivers required for the provision of adequate care depend greatly on the severity of the patient’s case, whereby some patients may require a team of 10 caregivers, whilst others may only require one caregiver.

Carpentier et al. [26] highlighted the importance of professionals and informal caregivers considering service integration. If there is a lack of coordination between institutions and family caregivers, the quality of care delivered to PWD may be compromised [47]. When taking into account the factors that influence home care outcomes among PWD, it is necessary to find strategies for creating effective long-term links between social systems, family caregivers, and formal care institutions [26]. Further research is required to investigate the impacts of multiple social and environmental factors on home care outcomes among PWD Table 3.

Limitations

While this study provides an interesting, and potentially novel, review of the literature, as well as a thorough synopsis of the articles included in the sample, there are some limitations. Only peer-reviewed articles, published in English were included in this narrative review, which may introduce a publication or selection bias, limiting the generalizability of the findings. Also, most of the selected studies for the review were conducted in Western countries, which limits the generalizability of the findings. Some of the reviewed studies had a small sample size and cross-sectional design which may increase the probability for type II errors and confounding effects.

Conclusion

There is a need for more research on the influence of multiple environmental and social context variables on home care outcomes for PWDs. Although some studies have reported associations between social network interaction and outcomes (e.g., agitation), these studies have not focused on outcomes, core network size, and frequency of contact among PWD specifically [25, 28, 48]. Therefore, further research in this area is recommended, as this could determine whether poor care outcomes among PWD are associated with core network size or the frequency of contact with care providers.

As a conclusion of this integrative review of literature, 3 main factors were identified related to home care outcomes among PWD which include environmental factors, caregiver-related factors, and social network factors. Carpentier et al. [26] encouraged professionals and informal caregivers to consider concepts related to service integration involving family caregivers. It was evidenced that poor coordination between family caregivers and institutions negatively affects the quality of care provided to PWD [47], and the importance to search for ways to create effective long-term linkages between family members as caregivers, social systems, and formal care institutions was emphasized [26]. It was also evidenced that active social participation of older adult PWD in social events and activities has a significant relationship with feeling of security, comfort, and productive aging [27]. Also, social environment and physical environment both contribute to the overall well-being of older adult PWDs. However, it was identified that social environment had a greater impact on PWD than physical environment. These social environment includes human contact, attachment, stimulation, assistance, supervision, and social integration [17].

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

The systematic searches were done by A.A.G. and M.R. Writing, review, and editing were done by A.A.G. and M.R. Conceptualization and study design were conducted by A.A.G and M.R. All authors have read and approved the final version of the manuscript.
References

