# Characteristics of asserting the identity of people with dementia in an old people's home

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## Abstract

Dementia poses a specific risk to the expression of identity due to the progressive decline of cognitive abilities and the general negative image of people with dementia. Prejudice and negative beliefs often lead to stigma and discrimination, which can depersonalise people with dementia and make it impossible for them to express their identity. The socially constructed image of people with dementia points to the need to explore the concept of identity of people with dementia. Based on qualitative research conducted in an old people's home and narrative interviews with residents with dementia, we demonstrate the possibilities of asserting the identity of people with dementia in an institutional setting. The paper highlights various factors that have a significant impact on the identity formation of residents with dementia. Among the most highlighted are appearance, physical abilities, social environment, activities, emotions, and religion. Residents with dementia develop different strategies to cope with the changes brought about by dementia and ageing (accepting change, redirecting negative thoughts, and maintaining skills through activities and employment). The paper presents the ability of residents with dementia to maintain or even transform their identity in an institutional setting, which has a strong impact on the expression and assertion of the individual's identity.

*Keywords:* social work, people with dementia, home for old people, coping mechanism, narrative inquiry

## 1. Introduction

The question of identity is one of life's fundamental issues (Vec, 2007). Definitions of identity focus on internal processes within the individual, encompass social structures that influence how we see others and ourselves, and describe the influence of social context on an individual's identity (Nastran Ule, 2000). Social identity and self-categorisation theory addresses the concept of identity in terms of social and contextual questions (Paddock, 2016). It emphasises that people have not only individual characteristics (physical, personality) but also those that are a product of our membership in social groups (Vec, 2007). Both characteristics influence the formation of positive or negative identities that are more or less

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consistent with social expectations (Hihara et al., 2018; Kenny et al., 2011). An individual's behaviour within a particular group depends on his or her self-perception and sense of self in a particular social setting (Postmes & Jetten, 2006).

Models of understanding dementia (Mali, 2019b; Mali et al., 2011) do not directly address aspects of the identity of people with dementia, and at the same time, the socially constructed image of people with dementia, which is often stigmatising and usually does not include a user perspective, points to the need to explore the identity of people with dementia. Boyle (2014, 2017) and Swaffer (2014) note that there is still a lack of research involving people with dementia and research on adjustment to identity loss due to dementia. Despite growing recognition of the importance of person-centred and integrated approaches to care planning, the inclusion of people with dementia in the care planning process has been neglected (Donnelly et al., 2019). Understanding the identity of people with dementia (Kuhar, 2019; Westius et al., 2010) is essential to improving care for people with dementia, as it enables support for residents with dementia to assert their identity and to develop working methods that respect the identity and promote the autonomy of residents with dementia.

The aim of this paper is to find out how people with dementia in old people's homes assert their identity in interactive processes in their environments. We want to discover the characteristics of the identity manifestations of people with dementia and to show the possibilities of identity assertion in institutional settings. Four themes are identified in this paper: (i) understanding and expressing the identity of people with dementia, (ii) key features of the assertion of the identity of people with dementia in old people's homes, (iii) the influence of the social environment on the identity of people with dementia, and (iv) the influence of social roles on the identity of people with dementia.

## 2. The importance of the institutional setting in understanding and supporting the identity of people with dementia

In order to understand the concept of identity, special attention needs to be brought to the social interactions (Kenny et al., 2011; Paddock, 2016) that people with dementia have with other people, as this is where they form their identity. Some authors (Moran, 2015; SinghaRoy, 2018; Vec, 2007; Worchel et al., 1998) distinguish between (i) personal identity, which emphasises an individual's personal characteristics or sense of self, and (ii) social identity, which relates to an individual's identification with social groups. Identity is understood as a complex and practical category (Kuhar, 2019; SinghaRoy, 2018) because it is formed in everyday contexts, interactions and social activities (Paddock, 2016). Vec (2007) and SinghaRoy (2018) emphasise that identity can be transformed and changed over the course of a lifetime, and that it is therefore not a static category, just as society and its characteristics are not.

Dementia poses a specific risk to the expression of identity due to progressive cognitive decline (Boyle, 2014; Swaffer, 2014) and general negative perceptions of the identity of people with dementia, leading to stigma and discrimination (Alzheimer Society, 2015; Downs & Bowers, 2014; Thies & Bleiler, 2012). Stigma and discrimination against people with dementia represent a significant additional challenge for people already coping with cognitive and functional impairment (Alzheimer Society, 2015; Alzheimer's Disease International, 2012). A review of research on attitudes towards people with dementia illustrates stigma (Innes, 2009; Mijoč, 2015; Rusac et al., 2013), which has a profound impact on loss of respect, personal integrity and autonomy. However, reducing societal expectations of people with dementia reinforces their marginalisation (Alzheimer Society, 2015; Innes, 2009; Milne, 2010; United Nations Economic Commission for Europe, 2015; World Health Organization, 2015). In

