

# Elderly people's perceptions of how they want to be cared for: an interview study with healthy elderly couples in Northern Sweden

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## Elderly people's perceptions of how they want to be cared for: an interview study with healthy elderly couples in Northern Sweden

Many countries encounter a demographic change where the number of elderly people will increase. As a result, the number of very old people needing care, services and medical assistance will increase. Care in the private home is often described as providing the best alternative for many elderly people. The aim of this study was to describe elderly people's perceptions of how they wanted to be cared for, from a perspective of becoming in need of assistance with personal care, in the future. Twelve couples of healthy elderly people living in a couple hood participated in an interview study. They were all 70 years and older and received no kind of professional care or social support. Open individual semi-structured interviews were conducted with the support of written vignettes. The vignettes were formed as scenarios that described three levels of caring needs where the elderly people would become ill. A

qualitative content analysis was used to analyse the interviews. The findings were interpreted in one main theme: maintaining the self and being cared for with dignity to the end. The theme was built from three categories: at home as long as possible, professional care at nursing home when advanced care is needed and fear of being abandoned. The categories reflect the perception that when minimum help was needed, care and support by the partner and nursing staff were preferred. As the scenarios changed to being totally dependent on care, they preferred care in a nursing home. There was a pervading concern of the risk of not being seen as an individual person and becoming a nobody with no meaningful relations. Thus, there must be a singular goal to support old people, in all stages of their lives, through the recognition and affirmation of self, and providing care with dignity to the end.

**Keywords:** qualitative approaches, care, elder care, ethics, nursing home care, quality of care.

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## Introduction

Many European countries as well as other countries in the western world will encounter a demographic change in the coming years. The growth in the number of older people is so dramatic that it has been described as a silent revolution (1). Parallel to this development, there will be an increase in home-based care and in the number of old persons above 60 years, who will require provided care in their private homes. Our perception about 'the home' as a place for privacy is in sharp contrast to 'the home' as a place of

work for healthcare staff where people get medical care and services (2).

Being healthy and well functioning is something that people strive for, but in cases of being ill and dependent of care, either being young or old, acutely or chronically ill, people wish and demand to meet qualified nursing and medical competence. To promote good care among persons living in nursing homes, different ways of interpreting respect for autonomy has been described among nursing staff (3). When caring, a respectful behaviour is necessary in intimate situations like assistance with personal hygiene. Being treated with respect and seen as a unique person has been described as the most important indicator of promoting good long-term care, among caregivers and elderly people getting palliative care (4, 5). In a similar manner has good care for elderly people with dementia been described (6).

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Developing good care is dependent on the nursing staffs' ability to create good relationships (7).

Freedom and independence are in the modern western culture seen as a goal of the human person with the right to make own decisions. Thus in a situation being dependent of care can these highly ranked values result in a feeling of uselessness and worthlessness (8, p. 112). Freedom and independence can at the same moment, mean something positive and something negative. When striving to be independent, there is a risk of becoming more isolated and lonely. To be dependent on others in daily life often means dependency on someone or something. As long as one is healthy, strong and able to take care of the own life, it seems strange and difficult to understand what it means to be dependent on others, especially when it comes to the basics such as, eating by one's self, putting clothes on and handling the intimate hygiene. Ageing means probably both morbidity and disability, and as a consequence, more dependency on others than usual (9). Strandberg et al. (10) describe the patient's aspects of dependence on care like a struggle for the existence from two dimensions, where the patient wants to show oneself to be worthy of receiving care, on the one hand because of the fear of being abandoned and on the other hand to be able to protect the self as a valuable human being.

Studies have highlighted the perceptions of good care among frail elderly persons (11, 12). In Sweden, it is a political standpoint to make it possible to get care and assistance at home instead of at a nursing home facility (13). This study focuses on the perceptions of best care among elderly persons who are still healthy and living with a healthy partner in their private home.

### The aim

The aim of this study is to describe elderly people's perceptions of how they wanted to be cared for, from a perspective of becoming in need of assistance with personal care, in the future.

