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# Care participation of older adults in nursing homes: A cross-sectional study of older adults' and caregivers' perspectives

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**Abstract**

This study aimed to explore the perspectives of older adults and their caregivers regarding older adults' participation in their own care in a nursing home. This descriptive, cross-sectional study included 441 participants (264 older adults and 177 caregivers) from a nursing home in Western Türkiye in 2025. Data were collected using structured questionnaires on sociodemographic characteristics, participation in care, information sharing, and involvement in care-related decisions. Among older adults, 33.7% reported making health-related decisions independently, whereas 62.1% reported making decisions after considering the opinions of both physicians and nurses. Older adults most frequently reported leaving decisions to the healthcare team for hospital check-ups (88.6%) and medication use (84.5%). Significant associations were found between the importance attributed to receiving explanations about care and treatment and gender, education level, and relatives' visit frequency among older adults ($p < 0.05$). Among caregivers, 78.5% reported that participation in care was necessary, 83.6% reported that providing explanations was important, and 61.6% stated that such explanations were actually given. In this Turkish nursing home sample, both older adults and caregivers valued participation in care, but participation appeared to rely more on shared decision-making and information exchange than on independent decision-making. The discrepancy between caregivers' views and reported practices may reflect organizational and communication-related barriers in institutional care.

**Keywords:** Aged, autonomy, caregivers, patient participation, nursing homes

## Introduction

Alongside the growing older population in Türkiye—an increase of 21.9% over the past five years—the number of older adults requiring care at home or in institutional settings has also increased [1-5]. According to recent national statistics, the population aged 65 years and over in Türkiye reached 9,112,298 and accounted for 10.6% of the total population. Current statistics indicate that approximately 460 nursing homes operate across the country and provide care for nearly 29,914 older adults [6-9].

Placing individuals' needs, preferences, and experiences at the center of healthcare has brought patient participation in care to the forefront as an ethical and practical issue [10]. Encouraging older adults to participate in nursing home care is recognized as an international priority and a core component of individualized and person-centered care [11]. Participation may improve communication, facilitate information exchange, and support engagement in physical, cognitive, and daily care activities [11-14].

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Participation in care is a multidimensional concept influenced not only by individual willingness but also by relational, communicational, and organizational factors within care systems [15,16]. Older adults are more likely to perceive participation positively when they are listened to, informed, and supported in expressing their preferences, whereas ageism, power imbalances, and ineffective communication may limit their involvement in care and shared decision-making [1,15,16]. In later life, chronic diseases and limitations in activities of daily living may further reduce active involvement in care [17,18]. For this reason, contemporary healthcare systems increasingly emphasize self-care, shared decision-making, and independence rather than traditional paternalistic models [19-21]. Participation may nevertheless vary according to health status, functional capacity, and the level of support available within care systems [22-24].

With the increasing prevalence of institutional care, understanding participation in nursing home settings has become increasingly important. Previous qualitative research has shown that participation in daily activities and care is associated with older adults' sense of well-being, autonomy, and perceived control, while organizational and contextual factors may facilitate or constrain such participation [25]. Studies focusing on frail older adults with complex care needs further suggest that participation often involves balancing independence with reliance on healthcare professionals and caregivers, particularly in care coordination and decision-making processes [26,27].

From the perspective of caregivers, supporting participation in care may also involve practical and organizational challenges. Healthcare providers in nursing home settings are expected not only to meet residents' physical care needs but also to support communication, information sharing, and involvement in decision-making. However, these processes may be influenced by workload, time constraints, institutional routines, and professional assumptions about residents' capacities [16,26,27]. Therefore, participation should be considered not only as a resident-related issue but also as a care process shaped by the attitudes, practices, and working conditions of caregivers [16,28-30].

Despite growing international interest in care participation, quantitative evidence simultaneously examining older adults' and caregivers' perspectives in nursing home care remains limited, particularly in the Turkish context. Understanding how both groups perceive participation is important for improving communication, supporting shared decision-making, and strengthening person-centered nursing home care. Therefore, this study aimed to explore the perspectives of older adults and their caregivers regarding older adults' participation in nursing home care, with a particular focus on decision-making, information sharing, and involvement in activities of daily living.

