Being taken seriously. Person-centredness and person-centred climate as experienced by patients and significant others when the patient is assessed as non-urgent by the Swedish Ambulance Service

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Being taken seriously

Person-centredness and person-centred climate as experienced by patients and significant others when the patient is assessed as non-urgent by the Swedish Ambulance Service

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Den tunna tråden mellan vitt och svart
Den tunna tråden mellan dag och natt
Den tunna tråden mellan att finnas eller ett stort ingenting

Peter Lemarc

Contents

Abstract

Background

The experience of person-centeredness and person-centred climate is poorly understood in the context of being assessed as non-urgent and, in many cases, left at home by the Ambulance Service.

Aim

The overall objective of this thesis was to explore experiences of person-centredness and the person-centred climate among patients and significant others when patients were assessed as non-urgent by the Swedish Ambulance Service.

Methods

Both an inductive and deductive approach has been used in combination with qualitative and quantitative research methods.

The study group consisted of I) 12 patients and II) 111 patients who were considered non-urgent and thus recommended for triage and non-conveyance by the Ambulance Service as well as III) 11 significant others and IV) 100 significant others of patients considered non-urgent and therefore not conveyed to the Accident and Emergency Department. Interviews were performed and analysed by means of phenomenological hermeneutics developed by Lindseth and Norberg.

The instruments used for data collection were the Person-centred Climate Questionnaire, Patient/Family version. In addition, questions from the inductive studies were tested for construct validity.

Results

The meaning of person-centredness among the patients was a strong wish to be taken seriously. The climate was perceived as highly person-centred. Being taken seriously resulted in feelings of trust and being an active partner in the decision-making process. In contrast, a sense of being rejected and insulted arose when not taken seriously. Eight aspects of person-centredness were established psychometrically with a one-factor solution covering 79.9 % of the variance. The patients reported the climate as person-centred.

Significant others wished to be de-burdened from their caring responsibilities and not abandoned in the present situation. The single most important factor for

achieving this was ensuring that the patient was taken seriously. The significant others reported that the psychosocial climate was person-centred.

Eight aspects of person-centredness and being de-burdened were established psychometrically with a one-factor solution explaining 58.8 % of the variance.

Conclusion

It is possible to achieve a person-centred climate within in the Ambulance Service irrespective of time and location, due to the fact that person-centredness mainly concerns taking patients seriously and providing a moment of de-burdening for significant others.

Original papers

This thesis is based on the following papers referred to in the text by their Roman numerals:

I Rantala, Ekwall, A., & Forsberg, A. (2016), The meaning of being triaged to non-emergency ambulance care as experienced by patients. *International Emergency Nursing*. 25: 65-70

II Rantala, A., Forsberg, A. & Ekwall, A. (2017). Person–centred climate and psychometrical exploration of person–centredness among patients not conveyed by the Ambulance Care Service. *Scandinavian Journal of Caring Sciences*. Accepted for publication August 7, 2017.

III Rantala, Ekwall, A., & Forsberg, A. (2016). The meaning of significant others' encounter with the ambulance clinicians in a non-emergency care context. *Nordic Journal of Nursing Research*. 36(1): 51-58.

IV Rantala, A., Forsberg, A., & Ekwall, A. Person-centred climate and person-centredness in a non-urgent Ambulance Service context, as experienced by significant others. *Submitted.*

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Abbreviations

AED	Accident and Emergency Department
HEMS	Helicopter Emergency Medical Services
PCC	Person-centred Care
PCQ-P	Person-centred Climate Questionnaire - Patient version
PCQ-F	Person-centred Climate Questionnaire - Family version
RETTS	Rapid Emergency Triage and Treatment System

Preface

Since 2004 my speciality has been as a specialist ambulance nurse within in the ambulance service. In 2009 I began working part-time as a teacher at Lund University and continued a specialist ambulance nurse on a part-time basis.

My interest in the field of research is based on experiences in clinical practice. The start of my career in the ambulance service coincided with a shift of paradigm. The prevailing system in which paramedics constituted the main workforce was changed and paramedics were partly replaced by nurses or specialist ambulance nurses, resulting in altered work practices. After a few years as a specialist ambulance nurse I became concerned about the fact that despite receiving an adequate medical assessment and treatment, patients and their significant others were dissatisfied with the ambulance service in general and the ambulance clinicians in particular. Examining the reported deviations, i.e., a written complaint by patients or significant others and/or healthcare providers to the healthcare organisation, revealed a pattern; most complaints were in conjunction related to the "new" setting, where patients were assessed, triaged and thereafter referred to a level of care other than the accident and emergency department. Patients and significant others expressed that they were not listened to and not involved in the decision-making process when assessed, triaged, referred or discharged at the scene. In addition, questions arose about what distinguishes non-urgent ambulance care from municipal home care nursing, as in both cases the care is provided almost exclusively in the setting of a person's own home.

By working both in a clinical setting and within the university I was more and more intrigued by above-mentioned issue. Why were there complaints among patients and significant others despite the ambulance clinicians working according to medical guidelines? Is there an expectation of being conveyed by ambulance to the emergency department? "Was something missing" in the encounter with the ambulance clinicians? What is the actual difference, if any, between home nursing care and non-urgent ambulance care?

In 2012 I was admitted as a doctoral student, enabling me to address the questions initially raised in an everyday clinical setting.

Introduction

In 2016 there were about 1.2 million ambulance assignments in Sweden, of which just under 500 000 were prioritized as life threatening by the Emergency Medical Dispatch Centres (SOS Alarm, 2017). This means that more than half of all assignments were deemed non-life threatening. However, this statistic only applies at the moment the ambulance is dispatched (SOS-Alarm, 2017). When arriving at the scene, ambulance clinicians assessed 14 % of cases as life threating, requiring a sirens and quick transportation to the Accident and Emergency Department (AED) (Ek, Edstrom, Toutin, & Svedlund, 2013). Furthermore, according to the prioritization system, utilized almost nationwide in Sweden, almost 50 % of all ambulance assignments were assessed as non-urgent, i.e., no immediate medical intervention required and therefore probably referred to alternative levels of care that resulting in non-conveyance to the AED. Non-conveyance to the hospital was highlighted as the number one of national research for pre-hospital emergency medical services in the Netherlands, due to the complexity of the assessments (van de Glind et al., 2016), which may imply the need the need of research within the same area in a Swedish context. Ambulance clinicians may find the encounter with patients and significant others challenging due to expectations of being transported to the AED by ambulance. Healthcare professionals' opinion about ambulance assignments has appeared in the media, e.g.:

> "People are call for the ambulance for many different reasons. They may be seriously ill, but they may also be scared, lonely, "half-sick", sad or have the perception that it is everyone's personal right to have an ambulance when they want" (By, 2016).

Public opinion and expectations about the ambulance service are likely to be influenced by the image depicted in the media. Ahl, Nyström and Jansson (2006) argue that not only the healthcare professionals' opinions about the ambulance service should be sought. Patients and significant others perceive many situations as a threat to life and health, even if a medical assessment does not lead to the same conclusion (Ahl et al., 2006).

As patients are no longer necessarily are transported to the AED, there is a greater demand for caring, interpersonal encounters along with the need for person-centred ambulance care. There is a lack of scientific knowledge of the inside perspective of patients and significant others, as well as whether they consider the ambulance care environment person-centred in the specific context of being assessed as non-urgent and, in many cases, left at home by the ambulance service. These research questions will be addressed in this thesis.

Perspectives and viewpoints

Caring values are linked to the foundation of human existence and become relevant in situations where people are dependent on and/or in need of nursing. In this thesis the ontological perspective stems from the assumption that the patient or significant other who contacts the healthcare system, is a meaning-seeking subject who strives to understand her/himself and her/his surroundings.

The patient role is viewed as one defined by the healthcare system and its staff. It is a fact that a person cannot maintain an objective distance to her/his own body. A person does not have a body, because a person is her/his body (Kristenson Uggla, 2014). A patient is mostly viewed as a passive recipient of care, while a person is a natural partner in the team providing the care (Ekman et al., 2011). In this thesis, a person is characterized as an indivisible whole in relation to everyday life.

A common understanding is that human and person are two words that imply the same concept. However, there is an important distinction between the two. To be human requires nothing more than belonging to the human species. On the other hand, to be a person presupposes certain characteristics and abilities (Heberlein, 2013). A person speaks, acts, narrates and assumes responsibility, i.e., is capable – homo capax (Ricœur, 2011). Furthermore, a person is a human being who is not only aware of e.g., pain, but also can reflect on her/himself and her/his life, which involves self-awareness and capacity for rationality (Heberlein, 2013; Ricœur, 2011).

In the thesis the term “patient” implies a capable person who is to be found within the healthcare setting in general and the ambulance service in particular. In that sense, when “patients” are described, they are not automatically placed in a situation of being a passive recipient of care, but with reference to the above contextual description.

All patients in the Swedish healthcare system are entitled to a medical assessment (SFS 1982:763). Who, or which profession should conduct the assessment is not regulated by law, but it is usually performed by a registered nurse (Göransson, Eldh, & Jansson, 2008). Therefore, the context in which this research was conducted mainly involves the nursing field. However, in this thesis it is assumed that nursing cannot take place without caring actions.

Caring is not linked to a particular professional role, thus all clinical professions within the ambulance service can adopt the results and implications.

This thesis has a specific context within the ambulance service. A synonym often used is pre-hospital emergency care. The Swedish legislation (SOSFS 2009:10) defines the prehospital emergency care as "immediate medical measures of health and healthcare professionals outside the hospital". On the other hand, the ambulance service is defined as "health care provided by healthcare professionals in or adjacent to the ambulance" (SOSFS 2009:10; Swedish National Audit Office, 2013). In this thesis, I have chosen to lean towards the latter definition, i.e., ambulance care, as it not only stipulates an urgent medical intervention, but also opens up a broader interpretation including interpersonal human relations. This is congruent with Rosén, Persson, Rantala and Behm (2017), who argue that the ambulance service in Sweden lacks a clear mission statement, that covers a broad range of aspects including being a gatekeeper and saving life, as well as providing guidance about self-care. Furthermore, in this thesis I also chose to use the term ambulance service in conjunction with organizational matters.

In this thesis, the assessment performed by ambulance clinicians in general, and specialist ambulance nurses in particular is understood as a central part of the care provided by the ambulance service. The assessments are carried out in parallel with care in a continuous process involving patients and significant others, i.e., not only identifying and treating diseases (Andersson, Hagiwara, & Wireklint Sundström, 2016). All descriptions of assessments in conjunction with a triage situation refer to everyday situations, as opposed to a mass casualty situation or disaster, where other conditions and guidelines would be applied.

Epistemological assumptions

It is possible to obtain knowledge by explanation and understanding, i.e., both by interpreting and measuring a phenomenon of interest.

The effort to obtain scientific knowledge involved looking for the unique aspects of each individual case (Paper I and III) as well as differences and relationships on a group level by means of statistics (Paper II and IV). For this reason, the data collection methods consist of both inductive and deductive approaches, including interviews and questionnaires (Table 1, p. 39). The inductive approach was chosen for Paper I and III because the area had been rather poorly examined and there was a lack of specific knowledge about the experiences of patients and significant others when the patient is assessed as non-urgent and triaged to a level of care other than the AED. In order to understand the inside perspective and meaning making, a phenomenological hermeneutic method was employed (Lindseth & Norberg, 2004) i.e., to grasp the meaning of reality and of being in the world expressed by patients and significant others, in this case when the patient was assessed as non-urgent by the ambulance clinicians. The phenomenological hermeneutical method implies that the person has a lifeworld. However, this thesis does not lean towards a lifeworld perspective, but rather strives to understand the experiences in relation to the phenomenon of interest.

Furthermore, the epistemological assumption is that knowledge of the environment, termed as person-centred climate, and person-centredness, as experienced by patients or significant others can be studied by means of measurement instruments, i.e., questionnaires. Numerical data were collected in Papers II and IV, enabling comparison and revealing statistically significant relationships.

Background

The patient – A person with a perceived illness

The role of the patient stems from the multifaceted reasons for summoning an ambulance (Yarris, Moreno, Schmidt, Adams, & Brooks, 2006; Toloo, FitzGerald, Aitken, Ting, McKenzie, Rego, & Enragh-Mooy; 2013). Previous studies suggest that patients arriving at the AED by ambulance were more likely to perceive their illness as serious, urgent and painful, than non-ambulance users (Toloo et al, 2013). Similarly, the factors that make a person more likely to seek healthcare at the AED as opposed to primary care are the perception of symptoms and previous hospitalization, highlighting perceived illness and acuity as key aspects (Backman, Blomqvist, Lagerlund, Carlsson-Holm, & Adami, 2008). Toloo et al. (2013) argue that these facts challenge discussions about appropriate ambulance use, which are generally are based on objective clinical criteria or healthcare professionals' views, and do not take the patient perspective into account. For patients, the decision to call for help is not something they take lightly. At the start, they often grapple with the situation on their own in order to try to maintain their independence and autonomy (Ahl et al., 2006; Ahlenius, Lindström, & Vicente, 2017; Forslund, Kihlgren, Östman, & Sorlie, 2005; Vicente, Castrén, Sjöstrand, & Sundström, 2013). As the situation progresses and the symptoms become unbearable, the need to get help is unavoidable. At this point, often after more or less extensive negotiation with her/himself or significant others, the patient finally phones for an ambulance (Ahl et al., 2006; Ahlenius et al., 2017). Being in need of help, regardless of whether or not ambulance clinicians or other healthcare professionals consider the presented condition as an emergency or not, is associated with extreme vulnerability and suffering caused by being dependent (Ahlenius et al., 2017; Holmberg, Forslund, Wahlberg, & Fagerberg 2014; Vicente, Ekebergh, Castrén, Sjöstrand, Svensson, & Sundström 2012).

Patients perceive the wait for the ambulance to arrive as a very long time that sometimes evokes emotions such as fear of being forgotten or not being found (Elmqvist, Fridlund, & Ekebergh, 2008). Being alone with suffering creates fear and waiting for an ambulance can reinforce those feelings. The waiting can be perceived as additional suffering for the patient, regardless of her/his primary condition, experiences, fear, vulnerability, dependency and involuntary loneliness (Ahl et al., 2006; Bremer, Dahlberg, & Sandman, 2009; Ahlenius et al., 2017).

Patients described the arrival of the ambulance clinicians as a shift from being alone, vulnerable, anxious and afraid to being cared for (Holmberg et al., 2014). Similar experiences were reported by patients at accident scenes, where the patients described a sense of relief at being able to hand over responsibility for themselves to those who arrived at the scene first (Elmqvist et al, 2008). This does not only apply to rescue personnel, but also to people passing by who stop at the scene (Franzén, Björnstig, & Jansson 2006). This sense of security and trust is experienced by patients regardless of which professional category is first on the scene and assume responsibility until the ambulance clinicians arrive and take over (Elmqvist et al., 2008; Holmberg et al., 2014). In order to alleviate anxiety about their health ambulance users also described the necessity of reassurance, from the moment that the clinicians arrived at the scene and during the care and transfer, in order to alleviate the anxiety that arises about their health (Togher, O'Cathain, Phung, Turner, & Siriwardena, 2015). Feelings of loneliness and fear of being abandoned arose when the patients were handed over to the AED (Holmberg et al., 2014). However, similar feelings surfaced when the ambulance clinicians objectified the patient and did not identify the perceived illness, resulting in failure to alleviate the suffering (Ahlenius et al,, 2017). Patients feel powerless if not acknowledged and treated as a human being, a feeling that also arises when they struggle for control or lack knowledge and information (Forsgärde, From Attebring, & Elmqvist, 2016; Holmberg et al., 2014). Research on low-priority patients conducted in the AED reveals that nursing staff did not take much notice them, which led to feelings of being insulted and embarrassed when the care was delayed, as well as inability to understand what was happening to them (Dahlén, Westin, & Adolfsson, 2012). Therefore, the preconditions for a holistic assessment and encounter must be provided if patients are to be involved in a caring relationship with the ambulance clinicians (Ahlenius et al., 2017; Holmberg et al., 2014; Melby & Ryan, 2005).

Significant others

To date, the knowledge about significant others of patients who received ambulance care is somewhat limited to date. However, significant others play an important role when it comes to being a participant in the ambulance service. In Sweden, with just over nine million inhabitants, as many as 1.3 million (of whom 900.000 are of working age) provide some kind of support to an ill family member

(Statistics Sweden, 2014; National Board of Health and Welfare, 2012). Bearing this in mind, previous studies reveal that 47-96 % of calls to the emergency medical dispatch centre are made on behalf of the person in need of help (Calle, Houbrechts, Lagaert, & Buylaert, 1995; Neely, Norton, & Schmidt, 2000; O'Cathain, Turner, & Nicholl, 2002; Wahlberg, Cedersund, & Wredling, 2003; Wahlberg & Wredling, 1999).

It is argued that the patient's world always includes her/his context, primarily persons usually considered as significant others (Dahlberg & Ekebergh 2015). The definition of significant others are any person who is close and essential to the patient (Linnarsson, Bubini, & Perseius, 2010), thus not necessarily someone connected through blood or law (Whall, 1986). When someone becomes ill, persons within her/his context also are also affected. All relationships and all interactions changes when an individual drops out of the ordinary system and has new needs. The healthcare system has a responsibility for the needs, health and situation of significant others (Arman, 2015a). The involvement of significant others in ambulance care can be understood as multi-dimensional; from being involved in the initial assessment of the patient's symptoms to traumatic personal experiences (Bremer et al., 2009; Tedim Cruz, Araujo, Alves, Magano,, & Coutinho, 2012; Weslien, Nilstun, Lundqvist, & Fridlund, 2005).