social work, we understand that the exclusion of people with dementia presents a risk of loss of identity, as it undermines and prevents the meaning of one's own identity from being shared and expressed (Alzheimer Society, 2015; Downs & Bowers, 2014). Existing studies report high levels of stigma associated with social isolation and social exclusion in the lives of people with dementia, which has a major impact on people with dementia's engagement in everyday interactions and social life, and consequently on the formation of social identity (Ošlak & Musil, 2017). Research on the care of people with dementia (Mali, 2008) has identified the presence of depersonalisation of people with dementia, which has a profound impact on the loss of respect and personal integrity of people with dementia. Social stereotypes have a strong influence on the subjective experience and behaviour of people with dementia (Mali, 2002). The latter can lead to a reduction in their individualisation, i.e., their sense of self, which can result in feelings of inferiority and deprive people with dementia of their dignity (Swaffer, 2014). Vulnerable social groups are pushed into identity formation with negative characteristics that deviate from societal expectations (Hihara et al., 2018; Kenny et al., 2011). These social practices describe people with dementia as peer-like, senile, conservative, unproductive and exploitative (Pečjak, 2001). People with dementia may internalise negative social attitudes about dementia, which can lead to depersonalisation due to the denial of their personhood (Kitwood, 2005). Dementia is studied by different disciplines and sciences, and different models of understanding dementia are known (medical, rehabilitation, ecological, psychological, sociological, social work) (Hvalič Touzery, 2010; Kobentar, 2010; MacKinlay & Trevitt, 2012; Mali et al., 2011; World Health Organization, 2012). The latter illustrates the challenges faced by people with dementia, their relatives and the social work profession in understanding dementia, and highlights the importance of the identity of people with dementia in planning care tailored to the needs of people with dementia. The social work model of understanding dementia (Donnelly et al., 2019; Mali et al., 2011; Mills, 2017; Quinn, 2010) is based on a person-centred approach to the person with dementia, the partnership relationship, social inclusion, destigmatisation, and finding answers to the challenges faced by people with dementia and their families. It is based on a power perspective that gives people with dementia back their social power as experts in their experience, focuses on finding new possibilities and opportunities, and creates a safe environment in which people with dementia can express their identity (Mali, 2008). Marsh (2002) and Quinn (2010) highlight the role of social work and involvement of people with dementia in the design and planning of institutional care and community activities for people with dementia and their relatives. Caring for old people, including people with dementia, is one of the fundamental concerns of any community. Care for people with dementia outside institutional structures is primarily the responsibility of women—partners, daughters, daughters-in-law, granddaughters (Brodar et al., 2018; Lymbery, 1998; McCallion, 2020) and is highly burdensome, often combined with formal forms of support, which in Slovenia are dominated by institutional care (Mali, 2019a). The concept of care for people with dementia developed by Kitwood (2005) has been an important influence on the development of new methods of working with people with dementia. It focuses on the personhood of the person with dementia and on identifying what is important to them in their living environment and what supports them in expressing and forming their identity. Through a dialogue with people with dementia, based on validation, verbal and non-verbal communication, people with dementia are enabled to interact with the social environment within which they answer important questions about themselves: who am I, how much more am I capable of, do I have a chance of success, whom do I belong to, and will I be accepted (Kobentar et al., 1996). Access to identity data, articulated and shaped by

the people themselves, and learning about and understanding the identity of people with dementia in institutional settings can trigger a critical look at the dominant understanding of people with dementia in society. It can help us to break down traditional stereotypes about age and prevent the depersonalisation of people with dementia (Mali, 2008). Research findings on the living environment of people with dementia provide guidelines for designing an environment that is appropriate and supportive for people with dementia (Fleming & Bennet, 2017; Greasley-Adams et al., 2014; Son et al., 2002). The move of a person with dementia from their home environment to an old people's home poses additional risks to the identity of people with dementia due to reduced contact with important social networks, loss of personal routines and personal items, and a change in their sense of autonomy, freedom and activity; all of which were part of the identity of the person with dementia. Therefore, knowing the residents and conceptualising the identity of residents with dementia plays a key role in providing care that supports their identity and is tailored to their individual needs (Cameron et al., 2021). At the same time, living in an old people's home is an opportunity for interactions in a new social environment that can have a significant impact on the identity of residents with dementia (Paddock, 2016; Riedl et al., 2013). Dialogue with people with dementia, established by social workers in old people's homes (Mali, 2008), enables the identification of identity and the prevention of depersonalisation of people with dementia (United Nations Economic Commission for Europe, 2015).

In order to lay the groundwork for the design of institutional care tailored to people with dementia, the central aim of this paper is to explore the concept of identity of people with dementia and to understand the characteristics of identity assertion of people with dementia in old people's homes. Gaps in the understanding of the identity of people with dementia are addressed by the following research questions: (i) how do people with dementia understand and express their identity, (ii) what are the key features of identity assertion for people with dementia in the old people's home, (iii) how important is the influence of the social environment on the identity of residents with dementia and (iv) how do social roles influence the identity of people with dementia in the old people's home.

The inclusion of a user perspective in research has always been part of social work practice; in the last four years, dementia research has been moving towards interdisciplinary research (Mali, 2019b). Providing a user perspective in identity research gives people with dementia an active role in expressing and shaping their own identity. Identity research articulated from the perspective of people living with dementia can trigger a critical perspective on the social understanding of people living with dementia and potentiate the consideration of the identity of people living with dementia in professional social work.

## 3. Methods

The aim of this paper is to present the results of a qualitative research, in which we explore the identity of people with dementia and reveal the characteristics of the manifestation identity of people with dementia and the possibilities of asserting it in an institutional setting.

The sample of old people's homes is a non-randomised purposive sample based on the results of research on innovation in old people's homes according to Mali (2018), who list three types of innovation: social, social welfare, and old people's homes. Considering the concept of quality of life, which does not isolate the person with dementia, but supports their inclusion in the community and thus enables them to assert their identity, social innovations were selected from the above-mentioned types of innovations. Social innovations in old people's homes represent a variety of support activities aimed at promoting the discovery

of residents' knowledge and skills, which helps residents with dementia to integrate into the community, provides the experience of productive roles, encourages self-advocacy, and promotes people with dementia as initiative-takers and equal members of society (Mali et al., 2018). From the social innovation type, one old people's home and four residents with dementia living in a secure unit or in a unit outside a secure unit, were selected, according to the principle of accessibility or readiness of the old people's home to participate. The residents with dementia were selected on the basis of the following criteria: (i) gender, (ii) stage of dementia, (iii) a diagnosis of dementia for at least one year, (iv) living in the old people's home for at least six months, and (v) a social network that is a source of information about their identity and life before going into the old people's home (they are in contact with their relatives by phone or they visit them regularly in the old people's home).

The sample does not include residents with dementia who have no social network and who are staying at the old people's home for a limited period of time (short-term or crisis placement in an old people's home), with the aim of returning to their home environment. Four residents with dementia were included in the final sample: two female residents and two male residents in the early and middle stages of dementia. All four residents included have had a diagnosis of dementia for at least one year, have lived in the old people's home for at least six months and have a social network.

