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NON-CONVEYED PATIENTS - A THESIS ON EPIDEMIOLOGY, AND PATIENTS' AND AMBULANCE CLINICIANS' EXPERIENCES

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Non-conveyed patients - A thesis on epidemiology, and patients' and ambulance clinicians' experiences

THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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To Hanna, Elias, Jonathan and Joshua

"We can be blind to the obvious, and we are also blind to our blindness."

Daniel Kahneman, psychologist and Nobel Prize winner

ABSTRACT

BACKGROUND

As a consequence of the increased overall number of ambulance assignments in combination with an increase in patients assessed as having non-urgent complaints, new demands are being placed on the ambulance service and the ambulance clinicians (ACs) regarding patient assessments and decisions. Alternative care pathways – excluding emergency departments (EDs) – such as non-conveyance, have increased over the last decade. However, knowledge regarding non-conveyance is limited. Increased knowledge from an epidemiological and qualitative research perspective is needed to enhance patient safety.

AIM

The overall aim was to explore situations in which patients were non-conveyed. Furthermore, it was intended to describe ACs and patients' lived experiences of non-conveyance.

METHODS

Four sub-studies were performed. **Study I** was an observational population-based study with the aim of describing the prevalence of non-conveyance, investigating associations and comparing patients' characteristics, drug administration, initial problems, and vital signs between non-conveyed and conveyed patients. Patient data were retrieved from ambulance medical records (CAK-net, Region Stockholm). **Study II** was a retrospective cohort study with the aim of increasing the understanding of elderly non-conveyed patients. The primary objective of this study was to present the prevalence of older adult non-conveyed patients and their characteristics – in comparison with younger non-conveyed patients – and identify and describe the risk factors associated with ED visits, hospitalisations, and mortality up to 7 days following non-conveyance. The secondary objective was to investigate the probable associations between abnormal vital signs and ED visits, hospitalisations, and mortality up to 7 days after non-conveyance among older adult non-conveyed patients. Patient data were retrieved from the ambulance medical records, and follow-up data were retrieved from The Regional Health Care Data Warehouse (VAL). **Study III** was an interview study of ACs conducted using a reflective lifeworld research (RLR) approach based on phenomenology. The aim was to describe ACs experiences of assessing non-conveyed patients. **Study IV** was also an interview study conducted using an

RLR approach. The aim was to describe experiences of becoming acutely ill and not accompanying the ambulance to a hospital from a non-conveyed patient perspective.

RESULTS

The results show that non-conveyance situations represent a non-negligible proportion of all ambulance assignments performed annually. Non-conveyance constitutes a complex caring encounter involving a great diversity of patients with variating characteristics and complaints. Ambulance assignments ending in non-conveyance were often dispatched as the highest priority – involving overall younger individuals – and patients' medical complaints were often assessed as non-specific or related to psychiatric problems **(Study I)**. Older non-conveyed adults represent a risk group for adverse events that need to be met with adequate measures to ensure patient safety. The observed increased risk of hospitalisation and mortality among older adult patients compared to younger adult non-conveyed patients raises questions pertinent to patient safety (**Study II)**. Furthermore, insufficient organisational support, a lack of non-conveyance education, and an absence of clinical performance feedback complicate ACs ability to perform accurate and person-centred non-conveyance assessments **(Study III)**. Patients' experiences of non-conveyance showed it to be a complex and versatile phenomenon in which patients need to be met with an ethical mindset in the creation of a caring encounter. Patients that are non-conveyed experience an existential fear and loss of bodily control that need to be met with confirmation, listening, and the establishment of a partnership **(Study IV)**.

CONCLUSIONS

Several conclusions with clinical implications stem from this thesis, including increased awareness and knowledge regarding the large group of patients with varying characteristics, complaints, and symptoms that are non-conveyed annually. Older adults that are non-conveyed were identified as a risk group for adverse events that need to be met with adequate measures to ensure patient safety. Performing non-conveyance assessments is complicated by several paradoxes that need to be met with sufficient organisational support, educational efforts, and the introduction of clinical performance feedback in order to perform person-centred care, ensure patient safety, and enhance professional development among ACs. Non-conveyance encounters are complex care meetings in which several existential aspects deemed important for non-conveyed patients need to be met in order to establish caring encounters based on person-centred care.

LIST OF SCIENTIFIC PAPERS

I **Lederman J**, Lindström V, Elmqvist C, *et al.* Non-conveyance in the ambulance service: a population-based cohort study in Stockholm, Sweden. *BMJ Open* 2020;**10**:1–9. doi:10.1136/bmjopen-2019-036659

II **Lederman J**, Lindström V, Elmqvist C, *et al.* Non-conveyance of older adult patients and association with subsequent clinical and adverse events after initial assessment by ambulance clinicians: A cohort analysis. *Submitted* 2020.

III **Lederman J**, Löfvenmark C, Djärv T, *et al.* Assessing non-conveyed patients in the ambulance service: a phenomenological interview study with Swedish ambulance clinicians. *BMJ Open* 2019;**9**:1–8. doi:10.1136/bmjopen-2019-030203

IV **Lederman J**, Löfvenmark C, Djärv T, *et al.* Non-conveyed patients in the ambulance service – a phenomenological interview study with patients cared for by Swedish ambulance clinicians. *Submitted* 2020.

CONTENTS

LIST OF ABBREVIATIONS AND DEFINITIONS

AC	Ambulance clinician
AOR	Adjusted odds ratio
CI	Confidence interval
COR	Crude odds ratio
ED	Emergency Department
EMCC	Emergency Medical Communication Centre
EMT	Emergency medical technician
IQR	Interquartile range
NACA	National Advisory Committee for Aeronautics score
OR	Odds ratio
RETTS	Rapid Emergency Triage and Treatment System
RLR	Reflective lifeworld research
VAL	The Regional Health Care Data Warehouse

Non-conveyance – The definition of non-conveyance within the ambulance service used by the National Health Service in England, that is, "a term used to describe a 999 call to the ambulance service which results in a decision not to transport the patient to a health-care facility" [1], will be applied in this thesis and also includes alternative terms describing non-conveyance, i.e. 'non-transport'.

1 INTRODUCTION

A growing body of research recognises the importance of and need for deepened knowledge regarding assessments of patients leading up to a non-conveyance decision in an ambulance service context [2,3]. Over one million ambulance missions are performed in Sweden annually [4]. Fewer than half of these missions were assessed as life-threatening. Consequently, a majority of all ambulance missions were categorised as non-urgent by the emergency medical communication centre (EMCC) [5]. Furthermore, ambulance clinicians' (ACs) assessments concerning the severity of patients' medical conditions are markedly distinct from the EMCC operator's assessments [6]. However, it is of importance to note that the EMCC uses a triage tool different from that of the ambulance service. Categorising and prioritizing individuals' care needs by telephone is a challenging task performed by EMCC operators [7]. Once the ACs meet the patients, fewer than one third of all patients are reported as severely ill [8]. As a consequence of the increased overall number of ambulance assignments in combination with an increase in patients assessed as having non-urgent complaints, new demands are being made on the ambulance service and the ACs regarding patient assessments and decisions.

In the past, the default final destinations for patients cared for by Swedish ambulance services were emergency departments (EDs) [9,10]. However, crowded EDs have been identified as a risk for patients assessed as having low acuity complaints [11]. Within the ambulance service, alternative care pathways have been introduced over the last 10 years [12–14], and non-conveyance is one of the fastest-growing pathways and the one on which knowledge is still most limited [15]. From a patient perspective, accurate non-conveyance assessments may help patients to find the necessary care in a reasonable period of time and thus avoid the ED if appropriate [13,16–18]. Further, incorrect non-conveyance decisions can adversely affect patients' health and, in some cases, even lead to death [2,19]. Patient safety issues regarding non-conveyance have been expressed both internationally [1] and nationally in Sweden [20]. Furthermore, in a broad Dutch consensus study, non-conveyance assessments were identified and highlighted as one of the most neglected and therefore prioritized areas for future research [3]. Consequently, due to organisational and educational similarities between The Netherlands and Sweden, this may also apply to the Swedish ambulance services.

2 LITERATURE REVIEW

2.1 THE SWEDISH AMBULANCE SERVICE – ORGANISATIONS IN TRANSITION

Descriptions of something resembling ambulance care can be found in the Bible and the story of the Good Samaritan (Luke 10:34, 2016). Nearly 1,800 years after Luke was written, Dominique-Jean Larrey, chief surgeon for Napoleon's fighting forces formed the world's first organised ambulance organisation. Civil ambulances were to be found in London in the 1880s. At the end of the 19th century, Stockholm had just a few ambulances reserved for patients with highly infectious and fatal diseases, such as cholera and smallpox [22]. The Swedish ambulance services underwent a process of intensive change during the end of the 20th century and the beginning of the 21st century. The result of this developing process can be seen in today's Swedish ambulance services, where formal regulations stipulate that the administration of drugs is reserved for registered clinicians only [23]. Therefore, a change occurred in 2005 regarding the ACs' formal competence: all Swedish ambulance services underwent a change from an emergency medical technician-based (EMT) organisation to a nurse-based ambulance service. Today, Swedish ambulances are crewed with at least one registered nurse. Thus, several counties – the Stockholm region included – have increased the formal requirements regarding the ACs' level of competence. Since 2009, the regional formal requirements in the Stockholm region have stated that at least one of the two members in the ambulance crew is obliged to pass an advanced level exam at a university (e.g. specialist nurses in ambulance care, anaesthesia, or intensive care) [24]. In accordance with the Swedish Higher Education act [25] a specialist nurse in ambulance care should have 'the ability to independently assess the sick/injured somatic and mental status and immediate needs as well as implement the measures which are required for patients of all ages under strongly varying conditions'. The increase in competence within the ambulance service is one important part of facilitating a change in emergency care to move the advanced care closer to the patient. To move the starting point of the advanced care from the ED to the EMCC and the ambulance services requires several other additional actions, such as educational initiatives, additional training in non-conveyance assessments, and the performing of high-quality research, whose results are to be implemented in the regional ambulance organisations [26].

In order to meet each patient as a person [27], and in relation to crowded EDs [28] the ambulance services must actively work to offer each patient an individual solution that is

based on the patients' individual needs. The services should more often exclude the ED as the final destination when appropriate [26,29]. The most fragile individuals in society – the elderly population – are exposed to physical and existential suffering when routinely transported to an ED instead of being offered individual care based on their own unique needs [12,30,31].

Several studies have reported positive patient outcomes following ACs' use of alternative care pathways instead of an ED [12,32,33], but other studies contradict these results [16,34]. Older adults having suffered a fall were found to be at risk of being undertriaged, and therefore an uncertainty regarding ACs ability to assess older adults was highlighted [34]. To routinely transport patients to EDs and thus not offer individualized care might indicate on the one hand a general healthcare organisation that lacks a person-centredness and a lack of structural preconditions for alternative care pathways. On the other hand, it may be a sign of underdeveloped support systems used by ambulance organisations [26].

2.2 NON-CONVEYANCE – AN UNEXPLORED FORM OF AMBULANCE CARE

The concept of non-conveyance is found in various ambulance service systems all over the world, and its prevalence is commonly diverted into two further categories: rates for non-conveyance overall and rates for specific non-conveyance patient populations (e.g. hypoglycaemia, paediatric patients, elderly patients, and post-ictal patients) [2]. The extent of non-conveyance is of interest because the phenomenon is not regarded as an isolated event but instead as a possibly justified outcome in an ambulance care process that is influenced by factors prior to the non-conveyance assessment. Such factors include low accuracy in the EMCC dispatch protocols [7], patients with primary care problems requiring an ambulance [35], and the ACs' competencies [36]. The rates for general non-conveyance populations varies considerably, and studies have reported rates of 4–94% [16,17,37–41]. However, these rates are to be viewed with caution due to suspected confounding and differences in how the non-conveyance population was defined and measured. A few published studies have investigated and reported non-conveyance rates in Sweden to be between 12 and 20% [14,42].

While some research has been conducted investigating the overall non-conveyance patient populations, there have been few empirical investigations into specific non-conveyance patient populations (e.g. hypoglycaemia, paediatric patients, elderly patients, and post-ictal patients). Rates for non-conveyed patients with hypoglycaemia have been reported at

between 12 and 84% [43–47]. The discrepancy in rates can partly be explained by methodological differences between the studies, where the highest rate of 84% examined the care performed by a physician-based mobile intensive care unit without conveyance possibilities [44]. Rates for non-conveyed paediatric patients have been reported at between 13 and 27% [48,49]. Assessing and caring for paediatric patients in an ambulance care context is a considerable challenge for ACs in general [50]. Deciding not to convey paediatric patients is a complex and challenging task for ACs in particular [51]. Varying pathophysiology, possible communication barriers, and parental involvement and perspective are three factors that might explain the complexity in the non-conveyance assessment of paediatric patients [48]. The reported non-conveyance rate for older adults is between 11 and 12% [52]. Moreover, assessing elderly patients' care needs is a difficult and complex task and requires deep knowledge and understanding of physiological changes occurring with increasing age [52,56]. Overall, patients over 65 represent the majority of all patients cared for by the ambulance service of Stockholm [55]. A similar pattern can also be seen in an international ambulance care context [19,56,57]. Therefore, it is worrying that only a few studies have specifically investigated elderly non-conveyed patients.