Being a significant other is associated with a great, often overwhelming, caring responsibility for the patient, which results in sense of vulnerability (Bremer et al., 2009; Holmberg, Forslund, Wahlberg, & Fagerberg, 2016). According to Holmberg et al., (2016a) the reason that significant others summon an ambulance is their need to be relieved of their responsibilities and have the opportunity for a moment of rest. In the ambulance service this has been described as a lonely struggle filled with feelings of helplessness and being terrified that the person (patient) might die (Holmberg et al., 2016a). Similar to the ambulance context, studies from high technological and emergency department settings reveals that significant others master the situation, which is characterized by fluctuating feelings of helplessness and being abandoned as well as a need to be involved and useful (Forsgärde et al., 2016; Mitchell & Chaboyer, 2010). Participating and being involved in the care was achieved by being provided with information about the patient. This was found to be a potentially viable approach to being involved in the care process, enabling the significant other to perceive ambulance clinicians as equals in a shared partnership with and for the benefit of the patient (Holmberg et al., 2016a; Mitchell & Chaboyer, 2010). Handing over responsibility is a double-edged sword. On the one hand the ambulance clinicians relieve the significant other of the responsibility, while on the other hand feelings of being deserted and lonely emerge because the ambulance clinicians focus their attention to the patient (Holmberg et al., 2016a). It was essential for significant others that the patient was treated in an open and kind manner, and they felt powerless when experiencing that she/he was not properly cared for or her/his condition was not taken seriously. (Ahlenius et al., 2017; Forsgärde et al., 2016). Significant others have their own suffering due to loneliness and insecurity, which might lead them to voluntarily withdraw themselves in order not to negatively affect or delay the care (Holmberg et al., 2016a). Identifying and confirming the suffering of the significant others should therefore be considered a necessity in both an emergency situation and a non-emergency situation in the homes of the patients, which is the focus of this thesis.

Caring for patients in their own homes

When the ambulance clinicians enter a person's home, assesses symptoms and makes decisions about medical treatment, caring interventions and level of care, it is important to understand the home as a place full of more or less implicit assumptions regarding the private sphere that is free from interference from society or the state (Öresland, 2008). The main reason for treating the patients in their own homes is to prevent delay or substitute long-term and acute institutional-based services (Öresland, 2008). As the population becomes older, the financial burden of hospital care is constantly increasing and in-patients with multiple health problems are often discharged earlier. This means that not only will home-based nursing care become more complex, but also the ambulance service will also face new demands (Schober, 2007).

Carolan, Andrews and Hodnett (2006) claim that place has relevance for people's health, for example that as a care site the home has a positive impact, benefitting patients in terms of autonomy and alleviation of suffering. The home can also be viewed as a private domestic sphere where decisions about intimate issues of individual and family life take place (Jaggar & Young, 2000). The private place is a spatial place where the person is the owner and thereby has power over the place (Peter E, 2002; Peter, Macfarlane, & O-Brien-Pallas, 2004). Jaggar & Young (2000) suggest three meanings of privacy:

- Physical freedom for the person from unwanted observation or bodily contact
- Informational secrecy, confidentiality, or anonymity of information
- Freedom from unwanted interference, ability to make one's own decisions and to act on those decisions.

The visit by the ambulance clinicians per se violates the three meanings of privacy since because the necessary assessment includes observing of signs and symptoms by bodily contact, limits anonymity of information and affects the person's ability to make decisions regarding her/his health. When providing care in someone's home, the ambulance service represents the public and the state entering other persons' private sphere. This situation demands ethical choices and decisions, which may involve conflicting values and norms between the patients and the nurses, e.g., conflicts related to decisions about how to handle resources such as time allocation, patient participation, autonomy and the use of technology (Öresland, 2008).

The experience of patients and significant others of being cared for at home in the context of non-urgent ambulance care is somewhat sparse in the research literature. However, research from the Swedish homecare nursing context reveals that patients were able to maintain their dignity and autonomy in their own home (Breitholtz, Snellman, & Fagerberg, 2013; Holmberg, Valmari, & Lundgren, 2012). Older adults described home as a place to which one is attached and where one feels comfortable and safe (Gillsjö & Schwartz.Barcott, 2011). At the other extreme Breitholtz et al. (2013) emphasized that patients receiving homecare expressed worries about not being seen as a person, especially when the caregivers were in a hurry. Similarities were found by Holmberg et al. (2012), who discovered that visits from unfamiliar nurses were stressful. Although older adults reported a sense of being independent, having strength and self-esteem due to care provided in their own home, in reality they were in a position of dependency (Breitholtz et al., 2013; Holmberg et al, 2012; Lundgren & Berg, 2011). Thus the home is often, but not always, a place of privacy, safety and self-determination but might eventually might turn into a workplace for the ambulance clinicians guided by various guidelines and with a professional agenda quite different from that of the person in need of care.

The Swedish Ambulance Service

The Swedish Ambulance Service has evolved from being purely a transport organization to an important part of the emergency care system. Persons who are injured or ill can be assessed and treated at the scene of accident or home as well as during the transportation to hospital or equivalent (Borland, Jacobs, & Rogers, 2002; Campeau, 2009; Gårdelöf, 1998). In the same way as most of the healthcare provided in Sweden, the ambulance service is financed by taxes (Bergmark, 2008). The county councils are responsible for planning and organizing the ambulance service (SOSFS 2009:10), leading some variety across the nation. However, homogeneity is achieved through the National Board of Health and Welfare regulations as well as by the Ministry of Health and Social Affairs (SOSFS 2009:10; SOSFS, 1995:8), and Swedish law (SFS1982:763). The main elements of the regulatory framework define the minimum level of equipment in ambulances, how an ambulance should appear physically and how dispatch prioritization should be organized. The regulations also state that only licensed personnel can administer a drug, which implies that the ambulances must be crewed by at least one registered nurse per ambulance. Because the laws and regulations that govern the ambulance service give county councils great freedom to shape the organization based on their own needs and conditions, objectives as well as access to and use of ambulance resources differ. Most counties have set availability goals, usually for potentially life-threatening assignments, with the aim of reaching a given percentage of the population within a certain time frame. This goal varies among the counties; between 60 and 100 % of the population are supposed to be reached within a timeframe of 10 to 30 minutes (Swedish National Audit Office, 2013).

Emergency Medical Dispatch Centre (112) and Swedish Healthcare Direct (1177)

Swedish Healthcare Direct, which can be contacted by phoning 1177 or via the web at *www.1177.se*, is a national around the clock organisation, that provides the public with an opportunity to ask questions about health care in general. The system is staffed by registered nurses who answer questions, assess care needs, provide self-care advice and refer the caller to the right level of care (Kaminski, Röing, Björkman, Björkman, & Holmström, 2017; Wahlberg & Gustafson, 2016). In 2014, the number of incoming calls was around 5.5 million. The assessment resulted in self-care in 39 % of the cases, primary care in 37 %, specialised care in 18 % and other (which includes referral to the ambulance service, where calls are diverted to 112, dental care and community care as well as follow-up) in 6 % of cases (Vårdguiden 1177, 2015).

Since 1996, there has been a common number (112) for emergency calls throughout the European Union (Swedish National Audit Office, 2013). Most counties in Sweden have signed an agreement with SOS Alarm, a company jointly owned by the Swedish state and the Swedish Association of local authorities and regions, for prioritization of emergency calls, ambulance dispatch and when applicable other pre-hospital resources. However, some counties that have built up their own organization or outsourced the function to companies other than SOS Alarm. It is important to stress that all calls made to the emergency number 112 are answered by an operator at SOS Alarm, who then decides whether care is needed and if so in what form. If it is decided that care is required, the call is either diverted to a nurse within SOS Alarm, or if it has been agreed otherwise, to another organization (Wahlberg & Gustafson, 2016). In 2016 about 3 million 112 calls were made to the 112, of which and about 1.2 million were allocated some form of care (SOS Alarm, 2017).

The Swedish Healthcare Direct, as well as the emergency medical dispatch centres (SOS Alarm or equivalent) share the dual role of both caring for the caller and acting as a gatekeeper for the healthcare organization (Holmstrom & Dall'Alba, 2002; Ek & Svedlund, 2015).

Previous research reveals that patients triaged to a level of care other than that of the AED experienced suffering and struggled to be considered as a patient. However, when the encounter with the telephone nurse was characterized as a being seen as person and being taken seriously, their health process began and no further encounter was necessary. On the other hand, patients who had a negative encounter continued to seek some form of care (Winneby, Flensner, & Rudolfsson, 2014). These results are consistent with those of Holmstrom, Nokkoudenmaki, Zukancic and Sundler (2016), who found that telephone nursing has two sides; patient friendly and patient unfriendly. The former relates to feelings of trust, confidence and being the centre of attention, while the latter involves feelings of being abandoned or dismissed and dissatisfied. Several studies on the provision of self-care advice to patients demonstrate that a nurse who is able to see the patient's perspective and involve her/him in decision-making is perceived as professional and reliable. Furthermore, patients who were satisfied with the telephone nurse e were more likely to follow the self-care advice and not seek further care (Williams, Warren, McKim, & Janzsen, 2012; Ström, Marklund, & Hildingh, 2009; Gustafsson, Vikman, Savenstedt, & Martinsson, 2015).

Being a nurse at the emergency medical dispatch centre involves both challenges and difficulties. From the nurses' perspective there is great focus is on the risk of incorrectly assessing the situation and thereby not making the right decision (Röing, Rosenqvist, & Holmström, 2013; Röing & Holmström, 2015; Ek & Svedlund, 2015). Another difficulty is presenting medical advice to patients or the person who calls on their behalf in, e.g., cardio-pulmonary resuscitation situations. Conflicts with ambulance clinicians, e.g., when it comes to whether or not the patient has been correctly prioritized, have also been highlighted as a demanding situation at the dispatch centre (Ek & Svedlund, 2015). As all encounters with persons phoning the 112 or 1177 number involve assessment and judgment, it is vital to understand the assessment and judgment process as well as the regulations and guidelines involved.

The process of assessing and judging patients in Swedish Ambulance Care

Nursing is the specific competence, for which nurses are responsible. It is conducted as team work with other professionals, the patient and her/his significant others, and comprises assessment, diagnostics, planning, implementation and evaluation of the nursing interventions (Carpenito-Moyet, 2007). According to Kirkevold and Larsson-Wentz (2000), the nursing process can be viewed as a description of the nurses' area of responsibility. The assessment phase of the nursing process is an important step for collecting patient data about the current health problem, which is a difficult task because health also involves human experiences. The following are four types of assessment (Kozier, Erb, & Audrey, 2015);

1. Initial assessment, carried out to establish as complete a picture as possible of the patient's health problems.
2. Problem focused assessment. An ongoing process, e.g., monitoring the patient's oxygen saturation level.
3. Acute assessment. Conducted in the event of an acute physiological or mental crisis to identify a potential life threating condition.
4. Long term assessment, e.g. in order to evaluate the current state of the patient's health in relation to the initial situation.

However, Andersson Hagiwara (2016) argue that to some extent the ambulance care assessment actually starts prior to the encounter with the patients at her/his home or at the accident scene. The authors divide the assessment in into four phases: Preparation, which starts when the as the ambulance clinicians are allocated to an ambulance assignment. The second phase constitutes the actual pre-hospital encounter, face to face with the patient, where a thorough assessment takes place in order to establish as complete a picture as possible. During this phase medical and/or nursing interventions are performed depending on the patient's health condition. The third phase takes place during transportation and involves problem-focused assessment. Finally the fourth phase constitutes checking the equipment, evaluating the interventions and providing feedback (Andersson Hagiwara et al., 2016).

Jansson (2010) claims that whether or not the assessment phase is considered acute, it is twofold, i.e., consisting of the actual assessment followed by the decision. To guide the decision, the ambulance service has adopted a clinical decision support system called the Rapid Emergency Triage and Treatment System (RETTS), which is mandatory and aimed at sorting patients into five levels on the basis of urgency. Like most triage assessment tools, the key purpose of the RETTS is to determine the medical risks pending assessment and interventions. The RETTS priority rating solely assesses medical risk and should be seen as a recommendation about whether to provide immediate emergency care or if it is safe to wait until capacity is available. The triage tool has been translated and validated for other countries, e.g., Norway and Denmark (Widgren, 2012; Widgren & Jourak, 2011). The priority recommendation is derived through a process based on an algorithm for vital signs (alertness, pulse and breathing rate, oxygen saturation, blood pressure and body temperature) together with some 45 emergency symptoms and signs (ESS) algorithms for a range of complaints and/or symptoms. Firstly, the nurse chooses the triage category in accordance with the measured vital signs. Secondly, the nurse selects one or more ESS algorithms that correspond to the patient's main complaint. The final triage score is based on the summary of the two algorithms for vital signs and ESS, where the highest scores generate the final score. There are five priority levels (from lowest to highest in ascending order): blue, green, yellow, orange and red. (Widgren, 2012; Widgren & Jourak, 2011; Widgren, Jourak, & Martinius, 2008). Red and orange indicate the need for immediate emergency care, whereas yellow and green are classified as "can wait" for assessment by a physician without medical risk. (Widgren, 2012). According to a Swedish study by Ek et al. (2013), about 50 % of all patients were assessed as green or yellow, i.e., "can wait", thus considered non-urgent.

A decision about the most appropriate level of care is made based on the result of the assessment and triage. In general, the levels of care available are:

- ambulance service (112)
- accident and emergency department
- primary health care (urgent or non-urgent)
- remaining at home with self-care advice

(Vårdguiden 1177, 2015)

As the Ambulance Service in Sweden is controlled and governed by the county councils, there are local differences in terms of regulations about whether ambulance clinicians can refer patients to a level of care other than the AED or are obliged to convey the patient to the AED (Larsson, Holmén, & Ziegler, 2016, 2017).

Physicians within the Ambulance Service in Sweden

Ambulance service physicians seldom or never participate in a face-to-face encounter with the non-urgent patients. Instead, the physician is an important but distant part of the process of the assessment and judgment process concerning the patient's condition and appropriate level of care (Haner, Örninge, & Khoram-Manesh, 2015; Kongstad, 2016).

Although some counties have operationally active physicians, who are directly involved in patient care in helicopters (HEMS) or land based vehicles, the Swedish Ambulance Service mainly deploys senior ambulance physicians and head physicians. Senior ambulance physicians’ tasks are exercising medical supervision, promoting medical development, participating in the medical education of other staff members as well as issuing guidelines and investigating medical oriented deviations (Kongstad, 2016; Samuelsson, 2014). Kongstad (2016) stressed that each organisation should employ a head physician, whose main duties consist of ensuring patient safety and assessing what can be considered adequate medical care within the organisation. In addition, some counties have adopted a telephone-based physician advice system, when for example patients are triaged to non-conveyance by ambulance to the AED (Gunnarsdotter, 2013).

Thus, within the Ambulance Service, face-to-face assessment of the patient is almost always performed by the ambulance clinician, mainly a registered nurse (or specialist ambulance nurse) whose judgments and interventions are supported by a summary of two algorithms for vital signs and ESS, which decide the level of urgency from a medical perspective.

Ambulance clinicians

In terms of competence and training, the Ambulance Service in Sweden differs somewhat from most other countries. Internationally, ambulance clinicians are usually Emergency Medical Technicians (EMT) and/or paramedics (World Health Organization [WHO], 2008; Langhelle, Lossius, Silfvast, Bjornsson, Lippert. Ersson, & Soreide, 2004). In the USA, UK and Australia the system is dominated by EMTs and paramedics. Many nations in Asia, Oceania and Europe have implemented a supplementary or physician-paramedic system for the ambulance service. However, like e.g., the Netherlands, Belgium, Finland, Slovakia and the Czech Republic, Sweden has adopted a system where nurses play a role in the Ambulance Service. The main requirement in the Swedish context is at least one registered nurse in every ambulance together with another nurse or the equivalent of an EMT (Suserud, 2005; Wilson, Habig, Wright, Hughes, Davies, & Imray, 2015). Of Sweden's 21 county councils, eight requires at least one specialist nurse in each ambulance. Most of these eight county councils prefer the specialist training to be within the area of ambulance nursing care. In the remaining thirteen the basic requirement set out by The National Board of Health and Welfare, i.e., a registered nurse, is sufficient. In addition to the training, ten county councils requires all ambulance personnel to have previous experience of emergency care, while for four counties councils it is sufficient if at least one of the ambulance crew member has emergency care experience. The remaining seven county councils have not set any requirements stating that ambulance personnel should have previous emergency care experience, although it is viewed as an advantage (Swedish National Audit Office, 2013). Despite the fact that a fully operative and effective ambulance team is essential for assessment, interventions and care in the Ambulance Service, the ambulance technician are not allowed to independently care for the patient (Abelsson & Lindwall, 2012; Suserud, 2005; Wihlborg, Edgren, Johansson, & Sivberg, 2017). Although several categories of nurse specialists, e.g., nurse anesthetists and intensive care nurses, are common within the ambulance service in Sweden, a postgraduate programme for specialist ambulance nursing, comprising 60 ECTS, has been available since 2001. The programme is offered by 12 universities across the nation generally includes a master’s degree in nursing is provided as well (Riksföreningen för ambulanssjuksköterskor [RAS], 2012). The educational content at all 12 universities was analysed by Sjölin, Lindström, Hult, Ringstedt and Kurland (2015). The result revealed that the curricula content could be divided into medical knowledge, nursing knowledge and context knowledge. The desired competencies have also been investigated from a professional perspective, where ten main areas of competence were revealed, including institutional collaboration, possession of relevant knowledge generic abilities and interpersonal communication (Wihlborg, Edgren, Johansson, & Sivberg, 2014).

