Perceptions of a good life for the oldest old living at home

BY ARIEL ALMEVALL*, PÄIVI JULIUS*, KARIN ZINGMARK* & CARINA NILSSON*

Abstract

An increasing number of people are growing older and living longer in their homes. This study aims to describe key stakeholders’ (politicians, managers, and professionals) perceptions of a good life for single-living oldest old persons living at home with extensive needs for support. Interviews with stakeholders were analysed with content analysis. The analysis resulted in the theme: An incongruence between intentions and actions in promoting a good life for the oldest old. Our findings show a gap between intentions and actions, which caused feelings of powerlessness in the key stakeholders. To promote a good life for the oldest old persons, a congruence is needed between individual awareness and the prerequisite of promoting a good life. Developing methods that identify and bridge gaps between intentions and actions could support the abilities of organisations to promote a good life for the oldest old persons with extensive needs for support.

Keywords: ageing in place, capabilities approach, caring, homecare, oldest old.

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Introduction
The number of people in Europe aged 65 years and older is expected to increase until 2060 (Rechel et al. 2013), and the number of people aged 80 years and older (often referred to in the literature as the oldest old) in Sweden will increase from half a million in 2018 to one million in 2040 (Statistics Sweden 2017). Even though it is important to note that the oldest-old age group is characterised by a high degree of within-age variability (Stone et al. 2017), conditions related to outcomes such as low physical activity, slowness, exhaustion, weight loss and weakness are considerably more prevalent in the 80+ age group compared to the entire group of 65+ community-dwelling older adults (Collard et al. 2012). Furthermore, belonging to the oldest-old age group is associated with an increased risk of adverse events such as falls, institutionalisation, disability and compromised mobility, which constitute a major concern for the individual as well as society (Buckinx et al. 2015).

The ageing population imposes higher demands for better and more effective health and welfare systems (World Health Organization 2012). Providing possibilities for older persons to remain in their homes as long as possible is one strategy to meet the demographic challenge and reduce the cost of institutional care. Therefore, the concept of ageing in place is central in ageing policy and favoured by many older persons (World Health Organization 2007). In Sweden, elderly care has been provided by larger institutions since around 1950 and in small-scale, home-like environments since around 1990 (Brink 1990). Since the 2000s, policies have been gradually developed towards providing the opportunity to age in one’s own home (Vasunilashorn et al. 2012).

The development of the policy towards ageing in place is not just about meeting the demographic challenge and reducing costs. It has also been described as supporting the older persons’ well-being through the sense of belonging the home can entail (Almevall et al. 2022; Board & McCormack 2018; Vasunilashorn et al. 2012; Wiles et al. 2012). Being able to remain in one’s own home has been described as related to independence, autonomy, security, connection and familiarity (Wiles et al. 2012). It has been argued that the home contains the most central aspects of human life (Kelly 1975).
The home is considered to contain physical, social, behavioural, cognitive and emotional aspects (Oswald & Wahl 2005) and has been described as a symbol of the self, a place where social and cultural identities become stated and stabilised (Dovey 2005). Nevertheless, expectations to remain at home despite increased frailty can be challenging and difficult (Iwarsson et al. 2007), especially for older persons with complex health problems and an extended need for support. The need for home modification and support, as well as a sense of isolation, has been pointed out by older persons as barriers to remaining at home and ageing in place (Martin et al. 2019). It has also been described that in relation to younger people, older people have fewer demands in the process of requesting care (Gautun & Grødem 2015) and may lack the opportunity and choice to decide where to live (Wiles et al. 2012), which can be crucial when health problems and care needs are increased.

In Sweden, the Social Services Act (2001) regulates the responsibility of municipalities regarding the older persons right to well-being and independence, with access to an active and meaningful existence in society with others. Older persons can apply for assistance from home help services funded by the municipality and carried out either by private or municipality-based carers. The extent of assistance is based on assessments of need and can cover all hours of the day. This means many older persons with extensive need for care can remain in their homes throughout life (Swedish Institute 2021). Examples of extensive needs for support at home include assistance with mobility, personal hygiene, food preparation, medication, oral care, social interaction, as well as more advanced interventions that carried out by healthcare staff. The older person in the focus of this study needed support from home care staff, with at least four and up to eight visits every day, evening and/or night.