2.3 NURSING ASSESSMENTS AND JUDGEMENTS

Two essential elements of everyday nursing are assessments and judgements. Nursing is performed regardless of context. It is most often performed as part of a team in dialogue with the patient, significant others (relatives, close friends), and other healthcare professionals [58]. Certain skills have been identified as important for conducting clinical assessments and judgements: clinical reflecting, intuition, reasoning, and practical skills based on best practice. In addition, the individual nurse's level of knowledge and clinical experience is further viewed as important when conducting clinical assessments and judgements with the aim to identifying and fulfilling the individual patient's needs [59,60]. The outcome of a well-performed process of clinical assessments and judgements are the creation of nursing diagnoses, more effective clinical decision making, and a positive impact on care quality [61]. The nursing interventions planned for and implemented should be evaluated in the aftermath of care [58].

2.4 CLINICAL ASSESSMENTS AND JUDGEMENTS IN THE AMBULANCE SERVICE

Assessments in the ambulance service context have been described from two different perspectives. From the first, the so-called diagnostic reasoning behaviour, the clinician's assessment is regarded as an analytical decision-making process in which different types of

standardized assessment tools are used for guidance and collecting and analysing measurable and hence 'objective' patient data (e.g. vital signs and clinical examination findings) [62]. Triage methods are examples of this type of assessment approach [63]. In comparison to an experienced nurse's ability to include different perspectives and aspects in an assessment, triage methods have been shown to account for fewer factors [64]. Assessments stemming from the second perspective are regarded as part of a larger whole: a process of care in which the patient's perspective and experiences are included in the assessment [65,66]. Research has indicated that ambulance care is more than medical care: it has an existential influence on patients [67,68]. Hence, ACs need to possess knowledge in emergency medicine and at the same time have the ability to include a patient's lifeworld in the assessment [69]. By the nature of ambulance care, where ACs most often care for one patient at a time, there are unique opportunities and circumstances for performing person-centred care [70].

Moreover, clinical reasoning is viewed as an important part of ACs' assessments. Different problems need different solutions, and clinical reasoning has been described in several different ways: on the one hand, as an unreflecting method as a rapid response to sudden changes in the clinical environment or working under stressful circumstances, and on the other hand as a slower process including a greater amount of reflection and analysis [71]. The latter allows ACs to reflect upon findings and include more information before making a decision. It has been suggested that mistakes made by ACs during the decision-making process are one of the main causes of a negative impact on patient safety in an ambulance service context [72]. Several factors distinguish clinical assessments and judgements – including decision making – in the ambulance service compared to intrahospital emergency care. The environment is a recurrent factor that is independent of location in the world and in which type of ambulance service system is being investigated [73]. Therefore, ACs need to possess ability and an understanding of why an improvised caring space in which the integrity of the patient is ensured should be created [74].

2.5 THE DECISION-MAKING PROCESS AND NON-CONVEYANCE

The decision-making process, which concerns patients' needs for an appropriate level of care, has been described as a complex process that should combine the patients', significant others', the ACs, and the healthcare systems' perspective and needs [12,75,76]. The ACs' working environment and clinical reality have been shown to differ significantly from existing non-conveyance guidelines. The latter has a simplified and uniform picture of the

assessment situation [77–79]. The assessment and decision not to convey patients to an ED require both deep medical knowledge and advanced nursing skills to optimize the outcome for the patient and significant others. Moreover, the decision-making process has been described as a negotiating decision between the patient, significant others, and the ACs. Furthermore, the ACs must develop and actively implement the ability to combine these different perspectives in their assessment [77,78,80]. However, additional higher training in relation to ambulance care, such as specialist nursing studies at the university, lacks specific content involving non-conveyance assessments, management, and decision-making processes in its curricula [81]. Hence, opposite expectations to the non-acute ambulance care reality are then formed [82,83]. Studies have suggested that additional non-conveyance training among ACs may result in increased non-conveyance rates [39,40]. However, research evaluating these educational efforts is lacking. Therefore, our knowledge is limited regarding the accuracy of the assessments and the patient outcome from a patient safety perspective.

2.6 NON-CONVEYANCE PROTOCOL (GUIDELINES), VITAL SIGNS, AND MEDICAL RECORDS

Valid non-conveyance guidelines are limited in access: therefore, this may adversely affect patient safety. Furthermore, the use of guidelines not specifically developed for non-conveyance situations can thus cause insecurity among the ACs when assessing these patients [2,78]. Overall, from an international ambulance service perspective, general non-conveyance guidelines are most commonly used, most often including abnormal vital signs as a basis for the non-conveyance decision [84,85].

The examination of vital signs is considered to be one of several important aspects for conducting an accurate assessment in the ambulance service context [86,87]. Thus, limited knowledge regarding vital signs and non-conveyance assessments is derived from the few studies that have reported non-conveyed patients' vital signs. Approximately 15–60% of non-conveyed patients have been shown to have abnormal vital signs [16,84,88,89]. Together with older age (> 70 years) and aetiology, abnormal vital signs are a predictor for subsequent events following non-conveyance, such as second ambulance call, ED visit, hospital admission, and to some extent even death [16]. Although some research has investigated vital signs and non-conveyance, there is still limited knowledge and therefore also clinical awareness of what importance abnormal vital signs have for non-conveyed patients and patient safety. Furthermore, to what extent non-conveyed patients' vital signs

differ from conveyed patients is still unclear due to the absence of research in the field. Moreover, the reason that non-conveyed patients present with abnormal vital signs is not known. It is therefore unknown to what extent the vital signs were previously present as a consequence of the slow deterioration of a chronic disease or a sudden onset of an acute illness.

Access to up-to-date patient health information and records is considered to be one crucial factor in performing assessments with a high degree of patient safety [90]. When performing safe non-conveyance assessments of patients – where patients are offered alternative care pathways based on individual needs, access to patient's health information and records is considered to be essential [91]. Lack of access to patients' medical records could initiate an unnecessary conveyance decision despite an existing care plan for the patient. The ambulance service in the region of Stockholm currently lacks the possibility of accessing patients' medical records, and therefore a possible important part of the non-conveyance assessment could be considered as missing. Meanwhile, the lack of studies comparing eventual differences in patient outcome when having access to patients' medical records compared to no access makes such an interpretation difficult.

Access to patients' medical records could be of benefit when caring for a patient with a known disease for which regional specific non-conveyance guidelines are available. Non-conveyance guidelines for specific patient groups are used but not commonly. As with the medical guidelines, the non-conveyance guidelines for a specific patient group – for example, hypoglycaemia and post-ictal patients – lack a clear evidence base [43]. Furthermore, the validity of specific non-conveyance guidelines for post-ictal patients has been questioned due to the increased risk of adverse events [43]. Compliance with these types of expert-based but not evidence-based non-conveyance guidelines might impair patient safety due to low sensitivity and specificity. The common occurrence of guidelines or triage tools in the ambulance service is of a more general basis, hence not developed specifically for the non-conveyance assessment and specific patient groups [2,86]. A non-conveyance guideline exists specifically for patients with hypoglycaemia in the regional medical guidelines for the ambulance service in Stockholm. Thus, the evidence base for this specific guideline is unclear, and the accuracy of the assessments following the guideline is currently unexplored.

2.7 REGIONAL MEDICAL GUIDELINES AND NON-CONVEYANCE PROTOCOL

In the medical guidelines used by the ambulance service in the Stockholm region, the concept of non-conveyance has been divided into two additional levels of care: (1) self-care and (2) reference to alternative care pathways. However, there is no difference between the criteria that should be fulfilled in order to apply non-conveyance. A clarification is made in the guideline for 'self-care' where it stipulates that *'prior to the decision of self-care, a valuation must be made of the patient's or significant other's conditions to manage the self-care safely.'* [92]. In addition to the ACs' assessment, a telephone consultation with an EMCC physician is obligatory prior to the decision not to convey a patient. Furthermore, self-care is not to be applied if there is a risk that the patient can suffer harm due to the decision of self-care [92]. A definition of 'suffer harm' is not clarified in the regional medical guidelines, and as a consequence, the absence of valid quality indicators measuring patient safety and non-conveyance becomes evident. Prior to the non-conveyance decision, an assessment including the use of a triage tool named Rapid Emergency Triage and Treatment System (RETTS) is to be performed. The RETTS combines vital signs with the patient's chief medical complaint, and as a result, a priority level is suggested (Widgren, 2012). The priority level 'green' is the lowest used by the ambulance service in the Stockholm region and indicates normal vital signs and most often also an absence of disease. However, RETTS is first and foremost developed for intrahospital use at the ED as an indicator of how long a patient can wait until meeting a physician and not for the ambulance care context [94]. Furthermore, the use of RETTS in a non-conveyance situation is further problematic due to questions of validity, specificity, and sensitivity. These perspectives have not yet been scientifically investigated. Moreover, it is not stated in RETTS that patients with a priority level of 'green' are not to meet a physician; instead, it is stated that these patients will not be adversely affected by some degree of waiting time due to a non-life-threatening medical complaint and hence are not in need of immediate care [94]. It is therefore problematic to use the RETTS in non-conveyance situations.

The seven criteria below are to be met when deciding not to convey a patient in accordance with the medical guidelines of the ambulance service in the Stockholm region;

- The patient has been triaged green according to RETTS (normal vital signs and absence of illness/injury)
- The patient has the ability to receive information (note dementia, intoxication etc.)
- The patient is able to understand the consequences of what the non-conveyance decision means

- The patient must have received sufficient information to make a decision (describe options)
- The patient must never be left without their consent
- Patient consent should be obtained without leverage
- Patients also include care-proprietors: for example, when assessing children

[92]

Provided that these seven criteria are fulfilled, the ACs may decide not to convey the patient after a telephone dialogue with the EMCC physician. The above criteria can be considered as a two-fold guideline: on the one hand, a 'treat and release' guideline and on the other a 'see and refer' guideline, thus with a more general design.

2.8 PATIENT SAFETY AND RE-ENTRIES IN THE (EMERGENCY) HEALTHCARE SYSTEM

In order to explore patient safety in relation to non-conveyance, several studies have aimed to investigate subsequent and/or adverse events following non-conveyance. The follow-up is usually divided into two sub-groups: (1) re-entries to the healthcare system and (2) patient outcome. With re-entry in the healthcare system, several aspects have been considered as subsequent events: second ambulance call or dispatch, ED visit, and general practitioner-visits [16,17,41,49,95–97]. The maximum range of the investigated follow-up time was 7 days. A large number of patients re-enter the healthcare system < 24 h following non-conveyance. Overall, there is a tendency towards increasing percentages for repeat access at increasing times after the non-conveyance encounter. For general populations of non-conveyed patients, subsequent visits to EDs within 24 h has been reported to be 5% [16].

Furthermore, to date, no published study has investigated the reasons for patients to re-enter the healthcare system. Knowledge of this is essential to evaluate patient safety and non-conveyance. To what extent patients re-enter the healthcare system with symptoms similar to during the non-conveyance situation is not described either. Moreover, a re-entry could be the result of compliance with ACs' recommendations given during the non-conveyance encounter. Therefore, in order to accurately describe non-conveyance, awareness and transparency regarding the challenges that accompany the use of a complexed outcome as 're-entries' is essential. Follow-up after non-conveyance should be considered as basic and essential knowledge in order to develop future assessments and decisions with high patient safety. However, the lack of consensus and – as a consequence – the absence of valid

quality indicators measuring patient safety complicates the development of non-conveyance.

The second recurrent subgroup in the follow-up of non-conveyance is factors associated with patient outcome. These are mortality, hospital admission, and to what extent patients suffer from recurrent symptoms. Mortality rate on general non-conveyance patient populations have been described as low [16,38,85,95,96,98]. The same pattern is true for hospital admission following non-conveyance [16,17,37,38,41,85]. For specific populations of non-conveyed patients, elderly patients have been described as having an increased risk for both hospital admission and mortality [19,99,100]. As with re-entries in the healthcare system, patient outcomes must be interpreted with an awareness of the time factor. The challenges and thus difficulties in linking the outcome to the non-conveyance assessment increase as time from the initial assessment elapses [16]. Furthermore, confounding factors are to be controlled for when using hospital admission and mortality as outcomes. However, due to methodological aspects, such as study design and data availability, this was not done in a majority of the earlier conducted studies concerning non-conveyed patients.

Regarding both the extent of non-conveyance and the characteristics and outcome of non-conveyed patients in Sweden, our knowledge is limited. In order to perform patient-safe non-conveyance assessments, further knowledge regarding patient characteristics and relevant points of outcome and thus a reasonable interpretation of these are needed.