In order to obtain as much detailed information as possible about the subject of the research, we conducted narrative interviews with the residents with dementia. Narrative interviews are unstructured in-depth interviews that allow people with dementia to share their life story, to shape it in their own words, and to highlight it with their own experiences (Plummer, 2001). The data collected are analysed based on a qualitative analysis according to Mesec (2009). In order to improve the reliability of the interpretations and interpretation of the results, the data collected are inductively analysed by regularly reviewing the original data. The inductive approach to data analysis involves using the actual data as a starting point to look for finding patterns, associations, grounding explanations and forming conclusions (Ritchie & Lewis, 2003).

Based on the literature (Innes, 2009; Mesec, 2009), guidelines for conversations with residents with dementia have been developed, which, in addition to demographic data, also cover thematic areas: understanding and expressing identity, characteristics of identity affirmation, the impact of the social environment on the identity of residents with dementia and social roles. The open conversation encouraged residents with dementia to share their life story in their own words, to tell stories about concrete situations from their life in the old people's home or before moving into the old people's home, and to explain their experiences. To get an insight into the usual daily routine of residents with dementia, and to ensure that the data collected reflected their views, opinions and experiences as accurately as possible, the course of the conversation was tailored to the residents with dementia during the data collection process.

In order to carry out the empirical research, we obtained the approval of the Ethics Committee of the Faculty of Social Work (University of Ljubljana) to carry out the research. Prior to the empirical research, consent was obtained from the participants who were also informed about the purpose of the research. The chosen research methodology allows for the subjective expression of the identity of people with dementia through the choice of activities, social roles, and the meaning they attach to them; it enables people with dementia to convey the meaning of their own identity to their social environment.

## 4. Results and discussion

The first theme focuses on the perspective of people with dementia and their perception of their own identity. It details the impact that being diagnosed with dementia and moving into an old people's home have on the formation of the personal and social identity of a person with dementia in an institutional setting. It presents the strategies developed by residents with dementia to form a positive identity that is socially acceptable. The second theme presents the ability of residents with dementia to express their identity through organised activities and interactions with their social environment. The third theme focuses on the impact that the social environment has on the identity of the person with dementia. It highlights the importance of the involvement of residents with dementia in interactions with their social environment in affirming their identity and strengthening their sense of self. The fourth theme addresses the loss of social roles and the diminishing roles within the family, which are key factors in the re-establishment of the identity of residents with dementia in their new living environment.

### 4.1. Understanding and expressing the identity of a person with dementia

The research focuses on the perspective of people with dementia and their perception of their own identity. The analysis shows that people with dementia have a preserved sense of self, which is reflected through first-person speech, the ability to engage in conversation about themselves and to communicate different aspects of their personality or identity. Regardless of the changes that dementia brings to their lives, residents with dementia perceive themselves as the same people they were before the onset of dementia. They have maintained a positive self-image and have a good opinion of themselves. They describe themselves as calm, emotional, hardworking, diligent, obedient, flexible, honest, modest, non-confrontational and humorous. Helping residents with dementia to maintain an aspect or aspects of their previous identity needs to be understood contextually and take into account the influence of different factors that may support or threaten different aspects of their identity (Scott, 2022). The conceptualisation of the factors and components that influence the formation of the personal identity of a person with dementia is important in order to develop different ways of supporting the identity of residents with dementia within the institutional setting. Appearance and physical abilities are two qualities that are of major importance for residents with dementia, as they enable them to express their own identity. One resident (Participant 5) said that it was her duty to be well-groomed and choose appropriate clothes for herself as a former post office clerk: "I look like a post office clerk. Absolutely important. It's my first duty. I'm not dressed properly today; this goes quickly in the morning. It's important to me that I'm tidy and today I'm not. I haven't had time. I came later." By choosing clothes that reflect her past professional role, she has kept in touch with the identity she had before coming to the old people's home. The staff help residents with dementia to dress by preparing clean clothes for them, which residents experience as helping them to keep clean and tidy. Clothes play a visible role in the lives and experiences of residents with dementia. Through their choice of clothing, residents with dementia can connect with their environment or social roles and remember that they are at home or at work. The look and feel that residents with dementia have when wearing certain clothes is linked to memories of certain aspects of identity. They are also important for linking the personal identity of residents with dementia to the social presentation of themselves and to the social environment in which they are integrated (Twigg & Buse, 2013). Creating a good impression and a positive self-image in society is important for residents with dementia in order to be accepted and to foster a sense of belonging. To create

a positive self-image, residents with dementia use a variety of strategies, such as engaging in different activities, being independent in their daily chores and clothing choices, as well as maintaining personal grooming. Remaining independent is important to them. Residents with dementia described themselves as emotional persons and identified emotions as an important part of their personality.

Exploring the social context of dementia refers to personal values and emotional relationships as key aspects of understanding the identity of people with dementia (Paddock, 2016). The concept is strongly associated with the notion of identity, as it stems from the relationship that residents with dementia have with people in their living environment. An interesting finding is that residents with dementia manage their emotions successfully by intuitively deciding in which situations to express them in order to maintain peace, happiness and contentment. In this way, they want to maintain their sense of self and create a safe environment to gain new experiences, connect with other residents, and express their own identity in an institutional context.

