

## ORIGINAL ARTICLE

# Ambulance clinicians' attitudes to older patients' self-determination when the patient has impaired decision-making ability: A Delphi study

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## Abstract

**Objective:** The proportion of older people is increasing and reflects in the demand on ambulance services (AS). Patients can be more vulnerable and increasingly dependent, especially when their decision-making ability is impaired. Self-determination in older people has a positive relation to quality of life and can raise ethical conflicts in AS. Hence, the aim of this study was to empirically explore attitudes among Swedish ambulance clinicians (ACs) regarding older patients' self-determination in cases where patients have impaired decision-making ability, and who are in urgent need of care.

**Materials and methods:** An explorative design was adopted. A Delphi technique was used, comprising four rounds, involving a group ( $N = 31$ ) of prehospital emergency nurses ( $n = 14$ ), registered nurses ( $n = 10$ ) and emergency medical technicians ( $n = 7$ ). Focus group conversations (Round 1) and questionnaires (Rounds 2–4) generated data. Round 1 was analysed using manifest content analysis, which ultimately resulted in the creation of discrete items. Each item was rated with a five-point Likert scale together with free-text answers. Consensus ( $\geq 70\%$ ) was calculated by trichotomising the Likert scale.

**Results:** Round 1 identified 108 items which were divided into four categories: (1) attitudes regarding the patient ( $n = 35$ ), (2) attitudes regarding the patient relationship ( $n = 8$ ), (3) attitudes regarding oneself and one's colleagues ( $n = 45$ ), and (4) attitudes regarding other involved factors ( $n = 20$ ). In Rounds 2–4, one item was identified in the free text from Round 2, generating a total of 109 items. After four rounds, 72 items (62%) reached consensus.

**Conclusions:** The findings highlight the complexity of ACs' attitudes towards older patients' self-determination. The respect of older patients' self-determination is challenged by the patient, other healthcare personnel, significant others and/or

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colleagues. The study provided a unique opportunity to explore self-determination and shared decision-making. AS have to provide continued ethical training, for example to increase the use of simulation-based training or moral case deliberations in order to strengthen the ACs' moral abilities within their professional practice.

**Implications for practice:** Ambulance services must develop opportunities to provide continued training within this topic. One option would be to increase the use of simulation-based training, focusing on ethical aspects of the care. Another option might be to facilitate moral case deliberations to strengthen the ACs' abilities to manage these issues while being able to share experiences with peers. These types of interventions should illuminate the importance of the topic for the individual AC, which, in turn, may strengthen and develop the caring abilities within an integrated care team.

#### KEYWORDS

ambulance clinicians, decision-making ability, ethics, older patients, patient autonomy, prehospital emergency nurses, self-determination

## 1 | INTRODUCTION

The number of people aged 60 years and older will increase from 1 billion in 2019 to 1.4 billion by 2030 and 2.1 billion by 2050. This increase is occurring at a unique pace and will accelerate, particularly in developing countries, in coming decades (World Health Organization, 2021). Every fifth person in Sweden is 'older' ( $\geq 65$  years of age), which is a proportion that is expected to increase to one in four within a few decades (Statistic Sweden, 2020). The increasing proportion of older people in society is a common finding in several western countries, which is reflected in the increased need for pre-hospital emergency care and the associated use of the ambulance services (AS) (Lowthian et al., 2011). This can be seen, for example, in Sweden, with an increase in ambulance assignments by 68% during 2009–2014 (Bremer, 2016). A significant contributor to this increase is the growing population of older people with greater healthcare needs. This is confirmed by a recent study indicating a considerable increase in dispatched ambulance resources for patients between 70 and 89 years of age, showing that 60% of the assignments involved older patients  $>70$  years of age (Hjalmarsson et al., 2020). Because autonomy is an important ethical value for most patients, it is also important to understand how ambulance clinicians (ACs) perceive and manage patient autonomy. ACs in Sweden comprise mainly registered nurses (RN) with or without specialist training in prehospital emergency care. These RNs are sometimes paired with emergency medical technicians (EMTs), who are commonly trained as assistant nurses. Henceforth, in this paper, ACs refer to these nurses of differing roles.

In this study of ACs' attitudes towards older patients' self-determination, we define autonomy as 'the power or right of self-government', while self-determination is defined as 'the act or power of deciding things for oneself'. Here, the concept 'attitude' is understood as 'a way of thinking or feeling about a fact or state'

(Encyclopædia Britannica, 2020). Taken together, autonomy in older people in AS—as the first link in the care chain—is important for nurses in the following phases of older people nursing.

Self-determination in older people has been found to have a positive relation to quality of life (Bölenius et al., 2019; Kalfoss, 2010). A primary quality aspect of self-determination is to independently manage oneself without support (Johannessen et al., 2004). However, certain conditions must be met to exercise self-determination. Older persons need to feel safe in relationships, be able to influence decisions, and feel involved (Ekelund et al., 2014). Building trustful relationships over time is important in environments supporting older people's self-determination (Souesme & Ferrand, 2019).

There is a dearth of studies examining self-determination in older patients within AS settings. However, ethical conflicts have been found to be related to self-determination when patients refuse the care offered by the ACs (Sandman & Nordmark, 2006). In a recent study from the AS context, Bremer and Holmberg (2020) found that a number of ethical conflicts originated from problems related to the patient's self-determination. Ethical conflicts arose because of the ACs' inadequate access to the patient's narrative, uncertainty regarding the patient's decision-making ability and conflicting assessments of the patient's best interest.

