

ORIGINAL ARTICLE

To maintain older family members lifestyle and self-identity for a meaningful daily life in nursing homes and home care – The relatives' perspective

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Abstract

In Sweden, national guidelines have been introduced to ensure that older persons in need of health care and social services enjoy a meaningful daily life. When new guidelines are introduced in elderly care, the experience of the older persons or their relatives are seldom taken into account as the guidelines often are formulated from using a top-down approach. Therefore the aim was to describe relatives experience about obstacles and opportunities for a meaningful daily life for their older family member. The analysis was based on a qualitative content analysis. Five themes describe how a meaningful daily life can be created and one overall theme emerged that describe a meaningful daily life as “In partnership to maintain the family member’s routines and habits in an everyday rhythm filled with meaning, in a home like environment and in community with others”.

Key words

Meaningful daily life, Elderly care, Routines and habits, Lifestyle, Self-identity

1 Introduction

The World Health Organization (WHO) ^[1] emphasized that deficiencies have been reported in elderly care globally. Many older persons are at risk of maltreatment when they are deprived of their dignity through insufficient care. Deficiencies in elderly care are also highlighted in international studies where home care staff’s lack of time creates anxiety and uncertainty in the older person’s daily life ^[2]. Also in Sweden deficiencies have been reported, work routines take priority over the needs of the older persons, and older persons and their relatives’ complaints are trivialized ^[3]. The Swedish government, who is in charge for overall health and medical care policy, has drawn attention to the deficiencies, and concludes that the deficiencies are general in terms of core values and attitudes towards older persons. Older person’s ability to influence the content and design of their care is limited ^[4]. To address the deficiencies in elderly care the Swedish government introduced national guidelines, with core values and local guarantees of dignity, and gave each municipality the responsibility to create its own guidelines ^[4]. The municipalities are responsible for the elderly care, mainly consisting of home help service, nursing home care and home care ^[5]. The aim of the guidelines was to assure the older persons dignity and well-being and that their daily lives should be organised in a meaningful way. The core values should guide the

way in which the work in elderly care should be carried out. The local guarantees of dignity provide the older persons and their relatives' concrete definitions of what they can expect in terms of municipal elderly care ^[4].

Haugans stresses the importance of activities in nursing homes as well as interaction between the staff, the older family members and their relatives, which in turn is directly related to meaning in life, hope and self-transcendence for the older family member ^[6-8]. Meaning in life also increases the older family member's physical and emotional health and global well-being ^[6, 7]. Relatives are also of great strategic importance to meet the increasing need in health and social care ^[9], thus they should be considered as co-providers of care ^[9, 10]. Internationally, informal care in the older persons' own homes (ordinary housing) is primarily provided by relatives ^[9-12], spouses, adult children, grandchildren ^[13, 14] or friends ^[9, 13, 15]. Relatives can help older family members by providing care or supervising daily activities ^[15]. Both practical and emotional care work are part of informal care ^[13], where the former refers to assistance with personal hygiene, household duties ^[14] and transportation, and the latter implies emotional support ^[16] and being close to the older family member ^[17]. Informal care can be burdensome ^[18-20] as well as positive ^[21]. It can be perceived as a moral obligation or as something natural that relatives want to do ^[22]. Many relatives also have a strong engagement in defending the older family members' interests as they, from own experience, know how the care receiver wants to be treated by others ^[23]. They can act as advocates ^[13, 24] and be protective ^[20, 22, 25, 26] due to low expectations or experiences with poor quality of care ^[13].

When the older family member is receiving home care or lives in nursing home accommodation, her/his relatives can find it stressful and difficult being involved and having to make decisions ^[25]. Relatives continue to be engaged in the older family members care in nursing homes, where they can contribute to almost all care activities ^[27, 28] including psychosocial care ^[25]. When an older family member moves to a nursing home, the relative might fear that the family member will have feelings of a new life without meaning ^[29], and not receive adequate, loving care and attention or be understood ^[30]. The experience of the older family members or their relatives are seldom taken into account, when new guidelines are introduced in elderly care, as the guidelines often are formulated using a top-down approach. The relatives have an important role ^[31, 32] as informal caregivers, specifically for older family members that not can make their voices heard ^[4]. Based on this reasoning, the present study uses a bottom-up approach. This mean that focus in this project is the relatives' perspective on a meaningful daily life for the older family member, with the aim to describe the relatives' experience about obstacles and opportunities for a meaningful daily life for their older family member.