### Aim

This study aimed to explore the perspectives of older adults and their caregivers on participation in nursing home care, particularly in relation to decision-making, information sharing, and activities of daily living.

## Material and Methods

### Research Design and Setting

This descriptive cross-sectional study was conducted between May and December 2025 in a nursing home in Western Türkiye. The facility has a capacity of 308 beds and accommodates older adults who are independent or partially dependent in daily activities.

### Population and Sample

The study population consisted of 296 older adults and 185 healthcare staff. As this was a single-center descriptive cross-sectional study, no formal a priori power analysis was performed; instead, the researchers aimed to reach the entire eligible population during the data collection period. Accordingly, 264 older adults and 177 caregivers participated, corresponding to 89.2% of the eligible older adult population and 95.7% of the eligible caregiver population. The caregiver group included 15 nurses and 162 care staff. In this study, "caregiver" refers to formal care providers working in the nursing home, including nurses and care staff, rather than family or informal caregivers. Inclusion criteria for older adults were residence in the nursing home, absence of mental disability or communication difficulties, and willingness to participate. Functional status was not required to be uniform across all care activities. For caregivers, the only inclusion criterion was voluntary agreement to participate.

### Data Collection Tools

Data were collected using two structured questionnaires developed by the researchers after a comprehensive review of the relevant literature [4-25]. The questionnaire for older adults, titled Views of Older Adults on Elderly Care Participation, included 24 items in three sections covering demographic characteristics, views on participation in care and decision-making, and willingness and self-reported involvement in activities of daily living (ADLs). The questionnaire for caregivers, titled Views of Caregivers on Elderly Care Participation, consisted of 25 items in three sections covering demographic characteristics, views on older adults' participation in care and information provision, and evaluations of participation in care activities and decision-making. ADLs were addressed in accordance with the Roper–Logan–Tierney Model of Nursing. All questions were close-ended.

As the instruments were developed as structured questionnaires rather than psychometric scales, they were not intended to yield a single total score; therefore, Cronbach's alpha was not considered appropriate for the full instruments. Content validity was evaluated by eight nursing academics, and the questionnaires were revised accordingly. A pilot study was conducted with 5 older adults and 5 caregivers who were not included in the main study. For test–retest reliability, the questionnaires were

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re-administered after a two-week interval. Cohen's kappa coefficients were 0.91 for the older adults' questionnaire and 0.88 for the caregivers' questionnaire.

### Data Collection Procedure

Data from older adults were collected through face-to-face interviews lasting approximately 20 minutes per participant. Caregivers completed the questionnaires independently. Face-to-face interviews were preferred for older adults to facilitate comprehension and reduce possible communication difficulties related to sensory or literacy limitations.

### Ethical Considerations

All participants were informed about the study purpose and procedures, and written informed consent was obtained. Ethical approval was granted by the Near East University Scientific Ethics Committee (Approval No: YDU/2025/133-1966; 30.04.2025). The study was conducted in accordance with the Declaration of Helsinki.

### Data Analysis

Data were analyzed using Statistical Package for the Social Sciences (SPSS) version 20.0. (IBM Corp., Armonk, NY, USA). Descriptive statistics (number, percentage, mean, and standard deviation) were used to summarize the data. Normality of continuous variables was assessed using the Shapiro–Wilk test, skewness, and kurtosis values. Associations between categorical variables were examined using the chi-square ($\chi^2$) test. Effect sizes were reported using Phi or Cramér's V, as appropriate. For items allowing more than one response, multiple response analysis was performed, and percentages were calculated based on the number of respondents. Statistical significance was set at $p < 0.05$.

## Results

### Characteristics of Older Adults

The mean age of the older adults was 73.57 ± 7.82 years (range: 56–95), and 61.7% were male. A total of 76.9% reported having relatives. Regarding visit frequency, 38.3% reported never being visited, 31.8% reported being visited once a month, and 11.0% once every three months (Table 1). A total of 97.0% of older adults reported that participation in their own care was important. Regarding information about care and treatment, 93.2% stated that they received explanations, and 98.1% reported that receiving such explanations was important.

