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Autonomy and Participation in Care For Older People

*Descriptions by Older People, Registered Nurses,
Case Managers, First Line Managers and Local
Authorities Senior Medicine Advisors*

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Abstract

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Overall aim: To describe the essence of autonomy and participation for older people in care, and how to promote this in care for them.

Method: A descriptive design with a phenomenological approach. Sixteen older people (I) and 13 registered nurses (II) participated in individual face-to-face interviews (I and II). Twelve case/care managers and supervisors participated in a focus group interview, they were grouped by profession, case managers, first line managers and local authority senior medicine advisors, four in each group and interviewed once (III and IV). The data analyses were guided by Giorgi's descriptive phenomenological method (I and II) and the systematic text condensation by Malterud (III and IV).

Findings: The informants were in agreement that maintaining older people's health and wellbeing promote autonomy and participation, and supportive relationships are relevant (I–IV). Older people focused on everyday life experiences they made by choice and managing on their own, as strengthening self-esteem and self-identity (I). The registered nurses focused on caring for frail older people and their need for acknowledgement in everyday care. They noted that of providing choices as enable older people to have joyful everyday life experiences (II). The managers and supervisors focused on informed consent, and legislation, and offered solutions to securing a meaningful everyday life by caring for older people's wishes and needs. They also spoke of the risk the severe consequences could result from older people's decision-making and their health conditions (III). Relatives were respected as a resource and attended to in everyday care for older people but the focus was the older person in their present life situation and their individual rights (IV).

Conclusion: Promoting to autonomy and participation for older people were maintained health and wellbeing, and the possibility to manage on their own terms. Informed consent, shared decision-making, supportive relationships and acknowledgement of relatives in the life-changing situations were ways to promote autonomy and participation. To promote autonomy and participation in care for older people is also to provide for choices that are meaningful to the older person at end of life in a joyful and permissive atmosphere.

Keywords: Autonomy, Participation, Older People, Chronic Illness, Healthcare, RN, CM, FLM, LASMA, Relatives, Municipal Care, Phenomenology

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*For the love of my family and our
shared everyday life*

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Hedman M, Pöder U, Mamhidir AG, Nilsson A, Kristofferzon, ML, and Häggström E. Life memories and the ability to act: The meaning of autonomy and participation for older people when living with chronic illness. *Scand J Caring Sci* 2015;29:824–833.
- II Hedman M, Häggström E, Mamhidir AG, and Pöder U. Caring in nursing homes to promote autonomy and participation. *Nurs Ethics* 1–13. Epub ahead of print 20 April 2017. DOI: 10.1177/0969733017703698.
- III Hedman M, Enmarker I, Pöder U, and Häggström E. Autonomy and participation in municipal care: managers and supervisors descriptions. (Manuscript)
- IV Hedman M, Pöder U, Enmarker I, and Häggström E. Including relatives to promote autonomy and participation for older people: municipal care manager's descriptions. (Manuscript)

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Abbreviations

ACP	Advance Care Planning
CM	Case Manager, authorized social worker in municipal care for older people
FLM	First Line Manager, care unit manager, managing everyday life in municipal care in ordinary homes or in nursing homes
LASMA	Local Authority Senior Medicine Advisor, RN employed in municipal care to secure healthcare
RN	Registered Nurse

Prologue

I have worked in nursing homes as a registered nurse specialized in care for older people and have extensive experience in clinical care in this field. I still occasionally work in municipal care for older people.

I first started to think about the study because of my experiences in working with older people living with multiple diseases, without cognitive impairment. They were capable of shared decision-making in their everyday life and care. I first gave older people the opportunity to share in decisions by including them in their annual health and medical treatment check-ups. These generally involved the physician and pharmacist, and the older persons contact person if they were available. At the time, including the older person to the meeting did not work out well because the meetings were never meant to include them because it was time consuming. However, now the yearly routine for health and medical treatment check-ups has improved and the older people are included in the meeting if that is what they want.

Every now and then I have violated an older person's right to autonomy and participation for a greater good, (i.e. my professional duty to care for the individual and the population justified my actions). The older people I care for motivate me to reflect on my experiences and possible optional actions to make a change. Where there is love there is hope!

Working on this thesis has been a great journey, which started with learning about what I thought autonomy and participation were to understand the importance of actual autonomy in everyday life world.

Starting to learn about phenomenology opened the door to the world where I felt I belong: to respectfully understand humans and their differences instead of convincing each other of our own truth. With the world changing, democratic rights and the acceptance of differences need to be actively protected. I hope you as the reader will find this thesis enlightening in your life world.

*You don't want to lose your autonomy
it's who you are inside
the poetic part of yourself*

Patti Scialfa, 2007

Introduction

Autonomy and participation need to be emphasized in caring for older people in their everyday life.^{1,2} Freedom of choice is fundamental to autonomy and participation and mandated by human rights legislation.³ The creation of individual's capabilities includes what the society offer their population in social, political and economic resources,⁴ influencing the persons possibilities in everyday life.^{4,5} A person's life experience, education, physical and cognitive functioning and their combined resources affect their possibilities and ability to make adequate and reasonable choices.⁴ To have their right to autonomy and participation in society and everyday life respected, older people who need assisted living and care have to be offered choices that they can understand and carry out as discussed by Nussbaum.⁴

In the middle of the 20th century, there were 14 million people age 80 years and older in the worldwide population. By 2050, this age group is expected to have 400 million people.⁶ Older people are defined as people 60 or 65 years of age or older in most developed countries but it can be lower in some developing countries.⁷ In 2013, 19 per cent of the Swedish population was 65 years or older. The average expected life span for women was 84.09 years and for men, 80.56 years. The age structure of Swedish citizens is expected to follow that of the worldwide ageing population with a greater proportion of people being in the older age group.⁸ Within the ageing population, older people suffering from chronic diseases' such as heart disease, stroke and cognitive impairment e.g. vascular or Alzheimer's dementia^{9,10} and multiple sclerosis (MS) and Parkinson disease.¹¹

Older people suffering from illness should not be regarded as a homogenous group.^{6,12} Their need for care and their healthcare expectations can vary but the person may be considered frail¹² and vulnerable.⁶ Perceived lower life satisfaction and self-esteem are indicated for frail older people,¹³ and their vulnerability require special attention.⁶

In Sweden, the right of older people to autonomy and to participation in their care is mandated by the Patient Act¹⁴ and Social Services Act.¹⁵ These legislations also include human rights³ of being regarded in equality^{14,15} and fundamental values of the right for older people to belong to social contexts and to experience meaningful content in everyday life.¹⁵ The older peoples right of autonomy and participation in care need understanding of the meaning of the concepts in their everyday life and how this is promoted in care.

Autonomy

Independence and self-determination are defined as crucial aspects of the concept of autonomy.¹⁶ Kant^{17,18} established the concept as being essential and fundamental for people; this means that people, have the right to be regarded as self-determined, independent of their actions, free in will and having a natural sense for morale reasoning. Kant discussed the idea of human consciousness and the intentionality and the innate morale sense of doing the right thing, acting upon morale aspects such as knowing the difference of what is doing good or what is doing harm. When a sense of doing good is act upon with respect for duty, that is an autonomous act of consciousness.^{19, 20} Kant also established that humans are connected to each other by nature.²⁰ The idealism in the philosophical discussion of autonomy as being independence, and having a free will is necessary, thus to underline the importance of the theory¹⁷⁻²⁰ respecting the individual human in society and the political government.^{1,2}

The definition of autonomy also depends on the context in which it is interpreted.²¹ An example is shared decision-making in healthcare which includes active participation by the patient, a request of healthcare professionals providing understandable information so the patient is able to make a reasonable decision. Decision-making may have to be shared with a person chosen by the patient to represent their best interests.^{21,22} Decisional autonomy does assume that the patient has executive ability which is not always the case.¹⁶ Furthermore, Sandman²³ claims that having one's desires fulfilled is part of autonomy. Agich² suggest in his framework in care for older people to accept dependence as part of the definition. Agich defines autonomy as being actual autonomy that relies on the 'concrete manifestation of autonomy in the everyday world of life', and the 'everyday sense of autonomy in concrete human actions in the shared world of social life' (p. 11).²

Participation

Participation is defined as involvement in a life situation such as social events in family and society.²⁴ In policy frameworks, participation is considered as one of the basic elements in individual ageing,^{25,26} and described as supporting older people's health, independence and life satisfaction.^{27,28} When it comes to decision-making in healthcare, autonomy and participation^{21,22} can be regarded as reliant on each other, such as in cases of exploring a person's functional status. To be in agreement of assessed function and needs respecting shared decision-making.^{29,30} In 2014, the Swedish Agency for Participation was established to govern the rights for participation in, for example, society and public spaces for people with variation in physical and/or cognitive functional abilities. The agency's website provide information about rights and about what can be done to enable participation.³¹

In accordance with Kemp³² one can reason that participation is part of autonomy. Including the abilities such as being able to shape ideas and set goals in a current life situation. Ethical awareness and moral self-regulation include relationships to other people and can be regarded as slightly different from the more self-centred ability to have a personal life and being capable of rational decision-making and coercion-free agency. Still, the abilities mentioned depend on interaction with other people and the same goes for being capable of political engagement and personal responsibility. Being able to give informed consent for medical tests and treatment and being able to ingest food are included as abilities in autonomy without being any given order of importance. In most ways, they depend on interaction.³²

Interdependent relationship

In exercising autonomy and participating in everyday life, a person is dependent on interaction with other people in various contexts and life situations,³³ such as in early childhood, in sickness and commonly in old age.^{33,34} In providing care for older people, the need for support and companionship² direct that dependency is to be included in autonomy and participation.^{1,2} When living with dependency, a person's experience of autonomy and participation can be supported by assistance from family members and/or healthcare professionals in a give-and-take relationship.³⁴ Kittay also discuss 'the virtues of acknowledged dependence' and suggests having disability as the norm rather than 'the temporarily able' (p. 50)³⁴ as a norm for autonomy. The latter stresses that the dependent and their carers face unreachable goals in everyday life and care. Kittay highlights the ability to identify needs and to care for each other in co-operative, respectful and attentive relationships as promoting connectedness.³⁴ The interdependent relationships are acknowledged in the fundamental values in care for older people. This is the right to be treated with respect of dignity and integrity such as being respectfully acknowledged in everyday care, being included in social life and their context through shared decision-making of comprehensive choices, and recognition of the social context to be important for the individual older person.¹⁵

According to this, autonomy and participation are integrated components with interdependent relationships in the sharing of everyday life between care-takers and caregivers. This needs to be acknowledged in care for older people to support their right to maintain their autonomy and to participate on their terms.

