

INSTITUTIONAL SUPPORT FOR PEOPLE WITH DEMENTIA OF ALZHEIMER'S TYPE AND THEIR CARERS – CRACOW'S EXPERIENCE

Katarzyna Wojtas^{1A,B,D,F}, Alicja Kamińska^{2,3A,B,C,D,F}

¹Department of Clinical Nursing, Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University Medical College, Krakow, Poland

²Laboratory of Theory and Fundamentals of Nursing, Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University Medical College, Krakow, Poland

³Municipal Care Centre for Elderly, Disabled, and Dependent People, Krakow, Poland

Authors' contribution:

A. Study design/planning • B. Data collection/entry • C. Data analysis/statistics • D. Data interpretation • E. Preparation of manuscript • F. Literature analysis/search • G. Funds collection

Address for correspondence:

Alicja Kamińska
Laboratory of Theory and Fundamentals of Nursing
Institute of Nursing and Midwifery
Faculty of Health Sciences
Jagiellonian University Medical College
12 Michałowskiego St., 31-126 Krakow, Poland
e-mail: alicja.kaminska@uj.edu.pl

SUBMITTED: 16.07.2020

ACCEPTED: 25.08.2020

DOI: <https://doi.org/10.5114/ppiel.2020.103531>

ABSTRACT

Introduction: Cognitive deficits in the course of dementia are commonly diagnosed among elderly people. In connection with their progressive, incurable nature it is necessary to provide professional care for patients and their caregivers. Unfortunately, help for people with dementia and their carers is not sufficient, and deficits in legal and social areas are also noticed.

Aim of the study: To present the functioning of the Day and Activation Centre for Dependent People in the Municipal Care Centre in Cracow, at 267 Wielicka Street.

Material and methods: Analysis of scientific literature and the authors' own experience from the implementation of the program for the Day and Activation Centre for Dependent People.

Results: The facility is an example of an indirect form of service provision between care in the community and round-the-clock care. It provides caregivers with support in various dimensions.

Conclusions: The establishment of day centres for people with dementia should be a trend in providing specialist assistance to patients and their carers. Providing caregivers with professional knowledge about dementia allows them to understand emerging changes in the behaviour and functioning of those under their care, and at the same time gives them the opportunity to prepare themselves to meet the challenges of a progressive disease.

Key words: dementia, day centre, carer.

INTRODUCTION

Dementia of the Alzheimer's type is characterised by irreversible deterioration of cognitive functions as well as secondary limitation of motor activity and a lack of self-care ability. The worsening condition of an ill person requires commitment and holistic care from others [1].

Scientific studies report the burdening of caregivers and its relationship with their quality of life [2], and some of the studies confirm that many carers, as a part of the provided care for people with dementia, perform nursing procedures: e.g. injections, feeding through a stomach probe, dressings. The above activities are related to the emotional burden of the guardians and the level of stress felt by them [3]. Other authors also point out the aspect of physical load of

caregivers and the feeling of misunderstanding and lack of support that accompanies them [4].

Providing care for people with Alzheimer's disease and their closest surrounding is a task based on the cooperation of many entities [5]. It should include informing caregivers about how to look after an ill person [6] and provide easy access to broadly understood treatment of the patients and various forms of professional care [7, 8]. An interesting way to provide support for people with dementia and their caregivers can be a telephone conversation [9]. Another, temporary form, functioning as a part of the non-stationary institutional support for people with Alzheimer's disease, is day care provided by a nurse, a psychologist, an occupational therapist, and/or a doctor [10]. It can be organised by social, local governmental, and private

entities. It is provided in accordance with the individual needs of ill people who do not require special supervision and do not show symptoms of agitation [11].

The literature proves that the undertaken therapeutic actions have, among others, an impact on improvement of cognitive functioning of patients, their behaviour and ways of spending free time, and prevent the consequences of disorientation [12]. Unfortunately, help for people with dementia and their carers is not sufficient, and deficits in legal and social areas are also noticed [13].

As part of their competences, the nursing team is prepared to provide care to both patients and their carers in various dimensions, including accompanying, educating, and informing about sources of support [10]. Some of the obtained research results indicate the necessity to pay attention to the relationship between the quality of care for dementia patients and nurses' knowledge and approach to patients [14]. Organising training to obtain the most optimal results of care for patients [15-17], as well as training their guardians, is also a subject of exploration for researchers [18].

