ORIGINAL ARTICLE

IMPACT OF ENRICHED DEMENTIA CARE PLANNING ON INDIVIDUALIZED CARE APPROACHES AND PSYCHOLOGICAL WELL-BEING OF RESIDENTS

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Abstract

Introduction: The enriched dementia care-planning program seeks to enhance the quality of life for individuals with dementia by addressing their physical, emotional, social, and spiritual needs. This study aims to assess the impact of enriched dementia care planning on caregivers' individualized care approaches and the psychological well-being of residents.

Materials and method: A pretest and posttest cross-sectional one-group study including caregivers and persons with dementia. Formal caregivers (n=32) and individuals with dementia (n=17) were recruited from two nursing homes. Pretest and posttest measurements were conducted using distinct data collection tools for both caregivers and individuals with dementia. The caregivers were exposed to life story booklets, training modules, "about me" profiles, and individualized care tips and reminders over an eight-week period.

Results: Pre-test and post-test analysis indicated that staff perceptions of persons with dementia were more positive and communication between staff and residents improved at post-test (8.52±2.04) compared with the pre-test (7.10±1.71) ($p<0.05$). However, there was no significant change in residents' psychological well-being at the post-test ($p>0.05$).

Conclusion: The implementation of enriched care planning has the potential to empower caregivers to engage with residents and deliver individualized care with a more positive attitude. Enhancing communication between staff and residents is recognized as a pivotal factor with substantial potential for advancing individualized care initiatives in nursing homes.

Keywords: Dementia; Nursing Homes; Person-Centered Care; Psychological Well-Being

INTRODUCTION

Individualized care (IC) in long-term care is widely acknowledged as the optimal approach for enhancing both the quality of life and care provided (1, 2). The implementation of IC leads to improvements in well-being, health outcomes, individual functioning, autonomy, and patient satisfaction by tailoring care activities, preferences, and decisions to the unique characteristics of each individual (3). While this approach is recognized as crucial for enhancing the quality of nursing care delivery, there is a need for more effective strategies to further improve IC. Key priorities for providing and assessing individualized care in long-term care settings (LTC) have been identified as centered around 'relationships', understanding the individual, and identifying what matters most to them. One of the primary outcomes of individualized care is the well-being of the individual (4). Factors most closely associated with the quality of life and well-being of individuals with dementia include social interaction, effective communication, and the application of functional skills.

Enriched care planning is a person-centered approach that values individuals regardless of age or cognitive ability. It treats each person as a unique individual, seeks to understand the world from their perspective, listens to their voices, and acknowledges that all human lives are rooted in social relationships (5). This process involves creating a profile of the person's life, identifying, and documenting their needs, implementing the plan, and assessing health and well-being as an outcome (6). By considering all these factors, enriched care planning provides a framework for both the person with dementia and their caregiver(s) to determine and address their needs effectively. This area of study holds great importance due to the tendency to overlook the individuality and needs of people with dementia, often stemming from detrimental social psychology, including treating them like children, negative labeling, stereotyping, and adopting humiliating attitudes (7).

Various interventions have been implemented to enhance the person-centered care behavior of caregivers. Recent studies have identified influencing interventions such as improving communication through the use of memory books, regulating emotional responses of the staff, emphasizing residents' existing skills, increasing social contact, incorporating sensory stimuli, and providing training in communication techniques (8, 9). Additionally, sharing life stories in nursing homes has proven to be instrumental in developing individualized care plans, aiding in a deeper understanding of the individual, and explaining their current reactions (10).

Reported outcomes of individualized care include increased verbal or non-verbal communication by caregivers, more positive attitudes toward people with dementia, reduced restrictive staff behaviors and practices, and enhanced sensory stimuli and communication, achieved through a greater focus on caregiving behavior and the feelings of individuals (8, 11). The essential components of the enriched care-planning framework for dementia care were considered during the design of the study interventions. This framework encompasses five stages: gathering the person's life story, identifying necessary requirements for promoting good health and well-being, documenting these needs to create a care plan, implementing the plan, and conducting regular reviews to assess its effectiveness in maintaining health and well-being (6).