2.9 NON-CONVEYANCE EXPERIENCES OF PATIENTS AND AMBULANCE CLINICIANS

Traditionally, a patient has been defined by the healthcare system and its representatives. The patient's role has been considered as one that engages a passive attitude towards one's own participation in the provided care. In the work by Charles, Gafni, and Whelan [101] regarding decision making in a healthcare context, the view of the patient as a passive recipient would be placed under the 'paternalistic model' of decision making. Thus, the patient is expected to adopt an inactive role in decisions regarding eventual treatment or upcoming care. The term 'patient' is not unproblematic, and in contrast to the paternalistic view of the patient, the caring science view of the patient advocates an approach in which the patient is explicitly considered as an important and active participant with situation-specific knowledge in the care meeting [102]. Furthermore, from a person-centred care

perspective, the person ‘behind’ the patient has been highlighted and is viewed as a natural part of the care process and one who engages an active attitude towards the provided care [103,104]. Hence, both the patient and career have a need to understand and to be understood. For these mutual needs to be managed and thus a caring encounter created, collaboration between the patient and the career is required to achieve the partnership, which is considered central within person-centred care [105]. Favourable conditions for the creation of a caring encounter are founded when the patient and carer acknowledge and thus have to respond to the mutual knowledge gap: a gap that can be decreased by the involvement of different perspectives. The patient possesses expert knowledge of how the situation is experienced and affects everyday life, and on the other hand, the ACs have medical and caring scientific expertise to contribute with [27]. In this thesis, a ‘patient’ is considered as a competent person with unique situation-based knowledge who is actively engaged in their care in the healthcare system in general and in the ambulance care context in particular.

Additionally, due to the Swedish National Audit regulation [23] regarding ambulance care, the non-conveyance assessments performed daily are most often performed by registered nurses in general and specialist nurses in particular. However, the results and implications stemming from this thesis are intended to be applicable to an ambulance care context in general and not to a specific profession. Caring for another person is not dependent on one profession; instead, it should be considered as the result of a respectful, mindful, and humble interaction between two or more human beings to reduce existential suffering and increase the individual’s perceived health.

The importance of well-developed nursing skills has been described as fundamental in succeeding with one’s assessments and non-conveyance decisions [106]. In the cited study, establishing a relationship founded on trust and respect with the patient and significant others was essential in order to feel confident in not accompanying the ambulance to the ED. To be taken seriously during the care meeting with ACs was highlighted as crucial, which could empower the patient’s own belief in their own unique resources. Patients also expressed the need to be confirmed by the ACs in relation to their feelings of insecurity in the experienced situation. On the contrary, if not being taken seriously by the ACs, patients expressed feelings of violation of their personal autonomy and in the long run, disbelief regarding their own view of what an emergency situation is [106]. Furthermore, ACs need well-developed caring skills in order to involve and confirm significant others, who in

many cases experience feelings reminiscent of patients' feelings of anxiety and fear prior to the encounter with the ACs. Moreover, significant others can experience great caring responsibility for the patient, and thus, requiring an ambulance can be the result of a process involving feelings of vulnerability, helplessness, and the need to be relieved of a perceived great caring responsibility [107]. Similarly to the patients need of being taken seriously, significant others experienced increased suffering and powerlessness when perceiving an absence of openness and kindness from the ACs towards the patient [108].

While some research has investigated patients' experiences of non-conveyance, limited attention has been paid to the ACs' experiences of assessing and deciding not to convey patients to the ED. Ambulance clinicians have been found to experience an ongoing struggle regarding their own and the patient's expectations of the outcome of the encounter [75]. The importance of being aware of and involving different expectations concerning the outcome of the non-conveyance encounter have been expressed from the patient and/or significant others' perspective. In case the ACs fail to do so, the patient's and/or significant other's suffering and feeling of loneliness could be exacerbated [108]. Conflicting perspectives involving the ACs strive to provide individual care for every patient – consequently resulting in a time-consuming non-conveyance assessment – and at the same time attempting to maximize ambulance resource availability for the general population can create frustration for the ACs [76]. Moreover, ACs experience misuse of ambulance resources due to a discrepancy regarding the EMCC dispatch prioritization and the ACs' assessment of the patient's need for care. In contrast, conducting the non-conveyance assessments was described as difficult, complex, and challenging. A major responsibility came with the non-conveyance assessment and decision-process [76,77]. Furthermore, the ACs experienced a lack of formal support from the ambulance organisation concerning limited support from medical guidelines and the absence of a specific non-conveyance protocol [75]. In addition, similar findings have been presented in a British ambulance service context regarding the use of alternative care pathways [78,109]. However, despite the studies by Barrientos and Holmberg [75], Höglund et al. [76], and O'Hara et al. [78], there is still a lack of knowledge regarding ACs' and patients' lived experiences of non-conveyance in relation to an ambulance service in transition that tends to involve more than medical emergencies, acute illnesses, and conveyance.

3 RATIONALE

As a consequence of the overall increased number of ambulance assignments in combination with an increase of patients assessed as having non-urgent complaints, new demands are being made on the ambulance service and the ACs regarding patient assessments and decisions. Alternative care pathways – excluding crowded EDs – such as non-conveyance have increased the last decade. There is a lack of use of non-validated non-conveyance protocols and triage tools. However, our knowledge regarding non-conveyance is limited: this includes both the patient's perspectives, ACs' experiences, and patient outcome from a patient safety perspective. Increased knowledge from an epidemiological and qualitative research perspective is needed to ensure patient safety.

4 AIMS

The overall aim was to explore situations when patients were non-conveyed. Furthermore, it was intended to describe ACs and patients' lived experiences of non-conveyance.

Specific aims were outlined as followed:

1. To describe the prevalence of non-conveyance, investigate associations and compare patients' characteristics, drug administration, initial problems and vital signs between non-conveyed and conveyed patients (Study I)
2. To increase the understanding of elderly non-conveyed patients, the primary objective of this study was to present the prevalence of older adult non-conveyed patients and their characteristics and, in comparison with younger non-conveyed patients, identify and describe the risk factors associated with ED visits, hospitalisations and mortality up to 7 days following non-conveyance. The secondary objective of this study was to investigate the probable associations between abnormal vital signs and ED visits, hospitalisations and mortality up to 7 days after non-conveyance among older adult non-conveyed patients (Study II)
3. To describe ambulance clinicians' experiences of assessing non-conveyed patients (Study III)
4. To describe experiences of becoming acutely ill and not accompanying the ambulance to a hospital from a non-conveyed patient perspective (Study IV)

5 ETHICAL CONSIDERATIONS

The Regional Ethical Review Board of Stockholm approved the PhD project in general and its four part-studies in particular (Dnr: 2017/2187-31). Studies I and II complied with the Code of Ethics of the Declaration of Taipei on health databases and biobanks regarding the dignity, autonomy, integrity, confidentiality, and discrimination aspects of handling data containing sensitive personal data [110]. In accordance with current procedures for implementing major registry studies in Sweden, informed consent was waived by the Ethical Review Board and was therefore not collected in Studies I and II. These two studies were further considered to be covered by the Swedish Personal Data Act's [111] 10§ eligibility basis, for which the current research 'clearly weighs the risk of improper intrusion of the integrity of individuals that the treatment may imply' (PUL, 1998: 204, 10§ f). The data collection, subsequent data processes, and storage strictly complied with the newly established General Data Protection Regulation regarding security in processing personal information and data in registry studies. Adequate technical and organisational measures to ensure the integrity and safety of the studied individuals were taken by the entity principally responsible for the research, the AISAB. The Regional Health Care Data Warehouse (VAL), used in Study II, offered deidentified follow-up data on almost all healthcare provided in the Stockholm region [112,113]. Thus, ensuring the integrity by automatically encrypting social security numbers of registered individuals.

In Studies III and IV, ethical reflections and actions were applied in line with the Code of Ethics of the Declaration of Helsinki [114]. Written informed consent was obtained, and all the informants received verbal and written information explaining the aims of the respective studies, describing actions that would be taken to ensure the confidentiality of the participants. Furthermore, information about the participants' ability to withdraw their participation in the respective study whenever they wanted was provided. Moreover, although there was a risk that the informants might experience an inconvenience as a result of their participation in the interviews – such as feelings that they had shared too much sensitive information with the interviewer – no participants expressed such feelings. Furthermore, regarding the risk that the interview could evoke memories from the encounter with ACs that the informant did not regard as positive memories, measures were taken to reduce these risks by expressing in writing and speech that the informant 'owns' their material and that they determine if the information would be part of the study or not. Regarding discomfort due to negative memories or events, I paid attention to various signs of discomfort during the interviews and was ready to take appropriate actions if deemed

necessary. Offering the informant to take a break during the interview is an example of such a measure. All informants chose the place and time for the interviews. In Study III, all ACs were off-duty during the interviews. Following each interview, the recorded material and transcribed data were stored electronically. Confidentiality was maintained throughout the data analysis and the writing of the two article manuscripts.

6 METHODS

In the following methods section, the four studies will be divided according to the two research approaches used in this thesis; epidemiology (Studies I and II) and reflective lifeworld research (RLR) approach (Studies III and IV).

6.1 SETTING – THE STOCKHOLM REGION

The region of Stockholm is the capital of Sweden and has 2.3 million inhabitants. The geographical area of the region is approximately 6,519 km^2 and covers both highly urban areas and less populated rural areas (the archipelago). A majority of all the region's inhabitants live in surrounding municipalities outside of the Stockholm municipality. As a whole, the region of Stockholm is one of the regions in Europe that is growing most intensively. Population forecasts have claimed that an annual increase of approximately 33,000 inhabitants is to be expected until the year 2026. The need of healthcare among older adults (> 65 years) is expected to increase the coming years, the prognosis further indicates that older adults will annually increase by approximately 30%. Inhabitants aged 80 years or over will increase the most after 2020 [115].

6.2 HEALTHCARE SYSTEM OF THE STOCKHOLM REGION

The Swedish healthcare system is a decentralized and largely tax-funded system that the entire population should have access to according to the Swedish Health and Medical Services Act [116]. Good health and equal care for the entire population is the overall goal of the healthcare system. Furthermore, care must be given with respect for the equal value and dignity of all human beings [117]. Sweden is divided into 21 regional councils in which each region's political leadership is responsible for the healthcare provided. The Region Stockholm Assembly is responsible for the largest regional healthcare system in the country [118]. The care offered ranges from non-emergency medical helpline to advanced specialist care at university hospitals. Approximately a third of all healthcare in the region is provided by private care providers. These providers can be found among general practitioners, dentists, and physiotherapists, to name a few. However, private care providers also operate within the emergency care context, including the ambulance service. The region has seven

emergency hospitals, one of which is a trauma level one hospital. The number of ED visits amounts to approximately 550,000 per year within the region. Primary care is provided during workday office hours and amounts to approximately 4,560,000 visits annually [119].

6.3 THE AMBULANCE SERVICE OF THE STOCKHOLM REGION

The ambulance service of the Stockholm region is provided on a 24-hour, year-round basis and is fully financed through taxes and provided by three companies, of which two are private care providers and the third a regional care provider. Approximately 220,000 assignments are performed by 83 ambulances, three physician manned units, one psychiatric emergency response unit, and one helicopter annually (an additional helicopter unit is deployed between 15 May and 15 September) [120]. The ambulance service is reached through the national emergency number, 1-1-2, and all ambulance assignments are dispatched through the regional EMCC. The dispatch operator decides whether an ambulance should be dispatched using a symptom-based clinical decision support system called the Swedish Medical Index [121]. Each dispatched assignment is prioritized on a three-level scale, with the highest priority as 1 and lowest as level 3. Since 2005, national regulations have stipulated that at least one of the two ACs serving in the ambulance should be a registered nurse. Regional regulations within the Stockholm region stipulate that at least one of the two ACs should have completed an additional year of university training and hold a specialist nurse exam [122]. The specialist nurse is medically responsible within the ambulance team [123]. Older adults (> 65 years) represent half of all patients cared for by the ambulance service of the Stockholm region. Women aged > 85 years or over form the largest patient group cared for by the regions ambulance service [124].

6.4 STUDIES I AND II

Studies I and II both had a retrospective study design, as observational population-based (Study I) and cohort studies (Study II), respectively. Data were collected from several regional healthcare registers, although Study I only involve data from the ambulance medical records (CAK-net, Region Stockholm) in contrast to Study II, which involved data from both ambulance medical records and VAL. The latter automatically collects and holds data regarding the regional healthcare provided, ranging from out-patient care (e.g. primary care, ambulance service) to in-patient care [125], thus enabling follow-up.