The consequences of the demographic situation affect politicians (Evertsson & Rosengren 2015; Finnbakk et al. 2012) and top managers (Finnbakk et al. 2012), who express worries about the possibility of providing good elderly care based on individual needs in the face of scarce resources. A study of decision-makers’ assumptions, norms and priorities found that assumptions regarding needs in different life phases risked the allocation of resources, affecting how resources were used, rather than the needs of the older persons (Finnbakk et al. 2012).
Gautun and Gredem (2015) showed that arguments should be made more explicit about older persons needs in different life phases.

There are different models and definitions of a good life. Nussbaum’s capability approach holds areas about what a person should be granted access to in order to live a good life. The approach (Nussbaum 2011) describes ten capabilities all humans, regardless of age, function, cognitive disability or gender, need to access in order to live a good life. They address the importance of being able to live to the natural end of one’s life, having good health, maintaining integrity and the ability to move from place to place. They also highlight the significance of being able to use one’s senses, imagination and thinking (including enjoying pleasurable experiences), and having emotions and emotional attachments to things and people outside oneself. The capability approach stresses the necessity of having access to the use of practical reasoning, being able to engage in critical reflection about planning one’s life and maintain social affiliations that are meaningful and respectful. Finally, they stress the importance of being able to live with concern for other species and nature, having opportunities to laugh, play and enjoy recreational activities, and having control over one’s material and political environments (Nussbaum 2011).

According to the Nussbaum’s capability approach, a good life requires that a person is able to be and do things according to what he or she wants in life. A good life is connected to equality, well-being and justice and contains capabilities considered central for a good life. Furthermore, the capability approach has been suggested for political planning (Nussbaum 2011), such as in social welfare (Evans 2017). The capability approach has been used in research regarding ageing in place (Grove 2021), informal caregiving for older persons (Horrell et al. 2020), person-centred care (Entwistle & Watt 2013) and for persons with dementia living in their own homes (Tellez et al. 2016). The capability approach has also been found appropriate to use by those who deliver care in local elderly care settings to promote dignity in the persons receiving care (Pirhonen 2015) and the care of persons with dementia (Melander et al. 2018).

Compared to younger age groups, persons aged 80 and over living at home with support often have a reduced network of friends and family. Therefore, the needs of the oldest old persons may also include different or additional areas compared to younger counterparts. The oldest old persons also often depend on more social services and providers.
Municipalities are responsible for the social services and care of older people at home, and politicians, managers and professionals in the municipality are obligated to provide support to older persons in accordance with the Social Service Act. As such, they can be considered key stakeholders in enabling a good life for the growing group of oldest old persons living at home with extensive needs.

To our knowledge, there are no studies on how key stakeholders perceive a good life for persons aged 80 and over living at home with support. Therefore, the aim of this study is to describe key stakeholders’ perceptions of a good life for single-living oldest old persons living at home with extensive need for support.

Methods

Design
This study has a qualitative design. Focus group interviews (FG) were used for data collection (Morgan 1997), and data were analysed by a qualitative content analysis (Graneheim & Lundman 2004).

Participants
This study was conducted in a municipal organisation for elderly care in a medium-sized city in the north of Sweden. The participants were key stakeholders at different levels in the organisation: politicians responsible for opinion formation, exerting influence over public decision-making; managers responsible for assistant nurses in home care service; social service officers assessing the need for support for people in home care; district nurses responsible for nursing in home care; and physio and occupational therapists responsible for rehabilitation.

A purposive sample of 28 key stakeholders participated in this study. Inclusion criteria were at least 2 years of experience in the municipal organisation for elderly care and a willingness to participate. An administrator in the organisation served as a contact person for recruiting the participants and distributed verbal and written information about the study and the information letter to those who met the inclusion criteria. All persons asked agreed to participate. An overview of the focus group
participants is presented in Table 1. The participants were key stakeholders at three organisational levels: political, management and care practice.