## Methodology

This study was designed as a qualitative inquiry focusing on elderly peoples perceptions. It was based on the anticipatory research tradition where the use of scenarios is fundamental tool (14, p. 200–202).

### Participants

A convenient sample of 12 elderly couples (24 participants) was selected with the assistance of two established organisations for pensioners from six different places in northern Sweden representing three villages and three cities. To get a broad sample with variations in living situations, participants were selected from all six places.

With the consent of the heads of each organisation, the first author visited member meetings and informed the group about the study through both verbal and written communication. Inclusion criteria were: living in couple hood at the same address for at least 5 years, more than 70 years old, no professional work at the time of the interview and receiving no kind of professional care. When the couples had acknowledged their interest, an informed consent of participation was given. The target was to recruit 2–3 couples from each place, where they were included in the order of when they acknowledged their interest to participate.

All couples were married except for one couple, who were cohabitants. The length of their relation varied between 16 years and 58 years (mean = 46.8, median = 50.5). The youngest was 70 years and the oldest 83 years old (mean = 74.8). No one had any kind of technical support such as alarm or assistive devices (Table 1).

### Data collection

Open individual tape-recorded interviews, based on vignettes were made with the 24 participants in the participants' home. However, one interview was excluded because of technical problems with the tape recorder. The vignettes were formed as short written scenarios (cf. 15, 16). The scenarios were designed to provide a picture of situations where the participant was in need of care and where the situation was stepwise and becoming more complicated. First step was 'little need of care, healthy partner at home' and was presented as a situation 'where you are doing fine but cannot take care of personal hygiene'. Second step 'dependent of care, healthy partner at home' was presented as a situation 'with several bodily

**Table 1** Socio-demographic characteristics of the elderly people (n = 23)

Variables	n = 23 (%)
Living today	
Private house	17 (74)
Terrace house	2 (8.8)
Cooperative flat/apartment	2 (8.8)
Flat with right of tenancy	2 (8.8)
Distance to primary healthcare centre	
1–20 km	19 (82.4)
21–40 km	2 (8.8)
41–60 km	2 (8.8)
Distance to hospital	
1–50 km	14 (60.8)
51–100 km	5 (21.8)
101–150 km	4 (17.4)
Living environment	
City	14 (60.8)
Village	9 (39.2)

dysfunctions and totally dependent of care from others'. The last step was 'dependent of care, no partner at home' and was presented as a situation 'with several bodily dysfunctions and totally dependent of care from others'. These three steps were presented at first from their own and then their partner's perspective. In the interviews, these scenarios were presented one after the other, followed by questions as: what is the best care for you/your partner in this situation? For each step the interviewer encouraged the participants to narrate freely about their perceptions using follow-up questions when necessary. The interviews, which lasted between 30 and 60 minutes, were conducted with each participant individually and transcribed verbatim. Notations of nonverbal expressions, such as silence, cries, laughter and bodily movements, were made directly after the interview.

### Ethics

The interviews were made in an environment which was well known for the participants and after the interview there was also time for reflection. The participants were all independent and could choose if they wanted to participate. They were informed that they could at any time break off from the study without any consequences.

### Data analysis

The interviews were analysed in a step by step process using qualitative content analysis (cf. 17, 18). The text was read and listened to first to acquire a first impression of the content. Thereafter, all the text was used in the analysis and divided into meaning-units corresponding to the aim. Those meaning units were condensed, and at first grouped from the person's own perceptions and the partner's perception. Gradually, it was realised that the two perspectives had the same dimensions of content and the two perspectives were merged into one. The step by step grouping of content into more abstract levels resulted in seven subcategories, that formed three categories and an over arching theme (Table 2). All three authors followed and discussed the analysis process until an agreement was reached.

## Results

The results are presented beginning with the categories, subcategories and after that the over arching theme.

### *At home as long as possible*

In a perspective of being in need of limited help with personal hygiene and otherwise doing fine, all participants had a perception that the best care was provided in the private home with different kinds of support.