6.4.1 Registers

The ambulance medical records (CAK-net, Region Stockholm) used in Studies I and II constitute information on several different patient demographic variables, such as social

security number, age, gender, and residential address. In addition to this, the records also hold specific assignment information, such as assignment date, dispatch prioritization, several time variables, geographical area, prehospital assessment code, administration of drugs, actions performed, conveyance status, vital signs, and observations. Furthermore, all ambulance medical records consist of a narrative text section written by the responsible ambulance clinician. This section was excluded from the data extraction due to the large number of ambulance assignments included.

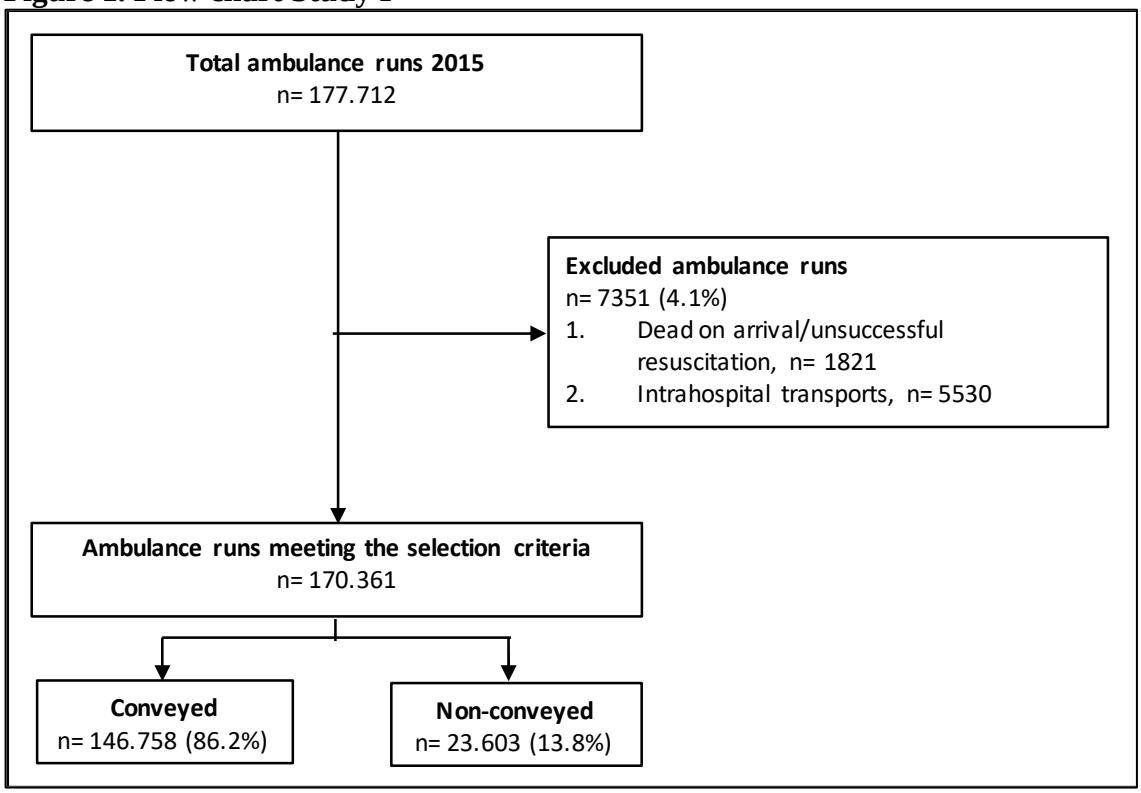
The VAL, used in Study II, automatically electronically records almost all healthcare utilization within the Stockholm region, hence constituting comprehensive regional healthcare data ranging from out-patient care (e.g. primary care, ambulance service) to in-patient care and enabling follow-up on an individual level. The social security number of patients is encrypted when a healthcare event is registered in VAL: it is automatically replaced with a unique patient identification number. Thus, identifying individual patients in VAL is not possible [112]. The use of VAL enables a validated and reliable follow-up of patients who utilized healthcare in the Stockholm region: this includes non-conveyed patients. As an example of the accuracy and validity of VAL, the Stockholm Regional Council uses data from VAL for updating regional healthcare use in the National Patient Register administered by the Swedish National Board of Health and Welfare [126].

6.4.2 Study populations

Table 1. Characteristics of study populations

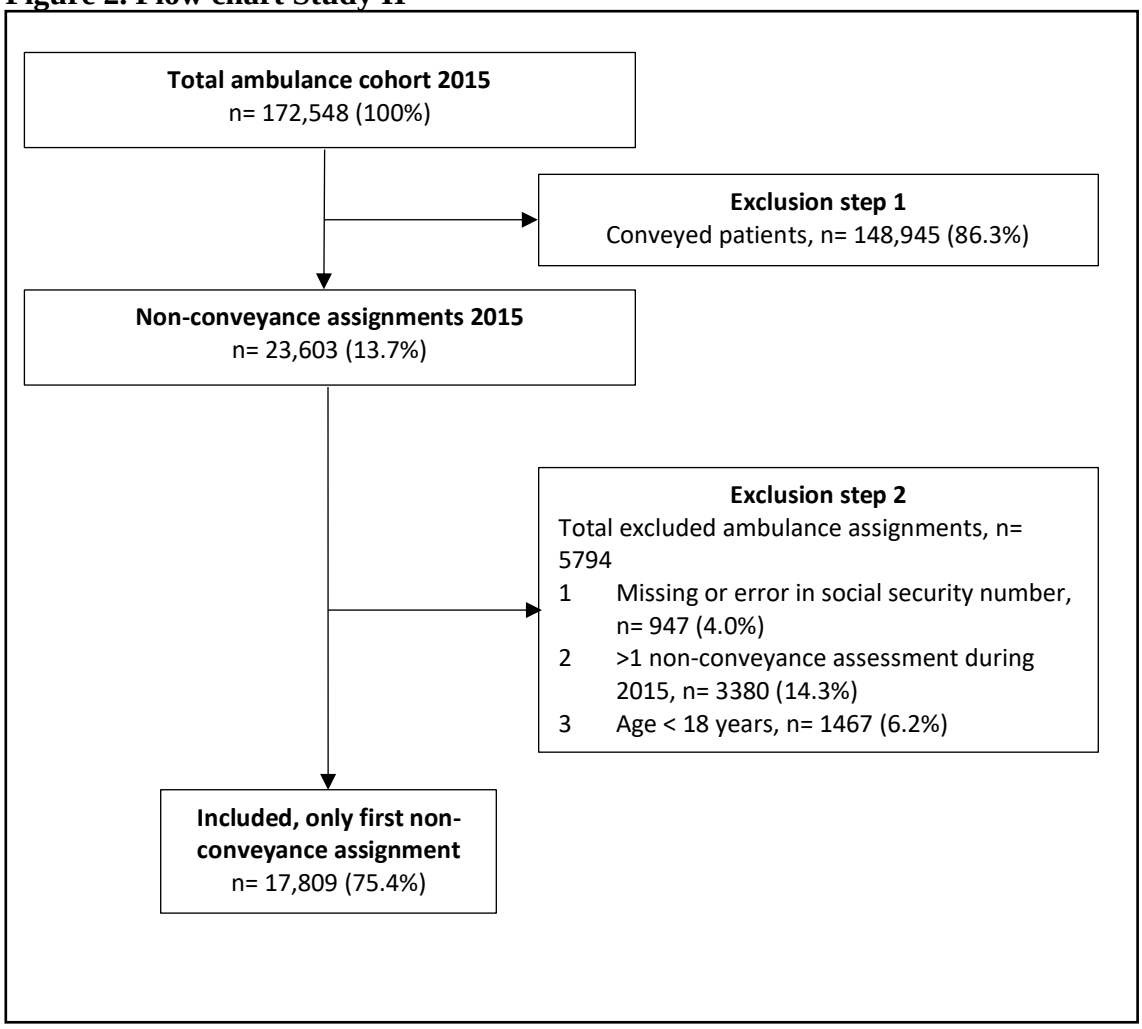
Study	Inclusion criteria	Exclusion criteria
I (Figure 1)	(1) Ambulance assignments performed by emergency ambulances	(1) Patient dead on ambulance arrival; (2) non-primary ambulance runs, excluding; intrahospital transports, physician-manned rapid response units, non-emergency ambulances and helicopters
II (Figure 2)	(1) Ambulance assignments performed by emergency ambulances **ending in non-conveyance**; (2) patient age ≥ 18 years	(1) Missing or incomplete social security number; (2) For all the included study informants, only the first registered non-conveyance event during 2015 was considered

Figure 1. Flow chart Study I



Flow chart over included and excluded ambulance assignments in the Stockholm region, 2015, in Study I.

Figure 2. Flow chart Study II



Flow chart over included and excluded ambulance assignments in the Stockholm region, 2015, in Study II.

6.4.3 Data collection

The data sources in Study I constituted of ambulance medical records registered in CAK-net from 2015: these were retrospectively collected. The research group received the data material in an Excel file. I performed all preparatory work before exporting the final data set to STATA.

Study II involved data material from both CAK-net and VAL. These were successfully linked by the help of SLL-IT and the development unit – and resulted in a dataset consisting of both ambulance medical record data and comprehensive regional data on ED visits, hospitalisations, and mortality up to 7 days after the index event. The index event was defined as the day the first non-conveyance assessment was registered for the unique patient. For all study participants, only the first registered non-conveyance event during 2015 was included in the final dataset.

6.4.4 Study designs and outcomes

The study designs of Studies I and II included an observational population-based study (Study I) and a retrospective cohort study (Study II).

Table 2. Overview of study design and outcomes in Studies I and II

Study	Study design	Outcomes
I	Retrospective observational population-based study	Primary outcome – prevalence of non-conveyance Secondary outcomes – associations and comparisons of patients' characteristics, drug administration, initial problems and vital signs between non-conveyed and conveyed patients
II	Retrospective cohort study Exposure group: non-conveyed patients aged ≥ 65 years in the Stockholm region Comparison group: non-conveyed patients aged 18-64 years in the Stockholm region	Primary outcome – prevalence of older non-conveyed patients, comparison of covariate variables and short-term outcomes (ED-visit, hospitalisation and mortality) between the exposure group and the comparison group Secondary outcomes – abnormal vital signs and 7-days hospitalisation among the exposed group

6.4.5 Statistical analysis

All statistical analyses executed in Studies I and II were conducted by using STATA version 15.1 (StataCorp. 2017; *Stata Statistical Software: Release 15*. College Station, TX: StataCorp LLC). The significance level was set at 0.05, all tests were two-sided. Descriptive statistics were used in Studies I and II – reported as percentages, interquartile range (IQR) or median where applicable. Measuring differences between two groups of patients were performed by using χ2-tests, Cramer's V-tests and t-tests where applicable. In both Study I and II multiple logistic regression analysis were performed. Logistic regression manages binary outcomes, i.e. presence or absence of the event of interest, e.g. disease or death. The regression coefficient generated from regression models are often presented as an odds-ratio (OR), which is easier to interpret than the log odds ratio. The measure of association between an exposure and a binary outcome is presented as an OR. The value of the OR can be between 0 and infinity. The presentation of an OR is joined by the 95% confidence interval (CI) for that OR. If the 95% CI includes the value 1 (one), then

the OR is not statistically significant, i.e. there is no difference in exposure and outcome [127]. The main statistical methods are described in more detail in the respective study.

6.5 STUDIES III AND IV

Studies III and IV were both conducted using an RLR-approach. ACs were interviewed in Study III, and patients being non-conveyed were interviewed in Study IV.

6.5.1 Reflective lifeworld research and preunderstanding

In order to fulfil the respective aims of Studies III and IV, a scientific approach that makes it possible to describe meanings in a complex phenomenon was chosen. The RLR approach is suited to studying complex phenomena that might have existential meaning for humans [128]. A scientific theoretical basis and methods and principles for implementation are offered through the use of the RLR approach. A brief introduction to the ontological and epistemological points of departure forming the foundation of phenomenology will be provided below. Through the work of the German philosopher Edmund Husserl conducted during the early 20th century, the meaning of the lifeworld theory for understanding how humans experience their lives based on a phenomenological perspective was introduced. With the goal of increasing knowledge regarding a specific phenomenon, according to Husserl, one should consider the 'things' themselves. From a phenomenological perspective, studying 'things' means studying how phenomena are experienced by humans [129].

In the light of Husserl's views on experiences, insight is gained into the theory of the intentionality of consciousness, in which Husserl argues that human consciousness is always directed towards something. In addition, when something is experienced by someone, it is always experienced as something. Meaning arises in relation to what one's consciousness is directed towards. Being aware of what one's consciousness is directed towards is an active process in which the individual leaves the everyday default setting, called 'natural attitude' – described by Husserl as 'unreflective' – in which our existence, environment, and experiences are taken for granted [129]. The researcher needs to actively leave the everyday default mindset and thus adapting to a reflective approach in which experiences are not taken for granted. A prerequisite for this adjustment of mindset is becoming aware of the fact that and how we experience things.

The researchers' understanding of the phenomenon can be deepened through the methodological principles of the RLR approach: reflectivity, openness, and bridling [128].