Consequently, life story booklets of individuals with dementia, communication training for caregivers, the use of 'About Me' profiles, and the sharing of person-centered care tips and reminders were implemented in two nursing homes. The eight-week program primarily aims to enable an individualized care approach for nursing home staff and, secondarily, to enhance the psychological well-being of the residents.

The research questions are as follows:

1. What is the impact of enriched care planning on the individualized care approaches (knowing the residents, autonomy and choice of the residents, staff-to-resident communication, and staff-to-staff communication) of nursing home staff?
2. What is the impact of enriched care planning on the psychological well-being of residents with dementia in nursing homes?

MATERIALS AND METHOD

Design

This study employed a pretest and posttest cross-sectional one-group study including caregivers and residents with dementia. The eight-week intervention program was applied in two nursing homes and this program consists of creating life story booklets of persons with dementia, training module for caregivers, the use of "About Me" profiles in residents rooms, and sharing of individualized care tips and reminders with caregivers in the nursing units. This study was carried out during Covid-19 pandemic between December 2020-February 2021.

Sample

Two private nursing homes were selected using purposive sampling. The author informed the management team (head of nursing, chief doctor, and owner) of the two nursing homes regarding the study. After obtaining their consent, the author communicated with all the formal caregivers individually and invited them to participate in the study. The residents with dementia and their relatives were also informed individually, regarding the study and written consent was obtained. The two facilities had similar operating procedures (e.g., administrative structure, staffing structure) and were accepted to participate in the study (the bed capacities of these two nursing homes were 54 and 66, respectively).

Registered nurses with a 4-year bachelor degree, nursing associates with a 2-year education in care for older adults, and certified nursing assistants with a 3-months care certificate are responsible for the care of older adults in long-term care settings. The aforementioned roles are termed formal caregivers, in this study. All formal caregivers (n=32), residents (n=22), and their primary relatives were asked to participate in the study. Residents who have different types and stages of dementia were included in the study (n=17), registered nurses (n=15), nursing associates (n=11), and certified nursing assistants (n=6) consented to participate and formed the sample for this study (Figure 1).

Procedures

Information for life story booklets was collected from family members of residents with dementia. The author contacted family members over telephone to inquire about the life stories of the residents. The open-ended interview questions for the life story booklet were designed in accordance with the content of the My Life Story booklet produced by Dementia UK. During the interview, information was obtained on the following topics: childhood memories, professional life, important relationships and places, past social activities and interests, significant life events, later life and retirement, and current interests and dislikes. Visual photographs or illustrations were included in the brochures to increase memorability. After the life story booklets were created, the stories of the residents were shared through face-to-face interviews with caregivers.

As part of the training module, the author created a presentation on communication and individualized dementia care. The contents of the training module were shared with three experts for feedback and revised accordingly. The training program lasted approximately 45 minutes per session. Caregivers were divided into four groups (5-10 staff in each group), and all the training sessions were completed in a week.