2 Methods

This research project has an action research approach which is characterised of cooperation between the participants and the researchers in part of or in the whole research process, in order to create knowledge about problems in practice ^[33]. Furthermore, the project is based on Participatory and Appreciative Action and Reflection [PAAR]. The difference between PAAR and other action research is the appreciative approach. This means that the researchers applied an appreciative approach and tried to identify what worked well in practice together with the participants, in this study the relatives. However, the intention was not to overlook problems and deficiencies but to adopt a creative yet critical stance and seek opportunities together with the participants ^[34]. In this project the relatives participated in the first step of the data analysis, as they also analysed and reflected on the content of the interviews.

2.1 Context and participants

This study was part of a larger action research project, with focus on what constitute a meaningful daily life for older persons living in ordinary housing with home care or in nursing homes. The larger project aimed to seek obstacles and opportunities for developing a meaningful daily life from the older persons' perspective by working together with the older persons, their relatives, staff and managers. Another aim was to use these data to formulate core values and local guarantees ^[35].

The older family members participating in the larger project were recruited from five randomly selected nursing homes and three home care units in one municipality in Sweden. To include places with variations^[36], the selection of nursing homes and home care groups was based on the results (favourable, average, and low ratings) in a user survey regarding quality of the elderly care^[35]. The three home care groups had received favourable, average, and low ratings in the user survey, and among the nursing homes, two received favourable ratings, one had average ratings and two had low ratings^[35].

Forty older family members participated in the larger study^[35,37,38], and twelve of them named an individual that she/he considered a relative. Older family members who didn't name a relative believed that the relative lacked time to participate in the research study or did not have a relative. The identified relatives received written information and were invited to participate in the present study. Consanguinity between the older family member and relative was not a study requirement. All 12 relatives, seven women and five men, accepted to participate. Their mean age was 59 years (range 44-80). Two spouses cohabited with their older family member, while one spouse, one sibling and eight adult children did not. All relatives had experience of home care and seven were also familiar with nursing homes.

2.2 Ethical considerations

Before presumptive relatives were contacted several ethical considerations were made.

Relatives can be in a vulnerable situation when their older family member is in need of home care or lives in a nursing home. They can be afraid to express their experiences as their older family member is dependent of care. The relatives were asked and informed by letter to participate in the study and provided their written consent to participate. Furthermore, at the first encounter and before each interview, they received oral information and were asked if they still wished to participate. It was stressed that participation was voluntary and that they could discontinue their participation at any time without explanation and without affecting their older family members care. An application to the ethics committee was approved (no. 2011/009).

2.3 Data collection

The research is built on a co-creation of data and knowledge, where the focus was on the relatives' experience of how to create a meaningful daily life for their older family member. The research was carried out in two phases. In phase one a series of interviews were carried out as reflective conversations^[35]. Three relatives participated once, seven relatives twice, and two relatives on three occasions. Three relatives only participated once due to lack of time and that they had no more information to add after the first interview.

The interviews were conducted by one of the authors (EL). The relatives chose the time and location of the interviews, for example their home or the author's (EL) workplace. It was important to build a trusting relationship in order to create a deeper understanding of the relatives' experiences.

The reflective conversations were held as "true" dialogues, *i.e.* that the author (EL) did not determine the direction of the conversation in advance^[39]. Issues for reflection were what factors could be positive for daily life at that particular time. The questions were; How can opportunities be created? Which factors are less favourable, Which obstacles can exist in daily life? The interviews were digitally recorded and transcribed verbatim, after which they were documented chronologically and compiled on an ongoing basis. The relatives then read the compilations and, together with the author (EL), provided their analyses and reflections on the content of what had been said regarding a meaningful daily life. These conversations were also recorded and transcribed verbatim.

