

## FACTORS INFLUENCING AUTONOMY OF NURSING HOME RESIDENTS WITH DEMENTIA: THE PERCEPTION OF FAMILY CAREGIVERS

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**Abstract:** *Background:* Being able to live the life you want to live within a nursing home might be challenging for residents with dementia, as they become dependent on others in achieving autonomy. However, little is known about which factors support or impede resident autonomy within nursing homes. *Objectives:* The purpose of this study was to gain insight into factors that support or impede autonomy for nursing home residents with dementia, from the perspective of their family caregivers. *Design:* A qualitative study was conducted. *Setting:* Five psychogeriatric nursing home wards within three care organizations in the Netherlands. *Participants:* 30 family caregivers. *Measurements:* Semi-structured interviews were held and a qualitative thematic approach was used. *Findings:* This study identified several factors that seemed to influence resident autonomy within six themes: activities; personal approach; visits from family and friends; being part of a group; physical environment; and organization of care. Within these themes, factors were mentioned that could either support or impede resident autonomy. For example, being socially engaged with family and fellow residents and participation in meaningful activities were supporting factors. The inability to go outside when wished or having inadequate private space were impeding factors. Overall, daily life was mostly organized from a communal and task-centered perspective instead of adaptation to individual preferences. *Conclusions:* The current study suggests that in order to improve the support of resident autonomy, nursing homes should focus on flexibility in providing care, finding ways to offer meaningful activities, and stimulating resident's social environment to continue social traditions.

**Key words:** Autonomy, nursing homes, dementia, family caregivers.

### Background and objective

There has been an ongoing culture change within nursing homes towards providing person-centered care that supports resident autonomy. This care philosophy emphasizes care provision that is tailored to residents' needs and wishes (1). Understanding the person, empowerment in decision-making and relationships in care are important concepts within person centered-care (2). Nonetheless, providing person-centered care might be challenging, especially when providing care to nursing home residents with dementia, as these residents often encounter difficulties expressing their needs and wishes and, therefore, are dependent on others (3). The nursing home sector recognizes the importance of making a shift towards person-centered care that supports autonomy as much as possible, yet, there seems to be a gap between recognizing the value of providing person-centered care, and clinical practice (4-5).

Nursing home residents with dementia are often highly dependent on their environment in achieving as much autonomy as possible. Nursing staff has an important role in supporting residents' choices over daily life (6). For instance, residents need other people to support them to make decisions regarding daily routines and care preferences. A general belief is that people's autonomy is restricted if they become dependent on others (7). This view, however, does not consider the fact that all humans are interdependent, and devalues people with disabilities who rely on the help of others. In light of a

person-centered point of view, relational autonomy is presently considered as a more appropriate approach of conceptualizing autonomy for residents within long-term care settings (7). This approach draws on the ideas of person-centered care, in which people's identities are developed and maintained within social relations, and a person can still be a free, autonomous individual within personal relations and mutual dependencies (8). Therefore, it is important that the environment addresses the need for autonomy for residents, regardless of living in a nursing home and needing help from others.

Together with staff, family caregivers can support resident autonomy. Feeling at home and being able to live the life you want might be challenging to individuals after moving into a nursing home (9). Limitations in privacy, the balance between feeling independent while being dependent on others due to the consequences of having dementia, and sharing a living space with other residents, challenge the sense of autonomy in daily life and feeling at home (10). Therefore, family involvement is of major importance, as family can contribute to care by sharing biographical knowledge of the resident with staff as well as residents' preferences in everyday life (11). Moreover, they can provide instrumental and emotional support, advocate for their relatives and indicate what might be valuable things in (daily) life and meaningful activities for the resident (12). Therefore, the family caregiver's role, requires to be better integrated in the current life of nursing home residents in order to be able to help them to live the life they want to live within

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the nursing home.

In many nursing homes, however, it is difficult for family caregivers to support resident autonomy and stay actively involved. Although there is growing attention for providing person-centered care, nursing homes often still have an institutional character and focus on the provision of task-centered care, in which residents' daily lives are often highly determined by organizational rules and routines (13). Moreover, supporting resident autonomy has not always been prioritized within long-term care (6). Efforts to provide better person-centered care were made when developing small-scale living facilities that focus on normalization of daily life and meaningful activities within a joint small household. Previous research regarding these small-scale living facilities, indicates that individual needs and wishes were better met when nurses actively sought residents' strengths and capacities (14). In addition, residents' interest was stimulated when engaged in daily household activities, which increases the sense of home and the ability to live the life you want within a nursing home (15).