An opportunity for reflection together with colleagues, communication skills and experienced-based knowledge were found to be intimately linked to essential parts of competence development and insight among specialist ambulance nurses (Wihlborg et al., 2017).

With regard to whether the need for an ambulance is justified, i.e., the view of the appropriateness of ambulance assignments, paramedics considered that only extremely urgent assignments, i.e., those where “lights and sirens” are appropriate, were justified (Dejean, Giacomini, Welsford, Schwartz, & Decicca, 2016). This is congruent with Holmberg and Fagerberg (2010), who found that ambulance clinicians’ experienced that their main mission was to provide medically focused interventions, despite the fact that all ambulance care arises from a single encounter with the patient. Research has also demonstrated that ambulance clinicians experienced the relationship with patients and significant others as being both professional and personal. The former concerns aspects of being aware of one’s power and authority together with using one’s experience and knowledge in order to be able provide protection and care for the patient. Despite the limited duration of the encounter, a key aspect for the ambulance clinicians was the importance of a shared decision-making, when appropriate. With regards to the latter, the personal relationship stems from aspects of becoming emotionally involved and not just having a medical focus (Holmberg, Wahlberg, Fagerberg, & Forslund, 2016b).

Bearing the patients perspective in mind, the ambulance clinicians should attempt to capture the most important dimensions of suffering and use all their senses to assess and try to understand what caused the patient's request for help (Bremer, Dahlberg, & Sandman, 2012). It is therefore essential that ambulance clinicians identify each and meet each individual patient’s care needs in diverse environments (Holmberg & Fagerberg, 2010). Adopting a person-centred approach might be the best option for providing individualized care.

Framework

As mentioned already in the introduction this thesis stem from reflections on the meaning of person-centredness among patients and significant others within the ambulance service context and whether a person-centred climate exists. In this thesis the three main concepts, i.e., person-centred climate, person-centred care and person-centredness, are viewed as different but interrelated and dependent on each other, which in line with previous studies (Edvardsson, Koch, & Nay, 2009a; Edvardsson, 2008; Ekman et al., 2011; McCormack & McCance, 2006, 2010). As proposed by Kristensson Uggla, (2014), viewing a patient as a person is important. A patient who enters the healthcare system almost automatically tends to be placed at a triple disadvantage, consisting of:

- institutional disadvantage; the hierarchical healthcare regime
- existential disadvantage; the person's perceived illness and how it affects life
- cognitive disadvantage; the knowledge gap

(Kristensson Uggla, 2014; Ricœur, 2011)

The triple disadvantage illuminates the possibility of an emerging asymmetry in the relationship between the career and the person in need of care (Ekman, 2014). In order to prevent or to minimise the effects of this asymmetry in the caring situation, Kasén (2002) emphasized the need for a caring relationship. In uncaring situations patients were objectified and the carers only performed tasks. In the absence of a caring relationship, patients were left with anxiety, pain, and fear. Therefore, Kasén (2002) argued for the need of a caring relationship that is mutual and takes account of the whole person, i.e., physical, mental and spiritual aspects (Kasén, 2002), much like the core aspects of person-centredness and person-centred care (Ekman et al., 2011; McCormack & McCance, 2010).

Person-centred climate

Person-centred Climate is the physical and psychosocial environment where the person-centred actions take place. The care environment constitutes an essential part of enabling, preventing or providing person-centred care and is thereby viewed as an important factor for the patient's well-being (Browall, Koinberg, Falk, & Wijk, 2013). The climate comprises interaction between three separate structures; the physical environment, people's doing and being in the environment and the organisational philosophy of care. The latter two represent the psychosocial part of the climate (Edvardsson, Sandman, & Rasmussen, 2008).

Person-centred care

Person-centred care has emerged as an important core competence in Sweden, where the patient is the target of caring and activities involving care, i.e. the caring action. Clinicians should strive to avoid taking patients' diseases and diagnosis as the sole point of departure (Edberg, Ehrenberg, Friberg, Wallin, & Wijk, 2015). While diagnosis is unquestionably a great help in medical and administrative contexts, from a caring science viewpoint it only provides a narrow and limited perspective. According to Dahlberg & Ekebergh (2015), the patient should be considered as a person who is at the centre of caring.

A prerequisite for person-centred care is the assumption that a person is someone with a disease, thus not allowing the disease to overshadow a person. This means a shift, where professionals' definition of disease becomes as important as the person's experience of illness (Ekman, 2014; McCormack & McCance, 2006). Person-centred care clearly reject the idea behind the term patient, which in Latin means "the one who suffers". It is therefore important to make a distinction between patient-centered and person-centred care, where despite her/his need of care, the former is also a person who has extensive knowledge and is in fact is an expert on her/his own health and illness (Ekman et al., 2011). Kristensson Uggla (2014) highlights that patient-centred care can be understood as a situation where the patient tend to end up in the shadow of the healthcare system and medical knowledge development, while person-centred care implies no of being placed in the shadow of the patient role (Kristensson Uggla, 2014).

We are all individuals who may encounter health problems, e.g. a disease. Person-centred care highlights the fact that persons do not become their disease. To provide person-centred care the healthcare system should modify the care and the care environment to suit the needs of individuals. The person should be involved and given the opportunity to make decisions in all aspects of her/his own care. The person's experience is the starting point in the quest to understand the symptoms and behavior (Ekman, 2014).

Person-centred care can be concretized based on three cornerstones of clinical care; the narrative, partnership and documentation (Ekman et al., 2011). The narrative captures the person's life world and subjective experience of illness, in addition to the traditional medical history. Hereby there is a shift from a patient consisting of a variety of "what" (e.g., test results) to "who" the person is, in addition to her/his preferences, concerns and thoughts that the person holds (Ekman et al., 2011; Ricœur, 2011; Wireklint Sundstrom & Dahlberg, 2011). According to Ekman et al. (2011), the partnership is generated by seeing the person as an natural and integral part of the care team. This means that persons are allowed to participate in decision-making about their own care. Person-centred care promotes self-determination and allows for codetermination. Finally, to ensure the outcomes of the narrative and the decisions taken, documentation of the content of the partnership is a mandatory requirement (Ekman et al., 2011).

Person-centredness

Person-centredness places the person at the centre of care, thus moving away from fragmented, medically dominated care and instead focusing on caring relationships and holistic, collaborative care (McCormack & McCance, 2010). Person-centredness is commonly theorised as an ethical, humanistic and holistic viewpoint on care, where the essential foundations are respect for subjectivity, capability and personhood. It is described as four core concepts that constitute person-centred nursing (McCormack, 2003);

- Being in relation highlights the importance of the relationship between the person being cared for and the healthcare providers.
- Being in a social world means that a person creates meaning through being in the world and thus interrelates with her/his social world.
- Being in a place is derived from the notion that the care environment has a great impact on perceived person-centredness.
- Being with self focuses on being are aware of one’s own values and beliefs, ensuring the person’s own choices are respected.

Being a person means having personhood. Recognizing personhood makes it possible for caregivers to provide care that is centred, i.e., specifically focused on a particular person (McCormack, 2003).

In sum, the three main concepts in this thesis, i.e., person-centred climate, person-centred care and person-centredness, are viewed as interrelated and dependent on each other. The assumption is that the person-centred climate is where all caring actions take place, person-centred care is the caring actions provided and person-centredness is interpreted from the patients' perspective as a subjective experience of the care provided. Finally, according to Edvardsson (2015), person-centred care should be seen as holistic, flexible, creative, personal and unique, consequently not reductionist, standardized, detached and task-based, unless the person wants it to be (ibid, p. 66).

Rationale

In recent years, the development of the Ambulance Service has led to advanced assessments and interventions already in the patients' own homes. A corresponding shift towards more advanced care in the patients' home has also been seen in the context of homecare nursing. Although research exists on care given in the patient's home in the organised homecare nursing setting, scientific knowledge regarding home-based care provided by ambulance clinicians is lacking. In view of the fact that person-centred care has emerged as a key component in Swedish healthcare, a knowledge gap has been identified regarding the provision of person-centred care within the Ambulance Service, especially non-urgent ambulance care.

The rationale behind this thesis was to understand the meaning of non-urgent ambulance care and perceptions of the person-centred climate among patients and significant others, as well as to explore whether the context of the ambulance services is configured and susceptible to person-centredness and person-centred climate. No studies were found that investigated person-centeredness and the person-centred climate in the specific context of patients – or significant others of patients – who were assessed as non-urgent and therefore were possibly selected for triage and then referred to a level of care other than the AED. Thus in the first study, the focus was on the subjective meaning (i.e., experiences) of patients who were triaged and then referred to a level of care other than the AED.

Since the first study revealed eight important aspects of person-centeredness, the seconded study aimed to psychometrically explore the construct of person-centeredness. The possible person-centred climate was also explored from the patients' perspective in order to establish any relationships between the construct of person-centeredness and the perceived climate.

It was already known that as many as 47-96 % of the calls to the emergency medical dispatch centre (i.e., 112) are made by others on behalf of the person with the perceived illness. Significant others tend to act as social supporters for the person with an illness. Therefore, the focus of the third study was to the illuminate the meaning of significant others' encounter with ambulance clinicians in a non-emergency ambulance care context, when the patient was referred to a level of care other than the AED. In order to possibly verify and generalise the findings from the third study, a fourth investigation was conducted. Here the objective was to statistically explore the concept of person-centeredness and the person-centred climate from the significant others' perspective.

In summary, to enable the implementation of person-centred care within the ambulance care, the knowledge gap regarding experiences of person- centeredness (Papers I and III) and the person centred climate (Papers II and IV) must be narrowed. Only when an in-depth understanding of the inside perspective of patients and significant others is achieved will it be possible to provide person-centred care and to develop the necessary professional skills for facilitating the three cornerstones of person-centred care, i.e., the narrative, the partnership and the documentation.

Aim

The overall objective of this thesis was to explore experiences of person-centredness and the person-centred climate among patients and significant others when patients were assessed as non-urgent by the Swedish Ambulance Service.

Specific aims:

I To elucidate the subjective meaning of non-emergency ambulance care among patients who were triaged to levels of care below that of the Accident and Emergency Department.

II To psychometrically explore the construct validity of a possible dimension of person-centredness, to explore patients' experiences of the person-centred climate and to explore possible relationships between person-centred climate and person-centredness.

III To illuminate the meaning of significant others' encounter with ambulance clincians in a non-emergency ambulance care contexts, where patients were triaged to a level of care below that of the Accident and Emergency Department.

IV To explore significant others' experiences of person-centred climate and person-centredness in a non-urgent ambulance care context.

Methods

This thesis alternates between an inductive and deductive approach when it comes to both patients and significant others.

Table 1. Research design overview

Paper	Study participants	Data collection	Methods of analysis
I	Patients assessed as non-urgent, thus not conveyed to the AED (n=12)	Individual interviews	Phenomenological hermeneutic
II	Patients assessed as non-urgent, thus not conveyed to the AED (n=111)	Questionnaires	Factor analysis, descriptive and analytical statistics
III	Significant others of patients assessed as non-urgent, thus not conveyed to the AED (n=11)	Individual interviews	Phenomenological hermeneutic
IV	Significant others of patients assessed as non-urgent, thus not conveyed to the AED (n=100)	Questionnaires	Factor analysis, descriptive and analytical statistics

AED = Accident and Emergency Department

Setting

The studies in this thesis were conducted in an ambulance district in the southernmost part of Sweden, comprising both rural and urban areas as well as a diversity in terms of socio-economic factors. The ambulance district catchment area encompasses approximately 250,000 inhabitants. In 2016, the Ambulance Service handled some 32,000 assignments (this figure includes all priority levels) within the catchment area, of which 24,000 were assessed as non-urgent by the ambulance clincians. The Ambulance Service operates eight to 13 land-based ambulances, depending on the time of day and season.

In this thesis, all the research questions address a reality where the home of the patients constitutes the main setting for the medical and nursing interventions. The significant others involved either resided in the home where the care was provided or were guests. In Papers II and IV the level of care recommended after the initial assessment and treatment in the patients' home was primary care, a visit by a General Practitioner or to stay at home with self-care advice.

Papers I and III

Papers I and III had an explorative inductive design aimed at illuminating the experiences of patients and their significant others to patients.

Sample selection and Participants

The sample in Papers I and III comprised patients and their significant others where the patient had been were assessed, triaged and referred to a level of care other than the AED, by the ambulance clincians. The inclusion criteria for the studies were adult patients and significant others (18 years or over), able to understand and speak Swedish and adequate cognition.

A total of 57 eligible participants, 36 patients and 21 significant others, agreed to be contacted by telephone and were invited take part in the study. The final group that took part in the interview consisted of 12 patients and 11 significant others. Drop-out is described in Table 2. The patients consisted of seven men and five women with a median age of 72 years (range 26-89), while the significant others had a median age of 55 years (33-81) years. The main complaints were associated with pain, anxiety and undefined discomfort.

Table 2. Reason for drop-out after initially agreeing to be contacted.

Reasons for drop-out	Patients, n	Significant others, n
Not contactble by telephone over a four week period	17	5
Did not answer the phone despite having agreed a time	2	3
Changed their mind about participating after initial contact	4	2
Other*	1	-

*= in need of medical attention when contacted by researcher

Data collection

The two studies were performed in conjunction with regular ambulance assignments and with the assistance of the ambulance clinicians. When the ambulance clincians had assessed a patient as non-urgent, thus not requiring conveyance to the AED, they selected participants and provided them with verbal information about the study, in addition to an information letter on behalf of the researcher. If the patients or significant others were in agreement, their telephone number, age, and whether they were a patients or a significant other, were collected and handed over to the researcher. Significant others and patients did not necessarily originate from the same ambulance assignment. The researcher phoned each potential participant within a four-week period to provide a more comprehensive description of the study and if she/he was still willing to participate, an appointment was made for the interview.

The participants were allowed to choose the time and place for the interview, and all opted to be interviewed by telephone. In order to ensure the accuracy and completeness of the recollections, all interviews were performed within a four-week period from the initial encounter with the ambulance service. The data collection took place between November 2013 and July 2014, except for a pilot interview in December 2012. Before the interviews began, the participants were again informed about the aim of the study, the voluntary nature of participation and given an opportunity to ask questions. The interviews started with the question “Could you tell me about your experience of the encounter with the ambulance service?” Additional probing questions were posed when appropriate. The interviews, which were recorded and transcribed verbatim, lasted between 15 and 46 minutes (median 35 minutes).

In the study of patients (Paper I), two participants were on a second occasion to expand on and verify the emerging comprehensive understanding, while in the study of significant others (Paper III) one of the 11 participants was re-interviewed for the same reason. The data therefore consist of 14 and 12 interviews respectively.

Data analysis

Phenomenological hermeneutics

A phenomenological hermeneutical method (Lindseth & Norberg, 2004) was employed in Papers I and III to illuminating the experience (i.e., the meaning,) of being a non-urgent patient, or a significant other of such a patient. The method of phenomenological hermeneutics developed by Lindseth and Norberg (2004) was inspired by Ricœur's philosophy of the interpretation of texts (Ricœur, 1981). In contrast to Ricœur's thoughts about the interpretation of only written texts (Ricœur, 1976), Lindseth and Norberg (2004) mainly utilize transcribed interview texts. In order to grasp the meaning of persons' experiences of a specific, the experiences of the phenomenon have to be transformed in to text, making them, i.e., the experiences, possible to interpret.

This means that the method should be used to search for a person's experience of a phenomenon as opposed to its potential objective essence (Fagerberg & Norberg, 2009; Lindseth & Norberg, 2004). The method originates from both phenomenology and hermeneutic traditions. Hence, central meanings can be studied and, in a sense, be discovered through the interpretation of the text (Fagerberg & Norberg, 2009).

When the text had been transcribed verbatim, we searched for the meaning was by means of the following three phases described by Lindseth and Norberg (2004):

The naïve reading. The text was read through several times in order to become familiar with the contents as a whole.

The structural analyses. The text was de-contextualized and its content explored. In this stage, the text was divided into meaning units, which were condensed and further sorted into themes. The themes were then reflected on in the light of the naïve understanding. Lindseth and Norberg (2004) state that reflection can lead to themes being either confirmed or rejected. Although rejections may make it necessary to perform a new naïve reading, in our studies the themes were confirmed in this phase.

The comprehensive understanding. The purpose was to achieve an interpretation of the whole. The themes were summarised and reflected on with the reference to the aim, context, naïve understanding and the structural analysis.

In Paper I, 20 sub-themes and six main themes emerged from the analysis, whereas in Paper III the analysis led to 27 sub-themes and seven main themes.

Papers II and IV

In Papers II and IV a deductive approach was employed to explore the person-centred climate as well as person-centredness among patients and significant others. The aim of both papers was twofold:

1. To establish the construct validity of a possible dimension of person-centredness.
2. To conduct a cross-sectional evaluation of the experiences of person-centred climate and person-centredness.

Sample selection and Participants

The sample in Papers I and III comprised patients and significant others of patients who were assessed by the ambulance clincians as non-urgent and left at the at home or referred elsewhere (not conveyed by ambulance to the AED). The inclusion criteria for the studies were adult patients or significant others (18 years or over), able to understand Swedish and adequate cognition.