2.4 Analysis

In phase two a qualitative inductive content analysis was carried out in a number of steps^[40]. In the first step, the first and last author read through the transcripts several times to obtain a general sense of the whole. In the second step, meaning

units related to the same central meaning and relevant to the aim were identified before being condensed into smaller units that remained close to the text (codes). In the third step, the manifest content of these codes was sorted into obstacles and opportunities for a meaningful daily life on the basis of their differences and similarities. In step four, the underlying meaning in the codes was interpreted, to determine the latent content. Finally in the last step the codes were compared and checked for differences and similarities, after which they were sorted into subthemes and themes. The latent content in the themes were summarized and an overall theme emerged that described the relatives’ experiences of what created a meaningful daily life for their family member. During the analysis, all authors scrutinized and repeatedly discussed the results to ensure the trustworthiness of the data analysis and the best form of presentation.

3 Results

The relatives’ experiences of obstacles and opportunities for a meaningful daily life for their older family member were interpreted into twenty subthemes. Five themes describe how a meaningful daily life can be created (see Table 1). Each theme presented in the results ends with a summary. Words that have been omitted are indicated by (...) and square brackets [] are used for comments by the authors. In the following, “staff” will be used to denote home care and nursing home staff.

Table 1. Overview of subthemes, themes and the overall theme

Subthemes		Themes	Overall theme
Obstacles	Opportunities	Creation of a meaningful daily life	
A Deterioration in Daily Life and Health	The Family Knows Best	Theme 1. Relatives and Staff should Maintain the Older Family Member’s Routines and Habits	In partnership to maintain the older family member’s routines and habits in an everyday rhythm filled with meaning, in a home like environment and in community with others.
Unsafe	Staff in Control		
No Time			
It’s not a Home	It’s a Home	Theme 2. Adaptation of Routines and Habits to Maintain Daily Life and Provide a Home-Like Environment	
Workplace or Home	Adapting		
Unfamiliar Staff	Familiar Staff	Theme 3. Staff should be responsive to the older family members everyday rhythm	
	Everyday Rhythm		
No Taste	Taste		
Loneliness	Togetherness	Theme 4. Daily Life Should be Filled with Meaning in Community with Others as it used to be	
Emptiness	Richness		
Marginalized	Participation	Theme 5. Relatives and Staff Should Collaborate to Maintain and Continue the older family members Routines and Habits.	

3.1 Theme 1: Relatives and staff should maintain the older family member’s routines and habits

- **A Deterioration in Daily Life and Health.** Relatives noticed that their older family member’s appearance and health deteriorated due to age and/or illness. An obstacle to a meaningful daily life was failing physical and

cognitive health as well as limited mobility. The older family member could no longer walk as before and was thus unable to maintain previous routines and habits such as shopping, going to the bathroom or taking a shower, which meant that she/he lost control over her/his daily life. The memory could also fail; the older family member sometimes forgot how to perform certain everyday tasks, such as turning off the oven. “not as meaningful as if she had been healthy, but she’s mainly restricted by her disability.”

- **Unsafe.** Another experience of the relatives was that their older family member felt insecure in daily life when no longer capable of maintaining habits and routines. Staff did not have the knowledge to compensate for the lost functions, which created a lack of balance in daily life giving rise to feelings of insecurity, “...the situation in the home made him feel very insecure.”
- **No Time.** Further obstacles to a meaningful daily life from the relatives experiences were that the staff members were stressed, under time pressure, and could only perform the most necessary tasks. They did not maintain the older family members routines and habits and the time pressure had a negative effect on their way of speaking and responding to the older family member, which was perceived as disrespectful and insulting. The older family member had to wait for staff to come and help, which was especially difficult when she/he needed to go to the bathroom. “Sometimes it took a very long time. And then he kept saying: look if you can see them; look if you can see them. But please X, they will come as soon as they can. And when they arrived – But you’re wearing diapers, you can crap in them. Yes of course I can but then it will be tougher for you, I don’t like it, he said. But all of a sudden it struck him that I could do it”.
- **The Family Knows Best.** An opportunity was that the relatives had experience, and could perform the necessary tasks when the staff failed to do so. Staff members were under time pressure, lacked experience, and did not manage to do what was necessary. The caring actions should be related to the older family members’ individual needs and performed by experienced hands. As the relatives had this experience it became an opportunity; that they could perform the care. It was not burdensome because they were used to it and could do it in a routinized way. “I do it as a matter of routine and it’s relatively quick. I’m familiar with all the different practical tasks and perform them without thinking. I wouldn’t feel any calmer, wouldn’t regard it as a relief if somebody else came and gave X a shower”.
- **Staff in Control.** The relatives also stated that some staff had experience and knowledge. It was an opportunity that they could assume responsibility for the older family member’s everyday habits and routines, which led to security for both the relatives and their older family members. These staff members were experienced as competent and knowledgeable and were generally available 24 hours a day in nursing homes as opposed to home care.
- **Summary.** There were several obstacles to a meaningful daily life. The older family member’s daily life and health deteriorated. Routines and habits could not be maintained, thus leading to insecurity. The relatives experienced that the staff that cared for the older family member lacked adequate knowledge and found the work stressful. An opportunity for a meaningful daily life was when relatives and/or staff tried to compensate for the deterioration in the older family member’s condition and took responsibility for maintaining her/his routines and habits. This could be done by providing care based on the older family member’s individual needs and the relative’s knowledge of their older family member.