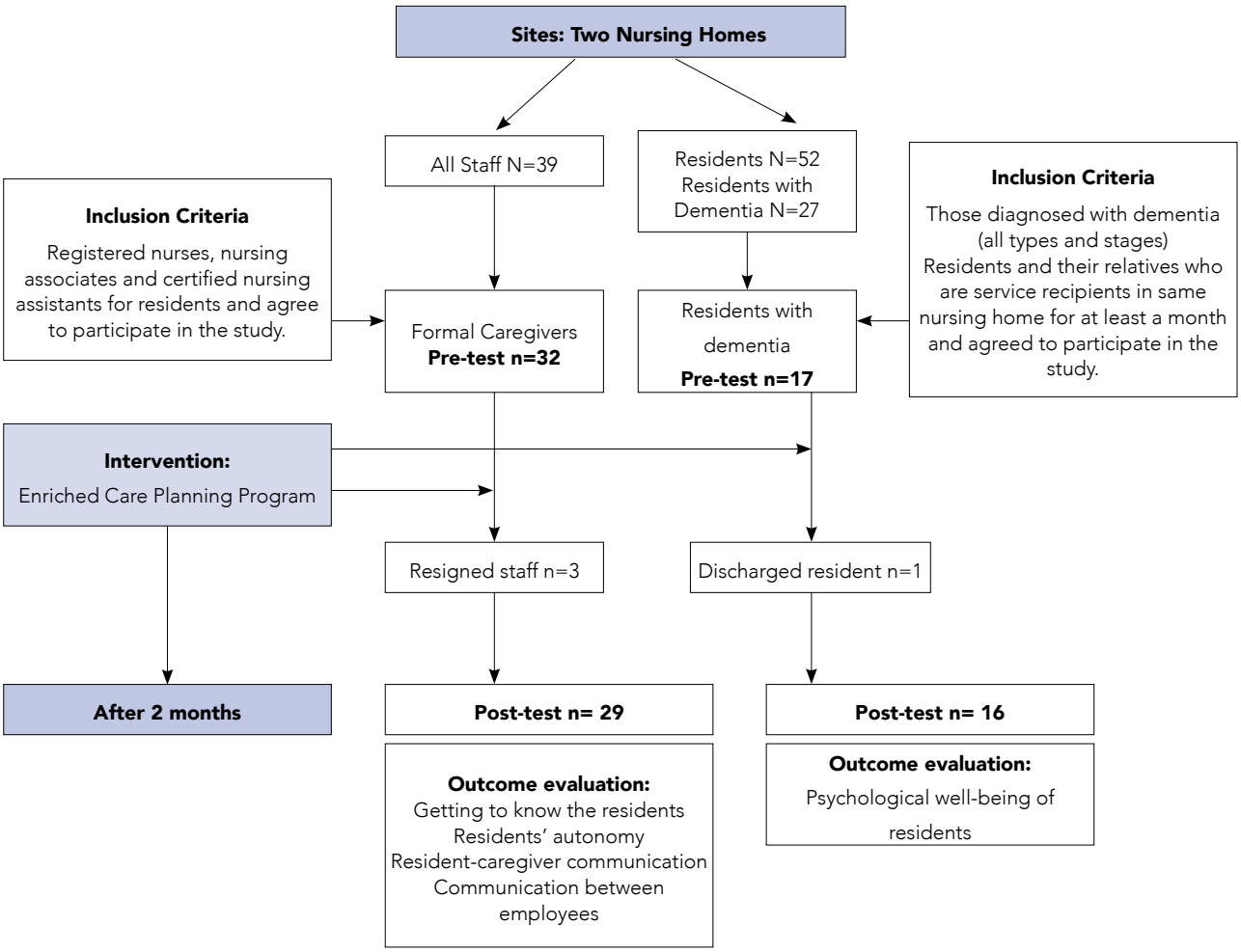

Figure 1. Study Sample

"About me" profiles comprise three parts. The first part of the profile presented the feedback from the caregivers regarding the measures required to improve the well-being of each resident according to their life stories. The second part of the profile comprised the resident's existing skills. The third part of the profile presented short notes regarding instances or articles that are of utmost importance to the residents. These profiles were displayed on a wall in the residents' rooms where it was easily visible to the nursing staff. Reminder tips for individualized care were posted once a week for four weeks, on the staff floors.

Instruments

Questionnaire for descriptive characteristics of formal caregivers (i.e., age, gender, education level, marital status, certificate status, overall dementia care experience, dementia-related education) and individuals with dementia (i.e., age, gender, educational level, marital status, independence status) were used to collect the data. The outcomes for this study were measured using the Staff-based Individualized Care Inventory (ICI) (12) and Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP) Scale (13). The Turkish short

Table 1. Characteristics of the Formal Caregivers (n=32)