Focus group interviews

Data were collected by focus group interviews in order to generate rich data through group interaction in a permitting climate (Morgan 1997). Focus groups were conducted to generate broad data and insights on the specific phenomenon by using the interaction in the group (Morgan 1997). The participants were divided into five focus groups, with four to seven participants in each group. Four focus groups were divided by profession, except the fifth group which consisted of a mixed group of occupational therapists and physiotherapists (Table 1).

According to Morgan (1997), three to five groups are generally sufficient for data saturation, as more groups seldom provide new insights. Furthermore, he states that the number of participants is determined by their level of knowledge of the topic, and he recommends four to six participants in each group. In our study, all participants were experienced in providing care to older persons at home, and the number of participants in each FG was considered sufficient. The groups were designed to create the conditions for in-depth understanding, which is recommended when participants have a lot of experience to share (Krueger 2014).

As for the researchers carrying out the FG, one had experience in clinical work in home health care and strategic work within the organisation. The others researchers came from outside the

Table 1. Overview of participants in the focus groups

<table>
<thead>
<tr>
<th>Focus group</th>
<th>Age (Y)</th>
<th>Experience (Y)</th>
<th>Number of participants</th>
<th>Key stakeholder</th>
</tr>
</thead>
<tbody>
<tr>
<td>District nurses</td>
<td>35–47</td>
<td>2–11</td>
<td>5</td>
<td>Patient care</td>
</tr>
<tr>
<td>Occupational therapists and physiotherapists</td>
<td>48–62</td>
<td>3–20</td>
<td>7</td>
<td>Patient care</td>
</tr>
<tr>
<td>First-line managers</td>
<td>31–59</td>
<td>4–12</td>
<td>7</td>
<td>Management</td>
</tr>
<tr>
<td>Social service officers</td>
<td>47–59</td>
<td>10–22</td>
<td>5</td>
<td>Management</td>
</tr>
<tr>
<td>Politicians</td>
<td>59–69</td>
<td>6–10</td>
<td>4</td>
<td>Political</td>
</tr>
</tbody>
</table>
organisation and had clinical and research experience in various contexts of care. The mix of researchers being based inside and outside the elderly care organisation provided conditions for a critical approach to pre-understanding and inside knowledge. To increase the dependability of data, the first author moderated all focus groups, the other authors took turns participating in the FG to assist and provide summaries of the interviews. An interview guide was utilised to ensure the same questions were asked in all five focus groups. However, new aspects of the subject can occur during the data collection process in this type of research and influence follow-up questions (Graneheim & Lundman 2004). The researcher encouraged the participants to discuss the given topics freely rather than following a chronological order of the interview guide (Morgan 1997).

An interview guide (Table 2) was used based on the capabilities approach (Nussbaum 2011). The interview guide was developed by the research group and tested on two occasions. The capability approach was used as a tool to expand the discussion about what a good life for older people meant to the key stakeholders. Initially, the participants and researchers presented themselves. Before the focus group began, the researchers introduced the concepts: oldest old person, single-living, extensive need for care and the capability approach.

First, a broad question was asked: “Please, tell us your view of the conditions demanded for the single-living, oldest old with extensive need for support in order to live a good life at home”. Thereafter, questions related to the capabilities were asked, such as having basic needs met, showing and receiving love and gratitude, discussing and reasoning with others, and engaging in activities that are interesting and fun. Clarifying questions were asked to enhance the dialogue, including “Give an example”, “What do you think about that” and “Tell me more about it”. Some capabilities of the oldest old persons, such as discussing and reasoning with others and being able to be creative, spontaneously arose without needing prompting from the interview guide.

The interviews were conducted in Swedish. Each focus group discussion ranged from 81 to 94 minutes and was digitally recorded and transcribed verbatim by the first author.
Data were analysed using qualitative content analysis with a deductive approach (Graneheim et al. 2017) and uploaded into the qualitative analysis software package NVivo (QSR International 2014). The transcribed interviews were read several times to get a sense of the material as a whole. Meaning units (words in a sentence or several sentences) related to the aim were extracted and condensed, that is, shortened without loss of the core message. The condensed meaning units were coded and compared regarding differences and similarities in several steps and sorted into categories, which constituted the manifest content.