Another factor that has a significant impact on the formation of personal identity is religion. Faith is often associated with coping strategies for people living with chronic conditions, and is therefore key to understanding the factors that may influence the well-being and identity of residents with dementia (Epps & Williams, 2020; Rote et al., 2022). Many people with dementia were also heavily involved in their faith communities or churches before the onset of dementia or leaving home (Epps et al., 2021). Residents with dementia highlighted the role of religious beliefs and traditions in the institutional setting. The regular practice of religious rituals and daily prayer reflect respect for and preservation of family traditions. They emphasised that religion was part of their upbringing and also the way they brought up their children. Residents expressed pride and satisfaction when describing how they had brought up their children in a religious spirit. They felt that they had passed on a part of themselves to their children. The consolidation and preservation of the identity of residents with dementia happens through the preservation and transmission of traditions to the children and the fulfilment of religious practices also in the institutional setting. Moreover, for residents with dementia, maintaining religious traditions and belonging strengthened their personality and provided a positive experience of identity. As the life circumstances of residents with dementia change, religious activities are an aspect of support and strength in coping with various challenges (Epps & Williams, 2020; Epps et al., 2021).

When exploring social identity, we found that people with dementia want to be social, because socialising brings joy and well-being. They feel accepted by the other residents and staff in the old people's home. However, they state that they do not have any company and that they have no real friends. The main reason for this is that they live in an old people's home and do not have enough time to socialise and get to know the other residents. The study highlighted the importance of creating a socially accepted identity for residents with dementia. Such residents express a desire to form a positive social identity that is socially accepted and valued. In essence, it is a desire for the perceived personal identity of residents with dementia to be embedded in a wider social context, and to be identified in the social environment as people who are able to be successful and recognised. Residents with dementia want to maintain a positive self-image and a certain status in the eyes of the other residents and staff. One resident (Participant 4) said: "I would like to be appreciated. … I don't want to be high, but I want to be appreciated if I help and work. To have some status. That's what everyone wants." Forming a positive identity and a recognised social identity that supports people to cope more easily and successfully with the changes brought about by age and dementia is an integral part of the experience of ageing or the experience of

dementia (Štebe, 2017). When describing their social identity, residents with dementia point out that they are well thought of by their family members, other residents and staff. They experience the respectful attitude and the work done by the staff in the old people's home as an expression of acceptance and belonging. This has an impact on their self-image and strengthens their sense of self in society, as well as in the process of forming a positive social identity.

Despite the differences between personal and social identities, identities are also interconnected, especially through the roles people play in society (SinghaRoy, 2018). The personal and social identities of residents with dementia are intertwined, which is manifested through the search for different ways and means of affirming and shaping the identity that best suits the resident with dementia in the new environment. The personal identity of residents with dementia is not only formed by the subjective experience of the self, but is also shaped by experiences with other residents with dementia or interactions with the social environment. One resident (Participant 1) with dementia says: "I am no different from anyone else. If I am here, in this unit, then we are the same. I feel the same if I am here. We are similar in terms of life in the unit." His opinion is that life in the unit is what makes him similar to the other residents. The experience of living in the old people's home has shaped his opinion of himself and his sense of belonging to the unit. Residents with dementia try to use positive personality traits (adaptability, calmness, obedience and being non-confrontational) to strengthen their sense of belonging and to bring about a quicker adaptation to the institutional setting. The personal identity of residents with dementia is important, but social identity becomes more important and more emphasised during the course of dementia. Thus, the more an individual perceives him/herself as a member of a group of residents with dementia, in terms of a social category, the less he/she perceives him/herself as a separate individual personality (Vec, 2007). Residents with dementia emphasise that they are part of a group of people with dementia (living together in a secure unit for people with dementia), but within this context they also act as individuals. They choose activities and tasks that are compatible with their personal characteristics and their personal identity. One resident (Participant 5) pointed out: "I want to have good relationships and be accepted everywhere. I am not different from the others in the unit. I want to be the same as them. Today you are here and tomorrow someone else will be. You have to adapt." When living in an old people's home, personal identity becomes less expressed, but still depends on the experience of the resident with dementia within the new social group to which he/she belongs. Residents co-construct and take on a social identity that is shared by all residents with dementia in the unit. So that they are alike and equal to each other. The latter indirectly indicates that the residents with dementia have internalised the social understanding of people with dementia as a homogeneous group with the same characteristics.

Interestingly, residents with dementia do not cite personal goals. They consider that personal goals are inappropriate for an old person in an old people's home, as they "live one day at a time" (Participant 1) and only maintain a sense of self in the current time and place. On the other hand, the realised goals and successes from their youth are useful in re-establishing their identity and sense of worth. Talking about the goals they have achieved has increased their sense of achievement and has had an impact on their well-being. Residents with dementia experience changes in personal characteristics, cognitive abilities and memory. They see dementia and ageing as key reasons for changes in identity, or changes in their experience of themselves and the world around them. They are afraid of "forgetting who they are" (Participant 1). Dementia poses the threat of changing or even losing the identity they have spent a lifetime building. In talking about the changes

brought about by dementia, they were aware of the progressive nature of the disease, which made them feel helpless, forgetful, less capable, changed, insignificant and "mindless" (Participant 3). The lack of understanding of the experience and the negative emotions evoked feelings of awkwardness and weight. Despite the usual negative feelings associated with dementia, some residents also recognise the positive side and accept dementia as a normal part of ageing. On the other hand, residents with dementia try to normalise their memory loss and see dementia as a normal part of ageing, i.e., as something "every old person has" (Participant 1). However, they try to maintain a positive sense of themselves and their identity, focusing on adapting to their new environment. They use different strategies to cope with the changes brought on by age and dementia, such as accepting ageing and dementia; embracing change; redirecting negative thoughts; maintaining skills through activity and work (exercise, folding dishcloths, preparing tables for meals, helping other residents or helping the staff). One resident (Participant 1) said that "it is easier if you accept the changes that age and dementia bring." The strategies focus on the emotions of residents with dementia and refer to processes that help them to reduce dementia-related distress, such as acceptance and positive reframing (Lloyd et al., 2019).