Between June and September 2016, the ambulance clinicians handed out 266 patient questionnaires and 241 questionnaires to significant others. The response rate was 42 % for the patients (n=111) and 41 % for significant others (n=100). The participating patients comprised 49 males and 61 females with a median age of 69 years (range 18-84 years), whilst the participating significant others consisted of 41 males and 59 females with a median age of 65 years (range 18-96 years).

Data collection

Papers II and IV were conducted with the support of ambulance clinicians in conjunction with regular ambulance assignments. When the ambulance clinicians had assessed a patient as non-urgent, thus not requiring conveyance to the AED, they selected participants and provided the patient and/or significant other with written information about the study, a questionnaire and a prepaid envelope in which to return the completed questionnaire. As stated in the written information, completing and returning the questionnaire was considered to indicate informed consent.

The questionnaire (APPENDIX 1 and 2) consisted of three parts:

- Demographics
- Person-centred Climate Questionnaire – (PCQ-P or PCQ-F respectively)
- Inductively developed items exploring possible person-centeredness

Person-centred Climate Questionnaire (PCQ)

The PCQ-Patient version was developed by David Edvardsson and presented in a psychometric analysis in 2008 (Edvardsson et al., 2008). The starting point for its development was to compare how patients in various in-patient units perceived person-centred care. The instrument was originality developed in Swedish, but translated into English (Edvardsson et al., 2009a), and Norwegian (Bergland, Kirkevold, & Edvardsspn, 2012). The PCQ has been further devolved for other contexts, such as a staff version, the PCQ-S (Edvardsson, Sandman, & Rasmussen, 2009b) and a family version, the PCQ-F (Lindahl, Elmqvist, Thulseius, & Edvardsson, 2015). Originally, the PCQ-P was originally developed based a theoretical framework described as a three dimensions or subscales:

- A climate of safety
- A climate of everydayness
- A climate of hospitality

The PCQ-F was developed from the same framework as the PCQ-P. However, adjustments were made to convey families' (with a broad definition of what constitutes a family) perception of the climate (Lindahl et al., 2015), perception of the climate. Both the PCQ-P and the PCQ-F are constructed as a 17-item, self-report instrument intended to evaluate to what extent the climate of the healthcare setting is perceived to be person-centred. The responses on the PCQ evaluating the psychosocial care environment are on a six point Likert-typ scale ranging from complete disagreement (1) to complete agreement (6) (Edvardsson et al., 2008). However, the PCQ-F has a six point scale ranging from 0 to 5. (Lindahl et al., 2015). In the studies where the instruments (PCQ-P, PCQ-F) were psychometrically evaluated they demonstrated good psychometric properties, including internal consistency, with a Cronbach's alpha of 0.93 for the total scale.

The Cronbach's alpha for the three subscales was as follows: safety (0.94, 0.95), everydayness (0.82, 0.88) and hospitality (0.64, 0.75) (Edvardsson et al., 2008; Lindahl et al., 2015). The PCQ-P has a score range between 17 and 102, while the PCQ-F originally has a score range of 0 to 85. A higher score corresponds to a more person-centred climate in the care environment (Edvardsson et al., 2008; Lindahl et al., 2015).

Inductively developed items exploring possible person-centeredness

In addition to the PCQ-P and PCQ-F, eight items covering specific aspects of person-centredness from Papers I and III were included. Based on a structural analysis, items were identified by an expert group comprising two senior nurse researchers (with experience of scale development), a doctoral student and two specialist clinical operational nurses with specific interest in and knowledge of the context and person-centred care. In addition, the expert group was asked to assess the relevance, clarity and readability of the items. The participants in Papers II and IV ranked their opinions about possible aspects of person-centredness on a six point Likert-type scale, similar to that of the PCQ-P and PCQ-F, i.e., from complete disagreement (1) to complete agreement (6).

Table 3. Inductively developed items exploring possible person-centeredness within the context of non-urgent ambulance care.

When the ambulance clinicians arrives it is important that they …	
Patients	**Significant others**
Listen at me	Listen to me
Help me to understand what has happened	Help me to understand what has happened
Help me to understand what is about to happen	Help me to understand what is about to happen
Take my concerns seriously	Take my concerns seriously
Take my symptoms seriously	Take my significant other seriously
Take me as a person seriously	Listen to my significant other
Make me feel good in the moment	Make me feel de-burdened
Make me feel safe	Ensure that I can handle the situation before leaving me

The sample size was estimated on the assumption that to obtain a trustworthy result the smallest requisite number of items required in the study should be a sample-to-ratio of 5:1 (Anthoine, Moret, Regnault, Sébille, & Hardouin, 2014; Suhr, 2006), i.e., a minimum 85 for the PCQ-P/PCQ-F and 40 for specific items possibly covering and constructing person-centredness.

Data analysis

Psychometric exploration of the construct validity of person-centredness

The SPSS Statistics 22 (SPSS Inc, IBM Corporation, Armonk, NY, USA) was used for analysing the data. An exploratory factor analysis was conducted. In order to measure the samling adequacy and test the strengh of the relationship among the items, the Kaiser-Mayer-Olkin Measure of Sampling Adequacy (KMO) was employed and set at 0.6 or above, in accordance with Pallant (2013). Values above 0.6 (range 0.0 to 1.0) were used to verify that the data was is suitable for factor analysis. Bartlett's Test of Specificity was employed to test the null-hypothesis, i.e., that there was no relation between the items. It was set at 0.05 or lower (Ferguson & Cox, 1993; Norman & Steiner, 2014; Pett, Macfarlane, & O'Brien-Pallas, 2003). Correlations between the items should be 0.3 or above, stated by Pallant (2013) to indicate medium strength. Finally, item loading should be 0.4 or above in order to be considered relevant (Ferguson & Cox, 1993; Norman & Steiner, 2014; Pett, Macfarlane, & O'Brien-Pallas, 2003).

Exploration of the person-centred climate and relationships between person-centred climate and person-centredness

All demographic data as well as the PCQ-questionnaires and the construct of person-centredness were analysed using descriptive statistical methods (Edvardsson et al., 2008; Lindahl et al., 2015; Pallant, 2013).

The Kolmogorov-Smirnov test revealed that the two samples (i.e., patient and significant others) were unevenly distributed, which led to the decision to use non-parametric statistics. The null hypothesis and statistical methods used are presented in Table 4. Where applicable, p-value <0.05 (two-tailed) were considered statistically significant (Brace, Snelgar, & Kemp, 2012).

Table 4. The null hypothesis tested regarding the PCQ-P/PCQ-F and person-centredness.

Statistical analysis	Null hypothesis
Chi Square	There is no difference in housing (living alone or with someone), educational level, contacting the Swedish Health Care Direct (1177) prior to calling 112 or time of contact with the Ambulance Service between men and women.
Kruskal-Wallis	There is no difference in PCQ scores (including the subscales when tested individually) or the experience of person-centredness due to different levels of education. There is no difference in terms of PCQ scores (including the subscales when tested individually) or the experience of person-centredness due to time of contact with the Ambulance Service. *Paper IV only:* There is no difference in terms of PCQ scores (including the subscales when tested individually) or the experience of person-centredness when it comes to the relationship with the patient. *Paper IV only:* There is no difference in terms of PCQ scores (including the subscales when tested individually) or the experience of person-centredness in relation to who phoned 112.
Mann Whitney U	There is no difference between men and women in terms of PCQ scores (including the subscales when tested individually) or the experience of person-centredness. There is no difference in PCQ scores (including the subscales when tested individually) or the experience of person-centredness between those living alone or with someone. There is no difference in PCQ-scores or the experience of person-centredness related to contacting the Swedish Health Care Direct (1177) prior to calling 112 or not.
Spearman's rho (r_s)	There is no relationship between the person-centred climate (PCQ) and person-centredness (inductively developed items exploring possible person-centeredness).
Binary linear regression (Paper IV only)	The PCQ-F does not explain person-centredness (inductively developed items exploring possible person-centeredness).

Ethical considerations

In all four studies the ethical principles of respect, autonomy, non-maleficence, beneficence and justice (Beauchamp & Childress, 2001) and the Declaration of Helsinki (World Medical Association Declaration of Helsinki [WMA], 2013) were adhered to. The studies were also in line with the Swedish research ethics legislation (SFS 2003:460), and the Data Protection Act (SFS 1998:204).

The Regional Ethics Board of Lund approved the project (No. 2012/253). The participants were informed about the aim, value and confidentiality of the study, that their right to integrity would be respected and their right to decline participation or to withdraw from the study at any time without having to give a reason. Informed consent was obtained for studies I and III. The questionnaires in studies II and IV included an information sheet stating that submitting the completed questionnaires constituted informed consent. Contact information and study data were stored in a way that ensured the confidentiality of the participants in all studies (studies I-IV).

The risk of causing harm, violation or suffering to the participants was considered low in all four studies. The benefits, such as the opportunity for individual persons to share their experiences and contribute to increased knowledge to the healthcare system, were considered to outweigh negative aspects. However, as there is always a risk of strong emotional reactions that patients or significant others might find difficult to handle, a team of a medical doctor and social workers was available.

In study I, one potential participant was immediately assessed with a severe condition when initially contacted by telephone, resulting in the interviewer alerting the emergency services. The interview was never completed and not included in the analysis.

There were no financial interests or incentives involved.

Results

The main results in this thesis are:

- The key concern among patients assessed as non-urgent is being taken seriously and having their needs and suffering confirmed.
- Being taken seriously evokes feelings of empowerment and being seen as a person.
- Not being taken seriously leads to a sense of feeling worthlessness, exclusion and powerlessness.
- Eight different aspects of being taken seriously are strongly linked to each other in what may be viewed as a context specific "package" of person-centredness, explaining 79.86 % of the variance among the patients.
- Significant others wish for immediate de-burdening, which is achieved when the patient is taken seriously.
- Eight aspects of de-burdening constitute person-centredness among significant others, explaining 58.79 % of the variance.
- The psycho-social climate is experienced as person-centred by both patients and significant others.

Being a non-urgent patient in ambulance care

Listen to me

Listening to the patient is a prerequisite for the feeling of being taken seriously in the ambulance care context. For the patients, the need to be listened to begins with the onset of an illness that they are unable to handle. Some patients found it necessary to verify through a friend or significant other that phoning for help was the right thing to do.

When the operator at Swedish Health Care Direct (1177) or the Emergency Medical Dispatch Centre (112) listened, assessed the situation and subsequently sent an ambulance a sense of confirmation replaced the previous feelings of loneliness, insecurity and vulnerability. Being allowed to make choices regarding health matters was also an important aspect of being taken seriously (r_s 0.436). However, a feeling of powerlessness arose when not listened to.

Help me to understand what has happened

For the patients, understanding what has happened is important, as evidenced by the fact that it was easy to talk to the ambulance clinicians (r_s 0.528). When the ambulance clincians listened to the patient's description of her/his health status and personal explanation of the illness during the face-to-face-assessment the patient had the impression of being approached in a welcoming and professional manner. On the other hand, when the encounters with ambulance clinicians were characterized by a lack of empathy and understanding, a feeling rejection arose.

Help me to understand what is about to happen

Patients felt confirmed and listened to when the ambulance clinicians assessed their general health status as opposed to only physical signs and invited them to participate and discuss the required level of care. Not being taken seriously, e.g., not being enabled to understand what was about to happen, was described as being completely dependent on others. This in turn meant feeling subjected to the will and wishes of the ambulance clinicians as well as their judgment regarding the seriousness of the condition. Help to understand what was about to happen was found to be of importance, as it was related to the PCQ-P item rely on receiving the best care (r_s 0.430).

Take my concerns seriously

It was important that the ambulance clinicians were knowledgeable (r_s 0.523). By confirming the patients' perceived illness and signs, e.g., by measuring vital signs such as blood pressure, oxygenation, heart rate, temperature and respiratory rate, the patient felt that the ambulance clinicians trusted them. Nevertheless, sometimes the ambulance clinicians did not take the concerns seriously, which was considered extremely neglectful and insensitive, resulting in a sense of worthlessness and feeling insulted. There were also situations where the patients felt unwilling to participate because they did not have the necessary knowledge about what was causing the symptoms and considered that the ambulance clinicians were the medical experts. As a result, these patients did not actively participate in the decision-making process about going to the hospital or remaining at home.

Take my symptoms seriously

When the ambulance clinicians took the patients' symptoms seriously, a partnership was established through the dialogue. A key aspect was that the ambulance clinicians having time for the patients (r_s 0.578). By spending time with the patient, the ambulance clinicians gave the impression of taking the symptoms seriously. However, patients experienced a sense of worthlessness when they felt obliged to trust and accept the assessment and decision made by the ambulance clinicians, regardless of whether or not it corresponded with their own perception of the illness.

Take me seriously as a person

Paying attention to what the patient said was as a key component in taking the her/him seriously (r_s 0.451). Being seen as person resulted in a sense of confirmation that banished feelings of uncertainty were replaced. This was further strengthened when the patient was invited to be part of the decision-making process. Being listened to and invited to be a partner in the dialogue were considered paramount by the patients and resulted in a sense of empowerment. When the ambulance clinicians made all the decisions, the patients felt excluded, which evoked feelings of shame and guilt. In such situations, they hoped that they would never have to phone for an ambulance again.

Make me feel good in the present moment

The patients highlighted the importance of the ambulance clincians creating a calm and peaceful atmosphere created by the professionals, e.g., by inviting them into to a partnership through dialogue and allowing them to share their narrative. Giving the patients "a little bit extra" (r_s 0.529) often resulted in them no longer feeling the need for emergency care at the AED.

Make me feel safe

When the patients and the ambulance clinicians came to a mutual agreement to remain at home, the patients were told to phone for an ambulance again if the situation worsened or new symptoms developed. This extra effort on behalf of the patients was considered very positive and gave the patients a sense of not being left to manage the illness alone, which can be seen as making a little extra effort on behalf of the patient (r_s 0.594). The patients also felt empowered and prepared for self-care activities. On the other hand, one participant who was discharged from hospital despite not feeling well/still feeling unwell described not feeling safe.

Being a significant other in non-urgent ambulance care

Listen to me

Significant others highlight the importance of the ambulance clinicians being able to talk to the patient in a manner that she/he can understand (r_s 0.361). An important aspect of de-burdening is to provide significant others with a sense of being listened to and understood. When the significant others perceived the situation as unbearable and decided to phone the Emergency Medical Dispatch Centre (112) it was important to be taken seriously and not be questioned about their decision to request an ambulance.

Help me to understand what has happened

At a certain point significant others were no longer able to handle the situation, i.e., the responsibility of caring for the patient. The significant others stated that when worries, anxiety, loneliness and uncertainty took over, their only option was to contact Swedish Health Care Direct (1177) or the Emergency Medical Dispatch Centre (112). When the relationship between the PCQ-F and person-centeredness was explored, the importance of the patient being offered a choice to take part in decision-making was revealed (r_s 0.410).

Help me to understand what is about to happen

The significant others pointed out that in order to understand what is about to happen, the ambulance clinicians must have time for the patient (r_s 0.503). It was perceived as positive when the ambulance clinicians arrived at the scene and, in a sense, permitted the significant others to hand over the immediate need for decision-making, thus instantly de-burdening them.

When the significant others felt that everything was in order, they were empowered to continue caring for the patient at home. A feeling of being a partner in the decision-making emerged. Nevertheless, if the encounter with the ambulance clinicians was perceived as superficial and did not lead to de-burdening, feelings of being excluded from the decision-making process emerged.

Take my concerns seriously

An important aspect for significant others is that the ambulance clinicians make a little extra effort on behalf of the patient (r_s 0.376). Being de-burdened from caring responsibilities was of major importance and the main reason for sending for the ambulance.

The significant others disliked being questioned by the ambulance clinicians about why the ambulance had been summoned, as it should have been evident that they would not have phoned unless they believed it was absolutely necessary.

Take my significant other (the patient) seriously

The significant others considered it important that the ambulance clinicians took a warm and professional approach towards the patient, as such an approach provided feelings of comfort. The fact that the ambulance clinicians took responsibility for the examination as well as keeping the examination bag and equipment neat and clean (r_s 0.525), resulted in both significant others and patients perceiving that the ambulance clinicians took the situation seriously. However, in some cases/instances the ambulance clinicians assumed a professional, outsider perspective and consequently failed to take the insider view into account. As it was of the utmost importance to take the patient seriously, lack of explanation or discussion with significant others about the reason for non-conveyance to the AED resulted in feelings of rejection and not being confirmed.

Listen to my significant other (the patient)

In order for significant others to perceive that the ambulance clinicians listened to the patient they needed to see that they made a little extra effort on the patient's behalf (r_s 0.454). Significant others preferred ambulance clinicians to address their questions directly to the patient. Previous healthcare encounters often resurfaced and could affect how the ambulance care was perceived. If significant others had previously felt abandoned, the present encounter was also perceived as uncaring. Listening to the patient and making sure that her/his situation was under control was described as paramount and made significant others feel secure.

Make me feel de-burdened

Significant others experienced a sense of calm when it was decided to send an ambulance, as help was on the way. Some informants/participants also highlighted the importance of the ambulance arriving quickly. The presence of the ambulance clinicians reduced the significant others' caring responsibilities, as they were able to temporarily hand over the interpretation of the patient's symptoms and decision-making. Significant others also thought that talking about everyday life and not only focusing on the illness was of importance (r_s 0.371). However, some encounters with the Ambulance Service were considered stressful. The significant others felt abandoned and did not obtain the requested support, leaving them with feelings of powerlessness as well as stunned about what happened during the encounter. They felt sad and angry about having to continue with their caregiving responsibility without temporary relief or being prepared for the situation. A sense of humiliation emerged due to not having their needs confirmed.

