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Review Article

Dementia Care in Family and Community–Building Resilience and Hope

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Abstract

Background: Dementia patients receive care from their families and communities which can have a beneficial or negative impact on their physical, psychological, social, and economic well–being. Giving care may have an attenuating or reducing effect due to personal resilience which is defined as a set of traits that safeguard an individual in adverse circumstances. According to the findings, Resilience is defined as the ability to go about one's daily life in a 'normal' manner and that a couple's connection and shared sense of resilience are essential to do so. The value of relationships in living well as well as the importance of dementia care within the family and community are emphasized. When supporting and caring for someone with dementia, caregivers must know how to assess family members' resilience, policy and practice must include such an assessment. When supporting and caring for someone with dementia, caregivers must know how to assess family members' resilience and policy and practice must incorporate an assessment of family members' resilience. This article intended to provide a theory and knowledge of resilience and hope between individuals with dementia living in family and community by reviewing resilience among family members and friends supporting and caring for a person living with dementia as how tenacious family caregivers and friends may be when it comes to supporting and caring for someone with dementia.

Methodology: The Researcher has collected data from a variety of sources including websites, journals, articles, e–books, reports, commissions, national education plans, and articles published in local, national, and worldwide publications. Secondary data sources for this review study include books, articles, libraries, reports, personal sources, journals, newspapers, websites, online data.

Aim and Objectives: The study came up with a definition for resilience and hope, as it figures out what elements contribute to people's resilience and how resilience influences their relationships and well–being. These studies will look into the notion of resilience and hope in dementia for both care recipient and the caregiver as well as the dynamics and components of their hope experiences. This is a summary of a comprehensive literature review on resilience in dementia patients and caregivers with the goal of better understanding the factors that promote resilience and hope and extent to which the viewpoint is maintained.

Conclusion: The findings suggest that people with dementia and their caregivers use resources to maintain their resilience and hope however this perspective has been overlooked in previous studies. Positive relationships between social support and resilience as the community integration and resource utilization were discovered and investigated considering the greater body of literature with their implications for future research. The existing evidence on the influence of resilience and hope on family caregivers of people living with dementia is compiled in this comprehensive study.

Keywords: Dementia; Older People; Family; Community; Resilience; Hope; Life; Implication; Caregivers; Social Support; Alzheimer's Disease; PWD.

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Introduction

Memory loss, thinking, problem–solving and language impairments as well as frequent changes in mood, perception and behavior are all indicators of dementia. These changes are usually minor at first but they have progressed to the point where they are affecting daily living for someone with dementia. Dementia is not an inevitable component of growing older. Alzheimer's disease and disorders that cause vascular dementia are the most common causes of dementia. Dementia is a progressive neurocognitive condition characterized by memory and cognitive impairment as well as behavioral abnormalities all of which affect a person's ability to perform daily activities. As a result dementia is a substantial contributor to the worldwide burden of disease costing an estimated $818 billion per year and expected to reach $2 trillion by 2030. In addition family and social care costs account for over 85% of costs. It is no surprise that dementia is regarded as one of the twenty–first century's most serious health, societal, and economic problems.

People with Dementia–Understanding and Support

Dementia is a syndrome that causes a formerly attentive person's capacity to execute daily activities to deteriorate gradually. Memory and at least one of the following cognitive functions are most affected: language, perception, vision and space perception, computation, judgement, abstraction, and problem solving. Caring for someone with dementia necessitates adaptability, problem solving, some trial and error as well as a great deal of patience and inventiveness. People with dementia have memory, cognitive, and behavioral problems that make it difficult for them to operate in daily life. These persons become progressively unable to live independently or handle their affairs, including their health care as the condition progresses. Despite the fact that researchers are working to better understand the causes of dementias, identify them as early as possible and develop efficient treatment regimens, the number of people affected is already high and will continue to rise as the population ages. In reality the task for health–care professionals is to design a stage–based treatment approach, target services to requirements and prepare the infrastructure to connect people with dementia–capable services.

Types of Dementia

Dementia comes in numerous forms. They are all caused by brain disorders that harm and kill brain cells. This section covers the most common kinds of dementia.