These principles are applied in order to achieve objectivity and to not make definite what is indefinite [130]. By actively reflecting and questioning (slowing down) the process of understanding, the impact of the researcher's preunderstanding is confined (bridled) and thus not allowed to uncontrolled influence how we understand the studied phenomenon. It is not possible or even desirable to exclude our preunderstanding, instead we should aim at controlling its impact on our understanding [131].

6.5.2 Managing my preunderstanding

Prior to conducting both Study III and IV my preunderstanding was outlined. On the one hand, I had lived experiences of non-conveyance through my clinical background as a specialist nurse in ambulance care. Hence, I had conducted countless non-conveyance assessments during my ten years in the profession. On the other hand, I had lived experiences of working as lecturer at a university giving the specialist nurse education in ambulance care. In addition, I had a good friend who were non-conveyed and subsequently admitted to hospital. These three lived experiences had given me a preunderstanding consisting of different perspectives on non-conveyance that could affect my research if not reflected upon and bridled. Prior to both study III and IV I wrote down my preunderstanding in order to become aware of it. I actively tried to achieve a reflective, open, and bridled attitude during the data collection and analyses of both these studies. My preunderstanding was used in the creation of the selection templates by discussing possible important factors to include for establishing a wide variety of lived experiences among the informants. My supervisors helped me bridle my preunderstanding several times during both studies by identifying situations where my preunderstanding took the over hand. In the beginning of both data collections, my supervisors read several of the transcribed interviews and gave me feedback. Hence, resulting in an awareness regarding my preunderstanding during the remaining interviews. During the analysis, I tried to achieve a bridled attitude. Though, my preunderstanding fastened my understanding of the phenomenon studied in study III and this was identified with the help of my supervisors. A curiosity about my process of understanding was established when my understanding was questioned, hence resulting in new perspectives of the studied phenomenon being revealed.

6.5.3 Informants

6.5.3.1 Study III

The investigated phenomenon in Study III was ACs' experiences of assessing non-conveyed patients. It is of the utmost importance within the RLR approach that researchers

seek to capture the phenomenon from all its possible variations. Prior to the data collection, discussions within the research group was performed regarding outer variations that were important to capture. These variations were placed in a selection template used during the recruitment of participants: 1) the geographical location of the ambulance unit (highly urban, urban, or rural area), 2) the ambulance company, 3) AC gender, 4) AC age, 5) ACs' years of working experience, 6) day or night shift, 7) work or week day, and 8) ACs' formal education training. All these variations were fulfilled during the data collection. The study was approved by the heads of department for all three ambulance companies, respectively, before the recruitment process of informants and data collection was initiated. Both written and verbal information was distributed among all three companies. Eligible ACs were those who had conducted non-conveyance assessments within the Stockholm region. A total of 13 ACs reported a willingness to participate following advertisement of the study. Of these, 11 gave approval. The median age for all informants was 39 (range 30–51 years), nine were specialist nurses, six of the informants were female, and median work experience in the ambulance service was 11 years for all informants.

6.5.3.2 Study IV

The phenomenon of interest in Study IV was 'becoming acutely ill and not accompanying the ambulance to a hospital'. Similar to Study III, a selection template was designed following internal discussions within the research group regarding outer variations that were considered to be important to capture when studying this phenomenon: 1) geographical location of the patient (highly urban, urban, or rural area), 2) ambulance company, 3) the patient's gender, 4) the patient's age, 5) chief complaint, 6) assignment during day or night, and 7) work or week day. All these variations were fulfilled during the data collection. The study was approved by the heads of department for all three ambulance companies, respectively, before the recruitment process of informants and data collection was initiated. Both written and verbal information was distributed among all three companies. Ambulance clinicians were supposed to present the study to non-conveyed patients who met the inclusion criteria once the non-conveyance decision had been taken. If the patient was interested in hearing more about the study, further information would be provided by me over the telephone. Patients eligible for participation had to fulfil the inclusion criteria that they had been non-conveyed. Moreover, they could speak either Swedish or English. Exclusion criteria were as follows: age < 18 years, clearly influenced by alcohol and/or narcotics, and patients who could not fully understand oral and/or written information about the study (e.g., due to cognitive impairment). In total, 11 non-conveyed

patients were asked to participate, two declined participation. The first refusal was due to prolonged COVID-19 illness, and the second patient did not offer a reason. Written informed consent was obtained from all nine informants. The median age for all informants was 67 (range 35–95 years), and 5 of the informants were female.

6.5.4 Data collection

6.5.4.1 Study III

In depth, open-ended phenomenological interviews were conducted from January 2018 to April 2018. All interviews were performed by me and digitally recorded. All informants were off-duty during the interviews, which were carried out at places chosen by the mentioned. The methodological principles of openness, flexibility and bridling were applied during all interviews, which all began with the same open question; 'Please tell me about a situation where you, as an ambulance clinician, assessed a patient who was non-conveyed'. Follow-up questions were used during all interviews, such as 'please expand on this point' or 'you mentioned family members in relation to your assessment, please tell me more'. The median interview time was 68 minutes (range 53-116 minutes). Digital verbatim transcription was performed in close connection to each interview.

6.5.4.2 Study IV

Using in-depth, open-ended individual interviews, data were collected from February 2019 to February 2020. All interviews were conducted, and digitally recorded – in Swedish by me. All informants were native speakers of Swedish and chose the place for the interview. As mentioned above, the methodological principles of openness, flexibility and bridling were applied during all interviews, which all began with the same open question; 'Please tell me about the situation when you became acutely ill and once assessed by ambulance clinicians, were non-conveyed'. The interviews were characterised by an open and flexible attitude towards the informant's experiences. Follow-up questions related to the phenomenon, were used repeatedly, during all interviews, such as "please expand on this perspective" or "you mentioned fear, please tell me more". The median interview time was 34 minutes (range 14-56 minutes), digital verbatim transcription was performed in close connection to each interview.

6.5.5 Data analysis

Respective data analysis for Studies III and IV were performed in Swedish and conducted using the aforementioned methodological principles and in accordance with the description

of the RLR approach [128]. The following description of the data analyses is made from an overall RLR perspective. In order to understand lifeworld research, some idea of essences is required. A phenomenon and its essence are not be regarded as two separate parts; instead, they co-exist in a mutual existence that makes the variations of essences infinite [132]. In order to categorise concrete lived experiences into abstract levels and thereby explain the phenomenon's essence, the analyses were characterised by a recurrent movement between the initial whole (the interview), the constituent parts, and the new whole (the essence). Prior to dividing the interviews into smaller parts – called 'meaning units', which were related to the studied phenomenon – all interviews were read several times. Each unit's meaning was then described, and 'patterns' were created by the abstraction of groups of meanings that were similarly and differently related to each other. Through a process called 'figure – background – figure', which helps discover new insights and perspectives [132], the patterns were repetitively compared with each other and then abstracted into 'clusters'. Moreover, actively asking questions to the data material, such as 'What does this cluster mean in comparison to this cluster', and 'How come I see this meaning in this way?' was performed repeatedly. The processes of the 'parts and the whole' aim to ensure that the data material is not distorted as the construction of clusters and the abstraction process diverge from the original text content. Furthermore, in the act of bridling one's preunderstanding, the researcher strives to not distort meanings or see meanings where they do not exist [128]. To enhance the validity of the studies, peer review was conducted together during several seminars. Finally, the essential meaning of the studied phenomenon is described in the essence: a non-variating meaning – that is, the highest abstraction level during data analysis. Variations of the phenomenon are described through the constituent parts and illustrated by quotes.

7 RESULTS

In this section, the main findings from each sub-study is presented. More detailed descriptions of the results are found in each of the studies placed at the end of this thesis.

7.1 STUDY I: 'NON-CONVEYANCE IN THE AMBULANCE SERVICE: A POPULATION-BASED COHORT STUDY IN STOCKHOLM, SWEDEN'

The aim of Study I was to describe the prevalence of non-conveyance, investigate associations and compare patient characteristics, drug administration, initial problems and vital signs between non-conveyed and conveyed patients.

7.1.1 Main findings

Non-conveyed patients represented a non-negligible proportion of all patients cared for by the ambulance service of the Stockholm region: 23,603 (14%). These patients differed significantly from conveyed patients with respect to several demographic and clinical aspects. Ambulance assignments ending in non-conveyance were often dispatched as the highest priority and involved overall younger individuals (Table 1 in Study I). Patients' medical complaints were often assessed as non-specific (AOR: 1.50; 95% CI 1.39–1.62; Table 3 in Study I) or related to psychiatric problems (AOR: 4.05; 95% CI 3.62–4.53; Table 3 in Study I). Older adult non-conveyed patients (≥ 65 years) were administered drugs to a lesser extent than younger patients (Table 2 and 3 in Study I). Abnormal vital signs among non-conveyed patients were found across all measured variables of vital signs, although low blood sugar level was highly associated with non-conveyance (AOR: 15; 95% CI 11.18–20.13; Table 5 in Study I).

7.2 STUDY II: 'NON-CONVEYANCE OF OLDER ADULT PATIENTS AND ASSOCIATION WITH SUBSEQUENT CLINICAL AND ADVERSE EVENTS AFTER INITIAL ASSESSMENT BY AMBULANCE CLINICIANS: A COHORT ANALYSIS'

Study II aimed to increase the understanding of elderly non-conveyed patients. The primary objective of this study was to present the prevalence of older adult non-conveyed patients and their characteristics and, in comparison with younger non-conveyed patients, identify and describe the risk factors associated with ED visits, hospitalisations, and mortality up to 7 days following non-conveyance. The secondary objective of this study was to investigate the probable associations between abnormal vital signs and ED visits, hospitalisations, and mortality up to 7 days after non-conveyance among older adult non-conveyed patients.

7.2.1 Main findings

Older adult patients (≥ 65 years) that are non-conveyed showed different clinical characteristics and attributes from younger patients (18–64 years). Older patients were more often female (54%), and the ambulance assignments were generally dispatched with a lower priority level. Non-conveyance of older adult patients occurred more often during the day, and ACs more often assessed these patients as having non-specific complaints and less often as having complaints related to trauma (Table 1 in Study II). Despite these facts, all measured short-term outcomes (ED visits, hospitalisations, and mortality) over a 7-day period following non-conveyance were more common among older adult patients (Table 2 in Study II). Approximately one in five older adult non-conveyed patients were hospitalised

following non-conveyance. The risk of dying following non-conveyance was 10 times higher among older adult patients (Table 2 in Study II). In particular, being assessed as having a complaint related to infectious symptoms (AOR: 9.80; 95% CI 2.02–47.85; Table 3 in Study II) or psychiatric complaints (AOR: 4.19; 95% CI 6.01–16.61; Table 3 in Study II) increased the risk of dying. Having a nonspecific complaint increased the risk of being hospitalized following non-conveyance (AOR: 1.59; 95% CI 1.26–2.00; Table 3 in Study II). In summary, the observed increased risk of hospitalisation and mortality among non-conveyed older adult patients raises questions pertinent to patient safety. Regarding abnormal vital signs and hospitalisation, a relatively wide variation was noted in the different age groups of older adult non-conveyed patients. An oxygen saturation level < 95% and systolic blood pressure > 160 mmHg had a significantly higher association with hospitalisation following non-conveyance among all age groups of older adult patients (Figure 2, Heatmap, in Study II). Presented with at least one abnormal vital sign during the non-conveyance assessment was associated with increased odds of ED-visits and hospitalisations, but not mortality (Table 3 in Study II).

7.3 STUDY III: 'ASSESSING NON-CONVEYED PATIENTS IN THE AMBULANCE SERVICE – A PHENOMENOLOGICAL INTERVIEW STUDY WITH SWEDISH AMBULANCE CLINICIANS'

The aim of Study III was to describe ACs' experiences of assessing non-conveyed patients.

7.3.1 Main findings

When assessing non-conveyed patients, ACs experience uncertainty in their ability to conduct accurate assessments. Making mistakes that could harm patients is present to a considerable degree both during and after the non-conveyance encounter.

Given the goal of conducting safe patient assessments, avoiding hasty decisions is important. Three paradoxes present in clinical everyday work of ACs complicate the circumstances surrounding the non-conveyance assessments: the responsibility, education, and feedback paradoxes. The essence of the responsibility paradox is that non-conveyance assessments are associated with increased individual responsibility but are not met with appropriate organisational support. Hence, frustration is experienced. Furthermore, the education paradox reveals everyday clinical work that is experienced as challenging and problematic in relation to one's limited and inadequate non-conveyance education. This is further complicated by limited support experienced in relation to the non-conveyance guidelines. In addition, ACs find the guidelines' unclear evidence base problematic. Finally, professional development is obstructed due to the absence of clinical performance

feedback. This – in combination with ACs basing a considerable part of their non-conveyance assessments on previous clinical experience – is further problematic and constitutes the feedback paradox. Additionally, the non-conveyance encounter is characterised by noticeable notions of loneliness.