Professional assistance in the field of social support should be based on a proper assessment of the condition of patients and their carers because this may significantly affect the overall quality of life of people who are in the relationship of a recipient and a caregiver [19]. The manner of communication and team cooperation are not without significance in this area [20]. References used in the study were included in the following databases: PubMed, Wiley Online Library, Science Direct (Elsevier), ProQuest Central, MEDLINE (EBSCO), Health Source: Nursing/Academic Edition (EBSCO), SAGE Premier, Oxford Journals, Europe PMC, The Polish Medical Bibliography.

AIM OF THE STUDY

The aim of the work was to present the functioning one of interesting proposals that favours and encourages seniors to be active and is also a factor eliminating their sense of loneliness, and above all allows carers of dependent people to rest is the Day and Activation Centre for Dependent People located in the Municipal Care Centre at 267 Wielicka Street in Cracow.

RESULTS

The Municipal Care Centre for Elderly, Disabled, and Dependent People in Cracow has created the project "Centre for the support of informal carers and care for dependent people in the Municipal Care Centre in Cracow", co-financed by the Regional Operational Programme for the Malopolska Region for 2014-2020 under the 9th priority axis Socially Coherent Region, Actions 9.2 – social and health services,

Sub-action 9.2.2 – care services and crisis intervention; ZIT. Project type A – activities supporting informal carers of dependent people, project type B – support for the creation and/or operation of facilities providing day care and activation of dependent people (co-financed from the European Social Fund) for the period from July 1, 2019 to June 30, 2021. This initiative is an example of good practice of creating a community that understands the needs of people living with dementia and their carers.

The facility is a form of day support, specialising in caring for people suffering from Alzheimer's disease and other types of dementia, but also for elderly patients after strokes who suffer from motor dysfunctions. A team of professionals organises occupational therapy and rehabilitation classes that improve functioning, activate patients, and also enable the fulfilment of charges' cultural, recreational, and social needs. The caretaking team consists of the following: 2 nurses, including 1 who is the head of the team and has a specialisation in geriatric nursing, 3 physiotherapists, 2 occupational therapists, a psychologist, a dietitian, and 2 medical carers. Team members develop an individualised support plan, which takes into account the capabilities and needs of the patient and is subjected to ongoing evaluation during therapy. The range of services for people staying in the facility is very wide and offers physiotherapy classes, occupational therapy classes, psychological support, cooking classes, and dietary advice as well as full nursing care.

Physiotherapy classes are conducted individually or in groups, mainly in the form of general rehabilitation exercises. The physiotherapist assesses the condition of the senior based on the following scales: Timed Up and Go (TUG) and Tinetti test. Charges struggling with dementia respond well to activities they know, which is why apparatus work, e.g. riding a stationary bike, rotor of the upper and lower limbs, and gait training on a running machine are used. Exercises take place in the form of individual classes, e.g. according to NDT Bobath, PNF, NAP methods, and in groups. During group classes, elements of games and playing that integrate the group are introduced. Physiotherapists also try to conduct outdoor activities in the garden as often as possible or go for walks, e.g. to a sensory garden where all of the patients' senses can be stimulated.

The main task of occupational therapy while working with dementia seniors is to activate them in order to maintain their ability to perform everyday activities. Taking into account the individual needs, skills, and the level of activity and interests of patients, occupational therapists implement various forms of therapy, including music therapy, choreotherapy, bibliotherapy, art therapy, horticultural therapy, cognitive training, and small motor skills exercises. Conducting integration classes in groups

that provide space for mutual interaction can work against social exclusion.

The scope of psychological help is determined on the basis of a preliminary assessment of the cognitive and emotional functioning of each charge. They have the opportunity to benefit from individual support and advice during regularly scheduled meetings or on an ongoing basis in response to current needs. The psychologist assessing the patient's condition uses the following scales: the Mini Mental State Examination (MMSE), a clock-drawing test, and the Geriatric Depression Rating Scale. The psychologist also conducts group classes stimulating cognitive functions, as well as psychoeducational and integration workshops. One of interesting forms of activities with a psychologist is reminiscence therapy, which involves stimulating long-term memory by evoking pleasant memories from the past. In order to do that, Memory Boxes are created by charges with the support of their families and carers [21]. They are filled with items such as family photos, postcards, newspaper clippings, or souvenirs from travels. The Memory Box paints a picture of a person's past. Stored items are personal belongings that reflect interests or a moment in history that matters to their owner. When choosing things for the Memory Box, the carer is obliged to remember that they must be safe and easy to use items made of material that could provide sensory stimulation and are associated with the patient's positive memories. The guardian handing over the item is also asked to briefly describe the event from the patient's life which is associated with the object.