Older people in society

The World Health Organization⁶ states that older people make important contributions as family members and members of society. Longer life expectancy means a greater opportunity to contribute to society. However, when older people are marginalized by negative stereotypes and barriers to participation that undermine their contribution to society, the costs of an ageing population increase. Poor health in older age is a burden for the individual, their families and for society as a whole.⁶

People who are defined as the most ill older people are individuals who require more or less regular contact with primary healthcare, specialist care, social service, and municipal home care or nursing homes for long-term care. They are surrounded by healthcare professionals such as nursing staff, physiotherapist and occupational therapists and with registered nurses (RNs) in reach 24 hours a day.¹²

Consequently, meeting the demand for acute and primary healthcare and municipal social, health and long-term care creates challenges for society. How society responds to an ageing population will be central in how people maintain good health in older age. When the disease burden is lessened by health investments, isolation can be prevented and benefits for society achieved, as older people's independence is maintained and they are less restrained.^{6,35}

Older people living with chronic illness

Living with chronic illness affects social life and older people who are ill describe the fear of not having support now and in the future.³⁶ Chronic diseases are complex and sometimes the disease leads to other health complications and associated functional impairment or disability.³⁷

Chronic illness affects a person's everyday life.³⁸ It is quite possible for people to living with chronic illness and having a joyful life experience during ageing,³⁹ but it is usually connected to the ability to adapt to situations.⁴⁰ Ageing with chronic illness is also described as having an insight about the forthcoming impact of ageing on physical and cognitive health because of disease symptoms that are similar to the ageing process.¹¹ In some cases, when older people meet with healthcare professionals the concealment of disease by age leads to lack of acknowledgment of the individual and of the progress of disease symptoms.⁴¹ To be acknowledged by being treated with respect and having the right to autonomy are important factors in rehabilitation for older people.⁴² Maintaining functional status is vital when living with chronic illness and functional limitations.⁴³ Older people's experiences and perspectives of their health and health situation are described as not given attention in healthcare such as in the hospital discharge process, which putting their right

to autonomy and participation aside.⁴⁴ In addition, some healthcare teams act as if they know what the older people needs better than the person, even though the older person has the experience of living with chronic illness.⁴⁵ In such cases, the healthcare teams are disregarding⁴⁶ to shared decision-making.⁴⁷

Care for older people

In the holistic and interdependent perspective of humans, caring is identified with a belonging to the universal love and the right to be cared for.⁴⁸ The ontology is based on the idea that caring is essential for human life, and that humans are naturally and universally interdependent. In the holistic perspective, the relational approach is fundamental when caring for patients and their life world experience of health, and suffering. Caring is viewed as natural, and requires openness to the patient in the meaning of 'seeing with the hearts eye'.⁴⁹ Turkel et al. say that the relationship of caring to health, healing and well-being of the whole person is focused within the context of the family, community, society, and the global environment.⁴⁸ Code of ethics such as doing good, seek justice and avoid harm⁵⁰ are recognized in professional code of ethics in social and health care^{51,52}

In order for long-term care, to respect older people who need assisted living and care in their relationships, Mahieu et al.⁵³ say that it needs to address fundamental values of human existence. Described values are: a decentred self, describing that we are self-determined only in the co-existence with others. Our own self-knowledge is influenced by stories told about us by others such as relatives, and sometime that is an illusion of our present life situation. Human embodiment, means that we exist, express ourselves, and satisfy our needs through our body. Our actions are guided by intentional habits developed in life. 'Being-in-the-world', is the perception of the functional relationship between oneself and the surrounding environment. It includes, for example, being able to distinguish public or private places or identify tools and how to use them. For humans, 'being-with-others', is the perception of human nature and co-existence among humans, but also the recognition of the individual as a unique person in the interdependent relationship. These considerations have to recognize the individual sphere, the partnership sphere, and the surrounding psychological and physical environmental sphere.⁵³

Older people living in ordinary homes and residential nursing homes

In Sweden, older people in need of assisted living and care can choose to be supported in their ordinary home by relatives such as a spouse or other family members or by municipal care professionals. They may also choose to become residents in nursing homes.^{6,12,14,15,54} Municipal care for older people involves mainly the older person, their relatives, and social and health care professionals. In order to be approved for assisted living and care, the older people apply for the municipal care needed. Their needs are assessed and the care granted by case managers (CMs), the social worker authorized as a street level bureaucrat in decision-making of distribution of available resources in municipal care.^{55,56}

Municipal care for older people can be provided by public or private care corporations, though the municipal care sector for older people is dominated by public care.^{57,58} In 2014, 79% of nursing home residents were living in municipal nursing homes only. At least 84% of all nursing homes in Sweden are run by public care for older people. Both public and private care corporations are funded mainly by municipal taxes and government grants.⁵⁷⁻⁶⁰

In 2015, 84% of those who received social and health care in their own homes, were age 65 years and older (i.e. 326,000 people, and 103,000 older people in nursing homes). Nearly every older person in a nursing home required health and medical care.⁵⁷ In 2014, the median age for women who moved to a nursing home was 87 and for men, 85. In the population of people 80 years and older, 23.1% received care in their home and 13% in nursing homes.⁵⁸

Older people have described the experience of autonomy and participation as residents in nursing homes as being influenced by their relationship with RNs and the healthcare team as well as with relatives. Permissive relationships built on caring and interaction between the person and healthcare professionals strengthen older people's autonomy and participation.⁶¹ Although older people in municipal care have been described by healthcare professionals as having their rights respected in decision-making⁶² and to be treated with respect of dignity and integrity,⁶³ older people described experiences of following healthcare professionals' directives, for example, when it came to medical treatment.⁶²

Professionals in municipal care for older people

In general, in accordance with Swedish legislation,^{14,15,54} municipality care for older people is carried out by social and health care personnel, such as first line managers (FLMs), aid assistants, the RN employed to secure healthcare (i.e. a local authority senior medicine adviser [LASMA]), RNs, occupational

therapists, physiotherapists, and nursing staff, such as licensed nurses and assistant nurses. A general practitioner (GP) employed in primary healthcare by the local council is responsible for the medical healthcare.^{14,15,54,57}

To support older people and CMs in shared decision-making about the care granted, the Swedish National Board of Health and Welfare, provide tools such as the assessment scale, Need of Assisted Living.³⁰ The purpose is to secure decisions in agreement with the older people's wishes and needs. CMs are guided by legislation¹⁵ and the professional code of ethics in their everyday work,⁵² and some in the profession have objected to the standards as they are argued to undermine professional discretion in the assessment of individual needs.⁶⁴ Organisational guidelines may narrow and increase subjective interpretations of directives by the CMs,⁶⁵ with a risk of reduced quality of care for older people.⁶⁶

The assessment of needs take place, for example, in the older person's home or in acute hospital care, and in the presence of relatives when that is wanted. Reassessments are carried out in ordinary homes, nursing homes or acute care hospitals.^{14,15,54,55} Healthcare professionals such as RNs are responsible to alert CMs of the need for care planning for municipal care in cases where, for example, an older person's health declines after being in hospital.^{14,54}

In general, FLMs are responsible to organize and supervise everyday life and care by managing the nursing staff.⁶⁷ While LASMAs are responsible to ensure that medical healthcare legislation is followed in municipal care,^{14,15,54} the RNs are in charge of organising healthcare in everyday life.^{14,15,54} Guided by their professional duty and code of ethics, social and health care professionals are responsible for supporting vulnerable populations such as frail older people in respect to their right to autonomy and participation.^{50,51,52} The professionals need to pay attention to shortcomings in self-determination in everyday life that older people, relatives and contact persons in municipal care describe.⁶⁸ The nursing staff provide the everyday care for older people such as helping with intimate hygiene, dressing, eating and medical intake, taking part in activities. They also report changes in health conditions to the RNs.^{69,70}

Professionals' ethical awareness is guided by their professional code of ethics,^{51,52} which emphasizes the recognition of older people's right to autonomy and participation in their care. In providing municipal care, professionals have to acknowledge the individual's perspective of their needs and capabilities^{71,72} as well as the impact of their social and cultural background.⁷³ That may have to be considered in relationship to everyday life and care for older people and their relatives.^{70,74}

Relatives in care for older people

Care planning typically involves older people, CMs, RNs and sometime other healthcare professionals such as GP or physiotherapist. But also their relatives.^{14,15,54} The variation within the perspectives on older people's health conditions, capabilities and the absence of professional teamwork affects the experience of secured health care for older people and their relatives.^{55,71,75} To support older people's right to autonomy and participation in care^{1,13} relatives' perspectives can be included.^{1,71} Including relatives in shared decision-making⁷⁴ is based on respecting the interdependent relationship within family members.^{1,4,33} The focus, however, is on the older people's present life situation so as to provide for individual wishes and needs.^{53,72} The relatives need recognition when older people's health declines.^{76,77} The decrease in older people's ability to participate in shared decision-making about care, transfers the responsibility for decision-making to their relatives. In such cases, shared decision-making in advance care planning (ACP) has been described as supportive.⁷⁷ The family members' life situation is complex and their capabilities and their desired level of support needs to be acknowledged.⁷⁶ Care for older people include end-of-life care,⁷⁷ a life-changing situation for relatives.^{53,55,71,76,77}

Rationale

Older people living with chronic illness are at risk of being marginalized by negative stereotyped attitudes in society⁶ and in healthcare when disease symptoms are regarded as part of normal ageing.⁴¹ When older people are excluded from decision-making in healthcare,⁴⁴⁻⁴⁶ there is a risk of increased disease burden for older people in everyday life. This may lead the older person to adapt to healthcare decisions and giving up some of their rights to autonomy and participation.^{6,35}

Autonomy and participation are described as having one's desires fulfilled,²³ which include being able to shape ideas and set goals, take part in decision-making in healthcare,³² and participating in social activities.²⁴ Shared decision making²² and to be offered the opportunity and possible choices to make a reasonable choice⁴ have been described as essential to autonomy and participation^{4,22} as have the experience of actual autonomy and interdependent relationships in care for older people.^{1,2,34,48} There is evidence that healthcare professionals have disregarded older people's right to autonomy and participation, and relative's participation in decision-making^{44,45,68,71,72} when older people are in a life-changing situation such needing social and health care in the end of life.^{53,55,71,76,77}

This evidence is argued to point to a lack of knowledge about shared understanding of autonomy and participation among the older person, RNs, and case/care managers and supervisors in caring for older people. There is also a lack of knowledge of how to promote autonomy and participation in municipal care. As a result, further investigation is needed of municipal care managers' and supervisors' experiences of promoting autonomy and participation for older people in the decision-making around granting care and in managing and supervising care. Such an investigation also need to look at promoting autonomy and participation in everyday care for older people.

Overall aim and specific aims

The overall aim of this thesis was to describe the essence of autonomy and participation and how to promote this in care for older people. The specific aims of included studies were:

- I To describe the meaning of autonomy and participation among older people living with chronic illness, in accordance with their lived experience.
- II To describe RNs' experiences of caring for older people in nursing homes to promote autonomy and participation.
- III To describe managers' and supervisors' experiences of and reflections on providing municipal care so as to promote autonomy and participation for older people.
- IV To describe how managers and supervisors included relatives so as to promote autonomy and participation for older people in municipal care.

Methods

Design

The design was descriptive with an overall qualitative approach guided by the descriptive phenomenology developed by Giorgi,⁷⁸ which is based on Husserl's phenomenological philosophy.⁷⁹ Table I shows the four studies' participants, data collection and analysis.

Table 1. Overview of the four study participants, data collection and analysis.