7.4 STUDY IV: 'PATIENTS BEING NON-CONVEYED IN THE AMBULANCE SERVICE – A PHENOMENOLOGICAL INTERVIEW STUDY'

The aim of Study IV was to describe experiences of becoming acutely ill and not accompanying the ambulance to a hospital from a non-conveyed patient perspective.

7.4.1 Main findings

Patients' lived experiences of the phenomenon of 'becoming acutely ill and not accompanying the ambulance to a hospital' involves a complex caring encounter comprising several dynamic movements of different emotions and experiences affecting the patients before, during, and after the non-conveyance situation. In connection with the onset of symptoms, almost paralysing fear is described. Moreover, a loss of situational and bodily control is experienced. These feelings are gradually replaced by safety in the situation: a prerequisite of this change is that confirmation and trust are experienced. Gradually regaining situational control through empowerment – and the establishment of a partnership – is facilitated by being listened to and being reassured. Becoming an active participant in both the dialogue and the decision-making process requires enough belief in one's own ability to manage the situation that arises once the AC leaves. However, once the patient is alone again, a shift towards a reality in which feelings of insecurity and unanswered question of what one had suffered from is experienced. In conclusion, non-conveyed patients have a strong need to be taken seriously in their unique situation. In addition, this requires ACs to reflect upon and act with a conscious ethical mindset during the entirety of the non-conveyance situation.

7.5 A NARRATIVE COMPILATION

In the sections below, selected parts of the results of each sub-study will be discussed in light of the results of the other studies. The overall high EMCC dispatch priority among assignments ending in non-conveyance (Study I) might be one explanation for the effects of previous events occurring before the ACs actually meet the patient (Study IV). ACs should be aware of the effect on patients' if one part of the prehospital emergency chain performs actions and communicates in such a way that the patient interprets their situation as acute. Non-conveyed patients have a strong need to be met with seriousness, confirmation, and

reassurance (Study IV). In order to create a caring encounter based on the patient's unique situation, ACs need to develop an understanding of events that occurred before the ACs' arrival. This can be done by including these events in the dialogue – and the establishment of a partnership – with the patient.

Approximately one in every seven patients cared for by the ambulance service of the Stockholm region is non-conveyed (Study I). It is therefore striking that ACs lack adequate non-conveyance education, and at the same time, it is not surprising that ACs sometimes find non-conveyance assessments difficult to perform (Study III). A great diversity of patients with different medical and caring needs (Studies I and II) – in combination with perceived limited support and application of the non-conveyance guidelines (Study III) – complicates the circumstances when performing non-conveyance assessments. This could be explained by the results of both Study I and Study II. A relatively large subgroup of all non-conveyed patients consisted of a great variety of individuals with different characteristics: young, old, women, men, assignments performed 24/7, high diversity of medical complaints, and in how the aforementioned were categorised. In addition, approximately one third of all non-conveyed patients had at least one abnormal vital sign registered (Studies I and II). Hence, the perceived limited applicability of a guideline in which vital signs are not weighted against age could possibly explain the limited support described by ACs (Study III). Lack of organisational support can be viewed from the results of both Study I and II, indicating a complexity surrounding non-conveyed patients. A complexity that needs to be accounted for when creating favourable circumstances for ACs to perform accurate non-conveyance assessments. A further factor influencing the complexity surrounding non-conveyance assessments is the fact that a significant proportion of all non-conveyed patients (Study I) are older adult patients (≥ 65 years). These patients were found to have an increased risk of subsequent adverse events following non-conveyance. One in five of all older adult patients were admitted to hospital within 7 days of the non-conveyance assessment (Study II). Moreover, we also found a 10-times higher risk of death among older adult patients compared to younger non-conveyed patients (Study II). These types of follow-up data rarely reach ACs in everyday clinical work: the lack of clinical performance feedback was described as one of the most important factors that influence the obstruction of professional development (Study III). It is further problematic that ACs describe previous clinical experience as the foundation of non-conveyance assessments when this experience in most cases lacks systematic feedback: this is referred to as the feedback paradox (Study III). Conducting non-conveyance assessments

means acting with a greater responsibility towards the patient and significant others in comparison with conveying patients (Study III). This can be seen in light of the increased risk of adverse events that older adult non-conveyed patients are exposed to (Study II).

Moreover, non-conveyed patients describe a considerable amount of trust towards the ACs in relation to their ability to perform accurate assessments (Study IV). When attempting to create a caring encounter, making the patient an active participant in the dialogue was described as an important factor (Study III). Actions such as acting calm and trying to be present in the moment (Study III) were confirmed by non-conveyed patients as strengthening actions during the decision-making process (Study IV). Deciding to call the EMCC means presenting oneself as vulnerable and helpless (Study IV). In order to establish a caring encounter, the ACs' should possess an awareness of – and thus reflect on – the often-challenging process that patients undergo when deciding to call the EMCC. The feelings of safety felt by patients when the ACs were physically present was sometimes replaced with uncertainty and unanswered questions of what one had suffered from once alone again (Study IV). ACs, on the other hand, described organisational shortcomings such as being in the periphery of the wider healthcare system, resulting in difficulties in arranging subsequent follow-up through primary care following non-conveyance (Study III). In summary, the complexity of non-conveyance can be seen through the high diversity of patient characteristics and complaints (Study I). The non-conveyance situation is further complicated by the increased risk of adverse events among older adult non-conveyed patients (Study II) in combination with a clinical everyday accompanied with paradoxes (Study III). Non-conveyed patients' vulnerability and dependence illustrated through several dynamic movements during the non-conveyance encounter together with a strong need of being met with an ethical mindset is adding to the complexity surrounding the creation of a caring encounter (Study IV).

8 METHODOLOGICAL CONSIDERATIONS

8.1 EPIDEMIOLOGY

Conducting research based on existing registers (Studies I and II) has both advantages and challenges. In comparison to conducting prospective studies, retrospective data collection has the advantages of time-efficiency, cost-effectiveness, and most often also reproducibility [133]. The main challenges are related to biases caused by the construction of the registers, the validity of the reporting source, and the internal validity of the register

itself. Knowledge of the register's data quality is essential in order to assess the register's validity and increase generalisability [134]. The electronic ambulance medical records used in Study I were not created for research purposes in the first place: hence, the results from Study I should be regarded as hypothesis-generating and not the truth based on statistical significance as such. The VAL register used in Study II has been considered valid and reliable in several previous studies [125] and the Stockholm Regional Council uses data from VAL for the continuous update of regional healthcare use in the National Patient Register administered by the Swedish National Board of Health and Welfare [126].

As a consequence of the retrospective nature of Studies I and II, the availability of data could not be increased. Hence, validity and reliability are affected negatively. When ACs document and register non-conveyance in the ambulance medical records, no differentiation between different types of non-conveyance is made. Although referral to a healthcare facility (see/treat and refer, e.g. ED or primary care unit) or self-care advice (see/treat and release) was given, all non-conveyed patients are categorised as one large group in the ambulance medical record of the Stockholm region. The possibility to include data regarding referrals to alternative means of transport to the ED – such as own car or taxi – would have increased both the internal validity and the reliability in Study II. Hence decreasing the risk of misclassification of exposure. Approximately 20% of all non-conveyed patients in a Finnish study were found to have been referred to a healthcare facility using an alternative means of transport [18]. Categorising between different non-conveyance assignments, such as the X-codes used in the Finnish ambulance service [135], would have had a positive impact on both the validity and the reliability of Study II. Further, the systematic patient safety work that Swedish caregivers are required to perform according to Swedish law [136] would also yield an increased validity and reliability if such categorisations were made. The absence of such a categorisation and differentiation of non-conveyed patients inhibits both ambulance stakeholders and caregivers from exploring and learning from non-conveyance situations in the past.

With respect to time to follow-up, a cofounding factor is that the data lacked information regarding referral to an alternative means of transport. However, the 7-day follow-up strengthens the validity and reliability of Study II. A majority of the older patients admitted following non-conveyance were admitted 3 to 7 days post assessment, hence dismissing alternative means of transport as a possible confounding factor when examining ED visits.

We consider possible natural selection bias to have a limited influence on the data available as a result of the Swedish healthcare system – including the ambulance service – being a tax-funded care system available for all Swedish citizens. Unfortunately, our data did not include EMCC categorisation, hence excluding information from an essential part of the prehospital emergency medical chain, information that would be of interest when trying to capture the whole picture of non-conveyed patients. In Study II, the absence of a registered and valid Swedish security number generated exclusion. In order to answer the aim of Study II, in which follow-up of subsequent healthcare contacts for non-conveyed patients was included, a registered and valid social security number was a prerequisite. A missing social security number or identity number is a known weakness among studies investigating the ambulance care context [137]. Possible bias as a consequence of missing registered social security number could mean that patients could be either less or more severely ill.

The categorisation of the initial 140 different prehospital initial assessment codes (Studies I and II) into 10 categories was performed by me. Enhancing validity – supervisors Lindström (RN specialist in intensive care) and Djärv (MD specialist in emergency medicine) – supported this process (Appendix II in Study II). Swedish ACs do not use the International Classification of Diseases (ICD-10) to diagnose patients: hence, comparisons with previous studies using ICD-10 in an ambulance care context is limited. In addition, the fact that the ambulance service and the physicians working in the intrahospital context use two different classification systems complicates research attempting to correlate prehospital initial assessment codes with the ICD-10 system. Three types of measures may be used when trying to link non-conveyance assessments with subsequent events following non-conveyance: the patients' experience and complaint (at the EMCC, ambulance encounter, ED visit), the prehospital initial assessment code according to ACs, or ICD-10 diagnoses completed by physicians after an often more comprehensive examination including both blood samples and often X-ray. Unfortunately, patients' complaints are not systematically registered in the emergency care system of the Stockholm region, hence excluding it as a possible linking variable.

8.2 REFLECTIVE LIFEWORLD RESEARCH

The methodological principles used in the RLR approach – reflectivity, openness, and bridling – are strongly related to the validity, objectivity, and transferability of RLR studies [128]. Reflective lifeworld research has a clear focus on meaning: the researchers thus focus on how the phenomenon is experienced. Hopefully, the results of RLR offer new

insight and knowledge regarding the phenomenon of interest. This new knowledge is conveyed through language. Therefore, it is important to actively work towards and maintain an openness to what is communicated by the informants. To deliver the absolute truth based on objective measures is not the goal of research based on the RLR approach. It is not the researcher's task to question or seek the truthfulness of the informants' lived experiences. Adapting to a reflective attitude when conducting RLR is essential in order to achieve an open and curious approach. The researcher has to be aware of one's own preunderstanding of the phenomenon. I worked actively both before, during, and after data collection in both Study III and IV with my preunderstanding in order to not make definite of what is indefinite. Prior to data collection, I became aware of my preunderstanding through different types of reflection; self-reflection, seminars with supervisors, and methods courses at Linnaeus University.

Great variation, both inner and outer, is a scientific criterion within the RLR approach [128]. Prior to both Study III and IV, two respective selection templates covering the outer variations judged important for respective phenomenon were constructed. The inner variations (differences in lived experiences) were revealed once the data collection was underway. For this reason, the concept of saturation is not applicable within the RLR approach [131]. Instead, data collection was stopped once the outer variations were covered and the inner variations no longer varied to a significant degree. Hence, a well-performed and accurate recruitment process is important for achieving valid results when conducting RLR. In Study III, we had issues recruiting EMTs. A possible explanation for this might be that the specialist nurse within the ambulance team is medically responsible and is the one who should conduct and document non-conveyance assessments [123]. The recruitment process of non-conveyed patients in Study IV was based on ACs' willingness to present the study and ask presumptive informants if they approved a subsequent telephone contact where they would receive further information about the study. There is a risk that ACs unconsciously or consciously became biased and chose to refrain from presenting the study to certain patients, such as non-conveyance encounters, which ACs perceived as having negative elements. It is impossible to know which patients the ACs refrained from introducing the study to. However, judging from the results of Study IV, both negative and positive experiences of non-conveyance situations were elucidated. Based on the results of Studies I and II, an overrepresentation of patients with psychiatric complaints was identified. Unfortunately, these patients were not found among those who participated in

Study IV, hence the findings of this study have limited applicability on non-conveyed patients with psychiatric complaints.

I experienced differences in interviewing ACs compared to patients. During the interviews with the ACs, it became apparent that there was a great need for them to share their experiences regarding non-conveyance, in contrast to patients, who easily described their lived experiences of the non-conveyance situation as isolated events. ACs' experiences of non-conveyance covered several years of conducting these assessments and also included several aspects other than just the non-conveyance encounter itself, such as the organisational and educational perspectives. After the interviews, several ACs described the conversation as almost therapeutic. It had a reflective impact on the ACs following the interviews. A possible explanation for this could be that everyday clinical work in the ambulance service of the Stockholm region lacks opportunities for ACs to reflect. Hence, their experiences came to mean something at the point of interview. Through the act of being listened to, they were seen as persons with valuable experiences and not just a person performing a task. In addition, this might explain the differences seen in median interview time between Study III and IV. One could argue that, in comparison to ACs, the phenomenon is relatively well limited to both time and space for non-conveyed patients. Consequently, sharing one's non-conveyance experience was performed with less distraction by patients compared to ACs, who experience non-conveyance during every shift. In summary, there is no absolute truth within RLR. Indeed, we do not claim that the results from Studies III and IV are absolute truths; instead, they should be viewed as important results representing new knowledge regarding the studied phenomena. The truth is changeable, and phenomena are always open, changeable, and indeterminate in nature [128].

