

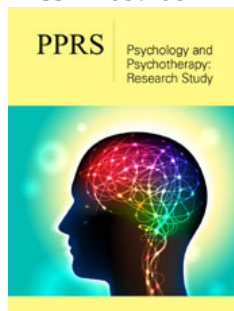
Gentlecare: New Approach to Providing Dementia Care

Letteria Tomasello^{1*} and Massimo Raffaele²

¹Sapienza university of Roma, Italy

²Department of Clinical and Experimental Medicine, University of Messina, Italy

ISSN: 2639-0612



Abstract

Dementia is a neuro-cognitive disorder, characterized by cognitive impairment and behavioural and psychological disorders. Dementia contributes to the impairment in Activity of daily living. There is no currently available cure for dementia. Various treatments and interventions have been researched; medications are considered the primary treatment. Non-pharmacological approaches are receiving increased attention as a critical part of dementia care. In addition to medication therapies for dementia, non-pharmacological interventions are recommended. In this review, we will mainly look at nonpharmacological treatment and one of the models of care considered to be the most innovative and usefully effective, the Gentlecare Model.

Keywords: Dementia; Care giver burden; Care ability; Gentlecare model

***Corresponding author:** Letteria Tomasello, Sapienza university of Roma, Italy

Submission:  December 03, 2024

Published:  January 03, 2025

Volume 8 - Issue 4

How to cite this article: Letteria Tomasello* and Massimo Raffaele. Gentlecare: New Approach to Providing Dementia Care. Psychol Psychother Res Stud. 8(4). PPRS. 000692. 2025. DOI: [10.31031/PPRS.2025.08.000692](https://doi.org/10.31031/PPRS.2025.08.000692)

Copyright@ Letteria Tomasello, This article is distributed under the terms of the Creative Commons Attribution 4.0 International License, which permits unrestricted use and redistribution provided that the original author and source are credited.

Introduction

Dementias are part of chronic diseases, as defined by the National Commission on Chronic Illness, are all those diseases “characterized by a slow and progressive decline in normal physiological functions” characterized by high variability in symptoms, clinical manifestations and intensity of care [1]. In the European context, the main definitions are those provided by the World Health Organization (WHO) and the European Health Interview Survey (EHIS). The former defines chronic diseases as those diseases that are not transmissible from one person to another and have the characteristics of long duration and generally slow progression. The EHIS definition, on the other hand, defines chronic diseases as those diseases of long duration or those health problems that last or are expected to last for at least six months. [2].

Creating a system of care that can yield positive and quality outcomes in the long-term care system should be a topic of particular concern for geriatric medicine. In Italy, the Health Care System is strongly hospital-cantered; the National Plan for Chronic Care was deliberated in 2016, but its organizational implementations in Italian regions are scarce. In the US, there is the Chronic Care Act.

Epidemiology and Risk Factors

According to the 2016 WHO and Alzheimer “s Disease International (ADI) Report, dementia, in its many forms, is “a global public health priority. The greatest risk factor associated with the onset of dementia is age. The gradual increase in the elderly population will lead to an increase in the prevalence of dementia patients. The prevalence of dementia in industrialized countries is about 8 percent in those over age 65 and rises to more than 20 percent after age 80. Each year 7.7 million new cases (1 every 4 seconds) and an average survival after diagnosis of 4-8-years. Italy is one of the oldest European countries (age 65 and older) and almost 17% of the population, a total of 9.5 million, is over 65 years of age.

Dementia, is manifested by a series of signs and symptoms, particularly by the decline in a person’s cognitive faculties, given by the chronic and progressive impairment of brain

functions, such as memory, language, comprehension, attention, spatio-temporal orientation, reading and writing skills, judgment, organization, and inhibition of behaviour. The symptomatology of dementia, given the impairment of cognitive functions, is characterized by a progressive disability whose clinical and care management is extremely complex, requiring the activation of a qualified integrated network of health and social welfare services, as indicated by the National Dementia Plan, in effect since the end of 2014.

“Assisting is an art; and if it is to be carried out as an art, it requires total devotion and hard preparation, as for any work of a painter or sculptor; with the difference that one is not dealing with a canvas or a cold marble, but with the human body the temple of God’s spirit. It is one of the Fine Arts. Indeed, the most beautiful of the Fine Arts.” - Florence Nightingale

The Role of a Dementia Caregiver

Assisting, supervising, and caring for a sick person is a task that can bring some satisfaction, but undoubtedly it is a task burdensome. Being in contact with the illness of one’s loved one carries an emotional burden that is difficult to manage. To be a caregiver is also to be part of a silent network of care and despite the importance of the role played by these figures, only for the past few years has the caregiver been the subject of attention within the framework of Welfare policies at regional and national levels and at the centre of legislative initiatives aimed at promoting their recognition and support.

