

EMPIRICAL STUDIES

Lived experiences of being cared for by ambulance clinicians when experiencing breathlessness—A phenomenological study

Wivica Kauppi CCRN, MNS, PhD Student^{1,2}  | Christer Axelsson RN, PhD, Professor^{1,2,3} | Johan Herlitz MD, PhD, Senior Professor^{1,2} | Maria Jiménez-Herrera RN, PhD, Associate Professor^{1,4} | Lina Palmér RN, PhD, Associate Professor¹ 

¹Faculty of Caring Science, Work Life and Social Welfare, University of Borås, Borås, Sweden

²PreHospiten- Centre for Prehospital Research, Faculty of Caring Science, Work Life and Social Welfare, University of Borås, Borås, Sweden

³Emergency Medical Service (EMS), Sahlgrenska University Hospital, Gothenburg, Sweden

⁴Nursing Department, Universitat Rovira i Virgili (URV), Tarragona, Spain

Correspondence

Wivica Kauppi, Faculty of Caring Science, Work Life and Social Welfare, University of Borås, Allégatan 1, 501 90 Borås, Sweden.

Email: wivica.kauppi@hb.se

Abstract

Background: Breathlessness is a serious and distressing symptom and a common reason why patients require prehospital care by ambulance clinicians. However, little is known about how patients experience this care when they are in a state of breathlessness.

Aim: The aim of this study is to describe the lived experiences of being cared for by ambulance clinicians when experiencing breathlessness.

Methods: Fourteen lifeworld interviews were conducted with patients who experienced breathlessness and were cared for by ambulance clinicians. The interviews were analysed using a qualitative phenomenological approach.

Findings: The essential meaning of being cared for by ambulance clinicians when experiencing breathlessness is described in two ways: existential humanising care, in which the experience is that of being embraced by a genuine presence or existential dehumanising care, in which feeling exposed to an objectifying presence is the main experience. This meaning has four constituents: surrendering to and trusting in the care that will come; being exposed to an objectifying presence is violating; being embraced by a genuine presence is relieving; and knowing is dwelling.

Conclusion: The findings reveal that the ability of ambulance clinicians to provide existential humanising and trustful care, which is the foundation of professional judgement, was essential in how patients responded to and handled the overall situation when breathlessness.

KEYWORDS

ambulance care, breathlessness, caring science, lived experiences, phenomenology, prehospital, qualitative research

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BACKGROUND

Breathlessness is an overwhelming experience and a common reason why patients need the prehospital care provided by ambulance clinicians (ACs) [1, 2]. Breathlessness is caused by many conditions [1, 3], is commonly accompanied by comorbidity [3], and is associated with adverse outcomes with a high mortality rate [4, 5].

In Sweden, when patients with breathlessness call an ambulance, they find themselves in the care of ACs. These clinicians consist of nurses with differing roles in the care of such patients, including, as a minimum, one Registered Nurse with or without specialist training in prehospital emergency care and one ambulance technician who is usually educated as an assistant nurse. The ACs in these situations have the challenge of identifying the main reason for the patient's suffering and meeting the patient's individual needs, since the subjective experience of breathlessness is unique for each person [6]. Within ambulance care, the existing knowledge regarding patients with breathlessness consists foremost of an understanding of care from a medical perspective, including treatment evaluations [7, 8]. However, the caring perspective also needs to be understood, i.e. how the patients experience the care they receive from ACs, in order to strengthen their healthy responses in the state of breathlessness [9, 10]. Previous research on patients' experiences of being cared for by ACs is sparse. Of the studies that exist, some have evaluated the overall satisfaction with the quality of care of patients with various conditions [11]. Studies on the lived experiences of being cared for by ACs mostly focus on the overall experience of ambulance care regardless of the complaint [12, 13], or in relation to other conditions, such as myocardial infarction, stroke [14], or chest pain, in which breathlessness may be present [15, 16]. However, with respect to breathlessness arising on its own, the knowledge is limited, especially on the lived experiences of being cared for by ACs when ambulance care is needed. It is crucial that ACs are aware of patients' unique needs for care from an intertwined medical and caring perspective, e.g., a holistic perspective [10], in order to relieve their suffering and enhance the outcome. The aim of the present study is to describe the lived experiences of being cared for by ACs when experiencing breathlessness.

