Being provided with a safe haven
Care-dependent older persons’ participation in prehospital emergency care

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CARE-DEPENDENT OLDER PERSONS’ PARTICIPATION IN PREHOSPITAL EMERGENCY CARE

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School of Health, Care and Social Welfare
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Abstract

Participation in care is a key concept in many welfare societies and serves to guide clinical practice and adapt care to personal preferences and needs in order to promote well-being and quality of life. Previous research has shown that practicing participation in care is complex due to the concept not being clearly defined. A significant risk is, therefore, that participation in care is practiced based on the professional caregivers' own definitions, which might be inconsistent with the cared-for persons' perceptions of what participation is.

Older persons can continue to live in their own homes with the support of municipal home care services that meet everyday care needs. Care-dependent older persons are known to have increased emergency care needs, which in Sweden require inter-organizational and inter-professional collaboration involving a care transfer between welfare levels. This thesis aimed to deepen the understanding of care-dependent older persons' participation in prehospital emergency care from lifeworld and welfare perspectives. The inductive design was based on a lifeworld approach and included triangulation of the phenomenon of participation in care using descriptive, interpretative, and comparative methods.

From the perspective of care-dependent older persons, participation in prehospital emergency care means a forced transfer of life responsibility to professional caregivers when being existentially unsafe and incapacitated due to acute illness. Through authorized representation, the professional caregivers act for the older person, with the power to bring about change and create opportunities for existence. Care-dependent older persons' participation in prehospital emergency care involves a deepened dependence that necessitates coexistence and being provided with a 'safe haven' through the entire emergency care chain. A 'safe haven' can be understood as an unconditional, calm, and sheltered interpersonal space for emotional rest that is provided to the older person during an existentially challenging situation. From the perspective of care-dependent older persons, the emergency care chain transcends organizational boundaries and includes mobile safety alarm services and emergency department attendance.

The involved professionals must be supported in practicing participation in care based on a comprehensive understanding of the concept, and emergency care options must be aligned with the care-dependent older persons' need for coordinated and continuous care. Collaborative challenges related to unstructured collaboration and professional hierarchy need to be addressed to support well-functioning collaboration in situations involving acutely ill older persons. The involved organizations need to recognize care-dependent older persons' deepened dependence when acutely ill, as well as their extended view of the prehospital emergency care chain.
Just say if I am disturbing you,  
he said as he stepped over my threshold,  
and I’ll leave immediately.  

You do more than disturb me,  
I answered, 
you turn my whole existence upside down. 
Welcome.  

Eeva Kilpi
Abstract

Participation in care is a key concept in many welfare societies and serves to guide clinical practice and adapt care to personal preferences and needs in order to promote well-being and quality of life. Previous research has shown that practicing participation in care is complex due to the concept not being clearly defined. A significant risk is, therefore, that participation in care is practiced based on the professional caregivers’ own definitions, which might be inconsistent with the cared-for persons’ perceptions of what participation is.

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**Keywords:** Acute illness; Ambulance care; Collaborative care; Municipal home care; Older persons; Participation in care; Prehospital emergency care
Svensk sammanfattning

Delaktighet i vård är ett centralt begrepp inom svenska vårdkontext med syfte att öka patienters inflytande över sin egen vård och därigenom främja välmående, hälsa och säkerhet. Delaktighet i vård betonas i lagar och styrdokument men forskning visar att delaktighet är svårt att implementera i vårdverksamheter eftersom det saknas förståelse för vad begreppet faktiskt innebär i klinisk praktik. En betydande risk är att delaktighet i vård då tillämpas utifrån vårdarneas egna definitioner vilket har visat sig ofta inte överensstämma med patienters uppfattning om vad delaktighet är. Forskningsprojektets övergripande syfte är att ge en fördjupad förståelse för vad delaktighet i vård innebär för vårdberoende äldre i akuta vårdsituationer som involverar all ambulanspersonal. Idag finns ingen tydlig förståelse för vad delaktighet i vård innebär för vårdberoende äldre i akuta vårdsituationer som involverar både omsorgspersonal och prehospital akutsjukvård. Akut sjukdom eller trauma hos vårdberoende äldre i eget boende initierar därför samverkan mellan kommun och region, mellan omsorgspersömal och ambulanspersonal. Idag finns ingen tydlig förståelse för vad delaktighet i vård innebär för vårdberoende äldre i akuta vårdsituationer som involverar både omsorgspersömal och prehospital akutsjukvård, vilket medför en risk att delaktighet uteblir med konsekvens för den äldres välmående, hälsa, och säkerhet.

Studie II belyser innebörden av delaktighet i prehospital akutsjukvård ur vårdberoende äldres perspektiv och baseras på intervjuer med 11 män och kvinnor med erfarenhet av akut sjukdom eller trauma hemma vilket involverat omsorgspersonal och ambulanssjukvård. Resultatet visar att delaktighet innebär att anförtro sit liv till professionella vårdare, där ingen åtskillnad görs mellan omsorgspersonal och ambulanspersonal. Att anförtro sit liv involverar flera dimensioner av delaktighet vilka kan förstås som att säkerställas i samvaro med professionella vårdare, att vara följsam i tilltro till medicinsk expertis, att få möjligheter genom vårdarnas försorg samt att möta beredskap genom hela den akuta vårdkedjan. Samvaron med professionella vårdare innehåller också en social dimension där den äldre och vårdaren möts på ett personligt plan där gemensamma livsreferenser delas och utmaningar antas tillsammans. En viktig aspekt av studiens resultat är de äldres utvidgade perspektiv på den akuta vårdkedjan där det mobila trygghetslarmet utgör den första länken, vilket betonar behovet av akutvårdsresurser och adekvat kompetens inom den kommunala äldreomsorgen.


Studie IV belyser innebörden av äldres delaktighet i prehospital akutsjukvård ur ambulanspersonalens perspektiv. Resultatet baseras på intervjuer med 11 ambulanspersonal med olika utbildningsnivå (undersköterska, sjukskötterska, specialistsjukskötterska). Resultatet visar att delaktighet är en balansgång mellan att ta och ge kontroll i form av att utöva eller utjämma professionell makt. Beslut att ta eller ge kontroll i den akuta situationen står i relation till det övergripande syftet att rädda liv utifrån en kritisk bedömning av den äldres hela livssituation. Delaktighet kan förstås som att tillhandahålla en 'trygg

Kunskapen från de fyra inkluderade studierna ger en fördjupad förståelse för vad delaktighet innebär för vårdberoende äldre inom prehospital akutsjukvård. Delaktighet visar sig som att erbjudas en ’trygg hamn’ genom hela den prehospitala akutvårdskedjan, vilken karaktäriseras av säkerhet, värdighet och emotionell vila och innebär ett överförande av ansvar för den äldres liv till professionella vårdare. Utifrån kompetens, förmågor och mandat agerar vården till förmån för den äldre i rollen som auktoriserad representant med makt att åstadkomma förändring och därmed skapa möjligheter för (sam)existens.
List of Papers

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


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Abbreviations

CIT  Critical incident technique
ED   Emergency department
EMCC Emergency medical communication center
EMS  Emergency medical services
EMT  Emergency medical technician
RN   Registered nurse
My entry into this research project happened by chance. However, after accepting the doctoral position, the project turned into a motivating life project. Early on, an entry about ambulance care in the local newspaper under the heading “Is this how you treat older people?” caught my attention. In that instant, I realized the significance of the research project. The text described how an older man had fallen down the stairs to the basement and was later diagnosed as having fractured five ribs. Despite excruciating pain and not being able to move or talk, the ambulance personnel decided to leave the older man in place since his vital parameters were normal. The writer of the text expressed anger and sadness since the ambulance personnel did not even help the older man up the stairs. The older man was merely left leaning against the wall in the basement for his wife to handle, who, due to her lack of strength and knowledge, could do very little for him. One week of suffering and pain followed before a primary physician urgently referred the older man to the hospital.

The decision to enter the project was the beginning of a journey characterized by both personal and professional growth, in addition to a developing commitment to the older persons who open-heartedly shared their life stories with me. The four studies each contributed to the development of a deepened understanding of older persons’ participation in prehospital emergency care. However, the studies also elucidated the functioning of welfare services for older persons and the contextual conditions impacting emergency responses for older persons experiencing acute illness at home. The contextual conditions hold both resources and deficiencies significantly impacting older persons’ lives. It is therefore my hope that the knowledge brought forward in this thesis will raise awareness of not only the phenomenon per se but also the conditions surrounding the context. Thereby, this thesis can serve as a guiding instrument when targeting interventions promoting quality in the prehospital emergency care context to benefit care-dependent older persons.
1 Introduction

1.1 Positioning the thesis

This thesis is founded in the discipline of caring science, which under the academic umbrella of Health and Welfare at Mälardalen University appertains to an area of research that focuses on health and social care for persons in exposed and vulnerable life situations. The purpose of the academic umbrella Health and Welfare is to provide scientific knowledge in an area where health and welfare converge. Within the research subject of caring science, the focus is on how to promote and preserve health and well-being throughout the lifespan (Mälardalen University, 2018). This thesis deepens the understanding of older persons’ participation in prehospital emergency care when experiencing acute illness at home involving municipal home care and ambulance services. The research focuses on an area where social care and health care overlap and contributes knowledge that can support the development of qualitative care for an expanding group of people in a vulnerable position, as well as the development of health-promoting, and sustainable welfare.

Caring science is a human science based on human experience (Arman et al., 2015; Dahlberg et al., 2009), and addresses the “art and act of caring” and “what it means to be a patient” (Arman et al., 2015, p. 288). The purpose of caring science is to develop a scientific body of knowledge that highlights the cared-for persons’ perspective to optimize caring efforts (Hörberg et al., 2011), thereby complementing the bio-medically driven paradigm (Arman et al., 2015). The scientific perspective is underpinned by existential philosophy, which also allows the perspective to be adopted outside the discipline (Arman et al., 2015). The existential underpinning of caring science makes caring holistic, which means that care has to be provided while respecting a person’s whole life, including elements such as experiences, surroundings, and relations (Hörberg et al., 2011).

One of the most important tasks of caring science research is to engage in concept development. Concepts constitute the building blocks of theory (Walker & Avant, 2014), and provide information that can guide clinical practice (Brandão et al., 2019). This thesis contributes to the development of the concept of participation in care by researching care-dependent older persons’ participation in the prehospital emergency care context. The concept development in this thesis is based on lifeworld phenomenology, which has a clear resonance with the caring science perspective. In lifeworld phenomenology,
concepts transform into experienced lifeworld phenomena, which allows more facets to emerge (Asp, 2022). The phenomenon thus becomes the empirical referent of the concept (Brandão et al., 2019).

Participation in care is considered a cornerstone in person-centered care practices and involve centering the cared-for person’s perspective by following a set of established routines (Ekman et al., 2011). From the perspective of person-centered care, the motive of participation is to actively engage the cared-for person in the care situation. With a focus on partnership, communication and shared decision-making, the cared-for person is encouraged to influence care efforts to achieve preferred outcomes (Castro et al., 2016; Håkansson Eklund et al., 2019; McCormack & McCance, 2006). The concept of participation in care is therefore highly associated with research positioned within the area of person-centered care. However, person-centered care is not the starting point for this thesis, where participation is a predefined concept with a specific purpose and outcome. In this research project, participation in care is viewed separately, as a phenomenon of a person’s lifeworld. A phenomenon exists in human experience and reveals itself through “a certain way of being in the world” (van Manen, 1997, p. 39). In this research project, the phenomenon is thus allowed to reveal itself through human experience, in this specific context, under these specific circumstances. The deepened understanding of the phenomenon of participation in care provided in this thesis can, however, beneficially be incorporated into person-centered care practices within the prehospital emergency care context.

Enacting participation in care requires a shared understanding of the concept’s meaning (Eldh, 2019), and neither older persons, caregivers nor policymakers are yet adequately prepared (Casado et al., 2020). Researchers thus emphasize the need to continue to elucidate the meaning of older persons’ participation in both research and clinical practice (Algilani, 2016; Casado et al., 2020; Foss, 2011). In line with the stated research agenda, this thesis contributes to the body of knowledge regarding older persons’ participation in care by providing a deepened understanding of the phenomenon under the influence of acute illness involving a care transfer between organizations and welfare levels. The knowledge provided constitutes a step toward shared understanding among stakeholders with the potential to guide clinical enactment and efforts to promote older persons’ well-being.

1.2 Defining the concepts

This thesis focuses on prehospital emergency care at a point where two levels of welfare in Sweden converge. The two welfare levels label the cared-for person differently. At the regional level, the concept of patient is used, and at the municipal level, the corresponding concept is service user. The two concepts have different inherent meanings which might influence how a person is
viewed. The label *patient* originally referred to someone who suffered or endured suffering (Eriksson, 2018). The label *patient* has, however, been criticized for being a construct made by the healthcare system that risks figuring the cared-for person as passive and only a recipient of care (Dahlberg & Segesten, 2010). The label *service user* instead suggests the person is a consumer with democratic rights and an active co-producer of care (Christensen & Pilling, 2019). To avoid confusion regarding the different labeling brought on by the welfare intersection, the patients/service users in the focus of this thesis will henceforth be referred to as *care-dependent older persons, older persons*, or just *persons* where appropriate.

In this thesis, the term *older* refers to persons who are 70 years of age or older. The age limit was chosen after discussion with a representative of the municipality being studied and was considered best for identifying the group of people of interest to the research project. The age cutoff was used as an inclusion criterion for studies I and II. In studies III and IV, however, the term older was not specified since the participants had to narrate a situation involving an older person whose age was not known to them. The interview question only directed the participants’ focus towards older persons, and the narrated situation was thus based on their subjective perception of an ‘older person’.

The concept *care-dependent* denotes the older persons’ utilization of municipal home care services for daily life, supporting continued living at home and thus ‘aging-in-place’. The word *dependent* is lexically defined as a need for support to operate or exist (Cambridge dictionary, n.d.), reliance on others, being conditioned or determined by others, the essential meaning being “decided or controlled by something else” (Merriam-Webster, n.d.). A similar lexical exploration of the concept of *care* gives the definition of an “effort made to do something correctly, safely, or without causing damage”, “things that are done to keep someone healthy, safe”, and a “responsibility for or attention to health, well-being, and safety” (Merriam-Webster, n.d.). Being care-dependent can lexically thus be described as conditioned existence, in which well-being and safety are maintained through the efforts of others. A care-dependent person living in his or her private home has an independent living arrangement but is, however, dependent on others to live. Thus, care-dependence indicates existential vulnerability.

In this thesis, the concept of *home care* refers to municipal assistance provided to older persons based on their everyday care needs to enable continued living at home (further described under 2.3). Home care in this thesis is not to be confused with home nursing, or home health care, which are services provided to persons in need of medical intervention at home (e.g. palliative care) and often include access to a registered nurse around the clock.

*Emergency medical services* (EMS) is a commonly used concept, which internationally often refers to all blue light personnel; the police, fire brigade, emergency medical communication centers (EMCC), and ambulance services.
In this thesis, EMS is narrowed down to only include the EMCC and the ambulance services.

*Prehospital emergency care* refers to advanced care provided on-scene in an out-of-hospital context, such as care-dependent older persons’ homes, and is a joint effort by the EMS.

*Ambulance personnel* refers to all personnel working within the regional ambulance services and includes registered personnel such as registered nurses (RNs) with bachelor’s degrees with or without specialist education, and unregistered personnel such as emergency medical technicians (EMTs), who are often trained as assistant nurses.

*Municipal care personnel* or *care personnel* refer to unregistered professionals working within municipal home care services, and include formally trained assistant nurses with upper secondary school level education, and care assistants without formal care education.

*Professional caregivers* or *professionals* refer to undifferentiated personnel working within care contexts at all welfare levels, and include both registered and unregistered personnel, such as RNs, EMTs, and municipal care personnel.
2 Background

In the following, Swedish welfare and current challenges, perspectives on aging, and the organizational contexts involved will be presented in an effort to provide a comprehensive understanding of the research context. Lastly, previous research on participation in care will be presented.

2.1 Swedish welfare and current challenges

The Scandinavian countries share a welfare model where the state takes responsibility for people’s welfare by ensuring subsidized public services throughout the lifespan to promote a good life (Fritzell & Lundberg, 2007). Public health issues, such as health equity and social sustainability, have long been on the Swedish political agenda and measures are taken to counteract inequalities in the welfare system (Lundberg, 2018), and promote people’s well-being, safety, and democratic participation (Raphael, 2014). Welfare research focusing on health inequality is, therefore, a strong tradition in Sweden (Fritzell & Lundberg, 2007).

Health and social care are collective resources provided by welfare institutions (Fritzell & Lundberg, 2007). From a welfare perspective, health relates to individual welfare and quality of life and can be defined as the ability to achieve vital life goals (Nordenfelt, 2006). However, the ability to achieve life goals is highly impacted by societal structures and social arrangements (Fritzell & Lundberg, 2007). People’s ability to control their own lives is, therefore, an important aspect of Swedish welfare and the objective of welfare is thus to provide resources, opportunities, and conditions that support and create “societal prerequisites for good health on equal terms for the entire population” (Lundberg, 2018, p. 22).