Alzheimer’s Disease

Hundreds of billions of nerve cells communicate with one another in the brain. Structures called '*tangles*' occur inside these cells and '*plaques*' form outside them in the brain of a person with Alzheimer's disease. Because these formations prevent cells from interacting with one another, they eventually cease operating and die. The brain loses cells throughout time leaving it with less cells to perform all of its duties resulting in memory, thinking, and reasoning issues. In the brain of someone with Alzheimer's disease, there is also a deficiency of some critical molecules. This means that messages do not travel as quickly as they should around the brain.

Vascular Dementia

Vascular dementia is the second most frequent type of dementia. It is caused by issues with the blood arteries that transport blood throughout the body (the vascular system). These vessels cannot convey enough blood to the brain when they are compromised by disease such as when arteries become 'hard' over time. Because the brain need oxygen from the blood to operate correctly, brain cells that do not receive enough blood may eventually die.

Dementia with Lewy Bodies (DLB)

Lewy bodies are small protein aggregates that form inside nerve cells and cause problems with brain function. They induce nerve cells to die by reducing the level of chemical messengers. This results in early planning, reasoning, and problem–solving challenges. DLB affects at least two–thirds of persons and causes alterations in their mental capacities.

Frontotemporal Dementia (FTD)

The phrase ‘frontotemporal dementia’ refers to a variety of disorders. Pick's illness is included, and it's also known as *frontal lobe dementia*. Damage to the frontal and temporal lobes of the brain causes FTD. In these lobes, clumps of aberrant proteins develop within nerve cells, causing the cells to die. Important molecules involved in the transmission of signals across the brain are also impacted. This has an impact on one's behaviour, emotional responses, and language abilities.

Mixed Dementia

Mixed dementia refers to when a person has more than one type of dementia. Alzheimer's disease and vascular dementia are the most prevalent combos, however additional combinations are possible. When someone has mixed dementia they are likely to have symptoms from all of the distinct varieties of dementia.

Dementia Treatment Management

There is currently no cure for dementia. However, there are therapies that can help with the symptoms. It is possible to live well with dementia if you use the proper combination of treatments. There are two types of therapies: non–drug treatments and medication treatments, treatments for a variety of additional medical issues, Alterations in a person's lifestyle.

1) Form and sustain a relationship with the Dementia people and his or her family.
2) Educate and assist Dementia people and their families.
3) Conduct a diagnostic examination and send the patient to any general medical treatment that is required.
4) Maintain and improve the patient's and others' safety.
5) Inform the patient and family about the dangers of driving and other actions that endanger others.
6) Provide financial and legal advice to the family.
7) Address family and caregiver concerns (e.g., provide respite care referrals, explore the possibility of the patient being transferred to a long–term care facility).
8) If depression and sleep disruption are present, assess and treat them using the previously outlined procedures.
9) Use particular psychological therapy to address loss concerns, boost mood, and change undesirable behaviors.

Dementia's Effect on Everyday Life

Taking up the role of dementia caregiver is going to have a significant influence on your life. It can be lucrative and uplifting, but it can also be challenging and have an impact on how you feel. When caring for someone with dementia, many people experience both good and difficult times. Help is available if you are having difficulty or are unsure about something. Everyone requires assistance from time to time, and it will enable you to fulfill the critical duty of assisting the individual. You probably know the person well, perhaps better than anybody else, which may make it easier for you to meet their specific demands. It is important to consider a few things right away. As the person's dementia worsens, it will have a greater impact on both your and their everyday lives. They will require more help as time goes on, and you could find it difficult to adjust. More information and advice on how to cope with these changes, as well as the resources accessible to you, can be found in this handbook. This provides information on how dementia can impact.