**Table 2** Subcategories, categories and theme describing perceptions of care

<i>Subcategories</i>	<i>Categories</i>	<i>Theme</i>
At home, as long as my partner and I can support each other	At home as long as possible	Maintaining the self and being cared for with dignity to the end
Getting medical care and service at home		
There is a limit for how much we can take care of each other	Professional care at nursing home when advanced care is needed	
Not at home when lonely and severely ill		
Difficult to be dependent on the nursing staff	Fear of being abandoned	
Trapped in myself without friends		
Frightful of being lonely and totally dependent on care		

*At home as long as my partner and I can support each other.* All participants spontaneously talked about their partner when they were asked to describe the best care, in case of loss of bodily function and in need of assistance. Both men and women emphasised the importance of living together with their partner as long as possible. As long as they were together, they felt more secure and they could support and advocate for each other when problems occur. Even if they could not help they could at least hold each other's hand. 'My partner is able to help me; I really think he is able when it only comes to minor health problems, a minor health problem or handicap. In those situations I think the best solution is that my partner assists'. The feeling that they, as a team, were much stronger than as two separate persons is based on an experience of a long trustful relation that provided a sense of security. In situations with limited need of care assistance, they were convinced that together, they could manage any situation and find a solution. Their feeling of being a good team was expressed in different ways by several of the participants, i.e. 'we are strong, we are close'. Few of the participants talked about their children and when they did it was with respect for their independent lives. No one ever mentioned them as a presumptive carer.

*Getting medical care and service at home.* All men and women expressed wanting to stay at home as long as possible, even if a home care assistant was needed. It was apparent that the thought of having professional assistance in the home was easier to accept for more men than women. They expressed that the best must be to stay at home with some sort of help from social worker, nurse or someone who came and helped them to get a shower and manage their

personal hygiene, 'in those situations maybe it is possible that he can get assistance, from the district nurse or the home care assistants'. Both men and women could also consider the use of assistive technology as a possible way of compensating for the loss of bodily function. One man was quite sure that if his partner was in good mental health, she would prefer to stay at home and receive help from someone with nursing competence.

#### *Professional care at nursing home when advanced care is needed*

As the scenarios changed to a situation of lost bodily function and need of advanced care, the possibility of leaving their home for a nursing home or some sort of institutional care became important for the participants. The participants' perception of what kind of institutional care they thought of was vague. Both men and women mentioned hospital, primary healthcare centres and nursing homes as a place where elderly people could get care and other elderly people were living. In the presentations of the results, the concept of nursing home is used when institutional care was described.

*There is a limit for how much we can take care of each other.* When scenarios with more advanced care were presented, men as well as women expressed a wish that their partner could be freed from an obligation to take care of the other. Behind this wish seemed to be a consideration of their relation with each other. They wanted their partner to have a good life on their own and not to take on a role of being a nurse. They saw their partner as an independent person who needed an independent life. 'I do not want a situation where he is compelled to care for me all day around, when he all the time takes care of me, I do not want that, he has to be able to live his own life'. The consideration of being a burden for the partner was mostly expressed by the women. They considered the partner so old and weak, that it was impossible to act as nursing staff. To care for the person might destroy the partner's health and that was absolutely wrong. More men than women expressed hesitation to take care of their partner because of their own health; it could make them feel insecure if more advanced care was provided by a partner with little experiences. All of them perceived that there was a narrow limit when the need for care would become overwhelming and they could not manage to provide care any longer.

*Not at home when lonely and severely ill.* Most of the participants were convinced that when they would become severely ill it was necessary to move to a nursing home. To live at home in such situation could result in loneliness and also a feeling of insecurity. Even if many of the interviewees felt that the best was to be at home as long as possible, there seemed to be a limit where the security of

the home became less important than the insecurity of being severely ill. 'You have to move to an institution at an earlier stage if you do not have a healthy person living with you, if you understand how I mean. It could work but for the safety there could be so much of anxiety and feeling of unsafe if you not are able to get out of your bed before you get assistance'. In a situation of being severely ill, the nursing home would provide more security. To know when the insecurity of illness would become stronger than the security of the home was regarded as difficult to anticipate.