In the 2030 Agenda for Sustainable Development (UN General Assembly), all countries and stakeholders are urged to empower vulnerable groups, such as older people, and promote well-being through access to quality care. In line with the stated agenda, the Swedish government has adopted a reform that serves to promote access, participation, and safety by directing efforts to out-of-hospital contexts promoting ‘good quality, local health care’ that ultimately will involve people’s homes (SOU 2020:19). At the micro level of welfare, care encounters must be fostered in such a way that health and equity are
promoted, which require a focus on the persons’ needs and individual welfare (Lundberg, 2018).

2.1.1 The collaborative challenge

The transformation toward ‘good quality, local health care’ (SOU 2020:19) necessitates inter-sectorial governance, inter-organizational, and inter-professional collaboration. However, Swedish welfare involves three levels of government (national, regional, and municipal level) with different legislation, agencies, organizations, and professionals, which makes collaboration complex (Lundberg, 2018). Swedish legislation serves to safeguard the rights of people in need of care (SFS 2014:821). However, although rights, such as participation, self-determination, integrity, and information, are emphasized, neither rights nor the professionals’ responsibility is compulsory (Dahlborg et al., 2021). Thus, individual welfare is highly dependent on the professionals’ skills and good will (Dahlborg et al., 2021).

Welfare professionals commonly refer to public sector employees that work in direct contact with welfare service utilizers in areas such as health and social care and provide services in the best interests of both the people and the state (Kamp, 2016). Being a welfare professional implies professionalism, which means “exclusive ownership of an area of expertise and knowledge, and the power to define the nature of problems in that area as well as the control of access to potential solutions” (Evetts, 2013, p. 788). Thus, being a welfare professional implies power, autonomy, and freedom in the practice of work (Evetts, 2013), facilitated by a societal trust to handle “complex cases in relative isolation” (Noordegraaf, 2015, p. 190). Societal trust resides in the fact that a welfare professional is highly knowledgeable, trained, experienced, and motivated (Noordegraaf, 2015). Professionalism also means sharing a professional identity, and professionals within the same occupation not only share a common educational background but also culture, norms, values, and behavior which influence their practice of work (Evetts, 2013).

Although professionalism applies to all professionals working within health and social care, there are important attributes that separate developed welfare professions from other welfare occupations. Attributes in common for both a profession and an occupation are shared culture, authority, and societal trust, but a profession also adheres to systematic theory and ethical codes (Greenwood, 1957). RNs belong to a nursing profession that is founded on caring science theory and codes of ethics, which means a practice of work based on advanced theoretical and ethical knowledge. RNs’ professional skill is acquired through academic education, in contrast to unregistered care personnel who often acquire professional skills by way of work and apprenticeships (Greenwood, 1957). Due to the lack of organizational requirements for specific skills or qualifications, the municipal care workforce is sometimes referred to as ‘nonprofessional’ (Guldvik et al., 2014). Collaborative care
involving registered and unregistered personnel thus implies an embedded professional hierarchy, which is known to impact inter-professional collaboration (Cohen Konrad et al., 2019). Although successful inter-professional collaboration has been found to be key in older people’s care (Bookey-Bassett et al., 2017; Gustafsson et al., 2019; Montano, 2019), gaps in care collaboration and care coordination are evident in many countries (Schoen et al., 2011).

2.1.2 The demographic challenge
Older people constitute a vulnerable group in terms of functional abilities and health, and their lives are highly influenced by the welfare structure (Fritzell & Lundberg, 2007). Life expectancy in Sweden is high, about 81 for men and 84 for women (The National Board of Health and Welfare, 2022d), and the aged population is rapidly increasing in line with the global demographic trend. Currently, approximately half a million persons in Sweden are aged 80 or older, and by mid-2040 the same population is estimated to be over one million (Statistics Sweden, 2017). The vast majority of older people in Sweden live in their own private homes. In 2017, 1.9 million older people aged 65 years and older resided in their own housing compared to about 90 000 residing in nursing homes (Sveriges Kommuner och Regioner, SKR, 2020). In European countries, the increasing aging population is often portrayed as a threat to welfare as they drain welfare resources, and the threat is further reinforced by a decreasing workforce able to provide care (Rechel et al., 2013). According to the World Health Organization (WHO), the most detrimental barrier to developing successful health systems is ageism, which is often shown by a focus on the burden and cost rather than opportunities (WHO, 2015). Iversen et al. (2009) describe ageism as explicitly or implicitly expressed discrimination and prejudice against older persons based on their age. A report on public perceptions concludes that older people are often perceived as being of less value to society, and stereotyped attitudes within care settings risk compromising care (Lyons et al., 2009). Ageism is thus a potent influencer of the health outcome of older persons.

2.2 Perspectives on aging, dependence, and health
Becoming older means becoming vulnerable (Palmér et al., 2019), and thus having to adapt to continuous disruptions and changes in life (Ebrahimi et al., 2012; Neville et al., 2021; Róin, 2015). Older age is associated with declining functional ability involving the onset of chronic and often multiple diseases, functional and cognitive impairments, and frailty, all of which impact life (WHO, 2015). The concept of ‘being old’ is often perceived as having a negative connotation linked to dependence and sickness (Palmér et al., 2019; Róin, 2015), while good health equals living a good life where ‘being old’ can
be postponed (Róin, 2015). Societal normative claims also emphasize people’s ‘successful aging’ as the desirable outcome of the aging process, which includes staying active, healthy, and independent (Ehni et al., 2018). Older people that cannot stay active, healthy, and independent might, therefore, experience being ‘unsuccessful’, which also nurtures self-inflicted ageism (Róin, 2015).

Older persons sometimes express fear of being forced into dependence due to illness and disabilities, a dependence that involves a risk of having to live an unworthy and alienated life (Palmér et al., 2019). The fear of dependence is further enhanced by having to face existential loneliness due to the passing of loved ones, and death being a constant follower that surfaces through illness (Palmér et al., 2019). Being able to live independently means freedom and the ability to realize projects by one’s own choice involving both acting freely (doing) and feeling free (being), both of which promote health (Dale et al., 2012). Dependence, on the other hand, is perceived as being unfree, and at risk of compromised health (Palmér et al., 2019). Aging well is, however, considered a personal responsibility that involves preparing in terms of living arrangements (Neville et al., 2021; Vasara, 2022), and keeping oneself physically active and socially connected (Neville et al., 2021), and not burdening others (Vasara, 2022). A safe home environment and coordinated health care have been identified as essential to facilitate aging-in-place (Campbell et al., 2021), as is easy access to services (Hancock et al., 2019; Schorr & Khalaila, 2018).

When no longer able to postpone ‘being old’, a new living situation arises. Existential loneliness among older persons is perceived by professional caregivers as relating to the new situation of dependence, missing one’s previous life, feeling unable to live a meaningful life in one’s home anymore, and having no one to share memories with (Sundström et al., 2019). The dependent situation also gives the home new meaning. The own home can be portrayed as a preserver of identity as well as a prison making the older person invisible (Sundström et al., 2019). Loneliness in older age is also highly associated with being physically impaired (De Koning et al., 2017; Klein et al., 2020), and physical decline has been found to reduce an older person’s self-determination (Ottenvall Hammar et al., 2016).

However, health and well-being can still be promoted and supported, despite dependency, by professional caregivers recognizing what is important to the older person (Sundström et al., 2019). Frail older persons perceive health in relation to their ability to experience harmony in life, which involves a continuous balancing of bodily functioning, and existential acceptance (Ebrahimi et al., 2012). The attitudes of others are an important aspect that significantly influences the health experience. Being validated as a person, socially included, and having one’s ailments taken seriously boost feelings of well-being (Ebrahimi et al., 2012; Soares et al., 2019). Thus, the relational aspects of care
are significant for older persons, where preserving dignity and recognizing individuality are the essential core values (Soares et al., 2019).

2.3 Municipal home care services

Aging-in-place is a governmental approach seen in many Western societies to meet the ongoing demographic change of the dramatic increase in the number of older people. The approach is an attempt to maintain a balanced welfare economy, and at the same time promote older persons’ independence and well-being (Rostgaard et al., 2011). In Sweden, the municipalities are responsible for providing older persons with the required assistance to continue living in their own homes and thus maintain a relatively independent life. Home care assistance includes services embracing activities such as mobile safety alarm responses, food distribution, eating, and cleaning, in addition to intimate and personal care (The National Board of Health and Welfare, 2021a). In 2021, mobile safety alarm utilization was the most common service provided by the home care organizations (The National Board of Health and Welfare, 2022a). In the last few decades, the Swedish home care system has been subjected to financial austerity and efficiency measures (Norberg, 2019). The consequences of such rationalization are an increased workload for care personnel in terms of more older persons to visit in less time, with less support (Strandell, 2020). A governmental report also concluded that in 2021, an older person on average received home care visits from 16 different professionals during a two-week period (The National Board of Health and Welfare, 2021c).

Frontline professionals working within the Swedish municipal home care organizations consist of assistant nurses with formal training corresponding to an upper secondary school level and care assistants without formal training. Few municipalities have overarching competence development plans for care personnel, and many face great shortages of professionals (The National Board of Health and Welfare, 2021b).

2.3.1 Providing home care

Previous research in the Scandinavian context has shown how providing home care means adapting to the unique needs and habits of many different persons and involves having to be inventive and creative to find workable solutions for emerging situations (Ekstedt et al., 2022). When entering an older person’s home, care personnel describe attuning\(^1\) to the person and the situation, and thus sharing their vulnerability in the moment (Andersson et al., 2022). Knowing the older person is key (Ekstedt et al., 2022; Strømme et al., 2020; Sundström et al., 2019), since it allows care to be provided while respecting

\(^1\) To sense the emotional state and vulnerability of the person.
the person’s preferences, peculiarities, worries, and needs, which not only makes the work feel meaningful (Ekstedt et al., 2022) but also provides meaning to the older person (Kristensen et al., 2017; Sundström et al., 2019). Knowing the person is also an important prerequisite for being able to detect health changes, since access to written information is often limited (Strømme et al., 2020). Being knowledgeable also facilitates an easy handover between professionals, which benefits the older person (Ekstedt et al., 2022).

Working close to older persons means being responsible for their well-being, and thus trying to solve whatever problems come their way (Ekstedt et al., 2022; Rasoal et al., 2018). The responsibility is described as both moral and limitless (Jarling et al., 2020) and involves ‘going that extra mile’, which means to adjust the way of work rather than forcing the older person to adapt, to make sure correct information is exchanged in care transfers, and to act as a representative in decision-making to protect the older person’s best interests (Ekstedt et al., 2022). In short, to look out for the older person in a system with many deficiencies and gaps (Ekstedt et al., 2022; Jarling et al., 2020; Rasoal et al., 2018; Strømme et al., 2020).

However, the often busy workdays including a preplanned and detailed schedule focusing on practical tasks leave little room for humane care or unexpected events (Ekstedt et al., 2022; Jarling et al., 2020; Kristensen et al., 2017; Rasoal et al., 2018; Strømme et al., 2020), and even less for detecting deteriorating health (Strømme et al., 2020) or exploring the older person’s expressed concerns (Kristensen et al., 2017). The discrepancy between time and workload also means having to prioritize (Jarling et al., 2020), which brings ethical dilemmas when not able to fulfill expectations and needs (Rasoal et al., 2018). Lack of time also produces time-saving strategies, such as ‘coaxing’ to make the older person comply (Rasoal et al., 2018).

Older persons’ ill health is recognized mainly by observing and listening to the older person’s description of the experience and symptoms (Kristensen et al., 2017; Strømme et al., 2020). Clinical monitoring of vital signs (pulse, blood pressure, breathing rate, oxygen saturation) is rarely used due to a lack of training, which accentuates the importance of having a ‘clinical eye’ (Strømme et al., 2020). Common guidelines for how to respond to health changes are often lacking, and if and how to take action is largely up to the individual to decide (Jarling et al., 2020; Rasoal et al., 2018; Strømme et al., 2020), which might result in faulty, unjust and unequal care (Rasoal et al., 2018).

Due to the autonomous character of the work, which involves visiting older persons alone and having to make decisions alone, professionals stress the need for collaboration and support to feel secure (Ekstedt et al., 2022; Strømme et al., 2020). Having too little time for each person, combined with a lack of support is frustrating (Ekstedt et al., 2022; Strømme et al., 2020). The organizational structure often limits easy access to co-workers, and a perceived distance between professionals with different levels of educational...
competence makes collaboration difficult (Strømme et al., 2020). However, being experienced facilitates handling unexpected situations, being more comfortable with ‘thinking outside the box’, and creating adapted solutions in collaboration with others (Ekstedt et al., 2022).

A South Korean study showed that when encountering older persons with acute illnesses such as airway obstruction, traumatic falls, or heart disorders, care personnel describe being emotionally affected, shocked, or even panicking, and in a situation of having to rely on their own experience due to a lack of emergency training (Kim & Bae, 2022).

2.3.2 Experiencing home care

Previous research focusing on older persons’ experiences of home care has shown that rigid home care systems tend to direct the older persons’ lives, and often involve having to accept care as it is provided and when it is provided (Boye et al., 2021; Breitholtz et al., 2013; Jarling et al., 2018; Roin, 2018; Sanerma et al., 2020; Witsø et al., 2015). The experience is described as sacrificing one’s privacy when one’s own home is transformed into a workplace, and involves having to come to terms with being dependent while independent (Jarling et al., 2018; Sanerma et al., 2020), where governance continuously shifts between others and self (Ottenvall Hammar et al., 2014). Continuous bodily deterioration involves a struggle against one’s own body (Ottenvall Hammar et al., 2014), and losing the struggle means being forced into a non-negotiable adaptation that complicates living, involving resigning oneself to restricted choice, and surrendering one’s way of life to fit the system (Jarling et al., 2018; Roin, 2018). Being dependent means being exposed to the looks, minds, and power of often multiple personnel, and accepting a subordinate, undemanding position to avoid the risk of facing negative consequences, or being perceived as a burden (Jarling et al., 2018). Not being involved in care means having to resign oneself to new routines that might not fit well with one’s own preferences (Roin, 2018). However, getting the help needed is described as the main objective (Sanerma et al., 2020).

The transformation of one’s private home into a common workplace means accepting strangers into one’s home (Sanerma et al., 2020). Thus, the relationship with the care personnel is pivotal for the overall experience. While the dependence brings forced relations, meaningful relationships characterized by shared interest are highly valued (Jarling et al., 2018; Roin, 2018), where meaningfulness equals feeling involved, in control (Roin, 2018), and secure (Sanerma et al., 2020). The quality of the relationship is paramount (Sanerma et al., 2020), and thus determines the older person’s ability to remain in control. The relationship requires ‘personal chemistry’, and the personnel being reliable, considerate, respectful, and in no hurry (Ottenvall Hammar et al., 2014; Roin, 2018; Sanerma et al., 2020). While being in a dependent position, independence means ensuring that no more help than absolutely necessary is
received, to avoid deepening the dependence further (Ottenvall Hammar et al., 2014).

When feeling ill, the older person often has to rely on the competence of the care personnel. In a governmental report targeting older people’s views on their care, older persons express difficulties getting in touch with care personnel, and even more difficulty in seeing a physician (The National Board of Health and Welfare, 2022c). Care personnel’s decisions to call an ambulance are perceived by older persons as often relating to their lack of competence and their own worry, and the decision is sometimes experienced as both tedious and excessive (Hallgren et al., 2015). However, when having a serious condition, hospital conveyance is experienced as being more secure (Hallgren et al., 2015).

2.4 Emergency medical services

The EMS provide advanced care outside of hospital contexts, commonly referred to as prehospital emergency care. The EMS includes the EMCCs and ambulance services, also denoted as ‘the early chain of health care’ (Norberg Boysen et al., 2017). The EMCCs respond to emergency calls (in Sweden 112) and dispatch ambulance resources based on assessments in relation to symptomatic criteria and medical priority guidelines (Bohm & Kurland, 2018). The ambulance dispatcher assesses the information provided by the caller and assigns a priority to direct the ambulance response, the objective being to match resources and needs (Snooks et al., 2009). In the Nordic countries, as well as in many European countries, ambulance dispatchers use the Criteria-Based Dispatch System, which to a great extent relies on the dispatcher’s interviewing skills (Bohm & Kurland, 2018). Ambulance dispatching personnel in Sweden often consist of RNs, in addition to assistant nurses and personnel with other education (Lindström et al., 2015).

The ambulance services respond to emergencies on-scene, and are capable of providing advanced care in unfamiliar out-of-hospital settings. The context commonly relates to acute situations involving life and death scenarios, requiring advanced medical skills and a rapid response time to decrease mortality (Esmaeilzadeh et al., 2022; Kurz et al., 2018). Speedy responses are also standardized in relation to specific conditions such as hip fractures, stroke, and cardiac arrest to optimize conditions for surgical interventions and recovery, internationally referred to as fast-track care (Adler et al., 2019; Hsieh et al., 2016; Larsson et al., 2016).