Ensure that I can handle the situation before leaving me

Taking the patient seriously was a prerequisite for making significant others feel reassured and willing to continue with their caregiving responsibility. It was vital that the ambulance clinicians had time for the patient (r_s 0.485) and stayed at the scene until the condition was under control and the significant others felt secure. When significant others were in control of the situation and informed that they could phone for an ambulance again at any time they gained the confidence to carry on with their caring activities.

Conversely, a sense of being abandoned emerged when the ambulance clinicians did not consider and confirm the significant others' needs, concerns about the patient and the often self-imposed caregiving responsibility. Some informants/-participants even expressed the need to receive a personal apology for such uncaring behaviour.

The construct of person-centredness

In Paper I, eight different aspects of being taken seriously were developed and tested in a context-specific construct of person-centredness. These aspects were strongly linked to each other as described in Table 5. The exploration of the items revealed a KMO-value of 0.9 and Bartlett's test of sphericity value <0.05, while all correlation coefficients between items were clearly above 0.3. The analysis indicated that all items would fit in a single factor, explaining 79.9 % of the variance.

Concerning significant others, a similar construct of person-centredness with eight aspects of de-burdening was found (Table 5). The exploration of the items covering possible person-centredness revealed a KMO-value of 0.831 and Bartlett's test of sphericity value <0.05. Furthermore, all correlation coefficients between items were clearly above 0.3. The analysis indicated that all items would fit in a single factor, explaining 58.8 % of the variance.

There was a relationship between the construct of person-centredness and the psychosocial part of the person-centred climate both among patients and significant others. In Paper IV a regression model indicated that the PCQ-F questionnaire could possibly explain the construct of person-centredness by 31.7 %.

The exploration of the items revealed a highly homogenous construct that can be viewed as context specific "packages" of person-centredness (PCN-package), involving eight different aspects of being taken seriously (Paper II) and being de-burdened (Paper IV), which are strongly linked to each other (Table 5). This allows the possibility of teasing out the essentials of person-centredness in the non-urgent ambulance care context.

Table 5. Inductively developed items covering possible person-centredness within the non-emergency care ambulance care context and factor analysis.

When the ambulance clinicians arrive it is important that they…		
	Patients	**Significant others**
Listen to me	0.836	0.750
Help me to understand what has happened	0.836	0.715
Help me to understand what is about to happen	0.844	0.785
Take my concerns seriously	0.947	0.846
Take my significant other seriously	-	0.801
Takes my symptoms seriously	0.962	-
Listen to my significant other	-	0.760
Takes me seriously as a person	0.923	-
Make me feel de-burdened	-	0.649
Makes me feel good in the present moment	0.906	-
Ensure that I can handle the situation before leaving me	-	0.810
Makes me feel safe	0.884	-

Experiences of the person-centred climate

The score levels of the person-centred climate (including the subscales) as well as those of the items possibly covering person-centredness for patients and significant others are presented in Table 6a and 6b. The results indicate that the climate as a whole was experienced as person-centred. However, when broken down to subscale level, *Safety* and *Hospitality* accounted for higher ratings than *Everydayness.* The latter corresponds to physical aspects of the climate, while the two former mainly measure psychosocial aspects. The participants scored the inductively developed items exploring possible person-centredness at the higher end of the scale and to a great extent the questionnaires were fully completed (Paper II: n=103 of 111 possible participants, Paper IV: n=92 of 100 possible participants).

Table 6a. The PCQ-P total and subscale score levels and scores of the inductively developed items exploring possible person-centredness.

	PCQ-P Total	**Safety**	**Everyday-ness**	**Hospi-tality**	**Person-centr. Patients**
Number (n)	78	100	85	85	103
Mean	92	57	19	16	45
SD, min-max	12.3, 43-102	5.6, 24-60	5.0, 4-24	2.6, 3-18	5.4, 11-48
Median	96	59	20	17	48
IQR	15	6	8	3	3
Skewness	-1.701	-2.815	-1.035	-2.146	-3.975

Table 6b. The PCQ-F total and subscale scores, as well as the scores of the inductively developed items exploring possible person-centredness

	PCQ-F Total	**Safety**	**Everyday-ness**	**Hospi-tality**	**Person-centr. Signifcant others**
Number (n)	58	88	59	70	92
Mean	93	57	20	16	46
SD, min-max	7.7, 70-102	4.1, 36-60	3.7, 7-24	2.1, 8-18	3.1, 31-48
Median	95,5	59,5	20	17	48
IQR	10.75	4	4.75	3	3
Skewness	-1.294	-2.658	-1.256	-1.833	-2.427

Discussion

Methodological considerations

Irrespectively of the chosen study design, several more or less obvious methodological aspects might affect the results in various ways. This thesis was based on two designs, namely the inductive phenomenological hermeneutics approach (Papers I and III) and the explorative cross sectional approach (Papers II and IV). In order to discuss and assess methodological issues, Papers I and III were scrutinized in terms of their trustworthiness, expressed as credibility, transferability, confirmability and dependability (Lincoln & Guba, 1985). Papers II and IV were assessed in relation to their validity, which including internal, external and construct validity (Kazdin, 2010).

Trustworthiness

Lincoln and Guba (1985) suggest four criteria for ensuring trustworthiness in qualitative research: credibility, dependability, confirmability and transferability. It is sometimes challenging to separate the four criteria of trustworthiness because they are so closely connected to each other (Lincoln & Guba, 1985).

Credibility

Credibility refers to confidence in the truth of the findings and data analysis. According to Lincoln and Guba (1985), credibility involves two aspects. Firstly, they emphasize the need to strengthen the believability of the findings when conducting the study and ensure that steps have been taken to establish credibility for external readers.

One potential threat to credibility is that all interviews with the participants in Papers I and III were conducted by telephone. Traditionally, telephone interviews have mainly focused on quantitative surveys (Trier-Bieniek, 2012). However, the interviews in this thesis were all conducted by telephone because none of the potential participants were interested in being interviewed face-to-face. In line with Hewison and Haines (2006), the potential participants in this thesis mentioned lack of time and unwillingness to travel or allow the interviewer into their home, while others gave no reason for declining to participate in a face-to-face interview. However, they expressed an interest in participating in the studies when offered the possibility of a telephone interview. Mealer and Jones (2014) suggest that telephone interviews are considered less intrusive when collecting information on sensitive topics, e.g., when patients consider themselves dependent on the care provided. Although being dependent on the care provided should not really apply to the participants in Papers I and III as they were clearly informed that the study was being performed by Lund University, it can nevertheless not be completely ruled out. Being unable to perform face-to-face interviews eliminates non-verbal communication. Fontana and Frey (1994) outlined four types of non-verbal communication:

1. Proxemics – How individuals communicate attitudes and trust by controlling their space.
2. Kinetics – How facial expression, posture and gestures are used when communicating.
3. Chronemics – How "time" is used, e.g. length of silence in interviews or conversations and the pacing of speech.
4. Paralinguistics – How our voice communicates in terms of tone, speed, pitch and volume.

(Fontana & Frey, 1994)

Proxemics and kinetics are lost in telephone interviews (Novick, 2008). However, Mealer and Jones (2014) argue that this loss of visual signs may be an advantage as it allows emotional distance and eliminates judgemental non-verbal communication on the part of interviewers. This can be applied to the participants in the present thesis (Papers I and III), as they were assessed and triaged as non-urgent, thus ensuring credibility despite the lack of a face-to-face interview situation.

Another possible threat to credibility is the generally short duration of the interviews. In Paper I the interviews lasted between 15 and 46 minutes and in Paper II between 16 and 40 minutes. Potentially, the short interviews could lead to a risk of limiting the depth and believability of the studies, thus affecting the results. However, as the potential participants in Papers I and III were informed about the aim of the studies in two steps; by the recruiting ambulance clinician (verbally) and by the interviewer (verbally and in writing) before the actual interview, the interviews were very focused on the phenomenon of interest.

In Papers I and III, the participants' statements were actively followed up with probing questions to prevent retrospective misinterpretations. The disadvantage of a researcher's pre-understanding has often been pointed out. However, when it comes to credibility, knowledge of the specific context may be an advantage, as it enhances the researcher's ability to step into the participants' descriptions and experiences. In this specific case (Papers I and III), while the descriptions and experiences. While the descriptions and experiences in Papers I and III are those of the patients and significant others, the interviewer was familiar with the context. Furthermore, quotations have been added to enable the reader to decide whether the analysis is reasonable.

Dependability

Credibility cannot be achieved if the dependability has not been established (Lincoln & Guba, 1985). Dependability describes the consistency and stability of the findings over time and conditions (Lincoln & Guba, 1985). The participants in Papers I and III were recruited by ambulance clinicians in conjunction with ordinary ambulance assignments. Thus, there is a potential for selection bias if the ambulance clinicians experienced the encounter with the patient and/or significant other as disadvantageous. However, dependability can be deemed satisfactory as patients and significant others were also recruited when the encounter was characterized by not being listened to and not being acknowledged or confirmed in their suffering.

Confirmability

Confirmability corresponds to what is termed objectivity and neutrality in a quantitative design. The data should reflect the voice of the participants expressed in the form of meanings, experiences or perceptions instead of the researcher's biases, motivation or perspectives (Lincoln & Guba, 1985). Allowing previous experiences of the phenomenon to influence the analysis, i.e., the pre-understanding, is an important factor when considering confirmability. The pre-understanding of my co-authors and my own pre-understanding has been present throughout the data collection as well as during the interpretation and analysis process. While the context of the thesis was very familiar to me, it was only partly familiar or not at all familiar to my co-authors. Disregarding the pre-understanding can be problematic because it is based on, e.g., previous experiences (Larsson, 2005) and one's professional perspectives (Malterud, 2009). A pre-understanding also provides benefits (Malterud, 2009), and in this thesis it pre-understanding helped us to decide how the data collection should be conducted. As proposed by Nystrom and Dahlberg (2001), researchers' pre-understanding of an area or phenomenon can prove to be of importance in all parts of the research and may possibly affect the understanding, interpretation and analysis of research results in a specific way. I conducted the interviews and made great efforts to bridle my pre-understanding by adhering to the interview guide as well as bearing in mind the aims and research questions of the studies. A constant dialogue and reflectiveness with the co-authors was helpful in the strive to minimize interview bias. As the co-authors are not connected with the field of interest, it enabled a "helicopter view", which was considered to prevent the analysis and the manuscript writing process from being negatively influenced by the pre-understanding. According to Lindseth and Norberg (2004), efforts have to be made to become aware of and develop our pre-conceptions, as the interpretations often emanate from them. Other persons or the literature can facilitate how pre-conceptions are utilized in the interpretation. By adopting a system of consensus and reflections within the research group, possible pre-understanding was identified. However, there was a constant awareness of the risk of pre-understanding bias.

To further strengthen the confirmability, the analysis and findings in Papers I and III were discussed during regular research meetings and alternative interpretations were formulated and questioned. Thus, the full text of the interviews, which was transcribed verbatim, as well as the analysis process was scrutinized by all three authors. Only data relevant to the aim were included in the final analysis. By "returning" to the participants using direct quotations in the results section, the reader can judge whether the participants' perspectives are clearly represented. The three researchers agreed on the findings and the final comprehensive understanding, which enhances confirmability.

Transferability

Transferability is analogue to the quantitative expression generalization and is qualitative research is used to determine the applicability of the findings in other settings and groups (Lincoln & Guba, 1985). Transferability is also strengthened through detailed description of the context and the research findings (Frambach, van der Vleuten, & Durning, 2013). All participants in Papers I and III were recruited within one specific ambulance district in the southernmost county of Sweden. Thus, there is a potential risk that the encounters were biased due to a context specific culture. However, the ambulance district in question involves both rural and urban areas. The participants in Papers I and III were also of various ages, both sexes and the patients were all considered non-urgent and thus left in their own homes. As the patients' conditions were non-urgent, we argue that the findings are transferrable to many other patients with chronic medical conditions.

Papers I and III employed a phenomenological hermeneutic approach as described by Lindseth and Norberg (2004). The analysis for the two papers was inspired by two-fold structural analysis, as the results revealed the importance of being taken seriously or not being taken seriously as the meaning of being a non-urgent patient. Similarly, the results from the significant others of patients who were considered non-urgent revealed the meaning of being in need of immediate de-burdening or not being de-burdened. Lindseth and Norberg (2004) argue that because texts are multidimensional, several structural analyses can be performed in order to reveal different meanings. Thus, our approach comprising two structural analysis is supported in the literature. Lindseth and Norberg (2004) argues that since texts are multidimensional, several structural analyses may be performed in order to reveal different meanings. Thus, our approach with two structural analysis is supported by the literature (Lindseth and Norberg, 2004). However, based on one reviewer's comments at the time of the publication of Paper III, the structural analysis changed from two to one.

Retrospectively, there were two aspects that differed from the chosen method; **1**) Unfortunately, in the first study the term saturation was used when the actual intention was to describe the richness of the data. The term is intimately associated with grounded theory methodology and thus not in line with the chosen method. However, the usage of the term saturation has shifted somewhat from a purely grounded theory oriented employment to e.g., descriptions of richness. In order to prevent lack of clarity the term saturation should have been avoided in the two qualitative studies (Varpio, Ajjawi, Monrouxe, O'Brien, & Rees, 2017). The conclusion made in Paper I regarding richness and whether there were sufficient data for a structural analysis and understanding of being taken seriously was further confirmed in Paper II. The understanding of the aspects of being taken seriously generated in Paper I and strengthened in Paper II indicates that the collected data were sufficiently rich *and* **2**) At the time of the work on Papers I and III, I was inspired by grounded theory as a part of my PhD-education. In order to establish trustworthiness and thus ensure that the comprehensive understanding was reasonable, two patients and one significant other were re-interviewed. Although Kvale (1996) and Frambach at al. (2013) argue that it may be advisable to re-interview participants in order to allow them to comment on the analysis as part of a "validation process", the phenomenological hermeneutic approach does not encourage re-interviews. However, as one participant was in obvious distress as a result of recalling the encounter with the ambulance clinicians, the second interview served to ensure that she/he was not negative affected by the interview and at the same time, a deepened understanding of the participant's encounter with the Ambulance Service was achieved. Thus, follow-up interviews served as a way to adopt an ethical research approach and also to validate the comprehensive understanding that emerged. Nevertheless, from a strictly methodological point of view, use of the term saturation and follow-up interviews were not in line with the chosen method.

Internal validity

Internal validity refers to whether or not the conclusions drawn are credible. The internal validity is therefore bound to the moment when the study was conducted (Kazdin, 2010). There are several potential threats, i.e., alternative explanations, to internal validity that have been grouped into to several classes, where issues mainly concerning selection and attrition are discussed in relation to this thesis (Polit & Beck, 2010).

In terms of the inclusion of participants in Papers II and IV, the intention was to employ consecutive sampling. However, in reality it was impossible to include all eligible participants for organizational reasons. The use of a convenience sample is typical in projects intended to evaluate a particular population (Kazdin, 2010), i.e., patients or significant others of patients who were assessed as non-urgent by ambulance clinicians. However, the available participants may be atypical, leading to the risk of bias (Polit & Beck, 2010), which might have implications for generalization of the results (Kazdin, 2010). The sampling in Papers II and IV aimed at a specific population, thus a convenience sample was considered most appropriate. The size of the sample was set for two reasons;

- The sample ratio should be at least 5:1
- The minimum number of questionnaires should be 100

(Anthoine et al., 2014; Suhr, 2006).

The ambulance clinicians therefore handed out 266 patient questionnaires (111 returned) and 241 questionnaires to significant others (100 returned). The data collection ended when 100 completed questionnaires had been returned. Ideally, the questionnaires should be sent by mail/post to a random sample derived from the register of Ambulance Service users. However, that was not possible when the project was designed and planned in 2012, because all patient records were on paper and not accessible for research purposes, hence the application to the Research Ethics Committee did not include this option. In the meantime the Ambulance Service register has been developed, possibly opening up alternative sampling options.

Another potential source of selection bias was that operational ambulance clinicians handed out all questionnaires to the potential participants. If the encounter with the patient or the significant other was considered negative by the ambulance clinicians, the willingness or motivation to hand out the questionnaire could have been impaired. However, as the returned questionnaires that contained various opinions, we are confident that the patients or significant others also provided critique and that the findings do not only give a positive view of the ambulance care. Nevertheless, this issue must be taken into account by the reader when interpreting the findings.

In Paper IV a linear regression analysis was employed in order to explore the relationship between the inductively developed items concerning possible person-centeredness and the PCQ-F (and its subscales). The use of a linear model when the residuals are unevenly distributed might be open to criticism. However, the alternatives, e.g., categorization requiring a logistic regression analysis, would imply arbitrary cut-off values and a risk of data/information being lost (Kazdin, 2010; McDowell, 2006). A larger number of observations (i.e., participants) and greater variety in the dispersion would have been desirable. However, in view of the fact that a previous study involving the PCQ used a linear regression analysis (Mullaney, Olausson, Sharp, Zackrisson, Edvardsson, & Nyholm, 2016), the chosen method provides an indicative result (Kazdin, 2010; McDowell, 2006).