Many of the participants expressed the importance of being cared for by well-trained nursing staff who were competent to see their need of care, and also were able to provide it all time around day and night. 'I think you should be at some nursing home, you never know what will happen if you are dependent of care all day around and lonely, it could be tragic, I like having people around me and then being alone and besides be in mourning and new people all the time coming in the home no, I prefer to be taken care of at a nursing home all day around'. Both men and women expressed the importance of getting professional care from professional staff, as they perceived that the partner could never replace nursing staff and give professional care.

#### *Fear of being abandoned*

Perceiving a situation of being in need of extensive care and living at a nursing home was connected to many different kinds of feelings and fears.

*Difficult to be dependent on the nursing staff.* One fear was to be alone when dependent of care from strangers. Both men and women perceived the situation of being alone and severely ill, to be a horrible situation. Some of the participants regarded the dependence on institutional care as something terrible. 'I do not know what the worst is but if you are at good mental health and realise you are totally dependent of care it seems so horrible then it must be better to be lost of mental capacity, the awareness about needing help with absolutely everything I think that would be terrible'. Many participants felt that they would never manage being alone; waiting for some staff to come for helping. They wondered what would happen if the time passes and no one came.

*Trapped in myself without friends.* There was a fear of being isolated, in being without the partner and friends, and having to spend many hours alone waiting for someone. With no one close, it is easy to feel abandoned. 'It is not good to be isolated to loose all relations it is not good if you are a couple than you have someone to talk to but I hesitate I do not think it is good to stay at home for ever, after a while the friends disappear if you are sick, they do not

have the strength to meet all this, they disappear that is what I think'. One woman told a story about a neighbour who lived alone and became ill. In the first month, the neighbours visited him often, but after a while they did not come to visit him any longer. All participants expressed a fear of being trapped in themselves, with loss of human relations and facing terrible loneliness.

*Frightful of being lonely and totally dependent on care.* Thinking about being lonely and dependent on care made many of the participants silent, someone cried, and another hoped this never would happen. Some of them stopped talking; another one whispered that they had never even thought or talked about this with the partner. Many of them formulated questions such as 'what could I do to help my partner then? what would happen then?' and 'what can I do to manage this?' A few participants talked about what they heard about examples of bad care in the medias. They were upset and felt strongly about what a shame it is for a rich country to not be able to take care of the elderly. They were worried about what would happen to themselves, but also expressed worries about their partner. The most difficult scenario seemed to be loss of bodily function and in need of help with everything, but still be in good mental health. 'I hope I will die before it happens it is difficult if you have a clear mind and realise that you are completely dependent, it is much better to be demented, I think it would be very difficult'.

#### *Maintaining the self and being cared for with dignity to the end*

An overarching theme for best geriatric care was interpreted, which concerned maintaining the self and being cared for with dignity. The desire to be treated as a unique person and to maintain the self was important, no matter the illness, state of mental health or living situation. It seemed that as this becomes even more important, the more in need of care and the more vulnerable the elderly became. An outmost threat was the thought that they could not express their needs and how, when and in which way they would need care and assistance, when they were among strangers who did not know them and their life story.

There was a paradox in their reflections about their trust in other people. They wanted to be taken cared of, but they did not want to hand over their life to unknown nursing staff who may fail to treat them with dignity. Being treated without dignity meant not being seen as a unique person and not being able to relate to persons they knew. Thinking about this scenario made them both indignant and angry. They realised that they were thrown into the existing healthcare system where there are few other alternatives in case of being dependent of care. Maintaining their self meant among other things, to be able to live in their private home together with family members as

long as possible. When in need of extensive care, it seemed important to be cared for by somebody who could assist them in maintaining their self, somebody who could recognise their spiritual, psychological and physical needs.

