

# LUND UNIVERSITY

### Family members' strategies when their elderly relatives consider relocation to a residential home

### Adapting, representing and avoiding

Söderberg, Maria; Ståhl, Agneta; Melin Emilsson, Ulla

Published in: Journal of Aging Studies

DOI: 10.1016/j.jaging.2012.07.002

2012

Link to publication

Citation for published version (APA):

Söderberg, M., Ståhl, A., & Melin Emilsson, U. (2012). Family members' strategies when their elderly relatives consider relocation to a residential home: Adapting, representing and avoiding. Journal of Aging Studies, 26(4), 495-503. https://doi.org/10.1016/j.jaging.2012.07.002

Total number of authors: 3

#### **General rights**

Unless other specific re-use rights are stated the following general rights apply:

- Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the
- legal requirements associated with these rights

· Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
You may not further distribute the material or use it for any profit-making activity or commercial gain
You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: https://creativecommons.org/licenses/

#### Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

LUND UNIVERSITY

**PO Box 117** 221 00 Lund +46 46-222 00 00

# Family Members' Strategies When Their Elderly Relatives Consider Relocation to a Residential Home – Adapting, Representing and Avoiding

PhD-candidate Maria Söderberg \*1

Prof. Agneta Ståhl<sup>2</sup>

Prof. Ulla Melin Emilsson<sup>1</sup>

<sup>1</sup> The School of Social Work. Lund University, Sweden

<sup>2</sup> The Department of Technology and Society, Faculty of Engineering, Lund University, Sweden

### Abstract

The aim of this article is to reveal how family members act, react and reason when their elderly relative considers relocation to a residential home. Since family members are usually involved in the logistics of their elderly relative's relocation, yet simultaneously expected not to influence the decision, the focus is on how family members experience participation in the relocation process in a Swedish context. 17 family members are included in 27 open, semi-structured interviews and follow-up contacts. Prominent features in the findings are firstly the family members' ambition to tone down their personal opinions, even though in their minds their personal preferences are clear, and secondly, the family members' ambivalence about continuity and change in their everyday lives. Family members are found to apply the *adapting*, the *representing*, or the *avoiding* strategy, indirectly also influencing their interaction with the care manager. Siblings applied the adapting strategy, spouses the representing strategy, while family members in the younger generation at times switched between the strategies.

Keywords: Older people, relocation, residential home, family member, decision-making

<sup>\*</sup> Email: Maria.Soderberg@soch.lu.se

# Introduction

Many older people express strong preferences to remain in their own homes for as long as possible, and in many societies there is even an ideology of ageing in place (Clough, Leamy, Miller & Bright, 2004; Cristoforetti, Gennai & Rodeschini, 2011; Heywood, Oldman & Means, 2002). However, due to declining health they gradually become dependent on others for their everyday lives, and eventually they reach a point when they start considering relocation to a residential home. This is a difficult situation not only for the older person but also for the family. In contrast to most countries in the western world, the care of older people in general is an integrated part of the welfare state in Sweden, which means that the responsibility for the care does not fall on the family (Welfare Commission, 2002). Through the Ådel Reform, put into practice in 1992, all Swedish long-term medical care of older people in residential care became a municipal responsibility, under the Municipal Social Welfare Services Department governed by the Social Service Act (Social Dept., 1989). But at the time when the reform was introduced, the 1990's economic recession strongly contributed to an increasingly restrictive approach. This has led, not only to a decrease in municipal home care (Johansson, Sundström, & Hassing, 2003; Szebehely, 2005a), but also to a situation in which admission to residential homes has become highly selective, in accordance with the Swedish sociopolitical principle of ageing in place.

There are a number of actors on different levels to influence the distribution of resources in Sweden (Thorslund, Bergmark & Parker, 1997), and the framework laws give local governments and professionals extensive command of the resources. The care managers' role is to carry out the needs-assessment process, make the decisions on whether to grant or reject the

support requested including relocation to a residential home, and they also control the distribution of available rooms under municipal co-ordination, which must be considered to be a prominent feature of the Swedish system. Today the older people who are granted a place in a residential home usually have needs appearing unpredictably in terms of difficulties in orientation, or caring needs with short and critical intervals (Westlund & Persson, 2007). As a consequence, even older people with considerable need of care have to stay longer in their own housing, and as a result their families are becoming increasingly involved in a daily helping role as well as in the relocation process. The Social Services Act (2001:453) stipulates respect for a person's self-determination and integrity, and in this context it provides that family members are not formally allowed to apply for a residential home placement on behalf of their elderly relatives. Instead, all people who need help caring for themselves have the right to claim assistance 'if their needs cannot be met in any other way', such as with the support of adult children (Larsson & Silverstein, 2004).

This article focuses on the family members' situation when their elderly relatives are about to make one of the most difficult decisions in their lives: to irrevocably leave their own private homes (Kontos, 2000; Nolan & Dellasega, 2000; Ryan, 2002; Sixsmith, 1990). It is based on data collected in the framework of the research program 'Changing Place of Living in Old Age', carried out within the context of CASE (Centre for Ageing and Supportive Environments) and the School of Social Work at Lund University. With the main focus on older people, the aim of the research program in its entirety is to explore the process related to a potential relocation to a residential home from the perspectives of older people, their family members and the professionals involved. Data used in the present article are related specifically

to the decision-making of family members who are trying to balance respect for their elderly relative's self-determination and integrity, their desire for the best possible care, and their own personal life situation. The material was thematically analyzed. With the aim of understanding family members' action and interpretation of the relocation process, the analysis was also inspired by a desire to try to understand the interpersonal processes. Combined with a social psychological starting point (Scheff, 1990), certain mechanisms within the life-course perspective (Bengtson, Burgess, Parrott & Mabry, 2002) were applied as a theoretical framework.