3.2 Theme 2: Adaptation of routines and habits to maintain daily life and provide a home-like environment

- **It’s not a Home.** The relatives experienced that the older family member’s indoor and outdoor environment was important for confirming the older family member as an individual, giving her/him a sense of belonging. Moving to a nursing home, not having the opportunity to decorate the new home with items of great personal value to the older family member, was an obstacle that prevented her/him from feeling ‘at home’ there. ”And then an otherwise nice

[staff member] says –the desk is actually in the way. And then I felt like...it's Dad and we didn't think it was in the way... Then I felt a bit upset, it has no value, but it's Dad. His desk ... And then I said that I will never, ever move any desk, never (laughing). No – it's Dad's cuddly toy”.

- **Workplace or Home.** Another obstacle was that the relatives experienced that both they and their older family members became marginalized in their own homes when the staff arrived and introduced routines that differed from their own usual routines and habits; wearing outdoor shoes in the house and not cleaning up. This meant that the home became untidy and was seen as a work place for the staff instead of a home, which the relatives found insulting. “Of course they do their job but after all it's my home and I don't want...but now I'm only bringing up the drawbacks, I think the towel should be placed on the towel hanger, not thrown, tubes of ointment in the bed, I find [them] all over the place”.
- **It's a Home.** When the indoor- and outdoor environment in ordinary housing or the nursing home was home-like, it became an opportunity because it allowed the older family member to continue to live as usual and gave a sense of belonging. If she/he had access to appropriate housing and the opportunity to cook it created a feeling of being at home.
- **Adapting.** One opportunity for creating a meaningful daily life involved helping the older family member to adapt and take advantage of the possibilities that existed. This meant that she/he could make choices in daily life to some extent. “I try to make Mom understand that she can still make choices; she can still influence her life. She can choose that [to stay] or she can choose to live in a nursing home and then there will be people around her who represent a more permanent group of staff”.
- **Summary.** Obstacles to a meaningful daily life from the relatives' experiences were that a nursing home differed from a home and staff treated ordinary housing as a work place. In order to create an opportunity for a meaningful daily life it was necessary for the older family member to adapt to her/his new situation and for the environment to be perceived as a home, where the older family member continued to live in the usual way having a sense of belonging and feelings of being at home.

3.3 Theme 3: Staff should be responsive to the older family members' everyday rhythm

- **Unfamiliar Staff.** The relatives experienced that an obstacle to a meaningful daily life was when the older family member did not know the staff that performed the care, and as these staff members did not know the older family member, they were unable to provide adequate care. “They say – now we have extra staff...they don't know where things are, they're not familiar with the routines. The old-timers [experienced staff] know exactly.” Another obstacle was furthermore staff members who did not speak clearly, were vague, and difficult to understand, especially if the older family member had a hearing impairment. When staff of the opposite sex assisted with personal hygiene, for example a male nurse helping an older woman to take a shower, was also seen as an obstacle. It was also stressful and tiring for the relatives and their older family member when staff did not know how to perform practical tasks like putting on stockings or changing the catheter bag, as they had to instruct them about practical routines and personal habits.
- **Familiar Staff.** An opportunity for a meaningful daily life from the relatives' perspective was the presence of staff who knew the older family member and the relative, and with whom they had a trusting relationship. The contact person was considered, “the best person of all.” A relative narrated that the older family member and other members of the family liked the contact person: “who he likes, her name is X. And then he says – how nice that she's on duty today, she'll put ointment into my eye and massage my hand, which they do every morning. So they're very conscientious. They check everything. I think they're great”.