The caregiver’s activity has been recognized by the 2018 Budget Law, which established a fund of 20 million euros per year for them for the three-year period 2018-2020, defining caregiver as “The person who assists and cares for a spouse, the other party to the same-sex civil union or de facto cohabitant of a relative or relative-in-law within the second degree, or a relative within the third degree if the parents or spouse (or party to the civil union) of the person being cared for have reached the age of sixty-five or are also suffering from a disabling condition or are deceased or missing.” The age groups most engaged in providing care are those between 45 and 54 and between 55 and 64. Commitment varies according to the amount of time devoted to caregiving.

Most (53.4%) devote less than 10 hours per week to this activity, followed by those who devote more than 20 hours per week (25.1%). 19.8 percent devote at least 10 hours but less than 20 per week, and a share of 1.6 percent give no indication of time. Regarding the level of education, those with an average level devote more to caregiving, but those who devote more hours (more than 20 per week) to caregiving are those with the lowest level of education, while those who devote less than 10 hours to it are those with a high level [3].

The literature review found that informal caregivers have problems in providing care for people with dementia at home such as: maintaining the caregiver’s physical, emotional, social, spiritual and financial well-being and caring with uncertainty and inadequate knowledge of the disease.

Integrating the advice of health professionals to the activities carried out by informal caregivers of people with dementia will help in the development of interventions to reduce negative caregiver and caregiver outcomes. On the Italian national territory, there is a differentiated organization between and sometimes even within individual regions and a marked variability in the qualitative-quantitative supply of diagnostic and treatment services for dementia [4]. One of the models of caring for people with dementia and their families that have proven useful and effective in improving the quality of life of the patient and caregiver is the Gentle Care model which we will detail below.

The Gentle Care Method

An interesting model of intervention aimed at the Alzheimer’s patient but also at family members is the prosthetic model. The starting point of such a model is the consideration with respect to the fact that Alzheimer’s being a degenerative and progressive disease, which with its persistence over the years entails incurable and irreversible many of its aspects, ends up producing mental and physical disabilities that, inevitably, cause over time an involvement in a pathological sense also of the family unit [5]. The main objective of the model becomes, therefore, not so much healing but the promotion of the person’s well-being and the containment of the stress of those who care for the sick person. The centrality of the patient and the search for and preservation of his or her existential continuity are, therefore, its foundational elements [6].

The Gentlecare system designed and promoted by Moyra Jones is an example of a prosthetic system. Such a system consists of a peculiar procedure in which the first methodological step is knowledge of the sick person. It is, however, a clinical-functional knowledge of the sick person, which is enriched in parallel with knowledge in the biographical sense of the patient himself. In this way, in the gentlecare model, elements of the pathophysiological order together with elements of the personal and contextual order combine to reduce the distance between objective knowledge of problems and the subjective experience of illness. The second methodological moment in the process of the gentle care model is the assessment of the impact of the disease on the individual sufferer, where assessment means both an analysis of the deficits induced by the disease and of the compensatory strategies that the sufferer uses independently.

According to the logic of the gentlecare model, moreover, assessment is not to be understood as a simple application of scales, but as a purely cognitive phase that precedes the operative moment and allows for critical consideration of the choices made and the results obtained. Deficit assessment uses the tools proper to multi-dimensional assessment while that related to spontaneous behaviour and compensatory strategies is based on observational elements carried out by caregivers, which are later translated into real operational indications within the care plan of care. A first level of assessment to be conducted by carers is a general assessment known in Gentle Care as “general awareness”; it includes observational elements such as: what the sick person can

do; what the sick person does; how the sick person performs that task; what part of the task he or she fails to perform; why he or she fails to perform it; and where and when he or she performs best in performing it [6]. The second level of assessment in the gentilecare model, on the other hand, makes use of two techniques for organizing information from direct observation of the sick person: the first is called the "stress profile" technique in which the day's events are mapped, sources of stress are identified, and guidance is given to all carers on what strategies to apply and when to apply them over the 24-hour period; the second is called the "behavior mapping" technique, which consists of observing the patient's behavior over the 24-hour period and translating the observation into a chart that staff use to represent the typical day of the sick person taken in charge.

The assessment culminates, then, in defining the stage of illness in which the sick person is placed. This phase allows the staff, not only to make a prognostic judgment, which is decisive for both the sick person and family members, but also to make basic choices for the construction of the care plan that involve realistic goals and avoid frustrating objectives, based on a careful balance between the strengths and weaknesses of the individual sick person. The third methodological moment represents the construction of the actual support, which in the Gentle Care methodology consists of three elements that cannot be separated and are in dynamic relationship with each other: the physical environment, the people who care, and the activities and programs that contribute to making sense of the sick person's day [6]. Regarding the physical environment, the gentilecare model attributes a crucial role of space in the care plan. There is much evidence that the person with dementia can be particularly sensitive to environmental changes, both in a positive and negative sense [6].