Little is known about which factors support or impede autonomy of nursing home residents with dementia. Therefore, this study explores factors that influence resident autonomy, which is operationalized as the ability to live the life you want to live, as experienced by family caregivers.

### Methods

For this study, a qualitative research design was chosen (16). Semi-structured interviews were held to assess family caregivers' opinions on the extent to which they perceive that their loved ones can live the life they want within the nursing home, and which factors support or impede this.

#### Setting and Participants

Participants were recruited from three different care organizations in the Netherlands, including three small-scale and two large-scale psychogeriatric nursing home wards. In the Netherlands, traditional, large-scale nursing home wards are characterized by providing care for a large group of residents per ward, where daily life is mostly determined by organizational rules and routines. In small-scale wards, residents live within a joint household with, generally, six to eight residents. Here, care aims to be provided within a fixed team and a homelike environment, and activities are integrated in daily life. The selected wards provided care for residents with moderate to severe cognitive impairment. Family caregivers were eligible for this study if they were involved in the care for a resident with dementia living at the included wards. Family caregivers who functioned as the main contact person, and were responsible for making decisions on behalf of the resident, were invited to participate in the study (N=58).

#### Procedure

All participants were informed about the study in writing and received a consent form. Family caregivers who were willing to participate returned the consent form directly to the researchers and were called and asked when the interview could take place. Participants were interviewed individually; however, if the participant preferred that a second family caregiver was present, this person was allowed to join. Interviews were held at a location of the participant's choice. Participants were interviewed by a member of the research team between February and October 2017. Before starting the interview, participants were verbally debriefed about the study, informed about how the data would be processed, and reassured that any data would be treated confidentially.

#### Data collection

Data were collected by semi-structured interviews (16). In addition, the following background characteristics of participants were collected: age; gender; relationship to the resident (spouse, child, other); and how frequent they visited the nursing home. An interview guide, including a topic list, was developed to standardize the interview procedure. Participants were asked about the extent to which their relative is able to live his or her life within the nursing home. Table 1 presents an overview of the topic list and examples of questions. When needed, the interviewer prompted participants to elaborate on factors that support having choice in valuable moments in the resident's daily life and things the resident appreciates and enjoys while living in a nursing home. Three researchers collected data (LH, EdV & RB). Interviews were audio-recorded and transcribed verbatim.

**Table 1**

Topics and example questions of the interview

Topic (themes)	Question (example)
Autonomy within the nursing home	To what extent do you feel that your relative can live his/her life in the way he/she wants in the ward?  What things were important to your relative at home, and are still important now? To what extent are they still possible and why (not)?
Contributing factors to autonomy	What factors contribute to your relative living the life he/she wants?
Impeding factors to autonomy	What factors impede your relative living the life he/she wants?

#### Data analysis

A qualitative thematic approach was used to analyze the data (16). Analyst triangulation was used in order to increase reliability of the data analyses (17). First, to acquire an overall sense of the data and become familiar with the text, researcher LH read all transcripts. Initially, three transcripts were coded (LH) and the coding was discussed in detail with

a second researcher (LH & HV). Relevant text fragments were identified, which were meaningful parts of the text, containing words and phrases. Fragments were compared among each other to find similarities and differences, assigned to a similar category and given a code that corresponds to and contains the meaning of the fragment. After that, all remaining transcripts were analyzed independently by two researchers (LH & EdV), using qualitative data analysis software MAXQDA (18), and interpretations were compared as a form of cross-checking. In the case of disagreement, the most suitable interpretation was chosen, e.g. the interpretation which best signifies the meaning of what was expressed. A code scheme was developed, in which connections between categories were made, and codes were integrated and refined. Relationships and connections between codes were made in order to develop central themes that derived from the qualitative data. All codes were grouped and collectively categorized and main themes were identified. Weekly meetings were held between the researchers (LH, EdV & HV) during the analysis to discuss coding of the transcripts and interpretation of the data. After coding all transcripts, codes and themes were discussed within the whole research team for general interpretation of the data.