Study	Participants	Data collection	Data analysis
I	Older people living with chronic illness n=16	Individual interviews	Giorgi's descriptive phenomenological method
II	RNs* n=13	Individual Interviews	Giorgi's descriptive phenomenological method
III	CMs* n=4	Focus groups interviews organised by profession	Malterud's systematic text condensation
IV	FLMs* n=4 LASMAS* n=4		

* RNs, registered nurses; CMs, case managers; FLMs, first line managers; LASMAS, local authorities medicine advisors.

In descriptive phenomenology, when a researcher is seeking the essence of a phenomenon under study, the phenomenological method allows the researcher to look for richness in descriptions of lived experiences.^{78,79} Research methods inspired by phenomenology⁸⁰ have a high level of relevance to achieving knowledge about individual experiences, interaction and relationships between patients, relatives, and healthcare professionals.^{80,81}

In this research project, the researcher sought to describe the general essential structure of the phenomenon under study rather than individual experiences. This allowed the use of multiple informants for variation in descriptions

within a given context. It allowed for explicitly describing the context within the context.

The researcher sought an understanding of the psychological values expressed in the descriptions i.e. the insight. The researcher also looked for the least variant structure of how the phenomenon was experienced. This was expressed in the empirical variation of the described experience.

The structure is the relationship among constituents and the constituents are building the whole. Within the constituents lies the empirical variation that justifies the general essential structure of the phenomenon^{78,82} (Figure 1).

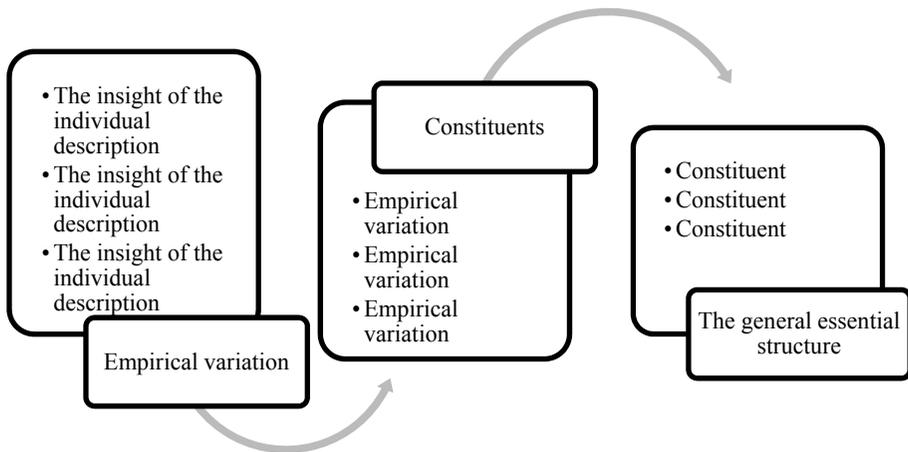


Figure 1. Building of empirical variation, constituents and general essential structure.

Malterud developed systematic text condensation (STC)⁸³ from Giorgi's method⁷⁸ to describe the essential structure of the study phenomenon. STC is characterised by the four steps for identifying themes, codes, subgroups and categories.^{83,84} Themes are the instant impression of the whole within the raw data text; codes describe the identified meaning units; and subgroups, the condensed insight. The method encourage elaboration between the codes and subgroups to improve the condensed content in each subgroups. The essential structure of the phenomenon is described in the identified category of the insights in the subgroups.

Study I

Recruitment, participants, and research context

The study was conducted in central Sweden in urban and rural counties. The inclusion criteria were men and women living in ordinary homes with a chronic illness, without a diagnosed cognitive impairment, 65–84 years old, and able to speak and understand the Swedish language.

The older people were selected from a study focusing on people 18 years and older living with chronic illness; the study included older people living with chronic heart disease, stroke, MS and Parkinson’s disease. The older people had previously answered a quality of life questionnaire (n=183). Of those, 32 older people were identified as eligible for this study. By purposive sampling,^{78,81} 18 older people were approached by telephone, and two declined to participate. Sixteen were selected to be in accordance with the research method and to achieve variation.⁸¹ Verbal and written information about the purpose of the study was provided along with informed consent letter, and then interview date was settled. On the day before or the day of the interview, contact was made again to verbally confirm that the interview would be conducted. Before the interview began, the informants provided written informed consent.

Of the informants, nine were men and seven, women. They were equally represented within the groups of living with Parkinson’s disease, stroke or heart disease, but three men and one woman were living with MS. Within the group there was variation⁸¹ in age at diagnosis onset, for example, at of 45 years of age (MS) or a year before interview (stroke). They had changes in lifestyle, current symptom level, and need for assistance and assistive devices such as walking sticks or wheelchair. Six informants were living in a house with a garden and ten were in an apartment. Seven were living in a single household; the others in a two person household. Table 2 describes the informants’ help from municipal home care services or private arrangements.

Table 2. Overview of municipal home care services or private arrangements and help needed.

Municipal home care service	Private arrangements
House cleaning	House cleaning
Food delivery	Clear away snow
Lawn mowing	Lawn mowing
Laundry	
Reminder of medical intake	
Putting on surgical stockings	
Regular visits from district nurses	

Data collection

The researcher, Maria Hedman (MH), conducted face-to-face individual interviews about the meaning of autonomy and participation for an older person when living with chronic illness. Data were collected over two months. The informants were interviewed once with each interview taking place in the informants' homes, thus in an environment they knew well in their everyday life. The interviews lasted between 45 minutes and two hours and were audio-recorded. The audio-recordings were transcribed verbatim.

The informants first described their life situation and diagnosis. Then the informants were asked, 'Please describe a regular day in your daily life', when necessary this was followed by 'Will you please give an example'. Probes such as 'Earlier you described...' and 'Will you please describe how that felt', and direct questions such as 'What do "a meaningful life", autonomy, and participation mean to you?' were used for clarification or to return to the phenomenon under study.

Data analysis

The data analysis was guided by the descriptive phenomenological method presented by Giorgi.^{78,82} The process began before interviews with phenomenological reduction^{78,79} by focusing the questions on autonomy and participation within the context of care for older people. It continued after all of the data were collected and was primarily carried out by MH. The progress and development of the process occurred in the context of discussion among the research team.

The pre-knowledge and subjectivity were reduced by having the pre-knowledge set aside by making side notes of reflected thoughts. Which was discussed during the analysis process within the research team to make the present description of the phenomenon explicit. The researcher's knowledge of the phenomenon was thereby bracketed, which reveals sensitivity to the phenomenon under study. Through this process the researcher is able to seek understanding of the psychological value i.e. insight in the understanding of descriptions.⁷⁸

The transcriptions were coded by numbers and raw data were read and re-read to get a sense of the whole. Coloured marks were made in the raw data text identifying the meaning units that describe the phenomenon under study.

The meaning units were transformed and the insight of what the participants described was made explicit by using free imaginative variation. This was done at different levels, based on the contents of the insight in the meaning units. The transformed meaning units were elaborated and rechecked in relation to the whole of the data to verify the researcher's closed-text understanding of the experience described. Empirical variations were sorted and structured, and the constituents of the insight of the lived experience were

identified. Finally, the general, essential structure of the phenomenon was described.^{78,82}

Study II

Recruitment, participants and research context

The study was conducted in central Sweden in three rural and urban municipalities. The inclusion criteria were RNs working in municipal nursing homes for older people or in a short-term care unit for older people situated in municipal nursing homes. The RN had to be stationed in a nursing home and have primary care planning responsibility for older people. The local authority of municipal care in the participating municipalities gave permission for the study. MH (in the case of one municipality) or the manager of municipal nursing homes verbally informed the RNs about the study at workplace meetings. The RNs who were interested in participating forwarded their e-mail addresses to MH, who sent information about the study by e-mail to them for consideration. Thirteen RNs (12 women and 1 man) agreed to participate. After the RNs provided e-mailed written informed consent, the day and time of the interview was settled.

The RNs represented 10 different nursing homes. The homes varied, some providing specialized care for dementia and some caring for older people suffering from physical chronic illness and/or dementia. The variation⁸¹ in age was between 28 and 61 years (median 39), and years in the profession varied between 3 and 25 years (median 13). Two participants were specialist in care of older people. The number of residents living in the nursing homes varied between 18 and 86 persons (median 40 residents). The RNs had primary care planning responsibility for between 9 and 24 older people (median 16). All of the RNs worked days, evenings and weekends. Evenings and weekends involved consultative work at nursing homes and the municipal home care service.

Data collection

To collect data, MH conducted individual face-to-face interviews about the experience of caring for older people to promote autonomy and participation in everyday life in nursing homes. Data were collected over four months. The informants were interviewed once and each time in a work office at the nursing home where the RN was stationed. The interviews, which lasted between 45 and 90 minutes, were audio recorded and transcribed verbatim.

The interviews started with the informants describing their educational background, years in the profession, work experience, and present work. Then they were asked, 'Please describe a regular day at your daily work/in your

daily work life', followed, when necessary, by 'Will you please give an example'. Direct questions were asked about the phenomenon under study such as, 'What do "autonomy and participation" and "meaningful life" for older people mean to you? How do you do to promote autonomy and participation?' Probes such as 'Earlier you described...' or 'Will you please describe how you involve the older person' were used for clarification.

Data analysis

For study II, the same process was used for the data analysis as for study I.

Study III and IV

Recruitment, participants, and research context

The studies were conducted in central Sweden in early spring 2017. Three municipalities participated, with the permission of the local authorities of municipal care. Written information about the study, including its purpose, design and interview topics were forwarded by the managers of the department to CMs and FLMs. The managers sent back to MH the contact information of those who had volunteered for participation. MH approach the LASMAs and sent them information about the study by e-mail. Written informed consent was sent by e-mail to the participants before the days and times were set for the interview.

Eleven women and one man participated; they met the inclusion criteria of being CMs, FLMs or LASMAs responsible for municipal care for older people in ordinary home or nursing homes. There was variation⁸¹ in age, which ranged between 29 and 69 years, working experience, which ranged between 0.8 and 30 years. The informants had varied educational background in health and rehabilitation, social work, economics, RNs, and district nursing.

Data collection

Focus groups were used for study III and IV because the aim was to understand the informants' perceptions, thinking and feelings about the studies phenomena. This method is useful when time is limited. The participants possess certain characteristics and provide qualitative data to help the researcher understand the topic of interest. To create a comfortable atmosphere for talking, a small group of participants is preferred when the topic is complex and the participants are experienced and/or have expertise.⁸⁵

The data were collected in three focus group interviews over two months.⁸⁵ The informants were grouped by profession with four participants in each. The interviews were audio recorded, moderated by MH and associate professor

Elisabeth Häggström, and lasted 70–90 minutes. They took place in an undisturbed conference room at the participants' work place at a time of their choice for their convenience.

The interviews began with the informants describing their background characteristics. By following an interview guide, the informants were then asked to describe their experience and reflections about autonomy and participation for older people, in a specific situation: 'Will you please describe a situation in your daily work where you promote the older person's right to autonomy and participation'. Further questions were asked such as 'What do you do to promote autonomy and participation for the older people? Can you give an example of a better or more difficult situation to promote autonomy and participation for the older people?' These were followed by 'Will you please describe what you do then to promote autonomy and participation for the older people', or 'Is there an example where your profession is limited in promoting autonomy and participation?'