### 4.2. Key characteristics of asserting the identity of a person with dementia in an old people's home

Mali and Kejžar (2017) note that after 2000, institutional care has changed precisely because of the increase in the number of residents with dementia, which has triggered the realisation that the mere enforcement of institutional rules of working and living in an old people's home is not the most appropriate method for this population of residents. People with dementia face the threat of losing their autonomy and self-esteem due to negative social perceptions of dementia (Mali, 2008). The way of life that the institution shapes and the attitudes of staff towards residents with dementia have a significant impact on the maintenance of the identity of people with dementia. Identity maintenance or even re-establishment can be strengthened by enabling residents to do the work they are still able to do, and by creating conditions for the expansion of social networks that guide the formation of the identity they need to survive in society (Mali, 2013). International research (Clarke & Wolverson, 2016; Postmes & Jetten, 2006) has found that people with dementia are able to live well and adapt successfully to living in an old people's home if they are able to articulate their subjective experiences of living with dementia.

Moving into an old people's home is an additional challenge for people with dementia because of reduced contact with their social network, loss of routine and sense of independence. It requires a rapid adaptation of the person with dementia to the new living environment. The resident with dementia is to a certain extent deprived of self-care, which poses a risk for a change of attitude towards oneself and one's identity (Mali, 2002). The move to an institution is usually prompted by others, especially people from the immediate social environment of people with dementia (Flaker et al., 2008). Analysis of the empirical data confirmed that the decision to go into an old people's home is usually made by important people in the life of the person with dementia or by their children. One resident (Participant 1) said: "I can't be at home, where they are going to put me. That's why they put me in an old people's home." Residents with dementia describe life in an old people's home as different from the home environment they are used to. One resident (Participant 4) describes: "I lived differently at home. I went to Štajerska a lot, to help. I was used to living like that. Except now it's not like that anymore." The changes refer mainly to the loss of daily routines and habits (working in the garden, helping the family, visiting friends, etc.)

and the reduction of social roles (the role of parent, housewife, friend). Moving into an old people's home is also an opportunity to establish new daily routines and to reshape the social roles of residents with dementia. During a conversation about the changes that living in an old people's home brings, a resident said (Participant 1): "I don't drive anymore. I like going to the gym. I never used to exercise, I used to drive. Now I exercise. I have been retired for two years. I think about it a lot." Although residents with dementia are successfully adapting to the institutional environment, they point out that they want to keep the identity and lifestyle that they had before coming to the old people's home, and which they miss. The resident explained (Participant 4): "I had a garden. I miss it. A little bit. I was used to working, I come from a farm. It would be nice to keep it. But here we have another one. Other activities." Residents with dementia do not feel at home in the old people's home, as confirmed by the statement of a resident (Participant 1): "It's like a hospital here."

The latter has a direct impact on reducing their independence and their ability to make decisions about their own lives. Because of the feeling of not being at home, they do not take an active role in the process of shaping the daily life and daily routines in the old people's home, but instead adapt to institutional rules (schedule and type of activities, timetable, house rules, expectations of staff). A resident pointed out (Participant 1): "This is where they decide where and when we go. I don't choose, no, no, no. How can I say where we should go. I have to obey. I would never suggest activities." While the institutional setting allows residents with dementia to express their identity through a choice of activities in interactions with other residents or staff, and through the use of personal items, residents with dementia are reluctant to share their thoughts, wants and needs with the staff. They experience the old people's home as a specific environment where they do not want to be exposed as individuals or to be different from other residents. The latter is confirmed by the opinion given by the resident (Participant 5): "No. I don't want to expose myself." Residents with dementia take a passive role and consciously give up the possibility to make choices and suggestions, as they directly associate the latter with the formation of a negative identity. One resident (Participant 4) even believes that she should not express her opinions, wishes and needs because then she would "get up everyone's noses." There is a fear among residents with dementia of offending the staff and risking the staff having a bad opinion of them. On the other hand, they would like more encouragement from the staff to take on a more active role in the old people's home or to be asked more often for their opinions or preferences. The role of the institutional environment in shaping and expressing the identity of residents with dementia is very evident. By providing care that includes the perspective of residents with dementia and respects their identity, an inclusive environment is created in which the person with dementia can express their personal identity and transform or consolidate their social identity (Kuhar, 2019; Westius et al., 2010).

Moving into an old people's home often results in the loss of personal belongings and makes it difficult to stay connected to memories, life stories and identity. Therefore, enabling people with dementia to keep their own clothes and belongings is important in supporting identity and providing person-centred care (Cruise & Lashewicz, 2022; Twigg & Buse, 2013). Personal items that residents with dementia bring with them to the old people's home help them to create an environment that is more familiar in an institutional context. They use personal items to evoke memories that help them to recall information about themselves, events and relationships. One resident said (Participant 4): "I have some pictures. I brought flowers from home and a vase. It reminds me of my home and my relatives. My family." The use of personal items has helped residents with dementia to create a sense of who they

used to be and to construct a story about their lives. They use personal items to evoke memories of their home and family, which has a positive impact on their well-being in their new living environment and on the continuity of the identity they have built throughout their lives. Most often, they bring with them clothes, paintings, vases with artificial flowers, sacred objects and pictures of their family.