**Ethical procedure**

This study had been approved by the Ethics Committee of Zuyderland-Zuyd (No. 16-N-233). Participants submitted informed consent after receiving information about the purpose and procedure of the study. Participants could withdraw their voluntary participation at any moment during the study. Confidentiality of the interviews was guaranteed.

**Findings**

In total, 30 out of 58 family caregivers agreed to be interviewed. Seventeen caregivers did not return the consent form and 11 refused to participate. Participant characteristics are described in Table 2. Of the participants, the majority were daughters who visited their relatives at least once a week.

**Table 2**  
Participant characteristics

Participants	Total (N=30)
Mean age in years (range)	57 (47–76)
Gender (n female)	26
Relationship with relative (n)	
Daughter	24
Son	3
Spouse	1
Niece	1
Legal representative	1
Visits relative more than once a week (n)	27

Most participants found it difficult to reflect on to what extent their relative is able to live the life he or she wants to live. They expressed difficulties determining whether their relative with dementia had the potential to carry out autonomy: most relatives were not able to express actively and verbally their wishes and needs. Participants stated that the cognitive decline caused loss of previous interests and the cognitive and/or verbal inability to express interests. Consequently, participants were asked to elaborate on specific situations that used to be important and meaningful for their relative at home, and whether these are still important and possible while living at the nursing home. Based on this, information on resident autonomy was deduced and reflected within six themes (Table 3) which are described in more detail below.

**Table 3**  
Main themes

Theme	Definition/meaning
1. Activities	Residents’ engagement in meaningful activities and stimulating their interest in activities
2. Personal approach	Personal attention for residents by staff and staff knowing residents’ preferences and life history
3. Visits from family and friends	Continuation of family traditions and meaningful social encounters for residents
4. Being part of a group	Adjustment to living with fellow residents
5. Physical environment	Residents’ personal belongings and freedom of movement
6. Organization of care	Nursing staff’s working routines, staff teams and work flexibility

**Activities**

The theme ‘activities’ concerns resident engagement in meaningful activities and stimulating their interest in activities. Participants indicated that autonomy was supported when residents were engaged in (meaningful) activities that suited their interest and when care professionals stimulated the interest of residents in participating in certain activities. The majority of participants indicated that care professionals could better address needs and adjust activities to residents’ cognitive abilities when they organized activities at an individual level, or in a small group of residents with similar interests. In addition, most participants mentioned that activities were not tailored to residents’ individual preferences. Activities were mainly organized by staff from a logistic point of view, instead of these being adapted to residents’ personal preferences. Furthermore, for those residents whose interests matched the organized group activities, family caregivers felt that autonomy was supported, whereas activities adjusted to residents’ personal preferences were rarely centrally organized.

“Nothing happens at the ward. There are no activities for my father. He will not join activities such as arranging flowers, and he doesn’t need his nails done. There is nothing to do for the gentlemen, I don’t see it” [Daughter,56]

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Moreover, some participants mentioned that participation in activities in a familiar environment, such as the ward's living room, better supported autonomy, compared to organized activities in a communal room outside of the ward.

### *Personal approach*

The theme "personal approach" pertains to staff providing care that suited residents' preferences and giving personal attention to the residents throughout the day. Correspondingly, a personal approach was the ability to choose a specific ward before admission, maintaining residents' daily routines, being offered preferred food and taking care of the physical appearance as residents would have wished. Participants indicated that an important factor in achieving resident autonomy was the nursing staff making an effort to get to know the resident, by asking both resident and their family caregiver about preferences regarding activities and life history. These aspects were mainly discussed during the intake at admission but rarely at another point in time. Some participants were asked about how they felt about an update conversation during the year and responded positively. According to them, this would contribute to support resident autonomy. One participant responded:

"At a certain point in time she started singing and they asked me 'do you think it's ok if she joined the singing group?' That's something I've noticed, they try things like 'wouldn't this or that be nice for your mother to do?'" [daughter,63]

Only a few participants spontaneously indicated that their relative had a close relationship with (a member of) the nursing staff. These participants were more satisfied with the support of the autonomy of their relative whenever their relative received care from these nursing staff members.