Thereafter, the informants were asked to describe their thoughts and reflections about the importance of relatives in relation to autonomy and participation for older people. They were also asked about a specific situation in their daily work where they "give relatives the possibility to participate in the older people's life". To gain further understanding of the study phenomenon, more questions were asked, such as 'Will you please describe a situation in your daily work, where you promote the older person's right to autonomy and participation in relation to their relative's wishes? If you have been in a situation or a conflict where the older people's wishes didn't agree with their relatives wishes?' The questions were followed by 'Will you please describe what you then do to promote autonomy and participation for older people?'

Data analysis

The verbatim-transcribed data texts were separated by study III and IV, and the data analysis began, guided by the four steps of Malterud's STCs.^{83,84}

Step 1. From raw data to themes. The data texts were initially analysed group by group: this began with reading to identify themes to intuitively organize the data. The results provided a sense of the whole and what the content was about.

Step 2. From themes to codes. The data were roughly sorted under labelling themes, thereafter meaning units describing the study phenomenon were discriminated out of the text, and initially codes were labelled. Then the relevant text was separated from irrelevant text and meaning units identified with a description. The meaning units classified by codes, grouped the relevant text units.

Malterud describe that codes are a tool and an organising principle. Flexibility in the process to label themes, identify and classify codes provide for the opportunity to systematically capture new findings in the data text. To

keep a logbook help to reflect the process of developing new understanding of the findings.^{83,84}

Step 3. From codes to subgroups and condensed text. The meaning units in each coded group were read and keywords that were relevant for subgroups were noted. The research team considered various perspectives for the keywords and subgroups so as to explore and elucidate the purpose. A code may also be generated in several subgroups. Subgroups descriptive for the purpose were extracted from the codes, and condensation of the meaning units were made. Flexibility in the data analysis were done by elaborating between step 2 and 3, for refining adjustment of codes and subgroups.

The condensed text summarize the various perspectives of the content in the meaning units in the subgroup.^{83,84}

Step 4. From condensation to categories. The three individual data analyses were compiled before the identification of categories in step 4. The categories were refined in group discussions within the research team and identified as the essential structure of the descriptions of the study phenomenon. The summary of the findings were validated by re-check of raw data text for justification of the data analyses.

Malterud describe that categories are developed by summarising the essence in each condensed code group and make the foundation of the subheadings of the findings. An analytic text is created as a summary, describing each code group and reporting each subgroup to describe the essence of the phenomenon. By re-contextualizing the result in relation to the raw data text the findings are validated, and to test the result for justification, contradiction is systematically searched within the text.^{83,84}

Ethical considerations

Research ethics are preceding to research projects, concerning the purpose of the project and the relationships to research participants.⁵⁰ How the purpose and method in research benefit the patients are guided by the code of ethics of doing good and avoid harm. Dominating is the justification of the relevance for practice, provided in the interest of the context, the participating informants and the identified population within the specific phenomenon.⁵⁰⁻⁵²

In accordance with the World Medical Association Declaration of Helsinki,⁸⁶ ethical consideration and approval, were obtained from the Regional Research Ethics Committee in Uppsala, Sweden (Reg. no. 2012/436 and 2012/436/1).

Each informant gave his/her written informed consent prior to the interviews. In each study the informants were informed that they could withdraw their participation at any time, and of having their privacy and confidentiality guaranteed. The informants were ensured that their participation or withdrawing would not interfere with their everyday life in the care they received or their employment. The informants' interview data were coded. The key code lists are kept separately and available only to the research team. The right to protected privacy for research subjects rest on the principle of the right to respect of autonomy.^{22,50}

During the interviews the stories that the informants shared could have evoked emotional feelings that the informants could have been expressed during or after interview. The knowledge about the context and the ability to care for the informants were secured by the researcher's professional experiences.

Findings

The overall aim of the studies was to describe the essence of autonomy and participation, and how to promote this in providing care for older people. The essence was relayed within four essential structures, each with three constituents, which were different for each group of informants: older people living with chronic illness (I), and RNs (II), case/care managers and supervisors in municipal care (III–IV). Generally, the informants were in agreement that maintaining older people's health and wellbeing promoted autonomy and participation, as was meaningful relationships (I–IV). The older people focused mainly on how everyday life experiences of making choice, including decision-making in healthcare, and of managing on their own, strengthen their self-esteem and self-identity (I). The RNs focused on their professional duty of caring for frail older people and their need for acknowledgement in everyday care. Being provided with choices enable older people to have joyful everyday life experiences (II). The managers and supervisors focused on informed consent and legislation, and offered solutions for securing everyday life for older people by attending to their wishes and needs. They also considered the risk older people's decision-making and their health conditions having severe consequences (III). They respected relatives as a resource and people to attend to in everyday care for older people but their focus was on the older person in their present life situation and their individual rights (IV).

Study I

The findings showed that the general essential structure of the meaning of autonomy and participation for older people living with chronic illness was built on one core and three constituents (Figure 2).

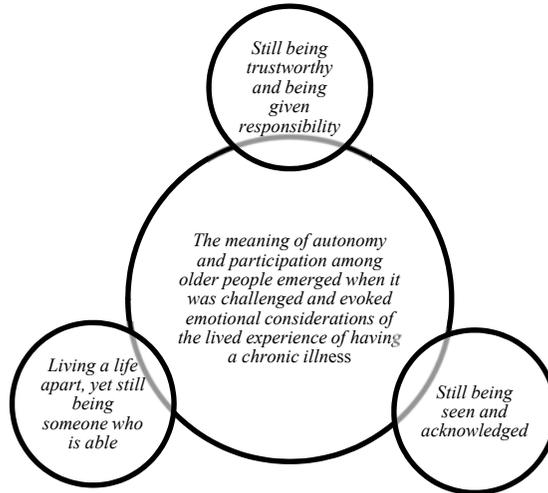


Figure 2. The core and three constituents describing the meaning of autonomy and participation among older people living with chronic illness in accordance with their lived experiences (I).

The core was that *the meaning of autonomy and participation among older people emerged when it was challenged and evoked emotional considerations of the lived experience of having a chronic illness*. The participants' responses showed that they derived the meaning of autonomy and participation through their life memories of self-identification in everyday life. The core revealed different levels of acceptance or no acceptance of their disease as part of life. They talked of adjusting to their abilities or adapting to disability to manage everyday life. Thus, they could handle their emotional feelings of control, curiosity, frustration, resigned understanding, certainty or feelings of uncertainty. The decision of what could be done and how in their everyday life was personal.

The constituent, *living a life apart, yet still being someone who is able*, indicates that mobility was flexible and ability was chosen by the older person. They wanted to be regarded as someone who was able regardless of disease symptom and mobility. They desired to manage everyday life by performing in privacy, doing things themselves such as dressing or doing handy-work in the garage. One reminder of disability was lack of access in the surroundings, restraining on managing on their own in everyday life. Accordingly they wanted to be included in social and political decision-making.

They described that balancing the everyday routine life such as managing hygiene, housekeeping and watching TV with adventure was desired. Mentioned was variety and unexpected joyful experiences such as participating in social events or learning to manage a personal computer, a tool to connect with grandchildren. Outdoor living such as visiting friends and family, visiting a garden, listening to birdsong, going shopping, and visiting a restaurant or

coffee shop. They also mentioned a holiday experience and indoor experiences such as having a pet to care for, share a cup of coffee, or playing games with friends or grandchildren as joyful experiences.

The constituent *still being trustworthy and being given responsibility*, shows that the older person wanted to be trusted with decision-making in life changing situations even though restrictive in the older person's life world such as not to drive a car due to being an unsafe driver or the solution to moving from a house to an apartment to continue to managing on their own.

They considered moving to a nursing home only in concerns about being a burden for a spouse or children. They did not consider moving to a nursing home an option for future wishes about managing on one's own or maintaining autonomy and participation in everyday life.

The constituent *still being seen and acknowledged*, shows that older people wanted to participate in family, friends, and social life by being asked for their opinion and to share concerns, or good times. They reflected on the sorrow of the loss of a spouse, other family members, and friends and how it affect their sense of being seen and acknowledged in everyday life. Sometime they found acknowledgement in speaking to people in the neighbourhood as they walked the dog. They mentioned receiving acknowledgement through participating in theatrical performances, listening to live music, and having a romantic dinner. One participant replaced former athletic performance by finding comfort in playing an instrument. They said that tiredness was to be accepted and having time to recover from tiredness was important for managing everyday life.

The older people wished to be acknowledged in decision-making for organisational changes in healthcare, as well as in their personal situations such as the discharge process from acute hospital care. Being included in a healthcare team, and having healthcare nearby of where they lived was suggested as strengthening the secure feeling in managing everyday life on one's own.

Study II

The findings showed that the general essential structure of the RNs described experience of caring for older people in nursing homes to promote autonomy and participation was built on three interdependent constituents (Figure 3). The descriptions also revealed the differences in the RNs professional role of involving older people in everyday care. They had found that older people could be involved by a person-to-person or a co-operative relationship approach or by a professional duty relationship approach.

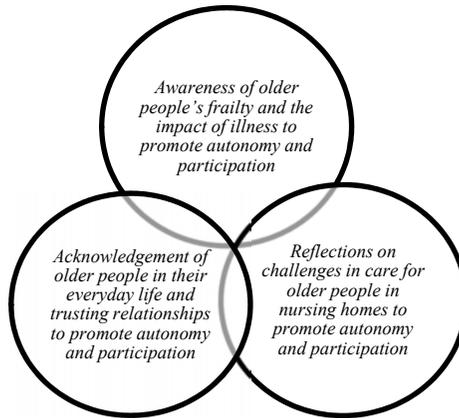


Figure 3. Three interdependent constituents describing RNs' experiences of caring for older people in nursing homes to promote autonomy and participation (II).

The constituent *awareness of older people's frailty and the impact of illness to promote autonomy and participation*, describes that RNs were aware of older people's risk of reduced autonomy and participation because of illness. Maintaining health and wellbeing were considered as promoting to autonomy and participation for older people. Older people's involvement in care planning and follow-up health status was encouraged by having them participate actively in regular check-ups on their health and functional status, fill out different healthcare quality registers with the RNs, and be given repeated information about the purpose of care they received, such as wearing surgical stocking, daily exercise and outdoor life. At the same time the RNs also observed individual changes in the older person's behaviour, such as in the ability to eat or dress independently, and discovered urinary problems, malnutrition or constipation. RNs described to be well oriented to person's behaviour and gathering information from nursing staff as being important in the clinical assessment of older people's health. The intention was to minimize the need for acute hospital care. The informants mentioned that working with a GP experienced in care for older people as helping to ensure adequate decision-making in the care for older people.