1 Cho K, Kim YJ. A study on family caregiver support programs in the USA: the case of the state of Georgia. Int J Hum Ecol. 2016;17(2):1–15.
2 Miranda-Castillo C, Woods B, Orrell M. People with dementia living alone: what are their needs and what kind of support are they receiving? Int J Psychogeriatr. 2010 Jun;22(4):607–17.
3 Association As. 2019 Alzheimer’s disease facts and figures. Alzheimers Dement. 2019;15(3):321–87.
4 Lakey I, Chandaria K, Quince C, Kane M, Saunders T. Dementia 2012: A national challenge. London: Alzheimer’s Society; 2012. pp. 68–73.
5 Halabi AK, Zafar JM. Care of the elderly in United Arab Emirates. Int J Geriari Psychiatry. 2010 Sep;25(9):925–7.
6 Baker SN. Management of acute agitation in the emergency department. Adv Emerg Nurs J. 2012 Oct-Dec;34(4):306–18.
7 Algase DL, Beck C, Kolanowski A, Whall A, Berent S, Richards K, et al. Need-driven dementia-compromised behaviour: an alternative view of disruptive behavior. Am J Alzheim Dis. 1996;11(6):10–9.
8 Lawton MP. Environment and aging. Center for the Study of Aging. 1986.
9 McCloskey RM. Caring for patients with dementia in an acute care environment. Geriatr Nurs. 2004 May-Jun;25(3):139–44.
10 Cohen-Mansfield J. Theoretical frameworks for behavioral problems in dementia. Alzheimers Care Today. 2000;1(4):8–21.
11 Cohen-Mansfield J, Marx MS, Rosenthal AS. Dementia and agitation in nursing home residents: how are they related? Psychol Aging. 1990 Mar;5(1):3–8.
12 Whitemore R, Knafl K. The integrative review: updated methodology. J Adv Nurs. 2005 Dec;52(5):546–53.
13 Cohen-Mansfield J, Werner P. The effects of an enhanced environment on nursing home residents with dementia: a randomized controlled trial of a home environmental intervention: effect on efficacy and upset in caregivers and on daily function of persons with dementia. Gerontologist. 1998 Apr;38(2):199–208.
14 Garre-Olmo J, López-Pousa S, Turon-Estrada A, Juviná D, Ballester D, Vilallarta-Franch J. Environmental determinants of quality of life in nursing home residents with severe dementia. J Am Geriatr Soc. 2012 Jul;60(7):1230–6.
15 Gitlin LN, Corcoran M, Winter L, Royce A, Hauck WW. A randomized, controlled trial of a home environmental intervention: effect on efficacy and upset in caregivers and on daily function of persons with dementia. Gerontologist. 2001 Feb;41(1):4–14.
16 Koski T, Jachimowicz V. Relationship of quality of life to dispositional optimism, health locus of control and self-efficacy in older subjects living in different environments. Qual Life Res. 2010 Apr;19(3):351–61.
17 Morgan DG, Stewart NI. The importance of the social environment in dementia care. West J Nurs Res. 1997;19(6):740–61.
18 Nikmat AW, Hawthorne G, Al-Mashoor SH. The comparison of quality of life among people with mild dementia in nursing home and home care—a preliminary report. Dementia. 2015 Jan;14(1):114–25.
19 Zeisel J, Silverstein NM, Hyde J, Levkov S, Lawton MP, Holmes W. Environmental correlates to behavioral health outcomes in Alzheimers special care units. Gerontologist. 2003 Oct;43(5):697–711.
20 Alvira MC, Risco E, Cabrera E, Farré M, Rahm Hallberg I, Bleijlevens MH, et al.; RightTimePlaceCare Consortium. The association between positive-negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study. J Adv Nurs. 2015 Jul;71(6):1417–34.
21 Jaglal S, Cockerill R, Lemieux-Charles L, Chambers LW, Brazil K, Cohen C. Perceptions of the process of care among caregivers and care recipients in dementia care networks. Am J Alzheimers Dis Other Demen. 2007 Apr-May;22(2):103–11.
22 Karlsson S, Bleijlevens M, Roe B, Saks K, Martin MS, Stephens A, et al.; RightTimeCarePlace Consortium. Dementia care in European countries, from the perspective of people with dementia and their caregivers. J Adv Nurs. 2015 Jun;71(6):1405–16.
23 Qadir F, Gulzar W, Haqanni S, Khalid A. A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia. Care Manag J. 2013;14(4):230–40.
24 Wang J, Xiao LD, He GP, De Bellis A. Family caregiver challenges in dementia care in a country with undeveloped dementia services. J Adv Nurs. 2014 Jun;70(6):1369–80.