METHODS

Design

This phenomenological study is based on the Reflective Lifeworld Approach (RLR) described by Dahlberg et al. [17]. The aim of the RLR is to describe the meanings of

a phenomenon, which, in this study, is 'being cared for by ACs when experiencing breathlessness'. The methodological principles of the RLR, openness, pliability, and bridling, have been used to describe the phenomenon. Using this approach, the researcher attempts to uncover the phenomenon while keeping an open mind and a bridling attitude towards it, which means listening to the participants' expressed meanings. In order to understand another person's lifeworld, the researcher's own experiences of the related issues must be bridled. For the researcher, this means questioning one's understanding of the phenomenon so that it can be uncovered in all its variations.

Participants and data collection

Data were collected through lifeworld interviews [17] with participants living in mid or southern Sweden between January and October 2020. The focus of a lifeworld interview was on the phenomenon and its meanings. During the interview, the methodological principles of the RLR were used. Inclusion criteria were the lived experiences of breathlessness, age ≥ 18 years, gender variation, ability to speak Swedish, no memory loss from the event, have called the emergency number (112), and were cared for by ACs. The participants were firstly recruited through nurses in ambulance services and at an emergency department ($n = 4$) and secondly through social media ($n = 10$). The first author contacted interested participants through a telephone call, wherein more detailed information was provided, followed up by written information sent by email. The participants decided on the interview time. Two participants were interviewed in person, and the remaining 12 through a telephone call. The study included 12 women and 2 men ($n = 14$) ranging from 35 to 85 years, with various aetiologies of breathlessness (Table 1). The median time between the breathlessness event and the interview was 6 months (range: 1 week to 2 years).

Each interview began with an invitation to talk about the phenomenon, first in response to the opening question, "When the AC arrived, can you describe how you felt?" Follow-up questions further explored the phenomenon, such as "Can you give an example of ...?", "What do you mean by ...?", and "How did you feel when ...?". The interviews lasted between 15 and 50 min, with a median of 30 min. All the interviews were conducted and audiotaped by the first author and transcribed verbatim.

Data analysis

The analysis followed the RLR principles [17] and consisted of movement between the whole and its data parts

TABLE 1 Participants characteristics ($n = 14$)

Participant/ Gender	Age (years)	Time interval between meeting with AC and interview	Breathlessness onset	Length interview (minutes)	
1	Female	75	2 weeks	COPD, panic attack	34
2	Male	48	2 weeks	Pain due to rib-fractures	24
3	Female	73	2 weeks	COPD	21
4	Female	49	1 week	Panic attack	15
5	Female	55	1,5 years	Pulmonary oedema	45
6	Female	75	8 months	Unclear main reason: COPD, myocardial-infarction, stroke	32
7	Female	85	6 months	Pneumonia, heart-failure, pleural fluid	35
8	Female	62	1 year	Myocardial infarction, unstable angina-pectoris	30
9	Female	35	3 weeks	Covid -19	44
10	Female	64	6 months	Asthma	29
11	Female	56	2 years	COPD/Asthma, infection	23
12	Female	52	5 months	Covid -19	30
13	Male	36	6 months	Covid -19	27
14	Female	63	5 weeks	COPD	50

Abbreviations: AC, Ambulance Clinician; COPD, Chronic obstructive pulmonary disease.