### Older Adults' Decision-Making Preferences

In response to the question "How do you make decisions about your health?", 33.7% reported making decisions independently, 26.1% after consulting with nurses, 26.1% after consulting with doctors, and 62.1% after considering the opinions of both doctors and nurses (Table 2). Because more than one response could be selected for this item, the total percentage exceeded 100%. In self-assessment, the activities most frequently reported as being performed independently were nutrition (94.3%), hand washing (87.5%), and toileting (83.3%). Willingness to participate was high across care activities, with the highest proportions observed for oral care, hand washing, and foot care (98.1% each). According to caregiver reports, older adults most frequently performed nutrition (88.3%), toileting (83.3%), and intellectual activities/hobbies (81.8%) independently, whereas greater support was more frequently reported for bathing (32.2%), foot care (34.1%), shopping (22.7%), and walking within the institution (20.5%) (Table 3).

### Caregivers' Characteristics and Views

Among caregivers, 8.5% were nurses and 91.5% were care staff; 62.1% were female and 41.2% had completed primary school education (Table 1). Regarding older adults' participation in care, 78.5% stated that such participation was necessary and 80.8% stated that sufficient opportunities were provided. In addition, 61.6% stated that older adults were given explanations about care and treatment, and 83.6% stated that providing such explanations was important. Caregivers identified physical limitations (71.8%), mental incapacity (42.9%), loss of strength due to aging (79.7%), unwillingness due to loneliness and isolation (37.3%), and reliance on the healthcare team due to trust (4.5%) as factors affecting participation in care.

### Factors Associated with Older Adults' Participation in Care

Among older adults, significant associations were identified between the importance attributed to receiving explanations about care and treatment and gender ($\chi^2 = 5.78$, $df = 1$, $p = 0.016$, Cramér's $V = 0.148$), education level ($\chi^2 = 24.80$, $df = 4$, $p < 0.001$, Cramér's $V = 0.307$), and relatives' visit frequency ($\chi^2 = 29.40$, $df = 3$, $p < 0.001$, Cramér's $V = 0.334$) (Table 4). All negative responses were observed among women and were most frequent among literate older adults (11.1%) and those visited weekly or more often (12.8%).

Among caregivers, significant associations were identified between age group ($\chi^2 = 13.85$, $p = 0.001$, Cramér's $V = 0.280$) and education level ($\chi^2 = 22.97$, $p < 0.001$, Cramér's $V = 0.360$) and the view that older adults should participate in their own care. The proportion reporting that participation was necessary was 90.9% among caregivers aged 26–34 years and 50.0% among those aged 45 years and over; by education, the corresponding proportions were 61.6% for primary school graduates and 97.5% for university graduates. Significant associations were also identified between gender ($\chi^2 = 5.26$, $p = 0.022$, Cramér's $V = 0.172$) and education level ($\chi^2 = 25.76$, $p < 0.001$, Cramér's $V = 0.382$) and the importance attributed to providing explanations about treatment and care. The proportion reporting that providing explanations was important was 93.9% among male caregivers and 77.5% among female caregivers, ranging from 63.0% among primary school graduates to 100.0% among university graduates.

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**Table 1.** Demographic characteristics of older adults and caregivers