Variables	Mean±SD	Number	%
Gender			
Women		19	59.4
Men		13	40.6
Age			
19-25 years		21	65.6
26-36 years	25.9±8.23	8	25
37-56 years		3	9.4
Marital status			
Single (never married and widowed)		27	84.4
Married		5	15.6
Education			
Primary School		1	3.1
High School		8	25
Vocational School		21	65.6
University Degree		2	6.3
Positions			
Nurse		15	46.9
Elderly care assistants		11	34.4
Personal care assistants		6	18.8
Experience Years			
0-1 years		13	40.6
1-3 years		6	18.8
3-6 years		12	37.5
6-12 years		1	3.1
Dementia Education			
At school		6	18.8
Seminars		3	9.4
In service		6	18.8
None		17	53.1

Table 2. Characteristics of Persons with Dementia (n=17)

Variables	Mean±SD	Number	%
Gender			
Women		12	70.6
Men		5	29.4
Age			
59-79 years		3	17.7
80-89 years	84.59±11.9	7	41.1
90-104 years		7	41.1
Marital status			
Married		4	23.5
Single (never married and widowed)		13	76.5
Education			
Primary School		5	29.4
High School		5	17.6
University		3	11.8
Graduate school		2	11.8
Profession			
Engineer		1	5.9
Government officer		3	17.6
House wife		7	41.2
Self-employed		5	29.4
Medical Doctor		1	5.9
Length of Stay in NH**			
5 months-2 years		11	64.7
>2 years		6	35.3
Stages of Dementia			
Early		4	23.5
Mild		3	17.6
Mild-to-Advanced		3	17.6
Advanced		7	41.2
Social Activity			
Able to Participate		6	35.3
Not able to Participate		11	64.7
Independence			
Independent		2	11.8
Semi-independent		5	29.4
Dependent		10	58.5

*There were 2 people who has no formal education in lifetime.

** NH: Nursing Homes

Table 3. Comparison of Individualized Care Approaches

Subscale and/or Items	Pre-Test	Post-Test	Z*	P value
	$\bar{X}$±SD	$\bar{X}$±SD		
IC-Know (5 items)	17.10±2.38	17.41±1.80	0.641	0.521
IC-Autonomy and Choice (7 items)	28.52±2.86	26.24±3.36	-2.691	0.007
IC- SR Communication (3 items)	7.10±1.71	8.52±2.04	-3.771	0.000
IC- SS Communication (5 items)	16.24±2.64	16.76±2.84	0.883	0.377

IC-Know: Invidiualized Care-Knowing

IC-Autonomy and Choice: Invidiualized Care- Autonomy and Choice

IC-SR Communication: Invidiualized Care-Staff-to-Resident Communication

IC- SS Communication: Invidiualized Care-Staff-to-Staff Communication

P< 0.05

*Spearman Correlation Test

Table 4. Comparison for Psychological Well-being of Residents

Subscale and/or Items	Pre-Test	Post-Test	Z*	P
	$\bar{X}$±SD	$\bar{X}$±SD		
PWB-CIP Scale (9 items)	30.44±3.79	29.69±3.00	-0.948	0.343
Positive Affect (4 items)	11.50±2.55	11.25±3.35	-0.147	0.883
Negative Affect (5 items)	17.44±2.96	16.88±2.63	-0.907	0.365

PWB-CIP: Psychological well-being in cognitively ill persons

P<0.05

*Spearman Correlation Test

version of Likert-type ICI has 20 items and 4 sub-domains; (1) knowing the person or resident (IC-know), (2) providing opportunity for autonomy and choice (IC-autonomy), (3) communication staff to staff (IC-communication-SS) and (4) communication staff to resident (IC-communication-SR). The response format uses a four-point Likert-type scale for IC-Know, IC-communication-staff to staff, and staff to the resident (1. strongly disagree; 2. somewhat disagree; 3. somewhat agree; 4. strongly agree) and five-point Likert-type scale for IC-autonomy (1. very frequently; 2. frequently; 3. occasionally; 4. seldom; 5. never). Higher scores indicate better results in each domain. IC-know refers to the staff's own perceptions of how well they know the individuals they are caring for, and the six-item IC-know scale results in scores between 6 and 24. The eight-item IC-autonomy scale measures the general environment in which the staff work, and the possible scores fall between 8 and 40. The three-item IC-communication-SR scale focuses on how the staff communicates with the residents, with possible scores between 3 and 12. Finally, the five-item IC-communication-SS scale reflects the way the staff communicate with one another and with their supervisors, with possible scores lying between 5 and 20 (14).