### *Visits from family and friends*

Continuation of family traditions and meaningful social encounters were considered important by the family caregivers in supporting autonomy. All participants reported that residents were able to continue social activities they used to do when living at home, when they were able to welcome family and friends at any time. One contributing factor that was mentioned was nursing staff making participants feel welcome whenever they visited, as well as the presence of nursing staff on the ward during visits.

"You really feel at ease, you feel like you're being invited. As if you could come over whenever you want" [Daughter,56]

Nonetheless, most of the participants were not able to visit their relative as much as they wished, due to work or travel distance. Keeping in contact by phone was mentioned as helpful for the resident to stay in touch with relatives. Residents, however, did not receive sufficient help with using the phone or with having a private area where they could make a call, according to some participants.

"For me, I call a lot less now, otherwise I would have called on a daily basis, I called her every day. [...] And when I call

now, it is more complicated because they have to transfer your call and then something goes wrong. Also, she sits in the living room, where the TV is turned on and people are chatting" [Daughter,58]

### *Being part of a group*

Participants' opinions differed as to whether living in a nursing home, and being a part of a group of residents or joint household, either supported or impeded the autonomy. Some participants felt that living in a group could positively support their relative's interest in socially connecting to others, e.g., other residents and their family members.

"Your mother is always cheery and peppy, she talks to everybody', staff say. We had a family with five children and other people also came over a lot, a 'Leave it to Beaver' household. So, she's always used to having people around. The only concern would be that my mother could get lonely, but I don't feel like that's the case. She sits and talks with everybody" [Daughter,57]

On the other hand, a small number of participants viewed that living in a group was sometimes too busy for their relatives and that they preferred spending more time on their own during the day. Therefore, it was considered important for these residents to have a place where they could seclude themselves from the group when they wished.

"It is hard for people to adjust to five other people you don't even know. And they all have a completely different background, they didn't choose them themselves. They are not friends or acquaintances or whatever" [Daughter,59]

Tailoring daily routines to residents' preferences played a major role in achieving autonomy; for example, getting up when they wanted to or having meals at a preferred time. Some participants mentioned that autonomy was currently restricted, as residents' daily life was oriented toward what fits the group instead of the individual.

"My mother doesn't like the music that's mostly played on the ward. She likes music we played at home back in the day. Now, she sings along with the music on the ward, only because she knows all the songs now by repeating and repeating" [Daughter,56]

### *Physical environment*

Being able to adjust the environment into a place that feels like home and experience the freedom to move within and outside the ward as much as residents wish, contributed to resident autonomy. In all cases, participants mentioned that being able to bring personal belongings and valuable belongings, such as furniture, carpets, photographs, clothes and toiletries, contributed to living in a familiar and homely environment.

"We asked her before: 'by the time you would have to live in a smaller place, what would you bring?' [...]. Her bedclothes, she even took her own mattress and bedclothes, all those kinds of things. The most important thing, she took my father with

her, the urn in her room, she brought things that were extremely important to her” [Daughter,53]

It was suggested by participants that the ability to walk around the ward freely, without restrictions, addressed the need for physical movement and freedom within the ward. This contributed to autonomy as residents can freely choose to go wherever they want and residents do not feel restricted within their living environment. This was also the case when nursing staff accompanied residents for a walk within or outside the nursing home. In particular, for those residents who are wheelchair-dependent, some participants viewed that regular walks would help them be exposed to a different environment during the day. In addition, for the majority of participants, help from nursing staff and family caregivers, and a freely, easily and safely accessible garden or outside space contributed to the feeling of having autonomy.

Some participants indicated that sufficient access to private areas, belonging to the resident, improved resident autonomy. For example, if residents had access to their wardrobe they would experience more freedom, according to participants, even though this might cause inconvenience for nursing staff. The ability to have a private space to be alone outside of the bedroom, as well as a private space for residents to welcome family, are also factors that contributed to autonomy, indicated by the participants:

“He needs his own space, right. And of course he has his own room but he is not capable of finding his own room and turning the key to open the door. So that is not an option” [Son,58]

A small number of participants mentioned that their relative considered the nursing home as their home. They pointed out that their relative felt satisfied and at ease, and visibly enjoyed daily life at the nursing home. For a few other residents, for example, the ward was a familiar and safe environment and felt like their own home.