## Discussion

The aim of this study was to describe elderly people's perceptions of how they wanted to be cared for, from a perspective of becoming in need of assistance with personal care, in the future. The main theme was interpreted as; maintaining the self and being cared for with dignity to the end.

Whatever the circumstances were, there was an agreement on the importance of being treated with respect and dignity. Especially in situations with bodily and intellectual impairments; when being alone and without support from a healthy partner, relatives or friends. The results indicate that the perceived possibility of maintaining their self was closely connected to how they were cared for. Perception of identity and self is formed in a social interaction with other people (19, 20) and one aspect of social interaction is care. According to van Manen (21), reciprocal care is something that most people have experienced from close relations. The human care involves someone to belong to and someone who can confirm that you are an important, loved and a very special person.

The participants in the couple hood expressed worries regarding what would happen if their partner could not care for them any longer. If they ended up in a caring situation where nobody would know them and nobody would be able to confirm their self in a meaningful interaction. Care as a worry presupposes a way of being and van Manen (21) discuss it from a phenomenological, philosophical and ethical view. Viewing care as a worry is an interaction process and that parallels the findings of this study. The more caring needs, the more important the relation with the partner became and the relation seemed to be a guarantee for being treated well. Without a partner, there was no perception of trust and only fear, loneliness and anguish. Savikko et al. (22) confirmed in their study that loneliness is a realistic and real threat for older people and the most common subjective causes were illness, death of a spouse and lack of friends. Atchley (23, p. 89) as well as Baumeister and Twenge (24) describe that losing a partner is in many ways stressful, a threat to the identity and could cause many reactions, i.e. anxiety, depression and isolation.

Another aspect of the importance of social interaction among older people is that passing through all changes in life gives another perspective of the meaning in life and makes a person able to accept that lifetime has passed, face mortality, and the presence of death (25, 26). When people become increasingly aware that they gradually approach the end of life, it becomes more important to appreciate

close social relations. They seem to be aware of making the right choices, give priority to goals like feeling satisfied, and for most people, such goals are connected to social relationships with highly familiar and emotionally close social partners (27).

An interesting part of the results is the absence of children in the older people's perception of care. Their thoughts revolved mainly around the partner's role as a prerequisite for receiving care at home. It is possible that this reflects values in contemporary family life in Scandinavia where children are an important part of the family but not expected to take care of their parents when they get old and in need of care. This is in sharp contrast with other parts of the world like East Asia where it is more or less an obligation for children to take care of the elderly (28, 29). When economic circumstances are improved together with a possibility for higher education of female children the attitudes towards institutional care among elderly are also changed (30).

All participants were aware that the circumstances would change as they get older and their relationship to the home, altered. The concept of home can be described from several points, sociologic, psychological, physical and philosophic. The meaning is complex and will probably change as people's circumstances will change (31). Our homes mean for most of us something very special, 'houses are assumed to become homes because they provide and become the environment within which family relationships – close, private and intimate – are located' (32, p. 334). The participants in this study focused on an understanding of home as a place where they could maintain a relation with their partner. Even if professional carers and technical devices would be a part of their home, it would still be their home. The partner is almost mentioned as a part of the home, the partner and the home was the basis for maintaining the self. This way of describing the home parallels the psychological point where the symbolic and representative nature of home is in focus, a place where people can develop bonds with certain places, to enter meaningful relationships with these places and incorporate them as a part of their self-identity (33). Some of the participants also perceived that it was like being trapped in their self and the home when dependent of care and without a relation with a partner. Moore (33) and Price (34) describe that the home means a wide set of associations and meanings, where on one hand, it can represent both a place for domesticity, privacy and comfort, and on the other it could be a prison and a place full of obligations.