The awareness involved the constituent *acknowledgement of older people in their everyday life and trusting relationships to promote autonomy and participation*. It describes that for the RNs caring relied on their relationships to the older person and their relatives. The trusting relationship with older people were described as being built on equality because they were meaningful in the RNs lives when the older people lived in the nursing home. Knowing the individual and what has been defining for their self-identity in their lived life

was important to the RNs being able to fulfil the older persons' desires. As the older people were living their last years in life, RNs thought they should have their wishes fulfilled by provided with customized activities to enable choices and offered spontaneous activity, such as being served the food they wanted, having a hand held and having a hug. An activity could also be walking or resting that was done made by choice.

Relatives were considered a resource in decision-making in care for the older person. They described having regular contact to build a trusting relationship rather than to only keep relatives informed about the older person's health or activity. The RNs mentioned keeping a personal diary to inform relatives of older people's activities in everyday life.

They also emphasized the importance of relationships with nursing staff, and other social and health care professionals in the everyday care for the older people, because both the older people and RNs rely on their performance. They mentioned that for the older people to get the assisting help they need to get enough water to drink, food, exercise, rest, or to go out for a walk if desired.

The constituent *reflections on challenges in care for older people in nursing homes to promote autonomy and participation* describes that the RNs were troubled by organisational work, the economy and the ageing population. Another challenge was how to provide meaningful and pleasurable everyday life for residents in nursing homes end-of-life care. They expressed that older people cannot be considered a homogeneous group because they are 65 years and older. They also noted that the older people could not decide everything about their healthcare such as to demand urinary catheter because of their convenience.

They expressed concern that nursing staff's everyday duty such as house-cleaning and washing were suggested to be replaced by spending time with the older people instead. The RNs expressed the need for paying attention to nursing homes routine work and organisational restraints and awareness of older people's adaptation to life in nursing homes. They wanted older people's wishes to be in focus for nursing staff scheduling, to allow for time consuming activities such as having the older people dress independently or shower at a time when they choose. As well, they would have liked to have food served to the older people who could not sleep at night as an option to medical treatment.

Study III and IV

The findings showed that the descriptions reflected that the informants in each of the three professional groups had different relationships with the older people (III) and their relatives (IV). The CMs were the authority and formal; the

FLMs were intimate and personal; and the LASMAs were focused on supervision of secure healthcare. When necessary to the context, the professional title is referenced in the findings.

Study III

The essential structure of managers and supervisors' experiences and reflections were identified by three categories describing the provision of municipal care for older people to promote autonomy and participation (Figure 4).

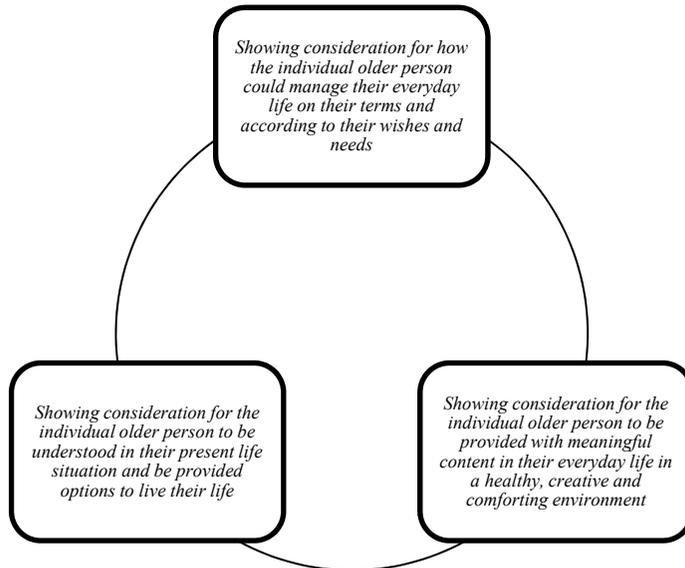


Figure 4. The categories describing managers' and supervisors' experiences and reflections of providing municipal care to promote autonomy and participation for older people (III).

The category *showing consideration for how the individual older person could manage their everyday life on their terms and according to their wishes and needs* describes that the older people were regarded as a person with individual needs with their right to self-determination in decision-making. Informed consent was the first matter to be considered in seeking care. The older people had to need, want, and confirm the municipal care offered. Documentation was done to secure decision-making. In care planning, the pressure from relatives, media and other healthcare professionals such as GPs, RNs and nursing staff had to be deflected by the informants to not influence their focus on the older people's wishes and needs.

The CMs expressed awareness of their professional power in serving the older people in decision-making on assisted living and care in their everyday

life. In the evaluation, the holistic perspective was mentioned as being considered and having face-to-face meetings were emphasized. To be granted admission to a nursing home living, the older people had to be physically disabled because of illness, and/or be anxious, feel insecure in their own home, or have cognitive impairment that affect their everyday life. However, older people's needs were the main focus in the CMs assessment of wishes and needs.

The FLMs focused on the mandatory social action plan as promoting autonomy and participation for older people. The plan documented details of the municipal care decided on, communicated by the older person and their relatives. In cooperation with the unit manager such as FLMs, and contact person in the nursing staff. However, unplanned wishes was to be respected. The FLMs described their leadership as being role models in how to perform service for the older people, caring for their wishes and needs in everyday life.

The LASMAs described that they were advisors regarding legislation and regulations in everyday care that promoted autonomy and participation for older people. They were consulted for their judgment of restrictions or requirements concerning supervision when resident went out of doors or required a movement alarm for fall prevention. Documenting risk analysis and action plans was described as mandatory to decision-making. One example mentioned was obtaining informed consent signed and documented by the GP when taking over the administration of medication from the older person.

The category *showing consideration for the individual older person to be understood in their present life situation and be provided options to live their life* describes that building trusting relationships was essential to the negotiation of available solutions. The older people were offered alternatives to enable their choices about how to have their needs provided for in present life situations. Some examples given were ways to provide for food delivery and regular check-ups at night and in the day or to enable participation in daily activities meaningful to the older person. While the older people made the decisions, follow-up decisions were necessary. When older people declined needed help, the GP could be consulted during decision-making to help older people consider the consequences of decisions and actions. Consequences as serious as an older person committing suicide were mentioned.

The informant's spoke of ways to acknowledge older people in their everyday life to break isolation such as by offering the older people the possibility of participating in a social context and contributing to group activities and being held important to other people.

They expressed that in considering older people's expectations they had to be clear about the resources such as the older peoples' physical and social capacities and the personnel available, for example, nursing staff and aid assistants. They mentioned that older people's wishes and needs should be held important in organising care. The FLMs and LASMAs trusted nursing staff to provide choices and reach solutions together with the older people in everyday life situations.

The category *showing consideration for the individual older person to be provided with meaningful content in their everyday life in a healthy, creative and comforting environment* describes that the older peoples wishes and needs could vary because of health conditions. The individual had to be cared for with respect for their integrity and dignity such as having privacy and their private life space respected. The informants mentioned that they involved the older people by letting them have the possibility to share their life experiences by asking questions that showed interest in the older peoples lived life and present situation. They participated with older people in social interaction, by sharing a cup of coffee, a meal, or afternoon tea.

The informants said that patience was essential. The CMs described doing follow-up and offering solutions one step at time to provide for older people's health and comfort in everyday life. The FLMS said that non-professional escort assistants were engaged to fulfil the older people's wishes and need for activity. Sometime language barriers could occur between an escort assistant and the older people; in such cases, the opportunity to choose another person protected the older person's rights. Respecting dignity were reflected in the older people's right to be treated in equality by meeting people other than the nursing staff. The LASMAs talked as well about taking time to provide information when establishing basic hygiene routines so the older people understood that certain arrangements were needed, why and for whom.

Study IV

The essential structure of the managers' and supervisors' experiences and reflections of relatives were identified by three categories describing how they included relatives in municipal care to promote autonomy and participation for older people (Figure 5).

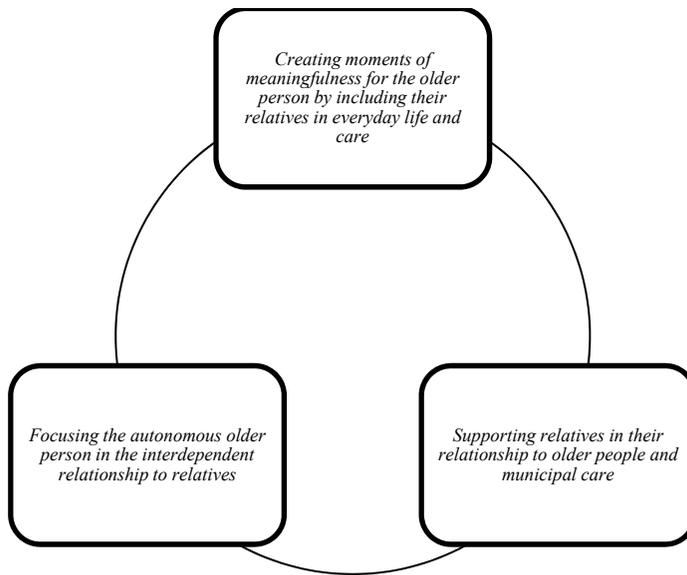


Figure 5. The categories describing how managers and supervisors include relatives to promote autonomy and participation for older people in municipal care (IV).

The category *creating moments of meaningfulness for the older person by including their relatives in everyday life and care* describes why there is a focus on including relatives. The relationship to relatives was considered important to older people’s health and wellbeing. Have the possibility to share joyful moments was also viewed as being supportive to the family members’ experiences of being included in a life changing situation such as the care for older people in the end of life.

The CMs expressed that the decision-making was done by respecting relatives’ opinions in the negotiation of the help needed. Navigating neutral conversation was helpful when family members had differences about the care needed, this required the CMs knowhow of when to step in or when to step aside.

The FLMs said that in dementia care social activities that included relatives were believed to ease the anxiety and the pressure for the older person and their family; the activities might be participating with other families in celebrating holidays. Relieving the discomfort of being alone in present situation with family members unrecognizable to each other.

The LASMAs highlighted that accessibility of municipal care needed to be supportive to relatives in their concerns about older people’s health and wellbeing. They could also receive information about options in municipal care such as customised palliative end-of-life care in ordinary homes or nursing homes. The choice was made by the older person. Advance care planning to avoid unnecessary acute hospital care in end-of-life care were described as

was the importance of talking about relatives' expectations, and older person's thoughts of death, and what needed to be covered in planning.

The category *focusing on the autonomous older person in the interdependent relationship to relatives* describes that emphasised was the respect for family members' shared past, focusing on the older people's present personality or their strength to carry on in everyday life. Sometime unfamiliar to relative's expectations on the older person's capability in everyday life. They also mentioned changes in what the older person wanted to eat, or to do as an activity, being too tired and no longer showing interest. The freedom of choice to accept or not accept participation in everyday activities was the older people's decision to make. Also mentioned was that the older people could sometime participate in activities to meet the relatives expectations.

The CMs mentioned ethical considerations in decision-making when older people were unable to participate in the informed consent because of illness. The FLMS described focusing on older people's need to live in a unrestrictive and comforting environment, when they cared for family member's emotional considerations by being helpful in providing solutions. Arrangements were said to ease the relatives' burden of despair but not take away their responsibility in their relationship to the older person.

The LASMA's described that relative's involvement in care was to be respected but attention had to be paid to relatives and their dependency to the older person. Relatives could want to speak but not dare to confront the older person about differences in their perceptions of the family situation.