### Family involvement

The access to formal care in northern Europe has sometimes been contrasted to the intergenerational care more prevalent in southern and central European countries (Haberkern & Szydlik, 2010). Nevertheless, filial solidarity is not incompatible with welfare state arrangements, nor do filial obligations per se imply that the family is considered to be the 'natural' care provider (Daatland & Herlofson, 2003). As ageing is inescapable, older people face a situation where they increasingly need assistance, and in many countries family members are forced into a situation of growing responsibility and finally a decision to carry out the relocation — without having any real choice (Nay, 1996; Ryan & Scullion, 2000). On an international level and in different societal systems, research has previously paid attention to family members when their burden is too heavy regarding everyday responsibilities (Gallagher, Mhaolain, Crosby, Ryan, *et al.* 2011; Epstein-Lubow, Davis, Miller & Tremont, 2008). On the research agenda there are studies about how to better support family members in their elderly relative's transition to a long-term care setting (Davies & Nolan, 2003; Flynn Reuss, Dupuis & Whitfield, 2005; Nolan, Walker, Nolan, Williams, *et al.*, 1996; Pruchno, Michaels & Potashnik, 1990), and how to better support them after the relocation (Dellasega & Nolan, 1997; Strang, Koop, Dupuis-Blanchard, Nordstrom, *et al.*, 2006).

Previous research finds that family members do not want to let their elderly relatives down, and the process tends to constitute a time full of ambivalence and agony (Dellasega & Mastrian, 1995; Fjelltun, Henriksen, Norberg, Gilje, *et al.*, 2009; Nolan & Dellasega, 2000; Penrod & Dellasega, 1998). Gradually the resources of the family members ebb, and their continuous loss of wellbeing is frequently referred to as a predictor for older people's nursing home placement (Chenier, 1997; Coehlo, Hooker & Bowman, 2007; Gallagher, *et al.*, 2011).

The situation calls for a change that might be hard to accept both for older people and for their family members. As concerns family members, in several countries they are increasingly expected to play a more significant role both in the initial decision to seek help and subsequently in selecting a residential home (Davies & Nolan, 2003; Dellasega & Mastrian, 1995; McAuley, Travis & Safewright, 1997). Correspondingly, previous research within the area has largely been focused on the family members' uncertainty and their need to validate the decisions they make (Dellasega & Mastrian, 1995; Penrod & Dellasega, 1998; Ryan & Scullion, 2000), as well as on the lack of available information and support mechanisms (Flynn Reuss, *et al.*, 2005; Kellett, 1999). Sandberg, Lundh & Nolan (2002) have studied the roles of adult children who support a caregiving parent in the placement process of an often life-long partner. However, few studies have focused on how family members handle their elderly relative's decision-making process when anticipating a potential relocation to a residential home, while simultaneously they are expected to refrain from influencing the decision. Since

the expectations placed on family members have increased in the Swedish welfare state, more knowledge is needed about how family members experience taking part in the relocation process. More knowledge is also needed about what influences that participation might have on the elderly person who is considering relocation to a residential home.

The aim of this article is to reveal how family members act, react and reason when their elderly relative considers relocation to a residential home. The intention is to answer the following questions:

- How do family members act and react when their elderly relative is considering whether to relocate to a residential home?
- How do family members think and reason about their own actions during the relocation process?
- Are there any differences between spouses, siblings and family members in the younger generation in handling their elderly relative's decision-making process and, if there are any, what are they?

### **Theoretical framework and methods**

The family members' way of handling the decision-making process can be understood in many ways. As several researchers in social psychology indicate (e.g. Sansone, Morf & Panter, 2009), there is interplay between the societal level and the individual level in which the family members try to uphold societal norms in their daily interactions. In the context of this article, there will be references to the norm of older people's self-determination and integrity, due to its relevance for the focus of the study. In Swedish policy documents in general, older people's right to self-determination, autonomy, integrity, and freedom of choice holds a predominant

position (Trydegård, 2000) and, beyond the reduction of institutional placements, the ideology of ageing in place is frequently related to the norm of older people's self-determination and integrity.

Inspired by Scheff (1990), this analysis is influenced by an interest in the 'social bonds' built up in encounters and rituals involving family members and their elderly relative in their everyday lives, in which the decision-making process is a part. Scheff argues that secure social bonds are the force holding a society together, and that this force involves a balance between closeness and distance. Pride is the sign of an intact bond, shame of a severed or threatened bond (Scheff, 1990); pride constitutes a confirmation of being able to meet prevailing ideals in the society, shame emerges from the reverse. Caring for the social bond to their elderly relative, the family members monitor their behavior, trying to safeguard the impression they think they convey (cf. Cooley, 1902/1922; Goffman, 1959/1987; Scheff, 1990).

As a tool to further explore family members' approach to the process, five mechanisms within the life-course perspective are applied, connecting individuals' lives with the aspect of time and social contexts (cf. Bengtson, *et al.*, 2002). In this analysis the mechanisms 'phase of life' and 'reciprocal states of dependence' were followed up in the division of family members in 'same generation' and 'younger generation' in relation to their elderly relative. These variables were correlated to the remaining mechanisms:

- the individual's control of the life-course, trying to adapt to changes
- accentuation of the interaction between personal background and capacity
- circumstantial requirements influencing the individual's ability to adapt to changes

The research question about how family members act and react receives special attention within the frame of the social psychology approach. The research question about the family members' reasoning regarding their own acting, and the research question about potential differences between siblings, spouses and family members in the younger generation, are primarily addressed through the five mechanisms listed above.