The ambulance service is a context that is perceived at times to require a tough attitude (Rantala et al., 2019), and is predominately staffed with male personnel. American research depicts the ambulance services as a ‘White male context’, and it is known to often lack diversity regarding both gender and ethnicity (Rudman et al., 2022). The development of the EMS originates from
a military context involving the transport of wounded soldiers, which was later transferred to a civilian context (Pollock, 2013) and integrated with health care in recognition that health outcomes improved if appropriate care was provided out of hospital (Ilkka, 2022). References to the military context still exist today. The clothing of ambulance personnel is commonly referred to as uniform, and American and British EMS contexts also involve military officer titles (National Health Service England, 2018; Orange County Emergency Services, 2018).

Internationally, ambulance personnel mainly include paramedics and EMTs of various educational levels ranging from basic to advanced level (WHO, 2008). Sweden is one of only a few countries that crew ambulances with mainly RNs, often with postgraduate specialist education involving areas such as ambulance care, anesthetic care, or intensive care. Common to ambulance nurse education is the main emphasis on medical knowledge (Sjölin et al., 2019). According to Swedish policy regulating drug administration, all ambulance vehicles must be crewed with at least one RN to ensure the prehospital onset of medical treatment (HSLF-FS 2017:37). Apart from RNs, Swedish ambulance personnel also include EMTs, who are often trained as assistant nurses. There are few physicians in the Swedish ambulance services and they usually only have an advisory role or act as crew in special emergency care units, such as helicopter units (Lindström et al., 2015). The RNs working within the ambulance services in Sweden thus operate relatively autonomously, and besides caring expertise, competence in acute medical care, communication, collaboration, leadership, and pedagogy are required (Wihlborg et al., 2014). Swedish ambulance vehicles include dyadic-crewed advanced life support (ALS) units for conveyance (Suserud & Lundberg, 2016) and single responder units providing on-scene care (Carlström & Fredén, 2017).

There is a global trend toward increasing ambulance demands involving an aging population and nonspecific conditions (Andrew et al., 2020; Christensen et al., 2017; Otten et al., 2022). Consequently, non-conveyance and on-scene care are increasing as a response to overcrowded EDs (Paulin et al., 2021). The ambulance service thus becomes “the stretched arm of the medical emergency department” (Ilkka, 2022, p. 40), a fact which stresses the importance of providing qualitative prehospital care. However, the standard procedure for assessing quality in the ambulance services has long been equated with measuring response time which, however, speaks little of the care provided and more about the transport itself (Snooks et al., 2009).

2.4.1 Providing ambulance care

Research focusing on ambulance personnel’s experiences in providing ambulance care shows that they work in a complex and unpredictable context that requires an open mind and flexibility while keeping the situation under control.
(Sjölin et al., 2020; Wireklint Sundström & Dahlberg, 2012). Broad experiential knowledge supporting clinical expertise is needed (Hörberg et al., 2017; Loef et al., 2021; Sjölin et al., 2020) to meet a wide range of physical and emotional needs (Togher et al., 2013). Ambulance care involves the paramount responsibility of saving lives, and therefore brings fear of not being successful in the effort (Hörberg et al., 2017; Loef et al., 2021). The responsibility is further emphasized by being alone in decision-making, and having to make the ‘right’ decision without the backup available in a hospital setting (Hörberg et al., 2017). Research also shows the ambulance context as increasingly characterized by a ‘blame culture’, producing defensive care practices through fear of being subjected to complaints and accused of practical errors (Kirk et al., 2018). The risk of being held liable is known to prompt decisions of conveyance to hospital, even though this is not congruent with a person’s care needs (Oosterwold et al., 2018).

The relationship with patients subjected to acute suffering is described to include being both a fellow human and a professional, and involves being an empathic presence in a caring relationship while also being an authority taking the medical lead (Holmberg et al., 2016). The challenge of combining the two is found to be accentuated under acute conditions, where a medical focus is often prioritized (Svensson et al., 2019) which risks inducing feelings of being mistreated and objectified (Ahlenius et al., 2017). Ethical dilemmas also arise when the patient is unable to communicate, which means having to interpret needs and decide on care based on limited information in a limited time, thus risking compromising patient autonomy and dignity (Bremer & Holmberg, 2020; Peran et al., 2021). De-personifying the patient, and deliberately treating the patient as a ‘medical case’ is also found to be a coping strategy in extreme situations (Loef et al., 2021).

A well-functioning collaboration within the ambulance team is perceived as vital for providing qualitative ambulance care, where shared consensus and responsibility facilitate smooth collaboration and trust (Carnesten et al., 2021; Holmberg et al., 2020; Ulrich Hansen et al., 2022). A well-functioning team also provides emotional support in critical situations (Loef et al., 2021).

2.4.2 Experiencing ambulance care

Research shows the experience of ambulance care as a surrendering, where the person in need of urgent care surrenders themselves into the hands of ambulance personnel (Holmberg et al., 2014; Kauppi et al., 2022), trusting in their professional competence (Norberg Boysen et al., 2017). The interpersonal and relational skills of ambulance personnel are thus of great importance for the ambulance care experience. Positive experiences relate to care being provided by competent, interested, and compassionate personnel, which makes patients feel reassured, calm, and safe in a stressful situation (Ferguson et al., 2019; Togher et al., 2015; van Doorn et al., 2021; Venesoja et al., 2020).
Being reassured is given prominent meaning when receiving ambulance care regardless of condition, to alleviate the emotional chaos involving fear, anxiety, or even panic inflicted by the illness or injury (Togher et al., 2015; van Doorn et al., 2021). Being validated, taken seriously, and thus receiving affirmation that calling an ambulance was the right thing to do is also found important (Ferguson et al., 2019; Togher et al., 2015) since misuse of ambulance resources induces feelings of guilt (Togher et al., 2015). Being invalidated by condescending personnel, and not having one’s illness taken seriously, instead bring feelings of being judged, and not worthy of ambulance care (Ferguson et al., 2019; Venesoja et al., 2020), which can be experienced as an existential violation (Kauppi et al., 2022).

Professionalism is experienced through thorough, calm, and well-executed clinical assessments and treatments, which enhance confidence in the ambulance personnel’s decisions (Togher et al., 2015; van Doorn et al., 2021). In contrast, encountering rushed personnel, and poor technical skills nurtures insecurity (Venesoja et al., 2020). Receiving continuous information about the assessment, treatment, and situational conditions is perceived as important for facilitating understanding, control, and safety (Bårdsgjerde et al., 2019; Togher et al., 2013; Togher et al., 2015; Venesoja et al., 2020). The style of communication also influences the ambulance experience, where humor and informal conversations matter in producing a friendly atmosphere (Togher et al., 2015; Venesoja et al., 2020), while silence leads to feeling alienated (Togher et al., 2013) and uncomprehending (Bårdsgjerde et al., 2019).

The ambulance care experience also includes the handover process in the hospital. Positive experiences relate to staying involved and well-informed in a smooth handover process (Ferguson et al., 2019; Togher et al., 2013; Venesoja et al., 2020), where the process is prepared beforehand by the ambulance personnel (Togher et al., 2013; Venesoja et al., 2020). Negatively experienced handover situations are characterized by compromised dignity, by being objectified or diminished when left out of the conversation (Ferguson et al., 2019), or by being left to wait (Togher et al., 2013).

Older persons’ experiences of prehospital emergency care are relatively unexplored, and researchers often focus on epidemiological aspects (Cantwell et al., 2017; Christensen et al., 2017; Yip et al., 2015), and how older people (mis)use ambulance resources (Horibata & Takemura, 2015).

2.5 Previous research on participation in care

Participation in care has been found to promote a person’s quality of life by preserving human dignity and autonomy (Cahill, 1996) and enhancing well-being (Nilsson et al., 2019). The concept is considered central in care contexts, not only for improving the quality of care but also for enhancing patient safety (WHO, 2013). Thus, the clinical enactment of participation is pivotal but what
it actually means in practice is not given. Participation is defined in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), as being involved in a situation in life “or ‘the lived experience’ of people in the actual context in which they live” (p. 127). Participation in care is thus the involvement of a person in need of care in care activities in a social or healthcare setting (Casado et al., 2020), which can be a person’s home. The concept, however, appears vague, overused, and clinically under-researched (Nilsson et al., 2019). In the research arena, the concept is frequently used interchangeably with other concepts, such as empowerment, partnership, involvement, or engagement (Barello et al., 2014; Casado et al., 2020; Longtin et al., 2010), which contributes to the confusion. Depending on the research discipline, different meanings of the concept are also emphasized, varying from a tool for compliance and self-management, to consumer empowerment, and recognition of needs and preferences (Barello et al., 2014).

Concept analyses of ‘patient participation’ conducted over the past three decades share the effort of trying to bring clarity to a concept that continues to be elusive, complex, ambiguous, and difficult to enact (Cahill, 1996; Nilsson et al., 2019; Sahlsten et al., 2008). The common denominator of participation in the studies by Cahill (1996), Sahlsten et al. (2008), and Nilsson et al. (2019) is the relationship between the professional caregiver and the person in need of care, the prominent features being sharing and trust (Nilsson et al., 2019). Additional attributes facilitated by the caring relationship are a transfer of power, sharing of knowledge, and common engagement in physical or intellectual activities (Cahill, 1996; Sahlsten et al., 2008). Cahill (1996) also puts forward a requirement for positive benefits for the cared-for person, and Nilsson (2019) emphasizes the elements of learning and reciprocity. In more recent years, social aspects of participation have been raised, and whether social participation and participation are two different concepts (Piskur et al., 2014). Piskur et al. (2014) suggest expanding the ICF definition to also include societal involvement and social roles which emphasize the social element of interactions and activities, or even changing the definition to “engagement in social roles” (p. 217).

From a welfare perspective, participation in care is part of value-based health care that considers the preferences of the persons in need of care while also supporting sound welfare finances (European Commission, 2019; Teisberg et al., 2020). Participation in care is, therefore, a legislative right in many Western societies, as in Sweden (SFS 2001:453; SFS 2014:821; SFS 2017:30). However, the existing confusion around the concept produces a gap between the visionary level and the executing level, when the vision comes to be transformed into practice (Magnusson et al., 2019; Vrangbaek, 2015). Participation in care is therefore often limited and focused on mutual decision-making (Chi et al., 2017; Eldh, 2019; Vrangbaek, 2015), practiced as something ‘prescriptive’ in common to all rather than individually adapted (Claasens et al., 2014; Selman et al., 2017). At times, participation in care is even
considered a ‘buzz-word’ (Magnusson et al., 2019). Thus, how participation in care is enacted is dependent on the attitude and knowledge of the professional caregiver, which demonstrates the power asymmetry existing between the person in need of care and the professional (Ringdal et al., 2017; Vrangbaek, 2015), where an exercise of power can be seen as the professionals having an ignorant or even bullying attitude (Ringdal et al., 2017).

Previous research focusing on older persons’ views indicates less interest in taking an active part in decision-making; rather decisions of care are entrusted to professionals (Bastiaens et al., 2007; Casado et al., 2020). However, the professional caregiver’s attitude is vital for older persons to experience participation, where benevolence, friendliness, respectfulness, and genuine interest facilitate feeling welcome and equal (Emsfors et al., 2017; Roin, 2018; van Dongen et al., 2017). Older persons’ participation in care is found to relate to existential issues, where the whole person needs to be acknowledged (Abu Al Hamayel et al., 2018; Nyborg et al., 2016; Roin, 2018; Selman et al., 2017). Participation in care should be based on the older person’s values (Witsø et al., 2012), where maintaining dignity and self-worth is important (Adamson et al., 2017; Casado et al., 2020; Witsø et al., 2012). To experience participation in care, a shared understanding in a trustful relationship with the professional caregiver is key (Abu Al Hamayel et al., 2018; Adamson et al., 2017; Claassens et al., 2014; Nyborg et al., 2016; van Dongen et al., 2017). The experience of participation is further facilitated by being acknowledged as a trustworthy and able person, thus being given responsibility (Hedman et al., 2015).

Temporal and environmental conditions are important aspects of participation that facilitate communication and trust, which means being provided with enough time (Algilani, 2016; Samuelsson et al., 2018; Schopf et al., 2018; Selman et al., 2017) in the ‘right place’ (Algilani, 2016). If not shown enough interest or provided with enough time, older persons have been found to delegate interaction with professional caregivers to a representative, often in the form of a relative (Abu Al Hamayel et al., 2018; Claassens et al., 2014; Nyborg et al., 2016; Schopf et al., 2018). Continuity in care, as in collaborative and coordinated care, is another significant aspect of participation in care, although often counteracted by rigid, fragmented, and medically focused care systems (Claassens et al., 2014; Selman et al., 2017; van Dongen et al., 2017). Another aspect of participation that seems more emphasized in the social care context is the social dimension and the ability to stay connected with society through the visits of professional caregivers and the mobile safety alarm (Witsø et al., 2015).

Older person’s participation in care under the influence of acute illness has not been sufficiently studied. The study by Frank et al. (2009) focusing on adult patients’ participation in an ED setting found that participation was perceived when acknowledged through verbal or nonverbal communication, and when needs were met without having to announce them. However,
participation in the ED environment can also be perceived as a struggle, when constantly having to seek contact (Frank et al., 2009). The ED environment is known to induce feelings of vulnerability related to loneliness and existential fear (van Oppen et al., 2019).

Although not addressing participation per se, research reviews describing older persons’ views and expectations on emergency care emphasize a comprehensive care perspective that includes continuous and frequent interactions with friendly and reassuring professionals, reduced waiting time, clear communication facilitating understanding, a comfortable physical environment, and support in urgent care decisions where the professionals take a leading role (Shankar et al., 2014; van Oppen et al., 2019).
3 Theoretical framework

The theoretical perspective framing this thesis is caring science and the life-world perspective, which emphasizes the qualitative world of human beings as the foundation for care (Galvin & Todres, 2013). The lifeworld perspective is founded in phenomenological and hermeneutical philosophy and the extensive body of knowledge concerning human existence developed over time by philosophers such as Husserl (1913/2004), Heidegger (1953/2010), Merleau-Ponty (1945/2002), and Gadamer (1993/1996). The shared motive of phenomenology and hermeneutics is to understand the human world and lifeworld phenomena as they are experienced, which provides an ontological, epistemological, and methodological foundation for this research project. The lifeworld refers to the unique experiential world of each human being, which is set in relation to the surrounding natural world that is shared with all others (Husserl, 1913/2004). The lifeworld is thus experiential and relational. Central to lifeworld philosophy are the natural attitude, intentionality, and the lived body. The natural attitude refers to the taken-for-granted everyday existence, a naïve approach that constitutes the basis for un-reflected understanding (Dahlberg, 2008). Intentionality denotes the conscious relationship with objects in our world, meaning that every activity of the mind is directed toward ‘something’ and places that ‘something’ in an imaginatively constructed context based on previous experiences (Sokolowski, 1999). The lived body denotes our being in the world, where the body is the subject through which we live, enter into, and experience the world (Merleau-Ponty, 1945/2002). How we pre-reflectively understand the world thus becomes embodied knowing in that our “body is constantly perceived and constantly perceiving” (Dahlberg, 2008, p. 41).

Phenomena of the lifeworld, for example, discourse, social processes, reactions, or practices (Lindseth & Norberg, 2022), manifest in human experience and are assigned meanings that can be understood through lived experience (Neubauer et al., 2019). Lived experience belongs to the natural attitude and the “non-reflective dimension in life” (van Manen, 1997, p. 38), and can

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2 Ontology describes the nature of reality (Polit & Beck, 2004) and answers the question ‘How is the world seen?’

3 Epistemology refers to the relationship between the researcher and the researched (Polit & Beck, 2004) and answers the question ‘How is the world known?’

4 Methodology is based on the scientific perspective (van Manen, 1997), such as the lifeworld perspective, and answers the question ‘How can knowledge be obtained?’
be described as units of meaning in the web of interrelated experiences that make up our lifeworld (van Manen, 1997). The experiential web makes the lifeworld holistic in character, and every event is assigned meaning in relation to the larger web that constitutes a person’s whole life (Galvin & Todres, 2013). According to Husserl (1913/2004), the manifestation of phenomena depends on who is watching and will differ depending on the perspective. Our understanding of the world is always the result of interpretation and every new experience is understood in relation to lived experience, which means that the “Things at hand are already understood” (Heidegger, 2010, p. 145). Thus, although situated in the same world, we all experience and interpret it differently.

The lifeworld can be understood further in relation to its five intertwined constituents; temporality, spatiality, intersubjectivity, embodiment, and mood (Heidegger, 1953/2010; Husserl, 1913/2004). These qualitative dimensions color all lived experience and provide guidance for understanding the lifeworld in relation to care (Galvin & Todres, 2013). Temporality refers to a person’s life story in relation to time embracing a past, present, and future. The temporal aspect of life includes continuities and discontinuities of the life course, influencing a person’s possibility to live forward. Illness can be understood as a discontinuity of life, where well-being is promoted by recognizing aspects that support the ill person’s continued life journey. Spatiality refers to environmental aspects and includes places and objects of importance for the person. Spatiality also embraces the space between situations or objects in relation to them being close or distant depending on their experienced significance in the specific moment of life. Intersubjectivity refers to the relational aspect of the lifeworld and our interactions with other persons who influence how we understand and identify ourselves. Language is described as an important facilitator of social understanding and shared meanings. The relational world can, however, be humane or inhumane, dignifying or objectifying, and needs to be recognized in care contexts to promote well-being. Embodiment refers to our lived body through which we act and position ourselves in the world. The lived body feels and reacts to the surrounding world and conveys cues of meaning. Mood, also denoted as emotional attunement, refers to the emotions coloring all lived experience. The dimension of mood is a complex and powerful conveyer of meaning that shapes all other dimensions and serves as both a motivator and a de-motivator.