External validity

Generalisation is the extent to which results are relevant to other situations, people, places and contexts. The results may emerge in a particular way because the participants may act differently when they participate in a study (Kazdin, 2010). Non-responders have to be addressed as they generally have an impact on the results in terms of generalizability (Polit & Beck, 2010). The design was not experimental or a case-control study where it is important to analyse non-responders in a consistent manner (Kazdin, 2010). In Papers II and IV, the operational ambulance clinicians recruited potential participants by handing out questionnaires in accordance with the inclusion criteria. Unfortunately the number of eligible participants that actually met the inclusion criteria is unknown. The point of departure was that returning the questionnaire was a voluntary, anonymous act and that declining to participate was also an act that should not be analysed or questioned. Thus, it would be unethical to record or analyse non-responders. Likewise, the approval from the Ethics Committee did not include analysis of the non-responders.

Declining participation could be an expression of strong personal autonomy (Lindberg, Fagerström, Sivberg, & Willman, 2014) and declining participation or withdrawing at any point without having to state a reason is in line with the Helsinki Declaration (VMA, 2013). The potential participants were asked/invited to participate and informed both verbally and in writing about the study and that participation was voluntary. A researcher could be questioned for registering and performing an analysis of non-responders when using an exploratory study design.

An analysis may deepen the understanding of whether the non-responders would have had some impact on the findings, if they suffered from particular medical or nursing conditions or had certain important reasons. Nevertheless, as the findings in this thesis suggest that patients and significant others are in a vulnerable and exposed situation (Papers I-IV), the question of participation and non-participation needs to be addressed with a high degree of sensitivity and should be taken into consideration when assessing the response rate of returned questionnaires.

The response rates were 42 % (sample size 266 patient questionnaires) and 41 % (sample size 241 significant other questionnaires). The fact that the participants were anonymous precluded sending a reminder to non-respondents. While we attempted to achieve a high response rate (Polit & Beck, 2010), in a review article on the subject by Badger and Werrett (2005), it is suggested that for self- reported postal questionnaires a response rate of 40 % is common and 25-30 % is typical. Some studies indicate that concerns about non-responders may be exaggerated, as rigorous recruitment (response rate of about 60 %) and a standard approach (response rate of about 35 %) revealed similar results (Keeter, Miller, Kohut, Groves, & Presser, 2000; Krosnick, 1999). It has also been demonstrated that patient enrolment and logistical problems are key issues for researchers in clinical settings (Cullati et al., 2016). Among patients eligible for enrolment in studies, the most common reason for declining participation is "not interested" due to older age (Agoritsas, Deom, & Perneger, 2011; Harrison et al., 2016). Of course to a large extent the underlying reason for the non-response of those who were asked to participate in Papers II and IV and initially agreed to do so is speculative. However, in a yet unpublished study on non-urgent patients arriving at the AED by ambulance, potential participants clearly did not want to participate due to lack of physical and psychological strength, but told the researcher that they perceived the encounter as satisfactory. If these findings were to be transferred to our setting it could be that they perceived the encounter as highly positive and therefore found no need to complete and post the questionnaire. On the other hand, an encounter that was experienced as negative could evoke feelings that prevent the potential participants from completing the questionnaire due to the wish/desire to leave the encounter with the ambulance care behind her/him.

The ambitions of Papers II and IV includes capturing the experiences of the person-centred climate and person-centredness among patients and significant others. The notion of measuring experiences has been questioned on the basis that it is impossible to measure everything that happens within healthcare (Foot & Fitzsimons, 2011). In addition, there are issues of validity, i.e., what is really measured and whether it is possible to address all aspects of the phenomenon as in qualitative studies (Polit, & Beck, 2010). However, the PCQ-P/F instruments rest on a solid foundation of an experience-based inductive research framework (Edvardsson et al., 2008; Lindahl et al., 2015). Studies that employ the PCQ explicitly express investigate experiences (Bergland, Hofoss, Kirkevold, Vassbo, & Edvardsson 2015; Edvardsson et al., 2008; Edvardsson, Watt, & Pearce, 2017; Sjögren, Lindkvist, Sandman, Zingmark, & Edvardsson 2013). The inductively developed items covering possible person-centredness do not rest on as strong a theoretical foundation as the PCQ, but still include inductively derived information on experiences. A combination of qualitative and quantitative information as in this theses is considered most useful for exploring experiences of the care provided (Foot & Fitzsimons, 2011), as presented in this thesis.

Construct validity

Construct validity concerns how accurately a particular method makes it possible to measure phenomena such as intelligence, ability to concentrate, perseverance, thoroughness, superficiality, primacy, affection, verbal ability and neuroticism (Kazdin, 2010). As reported by Polit and Beck (2010), validity is a quality criterion referring to the extent to which an instrument measures what it is intended to measure. More explicitly, when assessing the validity of an instrument the key questions would be what the instrument actually measures and if the abstract concept of interest is measured. To the best of our knowledge there were no questionnaires matching our research questions that had been tested and validated in the ambulance care context. Therefore, we chose to employ the Person-centred Climate Questionnaire, which had the advantage of being developed in a Swedish setting and addressing both patients and family (i.e., interpreted as significant others). The instrument demonstrated good psychometric properties including internal consistency, i.e., reliability, with a Cronbach's alpha of 0.93 for the total scale for both the PCQ-P and PCQ-F (Edvardsson et al., 2008; Lindahl et al., 2015). Since its development the PCQ-P has been employed in clinical studies (Edvardsson et al, 2017; Mullaney et al., 2016). A possible limitation is that the instruments were developed for an institutional setting, e.g., nursing homes or the AED. As a consequence, some adjustments were necessary. All 17 items in the PCQ-P/F originally started with "A place". As the patients were not conveyed by ambulance to the AED we chose to change the wording to; "*I experience the care provided by the ambulance clinicians as care where…*" after having consulted the designer of the instrument. This adaptation of the instrument to the context raises questions about whether it can still be considered to be validated. However, I argue that if the wording had not been altered it would have been difficult or impossible to use it in the present context.

To supplement the issues concerning the climate, we wanted to address questions regarding person-centeredness (Papers II and IV) by deriving items from the inductive studies (Papers I and III). Several efforts were made to establish the validity and reliability of the items covering possible person-centeredness. We assessed the content validity in two ways: comparison with the literature on person-centeredness and consultation with an expert group comprising two senior nurse researchers (with experience of scale development) and two clinical specialist nurses with specific interest in and knowledge of person-centred care. They were asked to assess the relevance, clarity and readability of the items. The scaling was similar to the PCQ-scales, i.e., a six point Likert-type scale from complete disagreement (1) to complete agreement (6). The experts considered the content validity good and that the items reflected what is described in the literature as central aspects of person-centeredness. The construct validity was satisfactory as the factor analysis resulted in one factor explaining 79.9 % (Paper II) and 58.8 % (Paper IV) of the variance, thus indicating that the items measure the underlying construct rather well. The reliability was assessed by the level of internal consistency and Cronbach's alpha was 0.96 (Paper II) and 0.88 (Paper IV), suggesting an almost too good internal consistency in Paper II.

The aim was not to develop or test an instrument, but to explore the person-centred climate in the context of Swedish ambulance care. Furthermore, it was considered useful to explore if, and how, the items possibly covering person-centredness derived from Papers I and III respectively, were interrelated. Hence, calculations of individual items and the overall construct (CVI) were not considered applicable. However, in retrospect it would have been useful to adopt the classic instrument development steps, e.g., applying face validity and content validity (index) to ensure adequate measurement properties in the construct (Norman & Streiner, 2014; Polit & Beck, 2010). Applying all the steps would have been especially valuable for the items possibly covering person-centeredness, but also for the PCQ instruments because they have never been used in the Swedish Ambulance Service context. Face validity, i.e., the relevance of the items/questions, would have "detected" that the *everydayness* subscale was not appropriate or relevant in the given context. Hence, the irritation experienced by some of the participants, expressed by written comments and unwillingness to continue answering the questions on the subscale, would have been avoided (Papers II and IV).

General discussion of the results

One of the main results of this thesis is that patients have a strong desire to be taken seriously. This can be fulfilled by listening to the patient, helping her/him to understand what has happened, what is about to happen and enabling her/him to feel safe and content in the present moment. The second is that for significant others it is important to be immediately de-burdened from caring responsibilities, achieved by listening to the significant other and the patient, taking both of them seriously and ensuring that the significant other can handle the situation before leaving them. These fundamental human, but also context specific needs can be understood by reference to Ricœur (1992), who implies that the most challenging suffering occurs when one's human abilities are not recognized, thus being reduced as a human being. The capable person acts and suffers and vulnerability is not a defect to be eliminated, but a constitutive part of the human being that opens up her/him up to other people. This is in line with Eriksson (1994), who argues that the suffering caused by care can be expressed in many different ways and can affect a person's dimensions of life, where practical, emotional and existential needs must be considered. In “The Suffering Human Being" Eriksson (1994) particularly emphasizes the aspects of violation of dignity, condemnation, exercise of power and non-caring. Being taken seriously and de-burdened are discussed from the perspective of being a patient and significant other, as well as a carer and from organizational perspectives.

Being a person in need of being taken seriously

The care environment is the context in which care is delivered and contains both psychosocial and physical elements (Edvardsson, 2009b; McCormack & McCance, 2010). The participants ranked the climate as a whole as person-centred (Paper II).

The patients’ point of departure is an experience that the situation is intolerable due to their experienced illness. However, phoning for an ambulance was in a way a process and not something that the patients took lightly. (Paper I). Similar experiences are described in other studies (Ahl et al., 2006; Ahlenius et al., 2017). According to Möller, Fridlund and Göransson (2010), patients in an emergency setting have concerns about being unable to describe and express their symptoms. Patients experienced loneliness, vulnerability, anxiety and even fear before the arrival of the ambulance (Holmberg et al., 2014).

Listening to the patient is a prerequisite for the ability to confirm the perceived illness and enable a sense of being taken seriously. When not listened to, patients were left with a sense of powerlessness (Paper I). Not being listened to or asked about their opinion is experienced as a disrespectful encounter (Lundgren & Berg, 2011). Being listened to and viewed as a unique person are considered as criteria for experiencing context specific person-centredness (Paper II). Truly listening to the patient provides an opportunity to understand how she/he thinks, feels and perceives her/his health status (Dahlberg & Ekman, 2017). Taking time throughout the encounter and listening to the patients' stories is perceived as enabling communication (Fredriksson, 1999; Melby & Ryan, 2005; Nygren Zotterman, Skär, Olsson, & Söderberg, 2016). Time should be considered an important factor. Patients described bad encounters as e.g., when the ambulance clinicians were stressed and unable to spend time with them (Paper I). When patients perceive that carers do not have time for them it is what Eriksson (1994) mentions as an example of non-caring suffering due to care, which could also be considered an example of being mistreated (Berglund, Westin, Svanström, & Sundler, 2012).

Helping patients to understand what has happened and is about to happen was intimately connected to the fact that it should be easy to talk to the ambulance clinicians and be reassured about receiving the best care (Paper II). The relationship between the patient and the carers (in this case the ambulance clinicians) is considered asymmetrical (Kasén, 2002). The ambulance clinicians possess knowledge about the healthcare system, as well as symptoms/signs and treatment for which the patient has sought help. However, the patient has the knowledge of how she/he experiences the illness. This highlights the cognitive disadvantage, i.e., a knowledge gap as part of the triple disadvantage (Kristensson Uggla, 2014). Being deprived of information and the mere awareness of the fact that the ambulance clinicians have more knowledge is an exercise of power (Arman, 2015b; Eriksson, 1994). This induces a sense of powerlessness as an expression of the suffering caused by care, which is described in Paper I and in other studies (Dahlberg, 2002; Eriksson & Svedlund, 2007; Forsgärde et al., 2016). The key strategy for preventing powerlessness is to embrace the patients' empowerment capabilities, i.e., the fundamental power and ability based on knowledge and experience of oneself as a person (Smith, Turkel, & Wolf, 2012). A caring relationship is perceived as positive when symmetrical, thus a partnership should be established (Ekman, 2014; Ekman et al., 2011). The value of being able to have a fruitful and mutual dialogue, i.e., that it should be easy to talk to the ambulance clinicians, is confirmed by previous studies (Nygren Zotterman, 2017; Nygren Zotterman et al., 2016). According to patients, an aspect of a good encounter is gaining an understanding of the health problems, which is achieved by receiving an explanation that is easy to understand (Nygren Zotterman, 2017; Nygren Zotterman et al., 2016).

Being taken seriously involves confirming the person (i.e. the patient) and her/his concerns and symptoms (Papers I and II), which is described as important in many studies (Ahlenius et al., 2017; Björkman, Simrén, Ringström, & Jakobsson Ung, 2016; Forsgärde et al., 2016; Georgsson, Linde, Pettersson, Nilsson, & Rådestad, 2016; Lidén & Yaghmaiy, 2016; Sandström, Nilsson, Juuso, & Engström, 2017; Schultz, Qvist, Mogensen, & Pedersen, 2013; Wikberg, Pettersson, Westman, Björkelund, & Petersson, 2016). The ambulance clinicians' competence was found to be an important factor in taking the concerns of the patients seriously (Paper II), which is in line with Holmberg (2015), who found that patients trusted the ambulance clinicians' competence. Both confirming the perceived illness and checking vital signs was considered essential. When concerns were not taken seriously, i.e., not believed or questioned, the encounter was seen as neglectful (Paper 1), which is supported by (Ahlenius et al., 2017; Eriksson & Svedlund, 2007). Taking the symptoms seriously requires time (Paper II). However, when the patient and/or significant other are not involved in the assessment and decision about further care or referral it can result in a feeling of worthlessness. Paying attention to what the patient said was paramount when taking her/him seriously, while being listened to and invited to participate in the decision-making process resulted in a sense of empowerment. Guilt and shame were evoked if the ambulance clinicians made all the decisions themselves (Papers I and II). In summary, being taken seriously involves balancing on a thin line, where the ambulance clinicians' implicit and explicit verbal and non-verbal expressions make the difference in how the encounter is perceived (Arman, 2015b).

Unpleasant encounters, including lack of participation, may result in negative consequences such as suffering and increased risk of adverse physical events (Andersson, Frank, Willman, Sandman, & Hansebo, 2015). In fact not being taken seriously is an infringement of the patient's dignity. Dignity is intimately connected to human value (Eriksson, 1994). A person needs to be taken seriously to maintain her/his own value. The violation can be viewed either explicitly by e.g., nonchalance or neglect, but also implicitly by the sense of not being seen as a person, i.e., being objectified. Perceiving illness and thus being in a vulnerable situation means experiencing suffering. If the ambulance clinicians fail to take this into account, the suffering is likely to increase (Arman, 2015b). Based on an ontological, ethical and existential perspective, suffering related to healthcare is essentially a matter of negligence and uncaring where the patient's suffering is not seen and the person is not viewed as a whole human being (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004). This can be linked to Ricœur's thoughts about suffering and human capability, where the most challenging suffering occurs when one's human abilities are not recognized, thus being reduced as a human being (Ricœur 1992; 2011). Perceiving an illness involves being in a vulnerable and exposed situation (Arman, 2015b; Dahlberg & Ekman, 2017). Ahlenius et al. (2017) conclude that to avoid objectification and suffering due to care, ambulance clinicians must establish a relationship to safeguard commitment and attentiveness to the patients' perspectives.

Furthermore, being taken seriously also included descriptions of making the person (i.e., the patient) feel calm and safe in the present moment, (Paper II), which was related to the psychosocial climate (PCQ-P) items "getting a little bit extra" and "making a little extra effort on behalf of the patient". Caring has been described as an act of togetherness by Holmberg (2015), where patients are either important and involved, or insignificant and powerless, depending on the nature of the encounter. Being in togetherness has also been characterized as a means of strengthening health and well-being by feeling welcomed as a person and being involved in one's own care (Nygren Zotterman et al., 2016), which is consistent with the findings of Papers I-IV.

Being a significant other in need of being de-burdened

Similar to the patients, the significant others rated the climate as person-centred. However, they focused on the psychosocial part of the climate, while the relevance of the physical environment that stems from an institutional setting was questioned, as illustrated by written remarks and the score levels (Paper IV).

Significant others generally act as social supporters to a patient with a perceived illness by providing emotional or instrumental support (Finfgeld-Connett, 2007). Instrumental support involves activities with a more practical orientation such as assistance with household tasks or providing tangible goods. Emotional support, on the other hand, consists of comforting gestures e.g., relieving uncertainty, anxiety, hopelessness and simply being available (Finfgeld-Connett, 2005). However, the person providing social support in turn depends on support from her/his family or social network, which directly affects the social support provider's capacity for coping with distress (Finfgeld-Connett, 2005; Sjölander & Ahlström, 2012). In this thesis the significant others wished to be de-burdened from the responsibilities of caring for the patient, which is the primary reason for significant others to contact Swedish Health Care Direct/1177 or the Emergency Medical Dispatch Centre/112 (Papers III and IV). The caring responsibility is characterized as almost overwhelming (Holmberg et al., 2016a). Being a significant other was perceived as being vulnerable (Maxwell, Stuenkel, &

Saylor, 2007). Significant others also have suffering of their own, triggered by being unable to handle the situation and the patient's suffering (Holmberg et al., 2016b). An encounter that enables significant others to experience the situation as person-centred, i.e., aspects of being de-burdened, could possibly alleviate their suffering caused by the distressing situation.