### Data collection and context

In all, 21 older people, 17 family members, and seven care managers have been interviewed in a medium-sized municipality in the southern part of Sweden, but this article concerns the 17 family members exclusively. Care managers assisted in the recruiting of older people who had applied for relocation to a residential home. When the first author met the older people, they were asked if it would be possible to access a family member's perspective as well. By way of approval, they handed over the name and telephone number of a selected family member. Only when the family members were expected to have a key role in the practical arrangements of the appointment with the older people were they approached by the care managers. Data regarding this part of the project were gathered between October 2009 and August 2010. The first author interviewed the 17 family members in a total of 27 open, semi-structured interviews.

On 11 occasions the interviews took place in the family members' homes or at their places of work, on 11 occasions by phone, and on 5 occasions at other places such as the first author's place of work. Starting out with the plan of carrying out only one open semi-structured interview with each family member, follow-up contacts took place with six out of 17 family

members (see Table 1). This initiative was taken when data from the older people were limited due to deteriorating health or reduced hearing or speech.

A thematic interview guide served as a checklist. The questions focused on the decisionmaking process, its causes, its course of events, and the family members' standpoints regarding available care of older people. On those occasions when there were follow-up contacts, the questions built on the preceding interviews. With an inductive starting point, the ambition was to maintain an informal tone in the interviews, and to guard 'the sharedness of meanings' (cf. Fontana & Frey, 2005), contributing to questions flowing from the immediate context as in informal conversational interviews (Patton, 2002). All the family members agreed to the request to record the interviews. In exceptional cases when recordings were not made during the interviews or in follow-up contacts, notes were taken simultaneously as the conversation proceeded. The interviews lasted from half an hour up to one and a half hours. After each conversations, notes were taken about additional observations. All 27 interviews and conversations were transcribed verbatim. Names of persons and places were eliminated, and minor details in the citations were changed to guarantee confidentiality.

### The family members

In total the family members consisted of 17 persons related to 18 elderly relatives, as there was a married couple among the latter. The family members were divided into two generations. Four family members belonged to the same generation as their elderly relative, and 13 family members represented a younger generation, hereafter referred to as 'the younger generation'. Two family members of the same generation as their elderly relative were *80-89* and two were 70-79. Five family members in the younger generation were 60-69, five were 50-59, and three were 40-49. Based on the age of the family members in the year of the first interview, their mean age was 61.6 and the range was 41-83. Among the family members there were 11 women and six men. Only spouses shared the same household as their elderly relative. The family members are presented in Table 1, together with the spread of interviews and conversations:

Table 1 Overview o	<i>f</i> the	familv mem	bers and the	spread o	of interviews and	conversations
		,				

Generation	Gender	Numbers of persons	Relationship	Numbers of interviews + conversations / family member
Family members in the same	Male	1	Brother	1
generation as their elderly relative	Female	3	Wife	4+4
			Sister	2
Family members in the younger	Male	5	Son	1+1+2+1
generation than their elderly relative			Son-in-law	1
retutive	Female	8	Daughter	1+2+1+1+1
			Daughter-in-law	2+1
			Niece	1
Total		17		27

Encouraging older people's free choice in the recruiting of family members for the study was more important than having an equal representation of family members from both generations. Nevertheless, building part of the analysis on generation membership and thus having an unequal division could jeopardize the trustworthiness of the findings, especially since only two spouses and two siblings represent the older generation. The ambition has nonetheless been to benefit from existing data beyond this imbalance and, as far as possible, to ensure the trustworthiness in data collection as well as data analysis regarding data from family members in both the younger and the older generation.

### Ethical considerations

Initially, letters of information were handed over to the family members by the first author, in exceptional cases by the care managers. The authors of this article in their role as project leaders wrote the information letter; it contained general project information and a presentation of the ethical principles governing the research. After they agreed to participate, the family members signed a formal letter of consent. Since family members taking part in the project were usually selected by their elderly relative, they most likely represented mainly affectionate relationships, which could have influenced the data collected.

The recruiting of the older people was made by the same care managers in charge of the management of their applications for a residential home. Therefore it had to be clear to them as well as to the family members that their anonymity was protected and that a potential participation in the research project was separated from the handling and outcome of the applications (cf. Creswell, 2007). The project was approved by the Regional Ethical Review Board (Dnr 2009/16).

### Data analysis

The data related to the family members consisted of three types of written material: transcribed interviews, field notes from follow-up contacts, and observations. With the ambition to reveal

how family members act, react and reason when their elderly relative considers relocation to a residential home, three questions were of special interest when the data analysis was initiated, namely:

- How do the family members act?
- How do the family members react?
- How do the family members reason?

With such a point of departure, a thematic analysis (Luborsky, 1994) was carried out. The transcripts were read and re-read, and in the coding system several themes emerged, which in this context were defined as units deriving from patterns of acting, reacting, and reasoning. The analysis was made in interplay between empirical data, interpretations by the authors, and theoretical perspectives. By applying this procedure the validity of the coding system was strengthened, while the coherence of themes rested with the authors, who studied how they matched (cf. Patton, 2002). Through a process of comparing data instances, a set of themes eventually emerged (see Table 2).