A lifeworld approach in care contexts provides balance to medical and technological care procedures, thus supporting a humanizing care practice that is of value to the persons in need of care (Galvin & Todres, 2013). Lifeworld-led care thus means recognizing the existential dimension of well-being, and embracing the human experience of illness and health (Dahlberg et al., 2009). Our relations with others and how they are experienced are important aspects of lifeworld theory, where meaningful relationships are significant (Galvin & Todres, 2013). In care contexts, therefore, the caring relationship becomes of great importance. Participation in care is a lifeworld phenomenon that
manifests in relation to the other ‘participants’ in a shared situation. In this research project, care-dependent older persons’ participation in prehospital emergency care is therefore understood and researched as a lifeworld phenomenon that manifests in relation to acute illness and the professionals involved. By researching the lived experience of all persons involved, essential meanings of the phenomenon can be disclosed. The ontological and epistemological underpinnings of the lifeworld also apply to the researcher, which necessitates controlling one’s own preunderstanding and knowledge (biases, beliefs, theories, assumptions) by making them visible and thus facilitating ‘being open’ to the phenomenon (van Manen, 1997).

Although the theoretical framework places this thesis within the qualitative paradigm, quantitative research methods are not excluded. Statistical inquiries can complement and add perspective that is beneficial in the effort to deepen the understanding of older persons’ participation in prehospital emergency care.
4 Rationale

Swedish welfare includes the provision of care services throughout the lifespan to promote control and a good life. Participation in care is key in that effort, and is considered to promote health, well-being, and safety for people in need of care. Transferring the concept from the welfare vision to clinical practice has proved challenging due to a persistent lack of clarity regarding clinical enactment. Research points to the existing disparity in perspectives between professional caregivers and the persons in need of care, which risks counteracting welfare incentives.

In line with current Swedish aging-in-place policies, older persons with various care needs are encouraged to remain living at home with the assistance of municipal home care services for everyday care needs. Care-dependent older persons are known to have increased emergency care needs. Acute illness initiates regional prehospital emergency care involving inter-professional collaboration and care transfer between organizations and welfare levels. Transitional care is known to harbor collaborative difficulties that might influence the enactment of participation in care. The lack of a common understanding of what participation in care means for acutely ill older persons holds a risk that the participation may not be practiced, leading to intensified suffering. To promote well-being, a deepening of the understanding of what participation in care means from the acutely ill older persons’ perspective is necessary.

This thesis provides a deepened understanding of care-dependent older persons’ participation in prehospital emergency care from a caring science and lifeworld perspective that focuses on lived experience. The generated body of knowledge can serve as a tool to support health-promoting and sustainable welfare, and clinical practice development in relation to prehospital emergency and transitional care. Most importantly, this thesis provides guidance for the professional caregivers involved in how to practice participation in care that favor care-dependent older persons in critical and vulnerable life situations. In this way, safe and qualitative prehospital emergency care that starts in older persons’ homes can be provided.
5 Aims

The overall research aim is to deepen the understanding of care-dependent older persons’ participation in prehospital emergency care from lifeworld and welfare perspectives.

The specific aims of studies I–IV were:

Study I: To describe characteristic patterns of dyadic staffed emergency ambulance assignments for older adults aged >70 years compared with adults aged 18–69 years requiring emergency care at home.

Study II: To illuminate meanings of participation in prehospital emergency care from the perspective of care-dependent older persons experiencing acute illness at home.

Study III: To describe municipal care personnel’s experiences of and actions in situations when older persons need emergency medical services at home.

Study IV: To illuminate meanings of older persons’ participation in ambulance care in the presence of municipal care personnel from the perspective of ambulance personnel.
6 Design and methods

6.1 The overall design

The inductive design guiding this research project is based on the lifeworld perspective (Galvin & Todres, 2013), and methods are chosen in accordance with this perspective. By triangulation of different perspectives, variations and nuances of the phenomenon can emerge that offer a more complete picture (Streubert & Carpenter, 2011). To deepen the understanding of the phenomenon of participation in care further and give the lived experience contextual bearing, the subjective perspectives of studies II, III, and IV are complemented with a welfare perspective in study I. When combining lifeworld and welfare perspectives, the horizon of knowledge not only broadens but also allows for contrasting perspectives, which adds dimensions of knowledge that further deepen the understanding.

Apart from different perspectives, triangulation also involved different data collection methods, and different methods for analysis (Table 1). The statistical data in study I serve as the background to the experiential data in studies II, III, and IV, and provide an understanding of the context from a welfare and ‘outer world’ perspective. The qualitative data in studies II, III, and IV triangulate the phenomenon by investigating the ‘inner world’, the lived experience of the persons involved. Whereas studies II and IV particularly focus on lived experience of the phenomenon of participation in care, study III focuses on experiences of contextual challenges related to older persons’ acute illness and the potential impact on participation in care. Each study is considered to contribute knowledge that when combined allows a deepened understanding of older persons’ participation in care in the prehospital emergency care context involving home care and ambulance services.

The quantitative analysis method in study I included descriptive and analytical statistics to show characteristic patterns of emergency ambulance assignments for older adults aged 70 years or older. The qualitative methods for analysis included phenomenological hermeneutics (Lindseth & Norberg, 2004, 2022) for elucidating meanings of participation in care from the perspective of care-dependent older persons in study II and from the perspective of ambulance personnel in study IV, and critical incident technique (CIT) (Fridlund et al., 2017) for describing municipal care personnel’s experiences of situations involving older person’s acute illness and ambulance care in study III.
### Table 1 Overview of studies I–IV

<table>
<thead>
<tr>
<th>STUDY</th>
<th>DESIGN</th>
<th>PARTICIPANTS</th>
<th>DATA COLLECTION</th>
<th>ANALYSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Quantitative, retrospective, comparative, descriptive</td>
<td>28,533 emergency ambulance assignments for adults (18–69) and older adults (70–104) requiring ambulance care at home</td>
<td>Registry data from the ambulance services containing all assignments between 2017 and 2018</td>
<td>Descriptive statistics, analysis of non-parametric variable correlations; χ², ANOVA, binary logistic regression</td>
</tr>
<tr>
<td>II</td>
<td>Qualitative, inductive, life-world approach, interpretative</td>
<td>11 persons aged 70–93 years utilizing home care and/or a mobile safety alarm service</td>
<td>Individual telephone interviews</td>
<td>Phenomenological hermeneutics</td>
</tr>
<tr>
<td>III</td>
<td>Qualitative, inductive, CIT, descriptive</td>
<td>19 care personnel, active within the municipal home care service</td>
<td>Individual interviews, online free text questionnaire</td>
<td>CIT</td>
</tr>
<tr>
<td>IV</td>
<td>Qualitative, inductive, life-world approach, interpretative</td>
<td>11 ambulance personnel, active within the ambulance service</td>
<td>Individual interviews</td>
<td>Phenomenological hermeneutics</td>
</tr>
</tbody>
</table>

#### 6.1.1 A preparatory discussion

As a starting point for the research project, older persons from the Swedish national pensioners’ organization (PRO) were invited to a discussion about participation in care, in order to come to an understanding of how older persons perceive and talk about the concept. Three older women with experience of ambulance care joined the discussion. These persons were not included as study participants. During the discussion, the phenomenon of participation in care was mostly portrayed in discourse by its absence. Care encounters lacking participation in care were negatively experienced, and were characterized by objectification, misbehavior, lack of collaboration and communication between hospitals, and hurried care. Care encounters fulfilling expectations of participation in care were instead characterized by being known, important and the center of attention, and being entrusted to choose based on competence.
and preference. Thus, participation in care was discussed more in terms of a feeling rather than an activity.

The discussion provided an understanding of how the phenomenon can manifest in situations involving ambulance care, and illuminated aspects of importance for these persons. The discussion served to enrich my preunderstanding but also served to test and improve my interviewing skills, both of which were beneficial in the subsequent research process.

6.2 Participants and setting

6.2.1 Ambulance assignments involving older adults (I)

Anonymized register data was provided from the ambulance services in the region under study, comprising all ambulance assignments performed in the region between January 2017 to December 2018 (N=75 088). The region is situated in the middle of Sweden and covers about 6 000 km², which can be considered medium-sized by Swedish standards. The region covers both rural and urban areas and is divided into nine municipalities. Approximately 300 000 citizens inhabit the region, of which about 17% are 70 years of age or older (Statistics Sweden, 2021). The ambulance services in the region consist of five ambulance stations located in the five largest municipalities. The ambulance services provide diurnal prehospital emergency care, in addition to transporting and assisting assignments.

The sample for analysis consisted of dyadic staffed emergency ambulance assignments to people’s homes. After the exclusion of assignments involving children, transfer, secondary response, assistance, deceased patients, single responder response, and missing data (time), a final sample of 28 533 assignments was eligible for analysis. The final sample represented primary assignments involving adult persons aged 18–104 years requiring an emergency ambulance response in their own private homes, resulting in conveyance or non-conveyance to hospital, with calculable on-scene time. To find age-dependent patterns, the sample was further divided into two age groups; adults aged 18–69 years (n=11 436), and older adults aged 70–104 years (n=17 097).

6.2.2 Care-dependent older persons (II)

The older persons (n=11) were recruited with the aid of the municipal home care organization in one municipality in the middle of Sweden. Information letters were distributed to two appointed staff members working within the municipal home care service organization with knowledge about ambulance responses for older persons. Under their supervision, the letters were sent to persons 70 years of age or older who had recently experienced ambulance
care. Additional inclusion criteria were the ability to narrate the ambulance care experience and give informed consent.

Older persons interested in participating in the study returned a signed consent and provided contact information. Due to the SARS-CoV-2 virus in December 2019 causing the Corona-virus disease 2019 (COVID-19), all contact with the older persons was by telephone and included an initial telephone call and telephone interview. The initial telephone call served several purposes; additional information about the study was provided, the older person could ask questions, and it also provided an opportunity for me as an interviewer and the older person to become acquainted. Bearing in mind that the participants must willingly share sensitive information, trust needs to be encouraged (Orb et al., 2001). In total, 12 older persons returned a signed consent to participate in the study. However, one older person was excluded due to not remembering signing the written consent.

The persons included in the study consisted of five women and six men aged 70–93 (mean=83). All older persons utilized mobile safety alarms, but only six persons utilized other home care services. The services included food delivery, cleaning, and activities of daily life (ADL). The older persons lived in their own housing in rural and urban areas, which included living in an apartment (multi-family residential) or in a detached house (single-family residential). Most of the older persons lived alone; however, one person lived with a grandson, one person lived with a partner, and one person had a live-apart relationship. The older persons’ acute conditions that prompted the need for ambulance care response included bleeding, dizziness, fatigue, fractures after falling, severe pain, and respiratory and heart conditions. All but one older person initiated the emergency response by activating their mobile safety alarm. The person who did not use the mobile safety alarm awaited the arrival of home care personnel visiting for planned assistance, since the mobile safety alarm was out of reach.

6.2.3 Municipal care personnel (III)
Municipal care personnel \( (n=19) \) working with planned (home care visit) and unplanned (mobile safety alarm response) assistance were recruited in one municipality in the middle of Sweden. The municipality is one of 290 in Sweden and covers about 1 250 km\(^2\), including rural and urban areas. The municipality has about 16 000 people aged 70 years or older (Statistics Sweden, 2020), of which approximately 26% utilize municipal home care services including planned and unplanned assistance (information provided by the municipality March 31, 2021).

The municipality was at the time of the study divided into 21 home care districts staffed with their own personnel. Planned home care services are diurnal and based on the older persons’ everyday needs. Home care personnel usually work alone during the day, and in dyads during the night. Mobile
safety alarm responders provide diurnal service to older persons’ unplanned and urgent needs in all home care districts in the municipality, including events such as toilet visits or falls. Mobile safety alarm responders work in dyads and during the time of the study, two dyadic-crewed vehicles were operational during daytime hours (07:00–21:00), and one vehicle during the night.

Mobile safety alarm responding personnel were provided with verbal and written information about the study at a workplace meeting, and 16 personnel reported interest in participating and volunteered for interview. Home care personnel providing planned assistance in three home care districts were also provided with verbal and written information at workplace meetings; however, no personnel reported interest in participating.

To fully meet the requirements of CIT and thus acquire as many incidents as possible, a questionnaire in the form of an anonymous web survey (Survey&Report) was therefore launched in a fourth home care district. The questions in the survey were open-ended, corresponding to the interview questions. Care personnel in the district were provided with verbal and written information at a workplace meeting, and an e-mail containing written information and a link to the survey was distributed to the local manager who forwarded the e-mail to the care personnel in the district. A returned questionnaire was considered as valid consent to participate in the study. A total of three questionnaires were returned. Three more districts were to be included in the web survey. However, due to the COVID-19 pandemic, access to home care personnel was limited and further participant recruitment was, therefore, canceled.

The total sample (n=19) included women (n=14), and men (n=5) aged 22–60 years (mean=49) working with mobile safety alarm response (n=16) and planned home care assistance (n=3), with work experience ranging between 3–40 years (mean=24). The participants’ educational level included formal assistant nurse training (n=17) and care assistants with no formal training (n=2).

6.2.4 Ambulance personnel (IV)

The ambulance personnel (n=11) were recruited from one ambulance station in the region previously presented in 6.2.1. The ambulance personnel included all persons providing ambulance care, regardless of their educational level. Information about the study was given at one workplace meeting and also provided in e-mails. Personnel interested in participating in the study reported back by mail or text message, for further contact and scheduling of interviews. A total of 11 ambulance personnel reported interest and were included in the study. The participants included both women (n=7) and men (n=5) ranging from 36 to 51 years of age (mean=43). The educational level included EMT (n=1), RN (n=2), RN with specialist education in intensive care (n=2), and RN
with specialist education in ambulance care (n=6). Work experience in the ambulance care context ranged from three to 22 years (mean=11).

6.3 Data collection

6.3.1 Variables (I)
The variables for analysis were age, gender, clinical assessment, priority level, result of response, on-scene time, and temporal pattern (Table 2). Age was used as a continuous or categorical variable, stratified into two or eight age groups.

Clinical assessment is the ambulance RN’s symptomatic assessment of the patient’s condition, which is chosen from a set of preselected symptomatic assessments. The preselection originally encompassed 134 symptomatic assessments in the registry data. These assessments were arranged into 14 categories in line with the emergency signs and symptoms (ESS) grouping system. The ESS system includes two categories that do not require clinical assessment (other, transfer), and the two categories were therefore not included in the variable.

On-scene time is not entered in clinical records by the EMS in the region, only the time of arrival and departure. However, on-scene time was considered of interest for analysis. Therefore, calculations of on-scene time were made, subtracting the time of ambulance arrival from the time of ambulance departure.

Priority level concerns the dispatch priority and transport priority. The dispatch priority is the priority assigned to the ambulance response by the EMCC based on the information provided by telephone. The transport priority is the priority assigned by the ambulance RN on-scene.

Result of response refers to the level of care needed, denoted as conveyance or non-conveyance. Conveyance means transport to the hospital, and non-conveyance means that the patient remains at home.