The category *supporting relatives in their relationship to older people and municipal care* describes reflected concerns about the relatives' experiences in everyday life of the older people receiving municipal care. The informants said that the older people's health conditions stress the situation. The informants' professional perspective on having empathy was expressed as providing information to and patiently guiding the relatives in municipal care, which focused on the older people's health security and wellbeing as an individual. The FLMS expressed that they cared for the relatives by providing face-to-face meetings to help them cope with changes in family relationships. The LASMA's expressed that it was necessary to provide information about regulations of restrictions and to include relatives in the understanding of interprofessional teamwork to support older people's health and wellbeing. For example, that healthcare professionals such as occupational therapists assess older people's capabilities in accordance with legislation and regulations, to prevent restrictions in the older people's everyday life and to promote their autonomy and participation.

Discussion

The overall aim of this thesis was to describe the essence of autonomy and participation and how to promote this in care for older people. The findings indicate that autonomy and participation in care for older people can be promoted, and their wishes in everyday life easily met through having their abilities and trustworthiness acknowledged by having dignity and integrity respected. Experiencing joyful and meaningful everyday life shared with relatives, friends, escort assistants and health care professionals.

The main source for autonomy and participation was secure health and wellbeing for older people (I–IV). When living with chronic illness, older people desired access to healthcare so they would feel secure that when disease symptom increased they could continue to manage everyday life on their own. Being capable of managing everyday life was found to strengthen self-identity. Experiencing variety in everyday life by their choice was desired (I). Recognising the frail older person, their rights to have the possibility to make a choice, and be acknowledged as individuals in everyday care for older people was identified as promoting autonomy and participation (II). Having joyful experiences and for the older person to be meaningful in other people's lives were emphasised as promoting autonomy and participation (I–IV). Shared decision-making and informed consent were the foundation of the negotiation in securing everyday life (III). With respect to relatives' expectations of care, the managers and supervisors made the older person in the present situation the focus (III–IV). The older people's relationships to nursing staff and relatives were held as being important to their wellbeing (II–IV). The older persons' interdependent relationships were recognised in the life changing situation when the older person was at the end of life; the relatives were acknowledged to promote the older person's autonomy and participation.

Promoting self-determination and shared decision-making by offering choices

Secured health and wellbeing were considered important to promote autonomy and participation (I–IV). Time and privacy were necessary for older people to the sense of acting independently (I). Other things that strengthen sense of maintaining autonomy and participation was the older person and those

providing care being meaningful to one another (II), being regarded as equal (I–III), and respectful dialogue such as ask for the older people’s opinion (II–IV). Factors described as having dignity and integrity respected.⁸⁷ The interdependent relationship³⁴ need encouragement in everyday care for older people as promoting to autonomy and participation. Being cared for in attentive relationship³⁴ was recognised in present research project as something that may secure health and wellbeing in care for older people. To secure healthcare in nursing homes variety in everyday life activities was important (II–III), which have been emphasised in previous studies.⁸⁷ Indicated is that garden greenery may provide for an exciting outdoor experience.⁸⁸ The ability and possibility to make a choice in decision-making concerning most of the aspects of personal and everyday life (I) is another contributor to autonomy and participation. Everyday life activities could be satisfying¹ if older people choose them from variety of possible choices.^{34,87,88} In addition, tiredness and the strength to carry out activities have to be acknowledged deterrents to possible activity so there is a need to provide for recovery in comfort (I–IV).

The older people asked for access to healthcare teams so they could have disease symptoms managed so as to maintain autonomy and participation in the everyday life experience (I). Having easy access to information about municipal care was mentioned in this connection by LASMAs (IV). The findings indicated a need for variation in providing access to resources in municipal care. Computerized municipal websites are available for easy access to information and for contact. Older people expressed a desire to learn to manage a personal computer as part of having autonomy and being able to participate (I). But knowing what to look for, where to find it, and how to apply for municipal care on one’s own requires skills such as reading, writing and comprehension.⁸⁹ Consequently, the use of computers may not be a possible choice for older people living with chronic illness.^{4,34,89} This risks creating subgroups among older people in need of care, such as of late-in-life immigrants⁹⁰ who do not know the language.⁹¹

Promoting involvement in society by respecting dignity and integrity in possible choices

Older people wanted to be included or have the opportunity to participate in decision-making in society and healthcare (I). Having the possibility to participate was not clear in descriptions provided by RNs, and managers and supervisors (II–IV). This could have happened because they considered themselves as representing the older people’s voice and respecting their rights to autonomy and participation.^{51,52} The individual approach to decision-making in society and healthcare needs to be further investigated to learn more about older people’s wishes and how to support their capabilities for participation

when living with chronic illness. Another area to investigate is how new technology can support health⁹² and decision-making in care.⁵⁰ Treating older people in nursing homes as being a homogenous group, which was identified as a problem (II), needs attention to promote autonomy and participation in care for older people.^{6,12} For example, older people could represent themselves in ethical discussions of accessible healthcare so they feel included in decision-making. There could be an ethics committee in the municipality that include older people in the development of municipal care.

Furthermore, it was suggested that municipal care could be organized so planning was done and carried out with respect for older people's wishes and needs (II–III). It was indicated that organising everyday care for older people needs to play a bigger part of workplace organisation and development. However, in organising municipal care different perspectives need consideration to respect the legal rights and fundamental values of autonomy and participation^{3,4,14,15} for both older people and healthcare professionals. Given as an example was nursing staff, their work duties and time schedules that could be planned to focus older people wishes and needs (II). They were considered as important for older people's experience of autonomy and participation (II–III) and were trusted with shared decision-making in everyday life (III). Nursing staff duties in everyday care for older people (II) need to be investigated so they can focus on older people's wishes and needs to experience joyful everyday life.

Creating meaningful life by the conscious act of caring for dependency

Relationships older people had in their everyday life were considered important to their autonomy and participation and to being connected in a social context, and relatives' influence (I–IV). Thereby, the RNs, managers and supervisors appeared to provide for older people's wishes and needs (II–IV) in accordance with the older people's experience of the meaning of autonomy and participation (I). For a further understanding of the phenomenon, studies are needed in the clinical context.

Legislations directs healthcare:^{14,15,54} national and local regulations and guidelines, tools such as assessment scales, mandatory action plans are provided to secure older people's right to autonomy and participation in decision-making of everyday care. In addition, national registers support older peoples' everyday care. Informed consent was important to collect from the older person before they filled out documents or registers (II–IV). The legislation of fundamental values¹⁵ in respecting rights to autonomy and participation in care for older people^{14,15} creates a possible foundation for organisations to be capable of involving the individual in shared decision-making²² and activities

such as meaningful experiences in everyday life.¹⁵ Related to this is the importance of healthcare professionals education in practicing the fundamental values that strengthens older people’s experience of having the opportunity to share in decision-making by being provided with choices meaningful to the older person.⁹³ Thus, the promotion of autonomy and participation in care for older people can be argued to be reflected in everyday life in municipal care and the approach of offering choices.^{1,2,34,93,94}

The nursing staff are described to be close to the older people and their relatives over time, and as are RNs and FLMs. CMs are not as close because they are involved for a short time and nor are LASMAS who have an advisory role (Figure 6).

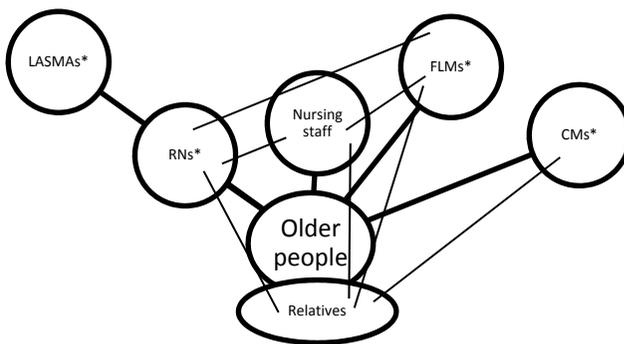


Figure 6. Illustration of municipal care professional’s relationship to older people, and their relatives. * RNs, registered nurses; CMs, case managers; FLMs, first line managers; LASMAS, local authorities medicine advisors.

Figure 6 illustrates the relationships of those providing older people with care so as to promote autonomy and participation in everyday care. Older people described mainly having a variety of indoor or outdoor everyday life experiences as being meaningful to autonomy and participation (I); this is possible to achieve in municipal care. Awareness of the values of autonomy and participation^{14,15} in everyday care^{32,34} may be reflected in the conscious act of caring⁴⁹ for the older person’s needs,^{1,2} of intending to do what the older person wishes and fulfil what is desired.^{23,94}

The shared decision-making^{21,22} appeared to involve clarifying expectations and negotiating of the choices offered in order to secure older people’s health and wellbeing (III–IV). The right to self-determination could collide with older people’s wishes if there is an assumption of how to ensure wellbeing.⁹⁵ The ability to perform everyday life activities may promote autonomy and participation defining one’s own sense of self-esteem and self-identity.^{1,96}

Trust the older people in need of care to make reasonable choices in their wishes in everyday life seems to be achievable according to the examples given to describe the meaning of autonomy and participation when living with chronic illness (I). Engaging non-professional to help fulfil the individual’s

sense of wellbeing and provide variety in everyday life in care for older people (III) was an example of creating capability.⁴ This provides older people and non-professional with an opportunity to share a social context in everyday life.

Caring for life in end of life care

Care planning can be influenced by the emotional considerations of health and disease development and the impact of not managing everyday life independently.^{55,74,75,77} The older people mentioned that they felt disregarded in the decision-making about care (I), which is confirmed by published research.^{42,44,94,96} Attention has to be paid to the older people and their relatives. They could need time to take in the thought of being dependent and to having different people caring for their needs, with access to family privacy. As well, they made need time to come to terms with needing end-of-life care.⁹⁷ ACP was mentioned as a means of securing adequate healthcare at end of life (III), which is supported by previous studies.^{77,97,98} However, individual differences in experiences of ACP have been reported, discussing whether its purpose is to be beneficial for older people and their relatives; or for healthcare professionals.^{99,100}

Filling in and documenting forms for informed consent, assessment scales, and actions plans (II–IV), are important for ensuring informed consent²² in legislations and regulations as respecting the right for older people to autonomy and participation.^{14,15} Accessibility to reasonable choices^{32,34} and interdependent relationship in everyday care for older people^{1,2,34} need to be highlighted as promoting autonomy and participation. Doing daily routines such as providing professional care by following regulations and guidelines risks putting a commitment to the individual and their perspectives aside.¹⁰¹

The consequences of decreased health such as suicide among older people (III) are given attention in care for older people.^{59,102} When respecting autonomy and participation, and the right to decline needed help a follow-up decision is necessary (III). Learning about older peoples' symptoms of depression are necessary^{102,103} to respect their dignity. More need to be learned about how older people experience their everyday life situation in order to target the older people at the risk of being suicidal.