## Findings

Three conceptually distinct but empirically overlapping strategies were identified in family members' way of handling the process when their elderly relative considered relocation to a residential home. The strategies were called the *adapting*, the *representing*, and the *avoiding* strategy. A strategy was defined as a set of acting, reacting, and reasoning, and since the character of the strategies was intentional, the family members' efforts were subsequently open to their elderly relative's interpretation, and indirectly also to the care managers. Siblings

applied the adapting strategy, spouses the representing strategy, and family members in the younger generation at times switched between the strategies. All the strategies could end up in completed or cancelled relocation to a residential home. Table 2 shows the themes constituting the three strategies:

### Table 2 Themes forming the strategies

#### Adapting

- Practicing self-control in front of their elderly relative
- Encouraging their elderly relative's self-determination
- Trying to assume an expectant attitude in the decision-making process

#### Representing

- Mediating their elderly relative's decision
- Calling attention to existing needs versus available support
- Experiencing distrust directed at the welfare state

#### Avoiding

- Staying out of the decision-making process
- Intertwined feelings of supporting versus betraying their elderly relative
- Thinking the relationship to their elderly relative should be reoriented

### Acting, reacting, and reasoning

From the theoretical starting point departing from a social psychology approach, in this text focusing on acting and reacting, the findings indicated that a prominent feature in all three strategies was the family members' desire to tone down their personal standpoint when in the

presence of their elderly relative, even though in their minds their personal preferences were clear. As the family members had a firm standpoint advocating the relocation, while their elderly relative was mainly hesitating, they thus jeopardized both their elderly relative's self-determination and integrity (cf. Trydegård, 2000; UN, 1991) and the predominant ideology of ageing in place (cf. Ashton, 2001; WHO, 2008). 'Making' their elderly relative responsible for the decision was a way of resolving this dilemma. When they fulfilled this normative context, the family members experienced pride, and shame when they did not.

Family members experienced pride when they:

- in the adapting strategy confirmed their elderly relative's self-determination
- in the representing strategy mediated what their elderly relative already had decided
- in the avoiding strategy strove for being 'just a family member'

Family members experienced shame when they:

- in the adapting strategy noticed it was demanding to not be the one in charge of the decision
- in the representing strategy occasionally felt they had gone too far in their commitment
- in the avoiding strategy felt they betrayed their elderly relative by their withdrawal

From the theoretical starting point departing from the mechanisms within the life-course perspective, in this text focusing on reasoning, the findings indicated that a prominent feature was the dynamic framework of the family members' alternating desire for continuity and for change in their everyday life (cf. Arber & Evandrou, 1993). In the adapting strategy they mainly referred to their and their elderly relative's need to control their day-to-day existence; in the representing strategy to the interaction between their personal background and capacity; and in the avoiding strategy to circumstantial requirements urging a change.

Family members in the same generation as their elderly relative thought:

- in the adapting strategy their elderly relative was competent to make the most appropriate decision
- in the representing strategy they made the decision their elderly relative would have made
- ---

Family members in the younger generation thought:

- in the adapting strategy there was a logic behind their elderly relative's handling of the process
- in the representing strategy their capacity helped to discover rules and regulations
- in the avoiding strategy their elderly relative's resistance to relocation forced them to leave the process

Below, each strategy is discussed initially from the social psychology approach regarding the family members' acting and reacting, and subsequently from the approach departing from the mechanisms within the life-course perspective regarding the family members' reasoning.

### Encouraging their elderly relative's decision

Siblings and family members in the younger generation usually had shared their elderly relative's agony for quite a while (cf. Kontos, 2000; Nolan & Dellasega, 2000; Ryan, 2002; Sixsmith, 1990), and mutual rituals had been established in their conversations about a potential relocation. Applying the adapting strategy, one daughter described the procedure in the telephone calls with her 85-year-old mother like this:

She [my mother] has frequently begun by saying "I sit here pondering, you know" [laughs]. Then it is that she has been thinking; should she stay or should she move, you know (---). Usually I listen to her and then we have discussed advantages and disadvantages (---). We support her whatever decision she makes, so to speak.

The daughter gave the impression of experiencing pride as she was able to stick to her intentions of emphasizing the importance of her mother's self-determination, but in the interview she stated that of course it would have been better if her mother had had access to 'that safety that there is at a residential home'. Like several other family members, she referred to the relief it would imply to know that personnel would be available day and night.

Considering the restrained advocacy of relocation among the family members, applying the adapting strategy was brought to the fore when their elderly relative declined a room offered by the care manager; this occurred to family members in the younger generation. One daughter commented on her 90-year-old mother's decision in this way:

That I felt you know, when she had said no, that there went that freedom away [laughs]. Yes, that I got to say, that I would have been relieved if she had moved there, so that everything would calm down for me (---). I have to accept her choice, you know.

Proudly, the family members made a point of not letting their elderly relative find out what they really wanted, and they experienced shame when they felt it was trying to accept not being the one making the decision. The following quotation indicated the delicate nature of the matter. The son-in-law of a 93-year-old mother-in-law stated, 'I think everybody agrees it is very important she [my mother-in-law] decides, and that she knows she decides'.

As noted in the initial section of the findings, the siblings applied the adapting strategy. In trying to control what they were not supposed to control, the siblings reasoned their elderly relative was competent to take initiatives and to be in charge of the process. 'When it comes to this decision, he [my brother] has thought of that himself, you know', as a sister of an 81-year-

old brother said. Family members in the younger generation, on the other hand, were engaged in trying to handle the waiting period prior to formal decisions (cf. Fjelltun, *et al.*, 2009; Flynn Reuss, *et al.*, 2005), as well as their elderly relative's hesitation in the decision-making process. The latter was explained and related to the influence of their elderly relative's life-long nondemanding attitude, or the influence of their fending-for-oneself attitude 'taking full responsibility in all parts, in all situations' as a daughter-in-law characterized her 92-year-old father-in-law. The family members' true standpoint was repressed in favor of rationality and self-discipline (cf. Daun, 1996), awaiting their elderly relative's decision.