| Variables | n | % |
|---|---|---|
| | **Older Adults (n = 264)** | |
| **Age (Mean ± SD)** | 73.57 ± 7.82 | |
| **Gender** | | |
| **Female** | 101 | 38.3 |
| **Male** | 163 | 61.7 |
| **Marital status** | | |
| **Married** | 35 | 13.3 |
| **Single** | 126 | 47.7 |
| **Divorced** | 103 | 39.0 |
| **Educational level** | | |
| **Illiterate** | 42 | 15.9 |
| **Literate** | 45 | 17.0 |
| **Primary school** | 135 | 51.1 |
| **High school** | 37 | 14.1 |
| **University** | 5 | 1.9 |
| **Presence of relatives** | | |
| **Yes** | 203 | 76.9 |
| **No** | 55 | 20.8 |
| **No response** | 6 | 2.3 |
| **Frequency of visit** | | |
| **Never** | 101 | 38.3 |
| **Twice a week** | 25 | 9.5 |
| **Once a week** | 11 | 4.2 |
| **Once a month** | 84 | 31.8 |
| **Once in three months** | 29 | 11.0 |
| **Once in six months** | 2 | 0.8 |
| **Once a year** | 9 | 3.3 |
| **I go when I want** | 3 | 1.1 |
| **Total** | 264 | 100 |
| **Variables** | **Caregivers (n = 177)** | |
| **Age (Mean ± SD)** | 37.54 ± 5.78 | |
| **Gender** | | |
| **Female** | 110 | 62.1 |
| **Male** | 67 | 37.9 |
| **Education level** | | |
| **Primary school** | 73 | 41.2 |
| **High school** | 64 | 36.2 |
| **University** | 40 | 22.6 |
| **Occupation** | | |
| **Nurse** | 15 | 8.5 |
| **Care staff** | 162 | 91.5 |

SD: Standard deviation

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**Table 2.** Older adults' decision-making preferences regarding their own care

| Questions/Items | n | % |
|---|---|---|
| **How do you make decisions on your health?** | | |
| **I make decisions for myself** | 89 | 33.7 |
| **I make decisions for myself after consultation with nurses** | 69 | 26.1 |
| **I make decisions for myself after consultation with the doctor** | 69 | 26.1 |
| **I make decisions for myself after consultation with both nurses and doctors** | 164 | 62.1 |
| **I make decisions together with a nurse** | 50 | 18.9 |
| **I make decisions together with a doctor** | 26 | 9.8 |
| **A nurse makes the decisions after consulting me** | 44 | 16.7 |
| **A doctor makes the decisions after consulting me** | 35 | 13.3 |
| **A nurse makes the decisions** | 31 | 11.7 |
| **A doctor makes the decisions** | 43 | 16.3 |
| **Which health-related decisions do you leave to the health team?** | | |
| **Daily life activities** | 69 | 26.1 |
| **Care** | 207 | 78.4 |
| **Going to the hospital for check-up** | 234 | 88.6 |
| **Taking medication** | 223 | 84.5 |
| **When an operation or other invasive procedure is necessary** | 217 | 82.2 |
| **Diagnosis and treatment procedures** | 214 | 81.1 |

More than one response could be selected

**Table 3.** Older adults' self-evaluation, willingness, and caregiver-reported current status regarding participation in ADLs