Furthermore, when caring for older people suffering from cognitive impairment, highlighted is the importance of focusing on offering choices that the person can grasp and comprehend without stress or feeling not being capable, which can happen if they do not recognize the situation and choices offered.⁵³ The older people wished to be acknowledged in their present life situation (I) and were described to be cared for with respect for their present personality, and their relatives' perspective (II–IV). Another area that needs acknowledging is that attention needs to be given to relative's expectations. As well, is there a need in care for older people of the understanding of the frail older

person and their reduced capability to cope with stress and disorientation and their risk of further developing diseases.^{6,12}

The conscious act of caring in a way to promote autonomy and participation in care for older people may need to rely in the meaning of the concepts as defined by what autonomy and participation actually means to older people. In caring for older people, their wishes in everyday life may easily be met by giving them time and acknowledging them. This could involve taking time to plan the day in the morning care, to consider options and make a choice. It involves reflecting their thoughts in respectful dialogue. To plan for something the older person want to do later during the week to have something to look forward to and imagine about. Experiencing variety in everyday life. Share moments can easily happen in ordinary home or nursing homes if time is provided and the sharing of everyday life in the interdependent relationships is emphasised as promoting to autonomy and participation in care for older people.

Methodological considerations

The phenomenological approach was chosen because of the purpose of the research project. The philosophical definitions of phenomenology and autonomy relate to each other by Kants' reasoning about conscious and intentional acts and the right of self-determination.^{17,18,20} Husserl developed philosophy of phenomenology⁷⁹ to emphasise the individual experience of the lived phenomenon. Given that there is no true reality because the perspectives differs.^{78,79,104} The credibility¹⁰⁵ of the study lies within the richness of perspectives in the descriptions of the purpose of the research project. There were variations in the groups of participants and in the informants' descriptions (I–IV) revealing corresponding findings. The findings in the present thesis may be transferrable¹⁰⁵ to similar contexts since they are confirmed by previous findings describing different study phenomenon and study groups.

The co-operating in focus groups interviews was in accordance with Kreuger and Casey's suggestions of having a moderator team.⁸⁵ One researcher moderates the discussion and the moderator assistant pays attention to group interactions, notices ambiguity, asks additional questions and takes field notes.⁸⁵ This also confirms the credibility¹⁰⁵ of the data analysis, because the findings can be verified to be in accordance with participants' descriptions (III–IV). The discussion within the research team was ongoing during the analysis of each of the studies (I–IV). Awareness of subjectivity was maintained by side notes that reflected knowledge and understanding and discussions within the research team. The bracketing^{78,79} began before the data collection and was sharpened over the years of the research project to distinguish the various perspectives on the study phenomenon. Since data collection lasted over five years, reflexive discussions within the research team were ongoing to protect objectivity (I–IV). The pre-knowledge and understanding are, however, considered as essential for the recognition of the study phenomenon (i.e. to know what to ask and look for). Having field experience strengthening the reliability of the researcher. By using descriptive phenomenology, the researcher are trusted with that analysis correspond with the closed-text description of the findings. The researcher knows that different researchers describe the same findings in different ways, although with a similar essential structure of the study phenomenon.⁷⁸

To achieve dependability¹⁰⁵ the study groups were well defined and described. The descriptive phenomenology required informants who had the lived experience and wanted to describe it, and, in addition, have the ability to

speak and understand the language. It can be argued that the study had limitations given the homogeneity within the study participants as a whole, as none of the minority groups in Sweden were explicitly represented. It is possible that the informants and researchers had a similar understanding of autonomy and participation. This indicates the need for further investigation targeting minority groups^{90,106} in a similar context and thereby the perception of autonomy and participation in care for older people. It can also be argued that the study groups were people with ability to act (I-IV). A different group may have provided for further understanding of the study phenomenon.

Furthermore, dependability¹⁰⁵ relies on the data collection and analysis and this has been thoroughly described to clarify the steps in Giorgi's⁷⁸ and Malterud's⁸³ methods. Malterud suggests that the use of the STC is not restricted to specific types of empirical data. For example, the method can be used in analysing data from individual face-to-face or focus groups interviews.⁸³ Also the wording in the findings may describe what has been revealed, as was done in previous published research directed by Malterud.¹⁰⁷ Although the identifying of categories is what is done in the data analysis. Once the method has been learned, Malterud suggests doing it with flexibility rather than rigor,⁸³ as does Giorgi.^{78,80} To conduct a closed-text analysis, creativity and flexibility are needed,^{78,83} and as well in the presentation of the findings.⁸³

Conclusions

The essence of autonomy and participation in care for older people was having secured health and wellbeing (I–III) and managing everyday life on the older persons own terms, in a self-identifying and strengthening atmosphere (I). A number of everyday life experiences meaningful to having dignity and integrity respected were emphasised as promoting autonomy and participation. One was for the older person to be trusted and acknowledged as capable and meaningful in their social context in everyday life (I–IV). Awareness of the frail older people (II) and their relatives in a life changing situation and the relationships in care for older people were acknowledged (II–IV). To have meaningful choices offered and to be provided with time in everyday life (I–IV), and in the negotiation of care needed were identified as promoting autonomy and participation (III–IV). Accessibility to healthcare for older people and their relatives was highlighted as supportive for managing everyday life (I–IV) and for secure care in end of life (II–IV). The older people in the present were focused in relation to relatives' expectations, but relative's needs were acknowledged in the concerns of caring for the older person to promote autonomy and participation (III–IV). To provide for possible choices in end of life meaningful to older people in a joyful and permissive atmosphere may be promoting to autonomy and participation in care for older people.

Clinical implications

Promoting autonomy and participation in care for older people:

- Having secured health and wellbeing, and the need for acknowledgment of being capable in everyday life.
- Respecting the privacy for older people to manage on their own.
- Acknowledgement of the importance of interdependent relationships
- Caring for dependency means caring for older peoples' wishes and needs by providing for possible choices that are meaningful to the individual in everyday life.
- Being given time means being treated with dignity in shared decision-making when considering possible choices.
- Time to have decisions followed up.
- Easy access to social and health care services.
- Choosing everyday life activities can easily be achieved in care for older people.
- Advance care planning needs attention and development.

Svensk sammanfattning

Autonomi och delaktighet inom vård och omsorg för äldre behöver belysas för att kunna tillgodose framtida behov för enskilda individer i ett samhälle där den åldrade befolkningen 65 år och äldre ökar förhållandevis snabbt i antal. Rätten till självbestämmande och för individen att göra ett eget val utan påverkan av andra är skyddat av internationell och nationell lagstiftning. Inom hälso- och sjukvården innebär det att vårdpersonalen också behöver informera på ett sätt som är förståeligt för individen för att personen ska kunna vara delaktig i beslut om sin egen vård.

För att erhålla kommunal vård och omsorg ansöker den äldre personen om den hjälp personen anser sig behöva. Biståndshandläggare bedömer och beviljar vård och omsorg i samråd och i samtycke med den äldre. Anhöriga och hälso- och sjukvårdspersonal kan också meddela en ansökan om den äldres vårdbehov. Kommunal vård och omsorg tillgodoses i den äldres eget hem eller i särskilt boende för äldre. Det dagliga vårdbehovet tillgodoses av sjuksköterskor och omsorgspersonal i samarbete med annan hälso- och sjukvårdspersonal som fysioterapeuter, arbetsterapeuter och läkare. Enhetschefer och medicinskt ansvariga sjuksköterskor ansvarar för organisering av arbetet och för att säkerställa att vården ges i enlighet med styrande svensk lagstiftning för hälso- och sjukvård.

Trots att sjukvårdspersonalen beskriver att beslut fattas i samtycke med individen upplever äldre personer med vårdbehov och deras anhöriga att deras rätt till självbestämmande och delaktighet förbises vid beslutsfattande om den äldres vårdbehov inom kommunal vård och omsorg. Det medför att förståelsen för hur den äldre personens autonomi och delaktighet kan främjas skiljer sig åt mellan vårdtagare och vårdgivare. Kunskap behövs således om äldre personers, sjuksköterskor, biståndshandläggares, enhetschefer och medicinsk ansvariga sjuksköterskors förståelse för innebörden av autonomi och delaktighet inom vård och omsorg om äldre i deras dagliga liv. Dessutom behövs förståelse för hur autonomi och delaktighet tillgodoses i beslutsprocessen om beviljat bistånd och i det dagliga ledningsarbetet inom vård och omsorg, för ett säkerställande av att den äldres vårdbehov tillgodoses.

Det övergripande syftet med avhandlingen var att beskriva essensen av innebörden av autonomi och delaktighet samt hur dessa kan främjas i vård och omsorg för äldre personer. I delstudie I var syftet att beskriva innebörden av autonomi och delaktighet utifrån äldre personers berättelser om erfarenheten av att leva med kronisk sjukdom. I delstudie II var syftet att beskriva sjukskö-

terskor erfarenheter av att vårda äldre och främja deras autonomi och delaktighet inom kommunala äldreboenden. I delstudie III och IV var syftet att beskriva biståndshandläggares, enhetschefers och medicinskt ansvariga sjuksköterskors erfarenheter och reflektioner av att tillgodose den äldres vårdbehov (III), samt hur de inkluderar anhöriga i kommunal vård och omsorg för att främja autonomi och delaktighet för den äldre personen (IV).

Delstudie I var en intervjustudie där sexton äldre personer berättade om sitt dagliga liv och erfarenheter av autonomi och delaktighet i samband med kronisk sjukdom som hjärt-sjukdom, Stroke, Multipel Skleros och Parkinsons sjukdom. Analysen av intervjuerna guidades av Giorgis beskrivande fenomenologiska metod. I berättelserna framgick det att *innebörden av autonomi och delaktighet framkom när den äldre personen utsattes för utmaningar och känslomässiga funderingar över erfarenheten av att leva med kronisk sjukdom*. Betydelsefullt var att själv få avgöra vad som kunde göras och hur det kunde utföras trots funktionshinder i syfte att fungera självständigt, som när man skulle klä på sig eller laga något i garaget. I samband med att klara sig på egen hand i det dagliga livet berättade de äldre om att respekten för privat utrymme och att själv få välja hur tiden skulle spenderas var viktiga aspekter. *Att fortfarande betraktas som en person med förmåga* innebar att för de äldre var det mer angeläget att självständigt genomföra en handling även om den var tidskrävande än att fler saker blev gjorda under dagen. Att få uppleva variation i vardagen beskrevs som en önskan av de äldre och upplevelser som berättades om var bl.a. att gå ut, vara i en trädgård, lyssna på fågelsång, umgås med nära och kära över en kopp kaffe eller spela sällskapspel men även att lära sig något nytt, som att hantera en persondator. Att umgås med barnbarn eller att sköta om ett husdjur nämndes också. *Att fortfarande betraktas som trovärdig och tilldelas ansvar* innebar att den äldre personen ville bli betraktad som jämlik och bli tillfrågad om råd eller att få vara delaktig i familjehändelser i vardagen och vid högtider. I de äldres berättelser framkom också att man ville bli betrodd med förmågan att fatta avgörande beslut om förändring i livssituationer som att sluta köra bil eller förändra sin bostad från villa till lägenhet. Däremot ansågs inte äldreboende som ett alternativ förutom om det i framtiden skulle underlätta bördan för anhöriga. *Att fortfarande bli sedd och bekräftad* i det dagliga livet, såsom de äldre hade blivit under livets gång av familj och vänner var något som man önskade sig vilket beskrevs stärkande för självbilden. De äldre berättade att man i sin nuvarande livssituation pratade med grannar när man rastade hunden, tog del av teater eller levande musik. Att spela ett instrument var stärkande för självbilden men även att få uppleva en romantisk middag nämndes. Den äldre personen berättade att kontakt med sjukvården var viktig för att känna sig trygg när sjukdomssymtom förvärrades och man önskade sjukvården var mer tillgänglig. Att få tillhöra ett sjukvårdsteam skulle medföra trygghet i det dagliga livet.