### **Organization of care**

Within the organization of nursing home care, several factors concerning nursing staff and working routines promoted resident autonomy according to the participants. Participants were unanimous in the view that deploying a fixed team on a ward enabled nurses and residents to know each other better. This would allow staff to develop a personal relationship with residents, and therefore enable them to approach residents in a more personal way, better addressing individual needs and preferences.

“Well, what I think is really important and keep on seeing, is of course linked to staff changes. My mom, she wouldn’t accept the way she’s being taken care of. She can’t express it anymore, but it’s not the way she would want it. She would get angry, so to speak. Right from the beginning, I took a picture of her and I put that photograph over there, just to give an example of ‘this is my mom, this is how she felt human’. And some of the staff pay attention to this and others completely

don’t [...]. And if I see her and how her hair is done, it’s greasy and she’s not wearing any make-up. My mom wouldn’t open the door to anyone like this back home” [Daughter,53]

“Well, a fixed team. Yes, it would be nice for mom if she had a steady, identifiable person instead of all these new faces. [...] Yes, someone who knows what she likes and prefers” [Daughter,53]

Moreover, participants indicated that when staff had more freedom to work without a predetermined list of care tasks, resident autonomy could be better supported. For example, they would be able to effectively address residents’ daily needs, such as timely toilet use, preferred physical appearance and meaningful activities. Furthermore, if nurses had more time for tasks other than physical care, residents could better live the life they want – for example, going outside with residents when residents wanted to, being able to support residents with keeping their pet and participate in daily activities.

“Someone takes care of the medicine, the other one starts with porridge [...]. It’s such a routine, right? Someone does this, the other one does that [...]. It’s ‘go, go, go, feeding, and done’ and then they clean up, it’s all that routine, it’s like ‘I have to be ready in time because my shift ends at 7 o’clock’. I think that’s what it is” [Daughter,59]

Furthermore, in order to increase resident autonomy, some participants indicated that changing staff working hours could contribute to addressing residents’ needs regarding daily routines and habits. For example, residents should be able to go to bed when they want and stay up late when visiting their children’s home without being dependent on staff working hours during the evening.

“For example, sometime last week, a staff member was in one of the living rooms and took all the residents to the other living room. Like she (staff member) said, she’d previously already done something with games: ‘for me to do that again, I feel like I’m not doing anything usefull’. She was really thinking about helping her colleagues with all those residents who had to be put to bed. That’s a typical example of nurses who might think ‘oh, I have to put ten people to bed’ or ‘I have to reach my quota for today’” [Daughter,60]

### **Discussion**

The current study identified six themes that influenced autonomy of nursing home residents with dementia: 1) activities; 2) personal approach; 3) visits from family and friends; 4) being part of a group; 5) physical environment; and 6) organization of care. Within these themes, factors were mentioned that could either support or impede resident autonomy. The most important factors that were considered by family caregivers to influence resident autonomy were: 1) residents being involved in individual activities that suited their interest, while activities that were organized from a communal and logistic perspective impeded autonomy; 2) providing a personal approach by getting to know the resident positively

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influenced resident autonomy; 3) autonomy was supported when family and friends were able to visit, though private spaces for family to continue family traditions were absent; 4) being able to socially engage with fellow residents had a positive influence, whereas, on the other hand, daily life with fellow residents was mostly determined by what fits the group instead of the individual; 5) creating a homely environment supported resident autonomy, while limited freedom of movement was considered impeding; 6) having a fixed team supported autonomy while, nursing staff having fixed routines regarding moments of care, impeded resident autonomy.

Some methodological limitations need to be considered. All first-contact persons of the residents from the selected wards were approached, which led to an inclusion of a high number of daughters. Consequently, experiences from spouses have been underrepresented in this study. This could have led to somewhat other findings as spouses may have a different, closer relationship with a resident (19). Adult children might grow into a different relationship, as they distance themselves from the parent when taking on a caring role (20). Accordingly, they may take over the decision process as the hierarchy within the child-adult relationship changes (21). Nonetheless, the sample is likely to be representative regarding gender, as women often take on the role of family caregiver (22). We used a descriptive generic research design, and our sampling procedure did not primarily focus on attaining data saturation when recruiting participants. Instead, we mainly focused on recruiting participants to capture a variety of experiences with resident autonomy from different wards, as previous studies suggested that the nursing home environment influenced family caregivers' perception on the care process (23), and autonomy in daily life in these homes may differ. Furthermore, participants had difficulties in determining whether their relative was able to live the life he or she wants. Other research methods, for example photo elicitation (24), which is an interview method that uses visual images to elicit comments, may have been able to stimulate more response.