| Care activities | Self-evaluation of the older people regarding the status of participation | | | | | | Willingness of older people regarding participation | | | | Current status reported by the caregivers | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | I can do it | | I can't do it | | I can do it with support | | I am willing to do it | | I am not willing to do it | | Self | | Friend's support | | Nurse's support | | Care staff's support | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| **Bath** | 184 | 69.7 | 27 | 10.2 | 53 | 20.1 | 246 | 93.2 | 18 | 6.8 | 176 | 66.7 | 3 | 1.1 | 0 | 0.0 | 85 | 32.2 |
| **Oral care** | 212 | 80.3 | 16 | 6.1 | 36 | 16.3 | 259 | 98.1 | 5 | 1.9 | 203 | 76.9 | 3 | 1.1 | 0 | 0.0 | 58 | 22.0 |
| **Hand washing** | 231 | 87.5 | 3 | 1.1 | 30 | 11.4 | 259 | 98.1 | 5 | 1.9 | 231 | 87.5 | 3 | 1.1 | 0 | 0.0 | 30 | 11.4 |
| **Foot care** | 184 | 69.7 | 27 | 10.2 | 53 | 20.1 | 259 | 98.1 | 5 | 1.9 | 166 | 62.9 | 8 | 3.0 | 0 | 0.0 | 90 | 34.1 |
| **Perineal care** | 192 | 72.7 | 38 | 14.4 | 34 | 12.9 | 251 | 95.1 | 5 | 1.9 | 187 | 70.8 | 3 | 1.1 | 0 | 0.0 | 74 | 28.0 |
| **Toilet** | 220 | 83.3 | 25 | 9.5 | 19 | 7.2 | 254 | 96.2 | 10 | 3.8 | 220 | 83.3 | 3 | 1.1 | 0 | 0.0 | 41 | 15.5 |
| **Nutrition** | 249 | 94.3 | 0.0 | 0.0 | 15 | 5.7 | 254 | 96.2 | 10 | 3.8 | 233 | 88.3 | 3 | 1.1 | 0 | 0.0 | 28 | 10.6 |
| **Physical activity** | 214 | 81.1 | 23 | 8.7 | 27 | 10.2 | 240 | 90.9 | 24 | 9.1 | 201 | 76.1 | 7 | 2.7 | 5 | 1.9 | 51 | 19.3 |
| **Medication management** | 204 | 77.3 | 26 | 9.8 | 34 | 12.9 | 246 | 93.2 | 18 | 6.8 | 157 | 59.5 | 3 | 1.1 | 71 | 26.9 | 33 | 12.5 |
| **Intellectual needs/hobbies** | 213 | 80.7 | 32 | 12.1 | 19 | 7.2 | 227 | 85.9 | 37 | 14.0 | 216 | 81.8 | 9 | 3.4 | 6 | 2.3 | 33 | 12.5 |
| **Shopping** | 176 | 66.7 | 45 | 17.0 | 36 | 13.6 | 254 | 96.2 | 10 | 3.8 | 150 | 56.8 | 54 | 20.5 | 0 | 0.0 | 60 | 22.7 |
| **Walking in the institution** | 232 | 80.3 | 36 | 13.6 | 16 | 6.1 | 245 | 92.8 | 19 | 7.2 | 200 | 75.8 | 10 | 3.8 | 0 | 0.0 | 54 | 20.5 |

Note: Self-evaluation reflects older adults' own assessment of participation in each activity, whereas current status reflects caregivers' reports of how these ADLs are currently performed

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**Table 4.** Relationship between selected socio-demographic characteristics of older adults and the importance attributed to receiving explanations about care and treatment

| Variable name | Yes n (%) | No n (%) | $\chi^2$ | df | p-value | Cramér's V |
|---|---|---|---|---|---|---|
| **Gender** | | | | | | |
| **Female** | 96 (95.0) | 5 (5.0) | 5.78 | 1 | 0.016 | 0.148 |
| **Male** | 163 (100.0) | 0 (0.0) | | | | |
| **Education level** | | | | | | |
| **Illiterate** | 42 (100.0) | 0 (0.0) | 24.80 | 4 | < 0.001 | 0.307 |
| **Literate** | 40 (88.9) | 5 (11.1) | | | | |
| **Primary education** | 135 (100.0) | 0 (0.0) | | | | |
| **High school** | 37 (100.0) | 0 (0.0) | | | | |
| **University** | 5 (100.0) | 0 (0.0) | | | | |
| **Relatives' visit frequency** | | | | | | |
| **Never** | 101 (100.0) | 0 (0.0) | 29.40 | 3 | < 0.001 | 0.334 |
| **Weekly or more** | 34 (87.2) | 5 (12.8) | | | | |
| **Once a month** | 84 (100.0) | 0 (0.0) | | | | |
| **Every 3 months or longer** | 40 (100.0) | 0 (0.0) | | | | |

$\chi^2$: Chi-square test; Cramér's V: Effect size measure for categorical associations

## Discussion

Participation in care was considered important by 97.0% of older adults, and 78.5% of caregivers reported that such participation was necessary. These findings indicate that both groups attached importance to participation in nursing home care, consistent with previous studies showing that older adults value involvement in decision-making, understanding their condition, and active engagement in care [13,15,16,31,32].