- Relationship with the person you are caring for
- Feelings
- Health
- Daily life and work
- Finances
- Responsibilities

Social Support model for Dementia in Community Care

Community care has become huge business in every sense of the word. However, increasing the amount of time people with dementia spend at home is not always the best sign of success or quality of life for all parties involved. As a result it may fail to recognise whether the person with dementia finds life organised around a 'care package' to be a gratifying experience, and it may lose sight of the fact that admittance into a care facility can be a positive choice and a happy experience for many individuals with dementia. Despite these reservations, community care is ‘here to stay’, and this chapter examines some of the tensions, issues, and opportunities that have arisen as a result of its socio political rise in importance in the health and social care field, as well as its current provision and future profile. An examination of the role of the community mental health nurse in promoting quality of life for people with dementia and their families as they use available support services is also part of this investigation. While overall social care provision involves a wide range of activities ranging from home help to nursing home placement, this section focuses on the services referred to as ‘home care’ – essentially, assistance with domestic tasks or personal care provided by social services or a care agency. The focus is on those chores and activities that are essential to keeping an older person at home and the intensity of the service is determined by the amount of time the service is required by an individual and is estimated using 'contact hours’. A small amount of assistance to a large number of people in need can make a huge difference to people with dementia who live alone and family carers who are experiencing difficulties of some sort.

Dementia Family Caregivers

Family caregivers of people with dementia, sometimes known as ‘invisible second patients’ are crucial to the care receivers' quality of life. Being a family caregiver has several negative consequences including high rates of burden and psychological morbidity, social isolation, physical ill–health, and financial difficulties. Caregivers who are vulnerable to negative consequences can be recognised as can factors that reduce or increase stress and strain. Psychosocial therapies have been shown to lessen caregiver stress and sadness as well as to delay admission to a nursing home. Building a collaboration between health professionals and family caregivers, referring to Alzheimer's Associations, and implementing psychosocial therapies as needed are all elements of comprehensive dementia management. Dementia patients typically require a high level of care, which is usually supplied by informal or family caregivers. People with dementia would have a lower quality of life and require institutional care sooner if carers were not available, and country economies would be swept away by the rising demographic tidal wave. This assistance, however, comes at the expense of caregiver anguish and a lower quality of life. The majority of people with dementia live in their communities (estimates in the United States range from 70% to 81%) with family and friends caring for about 75% of them. Around 10 million Americans were caring for someone with Alzheimer's disease or another kind of dementia in 2007. A dementia caregiver is typically a middle–aged or older female child or spouse of the dementia sufferer. In 2008, men made up 40% of family carers in the United States, up from 21% in a 1996 Alzheimer's Association research. Men over 75 are more likely than women to be caring for their spouse in the United Kingdom. A sense of love or reciprocity, spiritual fulfilment, a sense of responsibility, guilt, social pressures, or, in rare cases, avarice may inspire family caregivers to provide care. Caregivers who are driven by a sense of obligation, guilt, or societal and cultural norms are more likely to dislike their role and experience more psychological suffering than caregivers who are motivated by more positive motives. Caregivers who recognize more positive aspects of their position report reduced stress, improved health and relationships, and more social support.

Community Care

The paucity of evidence on what constitutes excellent community care for People with Dementia has several causes, some of which are philosophical, some of which are methodological, and some of which are policy–driven. Multiple definitions of community care have been disseminated, and given the complexity and scope of community care as a whole, research has tended to focus on interventions that address certain components within it (e.g. home care, day care, respite care). Furthermore, relatively little research has concentrated on generating sets of measures to assess care provided to PWD living at home, with the majority of research focusing on outcomes in institutional care settings. In many European nations, offering community–based care services for elderly persons living at home is becoming the preferred policy in a determined move away from traditional institutional care believe that community–based care for People with Dementia is superior from a user (societal) standpoint [1–7]. However, stating universal user preference for community–based home care overlooks the additional demands placed on family members and other informal caregivers when caring for someone with dementia [8].

Appeal of Collaborative Community Care

It emphasizes the complex balancing act between cost–effectiveness and user preferences as well as safety and freedom. The wishes of older individuals with dementia to receive care in their own homes should be prioritized in care planning and reflected in all policies. The preferences of informal carers, most of whom are women, are also essential; their support requirements and wellbeing play a large role in the indirect costs of community care. Caring for people with early to moderate dementia at home is less expensive than institutional care, however this may change as the disease develops. Because of the severity of care needs, home care becomes unsustainable at some point during the disease trajectory. Appropriate and effective community care on the other hand can go a great way toward delaying that possibility. The provision of high–quality assessment and care for PWD depends on primary care. Greater education and system organization at practice and organizational interfaces are required to raise awareness of dementia specifically. To improve the treatment of PWD in primary care, at least three particular issues must be resolved. (1) The need to standardize assessment methods and employ cutting–edge technologies to aid in early diagnosis; (2) The chance to raise awareness of the advantages of psychosocial interventions in primary care for PWD, such as psychological interventions for CGs, cognitive stimulation, and occupational therapy; and (3) The potential to encourage education on drug use by PWD and an improvement of supportive techniques for patients and caregivers.