At-homeness is described with several dimensions such as a feeling of being in the body, in the room and in contact with health care (35–37). They (35–37) describe at-homeness as being in the present, contact with others and a feeling of meaning and affinity with others. At-homeness is more described as a concept which is not always associated to the physical home but connected with a spiritual experience. For the participants in this study,

at-homeness was connected to being seen and cared for by someone who knew them well. The absence of at-homeness was related to not being seen and cared for by anybody. The most frightening scenarios for the participants was not being known or understood by anybody who knew their life story. The importance of being known and knowing someone's life story has been described as a way to enhance the options for a carer to get a deeper understanding of each individual (6, 38). There was a paradox in the participants' perception of professional health care as provided by nursing staff. On the one hand, they were doubtful that the professionals would be interested to know their life story and see them as individual persons, and on the other hand they knew that if they were in need of extensive care, the best care was provided at nursing home. This paradox made them hover between trust and distrust.

Being treated with dignity presupposes that the nursing staff is educated and has knowledge about the history of the person. To maintain and retain integrity, everyone must be seen as a unique individual. Randers and Mattiasson (39) state that when nursing staff treat the patient with autonomy, the integrity is protected and as a consequence of this their dignity is maintained. The same authors (40) also showed that respecting elderly people's social self would reduce feelings of loneliness, isolation and seclusion. If the nursing staff not is able to meet the patient's needs and desires, the patient could feel violated if their person/self is ignored (41). Nordenfelt (42) argues, when talking about elderly and dignity, besides a collective dignity of merit, we have good reason for paying attention for the special vulnerability of the elderly.

Lögstrup (43, pp. 18–28) talks about the human interdependence where we are reciprocally dependent of each other; which means that we have the power to take care of the others life either constructively or destructively. The ethical demand, taking good care of each other, and showing respect and dignity, was something which all participants were familiar with from their long relation with the partner. Providing good care to someone who is suffering from illness and dependent of care is something reciprocal. If the healthcare staff has a good understanding of the reciprocal aspect of care, they have a possibility to acquire competence and a deeper understanding about the life story of the person in need of care. Competence and understanding will in turn enhance the ability of the healthcare staff in providing good care.

#### *Methodological considerations*

The study focused on the perceptions of how elderly people want to be cared for. Each interview situation is unique and the context influences the content of the interview (cf. 14). To create a similar interview context for all participants, we used a vignette describing three different

scenarios that were presented in a similar way to all. Perceptions are easily influenced by the context; however, we think that the structured way of using vignettes was a guarantee for uniformity of the interview situation.

The nature of qualitative inquiry is that the results are difficult to generalise and have to be judged from a specific context. However, the participants were selected in a way to ensure variation in living situation and it is likely that their perceptions represent a Scandinavian context. Another aspect of context is that the interviews reflect the perceptions the participants had at the time of the interviews. It is possible that perceptions will alter over time as they get older and their personal health changes. Despite these limitations we think that the perceptions of good care among those healthy elderly persons that participated in the study provide an important contribution to the understanding of how elderly persons with large caring needs, want to be cared for.

Trustworthiness of the study was supported by using rigour in all part of the analysis process where all steps were checked by all the authors. The researchers collaborated in every step of the study until a general agreement was reached.

## Conclusions

The overall theme in the results emphasised the importance of being able to maintain the self and being cared for with dignity to the end. The perception of maintaining the self was closely related to maintaining relations. All participants in this study had long marital relation. However, among persons in younger generations in Sweden it is more common to have several long relations during a lifetime. It is likely that the next generation of older people cannot rely on their partner in the same way when maintaining their self and planners of care must take this into consideration. Nursing staff must be aware of possible changes in older peoples' family situations and be able to provide care that promotes the self with dignity even when relations between family members are changing. It is imperative that politicians and decision-makers give this aspect of elderly care serious attention and explore various options to deliver the best care, as perceived by the elderly.

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## Author contributions

Study conception and design was developed by Christina Harrefors and Karin Axelsson. Christina Harrefors con-

ducted the data collection and took part in all aspects of developing the manuscript. All the authors were involved in the analysis of data and the drafting of the manuscript. Stefan Sävenstedt and Karin Axelsson were responsible for supervision and critical revisions for important intellectual content.

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