### Delivering their elderly relative's decision

Family members in the younger generation and spouses usually characterized their role in the representing strategy on the one hand as mediating their elderly relative's desire, on the other hand as constantly scrutinizing whether relocation really was for their elderly relative's own good or for their own personal advantage (cf. Dellasega & Mastrian, 1995; Fjelltun, *et al.*, 2009; Nolan & Dellasega, 2000; Penrod & Dellasega, 1998). In the interview one daughter-in-law referred to an earlier discussion with her 87-year-old mother-in-law:

First she refused and then after one and a half hours she at least agreed on applying (---). We [me, my husband and a nurse] had to tell her that this is not a hospital. It is a home. There are personnel all the time (---). We told her [laughs] about all the difficulties she had (---). At that point she started to waver.

In the interview she was still vascillating between pride and shame, identifying the subtle difference between self-determination and persuasion. She experienced shame as the advantages of relocation had been maximized and the disadvantages minimized in the discussion when her elderly relative made her decision.

As noted previously, the spouses applied the representing strategy. In trying to underline their representative roles, the wives reasoned about what decision would be best for their husbands, such as 'If it would have been me, I would not have liked to be sitting at a residential home', the wife of an 84-year-old husband declared. It appeared that the wives needed assistance in deciding to carry out their husbands' relocations, rather than deciding not to (cf. Brown & Alligood, 2004; Davies & Nolan, 2003; Dellasega & Mastrian, 1995; Pruchno, *et al.*, 1990). Family members in the younger generation, on the other hand, reasoned primarily about their own motivation in the decision-making process and how their professional background guided them. They were able to distinguish between good and bad residential homes, and they turned up existing guarantees covering their elderly relative, which they subsequently presented to the care managers. A daughter described the established ritual in the conversations with her 89-and 91-year-old parents, and it was as though she experienced pride in only mediating what her elderly relatives had already decided:

They [my parents] sort of ask: "Do you know anything? Have you heard anything? Is there anything going on?" And I say that I have not heard anything. "I will call today" (---). Many times I think: "How do they make it, the ones who are much more alone?"

There was an air of distrust directed at the welfare state. Family members in the younger generation thought they had to push care managers who tried to get round things all the time. They 'blamed the fact that there must be a medical certificate and a whole lot of that', as the son of an 85-year-old mother stated. Family members in the same generation as their elderly relative had confidence in the capacity of the care manager and/or their elderly relative, while

family members in the younger generation rather focused on shortcomings in the ponderous administration.

### Leaving the decision-making process

The avoiding strategy was applied only by family members in the younger generation, who perceived strains in the relationship to their elderly relative. They felt their strength was ebbing (cf. Chenier, 1997; Gallagher, *et al.*, 2011; Coehlo, *et al.*, 2007). This development had culminated during visits to the doctor for a memory test or in needs-assessment meetings. In the presence of their elderly relative they had been asked to describe the present situation, which they felt tested their own loyalty. Such occasions were considered as contributing to their decision to withdraw from the decision-making process, and thereby to the experience of shame. A daughter struggled with the feelings of betraying her 78-year-old father:

I have had a hard time finding my role now. Should I be on his side? Should I try to help him, all the time being the one saying "I see" or should I say, "Now damn you got to listen, because you need this?" (---). So sometimes I have, maybe from cowardice, handed it over to others and kept my role in another way, which I think he needs too.

She could not help him as long as he did not recognize any need for change, and at the same time she felt she betrayed him, causing a constant interplay between pride and shame. Uncertainty characterized the situation (cf. Dellasega & Mastrian, 1995; Penrod & Dellasega, 1998; Ryan & Scullion, 2000), but she seemed to experience pride as she also tried to restore the core of their relationship by holding on to the conviction 'nothing changes, just because time is getting on', as she expressed it. She, like several other family members, returned to their elderly relative's personalities and to describing the conditions they were used to.

In trying to handle the emerging disagreement with their elderly relative and to maintain the relationship, family members in the younger generation reasoned they had no other choice than to withdraw from the decision-making process. A niece said she avoided any involvement in the decision-making process as her 89-year-old aunt panicked if she even mentioned the possibility of relocation: 'Then she got very angry, you know. It was just impossible to discuss it'. Again the family members' true standpoint was repressed in favor of rationality and self-discipline (cf. Daun, 1996).

When the elderly relative's resistance to relocate clashed with the unspoken preferences of the family members in the younger generation, the decision-making process changed from being a matter of relocation-or-not to a matter of refusing-to-be-held-responsible. One daughter decided she would be more restrictive in assisting her 73-year-old mother, reducing the daily visits to weekly visits:

I might be a little egoistic, but it feels like this that her whole life circles around me (---). She does not want to make the decision herself, but she wants somebody else to make it for her (---). I am not going to make the decision.

Applying the avoiding strategy was a subtle way to influence the process without risking future remarks, simultaneously as the reasoning of the family members in the younger generation in terms of 'from cowardice' and being 'a little egoistic' indicated both a sense of

responsibility and guilt (cf. Davies & Nolan, 2003; Fjelltun, *et al.*, 2009). In this phase, holding on to the picture of their elderly relative's autonomy could on the one hand make it difficult for the family members to talk about feeling responsible for their elderly relatives, but on the other hand referring to parental autonomy was also used in order to set limits on care provision, as well as to cope with guilt and helplessness (cf. Funk, 2010).