The PWB-CIP scale consists of 9 items and is completed by the nursing staff's observation of the behavior of the person with cognitive impairment over the past 24 hours. The Likert type PWB-CIP scale (1-4 points) has two sub-dimensions which are positive affect/interaction and negative affect/interaction. The scale can be scored between 9 and 36 in total.

Data Analysis

The Statistical Package for Social Science (SPSS Inc.) 26.0 for Windows was used for data analysis. This study used descriptive statistics to analyze participants' demographic data, and inferential statistics to compare the mean scores of pretests and posttests. The level of significance (p) was considered as (p) 0.05.

Ethical Considerations

Permission to undertake the study was obtained from the Koç University Ethical Review Board. The author informed individuals with dementia, their families, and formal caregivers regarding the study. The researcher obtained written and verbal consent from all the participants.

RESULTS

Individualized Care Practices

Descriptive information of the participants is presented in Table 1 and 2. The mean ICI scores before and after the programs were compared. The posttest scores increased in all ICI subscales except the IC autonomy and choice subscale. The resident-caregiver communication resulted in a significant increase in posttest (pretest: 7.10±1.71 and posttest: 8.52± 2.04) ($p<0.05$), whereas the autonomy of the residents indicated a significant decrease (pretest: 28.52±2.86 and posttest: 26.24±3.36) ($p<0.05$) (Table 3).

Psychological Well-Being of the Residents

The mean scores on the PWB-CIP Scale of individuals with dementia before and after the program were compared. There was a non-significant decrease between the pretest (30.44 ± 3.79) and posttest mean scores (29.69± 3.00) ($p>0.05$) (Table 4).

DISCUSSION

The results of this study provide outcomes of an eight-week enriched dementia care planning intervention program related to individualized care approaches of caregivers and the psychological well-being of residents with dementia. The enriched care planning interventions mainly focused on sharing the life stories of the residents, existing skills of residents, and individualized care training of caregivers. Comparing the before and after the program results, a significant increase in communication between the staff and residents was observed. Conversely, there was a significant decrease in residents' autonomy; however, their psychological well-being remained essentially unchanged throughout the study.

Prior to this study, it was not routine practice to share residents' life stories with caregivers at participating facilities. Formal caregivers' perception of knowing the residents did not change significantly in posttest results. The life stories of the residents were shared by researchers in face-to-face meetings, however, afterward, it is a challenge to expect and motivate all formal caregivers who work with time pressure to read the life stories, as reported in another study (15). Additionally, the increased workload and finding adequate time during the pandemic may have led to insignificant outcomes, which is supported by the literature identifying the key determinants of individualized care delivery such as access to adequate resources (i.e., materials and sufficient time to perform their duties) (16). In a similar study conducted in the United States (US)

(17), exposure to life story collages did not change the caregivers' perception of knowing residents on posttest scores, and there was a significant increase in the level of knowledge of caregivers about the work history and family of the residents.

Resident autonomy and the choice sub-dimensions evaluate the institutional environment that supports resident autonomy (12). Supporting residents' autonomy, connecting with them, maintaining relationships, and maintaining existing skills play an important role in person-centered care (18). In this study significant decrease was found in the posttest for "residents' autonomy and choice" sub-dimension. A qualitative study conducted in focus interviews with caregivers and residents revealed that the freedom, autonomy, social life, and social activities of the older adults staying in care centers are restricted and their basic psychological needs could not be met owing to the COVID-19 pandemic (19). Understanding the preferences of the residents and providing activities of daily living aligned to their preferences is a necessity for the residents to feel that they have autonomy (20). During the current study, all activities with residents were restricted, which created an inability to perform daily participation and socialization during the COVID-19 period.