Since the FGs were organised to catch possible similarities and differences between the various types of key stakeholders, the codes between the groups were compared, as were the identified categories. However, the findings turned out to be similar regardless of whether

Table 2. Focus group interview guide

<table>
<thead>
<tr>
<th>Opening question</th>
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<tbody>
<tr>
<td>Please share your views of the conditions demanded for single-living older adults with extensive need of support, in order to be able to live a good life at home</td>
</tr>
</tbody>
</table>

**Topical question themes**

- Life and basic needs
- Integrity and safety
- Creativity and thinking
- Emotions and close relationships
- Love and gratitude
- Planning one’s life
- Fellowship with others
- Living in relation to animals and nature
- Enjoying activities and having fun
- Control over one’s own environment

Follow-up questions were asked, such as *Give an example* and *Tell me more about it*
the interview data represented expressions from the political, management or care practice level of the organisation. Therefore, it was decided not to go any further with the analysis related to organisational representation in the groups and continue to analyse the deconstructed material as a whole.

The categories were then further analysed guided by the capability approach. This resulted in four subthemes. The subthemes expressed the content of the categories at a higher interpretative level. Thereafter, the subthemes were discussed several times amongst the authors, and a theme was formulated expressing the researchers interpretative meaning of the subthemes (Graneheim & Lundman 2004; Graneheim et al. 2017).

Study context, selection, characteristics of the participants and the analysis process have been described in order to facilitate transferability. During the analysis process, the connection between data and findings was confirmed by going back to the original text to verify that no content was missing, which improved dependability. Finally, the findings were compared and discussed with all authors until consensus was reached in order to strengthen the credibility and confirmability of the findings (Graneheim & Lundman 2004).

In the findings, quotations are used to illustrate original statements and strengthen dependability (Graneheim & Lundman 2004). The quotes are labelled with a number, as are the key persons (e.g. P1 and FG1) to show that quotes represent all five FGs and various persons.

Ethical consideration

This study was approved by the Regional Ethical Board in Umeå, 2015-10-12 (No. LTU-2706-2015). Participants received written and verbal information about the aim of the study and approach. They were informed that their participation was voluntary, and that they could withdraw from the study at any time without disclosing why. The participants were assured confidentiality. All participants were instructed to contact the researcher if they had questions or concerns. Grouping FGs by profession would allow for open discussions with others with similar experience and prevent discussions from being inhibited by eventual hierarchical structures.
Findings

The findings consist of one theme and four subthemes (Table 3) describing key stakeholders’ perceptions of a good life for the single-living oldest old persons living at home with extensive need for support.

**An incongruence between intentions and actions in promoting a good life for the oldest old**

The participants described a good life for older persons as promoting integrity, familiarity, strengthening identity through activity and being offered adapted support. They described their own and the organisation’s intentions to promote a good life for older persons. In contrast to these intentions, contradicting descriptions related to daily challenges were revealed, such as caring actions being dominated by dealing with limitations, loneliness, uncertainty and lack of accessible support in the daily life of the oldest old persons with the highest level of home care. The contrasting descriptions in the results are interpreted as an incongruence between intentions and actions to promote a good life for oldest old.

**Striving to promote integrity whilst being occupied with handling unfulfilled needs**

Participants described that promoting integrity was a vital part of a good life for older persons. Integrity was considered to be promoted when the

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
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<tbody>
<tr>
<td>An incongruence between intentions and actions in promoting a good life for the oldest old</td>
<td>Striving to promote integrity whilst being occupied with handling unfulfilled needs</td>
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<td>Striving to promote meaningful relationships whilst being aware of loneliness</td>
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<td></td>
<td>Strengthening identity through activity whilst ensuring safety and security</td>
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<td></td>
<td>Striving for support adapted to the older persons' needs whilst dealing with shortcomings in accessibility</td>
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**Striving to promote meaningful relationships whilst being aware of loneliness**

**Strengthening identity through activity whilst ensuring safety and security**

**Striving for support adapted to the older persons' needs whilst dealing with shortcomings in accessibility**
The older person was given opportunities to feel self-confident, valued and confirmed as a person. The participants emphasised the significance of paying attention to each person’s life story and inner abilities, such as courage, motivation and attitude, to support their integrity. However, they described that the older persons were not always adequately acknowledged by staff and society, which could hinder them from feeling appreciated and valued.