- **Everyday Rhythm.** Relatives also experienced staff members who were flexible and based the care on the older family members' needs, habits, and wishes and confirmed her/him as a person. It involved being close, and the staff member was also regarded as a proxy relative, where her/his responsiveness, involvement, and responsibility created a relationship with the older family member that provided an opportunity for a meaningful daily life. "What you hope and wish for is that someone will care and take personal responsibility, and see their needs the same way you would." From the relatives experiences it was important that in the encounter with the older family member, staff must try to put themselves into her/his situation; be interested, present, and focused, see and acknowledge the person, and not think about the next older person on their round, i.e. adopt the older family members' "everyday rhythm", and way of being. "It's about seeing, being interested in and curious about that person as well as being there when you're there. So even if it's only for five minutes, it's essential to really be there during that time."
- **No Taste.** The food and meal situation could be an obstacle to a meaningful daily life. Several relatives complained that the food was bland and should be adapted to older people's taste and habits. It was not just about the food as such, but also how it was served; it made a difference if the portion was too big and whether it was served on a plate or in a lunchbox. "Then my grandchild talked to them, sure he would be getting oatmeal porridge. So I went into the kitchen and spoke to the person there, and she said: I can't be making oatmeal porridge. I said, but please, it only takes two minutes, don't you have a microwave? Yeah. - I said, it takes two minutes, it's not any more work than putting out a carton of yoghurt".
- **Taste.** It was an opportunity if the older family members were served food they were used to. The older family members in elderly care in the municipality could, to some extent, choose between two courses, which were seen as something positive from the relatives' perspective. The various dishes should also have names that the older family member recognizes so that they are aware of what food is on the menu.
- **Summary.** The relatives experienced that obstacles to a meaningful daily life were staff who they and their older family members did not know, food that was not suited for the older family member's dietary habits, and staff that could not perform practical tasks. In order to create a meaningful daily life, it was essential that the older family member and the relatives knew and could trust the staff. Knowing the staff was seen as an opportunity. The creation of a meaningful daily life also requires an everyday rhythm characterized by interaction with staff members who are responsive to older family member's needs, habits and routines.

3.4 Theme 4: Daily life should be filled with meaning in community with others as it used to be

- **Loneliness.** Relatives experienced that an obstacle for a meaningful daily life was that their older family member had become lonely and isolated because of declining health or the illness and death of her/his partner. Due to this, it was often difficult to meet other people and participate in social contexts. The older family member was sometimes lonely and isolated, even in the nursing home. The other residents could be in their rooms and there might be no opportunity to make contact: "When I visit Dad, everybody is in their own little pigeonholes – rooms. That's what they do, even though they're completely lucid. He's always in his room."
- **Togetherness.** Several relatives believed that an opportunity for a meaningful daily life was if the staff worked more actively to ensure that the older family member met other older family members' by pairing them with each other, so that they could talk and experience a sense of community. Relatives also wished that the staff would have time to sit down and talk with their older family member. They considered it important that she/he was allowed to make use of and demonstrate the valuable knowledge she/he possessed. "Even if they don't have the energy to do very much themselves, they could at least get to take part in the process. Maybe give good advice. Mom was so proud about six months ago, when they were making their own rice pudding. And two young girls there didn't know what to do and Mom told them how to make it. She was so proud that she told me about it".

- **Emptiness.** Daily life became empty, meaningless when the older family member did the same thing every day or had nothing to do. Relatives found that this occurred when no activities were offered, or the available activity was perceived as meaningless. Another obstacle was that the older family member was unable to maintain her/his former interests. If previously an active person and such opportunities no longer existed, she/he became isolated due to lack of the familiar context. “But that’s not my Mom because my Mom was a working woman and professionally active, she belonged to a lot of societies and was a leader and that kind of thing.”
- **Richness.** An opportunity for a meaningful daily life was to facilitate the family member to participate in different social contexts. There was no need for any extensive programs but simply an opportunity to do something she/he enjoyed. In that way daily life could be associated with the older family members’ interests and personality. The activities could be initiated by the older family member her/himself, relatives or staff. “Every day, if he can’t do it [his training], he gets into such a bad mood. It’s part of his daily routine. Without it there wouldn’t be anything meaningful for him because he isn’t interested in reading, as he can only see the right-hand page”. Relatives described how staff arranged a range of activities, such as inviting the older family member to different forms of musical entertainment, and that people from the church came to play music and sing. The staff also organized different games, baking or cooking together with the older family member, and enjoyed a meal with them.
- **Summary.** One obstacle to a meaningful daily life was the older family members’ loneliness and that they felt that their life nowadays was empty and meaningless. Opportunities for a meaningful daily life could be created by making them part of a context in which they could experience a togetherness as it used to be, to be of value to others, and do things related to their interests in community with others.