In the present study, 93.2% of older adults reported that they received explanations about care and treatment, and 98.1% reported that receiving such explanations was important, whereas 61.6% of caregivers reported that such explanations were given and 83.6% reported that providing explanations was important. These findings may indicate a difference between reported experiences and reported care practices. This difference may be related to workload, time constraints, communication routines, or other organizational conditions in nursing home care. It is also possible that explanations are provided but are not always perceived, understood, or remembered in the same way by older adults. Therefore, this finding should be interpreted within both interpersonal and organizational dimensions of care.

Older adults most frequently reported being able to perform nutrition, hand washing, and toileting independently, whereas greater support appeared to be needed for shopping and medication management. Although these findings differ from those of Keskin et al. (2018), who reported lower independence in several daily living activities [33], such differences may be related to variations in sample characteristics, care settings, functional status, and measurement approaches. In the present study, older adults may have been more likely to participate in activities compatible with preserved functional capacity, whereas more complex activities may have required greater support.

Independent care-related decision-making was reported less frequently than consultation with physicians and nurses. Similar variability has been described in previous studies, suggesting that participation may differ according to the type of decision involved [26,31,34]. These findings may indicate that older adults value being informed and consulted even when they do not wish to assume full responsibility for decisions. In this context, participation may be expressed through shared and informed decision-making rather than fully independent decision-making, particularly for more technical or clinically sensitive issues.

This interpretation should nevertheless be made cautiously. Previous qualitative studies suggest that older adults may adjust their level of participation according to organizational conditions, staff workload, time pressure, and institutional routines [25]. Therefore, reduced direct involvement should not automatically be interpreted either as passivity or as fully adaptive participation; rather, it may reflect a context-dependent form of participation shaped by institutional conditions.

Previous literature has shown that visual impairment, cognitive decline, chronic pain, and other age-related conditions may

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negatively affect participation in nursing home care [10,28]. In the present study, 79.7% of caregivers reported loss of strength due to aging and 71.8% reported physical limitations as barriers to participation. Similar barriers, including low activity levels, limited alternatives, communication difficulties, and uncertainty related to changing health status, have also been reported previously [13,34]. These findings suggest that participation in care may be influenced not only by willingness, but also by functional limitations and the way care is organized and communicated within the institution. Accordingly, individualized communication strategies, attention to functional capacity, and supportive organizational practices may help strengthen participation in nursing home settings.

This study has several limitations. It was conducted in a single nursing home, which may limit generalizability. The data were based on self-report by older adults and report by caregivers, which may have introduced response bias. Because of the cross-sectional design, causal inferences cannot be made. In addition, the findings reflect reported views and practices rather than direct observation of care interactions. Some items allowed multiple responses, and the highly unbalanced distribution of some outcome variables limited the use of advanced multivariate analyses. Despite these limitations, the study provides comparative data from both older adults and caregivers regarding participation in nursing home care.

## Conclusion

This study showed that both older adults and caregivers attached importance to participation in nursing home care. However, older adults' involvement appeared to be shaped more by functional limitations, communication practices, and organizational conditions than by lack of willingness. Participation was more often expressed through being informed, consulted, and involved in shared decision-making than through fully independent decision-making. These findings suggest that person-centered nursing home care should support clear information exchange, shared decision-making, and participation opportunities adapted to older adults' functional capacity. Health policies and institutional care standards should therefore promote participation, communication, and shared decision-making as essential elements of nursing home care.

Further studies should examine participation in care in different institutional settings and with larger samples. Future research may also benefit from observational and longitudinal designs to better understand how functional status, communication, and organizational conditions influence participation over time.

Older adults should be involved in care planning and goal setting, and greater opportunities should be created for participation in daily care processes. Nurses and care staff should support older adults in expressing their preferences and in sharing decisions about care and treatment. In addition, organizational strategies that strengthen communication and reduce time-related barriers may support participation in nursing home settings.

**Ethical Approval**

*Ethical approval was granted by the Near East University Scientific Ethics Committee (Approval No: YDU/2025/133-1966; 30.04.2025). The study was conducted in accordance with the Declaration of Helsinki.*

**Patient Consent**

*All participants were informed about the study purpose and procedures, and written informed consent was obtained.*

**Conflict of Interest**

*The authors confirm the absence of any conflicts associated with this work.*

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