Dementia Care Needs

The conflicts emerging from the varied perceptions of the individuals participating in the care process are captured by decision–making along the disease's trajectory. People with dementia have worse decision–making abilities due to the cognitive impairment associated with the condition. This causes a significant burden on family members who are frequently called upon to help, and it can have significant practical ramifications in terms of matching care services to care needs. While people with dementia are more concerned about being socially isolated and the repercussions of losing their memory, family carers prioritize practical assistance with daily routines while care professionals focus on clinical, medical needs. It's no surprise however that care services are frequently judged to be unsuitable for users' needs.

Integrated Care

Integrated community support for individuals with dementia like other integrated care is based on the same ideas of seamless care coordination and continuity across providers, cooperative decision–making, and ongoing monitoring of the people with dementia. Integrated care is intended to adapt to the changing and complex needs of dementia patients. Integrated community support for individuals with dementia includes emotional and practical support for both the people with dementia and their caregivers, in addition to health and medical treatment. Integration can occur at various levels, including the integration of support structures (institutional working procedures) and support workers (multidisciplinary teams providing various parts of care for persons with dementia). Integrated care as opposed to more fragmented, inflexible, and task–oriented care, allows the most suitable expertise, resources, and abilities to be delivered at the correct time while protecting the dignity of people with dementia. People with dementia who receive integrated community help have fewer behavior difficulties and have a better mood. Continuity of care, coordination inside and across services, and joined–up decision–making are all principles that drive integrated care. The goal is to provide care in a timely manner, allowing for seamless care and ongoing monitoring of requirements as people get older. Multidisciplinary teams, cross–institutional service provision, and the linked health, social service, and related systems in which organizations function have all been understood as ‘*integrated care*’.

Resilience in People with Dementia

Psychosocial characteristics such as family load, coping methods and self–efficacy had a stronger relationship with quality of life in the current group of carers than demographic ones such as age and household income. With an ageing population, shrinking nuclear families and expected changes in family living arrangements for the disabled in the future, the issues of caring for the disabled will change in nature and form. Burden, coping abilities, and self–efficacy perception will all change. The main issue for healthcare practitioners and society will be to continue to investigate the needs and concerns of family caregivers and to create evidence–based interventions that match the requirements of different caregivers. Carers need to be resilient because they must be able to ‘*bounce back*' and cope in the face of hardship. Resilience, defined as "*the ability to identify chances for personal growth in the face of adversity may distinguish spouses who thrive from those who are overwhelmed by caring responsibilities*" [9]. Personal mastery, self–efficacy, and good coping strategies are three resilience dimensions that have been proven to reduce the impact of stress on caregiver health [10]. Social support, participation in pleasurable activities, self–esteem, good attitudes about the caring role, hope, and optimism are some of the variables that may help caregivers cope with chronic stress [11]. Caregivers have a 20% higher risk of mental illness than the general population [12].

The Framework for Resilience

The study literature reveals that the notion of resilience is ambiguous. We defined resilience as a "*dynamic process encompassing positive adaptation within the context of considerable adversity*" (p543). There is no doubt that being diagnosed with Alzheimer's disease or similar dementia is a source of great adversity. There hasn't been much research into how to quantify resilience in people with Alzheimer's disease. The research community is becoming more interested in resilience, and various resilience measures have been developed, but they all need to be validated. We noticed a surprising, yet genuine sense of well–being among many of the dementia individuals, regardless of how resilience is defined. Despite numerous losses that resulted in rapid and significant attacks on self–confidence (e.g., the inability to follow a recipe), these people showed resiliency by adapting to their ‘*new normal*’. They concentrated less on what they had lost and more on what they could still do with the support of their husbands, children, or friends. Families make adjustments to allow their relatives to continue to participate in activities. Personal meaning, a sense of purpose, and social involvement were all enhanced by participating in these activities. Continuing to engage in activities enjoyed pre–diagnosis contributes to a sense of normalcy and wellbeing, which sustain resilience. Supporting resilience in people with early dementia seems to include opportunities to retain and savor preferred adult identities while finding new satisfaction with their current identity. "*Having something significant to do each day or something to be involved in makes life worth living*" one participant in an early stage group said in Perspectives, a publication for persons with dementia. In people with early–stage Alzheimer's disease, meaning and purpose appear to be crucial for long–term resilience.