When numerous professionals gave support, the participants felt that the self-reliance and integrity of the older persons were threatened. Numerous professionals visiting could create feelings of insecurity and unease for the older person, which sometimes affected their opportunities to participate in decision-making concerning their need for support.

P2: Someone [from the staff] who sees the older person and confirms them can lead to feelings that someone is interested in them, which is important. I do not think that the staff is uninterested in the older person’s life, but they do not have time to do more than just the most necessary things. The older person gets stressed as the staff’s visit has to go hastily instead of them feeling acknowledged and having time with the staff. (FG.3)

Participants described opportunities to keep caring for the home and continue with previous routines as important for the integrity of the older person. Small support efforts were considered crucial for the older person’s independence as well as for maintaining and improving their abilities. Providing opportunities for the older person to take care of their home together with staff was described as contributing to their self-confidence and influence over their daily life. However, the participants described that the opportunities for independence sometimes collided with the need for help in daily life, which was perceived as an obstacle to maintaining a good life.

Participants described that the opportunity to make decisions about everyday life was part of a good life. Decision-making was considered difficult, as the older person sometimes lacked the ability to express their needs, due to, for example, hearing- or cognitive impairment. This leads to difficulties in finding a balance between supporting the older person in making decisions and deciding for them. Allowing the older person to make all decisions was regarded as leading to a lack of safety for them.
P1: Relatives have told us that we have to go in and fix this [medication] because they think she [their mother] cannot handle it... However, when we checked the drug list, everything was correct. It is often the relatives’ worries that make us go in and take over.

P3: Relatives’ fear.

P5: Yes, it is clear that it is about being confident that nothing will be wrong. Maybe it is both about protecting the older person and ensuring that we have a responsibility, as they are acting as if it is a kind of uncertainty.

P2: I had a case where a man had a pill organiser and went over the dosage package, as he took medicine several days in a row. Then family members wanted us to lock it in... The man became furious and broke it, as he wanted to take care of his medicine himself, so we went back to the pill organiser, and then it worked well. (FG 5)

Striving to promote meaningful relationships whilst being aware of loneliness

The participants described a good life for the oldest old as having meaningful relationships. The relationships with staff provided attention and closeness, which created an opportunity for the older person to feel love and happiness, which, in turn, created a sense of meaning. Pets were also emphasised as providing closeness and joy. The opportunity to shift between solitude and togetherness was described as part of a good life. Participants described that healthcare providers could play an important role in supporting and encouraging the older person to enjoy fellowship with others. However, they expressed concerns for the older person who lacked families and friends and those who did not want to socialise in groups.

P15: But just to have something to look forward to, so that the older person knows that they have something planned for the week... To have fun, and not just be at home where nothing else happens other than the visits by home service.

P13: Also, for the relatives, it is important to know that their older family members can enjoy and have something to do and not just sit there alone in their apartment day in and day out.
P17: Absolutely, it matters; they feel better from social interaction. Just to help them go somewhere, meet others, do things with others and break up this grey, everyday life is very important for recovery and capability. (FG 1)

Participants described feelings of powerlessness when the older person lacked family, friends or other close relationships. The participants wished they could give older persons the opportunity for social interactions and time with staff or the opportunity to find new relationships outside the home. Not being able to do this meant they felt unable to promote meaningful relationships amongst those who lived alone and lacked contacts outside the home.

P17: I think that for the older persons who are sitting alone at home, the staff is their whole world, while the staff may see the visits as short work efforts. (FG 2)

**Strengthening identity through activity whilst ensuring safety and security**

Participants perceived a good life for older persons with extensive needs as retaining the older person’s identity through continuing with previous activities. With its associated relationships and interests, the home and neighbourhood were a prerequisite for maintaining activities the older person had done throughout their life. Household chores, playing cards, socialising with peers or maintaining the home were considered vital for a good life.