# **Concluding discussion**

In modern western societies, 'individuals' are more emphasized than 'social relations', and individuals are expected to develop matter-of-factness and independence rather than emotionality and dependence (Scheff & Starrin, 2002). In that way the idea of independent individuals contributes to the expectations on family members not only to consider their own independence, but also to respect their elderly relative's independence in the decision-making process. Nevertheless, rationality and emotionality might clash. In the context of this study, different family relations are included with various relationships, emotional closeness and degree of contact. Without having any intention to accommodate all relations and perspectives, and with inspiration from Lüscher & Pillemer (2004) and their attempts to move beyond dualistic approaches, the presence of 'ambivalence' has been repeatedly noted. 'Ambivalence' reinforces the integration of family members' experiences of solidarity and conflict in relation to their elderly relatives, in the findings already expressed in the family members' duplicity and shifting desires for continuity and change. 'Ambivalence' also bridges different lines of previous research referred to in the text: one line focusing primarily on enduring ties and value consensus (e.g. Dellasega & Nolan, 1997; Flynn Reuss, Dupuis & Whitfield, 2005; Strang,

Koop, Dupuis-Blanchard, Nordstrom, *et al.*, 2006), the other primarily on caregiver stress and conflicts (e.g. Chenier, 1997; Coehlo, Hooker & Bowman, 2007; Dellasega & Mastrian, 1995).

The *adapting, representing,* and *avoiding* strategies stand out as a way for family members to control the situation. Their inner processes are repressed, expressed in subtle ways, and left to be interpreted by their elderly relative. They are balancing between feelings of pride related to the confirmation of their elderly relative's self-determination and integrity, and feelings of shame when their claim of having a personal life occurs at the expense of their elderly relative. Therefore it is argued that:

- Family members *act* in favor of their elderly relatives' self-determination and integrity
- Family members *react* in terms of a forced duplicity

Over the years the family members and their elderly relative have built up their partly shared lives as 'a sequence of socially defined events and roles that the individual enacts over time' (Giele & Elder, 1998, p. 22). In earlier research on caring for ageing parents, it has been found that the care is largely invisible in order to protect the parents' self-images and established parent-offspring relationships (Bowers, 1987). There is a lot indicating that a similar approach holds also for the family members in the current decision-making process. Their elderly relative is the same, even though the circumstances are not the same. Therefore it is argued that:

• Family members *reason* the process is continuously guided by their elderly relative

The combination of the family members' respect for their elderly relative's self-determination and integrity, the idea of best care possible and their own personal life situation, generates a seemingly impossible equation, and there might be reasons to ask if family members are forced into developing a hidden agenda, advocating relocation surreptitiously. For a better understanding and thereby implementation of the policy principles for older people and their family members in the decision-making process, further research is needed on the effects of:

- Family members' repression of their personal self-determination and integrity
- Family members' duplicity in the decision-making process

Family members' expectations for the welfare state differ between the generations. Siblings and spouses have grown up in a time when the welfare state was characterized by a universal distributive system (Titmus, 1968) that influenced their confidence in the care managers' readiness. But over the years there has been a change in socio-political practice rather than in official rules and regulations (Szebehely, 2005b). To the younger generation, life-long experiences from an individualized society are characterized by no absolute truths and no limitations regarding possibilities and choices (Giddens, 1991). In the light of the current socio-political development, the decision-making process concerning a potential relocation generally stands out as a lack of alternatives, where a room at a residential home is regarded a special favor rather than a matter of choice.

To conclude, if the prerequisite for self-determination and integrity were to increase in the decision-making process, then the welfare state would no longer contribute to making the situation even more complex than what it is already. Nor would it contribute to making the

decision of the care manager appear unforeseeable (cf. Lipsky, 1980). As it is now, and in intertwined roles, the restricted Swedish care of older people contributes to the stigmatization of older people considering relocation to a residential home (Söderberg, *et al.*, 2012), to family members' agonies and limited choices, and to care managers' exposure in the task of distributing limited resources.

### Acknowledgements

This study was carried out within the context of the School of Social Work at Lund University, and the interdisciplinary Centre for Ageing and Supportive Environments (CASE) at Lund University, funded by the Swedish Council for Working Life and Social Research.

# References

Arber, S. & Evandrou, M. (1993) 'Mapping the Territory. Ageing, Independence and the Life Course'. In S. Arber & M. Evandrou (Eds.), *Ageing, Independence and the Life Course* (pp. 9-26). London: Jessica Kingsley in association with the British Society of Gerontology.

Ashton, L. (2001) 'Promoting the health and social care of older people: gaining a perspective from outside the UK', *The Journal of the Royal Society for the Promotion of Health*, 121(3), 152-158.

Bengtson, V.L., Burgess, E.O., Parrott, T.M. & Mabry, J.B. (2002) 'Ingenting är mer praktiskt användbart än en god teori. Förklaring och förståelse inom socialgerontologin' [Nothing is more practically useful than a good theory. Explanation and understanding within the socialgerontology]. In L. Andersson (Ed.), *Socialgerontologi* [Socialgerontology] (pp. 17-43). Lund: Studentlitteratur.

Bowers, B.J. (1987) 'Intergenerational caregiving: adult caregivers and their aging parents'. *Advances in Nursing Science*, 9(2), 20-31.

Brown, J.W. & Alligood, M.R. (2004) 'Realizing Wrongness: Stories of Older Wife Caregivers'. *Journal of Applied Gerontology*, 23(2), 104-119.

Chenier, M.C. (1997) 'Review and Analysis of Caregiver Burden and Nursing Home Placement'. *Geriatric Nursing*, 18(3), 121-126.

Clough, R., Leamy, M., Miller, V. & Bright, L. (2004) *Housing Decisions in Later Life*. New York: Palgrave Macmillan.

Coehlo, D.P., Hooker, K. & Bowman, S. (2007) 'Institutional Placement of Persons With Dementia: What Predicts Occurence and Timing?' *Journal of Family Nursing*, 13(2), 253-277.