Research on older patients' own experiences from an ethical perspective is lacking when it comes to urgent situations in need of ambulance care. In a study by Kluit et al. (2018), it was found that the decision to transport older people to hospital was influenced by whether the patient was presenting with acute conditions, despite a period of complaints varying between hours and years preceding the decision. The older patients saw hospital admission as inevitable due to an unsatisfactory care environment at home and positive expectations of hospital care. Shared decision-making was rarely seen, and an ethical dilemma occurred when the next of kin consented to hospitalisation against the wishes of the patient.

## SUMMARY STATEMENT OF IMPLICATIONS FOR PRACTICE

### What does this research add to existing knowledge in gerontology?

- Ambulance clinicians, in regard to their professional status, consider themselves as having the upper hand over the older patient, leaving him/her exposed to possible abuse of power.
- Ambulance clinicians are disturbed by the influence of their colleagues, significant others and/or other health-care professionals in their ambition to respect older patients' self-determination.
- Acutely ill older patients with impaired decision-making ability risk negative discrimination as a result of unconscious bias among ambulance clinicians.

### What are the implications of this new knowledge for nursing care with older people?

- Ambulance clinicians need expanded theoretical ethical knowledge and training in managing ethical values in the care of older patients with impaired decision-making ability.
- Ambulance clinicians need continuous training to assess and consider potential impairments of older patients' decision-making abilities, as the number of such patients is expected to increase.

### How could the findings be used to influence policy or practice or research or education?

- Ethical conflicts in the care of older patients in the pre-hospital ambulance care context need to be explicitly highlighted to further develop professional care.
- Self-determination is an important aspect when deciding whether to provide care as well as emphasizing that care provided should take place in accordance with older patients' best interests.

Additionally, older patients' decision-making abilities in acute situations are often reduced and sometimes completely lacking. The patients' inability to express themselves has direct consequences for patient autonomy, integrity and dignity. Due to the lack of patient self-determination, ACs encounter forms of surrogate decision-making, often with support and information from family members, but sometimes entirely on the basis of the care team's independent assessment of what might benefit the patient, based on the signs of illness and available medical history (Bremer et al., 2012; Bremer & Holmberg, 2020; Hagiwara et al., 2013; Holmberg et al., 2016).

Older patients who need AS are often vulnerable and dependent, especially when their decision-making ability is impaired, which increases the risk of important ethical values being violated. When the patient is older and fragile, there is reason to believe that the risk is even more pronounced, making self-determination conditional (Ekelund et al., 2014). In urgent situations, older patients may have impaired decision-making ability or reduced ability to participate in decisions concerning their own care, making it more difficult for the ACs to understand and respect the patient's autonomy, as there is uncertainty about the patient's authentic wishes and own values. Hence, the risk of value conflicts is significant (Bremer & Holmberg, 2020). Older, acutely ill persons with impaired decision-making abilities also risk negative discrimination resulting from conscious or unconscious bias among ACs or the patient's needs are assessed based on the ACs' own values (Bremer et al., 2015). This risk can be assumed to be greater when older patients do not have a social network that can act as surrogate decision-makers in cases where the older patients are unable to identify, articulate and fight for their needs. In a worst-case scenario, older patients can be given lower priority, even though their needs are just as, or possibly even more, significant compared to younger patients with similar needs. Consequently, the delivery of unequal care may result (Giordano, 2005; Rantala et al., 2016).

Taken together, the older patient's vulnerability in urgent situations exposes the asymmetrical and unequal power relationship in the care relationship between the AC and the patient, partly due to ACs' own values and how they can influence the decisions made. Zaner (2000) suggests that it is the healthcare provider who has the power, through knowledge, skills, resources, social legitimacy and legal authority, and not the patient. Wiggins and Schwartz (2005) suggest that healthcare providers have the power to help, while at the same time, the patient becomes more dependent on them, exposing the patient to greater vulnerability and abuse of power. Consequently, the patient needs to trust not only the healthcare providers' professional knowledge, but also their moral character. Through relational autonomy, the shortcomings in an individualistic or sovereign perspective on autonomy can balance the principle-based framework of beneficence, justice and equality (Donchin, 2001; Mackenzie, 2008; Stoljar, 2011). Mackenzie argues for a relational approach to the principle of respect for autonomy, which means an obligation on the part of healthcare providers to respect patients whose autonomy is impaired by promoting the autonomy competence of these patients. Based on these descriptions of power relations in care relationships and individualistic versus relational aspects of autonomy, there is reason to pay attention to the ACs' management of their power and patient autonomy in care relationships with older patients.

Hence, the aim of this study is to empirically explore the attitudes among Swedish ACs about older patients' self-determination in cases where patients have impaired decision-making ability, and who are in urgent need of care.

## 2 | MATERIALS AND METHODS

An explorative design was adopted using a modified Delphi technique (Keeney et al., 2011). The Delphi method emanates from the assumption that a group's opinion, which in this case comprised a panel of Swedish ACs, is more valid than individual opinions.

### 2.1 | Study setting and participants

The study was conducted in two regions (A and B) in southern Sweden. Region A covers approximately 5,600 square kilometres and 300,000 inhabitants. Region B covers approximately 11,200 square kilometres and 240,000 inhabitants. The AS in region A has eight ambulance stations, while Region B has fifteen, covering both rural and urban areas. In 2018, each region dispatched an AS resource to approximately 35,000 calls. The participants were recruited in both regions. The inclusion criteria were ACs with professional affiliations, that is, RN with or without specialist training, and EMTs. RNs with specialist training in ambulance care, that is prehospital emergency nurses (PEN), were the most dominant subspecialty in the RN group (Table 1). Stratified sampling was performed to achieve variation in age, gender, and professions.