A prerequisite for enabling significant others to experience the situation as person-centred is listening both to them and the patient (Papers III and IV). Significant others highlighted ambulance clinicians' ability to talk to the patient in a manner that she/he can understand (Paper IV) and valued nursing that cares for patients by being present and listening (Clukey, Hayes, Merrill, & Curtis 2009; Maxwell et al., 2007). In addition, significant others were sensitive to non-verbal communication, tone of voice, pace and force of the caring actions or interventions (Clukey et al., 2009). Attentive listening has been seen as comforting, although a two-way conversation was preferable (Finfgeld-Connett, 2005). Being listened to provided significant others with a sense of security and brought emotional relief (Sjölander & Ahlström, 2012).

Other important aspects are being helped to understand what has happened and is about to happen, being invited to take part in the decision-making process and devoting time to the patient (Papers III and IV). Significant others have a key role in terms of providing the patient with a sense of well-being (Holmberg et al., 2016a). Despite this, significant others are often viewed as an appendix (Fry, Gallagher, Chenoweth, & Stein-Parbury, 2014). It has been shown that significant others often feel somewhat lost due to not knowing what was going to happen, e.g., lacking information on what to expect from the visit, in this case by the ambulance clinicians (Elmqvist, Fridlund, & Ekebergh, 2012a; Forsgärde et al., 2016). Significant others frequently felt left out of the picture as they were not included in the healthcare professionals' decision-making (Andersson, Borglin, Sjöström-Strand, & Willman; 2013). Being part of the decision-making process would make sense, as significant others often have to live their daily life with the decisions made (Nygren Zotterman, 2017). Being a partner in the decision-making process and perceiving that the ambulance clinicians ensured that everything was in order with the patient empowered the significant others, who could then resume their caring responsibilities (Paper III).

It is of importance for significant others to experience that their own concerns are taken seriously. They dislike being questioned, e.g., why they had phoned for an ambulance, as it was not something they would have done unless they considered it absolutely necessary (Paper III). It is essential that healthcare professionals recognize significant others as a team member together with the patient and give them the same information as the patient, especially as patients are not always capable of understanding the information. Significant others often assume the role of custodian (Nygren Zotterman, 2017). The necessity of obtaining information is raised in several studies (Andersson et al., 2013; Blindheim, Thorsnes, Brataas, & Dahl, 2013; Forsgärde et al., 2016; Hsiao, Redley, Hsiao, Lin, Han, & Lin, 2017; Milberg, Strang, & Jacobsson, 2004). An example of necessary information is being updated about the patient's condition (Blindheim et al., 2013).

Another important factor for the perception of immediate de-burdening is when the patient is taken seriously by e.g., the clinicians having a warm, yet professional approach and taking responsibility for the examination (Paper III). Previous studies reveal that significant others who were not informed about the patient's deterioration or about complications from an accident such as a fall, suffered from the fact that they had no opportunity to be close to their relative (Andersson et al., 2015). Studies have highlighted the fact that due to the dominant biomedical paradigm and organizational issues, both significant others and patients tend to be objectified and not viewed as persons (Forsgärde et al., 2016; Milberg et al., 2004). The ambulance clinicians may fail to embrace the significant others' experiences, which may intensify their suffering, thereby violating their dignity. All suffering due to care is unnecessary and should be eliminated (Eriksson, 1994). Confirmation, which is defined as being seen, trusted and understood, thus being taken seriously (Papers III and IV), is of the utmost importance in this potentially difficult situation (Holmberg et al, 2016a; Milberg et al., 2004).

Enabling significant others to feel de-burdened is a key mission for ambulance clinicians (Papers III and IV). Previous studies have found that when a person in their proximity perceives illness, significant others suddenly experienced being solely responsible for her/his well-being (Andersson et al., 2013; Milberg et al., 2004). The situation evokes feelings of loneliness (Blindheim et al., 2013). Additionally, as significant others tend to put their own well-being second in favour of the patient and her/his situation, the interpretation by Andersson et al. (2013) is that significant others' sense of responsibility is based on natural love and ethical demand.

In the ambulance care context, significant others struggle with loneliness before the arrival of the ambulance clinicians, who should be able to establish a relationship with the significant other and the patient. In many cases significant others who feared for the patient's life tended to be objectified and not viewed as persons but solely as patients (Holmberg et al., 2016a). An important factor for significant others in this thesis was worries about being unable to handle their role as a social supporter, thus wished for the ambulance to arrive as quickly as possible (Paper III). Significant others feel de-burdened when the ambulance clinicians enter, take over the caring responsibilities, confirm the significant other in the situation and take the patient seriously (Papers III and IV), which is consistent with the results of Holmberg et al. (2016a). Immediate de-burdening thus relieves the caring responsibilities, giving significant others a moment to rest (Paper III). Ambulance clinicians should be aware of the fact that significant others may perceive loneliness when they focus on the patient (Holmberg et al., 2016). Focusing exclusively on the patient may increase significant others' suffering, which highlights the importance of, when possible, providing significant others with information and confirmation This implies that when temporary relief from the caring responsibilities is not provided, significant others are left with feelings of powerlessness, anger and a sense of being humiliated (Paper III). Powerlessness and the "associated" word helplessness have been found in other studies and are expressions of being unable to handle the situation alone due to the patient's suffering and symptoms, struggling for control, lacking knowledge and information (Forsgärde et al., 2016; Holmberg et al., 2016a; Milberg et al., 2004). Moreover, powerlessness has been connected to depression in significant others, patients and care providers (Milberg et al., 2004).

The context of this thesis is non-urgent ambulance care, where the patient is not conveyed to the AED. As it is possible that the patient will be advised to remain at home, significant others will have to continue their social support role and assume the responsibility for caregiving (Papers III and IV). This is congruent with the core of person-centred care, where the patient's social network is included. Hence, it would be beneficial to deliver person-centred care built on a partnership that naturally includes the significant others (Ekman, 2014; Ekman et al., 2011). The significant others would have preferred the ambulance clinicians to stay until the patient's condition was completely under control (Paper III).

Being the person taking the person seriously

The papers in this thesis have primarily investigated how the caring and nursing actions performed by the ambulance clinicians were experienced by patients and significant others. In turn, the care provided by the ambulance clinicians influenced the experiences of the patients and significant others, which have been illuminated in the results of the studies.

The climate is the environment in which all person-centred actions take place (Browall et al., 2013; Edvardsson 2008; Edvardsson et al., 2008). There was concern that cut backs, savings and strict priorities could affect the perceived climate in a negative direction. However, both patients and significant others perceived the climate as person-centred, particularly the psychosocial climate. Bearing this in mind and based on the Promoting Action on Research Implementation in Health Services (PARiHS) framework, which determines research implementation on the basis of the following three factors; evidence, context and facilitation (Kitson, Harvey, & McCormack, 1998; Rycroft-Malone, 2004), it is suggested that:

- It is possible to establish and maintain a good person-centred psychosocial climate within the Ambulance Service.
- The climate is not dependent on the physical setting, i.e., the place where the care physically takes place.
- A person-centred psychosocial climate presupposes a reasonable good culture within the setting in which the care are provided. This implies a culture characterized by good leadership, which welcomes the evaluation of patients' and significant others' perceptions and experiences of ambulance care.
- A person-centred leadership in combination with a person-centred climate enables and encourages ambulance clincians to perform person-centred caring actions, e.g., taking the patient seriously and doing a little extra.

A prerequisite for being able to take the patient seriously is the desire to do so. At the same time, the ambulance clinicians must be willing to de-burden the significant other by taking the patient seriously, thus taking over in the moment and providing respite from the caring responsibilities. In a context specific study where ambulance clinicians described their experiences of the relationships with patients and significant others, it was revealed that the clinicians embrace both personal and professional aspects of the caring relationship (Holmberg et al., 2016b). This is partly congruent with the papers in this thesis, although not all results are positive (Papers I-IV).

This is summed up by the question: How would you as an ambulance clinician like to be perceived by patients and significant others?

As suggested by Smith et al. (2012), when establishing a relationship with patients (and significant others) there are benefits to be gained by consistently applying the five C's of caring, originally presented by Simone Roach; Commitment, Conscience, Competence, Compassion and Confidence. Hence, the role of care providers, in this case primarily ambulance clinicians, must be be discussed (Pusari, 1998; Smith et al., 2012).

Commitment

Commitment refers to sticking with patients through any health issue, being available when needed and letting the patient and her/his significant others know that the nurse is committed to them (Smith et al., 2012). Pusari (1998) argues that commitment involves reassurance, which has been highlighted as an important factor for patients and significant others in the ambulance care context in order to ease anxiety and worries about the perceived illness. This was achieved when ambulance clinicians provided patients and significant others with appropriate advice, treatment and care. However, the sense of being reassured was linked to the ambulance clinicians' behaviour, which evoked confidence in the care (Togher et al., 2015). The ambulance service has, however, evolved towards more non-urgent assignments, which does not entirely correspond with the educational curriculum (Sjölin et al., 2015) or the perceived role of an emergency ambulance clinician (Bourdon, 2012). According to Pusari (1998), dedication and commitment are not forced on clinicians, as those who give care want to do so.

Conscience

Conscience has been found to be an important constituent of ethical nursing care and can have a positive as well as a negative influence on advancing or limiting nurses' practice of care (Lamb, Evans, Babenko-Mould, Wong, & Kirkwood, 2017). In other words, there is a need for a sense of moral responsibility in order to work consistently on behalf of patient and her/his significant others, focus on empathy and put oneself in the patient's shoes (Smith et al., 2012). Findings on paramedics demonstrate a role conflict, as the paramedics were emergency response oriented, which contrasts with the pervading work reality of a shift towards more non-urgent assignments. The role conflict could result in cynicism and disengagement, thus possibly affecting the quality of care (Bourdon, 2012). Similarities were found in the AED setting, where staff felt they were there to deal with emergencies and handle seriously ill patients. The purpose of their role at the AED was saving lives, which they found satisfying and exciting (Elmqvist, Fridlund, & Ekebergh, 2012b; Nyström, 2002; Person, Spiva, & Hart, 2013).

Competence

Being professional and knowledgeable was pointed out as important in Papers I and III and confirmed in Paper II. Similar results were shown in a study by Togher, Davy and Siriwardena (2013), where patients' views of professionalism were strongly associated with the notion of the clinicians' competence. Smith et al. (2012) argue that competence is about knowing what the specific condition is about, how threatening it is and being aware of possible deterioration. However, not only medical aspects are of importance, as presenting oneself in a professional manner, maintaining a high standard of excellence, continually improving one's skills and understanding the needs of patients and their significant others are equally essential (Smith et al., 2012). Ambulance Service managers value ambulance clinicians' medical knowledge, e.g., treatment guidelines and pharmacology, as well as aspects more familiar within the nursing domain, e.g., encountering patients and maintaining a holistic approach. However, a formal education was not rated highly. (Holmberg, Fagerberg, & Wahlberg, 2017). This is in contrast other studies, where to a high extent the ambulance specialist nurse programmes were found to contain medical and contextual knowledge, which is considered important by professionals (Sjölin et al., 2015; Wihlborg et al., 2014). While patients' ideas of professionalism were linked with how the patient-clinician encounter was experienced, clinicians' interpretation of professionalism concerned clinical and technical skills (Togher et al., 2013).

From a medical perspective, studies indicate that patients discharged at the scene by ambulance clinicians had more subsequent events, i.e., the likelihood having to request an ambulance again within 24 hours. There was also a higher probability of death within 24 hours when discharged by the ambulance clinicians at the scene than when discharged from the AED (Tohira et al., 2016a, 2016b). Despite lacking knowledge of the safety of care, acknowledged as an important core competency (Edberg et al., 2013) of non-urgent patient in general and patients not conveyed to the AED in particular (van de Glind et al., 2016), ambulance clinicians have publically debated whether or not it is necessary for certain groups to phone for an ambulance (Rosberg, 2017). Besides medical aspects, there is undoubtedly a risk of causing guilt and shame (Elmqvist et al., 2012a; Möller et al., 2010) (Paper I) by defining some patients as eligible for ambulance care and others as not (Breen & McCann, 2013; By, 2016; Dahl-Bergkvist & Hammarbäck, 2014; Hjälte, Suserud, Herlitz, & Karlberg, 2007; Rosberg, 2017; Smith, Bouchoucha, & Watt, 2016). When experiencing guilt and shame, patients have reported feelings of powerlessness (Schröder, Ahlström, & Larsson, 2006) and being extra vulnerable (Baillie, 2009). These feelings are similar to those described by patients who were not confirmed, not listened to and not invited to participate in the discussion and decision-making (Paper I). For significant others the same feelings emerged when they were excluded from the decision-making process, abandoned and thus did not receive the necessary support (Paper III). This emphasises the importance of going beyond fixed medical diagnosis and protocols in order to acknowledge the uniqueness of a person's experience of illness and suffering (Abelsson & Lindwall, 2015).

Compassion

Compassion is a potent term that defines a powerful sense of empathy and a wish to help persons struck by misfortune. Nurses as well as most people recognize spontaneously in what way and at what time to offer compassion to relieve another person's suffering (Smith et al., 2012). In healthcare, compassion is a constant; it cannot be rationed because emergency nurses have limited time and resources to manage increasing demands. Compassion fatigue and burnout are increasing, primarily due to a busier and more stressful working environment (Hunsaker Chen, Maughan, & Hesaston, 2015) and are potentially a risk to the ability to care for the other, thus threatening patient safety and satisfaction (Potter, 2006). However, supportive managers are key players in perpetuating compassion satisfaction and lower levels of burnout. Managers are thus vital for the development of strong, positive, professional clinical environments (Laposa, Alden, & Fullerton, 2003). It is of the utmost importance that a nurse is compassionate, as otherwise her/his actions could constitute a pointless and harmful intrusion into the life of the patient requiring support (Pusari, 1998).

Confidence

Confidence should aim at communicating the ability to create a relationship built on respect without paternalism, including being honest and telling the patient and her/his significant others the truth, thus enabling them to make informed decisions in relation to their perceived illness (Pusari, 1998). The care should preferably be supportive of all aspects, i.e., holistic care including bringing significant others (the family) together (Smith et al., 2012). Even though an individual may be willing to adopt an approach characterised by confidence, she/he may face obstacles. An Australian study that explored difficult conversations within the Ambulance Service revealed that ambulance clinicians found it challenging to handle conversations between colleagues concerning behaviour of co-workers (Williams, Beovich, Flemming, Donovan, & Patrick, 2017). Therefore, the workplace culture may hinder discussions on disrespectful behaviour aimed both at colleagues and/or patients and significant others. Being badly treated as a patient has been associated with considerable suffering (Ahlenius et al, 2017), increasing the risk of suffering caused by the healthcare system and worsening the already existing suffering and symptoms from the illness (Eriksson, 1994). However, it is necessary to discuss what is connected to the individual ambulance clinicians' caring actions and what is dependent on organisational issues.

The need for organisational adaptation

In recent years, i.e., after the interviews in the inductive studies (Papers I and III) were conducted, a number of other prehospital resources and units have supplemented existing organisations. An example is an initiative from hospitals to staff mobile non-urgent units with nurses, physicians and in some cases a staff member with a mandate to organise municipal resources, e.g., home nursing care (Lindblad, 2016). Outside the specific setting of this thesis, e.g., in Gothenburg and Stockholm, special units aimed at dealing with psychiatric conditions have been employed. The establishment of special psychiatric units was identified by, among others, student master students (Alfredsson & Andersson, 2016; Johansson & Mannerbjörk, 2015; Margulies, 2013). This is an example of how academic specialist nursing programmes have changed working conditions by applying the core competencies, which e.g., state that evidence-based care and quality are paramount (Edberg et al., 2013). Thus, it is likely that the possibility of gaining the impression of being taken seriously has increased for more patient groups.

Most assessments and care in non-urgent ambulance assignments take place in another person's home (Rosén et al., 2017). Homecare nursing is based on an agreement between the local municipality and the patient, thus the number and time of visits are more or less planned. Ambulance care, on the other hand, is unplanned but may consist of the same type of assessments and caring interventions. Visits from unfamiliar nurses in a home setting were found to be stressful, highlighting the ethical issue of entering the home of a person who due to need welcomes a visit by unfamiliar ambulance clinicians (Holmberg et al., 2012). One could might therefore argue that the differences between homecare nursing and non-urgent ambulance care in terms of patients (and their significant others), assessments and the caring actions/interventions provided are small. However, the professional and organisational factor boundaries differ. Whether patients can cross these organisational boundaries depends on many factors. This requires further investigation, as many initiatives besides that of the municipal organisation now handle patients assessed as non-urgent {Lee, Pickstone, Facultad, & Titchener, 2017; Lee & Tichener, 2017; Lindblad, 2016; Magnusson, Kallenius, Knutsson, Herlitz, & Axelsson, 2016).

There is no clear mission statement concerning what patient groups or which illnesses and diseases are to be handled by the Ambulance Service in Sweden. It has been shown that the mission of the Ambulance Service is broad in terms of age (from birth to death), diagnosis as well as acuity. Present and former employees of the Ambulance Service described the need to act as gatekeepers and that the guidelines have a solely medical focus (Rosén et al., 2017).

The guidelines valid in the southernmost county of Sweden contain instructions for patients assessed for non-conveyance (some alterations due to translation):

> "An ambulance is for patients who require emergency medical interventions or monitoring during transport. A medical indication should be present, such as pharmaceutical administration, medical monitoring of vital signs or preparedness for medical treatment. If the patient does not meet these requirements, an alternative form of transportation should be considered, taking humanitarian and special circumstances into account."
> (Region Skånes Prehospitala Enhet, 2015, p.1.5.1)

If the guidelines cited above are compared with the results of this thesis, it is quite obvious that there is a need for an updated version that supports the care provided in a non-urgent ambulance context.