25 Burgio LD, Butler FR, Roth DL, Hardin JM, Hsu CC, Ung K. Agitation in nursing home residents: the role of gender and social context. Int Psychogeriatr. 2000 Dec;12(4):495–511.
26 Carpenter N, Pomey MP, Contreas R, Olazabal I. Social care interface in early-stage dementia: practitioners’ perspectives on the links between formal and informal networks. J Aging Health. 2008 Sep;20(6):710–38.
27 de Vocht HM, Hoogeboom AM, van Nieukerk J, den Ouden ME. The impact of individualized interaction on the quality of life of elderly dependent care on a result of dementia: a study with a pre-post design. Dement Geriatr Cogn Disord. 2015;39(5-6):272–80.
28 Giles LC, Metcalf PA, Glonek GF, Luszcz MA, Andrews GR. The effects of social networks on disability in older Australians. J Aging Health. 2004;16(4):517–38.
29 Nay R, Bauer M, Fetherstonhaugh D, Modey W, Tarrzsa L, McCauliffe L. Social participation and family carers of people living with dementia in Australia. Health Soc Care Community. 2015 Sep;23(5):550–8.
30 Nicholls D, Chang E, Johnson A, Edenhough M, Touch, the essence of caring for people with end-stage dementia: a mental health perspective in Namaste Care. Aging Ment Health. 2013;17(5):571–8.
31 Kolanowski A, Litaker M, Buettner L, Moeller J, Costa PT Jr. A randomized clinical trial of theory-based activities for the behavioral symptoms of dementia in nursing home residents. J Am Geriatr Soc. 2011 Jun;59(6):1032–41.
32 Kovach CR. Sensoriasis and imbalance in persons with dementia. J Nurs Scholarsh. 2006;38(2):379–90.
33 Bakker R. Sensory loss, dementia, and environments. Generations. 2003;27(1):46–51.
34 Volkers KM, Scherder EJ. Empowered environment, cognition, aging and dementia. Rev Neurosci. 2011;22(3):259–66.
35 Winocur G, Moscovitch M. A comparison of cognitive function in community-dwelling and institutionalized old people of normal intelligence. Can J Psychol. 1990 Dec;44(4):435–48.
36 Angevaren M, Aufdemkampe G, Verhaar H, Alem A, Vanhees L. Physical activity and enhanced fitness to improve cognitive function in older people without known cognitive impairment. Cochrane Database Syst Rev. 2008 Jul;(3):CD005381.
37 Egerton T, Brauer SG. Temporal characteristics of habitual physical activity periods among older adults. J Phys Act Health. 2009 Sep;6(5):644–50.
38 Mark RE. Understanding the individual with Alzheimer’s disease: Can socioemotional selection theory guide us? 2012.
39 Moniz-Cook E, Clarke C. Dementia care: coping with aggressive behaviour. Nursing Residential Care. 2011;13(2):86–90.
40 Colaco P, Ratappay M, Fantoni G. Nursing home institutionalization: a source of eustress or distress for the elderly? Int J Geriatr Psychiatry. 2006 Mar;21(3):281–7.
41 Egdev V. The needs of informal carers for people with dementia. Br J Healthcare Manag. 2012 Aug;18(12):628–35.
42 Sury L, Burns K, Brodaty H. Moving in: adjustment of people living with dementia going into a nursing home and their families. Int Psychogeriatr. 2013 Jun;25(6):867–76.
43 Cohen-Mansfield J, Billig N. Agitated behavior in the elderly. I. A conceptual review. J Am Geriatr Soc. 1986 Oct;34(10):711–21.
44 Al-Sabahi SM, Al Sinawi HN, Al-Hinai SS, Youssef RM. Rates and determinants of functional limitations among the elderly population in Al-Dakhlia region, Sultanate of Oman, Middle East J Ageing. 2013;8(1):1–13.
45 Nowak L, Davis JE. A qualitative examination of the phenomenon of sundowning. J Nurs Scholarsh. 2007;39(3):256–8.
46 Zarit SH, Femia EE, Watson J, Rice-Oeschger L, Kakos B. Memory Club: a group intervention for people with early-stage dementia and their care partners. Gerontologist. 2004 Apr;44(2):262–9.
47 Abbott KM, Bettger JP, Hampton KN, Kohler HP. The feasibility of measuring social networks among older adults in assisted living and dementia special care units. Dementia. 2015 Mar;14(2):199–219.
48 Srivastava SK. Applied and community psychology: Sarup & Sons; 2005.
49 Stephan A, Afram B, Koskenniemi J, Verbeek H, Soto MW, Bleijlevens MHC, et al. Older persons with dementia at risk for institutionalization in eight European countries: a cross-sectional study on the perceptions of informal caregivers and healthcare professionals. J Adv Nurs. 2015;71(6):1392–404.