### 2.2 | Data collection and analysis

Data were collected and analysed over four rounds between November 2019 and April 2020. The analysis of the focus groups was carried out in Swedish by Swedish-speaking authors, as well as the analysis that led to the statements that were included in the instrument and the preliminary categories that constituted the result. After the items and the preliminary result categories had been translated into English, the fifth and sixth English-speaking authors

also participated in the continued analysis process and the writing of the result.

#### Round 1

The data collection in the first round was carried out with 6 focus groups involving 4–6 participants in each group. The first and the last author moderated the focus group conversations (Morgan, 1997), one having the role as main-moderator and the other as co-moderator. Initially, the participants were informed about the aim of the study and the topic of the focus group conversation. The conversations were digitally recorded and lasted between 77 and 95 min (mean = 86 min) and transcribed verbatim. The focus groups were supported with an opening question: 'What does patients' self-determination mean to you?' Bearing in mind the inductive focus of the study, low-moderator involvement was selected (Morgan, 1997), to allow interaction within the group and facilitate great depth in participant-generated data.

The data analysis started by reading the transcribed conversations several times to obtain a sense of the transcripts as a whole. The first and last authors undertook a manifest and descriptive qualitative content analysis. Statements expressing attitudes regarding older people's self-determination were extracted from the data and entered into an Excel document. The statements were then reformulated for clarification, with the intent of remaining close to the concepts and words used by the participants. Subsequently, the statements were compared with each other to reduce redundancy. Statements expressing similar attitudes were grouped together into categories expressing the overall structure of the data. The statements and the grouping were then discussed and adjusted together with the second, third and fourth authors. Round 1 resulted in four categories concerning the ACs' attitudes to older people's self-determination, comprising a total of 108 statements, henceforth

	Round 1	Round 2	Round 3	Round 4
Gender, <i>n</i>				
Men	15	14	13	13
Women	17	17	17	17
Age, years (mean)	25–65 (45)	25–65 (45)	25–65 (45)	25–65 (45)
Experience from AS <sup>a</sup> , years (mean)	1.5–45 (16)	1.5–45 (16)	1.5–45 (16)	1.5–45 (16)
AC <sup>b</sup> professional affiliation, <i>n</i>				
Emergency medical technician	7	6	5	5
Registered nurse	10	10	10	10
Ambulance nurse	14	14	14	14
Number of participants, <i>n</i>	31	30	29	29

TABLE 1 Ambulance clinician demographic characteristics

<sup>a</sup>AS= ambulance services.

<sup>b</sup>AC= ambulance clinicians.

referred to as items. Finally, a face-validity check of the items was undertaken, involving the other Swedish-speaking authors.

## Round 2

For data collection in the second round, the 108 items emerging in Round 1 were used to develop a questionnaire employed in Round 2 (Table 2). To capture additional attitudes, the participants were given the opportunity to describe, in free text, any additional attitudes that they considered important. To enhance validity, the original questionnaire was piloted with a group of people who did not participate in the main study (Hasson et al., 2000). The pilot group consisted of three experienced specialist trained ambulance nurses and one RN, all active researchers.

The questionnaire for the following rounds was introduced with the question; 'To what extent do you agree with the following items?', encouraging the participants to rate the extent to which they agreed with each item using a five-point Likert scale, ranging from (1) 'not agree' to (5) 'strongly agree'. For analytical purposes, the scale was trichotomised to a three-point scale before determining whether consensus had been reached (Jirwe et al., 2009; Rådestad et al., 2013). Thus, 1–2 on the Likert scale represented 'not agree', 3 represented 'neutral' and 4–5 represented 'agree'. The level of consensus was set at 70% prior to data collection (Keeney et al., 2011). Thus, in the present study, an item was considered to have reached consensus when 70% or more participants agreed on any of the trichotomised scale responses.

For data analysis in this and the following rounds, descriptive statistics were used, focusing on mean values and standard deviation.

The questionnaire was distributed via e-mail to the 32 participants from Round 1. Three reminders were sent via e-mail. The participants who did not respond to the second reminder e-mail were contacted by telephone ( $n = 5$ ). The questionnaire was available for 19 days. In total, 31 participants answered the questionnaire, resulting in a 97% response rate in Round 2.

## Round 3

For data collection in this round, a second questionnaire was developed, comprising the items that did not reach consensus in Round 2 ( $n = 60$ ) together with one new item that emerged from the open-ended question (Table 2). Feedback containing the group mean values was provided for each item to stimulate the participants to reflect upon these values in relation to their reconsidered answers in the data collection round. The questionnaire was distributed via e-mail to the 31 remaining participants. Three reminders were sent via e-mail. The participants who did not respond to the second reminder were contacted by phone ( $n = 5$ ). The questionnaire was available for 17 days. One participant declined further participation. In total, 30 participants answered the questionnaire, resulting in a 97% response rate in Round 3.