3.5 Theme 5: Relatives and staff should collaborate to maintain and continue the older family members routines and habits

- **Marginalized.** Relatives experienced that it was an obstacles for the older family member and for themselves not being able to continue their own relationship as they were used to. Their relation was seen as important to create a meaningful day for the older family member. They had lived with the older family member, had long experience of caring for her/him, and knew how she/he wished to be treated. The staff did not listen to nor ask about their knowledge and experience. Relatives had the impression of not being trusted to participate in their older family member’s care and felt marginalized. “Then you can raise matters in a different way. What’s your opinion? We notice that your Dad isn’t feeling well at all, can we sit down and talk for a while, you know him best...how do you think he wants us to treat him? That would have felt better, but such conversations never took place”.
- **Participation.** An opportunity for their older family member and for themselves was if the relatives could continue to play a role in their older family members’ daily life by having a good relationship with the staff. Continuous participatory follow-up by monitoring and evaluating their daily life and health in dialog with the relatives was also necessary. Further it was determining whether staff routines and habits were satisfactory and what could be improved. When the staff confirmed both the older family member’s and the relative’s needs it created a sense of still belonging and continuing to be a family. “And I was waiting at home and then they called from NN; you shouldn’t be home all alone at Christmas, come join us. So I went there, it was the nicest Christmas gathering I’ve ever attended. They had made the place so nice and cozy and they even had a Santa. They’re so nice, which I appreciated”.
- **Summary.** One obstacle to a meaningful daily life was that relatives felt marginalized which effected their relation to the older family member. Their relation was an opportunity for creating a meaningful daily life for the older family member and it was important that the relation maintained. If staff and relatives actively worked together, monitoring and evaluating the older family member’s daily life it created meaning. Another opportunity were when relatives and staff collaborated to maintain and continue the older family members’ routines, and habits.

4 Discussion

The findings revealed that relatives' experience about obstacles and opportunities for a meaningful daily life for their older family member can be interpreted as: In partnership to maintain the older family member's routines and habits in an everyday rhythm filled with meaning, in a home like environment and in community with others.

In order to create a meaningful daily life in nursing homes and home care it is important to learn from the relatives' experiences. Their relation and interaction with the older family members is related to meaning in life^[41,42]. Therefore, it is useful to further analyse and discuss the results in the present study theoretically to deepen the understanding of the relatives' experiences of obstacles and opportunities for a meaningful daily life for their older family member. The result shows the importance of maintained habits and routines for the older family member. We found, in accordance with Giddens, that this can be described as maintaining the older family member's lifestyle. The lifestyle or routines are incorporated into our habits of dressing, eating, acting, and encountering others. Lifestyle is actions that we have chosen, that are practical and integrated in us, and that become our self-identity^[42]. In the following we will deepen the understanding of the importance of lifestyle and self-identity for a meaningful daily life for the relatives' older family member.

4.1 Lifestyle and identity

That the older family members' health deteriorated and that she/he no longer could maintain habits and routines, can be interpreted as a threatened identity^[43]. Relatives thus became spokespersons for their older family member's lifestyle and identity. They can be protective^[20, 22, 25, 26] act as an advocate^[13, 24], and feel responsible for ensuring that their older family member receives the care she/he needs^[22, 44, 45]. One obstacle to a meaningful daily life was that relatives believed that the staff had no social skills, no or little knowledge of their older family member's needs, and basic skills. Similar results can be found in other studies that describe how older people are obliged to eat, shower, or go to bed in accordance with a schedule tailored to the current staffing level instead of older people's individual needs.^[3, 22, 30] In our study as well as those by Eldh and Carlsson^[13] and Hasson and Arnetz^[46], relatives assumed responsibility for the care when staff did not take care of their older family member in a satisfactory manner. In this way relatives, in accordance with Giddens^[42] can safeguard their older family member's identity.