A Concept of Hope in Dementia Care

When it comes to maintaining a sense of normalcy and implementing cognitive, social, and behavioral methods to boost confidence in people with early–stage dementia, hope is essential. Hope, helping others, and being part of a supportive social network can all help with daily adaptability and self–concept preservation. The literature was studied using Walker and Avant's concept analysis method to investigate hope in early–stage dementia and to determine the dynamics and components of the hope experience. Understanding the concept of hope in early–stage dementia can help nurses and other healthcare workers help people with dementia and their family caregivers preserve hope and enhance a sense of self. In the medical literature, the topic of hope in early–stage dementia has received little attention. However, research on people with dementia in the middle and advanced stages suggests that hope can still exist and thrive in the setting of a caring relationship. According to Spector and Orrell's research, there is a correlation between residential care staff's hope and people with dementia having a higher quality of life. Cutcliffe and Grants have highlighted the relevance of interpersonal components of hope inspiration in dementia, claiming that nurses can inspire and maintain hope through humanistic practice, pragmatic knowledge, interpersonal relationships, organizing and planning.

Resilience is aided by Social Interaction

The importance of social interaction, environmental assistance and the person with dementia's remaining talents has been highlighted through three decades of psychosocial research on dementia care. This advancement in our understanding of social health calls into question the widely held idea that dementia cannot be avoided and that persons with dementia's abilities cannot be maintained or enhanced. Despite a large investment in a biological emphasis, epidemiological research has produced the most promising outcomes in dementia research, ‘borrowing’ putative risk and protective variables for dementia from cardiovascular research. Mental, physical, and social aspects all had a role in lowering dementia risk [13]. Early–stage Alzheimer's support groups cater to persons who have recently been diagnosed or are in the early stages of the disease. Many people attend because they want to meet other people who have recently been diagnosed. One woman, who had no recollection of having Alzheimer's disease but knew she had the ‘same thing as her mother’, was eager to join the early–stage group because she saw the value in being among ‘others in the same boat’. Being among others who are ‘in the same boat’ can help you to be more resilient.

Caregivers of Dementia People

As people live longer, society faces an ageing population, with dementia being one of the most common ageing issues. Caregivers for dementia patients are typically family members who combine job, family responsibilities, and patient care. Caregivers are at risk of developing depression, committing suicide, or abusing their patients. Because resilience is linked to surviving life catastrophes, improving resilience will equip people with coping skills and reduce depression [14]. Performed longitudinal research to assess the effects of a psychosocial intervention programme on the mental health of caregiver spouses. The primary caregiver and family members attended four formal family therapy sessions. Conflict resolution was a key component of the program's success during the four official family therapy sessions. Better family cohesion and caregiver depression resulted from improved dispute resolution strategies among family members. The researchers attempted to convey the causes for the dementia patient's behaviour during individual therapy. In addition, the caregivers learnt how to manage and engage with the patients. These two steps have also helped carers feel less depressed. In addition, the programme has raised awareness among family members of the impact of dementia on primary caregivers' mental health. Family members have been able to provide appropriate assistance as a result of this facilitation. Caregiver satisfaction has aided in the reduction of caregiver depression. This study found that long–term social support can help carers feel less depressed [15]. Individuals that are resilient persevere in their problem–solving efforts. Despite their dissatisfaction, they remain focused rather than distressed, distracted, and without a strategy. They chose to ignore their anxieties and stay on track [16,17]. Dementia is a long–term illness that can last up to 20 years. In this long path of caregiving, the quality of perseverance is crucial. Finally, a training module is based on these basic resilience qualities. It aims to strengthen caregivers' resilience to hardship and quality of life in order to ensure a long–term future. Health economic benefits include lower health–care costs by allowing caregivers to earn while caring for patients. Caretaker’s financial burden will be reduced. A resilient caregiver would effectively handle problems and enhance the patient's independence in daily living and cognitive function, so indirectly slowing illness development. The stage of being bedridden can be postponed even longer. Caregivers with resilience skills were able to use a proactive method to limit the chance of falling and take preventative action, reducing the requirement for acute treatment. The cost of acute health care and mental health issues have decreased. Countries that applied these resilience–building techniques would be able to keep health–care costs under control while maintaining economic development [18–20].