TABLE 2 Delphi flowchart of the four rounds

	Round 1	Round 2	Round 3	Round 4
Participants, <i>n</i>	32	31	30	30
Response rate, %	100	97	97	100
Participant drop-out, <i>n</i>	0	1	1	0
Round activity	Focus group conversations	Questionnaire 108 items	Questionnaire 59+1 items	Questionnaire 41 items
With consensus, <i>n</i>		↓	↓	↓
Without consensus, <i>n</i>		49	19	4
Total without/with consensus, <i>n</i>		59	41	37
				37/72

The data analysis followed the procedure presented under the heading '2.2.2 Round 2'.

## Round 4

For data collection in this round, a third questionnaire was developed, comprising the items that did not reach consensus in Round 3, resulting in 41 items. The same procedure as in Round 3 was followed, with the questionnaire distributed to the 30 remaining participants (Table 2). Three e-mail reminders were distributed. Those who did not respond to the second reminder were contacted by phone ( $n = 4$ ). The questionnaire was available for 13 days, resulting in a 100% response rate within this round. In total, 30 participants finished all four rounds, giving a response rate of 94%. The responses were analysed as in Round 3, and an additional 4 items reached consensus.

The data analysis followed the procedure presented under the heading '2.2.2 Round 2'.

## 2.3 | Ethical considerations

The study was carried out in line with the Declaration of Helsinki (The World Medical Association, 2013). Permission was granted by the Swedish Ethical Review Authority prior to the study (No. 2019-02127). All participants received verbal and written information about participation being voluntary and that they could withdraw consent to participate at any time without stating the reason. Participants were given the opportunity to ask questions and have them answered by the research team. Consent to participate was obtained from the participants. During the focus group interviews, maintaining confidentiality within the group was emphasised.

## 3 | RESULTS

The results indicate an ambition to respect older patients' self-determination, preferably in collaboration with the patient. This ambition was impeded by the influence of the AC colleague, significant others and/or other healthcare professionals. Alternatively, collaboration with others was also found to be an important aspect of respecting the patient's self-determination. The patients were perceived as sometimes not being willing or able to participate, thus delaying the ACs' decisions. However, ACs still experienced having to make clinical decisions for the patient, using their power over the patient because of their professional status. Additionally, the context, with dyadic teams and caring for one patient at a time, together with the varying patient population, may both support and undermine the ability to respect the self-determination of the individual patient.

### 3.1 | Round 1

The analysis of the focus group conversations generated 108 items grouped into four overarching categories, namely Category (1) attitudes regarding the patient ( $n = 35$ ); Category (2) attitudes regarding the patient relationship ( $n=8$ ); Category (3) attitudes regarding oneself and one's colleagues ( $n = 45$ ); and Category (4) attitudes regarding other involved factors ( $n = 20$ ).

### 3.2 | Round 2

Forty-nine of the 108 items reached the consensus level of  $\geq 70\%$  in Round 2 (Table 3 and Table 4): Category 1 ( $n=11$ ); Category 2 ( $n=5$ ); Category 3 ( $n=25$ ); and Category 4 ( $n=8$ ).

### 3.3 | Round 3

Nineteen ( $n = 19$ ) of the remaining items ( $n = 59$ ) reached consensus level of  $\geq 70\%$  in Round 3 (Table 3 and Table 4): Category 1 ( $n = 8$ ); Category 2 ( $n = 0$ ); Category 3 ( $n = 7$ ); and Category 4 ( $n = 4$ ).

### 3.4 | Round 4

Four of the remaining items ( $n = 40$ ) reached consensus level of  $\geq 70\%$  in Round 4 (Tables 3 and 4): Category 1 ( $n = 3$ ); and Category 2 ( $n = 1$ ). Of all items (108 from Round 1 together with 1 from Round 2, resulting in  $N = 109$ ), a total of 72 items reached consensus (66%). Of those, 53 items (74%) were 'agree', 14 items (19%) 'not agree' and five items 'neutral' (7%). In total, 37 items (34%) did not reach consensus after four rounds.

## 4 | DISCUSSION

The results indicate that the ACs' approach to older patients with impaired ability to make their own decisions is based on their respect for the patients' decisions and to safeguard the patients' dignity, as well as their self-determination. This is supported by the attitude '*protecting an older patient's self-determination means protecting his/her participation*' (category 3, item 1). This approach requires courage, sensitivity and an ability to show the patient respect. The results confirm findings from previous research indicating that self-determination is an important aspect when deciding whether to provide care, and also that the care provided should align with the patient's best interests (Sandman & Nordmark, 2006). The ACs also agreed '*there is a difference between motivating, recommending and persuading a patient*' (category 3, item 2). This consensus can be interpreted as an awareness of different ways to prevent the patient from being harmed, or risk losing an important ethical value such as autonomy.