An opportunity for a meaningful daily life was created when the same staff members cared for the older family member so that they got to know her/him and developed a routine in the performance of caring interventions. The routines should be adapted to the older family member. The way in which the routines are performed can be important because there are links between rituals and routines and illness and health^[47]. Both routines and rituals have been shown to have a protective function in chronic illness^[48]. Routines and rituals include roles and actions and thus contribute information about the older family members' identity^[47].

4.2 A homelike environment

Lifestyle is also about how we choose to live, organize our home and daily life, and gain control^[42]. Our study stressed the importance of being allowed to keep one's own furniture, which also represented the identity of the person, expressed by one relative as: "it's Dad." Relatives stated that a home-like environment in the nursing home could be an opportunity for their older family member to continue living as before, which contributes meaning to daily life. Rämgård^[49, 50] holds that people's relationship to places affects daily life. The design of physical environments can contribute to the exclusion of the individual. Peace^[51] described nursing homes as an example in society that can be likened to living a private life in a public place. However, the place where older persons live and die is also the workplace of staff.

When there is illness in the family, it is vital that there is a place that provides security^[49, 50]. As long as the older family member is living in ordinary housing, she/he can perceive it as home and a safe place. However, this study illustrated that it became more difficult when staff introduced their own routines, and Twigg^[52] described how the care moved into the

family home and changed the rhythm of daily life. This is especially true in the case of advanced care characterized by technology^[53] as the home can become unfamiliar which in turn affects the relationships and interactions within the family^[52]. Physical environment may thus be important for the older family member and relatives, family, as it represents continuity, meaning, context, and identity in daily life^[49, 50].

4.3 The body and self-identity

The body can be a source of joy and pleasure but also of pressures and diseases^[42]. Relatives observed their older family member's appearance and mobility problems. The body's ability to cope with daily life and interact with others is important for the sense of identity. The body is used to enhance the identity by creating a special impression of the self^[42]. Older persons often have multiple diseases and can become overwhelmed by pain and confusion, where the body can become a prison and dominate daily life. The older family member may be dependent on performing habits and routines as rituals to retain control, thus ensuring that the body continues to function^[54]. Older persons need time to perform bodily care, which is a way of retaining control. Relatives considered that staff members lacked the necessary time when the older family member needed more help, for example, with bodily care, which impacted on their way of expressing themselves, acting toward, and responding to the older person. The response of others was significant for how the older family member engaged in social interaction^[42]. Being obliged to use diapers instead of being allowed to go to the bathroom is not only a violation of a person's dignity but also of her/his identity. This raises the question of how the older family member will interact with the staff and her/his relatives as well as how she/he will view her/himself after such a violation. In order to interacting and for the self-identity the body is of importance^[42].

4.4 A meaning in life

The relatives described that daily life should be filled with meaning. However, the older family member was often alone or did not have anything to do; daily life became empty and meaningless. It appears that activities are not a priority either in home care or in nursing homes^[46]. Many nursing homes organize group activities, but the older family members wanted more individual pursuits. A wide range of activities is necessary to meet the needs of persons with different backgrounds and interests^[29]. The study by Cohen-Mansfield, Golander and Arnheim revealed that relatives' visits, music, walking outdoors, story-telling, watching TV, and talking about interests enhanced the older persons' sense of identity, which in turn increased their well-being^[55].

4.5 To be responsive to the everyday rhythm

Feedback from others is important for social interaction. Here the staff's responsiveness to the older family member is significant; how they use their face, voice, and body language^[23, 42].

Relatives argued that the staff should be able to identify their older family member's needs and being close and create a relationship. It is the relationship between the staff and the older family member that gives meaning to daily life. The relatives in our study stated that in the encounter with their older family member, the staff should be present in the situation, i.e. be interested and adapt to everyday rhythm, and way of being. This can be achieved by always greeting the older family member, shaking her/his hand, as well as through eye contact and facial expressions to indicate interest^[56].