Our findings suggest that when residents are being cared for according to the nursing staff's fixed routines regarding moments of care, and staff's working shifts, this impedes resident autonomy. This is an impeding factor to resident autonomy as this task-centered focus gives staff little opportunity to recognize and respond to the daily needs and wishes of the resident. These findings are in accordance with recent studies indicating that nursing staff are often too much involved in taking over caring tasks, and therefore residents are poorly stimulated to make their own choices (25). In order to provide care that incorporates residents' needs and wishes, care flexibility is essential (26). More research is needed to explore the relationship between the identified factors and cognitive status, duration of stay, and other background characteristics. Participants acknowledge that autonomy could be better supported when staff have more freedom to work without a predetermined list of care tasks. Therefore, it is important for

staff to view the nursing home as a place to live in rather than a place to be cared for, in order to address residents' needs and wishes (27).

Another finding was that family caregivers perceived that resident autonomy was impeded when activities were mainly organized from a logistic and communal principle. Therefore, it was perceived as important that the staff are able to spontaneously organize meaningful activities, in an individual or small setting. This would support resident autonomy as staff would be able to directly address residents' needs and wishes and activities, and could therefore be more meaningful to the resident. Our findings suggest that going outside is, amongst others, a meaningful activity for many residents. When staff are able to spontaneously arrange this activity, this would contribute to activities that are more meaningful and therefore, residents are better supported in living the life they want. This also accords with earlier observations, which showed that being able to go outside was mentioned as a meaningful activity and, therefore, is related to a higher quality of life for nursing home residents with dementia (28). In addition, our findings indicate that in order to enhance the feeling of having the choice to go wherever you want, the physical environment should be developed to facilitate the possibility for residents to independently go outside into a safe environment.

As is well known, it is exceedingly important for nursing home residents with dementia to keep a social connection to their family and friends. The current study found that while all participants were able to visit their loved one anytime during the day, there was a need to have a private space or suitable area to continue social traditions, such as celebrating birthdays together with family, or just being together amongst family, away from the communal group. In addition, besides being socially involved in the residents' life, it is also important for family to be involved in the care of their relative to support resident autonomy (29). In order to do so, they have to feel at home and welcome, and be able to take part in decision-making about the resident's care equally, instead of solely being a visitor (30). Nonetheless, communication between family and staff appears to remain challenging, causing shortcomings in discussing roles (31). This can hinder the support of resident autonomy. Moreover, as participants repeatedly mentioned frequent changes in care staff, family caregivers, nursing staff and residents might face difficulties in developing a strong relationship, which is needed to support resident autonomy. Therefore, this study indicates that low staff turnover is important for residents and family caregivers to allow them to adjust to the nursing home and develop a personal connection with nursing staff. In that way, knowledge of residents' life preferences can mutually be transferred, as a basis to create a solid partnership in supporting resident autonomy (28, 32).

Findings of this study indicate that several factors might improve the support of resident autonomy. Improvements should focus on good implementation of person-centered care by creating possibilities to better tailor care to residents'

preferences regarding daily routines, social and meaningful activities. Realizing improvements regarding supporting resident autonomy might be a challenge, as providing an opportunity to make own choices and, consequently, being able to live the life residents want, has not been a priority in current nursing home care (6). Nonetheless, the most important improvements that can be made concern the care professionals. They need to be given the opportunity to know and understand the residents in order to provide care and activities that suit the residents' interests. Care professionals should be able to provide care that is based on residents' personal preferences and support the life residents want to live. In addition, creating a familiar, homely environment and enabling residents to go outside whenever they want should be facilitated to better support autonomy. Lastly, the physical environment should encourage residents and family caregivers to continue social activities in private.

In conclusion, the current study suggests that there are still numerous possibilities to improve the support of resident autonomy. Enabling flexibility in providing care, finding ways to offer activities that are meaningful to residents, and stimulating resident's social environment to continue social traditions are of major importance in supporting resident autonomy. Based on the findings of this study, efforts should be made to improve the support of resident autonomy within nursing home care.

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