TABLE 3 Items for which consensus was reached in Categories 1 and 2

	Mean value	Standard deviation	Consensus reached in round
<b>Category 1</b>			
<b>Agree</b>			
An elderly patient's wishes may vary over time	4.6	0.8	2
It is difficult to assess a patient's capacity for self-determination if the patient is not fully capable of making a decision	4.5	0.8	2
Self-determination can entail refusing life-saving treatment.	4.4	1.2	2
There is a difference between being able and willing to exercise self-determination	4.2	0.8	2
If a patient is unable to speak for himself/herself, ambulance clinicians have less knowledge of the patient's wishes compared with others present around the patient (e.g. relatives or healthcare professionals)	4.2	0.8	2
If a patient has previously participated in a documented ELC (End of Life Care) discussion, it is easy to respect the patient's self-determination and not administer life-saving treatment in the event of cardiac arrest	4.2	1.2	2
There are elderly patients who do not want self-determination	4.1	0.7	3
Elderly patients who represent a danger to themselves or their surroundings have no right to self-determination	4.0	1.0	2
Elderly patients have a personal responsibility for their decisions and their consequences	3.9	0.7	3
Younger patients are more likely to demand self-determination than older ones	3.9	0.9	3
Even if a patient has critical medical symptoms, his/her self-determination must be respected	3.8	0.8	3
An elderly patient who wants to go to the accident & emergency department must not be denied this	3.8	1.0	3
Elderly patients have faith in the competence of ambulance clinicians and do not therefore request self-determination	3.7	0.4	3
It is common for patients to relinquish their self-determination to ambulance clinicians	3.7	0.6	2
<b>Neutral</b>			
An elderly patient is rarely involved in the decision to call an ambulance	3.0	0.5	4
It is easier to disregard the self-determination of elderly patients who are acting out	3.0	0.6	4
<b>Not agree</b>			
A patient's capacity for self-determination is limited if it requires a lot of time to respect it	2.3	0.7	4
Elderly patients may not make their own decisions about where they are to be transported	2.2	0.8	3
An elderly patient has an obligation to say whether he/she wants pain relief	2.1	0.8	3
The capacity of elderly patients for self-determination depends on their physical condition	2.1	1.2	2
If an elderly patient's self-determination is in conflict with the ambulance service's guidelines, the written consent of the patient needs to be obtained.	2	0.9	2
Elderly patients suffering from psychological ill health have no right to self-determination	1.7	0.8	2
<b>Category 2</b>			
<b>Agree</b>			
Respecting an older patient's self-determination is about making a decision together with the patient	4.5	0.8	2
Protecting a patient's self-determination is the joint responsibility of me and the patient	4.3	1.0	2
During a conversation with a patient, I assess his/her capacity for self-determination	4.2	0.8	2
Decisions based on a patient's self-determination are always made in consultation with the patient	4.0	1.0	2
It is easier to protect a patient's self-determination if only the patient is present	3.9	1.0	2
<b>Neutral</b>			
If I am unable to judge during a conversation whether a patient has the capacity for self-determination, the assessment is based instead on a generalisation with reference to previous care meetings	2.9	0.6	4

TABLE 4 Items for which consensus was reached in Categories 3 and 4

	Mean value	Standard deviation	Consensus reached in round
<b>Category 3</b>			
<b>Agree</b>			
Protecting an elderly patient's self-determination means protecting his/her participation.	4.7	0.6	2
There is a difference between motivating, recommending and persuading a patient.	4,7	0.6	2
It is important that I make the patient realise the seriousness of his/her situation.	4.7	0.6	2
To protect a patient's self-determination is to protect his/her dignity.	4.7	0.7	2
In CPR situations, I often lack information about the patient's wishes.	4,6	0.7	2
It is my task to create the conditions for a patient's self-determination by helping him/her to understand that there are different care options.	4.6	0.8	2
A responsive approach is needed to be able to respect the patient's self-determination.	4.5	0.6	3
I disregard the patient's self-determination if he/she threatens to commit suicide.	4.4	0.9	2
It takes creativity to accommodate the patient's self-determination.	4.3	0.8	2
It takes courage to respect a patient's self-determination.	4.3	0.8	2
There are situations in which I feel that the best thing for a patient does not corresponds with the patient's own opinion.	4.3	0.9	2
It is my job to make a patient understand that the patient has the right to self-determination.	4.3	0.9	2
It takes experience and confidence in the profession to protect a patient's self-determination.	4.3	1.2	2
The experience, personality and interest of paramedics influence the extent to which the patient's self-determination can be respected.	4,2	0.8	2
Forcing a patient is to abuse his/her self-determination.	4.1	0.6	3
I have an obligation to respect the patient's decision.	4.1	0.9	2
There are situations in which the patient's self-determination comes into conflict with what I considered dignified.	4.1	1.0	2
I use my colleague as support when deciding whether a patient has the capacity for self-determination.	4.1	1.0	2
To be able go along with a patient's wishes and show respect for his/her self-determination, it is sometimes necessary that my colleague and I switch roles.	4,0	1.1	2
If I make decisions that do not respect a patient's self-determination, I have a bad conscience.	3,9	0.8	3
In the event of a life-threatening condition, it is appropriate to make decisions that are in conflict with the patient's self-determination.	3,8	0.6	3
Protecting a patient's self-determination requires patience.	3.8	1.0	2
If a colleague makes a decision that does not respect a patient's self-determination, I raise an objection.	3,7	0.7	3
Because of their uniform and position of authority, ambulance clinicians have the upper hand over the patient.	3,7	1.2	2
<b>Neutral</b>			
I cannot question a doctor's decision if the decision is in conflict with the patient's wishes.	3.2	0.6	3
If I question a patient's self-determination, I do so even though I know it may harm the patient.	3,0	0.6	3

(Continues)

TABLE 4 (Continued)