Temporal patterns include diurnal, weekly, and seasonal variables. The dichotomized diurnal variable is based on the emergency ambulance disposition in the region. Daytime (08:00–17:59) means that all emergency ambulances are operational, while fewer units operate during the nighttime (18:00–07:59).
<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>TYPE</th>
<th>VARIABLE PROCESSED FOR ANALYSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Continuous, categorical</td>
<td>Variable 1: 18–104 years</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Variable 2: (18–69) / (70–104)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Variable 3: (18–29), (30–39), (40–49), (50–59), (60–69), (70–79), (80–89), (90–104)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Categorical</td>
<td>(Male) / (Female)</td>
</tr>
<tr>
<td><strong>Clinical</strong></td>
<td>Categorical</td>
<td>Variable 1: (Circulatory), (Eye), (Genital), (Infection), (Medical), (Neurology), (Nonspecific), (Orthopedic), (Psychiatric), (Respiratory), (Surgical), (Trauma)</td>
</tr>
<tr>
<td>assessment</td>
<td></td>
<td>Variable 2: (Assessment) / (All other assessments)</td>
</tr>
<tr>
<td><strong>On-scene time</strong></td>
<td>Continuous</td>
<td>1–235 minutes</td>
</tr>
<tr>
<td><strong>Priority level</strong></td>
<td>Categorical</td>
<td>Variable 1: (Priority level 1), (Priority level 2), (Priority level 3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Variable 2: (Priority level) / (All other priority levels)</td>
</tr>
<tr>
<td><strong>Result of</strong></td>
<td>Categorical</td>
<td>(Conveyance) / (Non-conveyance)</td>
</tr>
<tr>
<td>Response</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Temporal</strong></td>
<td>Categorical</td>
<td>Variable 1: Diurnal (08:00–17:59), (18:00–07:59)</td>
</tr>
<tr>
<td>patterns</td>
<td></td>
<td>Variable 2: Diurnal (00:00–03:59), (04:00–07:59), (08:00–11:59), (12:00–15:59), (16:00–19:59), (20:00–23:59)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Variable 3: Weekly (Monday–Friday), (Saturday–Sunday)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Variable 4: Weekly (Monday), (Tuesday), (Wednesday), (Thursday), (Friday), (Saturday), (Sunday)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Variable 5: Seasonal (December–February), (March–May), (June–August), (September–November)</td>
</tr>
</tbody>
</table>
6.3.2 Individual telephone interviews (II)

The interviews were conducted between March 2020 and January 2022, at a time and day chosen by the older person. At the beginning of each interview, the older person was once more provided with information about the study and reminded that they could withdraw at any time without consequence for them or their care situation. To enable recording by a separate voice recorder, my cell phone was on speaker mode. Before the recording began, I clearly stated that no one else was in the room apart from me to ensure privacy. Then the older person was encouraged to narrate an episode of their choice when they had needed ambulance care. The older persons were allowed to speak freely about their ambulance experience. The narratives often involved multiple ambulance care episodes and references to life in general. During the interviews, to avoid disturbing the narration, notes were taken about any issues to return to (Lechuga, 2012). Depending on what was said and how, follow-up questions were used to stimulate the narration further, for clarifying, or probing reasons. As the story developed, a comprehensive picture of the lived experience became clear which was used as a basis for asking more direct questions about the older person’s participation in the situation. Questions such as “How did you experience participation in this situation?”, “What was your role in the situation?”, or “How did you participate in the situation?” were used to stimulate storytelling based on lived experience of participation in the specific emergency care situation.

Due to the sensitive nature of the narrative and the absence of body language and nonverbal cues from both parties, a caring interest had to be conveyed by voice. Much emphasis was therefore placed on conveying empathy, which could include asking questions off topic to establish a conversational relationship (Rubin & Rubin, 2005). The interviews lasted between 17 and 120 minutes (mean=53). Four of the interviews were interrupted by home care visits, of which three had to end. The ended interviews did not need to be resumed since they were in a final phase. One older person whose interview was interrupted and rapidly ended when the care personnel arrived was later contacted by me again as the interview had ended in a hurry without proper closure.

6.3.3 Interviews and questionnaire (III)

The data collection, including interviews and free text written questionnaires, took place between October 2019 and March 2020. Care personnel responding to mobile safety alarm calls were interviewed on six occasions in a secluded room at their workplace. Although the interview was individual, they were conducted with care personnel present in groups of two or three by their choice. The interview arrangement allowed the interviews to be conducted during working hours, with 1.5 hours being allotted per group by the local
manager. The interviews started with two initial questions about work opportunities and challenges, followed by the main question where the participant was asked to describe a situation when an older person had needed ambulance care. Follow-up questions were asked to stimulate the participants to further describe the situation, explaining what and why actions had been done, what the consequences were, and the positive or negative aspects of the situation. The group constellation enabled the involved participants to interact and engage in the conversation, which in dyadic interviewing is considered an intentional benefit (Morgan et al., 2013). The interaction was not an intentional part of the study design but rather happened by chance due to the given circumstances. The interaction was, however, found fruitful for prompting memory recall and producing richer data as it allowed the participants to ask each other questions based on contextual knowledge. However, if the interaction between the participants produced loss of topic, the focus was reset to the individual participant and interview. The duration of the interviews ranged between 72 and 84 minutes.

The questionnaire presented as an anonymous web survey (Survey&Report) contained the same questions as used in the interviews, in addition to closed formal questions related to participant characteristics; gender, age, educational level, daytime or nighttime work, and work experience. The web survey yielded three written accounts of emergency situations. The data was very brief, but was considered sufficiently described to be included in the analysis.

Further data collection was canceled in March 2020 due to the onset of the COVID-19 pandemic. In total, the data collection process yielded 63 accounts of emergency situations involving older persons and ambulance care, which can be considered enough by CIT standards (Flanagan, 1954).

6.3.4 Individual interviews (IV)

The interviews were conducted in November and December 2021, in a secluded room at the ambulance station. Each participant was provided with information about the interview procedure before the recording started. The interview was initiated with the main question “Could you please tell me about an ambulance assignment to an older person where municipal care personnel were present?” The following questions were asked to stimulate reflection, for clarifying reasons, or to stimulate the narrative further to gather extensive experiential material (van Manen, 1997). Follow-up questions were also asked to encourage the participants to reflect on the older person’s participation in the care situation, and included questions such as “How was the older person participating in the situation?” To gain a better understanding of the phenomenon, the participants were also asked to narrate a similar situation where an older person was not perceived as participating in care.
The interviews held during work shifts implied that some participants were on alarm response duty, and three interviews were interrupted by alarm calls. The interruptions led to one interview being briefly paused, and two interviews ending. The interviews that had to end were in their final phase and did not need to be resumed. The interviews lasted between 38 and 70 minutes.

6.4 Data analysis

6.4.1 Statistical analysis (I)

Descriptive statistics were used to characterize the two age groups, generating frequencies, means, standard deviations, and proportions. One-sample χ² test was used to compare temporal and seasonal characteristics between age groups, showing between-group variation. To investigate age group differences, nonparametric variable correlations were analyzed. Binary logistic regression was used to investigate the association between dichotomized dependent and independent variables. Dependent outcome variables were clinical assessment, priority level, and result of response. Independent variables were age group (main predictor), clinical assessment, on-scene time, priority level, and time of day. Calculations were presented as both unadjusted and adjusted odds ratio (OR) with 95% confidence interval (CI). To investigate age and on-scene time correlations, one-way analysis of variance was used. In addition, Scheffe’s post hoc test was used for between-group multiple comparison. For statistical significance, \( p < 0.05 \) was chosen. IBM SPSS Statistics (version 24.0; IBM SPSS, Armonk, NY, USA) was used for all statistical analyses.

6.4.2 Phenomenological hermeneutics (II, IV)

The phenomenological hermeneutical method developed by Lindseth and Norberg (2004, 2022) was used in studies II and IV. The method is based on the common motives of phenomenological and hermeneutical philosophy to elucidate and understand meanings of lifeworld phenomena, which involve human practices or discourse, events, and social processes that have an impact on life. From an ontological perspective, the lifeworld is a world of experience developing through time and shown in discourse. From an epistemological point of view, knowledge is developed by understanding how persons relate to the phenomena as participants of the lifeworld (Lindseth & Norberg, 2022).

A phenomenological hermeneutical approach allows for an understanding of the essential meanings of a phenomenon to be disclosed by interpretation of narrated lived experience fixed in texts. The method is inspired by Ricoeur (1976), who emphasizes the importance of both understanding and explaining
the world disclosed by the text by moving between distance (understanding) and closeness (explaining) during the interpretative process. Therefore, the method involves both understanding and explaining in a tripartite hermeneutical circle. The hermeneutical circle means moving between the sense of the text (the whole) to its reference (the parts), which allows opening a new way of understanding the world (Ricoeur, 1976). The analysis starts with an extensive reading of the interview transcripts, which allows a naïve understanding of the phenomenon based on the ‘whole’ to develop and be formulated. The second part of the analysis involves a structural examination of the interview transcripts, which allows the first naïve understanding of the whole to now be explained by analyzing the text parts. The structural analysis process thus involves moving between the naïve understanding of the whole and the explanation provided by the text parts to disclose nuances and variations. The evolving understanding is then viewed in light of theory and the researcher’s own lived experience to form a comprehensive and new understanding. In contrast to phenomenological research which requires the researcher set aside their own preunderstanding and place it within brackets, phenomenological hermeneutics instead requires an intentional use of preunderstandings to elucidate the meaning. The knowledge of the researcher is described as a valuable guide in the search for meaning (Neubauer et al., 2019). However, what needs to be reflected upon, elucidated, and kept in brackets is instead a possible natural and judging attitude (Lindseth & Norberg, 2022).

In studies II and IV, the analysis procedure was initiated by repeated reading of the verbatim interview transcripts. The reading enabled a naïve understanding of the phenomenon as a whole to be formulated. Next, the naïve understanding was explained. The thematic structural analysis commenced with identifying text units that contained meanings of the phenomenon of participation in care. The meanings were condensed and reflected upon, then abstracted into subthemes, themes, and main themes. In the comprehensive understanding and final part of the analyses in studies II and IV, the results were elaborated on in relation to theoretical perspectives, which deepened the understanding further.

6.4.3 Critical incident technique (III)

CIT is an inductive qualitative method aiming at investigating human behavior. The method originates from World War II military psychology studies of failed aviation missions (Flanagan, 1954). Since then, the method has been extensively used in various service contexts (Gremler, 2004), and has proven beneficial in healthcare research (Fridlund et al., 2017). The method is deemed phenomenological in the sense that it researches lived experience, even though there is no clearly stated ontology or epistemology guiding the method. The critical incident to be investigated is described as an activity where the purpose and the consequences of the activity have a positive or negative effect on the
outcome (Flanagan, 1954), or simply put, how people experience and subsequently act in a critical situation (Fridlund et al., 2017). The data is based on memory reports, and is an investigation of behavior in hindsight. According to Flanagan (1954), a minimum of 50 described incidents are required for analysis, to allow for the data to be summarized and described adequately. CIT data collection is flexible and allows for various data collection methods to be used simultaneously, as long as full coverage of the described incident is obtained. The research questions aim at probing the course of the incident, emotions, and actions (Fridlund et al., 2017). CIT analysis of interview transcripts involves the identification of quotations describing an experience or action and sorting them into subcategories, categories, and generic main areas.

The data in study III were collected and analyzed in accordance with the CIT procedure, guided by the aim of describing municipal care personnel’s behavior in emergency situations involving the ambulance care needs of care-dependent older persons. In total, 63 unique critical incidents were described in full, accompanied by descriptions of more general experiences related to emergency situations involving older persons and ambulance care. The interview transcripts and the written descriptions from the questionnaires were read several times, which allowed me to become familiar with the text. Then, text sections indicating actions or experiences were inductively identified and sorted into subcategories based on similarities or differences in character. In a similar way, the subcategories were then sorted into categories describing the experiences and actions. In the final step, the categories were sorted into generic main areas. The separation of experiences and actions was considered a fruitful approach to explain what is experienced and what is subsequently done.

6.5 Ethical considerations

Research processes should be guided by a set of ethical principles, involving beneficence, autonomy, and justice to protect the persons involved (Orb et al., 2001). Ethical considerations have been taken into account in accordance with the Declaration of Helsinki (World Medical Association, 2013). Due to the sensitive character of the data, ethical approval was obtained from the Swedish Ethical Review Authority (Dnr: 2019-02027) for all four studies prior to the research onset. In addition, access to anonymized register data, personnel, and older persons was granted by the operation and area managers in the ambulance services and municipal home care services before each study commenced.

Information about the study was provided verbally and in writing to all participants prior to the individual interviews and questionnaires, and explained the study aim, handling of data material, how confidentiality was to be maintained, and that participation was voluntary and could be terminated.
at any time without having to state a reason or face any consequence. Not having to face any consequence was particularly emphasized with the older persons to reassure them regarding personal treatment and future care. All participants were provided with the opportunity to ask questions before the interviews, and contact information was provided to facilitate easy access should further questions arise. Written consent was obtained before each interview, and verbal consent for further contact was obtained after the interview in case questions arose on my part during the interview transcription. The older persons were also encouraged to contact me with any queries after the interview.

The digital recordings were transcribed verbatim by me prior to analysis. To ensure confidentiality, personal information that could possibly identify the participant, such as names or places, was removed from the transcripts. The interview transcripts were then coded, and the code key was kept at the university campus in a locked fireproof cabinet that was only accessible by me. During the research process, all processed data was password protected and stored on university servers, and only authorized persons were given access to the material. In publications, quotations are referenced with numbers or fictitious names to prevent personal identification. Fictitious names were used to maintain a personal focus and to emphasize the person behind the quotation. However, there was no resemblance between the fictitious name and the older person’s actual name.

Ethical risks and benefits had to be carefully considered in study II, due to the ongoing COVID-19 pandemic. The older persons included in study II were considered at high risk of contracting the disease and of suffering severe consequences. Due to the risk being higher than any benefit, the mode of the interview was changed from face-to-face interviews to telephone interviews. The interviews with ambulance personnel in study IV were conducted during the pandemic; however, measurements were taken to minimize the spread of the disease in line with the recommendations of the Public Health Agency of Sweden. All interviews with municipal care personnel were conducted prior to the pandemic onset.

The older persons in study II were asked to speak about a potentially traumatic ambulance care encounter that might have triggered stressful experiences. Thus I needed to demonstrate an ethical awareness during the interview involving evaluating the emotional tone of the narrative and the participant’s reactions (Orb et al., 2001). If emotional distress or other negative reactions were identified during the telephone interview and perceived as burdensome for the older person, guidance on professional support and counseling would be offered. If emotions were evoked, the older person was given time to recover and could thus set the pace of the interview. Speaking about emotional experiences can, however, also serve a therapeutic purpose that is of value for the narrator (Haynes, 2006).

In study III, the given preconditions of having to conduct the individual interviews in groups had to be considered. Confidentiality could not be
guaranteed; however, it was requested that the information shared in the se-
cluded room would not be discussed elsewhere. Another concern was that the
participants might refrain from telling the true story and keep details from each
other, since an interview might be associated with the sharing of secrets (Orb
et al., 2001). However, the participants spoke very openly about the emer-
gency situations and the group format even prompted more information to be
shared due to the participants asking each other questions, which is the ad-
vantage in dyadic interviews (Morgan et al., 2013).

Being a specialist nurse and conducting interviews involving a care context
requires reflection on the researcher role (Orb et al., 2001). All participants in
studies II, III, and IV were informed of my profession in the initially provided
information, which thus might have affected the research relationship. How-
ever, during the interviews, in an effort to convey a more ‘neutral’ researcher
role, I did not present myself as a nurse and I did not encourage discussions
involving clinical questions (Hay-Smith et al., 2016).

In study IV, my background as a specialist nurse and thus being a ‘specialist
of care’ might also have impacted the interview situation since my clinical
role offers a judging perspective over a fellow caregiver’s behavior. Thus, I
maintained continuous awareness regarding my own attitude during the inter-
view.
7 Results

This section presents the main results from the four included studies. The section concludes with a presentation of the deepened understanding developed on the basis of the included studies.

7.1 Results study I

The analysis of emergency ambulance assignments for older adults and the general adult population resulted in a pattern characteristic of the older adult group. Older adults constituted the largest portion presenting to the ambulance services, about 60% of all assignments (17,097) to people’s homes in the two-year period involved adults aged 70 years or older, the mean age being 81 years. A substantial increase in assignments was found in the 70 to 79, and 80 to 89-year intervals. Older women dominated the older adult group, representing about 54% of the assignments.

A comparison of temporal patterns between the age groups showed that the assignments for older adults increased in frequency during the daytime and particularly in the forenoon. Assignments were also more frequent during weekdays with a peak on Mondays. When comparing seasonal patterns, ambulance assignments for older adults were found most frequent during the winter months (Dec–Feb).

When investigating clinical assessments, the older adult group was found more likely to receive assessments related to circulation, respiration, trauma, infection, and nonspecific conditions. The likelihood more than doubled for respiratory, infection, and nonspecific assessments which makes these assessments particularly age specific.

An important finding was that older adults were less likely to receive the highest priority and blue light response in both dispatch priority (ambulance to patient) and transport priority (ambulance with patient to hospital). The likelihood of receiving a blue light response was decreased by 37% in dispatch priority and 26% in transport priority. The likelihood for older adults of receiving a lower priority (not life-threatening, waiting accepted) compared to the general adult group was, however, increased. The probability of receiving a dispatch priority level 2 increased by 48%, increasing to 73% for dispatch priority level 3. When comparing transport priorities, no difference was found
between the age groups in transport priority level 2, however, a 40% increased likelihood of receiving transport priority level 3 was found.

When investigating the result of the ambulance response, older adults were found to be more likely to be conveyed to the hospital. The likelihood of conveyance was increased by 79% in the older adult group compared to the general adult group. The analysis of on-scene time showed that increasing age also increased the time spent in the person’s home. However, the calculated difference in mean time between the youngest and the oldest age group was marginal and only about four and a half minutes.

7.2 Results study II

Older persons’ participation in prehospital emergency care when experiencing acute illness at home involving municipal care personnel and ambulance personnel manifests as ‘Entrusting life to professional caregivers’. Entrusting life to the responding professionals is a forced action due to one’s own powerlessness and being in a state of incapacitating illness. The manifestation of participation in care is dependent on the experienced suffering, which is characterized, to various degrees, by being stuck in space and time and involves existential uncertainty and life stagnation that cannot be mastered in solitude. Participation in prehospital emergency care means moving from insecure and helpless solitude to reassuring togetherness and safety.