Cooley, C.H. (1902/1922) Human Nature and the Social Order. New York: Scribner.

Creswell, J.W. (2007) *Qualitative Inquiry & Research Design: Choosing Among Five Approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Cristoforetti, A., Gennai, F. & Rodeschini, G. (2011) 'Home sweet home : The emotional construction of places'. *Journal of Aging Studies*, 25(3), 225-232.

Daatland, S.O. & Herlofson, K. (2003) "'Lost solidarity" or "changed solidarity": a comparative European view of normative family solidarity'. *Ageing & Society*, 23(5), 537-560.

Daun, Å. (1996) *Swedish mentality*; translated by J. Teeland. University Park, PA: Pennsylvania State Univ. Press.

Davies, S. & Nolan, M. (2003) "Making the best of things": relatives' experiences of decisions about care-home entry'. *Ageing & Society*, 23(4), 429-450.

Dellasega, C. & Mastrian, K. (1995) 'The Process and Consequences of Institutionalizing an Elder'. *Western Journal of Nursing Research*, 17(2), 123-140.

Dellasega, C. & Nolan, M. (1997) 'Admission to care: facilitating role transition amongst family carers'. *Journal of Clinical Nursing*, 6(6), 443-451.

Epstein-Lubow, G., Davis, J.D., Miller, I.W. & Tremont, G. (2008) 'Persisting Burden Predicts Depressive Symptoms in Dementia Caregivers'. *Journal of Geriatric Psychiatry and Neurology*, 21(3), 198-203.

Fjelltun, A-M.S., Henriksen, N., Norberg, A., Gilje, F., *et al.* (2009) 'Carers' and nurses' appraisals of needs of nursing home placement for frail older in Norway'. *Journal of Clinical Nursing*, 18(22), 3079-3088.

Flynn Reuss, G., Dupuis, S.L. & Whitfield, K. (2005) 'Understanding the Experience of Moving a Loved One to a Long-Term Care Facility: Family Members' Perspectives'. *Journal of Gerontological Social Work*, 46(1), 17-46.

Fontana, A. & Frey, J.H. (2005) 'The Interview. From Neutral Stance to Political Involvement'. In N.K. Denzin & Y.S. Lincoln (Eds.), *The Sage Handbook of Qualitative Researach*. (3rd ed.) (pp. 695-727). Thousand Oaks, CA: Sage.

Funk, L.M. (2010) 'Prioritizing parental autonomy: Adult children's accounts of feeling responsible and supporting aging parents'. *Journal of Aging Studies*, 24(1), 57-64.

Gallagher, D., Mhaolain, A.N., Crosby, L., Ryan, D., *et al.* (2011) 'Determinants of the Desire to Institutionalize in Alzheimer's Caregivers'. *American Journal of Alzheimer's Disease and Other Dementias*, 26(3), 205-211.

Giddens, A. (1991) *Modernity and self-identity. Self and society in the late modern age.* Cambridge: Polity Press.

Giele, J.Z. & Elder Jr., G.H. (1998) 'Life Course Research. Development of a Field'. In J.Z. Giele & G.H. Elder Jr. (Eds.), *Methods of Life Course Research. Qualitative and Quantitative Approaches* (pp. 5-27). Thousand Oaks, CA: Sage.

Goffman, E. (1959/1987) *The presentation of self in everyday life*. Harmondsworth: Penguin Books.

Haberkern, K. & Szydlik, M. (2010) 'State care provision, societal opinion and children's care of older parents in 11 European countries'. *Ageing & Society*, 30(2), 299-323.

Heywood, F., Oldman, C. & Means, R. (2002) *Housing and home in later life*. Buckingham: Open University Press.

Johansson, L., Sundström, G. & Hassing, L.B. (2003) 'State provision down, offspring's up: the reverse substitution of old-age care in Sweden'. *Ageing & Society*, 23(3), 269-280.

Kellett, U.M. (1999) 'Transition in care: family carers' experience of nursing home placement'. *Journal of Advanced Nursing*, 29(6), 1474-1481.

Kontos, P.C. (2000) 'Resisting Institutionalization: Constructing Old Age and Negotiating Home'. In J.F. Gubrium & J.A. Holstein (Eds.), *Aging and Everyday Life* (pp. 255-272). Oxford: Blackwell.

Larsson, K. & Silverstein, M. (2004) 'The effects of marital and parental status on informal support and service utilization: A study of older Swedes living alone'. *Journal of Aging Studies*, 18(2), 231-244.

Lipsky, M. (1980) *Street-Level Bureaucracy. Dilemmas of the Individual in Public Services.* New York: Russell Sage Foundation.

Luborsky, M.R. (1994) 'The identification and Analysis of Themes and Patterns'. In J.F. Gubrium & A. Sankar (Eds.), *Qualitative Methods in Aging Research* (pp. 189-210). Thousand Oaks, CA: Sage.

Lüscher, K. & Pillemer, K. (2004) (Eds.), *Intergenerational Ambivalence: New Perspectives on Parent-Child Relations in Later Life*. (Contemporary Perspectives in Family Research, Vol. 4), Emerald Group Publishing Limited. On line publication.

McAuley, W J., Travis, S.S. & Safewright, M.P. (1997) 'Personal Accounts of the Nursing Home Search and Selection Process'. *Qualitative Health Research*, 7(2), 236-254.

Nay, R. (1996) 'Nursing Home Entry: Meaning Making by Relatives'. *Australian Journal on Ageing*, 15(3), 123-126.

Nolan, M. & Dellasega, C. (2000) "I really feel I've let him down": supporting family carers during long-term care placement for elders'. *Journal of Advanced Nursing*, 31(4), 759-767.