	Mean value	Standard deviation	Consensus reached in round
<b>Not agree</b>			
I disregard the patient's self-determination if he/she is in a palliative stage.	1.8	1.0	2
It is usual for me to distrust a patient and therefore disregard his/her self-determination.	1.7	0.6	2
There are situations in which I, even when making my way out to a patient, have decided that the patient should remain at home.	1.7	0.7	2
I distrust certain patients and therefore show no respect for their self-determination.	1.6	0.8	2
Respecting the patient's self-determination is primarily the responsibility of others, not mine.	1.5	0.6	2
Sometimes my colleague and I lie to patients in order to persuade them.	1.4	0.8	2
<b>Category 4</b>			
<b>Agree</b>			
There may be a conflict between a patient's self-determination and the wishes of loved ones.	4.6	0.7	2
Other care provider have together with the ambulance clinicians responsibility to protect the patients self-determination.	4.6	0.8	2
It is frustrating when others present want me to make a decision that is in conflict with the patient's self-determination.	4.3	0.8	2
There are colleagues who, even when making their way out to a patient, decide that the patient should remain at home, regardless of the patient's wishes.	4.1	1.0	2
There are others (e.g. relatives, healthcare professionals) who delegate responsibility for the patient's self-determination to me.	4.0	0.8	2
It is common for relatives to make decisions about the patient.	4.0	0.8	2
It is easier to protect a patient's self-determination if others (e.g. relatives, home help staff, home care staff, etc.) are available to provide support.	4.0	1.0	2
In situations where a patient's self-determination is in conflict with ambulance service's guidelines, it is a relief to me if more senior medical competence (e.g. a doctor) makes decisions.	4.0	1.0	2
Relatives are helpful in respecting the patient's self-determination if he/she is unable to convey his/her wishes.	3.9	0.7	3
The opinions of relatives often get in the way of my being able to respect the patient's self-determination.	3.6	0.7	3
<b>Not agree</b>			
Following the ambulance service's guidelines takes priority over respecting the patient's self-determination.	2.1	0.6	3
The time of day determines whether a patient's self-determination can be respected.	2.1	1.0	3

Further to the two attitudes described above, relational aspects are emphasised even more by the item '*it is my task to create the conditions for a patient's self-determination by helping him/her to understand that there are different care options*' (category 3, item 6). This finding indicates that respecting the patient's autonomy means that the management of autonomy should be considered relational, in line with theories of relational autonomy (Mackenzie, 2008; Stoljar, 2011). It also indicates that the individualistic approach to autonomy may be a negative freedom, that is freedom from interference by other people and a notion that people are independent decision-makers, favoured by a relational approach where autonomy is considered as a socially constituted capacity which entails a

commitment to promote the interpersonal conditions necessary for its exercise (Mackenzie, 2008).

The results should be viewed from the process of ambulance care as it reflects the challenges facing the ACs through an attitude such as '*it is important that I make the patient realise the seriousness of his/her situation*' (category 3, item 3). The ACs viewed themselves as proprietors of the important knowledge that will guide the care in the best interests of the patient. During rapid and brief patient encounters, the AC is confronted with multiple undiagnosed patients. The primary focus of the AC is to identify and treat acute health problems (Carter & Thompson, 2015). This condition creates a challenge while respecting self-determination, particularly when

older patients have diffuse/atypical signs or symptoms of illness, or impaired ability to make their own decisions about their care (Shenvi & Platts-Mills, 2019). Confusion, fatigue, tendency to fall or general malaise are common. Expression of pain may be impaired, and signs of fever may be subtle or absent in case of infections. Unusual patient presentations can lead to difficulties in patient assessment, not least when working with older people diagnosed with dementia, where anxiety and aggression can be due to several different conditions. The cognitive function of the older patient can be negatively affected by factors such as environmental change, a turbulent environment, infection and pain. Old age, dementia, delirium, mental health illnesses (e.g. schizo-affective disorder and bipolar disease), cardiovascular disease, response to drugs or residual effects from previous strokes affecting the communication abilities of older persons can all increase the risk of impaired cognitive function (SBU, 2013). Consequently, it seems reasonable that the ACs consider the patient's fluctuating decision-making ability and the ability to participate in decision-making based on the patient's medical condition, and initial shortcomings in understanding their situation and the consequences of decisions.

Other attitudes emerging in the results are '*respecting an older patient's self-determination is about making a decision together with the patient*' (category 2, item 1) and '*protecting a patient's self-determination is the joint responsibility of me and the patient*' (category 2, item 2). These findings underline the importance of shared decision-making and joint responsibility while managing patients' self-determination. This is advocated when the patient has decision-making ability, albeit impaired, and supports alternative models for shared decision-making, depending on the balance between the patient's best interests, the patient's autonomy, and making an effective decision regarding patient compliance (Sandman & Munthe, 2009). When comparing four different models, it is argued that decision-makers should preferably use a model that is based on decisions that are shared, rational, and deliberative and where the patient and the healthcare provider agree. When the provider fails to reach agreement, there is reason to advocate a '*professionally driven best interest compromise model*' for respecting the patient's interests, as this harmonises the patient's interests, autonomy, compliance and continued care relationship. Attitudes in the present study, such as '*there are older patients who do not want self-determination*' (category 2, item 7) and '*because of their uniform and position of authority, paramedics have the upper hand over the patient*' (category 3, item 24), together with previous research (Bremer et al., 2012; Erbay et al., 2010; Nordby, 2013), underline how the professionally driven model (unconsciously) is applied and reinforces the status quo. The use of the model also means, in line with Wiggins and Schwartz (2005), that the ACs' '*upper hand over the patient*' makes the patient dependent on them, leaving the patient exposed to possible abuse of power.