Through participation in various activities, residents with dementia maintain their independence, which allows them to stay involved and be part of the community. By strengthening their sense of belonging, they connect with their own identity. Activities therefore allow residents with dementia to express their wishes and experience a sense of success through subjective experience. Most of the organised activities take place in the old people's home and are organised by the staff. The organisation of activities for residents with dementia involves knowledge of the residents, their beliefs, perspectives, lifestyles and experiences (Kielhofner, 2008). In the context of the institutional setting, activities have a major impact on maintaining the identity of people with dementia (Paddock, 2016; Tanner, 2013; Vec, 2007). Residents with dementia most often participate in activities that are aligned with their previous roles, such as exercise, spiritual activities, musical activities, assisting the staff (dishwashing, setting and clearing tables), or watching television. One resident (Participant 4) describes how working in the kitchen is still part of her daily life: "I used to work in the kitchen. I was a cook's assistant. In the cafeteria. … Here I just help to cook the compote. I feel good. Desserts are made in the kitchen. Food too. We only cook compote together." Their activities reflect the past roles or current wishes of residents with dementia, and are therefore one of the ways in which individuals can express their individuality and identity, and carry the meaning of their identity into their new living environment (Paddock, 2016). Residents are assertive about participating in activities that are meaningful to them. For residents with dementia, exercise is a means of maintaining their independence and reducing their need for assistance. Involvement in music activities in the old people's home strengthens the identity of residents with dementia and maintains a sense of connectedness with family members. One resident (Participant 5) described music as important to her because it has a positive effect on her well-being: "I like music. Everyone around me is a musician. My daughter. I feel great when there is music. That word means a lot to me. Music makes everything better." Music has always been an important part of her life and she keeps in touch with her own family through music, as her daughter is also a musician. Some of the activities in the old people's home are aimed at helping the staff. Residents with dementia help to set tables, wash dishes, and help with residents with dementia who want to leave the unit. When they helped the staff or were complimented by the staff, they felt appreciated and acknowledged, which had an impact on their well-being and enhanced their sense of worth. Residents with dementia do not need help to express their identity. They also state that they would find it difficult to ask for help and difficult to accept help if they needed it. Only one resident (Participant 5) has stated that she needs more help to stay informed about activities and events, and needs to be escorted to the common areas: "They come to invite and inform me. They help me go into the common areas. They escort me."

By organising a variety of activities, old people's homes allow residents with dementia to choose activities related to their previous hobbies or social roles. In this way, they provide opportunities for residents with dementia to develop a positive sense of identity and engage in meaningful activities, thereby increasing their sense of self-worth and maintaining their integrity (Mali & Kejžar, 2017; Talbot et al., 2021). At the same time, they support the identity of residents with dementia and create opportunities to experience their own contribution and strengthen their sense of belonging to a group. The subjective experiences

of residents with dementia in activities contribute to identity consolidation while promoting independence and well-being (National Institute for Health and Care Excellence, 2018). One of the important findings of this research is that staff members enable residents with dementia to function within the institutional setting and to affirm their identity according to their level of independence and in accordance with their preferences.

### 4.3. *The impact of the social environment on the identity of people with dementia*

The fundamental structure of the relationships that form the social network of a person with dementia is tied to the family (Mali et al., 2011). Moving into an old people's home has the effect of transforming the relationships that residents with dementia have with their social network (Riedl et al., 2013). This is why it is necessary to continuously explore how the social environment can respond to the needs of the person with dementia, what help and support it can offer the person with dementia to express and consolidate their identity in an institutional setting (Mali et al., 2011). In doing so, it is necessary to consider what help and support the person with dementia needs to participate in social interactions and in the narrative of their life story. Approaching identity through social interactions and narratives (Kenny et al., 2011) enables people with dementia to play the dual role of being both storytellers and subjects of their own stories. Social interactions are important in exploring the identities of people with dementia because stories not only describe events in the lives of people with dementia, but also describe the identities of people with dementia themselves.

The research focuses on understanding the impact of the social environment on the identity formation of people with dementia in an institutional setting. Residents with dementia emphasised that their relationships with each other and with the social environment in which they are embedded are very important to them. The latter is even more pronounced when leaving home and losing contact with the important people in their social network. One resident (Participant 4) even said "if you don't have any company, you are marginalised and you lose yourself." They are aware of the importance of company in order to maintain a sense of their own identity, a sense of self and a level of involvement in their relationships. Social interactions enable residents with dementia to form a shared identity that is socially accepted in the context of the institutional environment. Therefore, they allow them to express and transform their social identity in the present moment.

Residents with dementia only socialise and connect during activities or in the dining room during meals (with the residents they sit with at the table). One resident described (Participant 4): "We don't hang out in our rooms. Only in the dining room or at activities. I hang out with Mici, who sits at the table with me. There is another one at the table, but she often looks for the door to go home. I don't fight with the others, but I hang out with them the most. Because we are at the table together and at the activities." Activity and meal time is therefore a time for socialising and connecting between residents. For residents with dementia, participation in activities or a place at the table is an opportunity to engage in interactions and to express their identity. On the other hand, residents with dementia are not motivated to establish new relationships. This is due to the temporary stay in the old people's home and the structure of the residents in the unit, as they do not see opportunities for socialising among residents with dementia. Avoiding social interactions increases the social isolation of residents with dementia and contributes to social exclusion and loneliness (Mali & Kejžar, 2017; Talbot et al., 2021). This often makes them feel isolated and they retreat into their inner world, which reduces the possibilities for expressing their identity. They associate negative emotions, such as suffering, abandonment and generally feeling bad,

with loneliness. The loneliness experienced by residents with dementia is a consequence of the threat that dementia poses to their identity (Scott, 2022). They compared their current situation particularly negatively with the past, when they were open and sociable people. In this context, a resident described his life as follows (Participant 1): "It used to be more fun. I used to have more fun. And we used to dance. This was happening in the village, not in the cooperative home. I was alright, I wasn't dead, oh no. I was working. My father had a farm. I worked there from a very young age. As a young man I went everywhere, in every way. When you get older, that's gone." The conscious decision to prioritise positive company and to create quality relationships in which they can communicate information about themselves, and their identity reduces the threat of negative identity formation posed by dementia. They see residents with positive personality characteristics (rational, healthy, capable, independent and not in need of help) and those who are similar to them as positive company. One resident (Participant 1) with dementia points out that he mainly socialises with residents who are similar to him, i.e., with residents who have similar characteristics as him. He has only one friend in the old people's home for whom he says that they "are of the same mind" and that this is what distinguishes them from the other residents in the unit. Residents with dementia want to belong to a positive and healthy environment in which they feel safe and are not afraid to express their wishes and needs. They value more the relationships with the staff with whom they engage in conversations, and they like to help them in their work by being involved in the care of residents with dementia who need more help. They often help other residents with dementia who want to leave the unit. Residents with dementia manage their social life and privacy in a meaningful and functional way. They choose between time for themselves and socialising with other residents. The resident (Participant 4) said that she likes to be in good company, but she also likes her own peace: "Sometimes I like to be alone and sometimes I like to be in good company." They also choose their company carefully, avoiding residents whom they perceive as having negative characteristics (dementia, sneaky, selfish) or whom they see as different. A resident (Participant 1) described which residents she avoids: "No. Only those who think they are better than others. The ones who think I'm less. Sometimes a word I don't like comes out and I feel uncomfortable." One of the residents (Participant 1) shared his attitude towards his co-residents with dementia: "I sometimes talk to one resident. We understand each other, we talk a little bit. We talk. It's not like we're having coffee. We go for a walk. We are alike in that we have the same intelligence. We have common sense. I can talk to him. The others need help." Understanding dementia as a stigmatising identity encourages residents with dementia to reconstruct a socially acceptable identity. Distancing oneself from residents with dementia is a way of protecting oneself from the stigma of dementia (Paddock, 2016) or a way of maintaining a positive identity.