Patients are provided with coordinated care by a nurse, a caregiver, and a dietitian at the facility. The nurse's activities are aimed at strengthening self-care activities of the charges. The aim is to increase or maintain patients' independence (as far as possible) in the process of adapting to various restrictions caused by illness or disability. At the beginning of the stay, the individual needs and problems of each person are determined, and then a plan for their optimal solution is established. To assess the patient's condition, the nurse uses the following scales: Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), and Barthel. The next step is to implement the plan. At this stage, the nurse, through strengthening, supporting, and educational activities that result from contemporary professional functions, implements previously planned nursing care. Professional knowledge, skills, as well as human and material resources are used to encourage charges to perform the desired activity directed towards achieving the assumed care goals. The final stage is the assessment of the degree of effectiveness achieved in solving problems. Medical carers professionally deal with the implementation of hygiene needs, meet physiological needs, and provide support and help during

meals. The main tasks of medical caregivers include cooperation with the nurse in implementation of the care plan for charges and provision of assistance during performing nursing procedures, as well as the conduction of hygiene training, which also allows for the longest possible self-care.

Meals are planned by a dietitian and are provided by a catering company. The diet is selected individually and adjusted to the age and co-existing illnesses of patients. The dietitian assesses the nutritional status based on anthropometric measurements, nutritional history, and Mini Nutritional Assessment (MNA) scale and also conducts individual health education. In the case of dependent people, information and dietary recommendations are given to their carers. As part of the culinary workshop, the dietitian together with the charges prepare pastries and different kinds of tea from around the world. The "Bonanza café" is open every Thursday. It is combined with bibliotherapy classes. There are also occasional meetings connected with holidays or other events, as well as active participation of charges in the cultural life of the Municipal Care Centre for the Elderly, Disabled, and Dependent People in Cracow and celebrations organised by volunteers or children from primary schools (e.g. nativity plays, Christmas carol singing).

An important aspect of the facility's operation is providing information, education, support, and counselling to carers of people with dementia. The goal of these activities is to prepare the family and those taking care of ill people for a positive approach to care and its continuation at home, based on the principle of partnership. The professional knowledge, skills, and competences of all team members, which are reflected in the services provided to people with dementia, their attitude, and manner of communicating with those under their care become indispensable guidelines for the family and carers of people with cognitive deficits occurring in the course of dementia.

Taking care of people with Alzheimer's disease or other types of dementia is extremely aggravating. It is associated with caregivers' significant limitation or resignation from their previous social life, activities, interests, and hobbies [22]. The carers should know that they cannot, should not, and do not have to struggle alone to look after an ill person.

CONCLUSIONS

Using the support provided by professional facilities dealing with day care for people with dementia allows the very important needs of carers to be met, such as rest, relaxation and a sense of security.

Day centres are also designed to help caregivers in adapting to changes resulting from the progression of dementia and preparing for the need to provide further assistance to patients, on a 24-hour basis.

Providing caregivers with professional knowledge about dementia allows them to understand emerging changes in the behaviour and functioning of those under their care, and at the same time gives them the opportunity to prepare themselves to meet the challenges of a progressive disease.

Disclosure

The authors declare no conflict of interest.