Nolan, M., Walker, G., Nolan, J., Williams, S., *et al.* (1996) 'Entry to care: positive choice or *fait accompli*? Developing a more proactive nursing response to the needs of older people and their carers'. *Journal of Advanced Nursing*, 24(2), 265-274.

Patton, M.Q. (2002) *Qualitative Research & Evaluation Methods* (3rd ed.). Thousand Oaks, CA: Sage.

Penrod, J. & Dellasega, C. (1998) 'Caregivers' Experiences in Making Placement Decisions'. *Western Journal of Nursing Research*, 20(6), 706-732.

Pruchno, R.A., Michaels, J.E. & Potashnik, S.L. (1990) 'Predictors of Institutionalization Among Alzheimer Disease Victims With Caregiving Spouses'. *Journal of Gerontology*, 45(6), 259-266.

Ryan, A. (2002) 'Transitions in care: Family carers' experiences of nursing home placement'. *Nursing Times Research*, 7(5), 324-334.

Ryan, A.A. & Scullion, H.F. (2000) 'Nursing home placement: an exploration of the experiences of family carers'. *Journal of Advanced Nursing*, 32(5), 1187-1195.

Sandberg, J., Lundh, U. & Nolan, M. (2002) 'Moving into a care home: the role of adult children in the placement process'. *International Journal of Nursing Studies*, 39(3), 353-362.

Sansone, C., Morf, C.C. & Panter, A.T. (2009) 'The Research Process : Of Big Pictures, Little Details, and the Social Psychological Road in Between'. In C. Sansone, C.C. Morf & A.T. Panter (Eds.), *The Sage Handbook of Methods in Social Psychology*. On line publication. Thousand Oaks, CA: Sage.

Scheff, T.J. (1990) *Microsociology. Discourse, Emotion, and Social Structure.* Chicago: The University of Chicago Press.

Scheff, T.J. & Starrin, B. (2002) 'Skam och sociala band – om social underordning och utdragna konflikter' [Shame and social bonds – about social subordination and extended conflicts]. In A. Meeuwisse & H. Swärd (Eds.), *Perspektiv på sociala problem* [Perspectives of social problems] (pp. 167-184). Stockholm: Natur och kultur.

Sixsmith, A.J. (1990) 'The meaning and experience of "home" in later life'. In B. Bytheway & J. Johnson (Eds.), *Welfare and the Ageing Experience*. *A multidisciplinary analysis* (pp. 172-209). For the British Society of Gerontology. Aldershot: Avebury.

Social Services Act 2001:453. *Socialtjänstlagen*. On line. Available (2011-03-10) at: https://lagen.nu/2001:453 (I. G. Raadu ed.).

Socialdepartementet (1989) *Ansvaret för Äldreomsorgen. Rapport från Äldredelegationen* [The Responsibility for the Care of the Elderly. The Advisory Committee on Caring Services for the Elderly]. Ds 1989:27, Stockholm.

Strang, V.R., Koop, P.M., Dupuis-Blanchard, S., Nordstrom, M., *et al.* (2006) 'Family Caregivers and Transition to Long-Term Care'. *Clinical Nursing Research*, 15(1), 27-45.

Szebehely, M. (2005a) 'Anhörigas betalda och obetalda äldreomsorgsinsatser' [Family members' paid and unpaid care of older people]. In *Forskarrapporter till Jämställdhetspolitiska utredningen* [Research reports to the Political equality investigation] (pp.133-203). 2004:07: Utbildningsdepartementet. Available from: <u>http://www.regeringen.se</u> [Accessed 21 June, 2011].

Szebehely, M. (2005b) 'Care as Employment and Welfare Provision – Child Care and Elder Care in Sweden at the Dawn of the 21<sup>st</sup> Century'. In H.M. Dahl & T. Rask Eriksen (Eds.), *Dilemmas of Care in the Nordic Welfare State. Continuity and Change* (pp. 80-97). Aldershot: Ashgate.

Söderberg, M., Ståhl, A. & Melin Emilsson, U. (2012) 'Independence as a stigmatizing Value for older People considering Relocation to a Residential Home' (Published in *European Journal of Social Work*).

Thorslund, M., Bergmark, Å. & Parker, M.G. (1997) 'Difficult decisions on care and services for elderly people: the dilemma of setting priorities in the welfare state'. *Scandinavian Journal of Social Welfare*, 6(3), 197-206.

Titmuss, R.M. (1968) Commitment to Welfare. London: Allen & Unwin.

Trydegård, G.-B. (2000) *Tradition, change and variation. Past and present trends in public old-age care.* Thesis (PhD), Stockholm Univ.

UN (1991) *The United Nations Principles of Older Persons*. Resolution 46/91, [Online] Available at: <u>http://www.un.org/Newlinks/older/99/principles.htm</u> [Accessed 21 March 2011]

Welfare Commission (2002) Welfare in Sweden. The Balance Sheet for the 1990s. Translation of Part 1 of the final report of the Welfare Commission SOU 2001:79. Ministry of Health and Social Affairs. Ds 2002:32. Stockholm: Fritzes.

Westlund, P. & Persson, A. (2007) *Beviljad ansökan - Om flyttningar till särskilt boende* [Approved application – About relocations to residential homes]. (2nd ed.). Fokus-Rapport 2007:3.

WHO (2008) *Europe. The solid facts. Home care in Europe*, Tarricone, R. & Tsouros, A.D. (Eds.), Università Commerciale Luigi Bocconi. [Online]. Available at: <u>http://www.euro.who.int/\_\_\_data/assets/pdf\_file/0005/96467/E91884.pdf</u> [Accessed 6 December 2011].