The possibility to go outside and experience nature, visit city surroundings, stores and/or healthcare facilities was perceived as important for a good life. The participants described that it was important for older people to live in a familiar environment that supports their identity, personality, relationships and life history. A good life for older persons was described as one in which they can have fun and be active. Participants stressed the importance of the older person having events and experiences to look forward to, which could maintain and increase a positive sense of ageing. Activities for older persons were described as important, but participants described a lack of resources in the organisation to support this.
P28: I have an example from an older person with paralysis of one side of his body. He had home help service, and the staff said that they could not be held responsible because he risked falling in the home, so the relatives wrote a power of attorney that they take responsibility if something happens to him. He lived the rest of his life at home. The relatives said that if he had been forced into a nursing home, he would have lost his life, his freedom.

P27: Can the home help service say that they can take care of the older person but not take responsibility? Was the home not adapted for his needs?

P28: As the facilities were not so modern, they [staff] washed him and his clothes in the sauna. He got food deliveries every day, and he actually had everything he needed. (FG 4)

The home and neighbourhood were described as a place where activities were available on the terms and interests of the older person. The home was described as essential for continuing with previous activities. However, the home and neighbourhood were also described as unsafe and associated with a potential risk of injury for those with declined ability. Simultaneously, the participants stated that it was important to follow the wishes of the older person and accept possible hazards at home.

**Striving for support adapted to the older person’s needs whilst dealing lack of accessible support with shortcomings in accessibility**

Participants described that a good life for older persons required being offered support adapted to their needs. This was facilitated by flexible assessments of the home environment, the possibility to be spontaneous in activities and being involved in the support given to them. This adapted support could also prevent the older person from the feeling of being a burden to others. However, the participants perceived that the older person’s wishes to demonstrate independence during assessments by exceeding their actual everyday capacity could hinder an evaluation that would provide adequate support. Participants described feelings of shame and frustration when the conditions were not adapted to the needs of the older person as they felt that they as key stakeholders should do better to provide good conditions.
According to the participants, a good life for older persons meant having access to a diverse team of professionals who understood their complex needs and worked together accordingly. Support needed to be appropriate and sustainable to provide safety, which was created through cooperation and the professional’s individual responsibility. Adapted and adequate support was only possible when there was access to staff who reacted quickly to changes in the health status of the older person. A lack of communication between professionals regarding the older person’s needs was perceived as hindering a good life for them.

P10: You see how intertwined everything is and that everyone has to go hand in hand and work in teams in order to support the older person. (FG 5)

A good life for older persons was described as including support to relatives. In the planning of support, participants stressed the importance of relatives who knew the person well. However, they also described relatives as sometimes demanding different supports than the older person wanted. To give support based on older persons needs, participants stated that staff needed to increase their knowledge about diseases and how they affect the health of the older person. Increased competence amongst the staff could facilitate their ability to understand the significance of adapted support for the older person.

P22: Home service makes visits six times a day, but there is no continuity of staff. I do not know how many different staff the older person meets in a week. If they have a cognitive disability, it is chaos for them... just the feeling of knowing somebody is coming into their home, but not knowing who it is, and if it is someone they recognise. (FG 3)

In order to enhance the feeling of security for the oldest old, the participants expressed that adapted support should be provided according to the timetable by staff familiar to the older person, which is not the case today.
Discussion
This study explored key stakeholders’ perceptions of a good life for single-living older persons with extensive needs living at home. From the participating key stakeholders’ perspective, a good life for older persons was understood as promoting integrity, familiarity, strengthening identity through activity and being offered adapted support.

The key stakeholders had a clear view of a good life. On the one hand, they described an intention to promote a good life; on the other hand, they described an organisation preoccupied with handling unfulfilled needs, loneliness, a shortcoming in accessibility and insecurity at home. This expressed duality was interpreted in the result as an incongruence between intentions and actions, a clash between the ideal and the real. The findings reflect a situation where home care for those with the most extensive need and support, out of necessity, mostly focused on basic needs, hence limiting possibilities to promote a good life for older persons.