Shared decision-making, as part of self-determination, is not always possible, which makes surrogate decision-making necessary. This necessity is confirmed by the present results in the consensus to the attitude '*it is common for patients to relinquish their*

*self-determination to the AC*' (category 1, item 14). According to Johansson and Broström (2014), the fundamental problem with surrogate decision-making is the ambiguities that exist about the degree of decision-making ability of the patient, which, in turn, determines whether a surrogate decision is justifiable. There are ethical problems with making decisions for others based on principles such as the principle of the patient's best interests, the advance directive principle and the principle of implicit consent. Previous research (Ferrand & Marty, 2006; Nordby & Øyvind, 2012; Steen et al., 1997) contains examples from European AS where the application of these principles can be sensed, without the researchers explicitly linking it to surrogate decision-making. Nyström et al. (2003) found that older patients in an acute care setting felt their autonomy was easily overthrown, thus revealing their participation as almost non-existent. A sincere personalised interaction with the older patient has been found to improve autonomy and the older patient's feeling of participation in the care provided, making them feel empowered (Aronsson et al., 2014).

As stated in the result, '*there are colleagues who, even when making their way out to a patient, decide that the patient should remain at home, regardless of the patient's wishes*' (category 4, item 4), surrogate decision-making can be complicated. Holmberg et al. (2020) found this to be especially challenging within the AS, relating to the colleague's lack of competence disrespectful approach and common goals. However, having a competent colleague, together with consensus regarding the goal of the care, promotes functional co-operation within the dyadic AC team. This is supported by the present results and the attitude '*I use my colleague as support when deciding whether a patient has the capacity for self-determination*' (category 3, item 6). This could be seen as a way of counteracting one of the problems with the principle of the patient's best interests, that is the question of who in each case is best suited to decide what is in the patient's interest. It can be assumed, by discussing and sharing decisions between team members, that there is greater chance that decisions are made in the patient's best interests. In line with this joint decision-making between healthcare professionals, the ACs also agreed that '*other care providers have, together with the AS personnel, responsibility to protect the patients self-determination*' (category 4, item 2). However, the ACs in the present study agreed that it is difficult when '*the opinions of relatives often get in the way of my being able to respect the patient's self-determination*' (category 4, item 10). Hence, the co-creation in respecting the older persons' self-determination may be challenged when relatives are also present with the patient. It seems especially challenging when relatives try to influence the AC's decision, and '*it is frustrating when others present want me to make a decision that is in conflict with the patient's self-determination*' (category 4, item 3). Applying shared decision-making can be difficult. An interview study from an acute hospital context indicated there were both barriers and enablers to assisted decision-making. For example, ethical conflicts arose when healthcare professionals tried to support the will and preference of older patients, while other professionals colluded with family members and made decisions

for the patient's 'best interests'. Conversely, there was interdependence between older patients and their family members, and those patients with cognitive impairments needed their family to be involved in decision-making (Donnelly et al., 2021). However, despite common goals between the older patient and relatives, these goals tend to differ when the patient's condition becomes unstable, their functional or cognitive health fails, or when there is a threat to patient safety (Kuluski et al., 2013).

In the present study, the ACs agreed that *'it is easier to protect a patient's self-determination if only the patient is present'* (category 2, item 5). Normally, the ACs were privileged to only provide care for one patient at a time, which promotes focusing on that patient. This contributes to a unique situation for the co-creation of care between the patients and the AC (Rantala et al., 2019). Co-creation is based on shared goals, knowledge and respect, as well as frequent, timely, accurate and problem-solving communication (Gitell, 2011). Thus, co-creation can positively influence the satisfaction with care and well-being of patients (Kuipers et al., 2019) as well as influencing well-being and job satisfaction among health professionals (den Boer et al., 2017). Simultaneously, co-creation should be seen in the light that patients must frequently adapt to routines and procedures rather than obtaining care designed to emphasise the patient's care needs, preferences and values (Ekman et al., 2011). From a patient perspective, the key to the co-creation process is what evolves in the caring encounter, that is, being seen and listened to and thus an evolving feeling of being recognised, providing a sense of having value and being respected as a person (Lindberg et al., 2014). In the encounter, older patients portrayed the significance of communication, and being properly informed by the clinicians. Studies indicate that patients did not desire long conversations with the ACs, but requested the presence of ACs to acquire information on their health situation and what was about to happen (Aronsson et al., 2014; Melby & Ryan, 2005). Although co-creation has many positive aspects, there is reason to be cautious in interpreting the attitude *'it is easier to protect a patient's self-determination if only the patient is present'* and the extent to which it refers to older patients with impaired decision-making ability.

Our findings illuminate ACs' experiences that *'an older patient's wishes may vary over time'* (category 1, item 1). Like other people, the will of older patients is not constant and can change depending on circumstances, and should not constitute a major problem compared to other patients. Conversely, the ACs' attitude that *'older patients have a personal responsibility for their decisions and their consequences'* (category 1, item 9) can be problematic if the AC does not assess and consider a potential impairment of older patients' decision-making ability. In part, this problem can be sensed in research stressing that ACs might lack awareness of the older patients' physical and mental abilities as they are often disregarded because patients do not convey their desires (Boltz et al., 2013). A study indicated that the capability to communicate and understand the patient as well as to obtain consent can be difficult (Brooke & Stiell, 2017). It can be assumed that these factors influence co-creation in the relationship between the older patient and the ACs. However, there are situations in which

the ACs' own perceptions of what is best for the patient are given precedence at the expense of the respect for the patient's self-determination (Rantala et al., 2019). Ideally, the ACs and patients collaborate in the sense that ACs contribute with medical and health scientific expertise, whereas the patient adds knowledge about their own life experience, preferences and insight on what health means to them (Dahlberg & Ekebergh, 2015; Ekman et al., 2020). Therefore, it is imperative that ACs communicate with the older patients in a caring way concerning the older patients' health status and are conscious of this attentiveness throughout the encounter.