Reassuring togetherness emphasizes a human connection and means being recognized, relieved, and rescued in the presence of professional caregivers. The mobile safety alarm is portrayed as a lifeline and prerequisite for a quick response when in a powerless and existentially uncertain situation characterized by emotional distress including mortal fear, indignity, helplessness, and anxiety. The presence of unhurried and committed professionals who assume responsibility for one’s life and the acute situation means being secure, and able to emotionally rest, while the presence of uninterested and hurried personnel instead induces a feeling of being abandoned and unsafe. Being with professional caregivers also includes a social dimension characterized by social coexistence and connecting as persons in a shared situation. The social connection means being recognized as a competent and equal person who shares a world and common life references with the persons present and involves being part of a team that is facing situational and ‘worldly’ challenges together.

Trusting in the professional caregivers’ competence and emergency expertise means complying with their directives. The emergency expertise includes their medical, experiential, and technical skills. Through the trust in being in safe hands, bodily access is authorized which involves complying with medical procedures and interventions even though these may sometimes be forced and painful. The goal of bodily normalization justifies unpleasantness, just as
the professionals’ honest intention to help justifies accepting compromised dignity. The professionals’ commitment and actions are continuously interpreted. Being taken seriously by unhurried, interested professionals that engage in open reasoning and collaborative care strengthen the feeling of being in safe hands.

Togetherness means access to the professional caregivers’ agency when one’s own abilities (e.g. knowledge, bodily functioning, availabilities) are insufficient. Through the efforts of professionals, opportunities for existence can be created that enable progress from stagnation toward well-being and continued living. Enabling efforts include authorized representation, practical and advisory help, as well as access to medical resources and other care levels. The efforts needed are silently or verbally agreed on and set in relation to one’s own incapability to act, which necessitates the professionals having the ability to identify and understand implicit and explicitly expressed needs. If professional caregivers fail to identify and should shoulder responsibility for agency, seeking help from friends and family may be necessary. In a lack of human agency, a final resort may be trust in divine intervention.

Entrusting one’s life to professionals also means being safely transferred through the emergency care chain. A safe transfer requires every link to be prepared and ready to care, from the first chain link manifested by the mobile safety alarm to the last link at the ED. Readiness means that all professionals in each link shoulder the transferred life responsibility and safeguard well-being and dignity by providing togetherness, agency through representation, and coordinated care.

In existential gratitude, care is accepted as provided without making demands which means that care will be accepted regardless of whether it is provided in the best interests of the person or not. Thus, ignorant and objectifying care will be accepted even at the cost of dignity and well-being.

7.3 Results study III

Municipal care personnel’s experiences of and actions in situations when older persons need EMS at home are found to relate to the overarching main areas; ‘Lifesaving competence’, ‘Collaborative care’, and ‘Adjusting to situational needs and EMS authority’.

The main area of ‘Lifesaving competence’ includes the categories ‘Emergency knowledge’, and ‘A safeguarding relationship’ describing the care personnel’s experiences when faced with an older person’s emergency involving acute illness. Care personnel describe how they try to guide the trusting older person and respond to acute needs as best they can while being challenged with limited emergency knowledge. Although efforts are made to extend the knowledge as much as possible by addressing available, but often meager informational sources such as existing documentation, relatives, colleagues, and
regional phone support, uncertain decisions about whether to call the EMS or not have to be made. In response to the older person’s suffering and vulnerability, and being emotionally triggered, care personnel adopt a safeguarding role which includes a lifesaving responsibility and thus the obligation to resolve the situation. The lifesaving responsibility remains until transferred to EMS personnel. Safeguarding entails being a soothing presence and creating a state of calming togetherness providing reassurance.

The main area of ‘Collaborative care’ includes the categories of ‘Limited care options’ and ‘Conditions for EMS collaboration’ describing the care personnel’s experiences when trying to resolve an emergency situation involving an older person’s acute illness. Finding a solution requires considering the existing care options, which basically means conveyance to the ED or not and subsequently the appropriate transport involving an ambulance, the regional transportation service\(^5\), a taxi, or the help of a relative. An ambulance is the only choice that ensures rapid and advanced care, with the capacity to handle acute as well as worsening conditions. All other choices constitute a risk for the older person’s health and involve sometimes long waiting times before access to adequate care is obtained. The lack of available care options and time impedes the care personnel’s ability to provide appropriate and timely care, which causes challenging dilemmas where workload, time constraints, acuity needs, and limited EMS resources must be considered. Lack of time also leads to emergencies having to be prioritized, which means that older persons might have to wait for the response, and although experiencing acute illness they may be refused ambulance care.

Having to rely on the EMS for an emergency response is described as having to accept the conditions for collaboration involving EMS assessments, priority, and attitude, which leads to denied, delayed, or prompt ambulance response. Although EMS contact allows the lifesaving responsibility to be transferred to EMS personnel, following their lead might involve having to obey coercive directions perceived as ethically wrong, and accept decisions on care despite these not being perceived as optimal for the older person. Upon the arrival of the ambulance personnel, collaboration is characterized by inclusion or exclusion. The ambulance personnel’s engagement in care is often shown in relation to the level of acuity, where high acuity renders professionalism and skilled leadership, and well-functioning collaboration, whereas low acuity instead might render a perceived loss of interest. The attitude of EMS personnel (ambulance dispatchers and ambulance personnel) thus determines the municipal care personnel’s ability to provide the older person with a solution, and the perceived appropriate care.

The main area of ‘Adjusting to situational needs and EMS authority’ includes the categories of ‘Adapting to emergency needs’, ‘Representing the person’, and ‘Adapting to EMS leadership’, all of which describe how the care

\(^5\) Travel service to and from health care facilities for persons unable to use public transportation.
personnel act in emergency situations. Care personnel describe how they have to adjust their actions in relation to the shifting conditions of the situation. To come to terms with situational requirements, the older person’s illness is assessed by listening to their story and observing symptoms. The assessment leads to suggesting and negotiating a measure. In recognition of the older person’s vulnerability, care personnel shoulder a representative role in contact with involved stakeholders. As representatives, care personnel function as an extension of the older person, handling practical as well as collaborative matters and thus protecting and defending the older person’s interests. Such matters involve calling relatives and other personnel, packing bags, stating ambulance needs in contact with the EMS, including questioning denied ambulance care and making repeated calls to hasten response, in addition to transferring important information to ambulance personnel on-scene. Although care personnel are the initiators of care collaboration, actions have to be adapted to EMS directives. In contact with the ambulance dispatcher, this means transforming telephone directives to actions on-scene and thus becoming the hands and eyes of the dispatcher. In contact with ambulance personnel, this in turn means enabling rapid access, providing a workspace, and being prepared if further help is needed.

7.4 Results study IV

Older persons’ participation in ambulance care in the presence of municipal care personnel from the perspective of ambulance personnel manifests in two main themes involving passive and active dimensions. The main theme ‘Balancing human dignity in relation to manipulating the body’ includes the passive dimensions ‘Providing a safe haven’ and ‘Complying with bodily expressions’. The dimensions involve respectful coexistence where responsibility for well-being and dignity is shouldered. The main theme ‘Balancing influence in relation to perceived health risks’ includes the active dimensions ‘Agreeing on a common perspective’, ‘Directing decision-making mandate’, and ‘Sharing responsibility for well-being’, which all include demands on performance. Allowing the ability to influence the situation and care decisions is based on assessed health risk, the older person’s perceived cognitive and functional ability, and the municipal care personnel’s perceived competence. Participation is a balancing act between assuming or letting go of control, manifested in a coexisting exercise and equalization of professional power. Balancing is governed by the main objective of saving the older person’s life, and involves an existential view of life that includes the whole life situation. Thus, suffering is assessed and responded to in relation to vulnerability, functional abilities, and limitations. In recognition of the older person’s suffering, vulnerability and needs, an alleviating ‘safe haven’ is provided. Providing a ‘safe haven’ involves a promise of keeping the person well and safe in respect of human
dignity by being attentive to and guided by experiences, reactions, and needs. In recognition of existential needs, professional power can be used to advocate for the older person, and thus influence both situational and future life-changing measures.

Being the leader of a temporarily composed team involves finding a common perspective that can guide care efforts and safe decisions, which includes uniting everyone present (the older person, municipal care personnel and colleague) with the joint goal of restoring the older person’s well-being. Finding a common understanding means gathering as much information about the older person as possible and fusing the different perspectives of all present. If municipal care personnel oppose clinical assessments, the effort of finding a common understanding can turn into conflict. In situations characterized by conflict, losing is accepted in recognition of the older person’s vulnerable position.

The older person’s and municipal care personnel’s influential and decision-making abilities are directed in relation to perceived cognitive ability, competence, health risks, care options, guidelines, and liability. Allowing decision-making and influence is a matter of trust and trusting the competence and abilities of all present. Having trust means being able to let go of control and thus delegate authority. A lack of trust means holding on to control and assuming decision-making power, where decisions are made based on one’s own judgment and on medical measurements.

The municipal care personnel’s behavior determines the manifestation of collaboration. Municipal care personnel perceived as committed, knowledgeable, and acting in favor of the older person are trusted collaborators, which means that responsibility for the older person’s well-being can be shared. Sharing responsibility and ‘joining forces’ means enhancing the older person’s situational possibilities and providing opportunities for creating a care solution that better aligns with the older person’s preferences. However, collaboration is also dependent on the level of acuity, and in high acuity situations, the municipal care personnel are required to step back and await instructions.
7.5 A deepened understanding of the phenomenon

Based on the knowledge provided in the four included studies, a deepened understanding of care-dependent older persons’ participation as a phenomenon in prehospital emergency care has developed. Care-dependent older persons’ participation in prehospital emergency care is an interpersonal process embracing the older persons’ whole existence. Participation in care means a forced transfer of life responsibility to create opportunities for existence, and involves a deepened dependence that necessitates coexistence and being provided with a ‘safe haven’ through the entire emergency care chain. A ‘safe haven’ can be understood as an unconditional, calm, and sheltered interpersonal space for emotional rest while going through the turbulence of existential suffering.

Life responsibility is entrusted to professional caregivers when one is powerless and incapacitated due to acute illness, where the illness poses a significant threat to life. The mobile safety alarm functions as a beacon that ensures human contact and the professional intervention needed to breach the potential deadlock. Participation in care means togetherness and coexistence, and involves a power transfer through authorization. Authorizing medical intervention and representation means accessing the power and abilities of professional caregivers who act in the older person’s best interests.

The existential suffering displayed by life stagnation provides direction for well-being and guides how to enact participation in care. Well-being can be understood as movement, which involves being released from stagnation and thus enabled to move toward continued living through the efforts of professionals. Failure by the professionals to identify and shoulder the entrusted life responsibility means that a ‘safe haven’ will not be provided, leaving the older person mired in undignified and stagnated suffering.

Figure I presents the main contribution of each study to the deepened understanding of the phenomenon presented in the center of the figure.
Statistical investigations of the ambulance care context show the conditions of the welfare service. The results indicate that older people are assigned lower priority levels compared to general adults, which means that older people do not access welfare resources on equal terms. Welfare’s responsibility for older people’s lives involves providing equal access to ambulance resources, thus also providing equal opportunities for existence.

Participation in prehospital emergency care means entrusting life to professional caregivers when one is existentially unsafe. Entrusting life involves complying with directives and bodily manipulation while placing trust in professional expertise. Opportunities for (co)existence are created in togetherness and by accessing the professionals' power, competence, and abilities throughout the emergency care chain, beginning with the mobile safety alarm.

<table>
<thead>
<tr>
<th>I</th>
<th>Participation is manifested as a ‘safe haven’ throughout the emergency care chain characterized by security, preserved dignity, and emotional rest, and involves a transfer of life responsibility to professionals who act for the older person as authorized representatives, thereby creating opportunities for (co)existence.</th>
</tr>
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<tbody>
<tr>
<td>III</td>
<td>Challenges within the municipal home care organization relate to a lack of support, care alternatives, and dependence on collaborative care. In recognition of suffering and vulnerability, responsibility for life is shouldered which includes safeguarding efforts, extending abilities, and representing the older person in contact with the EMS. Opportunities for existence are created by overcoming organizational barriers.</td>
</tr>
<tr>
<td>IV</td>
<td>Participation means providing a ‘safe haven’ that holds a promise of keeping the older person safe while preserving dignity in a vulnerable situation. Professional power is used to advocate for the older person and influence future care measures. Life responsibility is shouldered while critically assessing emergency needs and the abilities of all involved to provide the opportunities for existence needed.</td>
</tr>
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Figure 1 Knowledge contribution of each study to the deepened understanding of care-dependent older persons’ participation in prehospital emergency care
8 Discussion

8.1 Participation – the manifestation of a ‘safe haven’

Care-dependent older persons’ participation in prehospital emergency care can, in this thesis, be understood as being provided with a ‘safe haven’ while being existentially unsafe. From a lexical point of view, a ‘safe haven’ is “an officially protected place in an area of military activity, or any safe or peaceful place in a dangerous area”, “a place where you are protected from harm or danger” (Cambridge dictionary, n.d.), or “a place, a situation, or an activity which provides people with an opportunity to escape from things that they find unpleasant or worrying” (Collins dictionary, n.d.). Being existentially unsafe involves a potentially lethal threat that can only be avoided in the presence of professional caregivers and professional intervention aiming at protecting the older person and keeping that person safe from harm. The manifestation of a ‘safe haven’ allows the older person to ‘escape from danger’ and experience emotional peace and safety despite being in a potentially life-threatening situation.

The deepened understanding of participation as the manifestation of a ‘safe haven’ shares significant similarities with previous research on alleviated suffering when living with life-threatening illness, where relieved suffering is described as an embodied experience of ‘being in a lived retreat’ (Öhlén, 2000). The metaphorical space is characterized by feelings of inner peace, dignity, connectedness, and being ‘at home’ which arise when lifted out of suffering (Öhlén, 2000). From this perspective, participation in prehospital emergency care means alleviated suffering.

The most salient aspect of the ‘safe haven’ portrayed in this thesis is the transfer of life responsibility to professional caregivers, who become authorized to act in favor of the older person to create opportunities for existence. The transfer emphasizes a deepened interpersonal dependence, and the following discussion, therefore, addresses meanings of inter-personality including lifesaving togetherness, the agency through authorized representation, and maintaining safety in continuous care. The manifestation of a ‘safe haven’ is also impacted by the current welfare structure involving preconditions, boundaries, and opportunities, and the section is closed with reflections on these welfare challenges.
8.1.1 Lifesaving togetherness

Togetherness is an essential aspect of older persons’ participation in all qualitative studies (II, III, IV), and a precondition for recognition of vulnerability, and needs as well as for life itself. The togetherness shown in the studies can be understood as the professional caregivers temporarily entering into the older person’s lifeworld, sharing the older person’s ‘living space’ and life situation (Galvin & Todres, 2013). Only in togetherness can the life responsibility that needs to be transferred by the older person be recognized. In studies III and IV, both municipal care personnel and ambulance personnel shouldered responsibility for the older person’s life, shown by safeguarding, acting as a representative, and using the available means and mandate to assist the older person in the best way possible. From a philosophical standpoint, shouldering responsibility for another person’s life means responding to an ethical obligation (Løgstrup, 1956/1992), a silent demand arising from seeing the vulnerability of a person’s ‘face’ (Lévinas et al., 1985/1993). The togetherness displayed in the studies (II, III, IV) aligns with Holopainen and colleagues’ (2014) reasoning of togetherness as being in mutual existence in a shared space characterized by genuine presence. Genuine presence means to recognize, be concerned, and be available, all of which convey a sense of communication that is felt by the other person (Holopainen et al., 2014).

An interesting aspect related to the professionals shouldering of life responsibility and keeping the older person safe is that this process is described in study III (municipal care personnel) as an ‘obligation’, but in study IV (ambulance personnel) as a ‘promise’, which implies different professional possibilities. A promise to keep someone safe includes having the possibility to fulfill that promise, while an obligation might include challenges that compromise the effort. Thus, ambulance personnel can shoulder life responsibility, while municipal care personnel can only try their best, which emphasizes the ambulance personnel’s overarching responsibility for the older person’s life and well-being.

In studies II, III, and IV, togetherness manifested as a passive dimension honoring dignity, and as something that must be provided since it demands more than just physical presence. Thus, togetherness is the result of an intended act, an intended emotional involvement on the professional caregivers’ part, which is sparked by an emotional trigger. That trigger can be understood as the professional caregivers recognizing the older person’s need to transfer life responsibility. Thus, successful togetherness honors human dignity, in line with a humanizing, open-hearted, and reflective care practice (Todres et al., 2014; Todres et al., 2009). Togetherness can thus be considered the start of the older person’s healing process, the start of a movement toward restored well-being. When considering togetherness as healing, the role of the professional caregivers involved in the prehospital emergency care encounter is accentuated. Gadamer (1993/1996) views healing as an art that involves a
complex use of self. In studies II, III, and IV, providing togetherness, and thus a ‘safe haven’ aligns with such complex use of self, where the professional caregivers engage both personally and professionally. Such personal and professional intertwining, being involved as a fellow human with a professional agenda, has been found in previous research to be an indicator of a caring relationship in prehospital emergency care (Holmberg et al., 2016).