Our findings show that a good life for older persons was seen as related to a sense of meaningful relationships. However, key stakeholders described how older persons often lacked close relationships and the possibility to shift between solitude and togetherness. Loneliness as a hindrance to a good life for older persons was also described in a study of nurses’ perceptions that shows the importance of establishing long-term relationships and balancing the need for independence with a feeling of loneliness (Carlson et al. 2014).

Tuominen & Pirhonen (2019) showed that close relationships were important for a good life for older persons, whilst loneliness was described as imprisoning and an overwhelming feeling of emptiness. According to Nussbaum (2011), people live with and for others, and life without this is not a worthy life. In our study, key stakeholders felt powerless when unable to support and enable social interaction and closeness for older persons, which we interpret as an inability to support what Nussbaum refers to as affiliation.

According to key stakeholders in our study, another aspect of a good life was integrity related to opportunities for older persons to make independent decisions about their everyday life. Findings illustrate difficulties in balancing and promoting the older persons’ own decision-making and the perceived need to decide for them. Continued independence in
chores and activities was recognised as key to the older persons daily life. This balance was described in the presence of identified risks associated with living alone. Similar perceptions have previously been described amongst physiotherapists, occupational therapists and social workers (Hjelle et al. 2018).

The expressed perceptions about decision-making in this study could be related to Nussbaum’s capability of practical reasoning (Nussbaum 2011), which entails the capability to form a conception about the good and critically reflect on decisions about one’s life. In some cases, the key stakeholders’ actions limited the older persons possibilities to take these steps. However, the key stakeholders had to choose between actions where neither of them fully supported the self-government of the oldest old when it could entail potential risk for danger and self-harm. Key stakeholders expressed that the independence of the elderly often needed to be negotiated to fulfil the organisation’s responsibilities for older persons safety.

The identified incongruence between intentions and actions in this study indicates deficient conditions for promoting a good life amongst older persons. In situations with deficient conditions, Nussbaum (2011) suggests supporting two specific capabilities that promote other capabilities: affiliation and practical reasoning.

Affiliation is related to the capability of living together, showing concern for others and being part of social interaction and friendship. Practical reasoning is related to the ability to be engaged in planning one’s life (Nussbaum 2011). Related to the findings in our study, it seems that the capabilities of affiliation and practical reasoning are involved in several of the identified aspects of a good life.

The incongruence that is central in our study can be interpreted as the key stakeholders being confronted with a tragic choice (Nussbaum 2000; 2011), which has been referred to as a way of understanding various caring situations for older persons (Horrell et al. 2020). A tragic choice occurs when no present alternative agrees with a person’s moral values. The person will then need to either ignore or acknowledge that such a choice has to be made. The nature of a tragic choice is that all available options involve a moral conflict.

By acknowledging a tragic choice, the focus is maintained on the fact that one is acting against their moral values in the current situation,
but this acknowledgment can have the potential to create conditions for future actions. To create such change in conditions, supportive capabilities must be possible to add to the scarce resources available (Nussbaum 2011).

In our findings, the incongruence between intentions and actions in promoting a good life for older persons seemed to reveal a stalled process in distinguishing the threshold between the most supportive capabilities and, by doing so, identifying the best course of action. By developing an understanding of affiliation and practical reasoning as supportive capabilities, a good life amongst the oldest old with extensive need for support could better be facilitated.

The capability approach has been suggested to strengthen the focus on human well-being in social work (Evans 2017) but is also noted as being excessively optimistic about what society can do for its citizens (Hugman 2008). Our findings show a gap between intentions and actions, which seemed to release feelings of powerlessness in the key stakeholders. The feelings of powerlessness were prominent, regardless of whether participants worked at a political level, as managers or in patient care.

The incongruence in this study shows similarities with a study of social workers’ professional ideals (Hendriks et al. 2016). Findings in this study show an incongruence between the ideal and the real, and in Hendriks et al. (2016) findings, amongst others, a powerlessness connected to the professional ideals and the hindrances that surround it.