Interactions with the social environment are a valuable source of information about the person with dementia, but also a space to express one's own identity. Residents with dementia report that their children and the staff in the old people's home know them best, and have a positive opinion of them. Knowing the person and understanding their identity is key to providing care that is tailored to the person with dementia (Cameron et al., 2021). The most important relationships for residents with dementia are those with their children. Relationships are described as good and respectful. The family often represents the core spectrum of relationships that create the social network of a person with dementia (Mali et al., 2011). In addition, the relationship between the person with dementia and their family members is a key factor in maintaining a sense of self and identity (Hellström et al., 2007; Parkinson et al., 2022). Creating a safe social environment in which the person

with dementia feels valued and important supports the expression of identity through the narratives of their life story. Conversations are one way of managing identity change, as interactions strengthen family bonds, reduce conflict, and reinforce the identity of residents with dementia (Branger et al., 2016). In conversations with relatives, children and friends, they reminisce about life before they left home. Recalling memories is a pleasant way for residents with dementia to express and preserve their identity in front of others (Sass et al., 2021). When they had the opportunity to share their life stories, they were reliving memories and expressing continuity of identity. One resident (Participant 5) described how her daughters help her to preserve the story about her life: "My daughters remind me of things. They know a lot. They preserve memories. Shared memories. Not only mine, but also those of my husband's." Relatives help people with dementia to remember their life story, through which we learn about their identity and information about their belonging or connection. Interactions allow residents with dementia and their relatives to articulate their experiences, their hardships, their strengths and weaknesses in the process of expressing and transforming the identity of people with dementia who are experiencing institutionalisation (Mali, 2018). Regular visits allow residents with dementia to maintain a level of connectedness with their family and to be included in family relationships. They also strengthen the sense of self within the family and influence the well-being of residents with dementia. The importance of a supportive environment and relationships with family members is highlighted as a possible way of strengthening the identity of residents with dementia in an institutional setting. Maintaining a level of involvement with relatives is important for residents with dementia.

### 4.4. The impact of social roles on the identity of people with dementia

The experience of residents with dementia in an old people's home is often accompanied by a struggle for autonomy and an active role in society (Riedl et al., 2013). The loss of active roles of people with dementia is important for social work research, as recognising and understanding the identity of people with dementia can change society's attitudes towards people with dementia and the forms of support that emerge from society. To better understand the identity of people with dementia, we need to engage with the meaning that people with dementia attach to certain social roles, and consider them as individuals who are able to become creative and spontaneous about performing any given role (Chalari, 2017). Managing their choices, desires and needs, in turn, enables people with dementia to form and re-establish an identity that is consistent with the social context in which they live (Tomić-Koludrović & Knežević, 2004).

The findings show that residents with dementia develop strategies to partially maintain the social roles they had before they moved to the old people's home. They use past roles as a source of knowledge about themselves and as a central guide to re-establish their identity in the new environment. Residents with dementia are aware of the loss of past social roles and perceive a retreat from an active role in the family as a result of moving into an old people's home. One resident said (Participant 3): "I played an important role in the family. Now there is nothing special in the family. Let's just say I miss it." There is a perceived decline in family roles such as the parental role (raising children) and the domestic role, which are still the most important roles for residents with dementia. The relationships that residents with dementia have with their family members are also changing. Residents with dementia perceive that the high level of involvement in family dynamics and continuous support for children has been reduced to passive leisure time in the form of conversation or socialising. One resident (Participant 4) described how helpless she feels now that she is in

an old people's home: "I used to take care of my family, bring up my daughter. Nowadays she just comes to visit, and we talk. Nothing else. I can't do anything because I'm in here. If I was at home, I would have a bigger role. Maybe it would have been different." This change makes residents with dementia feel irrelevant, useless and redundant. Identity change, as reported by residents with dementia, is associated with a change in the sense of their own identity as carers and their perceptions of connectedness and responsibility in relationships with their children, resulting in a loss of reciprocity, of the valued set of attributes and of opportunities to contribute within roles and relationships (Enright et al., 2020; Sanford et al., 2019; Scott, 2022). Although there is a loss of social roles and changes in the structure of family relationships, residents with dementia successfully take on new social roles in institutional contexts and transform or reconstruct their identities. By taking on new roles in the community and promoting involvement in household activities, residents with dementia strive to maintain purpose and meaning in the social environment in which they are embedded (Sanford et al., 2019). They reconfigure meaningful roles in a way that they engage with similar roles in the old people's home (Participant 4): "I love helping caregivers. I try to work hard. I am used to working and I like to help. I wipe the tables and do the dishes quite a lot. We fold the cloths. No work, no eating. That's what people say. That's my goal." Residents with dementia whose primary role was caring for their family and raising their children engage in household activities in the old people's home (washing dishes, setting and clearing tables, folding dishcloths) and assist the staff in caring for residents with dementia who require more assistance and supervision. A resident who had worked as a chauffeur all his life exchanged his professional role for exercising. By choosing similar activities, he retained the sense of dynamism and activity that the role of a driver had entailed. Newly assumed roles have been found to affect the sense of worth and personal integrity of residents with dementia. Assisting the staff makes them feel useful, helpful and important, which contributes to maintaining a positive self-image. The search for new social roles that enable people with dementia to live independently and provide opportunities for their inclusion as active co-creators of the support process enhance the quality of life of the resident with dementia in an institutional setting (Mali, 2018).