References

1. Pudelewicz A, Talarska D, Bączyk G. Burden of caregivers of patients with Alzheimer's disease. *Scand J Caring Sci* 2019; 33: 336-345.
2. Park MH, Smith SC, Hendriks AAI, et al. Caregiver burden and quality of life 2 years after attendance at a memory clinic. *Int J Geriatr Psychiatry* 2019; 34: 647-656.
3. Lee DM, Ryoo JH, Campbell C, et al. Exploring the challenges of medical/nursing tasks in home care experienced by caregivers of older adults with dementia: An integrative review. *J Clin Nurs* 2019; 28: 4177-4189.
4. Rachel W, Turkot A. Jak pomóc opiekunom pacjentów z otępieniem w chorobie Alzheimera? *Psychoterapia* 2015; 1: 59-71.
5. Lipińska-Lokś J, Wawryk L. Profilaktyka przemocy domowej wobec osób z chorobą Alzheimera. *Niepełnosprawność. Dyskursy pedagogiki specjalnej* 2018; 31: 100-115.
6. Kaczmarek M, Durda M, Skrzypczak M, et al. Ocena jakości życia opiekunów osób z chorobą Alzheimera. *Gerontol Pol* 2010; 18: 86-94.
7. Szczudlik A, Barcikowska-Kotowicz M, Gabryelewicz T, et al. Sytuacja osób chorych na chorobę Alzheimera w Polsce. Raport RPO. Biuro Rzecznika Praw Obywatelskich, Polskie Towarzystwo Alzheimerowskie, Warszawa 2016; 23.
8. Kramkowska K. Kampania społeczna jako forma aktywności mediów na rzecz kształtowania odpowiedzialności społecznej wobec osób z chorobą Alzheimera i ich rodzin. *Psychiatria* 2015; 12: 271-277.
9. Nakano Y, Hishikawa N, Sakamoto K, et al. A unique telephone support system for dementia patients and their caregivers managed in Japan (Okayama Dementia Call Center, ODCC). *Neurol Clin Neurosci* 2018; 6: 100-103.
10. Misiak K, Kopydłowska E. Przygotowanie rodziny do opieki nad osobą starszą, cierpiącą na chorobę otępienną. *Pielęgniarstwo i Zdrowie Publiczne* 2011; 1: 65-75.
11. Durda M. Organizacja opieki nad osobami z demencją w Polsce na tle krajów rozwiniętych i rozwijających się. *Gerontol Pol* 2010; 18: 76-85.
12. Długosz-Mazur E, Bojar I, Gustaw K. Niefarmakologiczne metody postępowania u chorych z otępieniem. *Medycyna Ogólna i Nauki o Zdrowiu* 2013; 19: 458-462.
13. Walczak M. Narażenie osób opiekujących się pacjentami z otępieniem wynikające z podejmowanych obowiązków wobec tych pacjentów. In: Kojder I (Ed.). *Neurokognitywistyka w Patologii i Zdrowiu 2009–2011: sympozja 1*. Wydawnictwo Pomorskiego Uniwersytetu Medycznego, Szczecin 2011; 68-71.
14. Lin PC, Hsieh MH. Hospital nurse knowledge of and approach to dementia care. *J Nurs Res* 2012; 20: 197-207.
15. Lillo-Crespo M, Riquelme J, Macrae R, et al. Experiences of advanced dementia care in seven European countries: implications for educating the workforce. *Glob Health Action* 2018; 11: 147868.
16. Wang Y, Xiao LD, Ullah S, et al. Evaluation of a nurse-led dementia education and knowledge translation programme in primary care: A cluster randomized controlled trial. *Nurse Educ Today* 2017; 49: 1-7.
17. Wang Y, Xiao LD, Luo Y, et al. Community health professionals' dementia knowledge, attitudes and care approach: a cross-sectional survey in Changsha, China. *BMC Geriatr* 2018; 18: 122.
18. Amado DK, Brucki SMD. Knowledge about Alzheimer's disease in the Brazilian population. *Arq Neuropsiquiatr* 2018; 76: 775-782.
19. Wang Z, Ma C, Han H, et al. Caregiver burden in Alzheimer's disease: Moderation effects of social support and mediation effects of positive aspects of caregiving. *Int J Geriatr Psychiatry* 2018; 33: 1198-1206.
20. Häikiö K, Sagbakken M, Rugkåsa J. Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services. *BMC Health Serv Res* 2019; 19: 635.
21. What is Memory box. How to make one? <https://www.dementia.co.uk/?s=memory+box> (Accessed: 2 April 2020).
22. Lech A. Moralne aspekty opieki nad osobami cierpiącymi na choroby otępienne. *Zeszyty Naukowe Politechniki Śląskiej. Organizacja i Zarządzanie* 2015; 85: 275-286.