Powerlessness has been described as the expectancy or probability that one cannot determine the outcome one is striving for (Seeman 1959). Sharing perceived powerlessness is important for the process of dealing with value conflicts (Grönlund et al. 2016). The importance of inter-professional support to cope with ethical issues is common in clinical care (Molewijk et al. 2008). Relating to the findings in this study, ethical support could be reasonable to implement in care settings within municipalities involving politicians, managers and care personnel. Such interventions could be used to support reasoning towards a new, common understanding to increase the ability to identify the best place for action and thereby promote a good life for older persons.

Our findings of key stakeholders’ perceptions of a good life for older persons include integrity, familiarity and identity as well as facilitating
adapted support, all relating to different aspects of living at home. Living at home relates to the concept of ageing in place and is part of ageing and welfare policies in many countries. Ageing in place refers to the ambition to provide opportunities to grow old in one’s home and community instead of in residential care (Davey et al. 2004). The meaning of ageing in place is considered important for security and familiarity (Wiles et al. 2012). A disadvantage of an ageing-in-place policy might be that older persons are expected to remain at home despite their possible frailty and need for care (Iwarsson et al. 2007).

Our findings show that it is important to learn more about the organisation giving support to older persons with extensive need for support and to develop methods that promote a good life for them. Such methods should not only consider basic needs but also evaluate capabilities and prerequisites for a good life, and, of course, the care organisation’s possibilities to promote the good life. This knowledge can increase the opportunities for older persons to enjoy the benefits of being at home and age in place and prevent the physical home from turning into an experience of homelessness, with dimensions of detachment and captivity (Zingmark 2000).

Conclusion
This study reveals an incongruence between intentions and actions in promoting a good life for oldest old. The incongruence causes feelings of powerlessness amongst key stakeholders at different levels of the organisation. To promote capabilities and a good life for older persons with extensive needs, a congruence is needed between the key stakeholders’ individual awareness and the prerequisite of promoting a good life and the organisation’s ability to support this endeavour. In the case of older persons with extensive need for support at home, it seems essential to identify methods to promote a good life for them. Such knowledge is important for both the older person and the organisation to identify and bridge the gap between intentions and actions in the promotion of a good life.

Acknowledgements
We would like to thank all participants for their contributions.
Ethical approval
This study was approved by the Regional Ethical Board, Umeå, Sweden 2015/338-31Ö.

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References


Hendriks, P., van Doorn, L. & van Ewijk, H. J. (2016). Turkish and moroc-
can dutch professionals in social work. *European Journal of Social Work*

teams’ roles: A qualitative study of interdisciplinary teams’ expe-
riences. *Journal of Multidisciplinary Healthcare* 11(1), 305–316. doi:
10.2147/jmdh.s160480

capabilities to understand caring for older people in New Zealand. *In-
220X15936247038641

*Australian Social Work* 61(2), 141–145. doi:10.1080/03124070801998400

Iwarsson, S., Horstmann, V. & Slaug, B. (2007). Housing matters in
very old age – yet differently due to ADL dependence level dif-
doi:10.1080/11038120601094732

man* 52(2), 151–168. doi:10.5840/schoolman19755223

Krueger, R. A. (2014). *Focus groups: A practical guide for applied research* (5th

ating the voice of elders to promote quality of life. *Journal of Housing
for the Elderly* 33(4), 382–392. doi:10.1080/02763893.2019.1593280

capabilities in advanced dementia: Nussbaum’s approach. *International
Journal of Older People Nursing* 13(2), e12178. doi:10.1111/opn.12178

ethics in the clinic. The theory and practice of moral case deliberation.
*Journal of Medical Ethics* 34(2), 120–124. doi:10.1136/jme.2006.018580

Sage.

Nussbaum, M. C. (2000). The costs of tragedy: Some moral limits of
doi:10.1086/468103

Nussbaum, M. C. (2011). *Creating Capabilities: The Human Development
Perceptions of a good life for the oldest old