Family Care Giving

Caregivers in the research work hard every day to persuade their ailing relatives to accept their care and accept them as caregivers. This might be a difficult endeavour that requires the caregiver's ingenuity and practical intelligence. As caregivers remarked during interviews, care in severe stages of dementia is not only intimate, but also basic; they do everything for their relatives, including feeding them, transporting them to the bathroom, clothing them, changing their dirty underwear, and putting them to bed. Relatives will often refuse to allow their caretakers to assist them with such chores of daily living. Dementia is a life–altering chronic illness that follows an uncertain and unpredictably unpredictable path. Caregivers must deal with chronic and debilitating physical and behavioural issues [21]. Their caring tactics maintain the humanness of the dementia–affected relative, which is linked to dementia care quality [22]. Thus, caregivers' reaffirmation of dementia patients' humanity in the middle of a condition that attempts to destroy it is a significant contribution. A prior study discovered that family caregivers define and redefine the individual with dementia [23]; this study adds to that finding by demonstrating that caregivers see their sick relatives with advanced dementia. Caregivers, if we consider the body as an expression of social practises [24], take care of their relatives' social presentation, maintaining their individuality, dignity, and human attributes by interpreting their feelings and translating them for those who do not understand their special, unique language. Caregivers thereby maintain their ailing relatives' social bodies, not only their physical bodies; they maintain their persona, and in doing so, they become their parents and nurses. Indeed, the rising complexity of home care has been recognized as transforming carers into health care personnel capable of doing complex activities with great ability [25]. “The process of effectively negotiating, adjusting to, or managing severe causes of stress or trauma” says [26]. A 'behavioral process' that focuses on improving personal characteristics and external assets. Dementia is difficult not just for those who suffer from it, but also for those who care for them and their families. It is one of the leading causes of disability and reliance among the elderly around the world. In most countries, there is a lack of awareness and understanding of dementia, which leads to stigmatisation, impediments to diagnosis and care, and physical, psychological, and economic consequences for carers, families, and society. Dementia can no longer be ignored; it must now be included in all countries' public health agendas. To emphasise that dementia is a public health concern that requires a public health strategy, and to push for action at the international and national levels based on the values of inclusion, integration, equity, and evidence, awareness must be promoted. Resilience is defined as a person's ability to adapt and thrive in the face of adversity [27]. It is linked to positive outcomes such as maintaining well–being (Wilmshurst, Peele & Wilmshurst, 2011). However, research has revealed that there is some confusion on how to define and quantify resilience [28]. Informal caregiving has been linked to adversity, with research indicating that it may pose a threat to one's quality of life [29]. The degree to which caregivers can preserve resilience is a critical problem. Family caregivers who are resilient are able to face the challenges of their job while maintaining their own health and well–being and established a resilience framework to explain the variables that help caregivers of older individuals develop resilience in the face of adversity and obstacles.

Caring for a family member with Dementia

Caretakers must deal with difficult behavioral and personality changes in their loved ones, including hostility in some situations. Caring for a loved one full–time might leave family members feeling socially isolated and unable to pay unexpected expenses. Caring for others can be a highly rewarding experience that can help to improve family relationships because of the close and intimate interaction that is shared. Changes in behaviour and personality can compel family caregivers to approach their loved one differently as if they were a child. As the amount of care required grows, carers' relationships with their siblings may become strained. The unfavourable health repercussions of caring for a family member with dementia are well recognised.