In the context of the Gentle Care methodology, the paradigm of the prosthetic environment is identified in the home, since it represents the synthesis of many elements connected with the person's subjectivity: it represents, in fact, the space of maximum familiarity, the area in which the recognition of the space and its meaning of use is immediate, because it is now introjected; moreover, it constitutes the place where the most private and most meaningful experiences and emotions for the person's life are kept. In the construction of the prosthetic environment, it is possible to refer to some guiding criteria:

Security

The cognitive deficits, loss of criticism and judgment inherent in the disease, mean that the person with dementia tends to put himself or herself in risky situations. Relatedly, what most frequently occurs in caregivers is the emergence of a need for tight control over the sick person that conflicts with respect for the patient's autonomy and self-determination. Such conflict often becomes a source of stress for caregivers. The goal in the gentilecare project in both residential and home settings is therefore to create indoor and outdoor spaces that are protected to the point that the sick person can enjoy maximum freedom in the midst of safety [7].

Ease of access and mobility

Freedom of movement and usability of the environment allow the sick person to retain the feeling of being able to control the surrounding space and thus increase his or her sense of belonging and mastery over the different areas. Within the gentle care model, it has emerged that crucial for the sick person, even in the moderate-severe phase, is the feeling of mastery over the most intimate space, namely the room, with its own bed and personal belongings. This feeling can be enhanced or diminished by the attitude of hospital staff, for example, it has been seen that entering the patient's room without asking permission undermines the sense of control, conversely asking for permission reinforces it. The visibility of usable areas, also becomes critical, as does the masking of prohibited areas. Alongside direct visibility, the gentle care project considers the facilitation of the patient's interpretation of the spaces in which he or she lives to be fundamental; it makes use, therefore, of unconventional signage that can be easily interpreted by the patient. Such elements can be used to identify personal and constructed spaces with the help of the family, and in addition to enabling the sick person to identify his or her own space, they restore his or her sense of belonging and self-esteem.

Function and activity

since the sick person is often unable to ascribe to space its proper meaning of use, gentle care design assumes that it is necessary for each environment to suggest to the sick person the function for which it is intended, whether through configuration, furniture, infrastructural elements that stimulate interest and possibilities for interaction. Therefore, it is necessary to provide points of interest (e.g., view of the outdoors), arrange the furniture in such a way as to facilitate interaction and conversation, compensate for sensory deficits by arranging interesting objects within real reach of the visual field, and create opportunities for the use of objects normally present in everyday life. The ready availability of everyday objects, allows the patient to exercise functional independence with positive repercussions at least on two levels: it increases the autonomy, the ability to choose for the person with dementia, it relieves caregivers from having to prompt the patient to perform activities.

Flexibility and change

The environment must be able to change in relation to the changing needs of the sick person and carers. The guiding elements of this change are: enhancement of residual abilities, comfort and compensation of deficits for the sick person, and better management of aspects of care by carers. As for caregivers, within the gentle care project, in addition to being adequately trained and motivated, they are urged to operate according to the principle of sharing both goals and care plans. Real sharing makes it possible, in fact, to concretely implement the care plan outlined for the individual patient and to review and adapt the same plan to the changing needs of the patient as well as to changing context situations. The ability of each caregiver to use an interpretive approach to the illness with its set of cognitive and noncognitive symptoms is seen by the gentle care model as a guarantee of adequate interpretation of

behavioural disorders and less recourse to psychotropic drug use. Crucial in this regard is the therapeutic alliance between family and caregivers. In both residential and home care settings, therefore, an important moment is the caregiver's understanding of the dynamics of caregiving and the identification of the coping styles used by the caregiver, in order to redesign the style of caregiving, seeking primarily to leverage the interpretive approach, that is, the understanding from the disease from the pathophysiological point of view and the family member's interpretation and understanding of the patient's behavior in light of the neuropsychological deficit.

Regarding programs and activities in the Gentle Care model, the reference is to concepts related to normality and everyday life. The activities elaborated are not recreational activities, conceived in a standard way and proposed in an undifferentiated way to different patients, but rather of all those activities that for each, constitute the subject's day. In Gentle Care, therefore, the main intent is to reconstruct for each sick person a personalized daily routine that refers to the biographical and contextual elements known for that person (thus cultural and moral values of reference, attitudes, propensities, specific expertise) that emphasize existing functional levels and optimize the patient's strengths.