However, togetherness requires anticipation and patience (Todres et al., 2014), and the ‘safe haven’ can easily become unsafe and alienating if the older person is subjected to the efficient and ignorant attitudes of professional caregivers, incapable of recognizing the older person’s needs for transferring life responsibility. The results of study II showed how older persons felt ignored, objectified, and abandoned when encountering uninterested or stressed professionals who focused on appearance rather than experience. Being unworthy of care, or just being treated as a package in transition, is an existential violation that increases suffering. According to caring science theory, suffering can be understood as ‘dying’ (Eriksson, 2018). Being objectified in an efficient or ignorant care practice can thus be viewed as annihilating since the unique human becomes non-existent. Gadamer (1993/1996) also points out that the memory of care will linger, which might affect the older person’s perception of the self, and subsequently how to act when experiencing acute illness in the future.

If not recognized in togetherness, there is a risk that the life responsibility that needs to be transferred will not be identified. The inability of professional caregivers to identify the older person’s needs increases the risk of them taking over life responsibility rather than accepting what is to be given, and thus subjectively deciding what needs to be done, which leads to paternalistic and ignorant care that compromises autonomy (Sandman & Munthe, 2010), and dignity (Todres et al., 2014). The results of study II showed how older persons will accept care as it is provided in the moment, which further emphasizes the importance of professional caregivers’ engagement and their active searching for the older person’s needs. The appearance of professional caregivers as unengaged and uninterested might be an expression of ageism, where individual recognition is lacking in favor of stereotypical attitudes related to older people being a homogenous and burdensome group (Pritchard-Jones, 2017), that misuses ambulance resources (Horibata & Takemura, 2015).

8.1.2 Agency through authorized representation

Another essential aspect of care-dependent older persons’ participation is the professional caregivers’ representative role (II, III, IV), which can be understood as the professionals shouldering and responding to the entrusted life responsibility. In recognition of the older person’s suffering, vulnerability, and inability to act, the professional caregivers take on the role of a representative, which involves doing what the older person cannot do him/herself. As
representatives, professional caregivers defend and protect the older person’s well-being. This is shown in study III as the care personnel provide support in calling the ambulance, defending the older person’s right to emergency care, preparing for emergency care, packing bags, cleaning up, and contacting relatives and others that help the older person. In study IV, the ambulance personnel similarly adopt a sheltering stance, and advocate for the older person in contact with other professional caregivers to influence both situational and future care in order to benefit the older person’s well-being. Thus, older persons are given the ability to act and become active agents through representatives. Previous research similarly emphasizes older persons’ ‘ability to act’ as essential for experiencing participation, autonomy, and self-esteem (Hedman et al., 2015).

Older persons’ need for representatives acting for their benefit has been highlighted in previous research, and is a responsibility often shouldered by a relative (Abu Al Hamayel et al., 2018; Nyborg et al., 2016). Under acute conditions in the context of living in care-dependence at home, which is the focus of this thesis, the representative role transfers to professional caregivers. In study II, the older persons’ narratives included the presence of significant others, but they were not assigned a representing role due to their perceived lack of knowledge. Thus, trust is key when experiencing acute illness at home. Professional caregivers’ authority is seldom questioned (WHO, 2013), emphasizing the ethical obligation to act in favor of the care-dependent older person.

The amount of transferred life responsibility also guides the amount of representation needed. However, if the life responsibility that needs to be transferred is not identified, the professional caregivers risk acting according to their own beliefs and not for the benefit of the older person. Such misplaced or forced representation risks belittling the older person’s competence and autonomy. Although intentions are good, misplaced and forced representation might be an expression of ageism involving negative stereotyping of abilities due to age (Kagan, 2018; Pritchard-Jones, 2017). A collective view of older persons as incapable and needing help risks turning care into parental behavior, where the older person (unreflectively) is treated like a child (Kagan, 2018). Pritchard-Jones (2017) states that autonomy is relational, and therefore positively or negatively impacted by the attitudes of professional caregivers. The relational aspect of autonomy is further emphasized by the fact that older persons’ decision-making is two-fold; making the decision, and being provided with help in executing the decision (Pritchard-Jones, 2017). In this thesis, the older persons’ decision-making can be understood as concerning the decision on how much life responsibility needs to be transferred. As representatives, the professional caregivers then execute that decision, as in shouldering the given life responsibility. In study IV, ambulance personnel were found to subjectively assess the cognitive ability of older persons, and based on the assessment, allow decision-making or not. Such subjective assessments
risk becoming ageist judging and thus lead to misplaced representation, even if made with respect for the older person.

In studies III and IV, the professionals’ shoudering of life responsibility and becoming a representative involved acting in respect of and protecting the older person’s life and dignity without demands. If the life responsibility, and subsequently the representative role is not shouldered, the professional caregivers risk becoming ‘judges’, who question and pass judgment in relation to the older person’s ability to ‘state one’s case’. Being questioned and metaphorically ‘put on trial’ means being abandoned, isolated, and not worthy of care, which questions identity and compromises human dignity (Todres et al., 2009).

In the ethical reasoning by Davy (2019) involving autonomy, dependency, and disability, the concept of relational autonomy and representation is raised. Although set in a context involving intellectual disability, the reasoning also applies to the context of care-dependent older persons and situations involving acute illness, where the articulation of needs might be difficult due to acute suffering. The author argues that autonomy and care presuppose one another and that neither can be enabled without the other. Thus, if the preferences, interests, and experiences of a person are to be made public, they have to be represented by professional caregivers. However, speaking for another might be mediated by the biases of the speaker, such as context, position, and privilege. Therefore, the author suggests ‘speaking with’ in a temporarily joint voice, which emphasizes the ethical dimension. However, all representation is situated in a context of power and therefore requires engaged representatives capable of interpreting, translating, communicating, and advocating needs (Davy, 2019). Being capable of interpreting correctly also emphasizes a need to know the person, which is shown in studies III and IV by the professionals’ efforts to gather as much information as possible. Previous research similarly emphasizes the importance of knowing the older person, which is portrayed as key to providing care in respect of preferences and needs (Ekstedt et al., 2022; Strømme et al., 2020; Sundström et al., 2019).

8.1.3 Maintaining safety in continuous care

Being safe in continuous care can be understood as the ‘safe haven’ being maintained throughout the emergency care chain, which means that the life responsibility must be transferred to and shouldered by all professional caregivers involved in the ‘rescue mission’. The concept of continuity in care can be defined as the experience of linked and coherent care provided over time, and includes relations with professional caregivers, information, and management (Reid et al., 2002). However, the results of all the studies (I, II, III, IV) showed deficiencies in the organizational structure of the ‘early chain of health care’ responding to care-dependent older persons’ emergency needs. Currently, a mobile safety alarm-initiated emergency response might involve
contact with five different groups of personnel (a mobile safety alarm operator, municipal care personnel, an ambulance dispatcher, ambulance personnel, ED personnel) with different affiliations and educational levels, in addition to two care transfers (care personnel/ambulance personnel, ambulance personnel/ED personnel) which underlines the importance of well-functioning collaboration under critical conditions.

Studies I, III, and IV all showed challenges related to continuous care that significantly impact older person’s participation in care, health outcome, and well-being. Study I provided statistical knowledge that older persons are systematically subjected to lower priority assessments compared to the general adult population, which can be an indicator of organizational age discrimination at play (Pritchard-Jones, 2017). Receiving a lower priority implies unequal access to ambulance and emergency care resources and subsequently longer waiting times before receiving adequate care. Restrained access to ambulance care is further elucidated in study III by the municipal care personnel’s descriptions of sometimes having to make repeated 112 calls and ‘fight’ for an ambulance. Studies III and IV also revealed the consequences of unstructured collaboration between municipal care personnel and ambulance personnel during the first care transfer, increasing the risk of collaboration breakdown and conflict. Study II additionally revealed the importance of the readiness of the ED to maintain a feeling of safety. Previous research similarly stresses the importance of maintaining trust throughout the health care chain, a trust that needs to be restored in every link in the chain facilitated by feeling welcome (Norberg Boysen et al., 2017). In this thesis, such ‘welcoming’ might be seen as a sign of the professional caregiver’s recognition and shoul-dering of life responsibility.

The results in study III revealing how municipal care personnel sometimes have to struggle to get an ambulance, points to the salient role of the ambulance dispatcher in assessing ambulance needs and directing ambulance resources. Research on ambulance dispatch nurses’ decision-making shows a complex and challenging context involving assessing without seeing, fear of making faulty decisions, mandatory guidelines to follow, and conflicts due to differing perspectives (Ek & Svedlund, 2015). The accuracy of medical dispatching systems is also disputed, leading to both over- (unnecessary dispatching) and under-triage (lack of necessary dispatching) (Bohm & Kurland, 2018).

Studies III and IV showed how the current lack of structured collaboration between care organizations in care transfer processes fragments care. A problem with the current organizational structure dividing everyday care and acute care is that care-dependent older persons living at home are considered independent. Although dependent on care for daily life, when acute illness arises, older persons have to follow the same emergency care procedure as the general adult population and are thus referred to the same emergency resources. Under the influence of acute illness, the care-dependent older person is thus
expected to be able to perform an activity without support (since acute illness is not the responsibility of the municipality) where 112 must be telephoned, the emergency need accounted for, and if an ambulance is denied because the need is not deemed life-threatening, the older person must also ensure their own transport to the ED if they need to see a physician. The situation resembles a ‘Catch 22 situation’. In daily life, care-dependent older persons are recognized as unable to cope on their own, but under the influence of acute illness with potential danger to life, they are nevertheless expected to cope. Such rigid care systems also increase the risk of feeling objectified and insignificant (Boye et al., 2021).

Maintaining safety in continuous care also involves the care transfer at the ED. However, the care transfer between ambulance personnel and ED personnel is subject to deficiencies, which risks making the transfer unsafe. An Icelandic study report clarified responsibility, structured communication, and teamwork as key in the ED care transfer (Dúason et al., 2021). However, confusion exists regarding how, and when the patient responsibility (read life responsibility) should be transferred, and whether the responsibility is moral or legal (Dúason et al., 2021). In addition, all personnel involved in the transfer are perceived as responsible for the process itself, but only one (often a physician) shoulders responsibility (read life responsibility) for the patient. Stress and the hierarchy among personnel further complicate the transfer process (Dúason et al., 2021). The results of study III also showed the older persons’ perceived reluctance to ED conveyance due to previous negative experiences. Research into older persons’ experiences of ED care emphasizes the relational aspects of care that support dignity, involving being seen, heard, and included (Bridges et al., 2010), although the opposite might be more common. The level of individualized care in the ED varies greatly, and processes are fragmented (Petry et al., 2019). Dissatisfaction with ED care is often due to powerlessness, lack of control, and lack of information (Forsgårde et al., 2016).

Older persons describe experiencing continuity in care during care transfers when understanding the care decisions and actions, feeling involved and in control, and having fulfilled expectations and individually adapted care (Boye et al., 2021). However, care transfer experiences often involve objectification, alienation, improper solutions, and lack of communication (Boye et al., 2021). The current organizational structure in Sweden involving medically focused care objectives, lack of care options, and lack of structured inter-organizational collaboration, impedes participation in care. Trust, understanding of roles, and scope of action, along with a joint notion that working together will optimize care are fundamental in collaborative care involving older persons, and organizational support is key (Bookey-Bassett et al., 2017). The results of studies III and IV showed how the professional caregivers involved in care transfers are left to resolve the situations themselves, increasing the risk of hierarchical conflict that is counterproductive to qualitative care that promotes practicing participation in care. The older persons thus risk being subjected to
professionals with different agendas protecting disciplinary boundaries, leading to fragmented care (Montano, 2019), where the responsibility for life becomes lost.

8.2 Providing a ‘safe haven’ – welfare challenges

The knowledge provided in this thesis points to several welfare challenges related to care-dependent older persons’ emergency needs and the provision of a ‘safe haven’.

8.2.1 The split welfare responsibility

One major welfare challenge is the current split responsibility for older people’s care, separating everyday care needs and emergency care needs. Splitting the responsibility between welfare levels and organizations might work on a rhetorical level but the studies included in this thesis provide evidence that the split in practice constitutes a health risk for care-dependent older people, involving risks of faulty care decisions, delayed care, collaboration breakdowns, and lack of appropriate care options. The Swedish government addresses some of the problems in the ongoing reformation toward ‘good quality, local health care’ (SOU 2020:19). However, the focus of the stated reform is preventive measures and health promotion, which means that older peoples’ emergency care needs still represent an urgent matter to address. The welfare challenge is accentuated by the care-dependent older persons’ extended view of the prehospital emergency care chain, which transcends organizational boundaries, as shown in study II. The use of the mobile safety alarm service as the first link in the prehospital emergency care chain must be recognized to ensure care-dependent older people receive safe care when acutely ill.

8.2.2 The unequal distribution of ambulance resources

The systematic assigning of lower priority levels for older adults shown in study I is another problem that must be addressed. Lower priority levels include a risk of having to wait for ambulance response and emergency care, which impact health outcomes. Thus, the welfare responsibility to provide resources on equal terms for all (Lundberg, 2018) is not fulfilled. The COVID-19 pandemic further highlighted the (lack of) welfare responsibility for older people. The Swedish strategy involved prioritizing younger people for hospital care and, as a consequence, more older people were denied crucial hospital care with mortal outcomes (Lindström, 2021).
8.2.3 The municipalities’ lack of emergency care readiness

The current organizational lack of requirements for specific emergency care skills and qualifications of municipal care personnel combined with a lack of medical support within the municipal home care organization is another challenge, as shown in study III. In practice, this means that responsibility for assessments of whether ambulance care is needed or not is placed on assistant nurses or even personnel without any formal training, who have to make emergency care decisions without adequate competence or organizational support. A government resolution is adopted to regulate what educational competence is needed for acquiring the professional title ‘assistant nurse’. However, directives regarding what specific skills are needed only include upper secondary school level education in care, Swedish, and social studies (HSLF-FS 2023:14). Older persons’ acute illnesses are often difficult to identify even for a physician and symptoms can be masked by concurrent conditions like cognitive decline, multiple chronic conditions, natural bodily aging, or polypharmacy (Shenvi & Platts-Mills, 2019).

Study I showed that distinguishing clinical assessments for older adults presented to the ambulance services involved circulatory, nonspecific, and respiratory conditions, infection, and trauma, which are all serious conditions that require medical attendance and advanced care. Nonspecific conditions, in particular, constitute a challenge when it comes to assessing the level of severity, due to being an ‘unclear problem’ (Otten et al., 2022). Ivic and colleagues found that of the adults included in their study (median age 77 years) and presenting to the EMS with a nonspecific condition, more than 30% had a more serious underlying condition which increased the probability of both hospitalization and death (Ivic et al., 2020). In municipal home care services, assistant nurses and care assistants without any formal training are the first on-scene when older persons become acutely ill, and they have to assess the situation and decide the proper response for the acutely ill person without support, as shown in study III. The older persons’ extended perspective on pre-hospital emergency care involving the mobile safety alarm further accentuates the problem since the older persons greatly rely on the safety alarm service, as shown in study II. This is highly problematic and constitutes a severe health risk for care-dependent older persons required to age in place by welfare policy.

The analysis of temporal patterns in study I also revealed that ambulance assignments are more frequent on weekdays, especially on Mondays and in the morning. The increased frequency on weekdays indicates the important role of municipal care personnel as well as their exposure to older person’s acute illnesses when conducting visits during the daytime. The increased frequency on Mondays is interesting and one might speculate that the increase relates to fewer home care visits during the weekend in addition to more
temporary personnel, both of which might prevent the detection of emergency care needs.

8.2.4 The lack of adapted emergency care alternatives

The current lack of care options for acutely ill older persons is another pressing challenge that must be addressed. Study I showed that almost 90% of ambulance assignments for older adults result in hospital conveyance. The lack of options not only makes existing options coercive but also constitutes a health risk. In Sweden, hospital conveyance and ED attendance is the predominant care option when acutely ill. A Swedish governmental report state that older persons aged 80 years or older have the longest stays in the EDs, and on a diurnal average, 88 older persons stay more than nine hours at the ED (The National Board of Health and Welfare, 2022b). Long waiting times at the ED are often the result of a lack of available beds in hospital wards. During the past two decades, Swedish hospital bed capacity has decreased substantially in all regions, which researchers have found to negatively impact population mortality (Siverskog & Henriksson, 2022).