I delstudie II deltog tretton legitimerade sjuksköterskor i individuella intervjuer där de berättade om erfarenheter av att vårda äldre personer och hur de i sitt dagliga arbete på kommunala äldreboenden främjar äldres autonomi och

delaktighet. Analysen av intervjuerna guidades av Giorgis beskrivande fenomenologiska metod. Sjuksköterskorna beskrev *medvetenhet om de äldres skörhet och påverkan av sjukdom* vilket innebar att de äldres hälsa och att förebygga hälsa var det mest betydelsefulla för att bevara deras förmåga till autonomi och delaktighet. Att alltid tillfråga och involvera personen i sin vård gjorde att sjuksköterskorna utförde sitt dagliga arbete och samtidigt lärde känna den äldre personen och deras funktionsförmågor. På så vis var det möjligt att tidigt urskilja symtom på bl.a. minskat näringsintag, förstoppning eller urinvägsinfektion. Sjuksköterskorna berättade att gott samarbete med omvårdnadspersonal och läkare medförde en säkrare vård för den äldre personen dessutom att påfrestande akutsjukvård kunde undvikas. *Att bekräfta den äldre personen i deras dagliga liv och tillitsfulla relationer* var främjande för deras autonomi och delaktighet. Sjuksköterskorna berättade att mötet med den äldre personen hade betydelse i deras inre liv, samt att de var angelägna om att ha en mer vänskaplig relation till anhöriga än rent yrkesmässig. I berättelserna framkom att sjuksköterskorna var medvetna om den äldres behov av meningsfullhet och borde ges möjlighet att välja vad de vill fylla dagen med och vilken mat de vill äta. En aktivitet kunde vara promenad eller vila under förutsättning att det var ett val gjort av den äldre personen. Att ha betydelse för andra människor i det dagliga livet nämndes också i sammanhanget. Relationerna till omvårdnadspersonal och andra yrkeskategorier som arbetsterapeut var också viktiga för att säkerställa den dagliga vården av den äldre personen.

Sjuksköterskorna *reflekterade över utmaningar inom vården för äldre personer på äldreboenden för att främja autonomi och delaktighet* där organisationen och det rutinemässiga dagliga arbetet, ekonomi och den ökade äldre befolkningen bekymrade sjuksköterskorna. Hur de äldre personerna skulle kunna få uppleva ett mer meningsfullt och glädjefyllt liv på äldreboendet i deras sista tid i livet var viktigt för sjuksköterskorna. De menade att en grupp som är 65 år och äldre inte kunde betraktas homogen utan individuella behov behövde uppmärksammas. Likaså reflekterade de över att de äldre inte kunde få bestämma vårdinsats själva, som till exempel att begära en urinkateter för att det var bekvämt.

Sjuksköterskorna berättade att omvårdnadspersonalens dagliga arbete behövde ses över för att ge mer tid till den äldre personen. De beskrev att personalens sysslor omfattade städning och klädvård. Istället kunde den äldre personen få mer tid till att klä sig själv eller duscha när personen själv kände för det. Även att bli serverad mat under natten om den äldre personen var vaken om nätterna föreslogs i sammanhanget.

I delstudie III och IV deltog fyra biståndshandläggare, fyra enhetschefer och fyra medicinskt ansvariga sjuksköterskor i enskilda gruppintervjuer. Analysen guidades av Malteruds systematiska text kondensering. I delstudie III berättade informanterna om sina erfarenheter av att tillgodose vård och omsorg för den äldre personen för att främja deras autonomi och delaktighet. Informanterna beskrev *omtanke om hur den äldre personen kunde leva sitt dagliga liv på sina villkor i enlighet med sina önsningar och vårdbehov*. Det

innebar att den äldre personen respekterades som en person med individuella behov, med rätt till självbestämmande och beslutsfattande. Informerat samtycke var det första som behövde fastställas i samband med att vårdbehov skulle tillgodoses. Dokumentation av vårdplanering och beslut var grundläggande i processen.

Biståndshandläggarna beskrev ett helhetsperspektiv över den äldre personens livssituation i sin bedömning och vid beviljande av kommunal vård och omsorg i samråd med den äldre personen. Även om vårdbehov föregick önskingar vid fastställande av beviljad vård.

Enhetschefer fokuserade på individuellgenomförandeplan i detalj beskrivet vad den äldre behövde hjälp med i sitt dagliga liv. Planen fastställdes i samråd med den äldre personen, anhöriga, kontaktperson i omvårdnadspersonalen och enhetschefen.

Medicinskt ansvariga sjuksköterskor beskrev att de var rådgivare angående lagstiftning, som till exempel om rörelselarm vid fallprevention kunde betraktas som övervakning och begränsning eller inte. Dokumentation av riskanalys och handlingsplan var tvunget i beslutsfattandet för att respektera den äldres rätt till autonomi och delaktighet.

Att visa omtanke om den äldre personen som individ i sin nuvarande livssituation och tillgodose valmöjligheter till att leva sitt liv innebar att bygga tillitsfulla relationer till de äldre ansågs som ett viktigt verktyg för informanterna i förhandlingen om tänkbara lösningar i det dagliga livet. Det handlade om att erbjuda alternativ för att möjliggöra val som tillgodosåg vårdbehov i den nuvarande livssituationen, som till exempel matleverans, att få besök regelbundet dygnet runt för ökad trygghet eller att få hjälp till att delta i aktivitet som är meningsfull för den äldre personen. Informanterna berättade att de uppmärksammade att de äldre personerna fick möjlighet till att delta i sociala sammanhang och vara betydelsefulla i grupp med andra personer.

Förväntningar behövde klargöras för att tillgodose behov, till exempel så behövde den äldre personens fysiska och psykiska kapacitet beaktas och även organisationens, som tillgänglig omvårdnadspersonal. Informanterna framhöll att den äldres vårdbehov skulle styra över hur arbetet organiserades. Enhetschefer och medicinskt ansvariga sjuksköterskor beskrev också att de hade tillit till att vårdpersonalen erbjöd valmöjligheter till den äldre och att man gemensamt kom fram till lösningar i det dagliga livet och arbetet.

Att visa omtanke om meningsfullt innehåll i den äldre personens dagliga liv i en hälsosam, kreativ och trygg miljö innebar att informanterna ansåg att äldre personers behov kunde variera utifrån hälsotillstånd. Att ge tid till den äldre genom att visa intresse för deras livsberättelse och lyssna in deras nuvarande livssituation var betydande i mötet med personen. Att respektera de äldres privata livsmiljö beskrevs som grundläggande för att främja deras autonomi och delaktighet inom vård och omsorg. Tålmod, information och att återkommande följa upp beslut samt att finna kreativa lösningar, som att anlita icke-professionella för att ledsaga den äldre personen till aktiviteter beskrevs som att den äldre personen blev respekterad som jämlik.

I delstudie IV berättade informanterna om hur de inkluderade anhöriga i vården för att främja den äldre autonomi och delaktighet. *Att skapa tillfällen till meningsfullhet genom att inkludera anhöriga i det dagliga livet och omsorgsvårnaden* innebar att informanternas intention var att öka anhörigas känsla av att vara delaktiga i den äldres dagliga liv. Genom att erbjuda anhöriga att delta i vårdplanering och beslut om vård och omsorg eller att delta i aktiviteter tillsammans med andra familjer i liknande situation. Att fira högtidsdagar tillsammans med andra familjer kunde underlätta pressen som det innebär att vara främmande personer för varandra i relationer med personer med demenssjukdom. Vårdplanering som omfattar när den äldre personen själv inte längre kan vara delaktig i beslut om sin vård efterfrågades. För att bättre säkerställa vårdbeslut med respekt för äldres autonomi och delaktighet.

Att fokusera den äldre personen i sin relation till anhöriga innebar att informanterna uppmärksammade betydelsen av de äldres och anhörigas gemensamma livshistoria men att man bekräftade den äldre personen i sin nuvarande livssituation. Förändringar i den äldres personlighet som intressen, fysisk och psykisk kapacitet kanske inte längre stämde överens med anhörigas förväntningar. Den äldre personens möjlighet till att göra egna val utifrån sin nuvarande livssituation fokuserades för att främja deras autonomi och delaktighet. Anhöriga bekräftades genom att erbjudas hjälp med avlastande lösningar för att minska bördan.

Att stödja anhöriga i deras relation till den äldre och kommunal vård och omsorg innebar informanternas omtanke om anhörigas upplevelser i sitt dagliga liv av att vård och omsorg som den äldre personen fick del av. Informanterna reflekterade att det var den äldres hälsotillstånd som framtvingade den nuvarande livssituationen. Anhörigas perspektiv respekterades och informanterna beskrev att de tillhändhöll information, samt att anhöriga behövde vägledning i den kommunala vård och omsorg som omgav den äldre som individ. Enhetschefer erbjöd samtal och medicinskt ansvariga sjuksköterskor ansåg det nödvändigt att anhöriga förstod det interprofessionella teamarbetet. Att bedöma vårdbehov är förbehållet olika professioner och reglerat i lagstiftningen för att skydda mot begränsande åtgärder och för att främja äldre personers autonomi och delaktighet.

Det sammanfattande resultatet visar att bevara den äldres hälsa och välbefinnande var betraktat som den viktigaste källan till att främja deras autonomi och delaktighet. Äldre som lever med kronisk sjukdom ville ha enkel tillgång till hälso- och sjukvård när sjukdomssymtomen förvärras för att känna trygghet i att fungera självständigt i det dagliga livet. Att få känna sig kapabel var stärkande för självbilden likaså möjligheten till självvalda dagliga aktiviteter.

Den äldre personen inom vård och omsorg uppmärksammades som skör och deras behov av att få individuella valmöjligheter tillgodosedda i sitt dagliga liv var betydelsefullt för att bevarandet av deras autonomi och delaktighet. Att få uppleva meningsfulla och glädjefyllda stunder tillsammans med andra personer, som anhöriga beskrevs som aktiviteter som främjade autonomi och

delaktighet inom vård och omsorg för äldre. Delat beslutsfattande och informerat samtycke var grundläggande när vårdbehov skulle bedömas och säkerställas i det dagliga livet för den äldre. Med respekt för anhörigas upplevelser fokuserades den äldre personen i sin nuvarande livssituation.

Relationer till vårdpersonal och anhöriga i den äldre personens dagliga liv, samt relationernas betydelse för den dagliga vården och omsorgen betraktades, som grundläggande för att främja den äldres autonomi och delaktighet i deras sista tid i livet.

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