In Gentle Care, therefore, programs are constructed in such a way as to: be as close as possible to the sick person's lifestyle; provide activities corresponding to actual skills appropriately reevaluated at different stages of the illness; and meet psychological needs such as the need for security, biological integrity, belonging, self-esteem and self-actualization. Examples of matching needs and activities, with respect to the need for safety and biological integrity, are: pain control, comfortable positions, massage, adequate rests, energy conservation, familiar routines, involvement in instrumental and basic activities of daily living. With respect to sense of belonging: meaningful personal objects to look at and keep, animals, plants, opportunities to listen, to touch, environments to set up. With respect to self-esteem: reminiscences and memories, control of money, possibility to help others; and finally with respect to self-actualization: teaching, learning, remembering, creative activities, work [8]. In the gentle care model, therefore, the singularity of the patient and the family system in which the person is embedded are embedded within the everyday which becomes the pivotal element of the program.

Conclusion

The results of the literature review, highlight that the presence of indicators of stress, physical and psychological symptoms have a negative impact on the quality of care provided by caregivers. In addition, it is important to point out that knowledge of the variables that most affect the manifestation of a higher degree of burden can enable the implementation of more targeted caregiver interventions and the development of tools for personalized care planning. It is essential to pay special attention to the interactional, communicative and role aspects of family functioning that can affect both the caregiving function and the psychological stress processes of the primary caregiver. It would also be desirable to ensure greater continuity between the hospital and the local area

by strengthening links between different services, and to schedule follow-ups to monitor the changing needs of caregivers.

The issues of illness negatively affect the health of the caregiver and more broadly in the family of the caregiver. However, it is evident from the literature and the norms viewed that there is no real legal recognition to reconcile the caregiver's work time with the caregiving time and to allow for facilitations/facilitations at the economic, insurance and pension levels. It would be crucial for policy choices to address these needs for the purpose of legal, cultural and social recognition of the caregiver. Caregivers of people with dementia are often referred to as the "hidden victims" of this most debilitating disease, placing themselves in a gray area of the care process of the person with dementia. As important as they are neglected. The survey conducted shows how caregivers of an elderly person with dementia present a variable but mild-to-moderate subjective burden on average. Perceived stress is mostly related to the fact that most of the caregiving goes to the families.

What follows is that the caregiver must spend most of his or her time meeting the needs of his or her loved one at the expense of his or her own life. In the evolution of the Health Care System in Italy, since the early 1970s the hospital-territory relationship has gone through profound changes, ensuring greater moments of integration between hospital and territory activities. The goal of a fully integrated health care system capable of ensuring continuity of care between all levels does not seem, however, to have been fully realized.

The application of multiple informational, psychological, educational, supportive, and formal interventions is again revealed as the most effective strategy in reducing caregiver burden and negative outcomes affecting psychological and physical health. Caregivers of people with dementia are often referred to as the "hidden victims" of this most debilitating disease, placing themselves in a gray area of the care process of the person with dementia. Yet they represent the pinnacle and the main figure to whom attention should be directed both from the point of view of support, both financial and social.

In the relationship with the caregiver must be present in every professional "If, on the one hand, without memory there is no self, on the other, whoever is not recognized by their beloved after a life together, runs the risk of feeling deprived of their relationship and of their emotional background. Professionals therefore have an ethical duty toward patients and their families. The analysis of the real needs allows us to deal with the several ethical questions arising in the course of the illness, in compliance with the principles of: independence - self-determination, charity and social justice.

Nowadays it seems that a person affected by dementia has no dignity. A human being, as a person, possesses an original dignity at any stage of his/her existence, and both patient and caregiver will be guaranteed a social inclusion, respectful of the condition of disability and no longer marginalizing and stigmatizing the condition of dementia. "Prosthesis of care" for each individual that is intended to compensate for the lost function(s). The main goal of

the prosthesis is not to regain cognition or function, but to deal with the well-being of the person, to achieve the best status in absence of distress and pain” [7].

References

1. National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) (2020) Guidelines for chronic disease, USA.
2. Higher Institute of Health (2016) Austrian health survey, French 2011 plan for the improvement of the quality of life of people with chronic diseases, Portuguese national health survey, Danish health and medicine authority, Roma, Italy.
3. Ministry of Health (2016) National chronic disease plan. Bolzano, Italy.
4. National Dementia Plan (2014) Strategies for the promotion and improvement of the quality and appropriateness of care interventions in the dementia sector (Rep. atti n. 135/CU), Italy.
5. Branca S, Spallina G, Caprino C, Ferlito L, Motta M, et al. (2005) Demented patient, caregiver, services: a triad to be built and defended. *Editoriale G Gerontol* 53: 104-111.
6. Jones M (1999) *Gentlecare*. A positive model of care for Alzheimer's. Carocci Faber, Rome, Italy.
7. Guaita A, Jones M, Guaita A, Jones MA (2011) "Prosthetic" approach for individuals with dementia? *JAMA* 305(4): 402-403.
8. Bortolomio E, Lionetti L (2016) *Gentle care: care chronicles, solutions, methods and ideas for applying the Erickson method*.