Old age is commonly associated with longer waiting times at the ED (Bunn et al., 2019; Maynou et al., 2023). ED attendance is also known to involve an increased risk of developing pressure ulcers (Dugaret et al., 2014), and delirium (Giroux et al., 2021) as well as for missed diagnoses (Hwang & Morrison, 2007), and inadequate care (Regen et al., 2022). Criticism of Swedish hospital emergency care is also presented in a report by the Swedish Health and Social Care Inspectorate (Inspektionen för vård och omsorg, IVO, 2023). According to the report, patient safety cannot be guaranteed due to long waiting times, missed drug administration, lack of medical monitoring based on needs, and inadequate care involving nutrition, basic hygiene, and fluid intake. The report also notes that the Swedish regions have cut bed capacity without ensuring that care can be provided elsewhere in the healthcare system and that the outplacement of care is moving too slowly.

Due to the ongoing and dramatic increase in the aged population, care-dependent older people’s specific emergency care needs must be addressed. As shown in study I, about 60% of ambulance assignments to people’s homes involve older adults, a number that will increase in step with the population increase. In addition, the majority of assignments for older adults involved priority level 2 assessments, which indicate critical conditions that need advanced care but not necessarily at a hospital. Finnish research concludes that EMS must be redesigned to meet future challenges, a process which would involve changing the current focus on critical and high acuity patient groups to less critical groups, such as older people, with low acuity care needs (Paulin et al., 2020). Changing the focus places greater emphasis on treatment at home, which means the older person’s own home will become a more important arena for emergency care in the future.
8.3 Methodological considerations

In line with the proposal and reasoning regarding the evaluation of qualitative research by Lincoln and Guba (1985), the methodological considerations will concern the research project’s trustworthiness. Although trustworthiness can never be completely assured, it is strengthened by openness to possible bias. Therefore, the overall design and possible bias in relation to the participants and sample, and the data collection and analyses will be addressed in the following.

8.3.1 The overall design

The overall design of this research project involved completing a puzzle, where each study constituted a piece of contributing knowledge that deepened the understanding of the phenomenon of participation in care in the prehospital emergency care context. According to Lincoln and Guba (1985), the credibility of research is strengthened by triangulation. Thus, the design involved conducting high-quality research by finding the right pieces to triangulate the phenomenon. The task of phenomenological research is “to construct a possible interpretation of the nature of a certain human experience” (van Manen, 1997, p. 41). Studies I and III can, however, be questioned as rightful components of a phenomenological research project, study I being a statistical exploration and study III being a critical incident study without clear ontology, epistemology, or even methodology, and with little relation (or none, some could argue) to phenomenology. However, both studies I and III were considered important components by placing the lived experience in studies II and IV in a welfare context. Study I showed the characteristics of ambulance assignments for older adults and the actual conditions the professionals must face in their line of work. The critical incident study (III) provided knowledge about contextual challenges related to care-dependent older persons’ acute illness and how the challenges are experienced and handled by the municipal care personnel who are first on-scene. Both studies were thus considered important contributors that added welfare perspectives that enabled a deepened understanding of the phenomenon of participation in care from a lifeworld perspective. This design offers one way of illuminating the phenomenon, although other designs are conceivable. The current design was, however, considered relevant and plausible within the frame of research education.

8.3.2 Participants and sample

The register data used in study I comprised all ambulance assignments performed by the ambulance service in the region over a two-year period. The two-year period was chosen to ensure a large enough sample size and thus statistical rigor. The final sample comprised all dyadic staffed primary
emergency ambulance assignments to private homes involving adults (>18 years), stratified into two age groups (18–69, >70) to allow between-group comparison and the ability to investigate distinguishing patterns characterizing assignments for older adults.

Ambulance responses by single responders (single-staffed ambulance vehicles) were not included in the sample due to a risk of faulty data. All ambulance assignments are recorded separately, which means that a response to one unique person is recorded as two assignments if both a single responder and an emergency ambulance are dispatched, thus producing inconsistency in the data. The accuracy of the data also greatly relies on correct entries being made in clinical records by the ambulance personnel. Incorrect entries, such as negative on-scene time, or missing entries lead to exclusion, which affects the sample size and analysis.

Another limitation in study I was the inability to cross-reference regional and municipal records to enable the identification of ambulance assignments involving older adults utilizing municipal home care services. Such cross-referencing would have enabled targeting of the group in focus in this thesis. However, the total population sample was deemed appropriate for the overall design, producing important data in relation to age.

The participants in studies II, III, and IV were purposively selected based on them having first-hand experience of the phenomenon (Streubert & Carpenter, 2011). The selection of participants took account of their various perspectives of the same phenomenon which enhances credibility (Rubin & Rubin, 2005). However, some challenges arose in the process of recruiting participants for studies II and III. The recruitment process in study II lasted nearly two years, resulting in only 11 interviews. Between March 2020 and January 2022, 93 recruitment letters were sent with the assistance of the municipal home care organization. Of those receiving recruitment letters, 16 participants declined participation by returning the enclosed reply letter. Of the declining participants, eight reported reasons for not wanting to participate. Reasons for declining participation were admittance to a nursing home, lack of memory recall, loss of hearing that hindered interview by telephone, lack of strength, and already having participated in other research projects. One participant who returned a written consent was later excluded due to not remembering signing the consent. Poor health and feeling too old and tired are salient barriers to engaging in research activities making this particular group of people difficult to reach (Liljas et al., 2017). Another limitation of the recruitment process was that the information letter was only provided in the Swedish language, which excluded the recruitment of older people who could not read Swedish. Translated material might therefore have facilitated the recruitment process.

Recruiting municipal home care personnel providing planned assistance in study III was also found challenging. Although information about the study was provided face-to-face at workplace meetings in several home care
districts, no personnel expressed interest in participating in an interview. The reluctance to participate demanded a new approach. The new approach involved launching an anonymous online questionnaire. This approach was fruitful, and after presenting the online questionnaire at a workplace meeting in a new home care district, three personnel accepted participation. Being able to maintain anonymity, and answering the questionnaire at any chosen time might have been the successful facilitators.

The design of this research project included triangulation of the phenomenon based on the perspectives of older persons, municipal care personnel, and ambulance personnel. However, studies I and II both revealed substantial impact of the EMCC and the ambulance dispatchers. Interviewing EMCC personnel would have been beneficial to show a more comprehensive picture of the prehospital emergency care chain.

8.3.3 Data collection and analyses

To ensure the correct handling of the vast dataset in study I, a professor in psychiatric research with longstanding statistical expertise at the Center for Clinical Research Västerås was temporarily linked to the project in the role of a statistical consultant. The study design, variables, and analyses were discussed and developed under the supervision of the consultant professor. The analyses involving the one-sample $\chi^2$ test, one-way analysis of variance, and binary logistic regression were deemed appropriate for investigating group differences, and were in line with the aim of study I.

In phenomenological interviewing, the goal is to achieve an open, and reflective dialog, allowing the researcher to tune in to the interviewee’s lifeworld voice (Dahlberg, 2008). Lived experience denotes the non-reflective dimension of human life, of which we are unaware until it is reflected upon (van Manen, 1997). During the interviews with both ambulance personnel (IV) and municipal care personnel (III), they reflected on their behavior, which led them to even question themselves, asking questions such as “Why do I do that?” Such reflections signal lived experience, and the phenomenon is brought to light (Dahlberg, 2008).

As a researcher, I too bring my own lifeworld into the interview, and it is essential that it is not my lifeworld that is voiced. As a researcher, I share an interest in the phenomenon, but my lifeworld must be silent. Although the intention was to be as objective as possible during the interviews conducted in studies III and IV, I occasionally became emotionally provoked, which could impact the quality of the interview (Rubin & Rubin, 2005). Such provocation might be seen as a breach of my own lifeworld voice, resulting in my own judgments of right and wrong, and turning the focus onto the interviewed person rather than the phenomenon. Such judging clouds the understanding of the interviewee’s lived experience and the phenomenon. Clarification of personal bias, such as writing down one’s own beliefs and possible judging
attitude allows a more open and honest approach in both data collection and analysis (Streubert & Carpenter, 2011). To avoid clouding the interviews and keep the focus on the phenomenon, my own beliefs and reactions were made clear and reflected on in writing and dialog with supervisors. Thus, I could recognize them and I was better able to control them during the interviews.

Due to the COVID-19 pandemic, the data collection in study II had to be done by telephone to avoid risk to the participants. Although the health risk outweighs any concern regarding the mode of data collection, considerable limitations exist. Interviews by telephone were not optimal, especially since several potential participants stated loss of hearing as a reason for not participating in the study. The interviews were conducted using cell phone speaker mode, and the recording was carried out using separate sound recording devices. The setup was not optimal for noise reduction, and participants’ hoarseness and dialect resulted in some words being inaudible and therefore lost in transcription.

Significant drawbacks when conducting telephone interviews are the absence of body language, such as physically expressed cues, and that interviews are often kept short, which risks producing poor data (Lechuga, 2012). The interviews in study II, however, provided very rich data despite being conducted over the telephone. The participants openly narrated their experiences, and the interview duration (17–120 min) might be considered equal to the length of face-to-face interviews. According to Lechuga (2012), sensitive information might even be easier to share in a telephone interview due to the anonymous character of the conversation. The focus on care in a critical life situation involved a risk of invoking traumatic memories causing negative reactions and distress. No negative reactions were identified during the interview. Due to the absence of body language and therefore having to rely solely on verbal cues or explicit requests, there is a substantial risk for missed reactions. However, researchers suggest that the telephone mode is a particular advantage when interviewing persons subjected to trauma since it allows for emotional distancing (Mealer & Jones, 2014). The telephone mode can also ameliorate the power asymmetry between interviewer and interviewee, and narrating a trauma is known to have therapeutic effects in having someone who listens which facilitate being heard and understood (Mealer & Jones, 2014). My hope is that such a therapeutic effect can outweigh the risk of having missed negative cues.

The qualitative interview shares similarities with day-to-day conversations, apart from the researcher taking on a guiding role by listening to the answer and thus determining the direction of the subsequent question (Rubin & Rubin, 2005). The interviews in study II were not intentionally carried out as day-to-day conversations, but they rather quickly developed into day-to-day conversations, since the approach was found to stimulate the narratives. Conducting a qualitative interview requires skills, which in turn require practice (Rubin & Rubin, 2005). Since the data collection of study II lasted about two years, the
interviews developed over time, and the length of the interview increased as my confidence as a researcher and my interviewing skills increased.

The data in study III was originally intended to only be collected through individual interviews. However, the data collection had to be adapted to contextual conditions and therefore developed into two different data collection modes consisting of individual interviews performed in the presence of two or three colleagues, and an online questionnaire. A pragmatic stance had to be adopted which meant making the best of the given preconditions. Narrating a critical situation and how it is handled in the presence of colleagues raises questions about the accuracy and whether the interviewee dares to speak the truth. For example, critique against others’ behavior is usually avoided in joint interviews where the interviewees know each other (Polit & Beck, 2004). Criticism against the behavior of colleagues was lacking during the interviews, however, critique against their own behavior was sometimes expressed. Self-criticism might be seen as a sign of being comfortable narrating in the presence of colleagues. The joint interview mode, however, was found beneficial in terms of data collection since it stimulated more incidents being told. Several of the participants had their memory triggered by the narratives of the others and could therefore account for additional incidents. Another benefit of conducting the individual interview in the presence of colleagues was that it facilitated them asking each other questions based on contextual knowledge, shared experiences, or pure interest. The participants thus became co-interviewers, which aided the data generation and enriched the narratives. Such interaction between the participants is an emphasized benefit of dyadic interviewing (Morgan et al., 2013).

Although several advantages exist regarding questionnaires including preserved anonymity, time-effective execution, and prevention of interviewer bias, questionnaires are known to produce lesser data (Polit & Beck, 2004). In contrast to the interviews where each participant often narrated several incidents, the respondents of the questionnaires only described one incident although encouraged to describe more. The written descriptions of critical incidents were also kept short, which is a dilemma when using open-ended questions in questionnaires (Polit & Beck, 2004). However, the written descriptions provided important data that aided the analysis process.

Another difficulty relates to my role as a novice researcher in combination with being an experienced specialist nurse. Combining the two roles occasionally posed a dilemma in the interview situations, especially when interviewing older persons in study II. All participants in all studies were informed of my professional role as a registered nurse, and some of the older persons assumed a patient role during the interview. The switch from a researcher/interviewee relationship to a nurse/patient relationship became evident when being asked for medical advice during the interview, or when an older person replied “But you know that already”, or “What do you think about that?” implying awareness of my knowledge as a nurse. This was challenging, especially when older
persons expressed dilemmas in care which I as a nurse am supposed to act upon. Thus, there was a struggle to remain neutral during the interview, and to avoid appearing as a nurse.

One of many challenges in conducting qualitative research is how to control your own preunderstanding as not to carelessly jump to conclusions during analysis (Dahlberg, 2008). With reference to existential philosophy, Dahlberg and Dahlberg (2019) emphasize how the researcher is always directed to textual meaning, which means always having an initial understanding and therefore anticipating what the text will disclose. The challenge lies in allowing what has already been understood to evolve into new understanding. Remaining open to the text is described as one of the researcher’s huge responsibilities and involves raised self-awareness and questioning, such as ‘What do I understand’, ‘Why do I understand it like this’, and ‘Can I understand it in another way’ (Dahlberg & Dahlberg, 2019). During analyses, initial preunderstandings were written down, reflected upon, and subjected to constant questioning by me as well as my supervisors as the analysis process evolved. In the phenomenological hermeneutical analysis method used in studies II and IV, preunderstanding is used in a deliberate but controlled way. Lindseth and Norberg (2022) even describe preunderstanding as a “necessary condition to be able to think of it [the phenomenon] and to investigate it more thoroughly” (p. 884). From this perspective, the own preunderstanding is used as a tool for identifying the phenomenon in the text. Preunderstanding in this respect is, however, not ‘random knowledge’ but derived from research literature, discussions with supervisors and peers, and in my case, clinical practice as an operating room nurse. In line with the reasoning of Lindseth and Norberg (2004) and the prerequisites of this research project, this thesis offers one plausible way of understanding the phenomenon of participation in care, although other interpretations may exist.
9 Conclusion and clinical implications

Care-dependent older persons’ participation in prehospital emergency care means a deepened dependence that involves a forced transfer of life responsibility to the responding professionals, thereby accessing their power, competence, and abilities to create opportunities for existence. The transfer of life responsibility emphasizes coexistence and being provided with a ‘safe haven’ through the entire emergency care chain involving coordinated and continuous care. A ‘safe haven’ can be understood as an unconditional, calm, and sheltered interpersonal space for emotional rest while going through the turbulence of existential suffering. The included studies demonstrate that participation in care is an existential phenomenon that requires comprehensive understanding. Participation in prehospital emergency care is highly ethical, which emphasizes the professionals’ competence and ability to shoulder responsibility for the older person’s life. The municipal home care and regional prehospital emergency care organizations involved need to adapt services to promote a ‘safe haven’ and help their professionals to practice participation in care based on a comprehensive understanding of the concept. Based on the knowledge provided in this thesis, the following implications are suggested:

On a personal level, participation in care means recognition of:

- The existential dimension, which means being entrusted with an older person’s life emphasizing a deepened dependence.
- The older person’s need to access professional power, competence, abilities, and resources, which means being an authorized representative who acts in the older person’s best interest.
- The social dimension of the care encounter, which means connecting on a personal level through sharing common life references and facing challenges together.

On a collaborative level, participation in care is promoted by:

- Joining forces in order to optimize emergency care efforts.
- Recognizing the professionals involved as equally authorized representatives, despite different perspectives.
• Recognizing the ambulance personnel’s overarching responsibility for accomplishing collaborative care.

On an organizational level, fulfilling welfare incentives regarding participation in care requires the involved organization to:

• Recognize older persons’ extended perspective of the prehospital emergency care chain and use of the mobile safety alarm as the first link.
• Recognize the older person’s home as an arena of growing importance for emergency care, emphasizing inter-organizational collaboration.
• Recognize and address the collaborative challenges that currently exist to optimize care efforts when older persons experience acute illness at home.
• Ensure that all professionals involved have appropriate competence, means, and support to handle complex situations involving older persons’ acute illness, to promote safe care.
• Recognize the importance of continuous and coordinated care for acutely ill older persons.
• Provide care alternatives adapted to older persons’ various emergency needs.
• Support professionals in enacting participation in care based on an existential understanding of the concept.

9.1 Future research

The studies included in this research project revealed important aspects of prehospital emergency care that need further research attention to ensure qualitative care for care-dependent older persons experiencing acute illness at home. Further research needs to focus on:

• The frequency of situations involving acute illness handled by municipal care personnel to reveal their exposure to emergency care needs.
• The mobile safety alarm operators, who become key figures when older persons experience acute illness at home. Research is needed to raise awareness of the mobile safety alarm operator’s role in emergencies, and the operator’s impact on older persons’ safety, health, and well-being.
• The EMCC personnel’s systematic assignment of lower priority levels for older people and underlying causes.
• The interaction and collaboration by telephone between municipal care personnel and EMCC personnel to promote collaborative care in critical situations.
• Interventions targeting inter-organizational prehospital emergency care collaboration involving municipal care personnel and ambulance personnel to promote the quality of care and optimize care efforts.
• The experiences of spouses, partners, or relatives present during pre-hospital emergency care for care-dependent older persons as they are part of a possibly dramatic and life-changing event.
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