In addition to an active role in the family, residents with dementia feel that they have lost an active role in society and control over their own lives, which has led to negative feelings, insecurity and fear. The loss of the ability to care for their children and the loss of a meaningful social role is central to the social identity of residents with dementia, which has compromised their sense of self (Scott, 2022). Despite this, residents with dementia are seeking ways to maintain control and regain a more active role in their lives. Participation in activities organised in the old people's home and support from staff are areas in which residents with dementia take on more active roles and enact their identity. They strive to preserve a biographical identity, or an identity from the past that they have spent a lifetime building, and which is linked to their life story. Residents with dementia want the support of family members and the staff of the old people's home in the process of preserving their biographical identity. Through the revival of shared memories and the reminiscence of past events, residents with dementia get in touch with their own identity and re-establish it in the present. The social roles and relationships of people with dementia are changing, but can still remain an important part of their lives (Mali, 2002). They experience participation in research as a value and an opportunity to share their life story. Valuing the unique insights and experiences of residents with dementia is seen as an affirmation of such residents; providing opportunities to participate in research enhances their dignity and values (Bartlett et al., 2019; Murphy et al., 2015). By talking about their identity, we create opportunities in

which residents with dementia can take on an active role and control over their identity and self-image in society.

## 5. Conclusion

The findings show that residents with dementia retain different aspects of their identity and have a preserved sense of self. They perceive themselves as the same people they were before the onset of dementia, even when they perceive personality and cognitive changes due to memory loss. The normalisation of memory loss and the understanding of dementia as a normal part of ageing allows residents with dementia to develop different strategies to cope with the changes brought about by dementia and old age. In an old people's home, the personal identity of the person with dementia becomes less pronounced, but residents actively co-construct and take on the shared social identity of residents with dementia and strengthen their own sense of belonging. They internalise the negative views of dementia and do not want to be part of a group of people with dementia (living together in a secure unit for people with dementia).

Conceptualising the different factors that have a significant impact on the identity formation of people with dementia, both personal and social identity, is crucial to understanding the process of identity formation of people with dementia in an institutional setting. Residents with dementia explore positive identity formation in institutional settings and actively engage in interactions that challenge stereotypical assumptions about people with dementia. In this way, they reinforce their identity as a person who can live well with dementia (Talbot et al., 2021).

Through the experience of living in an old people's home, residents with dementia form a sense of self and enact their identity in the current time and place, which allows them to preserve many aspects of their identity, to re-establish it, and to convey the meaning of their own identity in an institutional setting. One of the important findings of the research is that the institution plays a key role in allowing residents with dementia to play an active role in care planning and to assert their identity according to their level of autonomy and in accordance with their preferences and needs. Keeping personal belongings and engaging in activities are an important part of supporting identity in the context of an institutional setting. They can help to create an inclusive environment that supports the individual characteristics, preferences and needs of the resident with dementia (Twigg & Buse, 2013).

From the perspective of the residents themselves, dementia has a significant impact on their social identity, as well as on their level of integration into the social environment. Although changes in family relationships and social roles often lead to negative feelings, residents with dementia actively participate in interactions in which they gain information about their life story and consolidate their identity. Therefore, social interactions allow residents with dementia to form an identity that is socially accepted in the context of the institutional setting. They take on new social roles that allow them to find meaning and new opportunities for social inclusion. Past roles are a source of knowledge about the resident with dementia and a central guide for re-establishing and strengthening identity in the institutional setting.

The findings of the study further highlight the importance of comprehensive research on the identity of people with dementia. In addition to the perspective of people with dementia, the perspective of their relatives and of social work should be included to ensure a holistic approach to researching the identity of people with dementia. In dialogue with residents with dementia, social workers use well-known techniques of communicating with people with dementia according to Feil (as cited in Lipar, 2012), which help people with dementia to

maintain the existing relationships with their social environment. Social work also involves the person's support network, family and relatives in the process of understanding and helping people with dementia. It is from these relationships that people with dementia draw strength and security to maintain their identities and roles. They also prevent the loneliness that people with dementia often experience. Social networks are an important part of the lives of people with dementia, a source of information about their identity, and a way of empowering people with dementia to maintain and rebuild their identity.

Dementia has a significant impact on the experience of one's identity. The experience of people with dementia in the process of asserting their own identity in an institutional setting, as directly experienced by them, is a valuable aspect of understanding their identity, as it is the lived experience of people with dementia that grounds their participation in the process of exploring the concept of identity. Although the process of expressing and asserting identity in an institutional setting poses many challenges for people with dementia, it can also bring positive aspects such as comparison with peers, the development of different strategies to reduce the negative consequences of identity change, and the ability of people with dementia to reconstruct their current identity or even to adopt a completely new identity that is valued and socially accepted. People with dementia retain certain aspects of their identity and have the ability to persist in interacting with their social environment to learn about their identity and to express the meaning of their identity, despite the challenges that dementia, stigma and going into an old people's home bring to their lives. The perspective of people with dementia is endemic in identity research, but the paper nevertheless provides a unique insight into an under-researched context and highlights the capacity of people with dementia to construct a story about themselves with the aim of maintaining and shaping a positive identity in an institutional setting.

## 6. Research limitations

There are several limitations to interpreting the findings of the research, in particular the sample size, which is small despite heterogeneity in terms of gender, age and stage of dementia. The results are contextualised to a specific institutional setting and cannot be generalised to other institutional settings and to people with dementia living in their home environment. Despite these limitations, the paper highlights important themes that address the identity of people with dementia and sets cues and possibilities for further research. Methodological triangulation, data triangulation and a larger sample would increase the reliability and credibility of the data.

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