As previously mentioned, the ambulance clinicians' assessments and decisions are mainly based on the adapted Rapid Emergency Triage and Treatment System (RETTS), a clinical decision support system. The RETTS is based on objective vital signs and some 45 algorithms for a range of complaints and/or symptoms, all of which correspond with the mandatory ICD-10 medical classification system (Widgren & Jourak, 2011). However, the RETTS has a four question checklist for assessing personal autonomy: oriented to person, place and time, ability to stand/walk, use the bathroom and drink (Widgren, 2012), which might be considered a narrow and insufficient perspective on the patient.

Healthcare personnel have the power to e.g., interpret symptoms and signs, diagnostics as well as to make the final decision on the outcome of examinations, interventions and treatment. Traditionally, healthcare professionals have the interpretative prerogative and thus decide what to write in the journal, e.g., how the situation is perceived, what examinations have been performed and what the results reveal. Those who possess power have a responsibility to create trust and handle the power with great thoughtfulness and good judgment (Dahlberg & Ekman, 2017). However, when power is not correctly handled, it may induce suffering. Not being taken seriously is an example of managing power in an improper manner. Only the patient can decide if, and in what way something does not feel right, i.e., the presence of a perceived illness, regardless of whether or not objective signs are manifested (Ricœur, 2011; Ricœur, 1992). It is therefore important to try to maintain and uphold the patients' (and significant others') autonomy, to pursue the interpretative prerogative and investigate a perceived illness, thus consolidating their personal integrity and enabling them to recover and regain empowerment (Dahlberg & Ekman, 2017; Lindberg et al., 2014).

Unfortunately, organisational issues, guidelines and triage systems, i.e. the RETTS, have a clear focus on the medical paradigm (Widgren, 2012; Widgren & Jourak, 2011). This may restrict the ambulance clinicians' possibilities to adopt and provide person-centred care. However, the obstacles are not impossible to overcome. An inclusive mission statement firmly grounded in existing research should be developed by the Swedish Ambulance Service. Guidelines must be adjusted or developed to fit the non-urgent situation, including a description of the boundaries between the Ambulance Service and the Homecare Service. Furthermore, the curricula of the ambulance specialist nurse programmes should contain clear learning activities pertaining to non-urgent ambulance care and how to adopt the five Cs of caring. Finally, scheduled meetings about how to handle the ethical tension related to patients' triplicate disadvantage is warranted, in addition to the existing mandatory debriefing sessions after urgent and traumatic assignments. Ambulance clinicians must be aware of, and reflect upon, the asymmetry in the caring relationships, as well the triplicate disadvantage in all encounters (Kasén, 2002; Kristensson Uggla, 2014). The ethical tension imposed on ambulance clinicians in every encounter with patients and significant others in ambulance care is depicted in Figure 1.

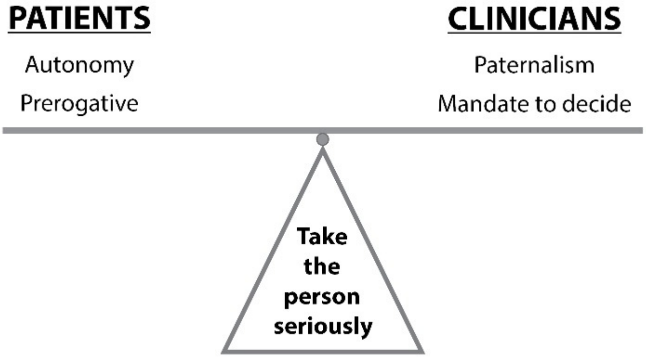

Figure 1. The ethical tension within the Ambulance Service.

Conclusions and clinical implications

The main conclusions in this thesis are:

- Non-urgent ambulance care involves a strong need to be taken seriously as a person.
- Not being taken seriously as a person infringes personal autonomy.
- Being taken seriously and remaining at home when applicable by mutual agreement represent key aspects of person-centred care
- De-burdening among significant others means being relieved from a caring responsibility for a short time thanks to being empowered and confirmed by the by ambulance clinicians.
- The absence of de-burdening by ambulance clinicians might generate profound suffering among significant others
- Significant others can be empowered to continue to act as social support providers by means of four simple interactive steps.
- It is possible to create a person-centred psychosocial climate within non-urgent ambulance care.sök
- A core construct of person-centredness was identified among both patients and significant others within non-urgent ambulance care.
- Person-centredness and the psychosocial part of the person-centred climate are interrelated within non-urgent ambulance care.
- Person-centredness can be evaluated by eight items in a single factor, which can enable the ambulance service to assess the ambulance clinicians' performance in terms of the core competence of person-centred care.

Based on these conclusions, it is necessary to adapt non-urgent ambulance care to the needs and preferences of patients and significant others. Person-centred care should be implemented and important aspects of the psychosocial climate emphasized and highlighted for staff in order to enable professional skills development. Personal skills are linked to personal conduct, thus implementing person-centred care and promoting a positive psychosocial climate do not require major investment. In addition, the organizational structure of the Ambulance Service should promote a positive psychosocial person-centred climate in order to enable the provision of person-centred care. As described earlier, meetings about how to fulfil the ethical demands of taking persons seriously and providing de-burdening could be arranged on a regular basis. Furthermore, Ambulance Service guidelines, triage assessment and decision tools should be designed or adapted for non-urgent ambulance care, meaning that they should not solely focus on vital signs and medical aspects, but on self-care ability, empowerment, suffering and nursing interventions.

A person-centred approach checklist as presented in Table 7 below will be developed and employed by all ambulance clinicians. This will mean that the eight core aspects of person-centredness will be present in everyday practice. Furthermore, the caring encounters within non-urgent ambulance care will be evaluated on the basis of these eight aspects by the means of Patient Reported Experience Measures (PREM).

Table 7. Checklist for person-centredness in clinical encounters within the within ambulance care.

When the ambulance clinicians arrive it is important that they …	
Patient	**Significant other (SO)**
Listen	Listen
Help the patient to understand what has happened	Help the SO to understand what has happened
Help the patient to understand what is about to happen	Help the SO to understand what is about to happen
Take the patient's concerns seriously	Take the SO's concerns seriously
Take the patient's symptoms seriously	Take the patient seriously
Take the patient seriously as a person	Listen to the patient
Make the patient feel good in the moment	Make the SO feel de-burdened
Make the patient feel safe	Ensure that the SO can handle the situation before leaving her/him

Future research

The first priority of future research will be to develop a PREM-measurement tool for evaluating person-centredness among patients and significant others and to explore whether the single construct found is generic or highly context specific. In addition, there is a need to explore the consequences of not being taken seriously and not being de-burdened in greater depth in order to fulfil one of the key missions of nursing, i.e., the alleviation of suffering.

The existing operationalized measurements of person-centred climate are not fully applicable within the non-urgent ambulance care context. Therefore, a context specific tool for measuring the person-centred climate will be developed and tested.

Finally, the findings in this thesis indicate that there are similarities between non-urgent ambulance care and home nursing care that require further exploration in order to ensure the availability of resources to fulfil the needs of patients and significant others in an optimal manner.

Summary in Swedish/ Svensk sammanfattning

Ambulanssjukvården har de senaste decennierna genomgått stora förändringar från att vara en del av räddningstjänstliknande beredskap och att vara en transportorganisation, till att idag vara en del av akutsjukvårdskedjan och därmed vara den första sjukvårdsinsatsen en patient möter. För att kunna svara upp mot detta är det sedan 2005 ett lagstadgat krav att minst en i varje ambulansbesättning måste vara legitimerad med kunskap och rättighet att kunna iordningställa och administrera läkemedel. I praktiken innebär det att minst en i varje besättning är legitimerad sjuksköterska. I många landsting har kravet med tiden uppgraderats till specialistsjuksköterska. Den andra personen i besättningen kan vara en ambulanssjukvårdare, legitimerad sjuksköterska eller ytterligare en specialistutbildad sjuksköterska (i denna svenska sammanfattning beskrivna som ambulansvårdare). Läkare förekommer i låg utsträckning i operativ, klinisk tjänst inom ambulanssjukvården och i sådana fall främst inom akutbilsverksamhet och luftburen ambulanssjukvård. Däremot har läkare en viktig roll avseende utfärdande av medicinska behandlingsriktlinjer och PM, utbildningsverksamhet samt upprätthållande av patientsäkerhetsaspekter inklusive hantering av medicinska avvikelser.

Under 2016 genomfördes nationellt ungefär 1,2 miljoner ambulansuppdrag, varav ca 500 000 karakteriserades som livshotande då ambulans larmades ut från larmcentralen/112. Däremot visar studier att då ambulanssjukvården anlände till den sjuka eller nödställda uppskattades 14 % vara livshotande, d.v.s. krävde omedelbar handläggning samt blåljus och sirener till akutmottagning. Då uppemot hälften av alla uppdrag har visat sig vara av icke-brådskande karaktär, har det i Sverige börjat sprida sig ett arbetssätt med bedömning, triage och hänvisning till andra vårdnivåer än akutmottagning. Uppemot 20 %, beroende på landstingens riktlinjer, hänvisas idag av ambulanssjukvården till primärvård, jourläkare eller kvarstannar i hemmet med egenvårdsråd.

Forskning tills idag, liksom debattartiklar skrivna av professionsföreträdare inom ambulanssjukvården, tenderar att fokusera på hur förändrade arbetssätt kan påverka flödet av patienter till akutmottagningar, respektive att patienter med ”fel symtom” felaktigt söker sig till akutmottagningar. Omvårdnadsforskning visar dock att tvingas kontakta larmcentralen/112 ofta föregås av mycket kval. Steget att ringa 112 tas inte förrän närstående eller patienten upplever att situationen är ohållbar. Från det att känslan att inte kunna hantera situationen infinner sig, upplever sig patienten sårbar och orolig, vilket kan förändras till förtroende och en känsla av att vara i säkerhet då ambulansvårdarna anländer till platsen. Patienten känner sig dock övergiven då de lämnas över till akutmottagningen. Närstående har i forskning visat sig agera stöd åt uppemot 1,3 miljoner och står för 47-96 % av alla påringningar till larmcentralen/112. Att ta sig an ett mer eller mindre självpåtaget ansvar att vårda är förenat med en stor känsla av sårbarhet. Närstående visar sig vara i en ensam kamp med känslor av hjälplöshet och en oerhörd oro för att patienten ska dö. Då ambulansvårdarna kommer kan de ta över ansvar att vårda patienten och närstående får en stund av vila.

Det övergripande syftet med denna avhandling var att studera patienters och närståendes upplevelser av personcentrering och personcentrerat klimat då patienterna bedömes vara icke-brådskande av ambulanssjukvården. Fyra delstudier genomfördes med olika syften. Studie I hade som syfte att klarlägga den subjektiva innebörden av icke-akut ambulanssjukvård hos patienter som triagerades till en lägre vårdnivå än akutmottagningen. Studie II hade som syfte att psykometriskt undersöka begreppsvaliditeten av en möjlig dimension av personcentrering, att undersöka patienters upplevelser av det personcentrerade klimatet samt att undersöka möjliga samband mellan det personcentrerade klimatet och personcentrering. Studie III hade som syfte att belysa innebörden av närståendes möte med ambulanssjukvårdarna i en icke-brådskande ambulanssjukvårdskontext, där patienter triagerades till en lägre vårdnivå än akutmottagningen. Slutligen var det fjärde syftet att undersöka närståendes upplevelse av personcentrerat klimat och personcentrering i en icke-brådskande ambulanssjukvårdskontext. Olika former för datainsamling och metoder för analys användes. Gemensamt för alla studier (I-IV) var att alla studiedeltagare varit i kontakt med ambulanssjukvården och blivit bedömda som icke-brådskande och därmed inte medföljt till akutmottagning. I studie I och III genomfördes individuella intervjuer som analyserades med en fenomenologisk hermeneutisk metod. För studie II och IV användes enkäter till patienter och närstående som analyserades med faktoranalys samt deskriptiv och analytisk statistik.

I studie I framträdde två strukturanalyser; vikten av att bli tagen på allvar och bekräftad i deras behov och lidande samt innebörden i att inte bli tagen på allvar. Patienten upplevde att de blev tagna på allvar då sjuksköterskan och/eller operatören vid sjukvårdsrådgivningen/1177 eller larmcentralen/112 lyssnade, bedömde och diskuterade patientens upplevda ohälsa. Patienterna kände sig bekräftade då det beslöts att en ambulans skulle skickas till patienten. Då ambulansvårdarna anlände till platsen var det viktigt att de lyssnade till patientens situation och tolkning av symptom samt bekräftade patientens upplevelse. Att bli behandlad med empati, att ambulansvårdarna tog sig tid för patienten och att få vara delaktig i beslutsfattandet uppfattades som positivt. Då patienten sågs som en person, liksom fick information om hur han eller hon skulle agera i händelse av försämring eller att något nytt tillstötte efter det att ambulansvårdarna lämnat platsen förstärktes känslan av att bli tagen på allvar. Å andra sidan, då ambulansvårdarna inte visade intresse för patienten, gjorde en ofullständig bedömning eller inte alls bedömde patienten framkom känslan av avvisande, oro, ledsamhet och ilska som en konsekvens av att inte bli tagen på allvar. Patienter beskrev hur de blev uteslutna från beslutsfattande och tvingades att finna sig i situationen och lita till ambulansvårdarnas beslut. Härmed uppkom känsla av orkeslöshet och maktlöshet.

I studie II konstateras att personcentrering bildar en sammanhängande konstruktion bestående av åtta frågor. Utifrån ett sedan tidigare validerat instrument, Person-centred Climate Questionnaire – Patient version (PCQ-P) bedömde studiedeltagarna klimatet som personcentrerat. Mellan personcentrering och PCQ-P fanns det vissa samband, som vikten av att det är enkelt att tala med ambulansvårdarna, att ambulansvårdarna har kunskap och tid att tala med patienterna, att ambulansvårdarna ger ”det lilla extra” samt anstränger sig för att patienten ska ha det bekvämt.

Studie III fokuserar på närstående till patienter som bedömts som icke-brådskande och därmed inte medföljer till akutmottagningen. Strukturanalysen visade en stark önskan av att omedelbart få bli avlastad från ansvaret att vårda den sjuke. När den närstående inte längre kunde klara av situationen på grund av oro för den sjuke, vilket väckte oro, osäkerhet och en känsla av ensamhet, kände de sig tvingade att ringa 112. Då ambulansvårdarna anlände var det viktigt att de lyssnade och försökte förstå den närståendes situation. Närstående uttryckte att det var viktigt att ambulansvårdarna hade ett varmt och professionellt förhållningssätt gentemot den sjuke, och inte minst tog den sjuke och dennes situation på allvar. Genom att vara i konstant dialog och delaktig i beslutsprocessen kände närstående sig avlastade. Genom att ambulansvårdarna sörjde för att den närstående fick känna att han eller hon hade kontroll över situationen, blev närstående rustade för att återigen ta över ansvaret att vårda. Om beslut togs utan att involvera närstående i beslutsprocessen att den sjuke inte skulle medfölja till sjukhus gavs den närstående ingen möjlighet att känna sig avlastad från ansvaret att vårda. Härmed kände sig närstående maktlösa, kraftlösa, övergivna och i vissa fall också arga. Dessutom var de närstående kvar med en rädsla för att fortsätta att axla ansvaret att vårda för den sjuke.

I Studie IV fokuseras det på åtta frågor som möter närståendes upplevelse av personcentrering. För att kunna mäta hur närstående uppfattade klimatet användes ett sedan tidigare validerat instrument, Person-centred Climate Questionnaire – Family version (PCQ-F). Instrumentet har, som liksom instrumentet för patienter (PCP-P), utvecklats i institutions- och sjukhusmiljö. PCQ-P och PCQ-F har tre subskalor: *safety*, *hospitality* och *everydayness*, där de två första avser det psykosociala klimatet medan det senare har ett fokus kring det fysiska klimatet. Närstående uppfattade den psykosociala delen av klimatet som personcentrerat, men uttryckte både genom hur man fyllde i instrumentet (eller inte) samt genom klart uttalade påpekanden att det fysiska klimatet inte var tillämpbart inom icke-brådskande ambulanssjukvård. Det fanns vidare vissa samband mellan personcentrering och PCQ-F såsom att den sjuke (patienten) ska kunna få göra egna val, att tid ges för patienterna, att det är rent och snyggt, att det är möjligt att tala om annat än sjukdom samt att personalen anstränger sig lite extra för patienten.

Sammantaget visar denna avhandling att för patienter och närstående i en icke-brådskande ambulanssjukvård är den viktigaste betydelsen att bli tagen på allvar respektive att bli avlastad. Ambulansvårdarna är ofta de första i vårdkedjan som fysiskt möter patienter och närstående. Det är därför av stor vikt att ta ansvar för att försöka förstå och bidra till att uppfylla dessa basala behov. Som ett resultat av avhandlingen behöver saker förändras:

- För att kunna tillgodose patienters och närståendes basala behov, ska personcentrerad vård implementeras och erbjudas.
- Den organisatoriska strukturen inom ambulanssjukvården ska främja ett positivt psykosocialt personcentrerat klimat för att personcentrerad vård ska kunna tillhandahållas.
- Behandlingsriktlinjer och triage-instrument ska utformas på ett sådant sätt att patienter tas på allvar och närstående kan bli avlastade.
- Ambulansvårdare ska tillämpa vårdande bedömningar och interventioner på en sådan sätt att patienter och närstående uppfattar vården som personcentrerad vid varje möte med ambulanssjukvården.

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