9 DISCUSSION

9.1 MAIN FINDINGS

The overall aim of this thesis was to explore situations in which patients were non-conveyed. Furthermore, it was intended to describe ACs' and patients' lived experiences of non-conveyance.

The results indicate that non-conveyance situations represent a non-negligible proportion of all ambulance assignments performed annually. Non-conveyance constitutes a complex caring encounter involving a high diversity of patients with varying characteristics and

complaints. Older non-conveyed adults represent a risk group for adverse events that need to be met with adequate measures to ensure patient safety. Furthermore, insufficient organisational support, a lack of non-conveyance education, and an absence of clinical performance feedback complicate ACs' ability to perform accurate and person-centred non-conveyance assessments. Patients' experiences of non-conveyance showed themselves to be a complex and versatile phenomenon in which patients need to be met with an ethical mindset in the creation of a caring encounter.

9.2 NON-CONVEYANCE AND PATIENT SAFETY

The overall findings from Study III reveal a clinical reality accompanied by three paradoxes complicating non-conveyance situations and thus ACs' ability to perform person-centred care: the responsibility paradox, the education paradox, and the feedback paradox. To deliver good and safe care [136], several core competencies applicable to the whole healthcare system and its different professions have been identified as essential. Person-centred care is one of these five competencies, and the most central feature within this competence is the creation of a partnership with the patient [105]. Creating a trusting partnership requires both individual efforts and favourable organisational circumstances. It is therefore problematic that ACs find organisational support to be insufficient in connection to non-conveyance situations (Study III). From a risk perspective, the findings of Study III indicate that conducting non-conveyance assessments means acting with greater responsibility compared to conveying patients to an ED. These findings are supported by previous studies [16,76]. The increased risk of adverse events for non-conveyed patients – and in particular specific sub-groups such as elderly patients – are confirmed in Study II. These increased risks need to be met with sufficient organisational response and support. However, ACs perceived the clinical reality as having insufficient response and support (Study III). A prerequisite for establishing favourable circumstances for healthcare personnel to provide person-centred care is on the one hand a person-centred leadership and on the other a person-centred climate [138]. The latter has been described as an environment in which person-centred care is provided [139]. ACs are influenced by leadership in an environment shared with several others: for example, the ambulance station. In addition to the shared environment, in which there are no direct patient contacts, ACs performs the majority of their work in the ambulance or patients' homes. These are environments which a limited number of individuals have access to: this also applies to the leadership. Thus, responsibility rests on both persons in the ambulance team to create a climate in which person-centred care is provided. When not met with confirmation from the

colleague and interest in discussing the assessment, ACs described feelings of loneliness in connection to non-conveyance situations (Study III). Medical guidelines used by Swedish ambulance services have been shown to lack a person-centred perspective [15]. This could be a possible explanation for the perceived lack of support described by ACs when discussing the medical guidelines in general and the non-conveyance guideline in particular (Study III). In summary, the insufficient organisational response and support – including medical guidelines with limited applicability in connection to non-conveyance situations – creates frustration. Ambulance clinicians' ability to provide person-centred care and patient-safe assessments does not benefit from experienced frustration.

Elderly individuals have been described as frail and vulnerable in a general ambulance service context [140]. This is largely confirmed by the results of Study II. This indicates that elderly non-conveyed patients constitute a risk group which requires changes in both systematic (ambulance organisation) and individual (ACs) levels in order to create more favourable circumstances for accurate assessments. The risk of subsequent and adverse events following non-conveyance was consistently higher among elderly patients compared to younger adult non-conveyed patients (Study II). However, it is not unproblematic to conduct cohort studies, including follow-up of patient outcome. As well as the absence of a uniformed definition of non-conveyance aforementioned, there are also no defined relevant points of outcome following non-conveyance [2,141]. Researchers conducting these types of studies have to answer several questions, such as 'Which outcomes are relevant to include in the study and why?' and 'What is a subsequent or adverse event in a non-conveyance context?' From a patient perspective, a subsequent hospital admission following non-conveyance was not viewed per se as an adverse event (Study IV). Few studies have examined patient outcome for the general non-conveyance population, and even fewer studies have investigated patient outcome for older adult non-conveyed patients [2,141]. Comparisons between non-conveyance follow-up studies are complicated due to the considerable heterogeneity of the points of outcome used [141]. To date, however, there is an absence of consensus in the research community with respect to how to evaluate repeated access to the healthcare system – due to independent events – from a patient safety perspective. The absence of valid quality indicators for patient safety in the chain of emergency care in general and non-conveyance, in particular, makes it difficult and risky to evaluate and classify patient's re-entries into the healthcare system as justified or not justified [2,16]. Healthcare injury is defined in the Swedish Patient Safety act [136] as 'suffering, physical or mental injury or illness as well as deaths that could have been

avoided if adequate measures had been taken in the patient's contact with the health service'. This definition served as a basis for the internal discussions when deciding upon relevant points of outcome investigated in Study II. Furthermore, a healthcare injury can be the result of care and treatment received by the patient but also the result of the absence of care and treatment [136]. Both these perspectives are applicable in Study II.

All measured points of outcome in Study II – ED visit, unplanned hospitalisation, and mortality –were followed up within 7 days of non-conveyance. Overall, older adult patients were at higher risk for all measured subsequent and adverse events compared to younger adult non-conveyed patients. However, worth noting is that a majority of patients did not seek care at an ED following non-conveyance. However, the figures for ED visits are even larger in our study compared to a previous study with the same follow-up time [41]. These findings might indicate on the one hand that non-conveyed patients have a reduced need for further medical care and on the other that non-conveyed patients seek care at levels that are not optimal for their specific medical complaint. A possible reason for the latter could be limited accessibility to the healthcare system in general and the primary care system in particular [142]. One in five older adult patients were admitted to hospital within 7 days, compared to one in eight among younger adult non-conveyed patients (Study II). The figures for older adult patients are placed in the upper bound of hospitalisation rates when compared with previous studies [16,37,52,96]. However, to our knowledge, no previous study has analysed older adult non-conveyed patients explicitly in comparison with younger adult non-conveyed patients. The overall low mortality rates seen in the whole cohort are comparable to previous studies [16,38,41,95,96]. Older adult patients with psychiatric symptoms had an increased mortality rate: the reasons for this requires further studies on this frail and vulnerable patient group. Moreover, mortality rates increased 10-fold among older adult patients compared to younger adult non-conveyed patients (Study II). These results should yield changes in how the ambulance organisation identifies, analyses, and learns from adverse events following non-conveyance.

9.3 THE PERSON BEHIND THE PATIENT

Patients' lived experiences of becoming acutely ill and not accompanying the ambulance to a hospital most often began with a sudden onset of physical symptoms (Study IV). In connection to this sudden debut, patients experienced vulnerability and existential fear. The patient's lifeworld underwent an unexpected rapid change in which a loss of bodily control was experienced. According to the French phenomenological philosopher Maurice

Merleau-Ponty, human beings experience their lifeworld primarily through the living body. Hence, the lived experiences and the body are inseparable parts [129]. In connection to not recognising one's body, patients experienced a loss of situational control (Study IV). They were suddenly dependent on others, both existentially and physically. Being dependent on others in connection to sudden illness or trauma was described earlier in an ambulance care context [67]. However, our results indicate that non-conveyed patients also experience a strong vulnerability and dependency towards others before even calling an ambulance (Study IV). These results are congruent with previous studies in an intrahospital setting, indicating that seeking healthcare means showing oneself as weak, vulnerable, and powerless [143]. In relation to not recognising one's own body, the patients most often seek confirmation from others by involving significant others in a dialogue regarding the symptoms and possible measures to be taken (Study IV).

Another important finding for ACs to be aware of and act upon is the possibility that several events might have occurred before they arrive at the scene. Non-conveyed patients actively seek confirmation regarding their actions and in regard to whether they acted correctly or not (Study IV). If they are met with nonchalance and lack of confirmation from ACs, in their already vulnerable and dependent lifeworld, a violation of their dignity can be experienced [108]. Patients have a need of being taken seriously by ACs [106]; if not, patients can experience increased suffering and vulnerability (Study IV). A majority of all non-conveyance assignments are dispatched as the highest priority level (Study I). Non-conveyed patients might have a further need of being taken seriously because of the way the EMCC acted and communicated. As a consequence, ACs should reflect and act upon this fact. In order to optimally utilize the limited number of ambulance resources available, accurate dispatch priority is essential [144]. A correspondence between high dispatch priority and non-conveyance has been observed previously [10], though our results show an even higher proportion of non-conveyance assignments dispatched as the highest priority level (Study I). We investigated our data material closely and could not find an explanation for these findings within them. One possible explanation could derive from a high incidence of on-scene treatable medical conditions, such as hypoglycaemia. Though, the incidence of hypoglycaemia among non-conveyed patients in our data set does not explain the high proportion of dispatched assignments receiving the highest priority level (Study I). In order to dispatch ambulance assignments with high accuracy, the dispatch system used needs to have a specificity and sensitivity that are well investigated and validated [145]. Our findings call for further studies in the EMCC context relating to dispatch accuracy.

Non-conveyed patients were found across all 10 possible initial assessment codes registered by the ACs (Studies I and II). These findings are confirmed by ACs, who describe a great variety of non-conveyance patients with different complaints and characteristics (Study III). Our results (Studies I and II) do stand out compared to previous non-conveyance studies [89,146]: specifically, a greater proportion of non-conveyed patients were categorised as having a non-specific complaint or symptoms related to psychiatric problems. Non-specific complaints had a strong association with non-conveyance compared to conveyed patients (Study I). Having a non-specific complaint, both in the prehospital setting and at the ED, have previously been shown to correlate to underlying serious conditions and also increased risks of both hospitalisation and mortality [147–149]. An overrepresentation of elderly patients has been shown in the patient group with non-specific complaints [147]. As such, both patients with non-specific complaints and patients with complaints categorised as psychiatric problems have been described as fragile and vulnerable in a prehospital setting [100,140]. There is a need for further in-depth knowledge regarding the specific needs of these vulnerable patient groups in order to create favourable circumstances for ACs in establishing a caring encounter and conduct accurate non-conveyance assessments.

The physical examination performed by ACs was perceived as reassuring by non-conveyed patients (Study IV). Approximately one in three non-conveyed patients presented with at least one abnormal vital sign during the non-conveyance assessment (Study I). The occurrence of abnormal vital signs among non-conveyed patients has been sparsely investigated previously. Our results place themselves in between previously reported numbers of abnormal vital signs [16,43,89]. A conflict of interest was described by the ACs (Study III) in which one side holds the non-conveyance guideline, in which it is stated that patients suitable for non-conveyance must not have abnormal vital signs. On the other hand, ACs describe the importance of conducting individual non-conveyance assessments involving unique individuals with unique needs and backgrounds (Study III). Being met with interest by ACs and as a unique individual with specific needs was highlighted by non-conveyed patients (Study IV). Measuring vital signs as an indicator of severe disease have been shown to be reliable among individuals with already affected vital signs [150]. It is less applicable among individuals with unaffected vital signs [151], such is the case with a majority of the non-conveyed patients (Study I). An additional aggravating circumstance is that elderly patients do not always present abnormal vital signs when becoming acutely ill [147]. This is due to normal age-related physiological changes and comorbidities [152].

Measuring vital signs as a single-point examination has less sensitivity compared to repeated measuring [153], especially when assessing elderly individuals [152]. In summary, these findings call for new ways of solving the challenges that come when assessing frail non-conveyed patients.

9.4 MUTUAL KNOWLEDGE GAP

Non-conveyed patients constitute a non-negligible proportion of all patients annually cared for by the ambulance service of the Stockholm region (Study I). The prevalence of non-conveyance found in Study I would be placed in the lower bound of the non-conveyance spectrum [2]. However, the absence of a uniformed definition of non-conveyance both at the national and international levels affects the study designs, methodology, and results of previous non-conveyance studies [141]. Comparisons of different systems of ambulance services in different countries should be made with caution. There is a need to validate data sources in order to yield reliable results that can be implemented in clinical practice, hence increasing the organisational knowledge regarding non-conveyance.