The results indicate, above all, that the ACs have a clear picture of older patients in relation to self-determination and autonomy, and confirm similar findings in extant research (Rosén et al., 2018). Possibly, this is based on the so-called golden rule, that is, treat others the way you want to be treated, in managing situations when patients' own capacity to determine possibilities and/or willingness of self-determination is compromised. However, this approach does not take the patient's own experiences and preferences into account. It has been emphasised that a person, whenever or wherever, is a person who speaks, acts, narrates and assumes responsibility, that is capable (Ugglå & Ricoeur, 2011). This notion implies that, although it can be challenging to assess whether the patient is fully capable of making a decision, it is necessary to shift from patients' needs, as perceived by ACs, to instead assess and strengthen the patient's unique and personal abilities (Rantala, 2020). This has been successfully proven in residential older persons' care (Edvardsson et al., 2014) as well in care of persons diagnosed with dementia (Brataas et al., 2010). By truly listening to the patient's narrative, the possibilities of understanding their preferences, as well as how the perceived illness affects everyday life, increase (Rantala et al., 2018).

#### 4.1 | Strengths and limitations

The initial question posed in the focus groups was rather broad. This may be recognised as both a strength and a limitation (Skulmoski & Hartman, 2007). With a narrower question, one might have ended up with less data to analyse in the first round and less items in the subsequent rounds. However, the research topic is wide, and it was judged to be congruent with the aim to strive for a large amount of different attitudes as possible. Therefore, the use of focus group conversations in the first round was appropriate.

The focus groups were conversation-oriented, using the interaction within the groups as a means of generating data (Morgan, 2012). To maintain the interaction within the group, low-moderator involvement was chosen. Alternatively, a higher level of moderator involvement may have produced more focussed data and items in the following rounds. However, the first round's aim was to inductively identify a wide array of views, and thus, the chosen level of moderator involvement was deemed suitable.

Other research methods could have been used to design the study and analyse the data. However, in line with the aim, the ambition was to reach consensus within a panel. Hence, a Delphi

technique was assessed as appropriate. In the present study, this panel consisted of ACs, which are understood to be a homogenous sample. Conversely, the sample included a diverse range of participant characteristics. Regarding the predefined level of consensus for the present study, it might be considered as both a strength and a limitation. The level of consensus is described as being dependent on the research topic. The present topic of attitudes regarding older persons' self-determination was judged to generate a variety of different attitudes, and therefore, the level of consensus was set to 70%. However, the result might have been different if the consensus level was set higher, especially as some items that reached consensus in rounds 3 and 4 barely made it over 70%. There is no universal agreement regarding the appropriate level of consensus, and the literature supports levels between 51 and 100%, depending on the research topic (Keeney et al., 2006). Additionally, consensus in Delphi studies has been defined in a variety of ways (e.g. percentages, mean value and standard deviation), which might be seen as a methodological limitation (Powell, 2003).

In this study, the response rate was high throughout Rounds 2–4 (97%–100%). The response rate for those who participated through all rounds was 94%, which is considered high in the literature (Keeney et al., 2006). This is judged to have strengthened the validity of the results.

Despite the small population group, the transferability of the findings may be considered through the authors' efforts to describe in detail the participants, context, data collection and analysis as carefully as possible. However, the study into this sparsely researched topic provides a first exploration of ACs' attitudes to the topic and needs to be followed up with similar studies in other ambulance settings, nationally and internationally.

## 5 | CONCLUSIONS

To the best of our knowledge, this is the first study to explore attitudes among ACs regarding older patients' self-determination in cases where patients have impaired decision-making ability, and urgent need for care. The study underlines the complexity of ACs' attitudes towards older patients' self-determination. The ACs' ambition is to respect self-determination; however, this is challenged by the patient, other healthcare personnel, significant others and/or their own team colleagues. The AS context has unique opportunities to probe self-determination and shared decision-making. It could be suggested that, in contrasting the present results with the literature, one conclusion might be that ACs need more theoretical knowledge as well as training in managing ethical values in the care of older patients, a population expected to increase within the AS. As this is a global phenomenon, there is a need to further study international differences among ACs' attitudes regarding older patients' self-determination, as well as studying how to strengthen ACs' ethical competence.

## 6 | IMPLICATIONS FOR PRACTICE

Ambulance services must develop opportunities to provide continued training within this topic. One option would be to increase the use of simulation-based training, focusing on ethical aspects of the care. Another option might be to facilitate moral case deliberations to strengthen the ACs' abilities to manage these issues while being able to share experiences with peers. These types of interventions should illuminate the importance of the topic for the individual AC, which, in turn, may strengthen and develop the caring abilities within an integrated care team.

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### CONFLICT OF INTEREST

The authors report no conflict of interest.

### AUTHOR CONTRIBUTIONS

All authors contributed to the study design. AS and MH performed the focus group interviews. All authors supported the data analysis and the interpretation of data. All authors contributed, read and approved the final manuscript.

### DATA AVAILABILITY STATEMENT

Data are available on request due to privacy/ethical restrictions.

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