Furthermore when the staff was flexible and proceeded from the older family members' needs, habits and routines that she/he was used to in daily life, her/his lifestyle and identity could be confirmed. This can be seen as that the staff used the right tact, where one senses and reads where another person is in a particular situation. Based on this, the staff can adjust the tact, the way of being, to the older family member's everyday rhythm^[39]. The staffs interaction with older family member has significance for the older persons experiences of meaning in life and can also increase their physical and emotional health and global well-being^[6, 7].

4.6 In community with others

The relatives know how their older family member wants to be treated by others^[23]. They protected her/his lifestyle and identity and knew how routines should be performed. On the other hand, a person's identity is not permanent^[42] and can also change as a result of disease^[55, 57]. Abma et al.^[57] described how an older man with dementia did not recognize any of his relatives. After moving to a nursing home, he returned to his former role as manager. The staff confirmed his identity, let him sit in an office and gave him documents to fill in, which increased his well-being. If the older person has no role it might be beneficial for the staff to assign one to her/him. In the present study the relatives related the impact of giving their older family member a role, even for a short time: "And two young girls didn't know what to do and Mom told them how to make it [rice pudding]. She was so proud that she told me about it." The relatives in this study wished that the staff should pair the older people with one another so that they could experience a sense of community and a meaningful life. Somewhat surprisingly, Wolff's^[58] study revealed that friendship with other elderly individuals in nursing homes is more important for satisfaction with living conditions as well as for preventing feelings of sadness or depression than visits from relatives.

4.7 Participation and partnership

The relatives' experienced that they were marginalized, which is surprising since it is acknowledged that they provide extensive informal care^[4, 9, 12, 59] and can be considered co-providers of care^[9, 13]. Informal care has been, and may still be, a prerequisite for family health^[60]. It could be that the staff has no interest in interaction with relatives^[13, 25, 61], which could involve an involuntary "divorce" between relatives and their older family member. Irrespective of what the previous relationship was like between the relatives and the older family member, for example burdensome and/or meaningful, divorce always involves grief^[42]. This study demonstrated that the relatives wanted to participate in the care of their older family member, in order to remain close and continue the relationship. Apart from the emotional relationship, it can be a way of monitoring her/his needs and interests^[13]. It can also be described as that the relatives had adopted an advocate's role where they represented their older family member's lifestyle and identity.

However, the concept of advocacy can involve a form of paternalism where one tries to obtain what is believed to be good for the other person^[62]. In such situations staff can adopt an advocacy role and protect the older family member from her/his relatives and the caring intervention they propose^[22]. This can cause conflict as well as a tug of war between staff and relatives^[3]. On the other hand, the older family member may want care according to her/his wishes in order to maintain control over her/his life^[22].

Nursing care must be based on a partnership perspective where the relationship and care are co-created by the staff, the older family member and her/his relatives. The relationship should be based on collaboration and partnership in mutual learning to maintain the older family members' lifestyle and self-identity^[42, 56]. Staff is important as its members may have knowledge about any changes in the older family member's routines and habits, *i.e.* lifestyle. However, when working together in partnership, it is important that both relatives and staff are aware that identity develops throughout life^[42].

5 Limitations

One limitation in the present study is that we did not distinguish between relatives' experience of home care and nursing homes, which would have been valuable. However, as some of the relatives had experience of both, this would have been difficult and the result might have been misleading. Another limitation is that the older persons did not participate in the study; however this will be rectified by other studies^[37, 38].

6 Conclusion

The partnership between the relatives, older family member and staff should result in that the family members' routines and habits i.e. lifestyle should maintain. The partnership should be built on mutual learning without hierarchy where everyone's voice is equally important^[56]. The older family member's life story could be a useful tool; who the person is, her/his self-identity, how she/he relates to others, and her/his values become visible in her/his life story^[42]. Furthermore, how to create a homelike environment, perform bodily care and how to be responsive to the everyday rhythm and find a meaning can also be explored in the older family member's life story. A biographical approach in elderly care can mean that the older person feels confirmed and that the relationship between staff, the older person, and her/his relatives is strengthened^[63]. Relatives may experience satisfaction and empowerment by providing knowledge about their older family member using a biographical approach, which could increase participation^[64]. On the other hand the older family members can sense that they contribute to their relatives' experiences by telling about her/himself. Together they can continue the family life story.

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