The non-conveyance situation is complicated by the education paradox (Study III). According to ACs, performing accurate non-conveyance assessments requires in-depth knowledge of the many symptoms and diseases encountered during different non-conveyance situations. The high diversity of patients with varying characteristics and complaints described by ACs (Study III) are confirmed in Studies I and II. Specialist nurse studies at the university have been shown to lack educational parts involving caring for patients with non-urgent needs, including non-conveyance [81,83], hence indicating a discrepancy between the curriculum content that students encounter during higher education and the clinical context ACs are confronted with once working in the ambulance service. Not being adequately prepared for one's clinical work risks creating frustration (Study III) and compassion fatigue [75]. The latter is a risk for decreasing patient safety [154]. Moreover, there is a risk of unfavourable circumstances when ACs experience frustration during non-conveyance situations (Study III). Patients need to encounter calm, supportive, and interested ACs with a good and adequate knowledge base (Study IV). Supportive leadership is of crucial importance for reducing the risk of development of compassion fatigue among healthcare workers [155]. The insufficient support from the organisation perceived by ACs is therefore further problematic (Study III). The effects on non-conveyance situations, including patients and ACs, if ACs develop compassion fatigue

as a result of inadequate education and insufficient organisational support in connection to non-conveyance requires further studies.

An additional aspect of creating favourable circumstances for providing person-centred care is that the person-centred climate should be influenced by an openness to critical reflections and a will to change and improve praxis [156]. Without clinical performance feedback, these actions will be hard, if not impossible, to perform. Hence, the organisations' – and ACs' – ability to provide person-centred care will be limited. Moreover, with the aim of increasing patient safety and thus creating favourable circumstances for ACs to establish a caring encounter, enhancing learning possibilities for ACs based on reliable follow-up data should be implemented in everyday clinical work by the ambulance organisations. However, the feedback paradox (Study III) constitutes a lack of systematic clinical performance feedback following non-conveyance situations and is the most important factor limiting professional development according to ACs (Study III). Previous clinical experience of performing non-conveyance assessments was described as a basis for future assessments (Study III). However, when the previous clinical experience lacks clinical performance feedback, the situation becomes more complicated. The implementation of clinical performance feedback within ambulance organisations has been shown to have a positive impact on patient safety culture [157]. Results from Study II, where varying increased risks of adverse events were found among older adults, indicate a need to use clinical performance feedback for enhancing patient safety through the feedback paradox (Study III) and patients' need for reassurance through competent ACs (Study IV). Hence, this type of feedback could be a valuable tool when creating a person-centred climate [70]. However, which type of feedback is needed in order to achieve accurate non-conveyance assessments falls outside the scope of this thesis.

The lack of knowledge regarding non-conveyed patients present among ACs and ambulance services (Study III) could be partly explained by the absence of definitions of adverse events in a non-conveyance context [2]. When analysing abnormal vital signs among older adult patients (Study II), unplanned hospitalisation was chosen as the point-of-outcome indicating a possible adverse event. Emergency department visits were excluded as an adverse event due to several possible confounders and mortality due to too few events (Study II). Based on our results in combination with others [147], there is a need to further investigate other ways of identifying possible underlying severe disease than measuring vital signs at a single point-of-measure in a non-conveyance context. Hence, our results

confirm the possible benefits of using personalized reference ranges to increase sensitivity when measuring vital signs among older adult individuals [152]. A closer collaboration between the ambulance services and primary care could possibly yield positive effects on continuity during non-conveyance situations [10,13].

In relation to a patient not knowing what they suffered from, some patients described the time after the non-conveyance encounters as hard and burdensome (Study IV). These findings indicate that ACs might lack favourable circumstances in creating a safe situation following non-conveyance partly because of organisational constraints. Ambulance clinicians' experiences confirm these limitations (Study III), hence indicating the need for further studies investigating post-non-conveyance encounters from an organisational perspective in order to create safe environments for non-conveyed patients. Closer collaboration and dialogue between the ambulance service and primary care in connection to non-conveyance assessments [13] could enhance ACs' possibilities for conducting safer and more person-centred care (Study III), thus decreasing non-conveyed patients' feelings of uncertainty (Study IV).

10 CONCLUSIONS

By the use of epidemiological methods and an RLR approach we have explored situations in which patients were non-conveyed. This thesis has shown that a non-negligible proportion of all ambulance assignments performed annually constitutes of non-conveyance situations. The high diversity of non-conveyed patients with varying characteristics, symptoms and complaints generates clinical challenges for ACs when performing these complexed assessments. Based on our results, ambulance organisations should consider applying measures in order to ensure patient safety among non-conveyed patients, in particular, among elderly patients who represents a risk group for adverse events following non-conveyance. The results indicate that ACs faces a challenging clinical reality because of several paradoxes that complicates their ability to perform person-centred care and patient safe non-conveyance assessments. To better understand the implications of these results, future research studies could address the role of clinical performance feedback following non-conveyance situations. Further, patients' experiences of non-conveyance involved a complexity of different emotional stages – ranging from fear to security to uncertainty. Our results suggest that these patients have a need of being confirmed through the act of being listened to and by being reassured. Furthermore, several existential aspects

affecting non-conveyed patients during these situations need to be met by ACs if a caring encounter is to be established.

10.1 CLINICAL IMPLICATIONS

This thesis represents one of the first to comprehensively investigate and elucidate non-conveyance from an epidemiological and RLR perspective. Hence, several clinical implications stem from this thesis, including the following:

- Increased organisational awareness and knowledge regarding the large group of patients with variating characteristics, complaints, and symptoms that are non-conveyed annually.
- Increased awareness and knowledge by organisations and individual ACs regarding the identification of non-conveyed older adults as a risk group of adverse events that should be met with adequate measures in ensuring patient safety.
- Identification of important aspects of performing non-conveyance assessments, complicated by several paradoxes that need to be met with sufficient organisational support, educational efforts, and the introduction of clinical performance feedback in order to perform person-centred care, ensure patient safety, and enhance professional development among ACs.
- Elucidation of non-conveyance encounters as complexed care meetings in which several existential aspects deemed important for non-conveyed patients need to be met in order to establish a caring encounter based on person-centred care.
- Acknowledgement that the ambulance service and ACs possess a unique opportunity to perform person-centred care during non-conveyance situations – through the establishment of a partnership – and through the act of handing back responsibilty by the end of the non-conveyance encounter.

10.2 FUTURE RESEARCH

The new knowledge offered by the results of this thesis is as an important part of our premature understanding of non-conveyance situations, but at the same time, one should be aware that research on non-conveyance is in its infancy. As a consequence, there is a need for research investigating relevant points of outcome measuring patient safety in order to establish a standard that researchers and ambulance organisations can use when evaluating patient safety in a non-conveyance context. There is currently an absence of involving patients when evaluating patient safety in Swedish ambulance services. Relevant measurements based on patient-self reported outcomes would further increase the validity

and reliability of such research and organisational patient safety work. Further research investigating the effects of a closer collaboration between the ambulance service and primary care units is needed in order to increase our understanding of how to create safer environments following non-conveyance for patients – and ACs. In addition, further understanding of patients' experiences of adverse events following non-conveyance is needed to fully capture the complexity of the non-conveyance situation. There is also a need for research investigating relevant and sufficient organisational aspects in creating favourable circumstances for ACs to perform person-centred care and safe non-conveyance assessments. This includes studies evaluating the implementation of a clinical performance feedback system from both a patient safety and a user-perspective. The rapid development and increased use of machine learning systems (artificial intelligence) within healthcare could possibly be applicable in non-conveyance situations, though further research is needed in order to achieve systems that complement ACs' assessments and thus enhance patient safety.

11 SVENSK SAMMANFATTNING

BAKGRUND

Till följd av det generellt ökade antalet ambulansuppdrag i kombination med en ökning av antalet patienter som bedöms ha icke-akuta besvär ställs nya krav på ambulanssjukvården och dess medarbetare avseende patientbedömningar och beslutsfattande. Det senaste decenniet har så kallade alternativa vårdnivåer, såsom hänvisning till vårdcentral alternativt fortsatt egenvård, ökat i användning. Kunskapen om när ambulanspersonal hänvisar patienter till så kallade alternativa vårdnivåer är begränsad. För att säkerställa och stärka patientsäkerheten krävs ny kunskap från både epidemiologisk och kvalitativ forskning.

SYFTE

Det övergripande syftet var att studera situationer där patienter blivit hänvisade (inte medföljt ambulansen till en sjukvårdsinrättning). Vidare avsågs att beskriva ambulanspersonals och patienters levda erfarenheter av dessa hänvisningssituationer.

METOD

Fyra delstudier genomfördes, **studie I** var en populationsbaserad observationsstudie med syftet att beskriva prevalensen av hänvisning, undersöka associationer och jämföra patientkaraktäristika, läkemedelsbehandling, sökorsaker och vitalparametrar mellan

hänvisade och icke-hänvisade (transporterade till akutmottagning) patienter. Data hämtades från ambulansjournalsystemet (CAK-net, Region Stockholm). **Studie II** var en retrospektiv kohortstudie med det övergripande syftet att öka kunskapen om äldre patienter som blivit hänvisade. Studiens primära syfte var att presentera prevalensen av äldre patienter som blivit hänvisade samt deras karaktäristika och, i jämförelse med vuxna hänvisade patienter (18–64 år), identifiera och beskriva riskfaktorer associerade med akutmottagningsbesök, sjukhusinläggning och mortalitet upp till sju dagar efter hänvisningstillfället. Studiens sekundära syfte var att undersöka möjliga associationer mellan avvikande vitalparametrar och utfallen akutmottagningsbesök, sjukhusinläggning och mortalitet upp till sju dagar efter hänvisningstillfället. Patientdata inhämtades från ambulansjournalsystemet (CAK-net) och uppföljningsdata hämtades från den regionala hälso- och sjukvårdsdatabasen (VAL, Region Stockholm). **Studie III** var en intervjustudie med ambulanspersonal, genomförd med en reflekterande livsvärldsansats (RLR) baserad på fenomenologi. Syftet var att beskriva ambulanspersonals erfarenheter av att bedöma patienter som blivit hänvisade till alternativa vårdnivåer. **Studie IV** var en intervjustudie med patienter som blivit hänvisade, studien genomfördes med en RLR-ansats. Syftet var att, utifrån patienter som blivit hänvisades perspektiv, beskriva erfarenheter av att bli akut sjuk och inte medfölja ambulansen till ett sjukhus.

RESULTAT

Resultatet visar att patienter som blivit hänvisade utgör en betydande andel av alla ambulansuppdrag som utförs årligen. Hänvisningssituationerna utgör ett komplext vårdmöte som involverar en stor mängd olika patienter med varierande karaktäristika, sökorsaker och symtom. Dessa ambulansuppdrag utlarmas oftast som högsta prioritet av larmcentralen, involverar generellt yngre personer och ambulanspersonal bedömer ofta patienters sökorsaker att vara av icke-specifik karaktär eller relaterat till en psykiatrisk problematik (**Studie I)**. Äldre hänvisade patienter (> 65 år) har en ökad risk för negativa händelser i efterförloppet till hänvisningar. De ökade riskerna behöver tillgodoses med adekvata åtgärder för att patientsäkerheten ska säkerställas. Äldre hänvisade patienters ökade risk för sjukhusinläggning och mortalitet väcker frågor kring patientsäkerheten (**Studie II**). Vidare försvåras ambulanspersonalens möjligheter att genomföra korrekta och personcentrerade hänvisningsbedömningar på grund av ett otillräckligt organisatoriskt stöd, en avsaknad av relevant utbildning och en avsaknad av klinisk prestationsåterkoppling (**Studie III**). Patienters erfarenheter av hänvisning visade sig som ett komplext och mångfacetterat fenomen där patienter har ett behov av att mötas med en etisk medvetenhet

för att vårdande möte ska kunna skapas. Hänvisade patienter upplever en existentiell rädsla och förlust av kroppskontroll som behöver mötas med bekräftelse, lyssnande och partnerskap för att stärka den hjälpsökande (**Studie IV**).

SLUTSATSER

Denna avhandling erbjuder flera slutsatser med klinisk implikation, såsom; en ökad medvetenhet och kunskap på både organisatorisk (beställare/ambulansföretag) och individuell nivå (medarbetare) gällande den stora grupp av patienter med skiftande karaktäristika, sökorsaker och symtom som hänvisas alternativa vårdnivåer varje år. Den ökade risken för negativa händelser för äldre hänvisade patienter behöver mötas med adekvata åtgärder för att säkerställa patientsäkerheten. Flertalet paradoxer försvårar ambulanspersonalens kliniska vardag och hänvisningssituationerna. Med målet att vårdmötena ska präglas av en personcentrerad vård behöver dessa paradoxer hanteras med bland annat adekvat organisatoriskt stöd, relevanta utbildningsinsatser och införandet av klinisk prestationsåterkoppling. Utifrån ett patientperspektiv är hänvisningssituationerna komplexa vårdmöten där olika existentiella aspekter behöver mötas med en etisk medvetenhet för att ett personcentrerat vårdmöte ska kunna skapas.

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