Strengthening communication with individuals with dementia is an initiative that supports person-centered care processes (9). In this study, in addition to sharing life stories with caregivers, "about me" profiles comprising brief information regarding individuals with dementia were posted in the residents' rooms. After these interventions, the communication scores between the residents and caregivers increased significantly in the post-test. Similarly, life stories and practices for becoming acquainted with the individual increased communication between staff and individuals with dementia (21-23). When caregivers know the residents' life stories, they feel empowered and become relationship-oriented rather than task-oriented (24).

In person-centered care, the quality of communication between formal caregivers is important, and therefore, insufficient communication can be an obstacle in the provision of person-centered care (24). Teamwork, having shared values, and value-based work improve the collaboration and dedication to care for residents in a person-centered manner, as expressed in qualitative studies in LTC facilities (25).

Another aspect of this study was to observe the changes in the psychological well-being of residents during the intervention. There was a significant positive change in nursing home staff attitudes, while there was no change in the well-being of the residents with dementia. Nursing home staff benefited more from the enriched care planning program and significant changes has been seen in their attitudes due to the possible positive effect of "investing in them at an educational level" (as an important human factor that increases team member productivity in working environments). The factors mostly associated with the quality of life and well-being of individuals with dementia were social interaction, communication, and the use of functional skills but there are also disease related factors effecting well-being of residents such as dementia stage progression and environmental conditions. It has been reported that with the decline in physical and mental health, well-being and quality of life also begin to decline. Further, as the dementia stage progresses, environmental factors and well-being are more related to one another (13). Accordingly, the number of people with advanced stage dementia participating in this study and the potential effects of the COVID-19 restrictions on resident autonomy may have had a negative impact on some indicators of well-being that are affected more by environmental conditions.

There are certain limitations to this study, such as the small sample size with one-group pre-test and post-test design. Since the research coincided with the COVID-19 pandemic, the restrictions and measures during this period caused certain changes

in the research process, and consequently, certain limitations were inevitable. During the COVID-19 pandemic factors such as restriction on visits to the long-term care environment, restricting residents to their rooms, interrupting social and daily activities, and longer working hours of the staff should be considered in the interpretation of the results of the study. The reason for the lack of impact on the well-being of persons with dementia from the implemented program could be an important limitation due to the fact that this patient group has different types and stages of dementia. Information about the types of dementia was not available, so this could be another limitation of the study.

CONCLUSION

The results demonstrate that using enriched care planning has the potential to improve communication between caregivers and residents in long-term care environments. Easily accessible life story booklets that were enriched with visual images and original photographs helped to develop more positive attitudes toward individuals with dementia. Improvement in communication between staff and residents should be considered as useful initiatives for individualized care improvement. Additionally, eye-catching "about me" profiles displayed in residents' rooms were easily readable that reminded caregivers to initiate communication during the daily resident care activities. Other supportive interventions such as person-centered communication training, reminders about person-centered dementia care, and communication tips posted on the staff unit walls were effective in sustaining the intervention. Formal caregivers may have difficulty becoming acquainted with residents with dementia, who often have communication and social skill deficits. Introducing formal caregivers to residents' life stories and profiles and educating them about individualized care can improve relationships and commitment to individualized care. Strengthened relationships can have a positive impact on formal caregivers and can also lead to higher job satisfaction and reduced staff turnover. Enriched care planning should become routine practice in nursing homes, as currently it is not practiced to the expected extent in many countries. Recruitment of gerontological nurses in nursing homes with well-designed individualized care planning can improve nursing practice.

Future studies with larger samples and without the pandemic restrictions are recommended with additional measures such as the effect on quality of life, aggression, teamwork, and staff knowledge. The methodological strength of the same study would be enhanced by including a control group consisting of nursing home staff who did not receive the intervention program at all, providing only standard care, along with dementia patients residing in nursing homes receiving standard care in the future.

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