Coordination of Care

The friction point between care coordination and appropriate care mix highlights the difficulties that persons with dementia and their families confront while navigating a patchwork of fragmented and mismatched community–based services. Case management can be an effective tool for coordinating care services, not only because of its ability to inform and assist families and organise services, but also because of the role case managers play in resolving conflicts within families and between families and care providers. Most countries have a long way to go before services are fully integrated and coordinated at the local level. The gap between acute care facilities and outpatient and home–based treatment as well as undeveloped training systems for health–care professionals, are major roadblocks. Offer persons with dementia with a single designated health or social care professional who is responsible for coordinating their care, schedule an initial evaluation of the person's requirements, preferably face to face, and provide information about available resources and how to access them. Include the person's family members or carers in support and decision–making. Pay special attention to the perspectives of persons who lack the capacity to make decisions about their own care, ensure that people are aware of their rights to and the availability of local advocacy services and if appropriate to the immediate situation have an independent mental capacity advocate develop a care and support plan, and agree and review it with the person, their family members or carers and relevant professionals, indicate when and how frequently the plan will be revisited, evaluate and document progress toward the goals at each review, and make sure it addresses the treatment of any comorbidities, provide the individual and their family or caretakers a copy of the plan as appropriate.

Supporting Carers

Provide dementia carers with a psycho education and skills training intervention that includes: education about dementia, its symptoms, and the changes to expect as the disease progresses; developing individualised strategies and building carer skills training to help them provide care, including how to understand and respond to changes in behaviour and communication style training to help them adapt their communication styles and advice on how to look after their own physical, mental, emotional, and spiritual wellbeing advice on planning enjoyable and meaningful activities to do with the person they care for information about relevant services including support services and psychological therapies for carers and how to access them to improve interactions with the person living with dementia Planning for the future is a good idea. Ensure that the assistance offered to caregivers is targeted to their needs and preferences as well as the goals they wish to achieve (for example, offering information on carers' employment rights for those who work or want to work) designed to assist them in supporting persons living with dementia accessible at a convenient location and in a manner that is appropriate for them (for example, individual or group sessions, or online training and support) available from the time of diagnosis and as needed thereafter.

Approach that focuses on the Family

In all contacts with members and families, the Day Care Services (DCS) should have a family–centered approach. Respecting and responding to the individual member's as well as the family's preferences, wants, and values is what a family–centered strategy entails. All therapeutic choices should be guided by member and family values (derived from IOM, 2001 a concept of ‘person–centered care’). The DCS should ensure that the member's dignity is respected, that the member's and family's well–being is promoted, that values, culture, language, and preferences are respected, that the member is fully engaged, that activities are meaningful, and that social connectedness is emphasised when using best practise care plans. The more information the DCS has about members and their families, the more family–centered the standardised care plans will be. To gain a better overall understanding of needs, values, and preferences, the DCS might consider asking the member and family the questions below.

Perceptions of care needs

The physical, social, and psychological demands of the person with dementia, as well as the family caregiver, are referred to as ‘care needs’. People with dementia have a wide range of perceived and objective care demands which can be dramatic. Family members frequently underestimate the cognitive abilities of dementia patients. Von Kutzleben and colleagues (2012) found that the majority of requirements reported by People with Dementia are connected to social inclusion and preserving a good sense of self and general well–being in a systematic evaluation of research concentrating primarily on the expressed needs of People with Dementia. People with dementia, on average have less unmet care requirements than their formal or informal caregivers, and they place a greater emphasis on various types of needs. In a study conducted in the Netherlands, dyads of people with dementia and their family caregivers were interviewed to elicit perceived care needs of the person with dementia from both perspectives. Memory, information, and psychological distress were the most frequently cited unmet needs by the person with dementia, while caregivers cited memory, daytime activities, and company the most frequently. People with dementia, their informal caregivers, and formal care professionals in the UK were interviewed by Miranda–Castillo and colleagues (2013) who found that people with dementia have less unmet needs than either informal or official carers. People with dementia and informal caregivers both reported much more unmet needs than official care providers, which represents a sorely under–researched perspective. While all three groups indicate daytime activities (e.g. social, stimulating, or leisure activities) company, and psychological anguish as the most pressing unmet requirements, People with Dementia report the latter the most frequently. These findings highlight the fact that for people with dementia, wellbeing, particularly its social and psychological aspects is the most essential factor but caregivers prefer to focus on demands related to practical and day–to–day problems.

Family–Centered Approach and Informal Care Givers

Informal caregiving is a less organised type of caring in which the carers are not compensated for their services. Informal caregiving, according to a Los Angeles public health magazine, is the everyday support and assistance provided by family members and friends to their temporarily or permanently disabled relatives. Because of the close proximity of the family caregiver to the person with dementia and their critical role in ensuring the highest possible quality of life for those who require care, it is often neither possible nor desirable to fully relieve family members of their caring responsibilities by transferring them to formal service providers. Instead, carers should be provided with the assistance they require to lessen perceived stress and maintain their own well–being and health. Formal care providers should strive to relieve family carers of the 'heavy–lifting' or physically exhausting activities, allowing them to focus on lighter tasks and tasks that are crucial for sustaining their relationship with the person with dementia, according to focus group specialists. The research lists a number of interventions that have been shown to reduce caregiver strain and improve caregiver health outcomes, but it stops short of determining which specific services are most beneficial and which care providers are best positioned to provide them. Parents, grandparents, siblings, children, cousins, spouses, in–laws, and other relatives are frequently involved in informal caring. Friends, neighbours, and good Samaritans may be involved in some circumstances. It is primarily centred on a social interaction between the caregiver and the care receiver, and it frequently develops partially as a result of societal expectations of a family as the intrinsic commitment of one family member to the other.

Advocacy and Awareness–Raising

Despite its expanding worldwide effect, dementia is still stigmatised due to a lack of knowledge. Stigma adds to social isolation and delays in seeking diagnosis and support for persons who are living with dementia (both the person and their family). As a first step in improving the quality of life for persons living with dementia and their carers, there is an urgent need to raise dementia knowledge and understanding at all levels of society. Governments can help fund public awareness programmes and ensure that relevant stakeholders are participating. Campaigns to raise awareness should be contextually and demographically appropriate. They should be accurate, effective, and informative, and they should be produced in collaboration with dementia patients, their families, and other stakeholders, including civil society.

End–of–life dignity and care

The majority of current studies on the quality of end–of–life care for patients with dementia comes from the United States. In a retrospective cohort research comparing the care received in nursing homes by persons who died of dementia with those who died of terminal cancer in their last year of life, the former received sub–optimal care in various categories. People with advanced dementia, as well as their caregivers, should have access to appropriate palliative care and support. It's crucial to note that palliative care isn't only necessary when death is near, but it may also be beneficial for several years before death. Unfortunately, patients with dementia have limited access to palliative care services in hospitals, at home, and in specialised facilities such as hospices. Palliative care is growing more popular among dementia patients in the Netherlands, and it is also gaining popularity among caregivers. The Netherlands has one of the most liberal legislative systems in the world for making end–of–life decisions. It allowed the use of advanced written requests for physician–assisted suicide for patients with dementia in 2016, a contentious topic that has sparked heated discussion. As dementia advances, a person's cognitive and communication abilities deteriorate, making it more difficult for both lay and professional caregivers to appropriately assess the person's wants and requirements. Information and observations from staff are frequently essential to patients with dementia in nursing homes, but significant staff turnover can lead to false reports and misreading of the severity of symptoms, creating a ‘malignant social environment’.

Conclusion

Resilience, according to evidence from non–dementia–specific research, is a multi–dimensional notion that includes environmental, social, economic, and communal components, and as such, the focus is shifted away from people and toward individuals' participation with systems. Resilience is a trait linked to adaptive abilities and a strong track record of functioning and adaptability in the face of adversity. Because this dynamic process involves the interplay of biological and psychological elements, it is more difficult to investigate. Because studies define resilience differently, it's difficult to get consistent results, which impedes understanding and exploration of related elements. Support groups should focus on variables that may promote caregiver resilience, such as task–focused coping methods and self–efficacy, as well as knowledge and sentiments regarding the diagnosis and caring routines. Longitudinal studies should be done to track illness development evaluate relationships with other factors and better understand the dynamics of resilience, all of which might improve carers' quality of life. Positive links between social support and resilience whereas the community integration and resource utilisation were identified and studied as well as their implications for future study in light of the larger body of literature. This thorough research compiles all of the known information on the impact of resilience and hope on family caregivers of dementia people.

Contribution of the Authors

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