(meaning units) to arrive at a new whole (the essential meaning). The goal was to maintain an approach characterised by closeness to the phenomenon, as well as a pliable and bridled attitude, in order to remain open and reflective. At first, the transcribed interviews were read through several times to obtain a comprehensive understanding of the whole data. Then, the analysis began by searching for the meaning units related to the phenomenon. Similar meanings were merged together in clusters in a process that involved trying out different possibilities in search of the essential meaning structure of the phenomenon, which is the most abstract level. Meanings that constituted the essence were further clarified within their constituents, as exemplified by quotes from the interviews [18].

Ethical considerations

Ethical standards were followed according to the Helsinki Declaration [19]. Verbal and written information about the aim of the study were given to the participants, with assurance that their confidentiality would be maintained throughout. This information included the voluntary nature of participation and their ability to withdraw from the study at any time. A written consent was signed by two participants, and the remaining 12 gave their recorded verbal consent during the telephone interview, which is permitted by the Swedish Ethical Review Authority.

RESULTS

Essential meaning

The essential meaning of being cared for by ACs when experiencing breathlessness is described in two ways: (i) existential humanising care, in which the experience is that of being embraced by a genuine presence; or (ii) existential dehumanising care, in which feeling exposed to an objectifying presence is the main experience. When the former experience dominates, biological and existential needs are sensitively integrated in the caring practice. A sense of genuine presence confirms the existential experience, and fosters an environment that promotes surrendering to the situation, which brings hope for continued life. This surrender also enables finding the inner strength necessary to cope with the condition despite the fragility and exhaustion. Contrarily, when the experience of being exposed to an objectifying presence dominates, the feeling of being dehumanised arises, as individual needs are not seen and confirmed. There is also the sense of being existentially violated, which causes feelings of being insecure.

The experience is that of having to battle the situation alone in a fragile and diminished capacity. Additionally, trust in ACs and their ability to provide the necessary care is weakened. The essential meaning is further described in terms of four constituents: (i) surrendering to and trusting in the care that will come; (ii) being exposed to an objectifying presence is violating; (iii) being embraced

by a genuine presence is relieving; and (iv) knowing is dwelling.

Surrendering to and trusting in the care that will come

Being cared for in a state of breathlessness can be described as surrendering to the intuitive sense and trusting that the necessary care is imminent. The assurance that the AC will soon arrive brings a feeling of safety because someone will be present to share the experience with, and the struggle to regain breath will no longer be a solitary affair.

‘You have someone to talk to. You feel safer in some way when you have someone with you’.
(Participant 3)

During this experience, the competence of the ACs is taken for granted because of an intuitive sense that they will have sufficient knowledge to manage the condition regardless of how it develops. This inner sense of safety and security allows surrender to the care of the ACs.

‘Then, I just need to focus on going into my bubble and surviving, and they will take care of the rest. // They will help me breathe, and give me the medicine I need’.
(Participant 5)

Amidst the sensation of the loss of bodily control that accompanies breathlessness, an inner belief that the ACs will provide the necessary care exists. It also brings hope that soon relief from the condition will come. Even when there is an awareness that the care may not have the immediate effect of ending the breathlessness, a feeling of hope is still present in surrendering to the situation.

‘And then when the blue lights came, I knew I would get help. I would get a CPAP on me, and I would receive morphine so that I can avoid the anxiety. // The anxiety is so severe’.
(Participant 5)

In addition, there is a belief that the ACs have the knowledge and competence to use the measuring equipment properly to gauge the severity of the condition.

‘I felt that I would be taken care of by someone who knows his job. He can examine my body with measurable instruments, and

instruments we use to make sure of certain things. // It felt safe’.

(Participant 9)

Being exposed to an objectifying presence is violating

Being cared for by ACs can also be described as being exposed to a violating and objectifying presence. There is a feeling that the ACs distrust the experience of breathlessness and question its severity. It precipitates feeling let down, and adds further stress to the experience. It also engenders a sense of powerlessness, in addition to being forced to battle a body that feels out of control all alone.

‘She stood so nonchalantly, staring at me, and said “So, what is wrong with you, then, if you did not go to the hospital by taxi?” // I got very angry, and then I felt like my panting became even stronger. I coughed and it was so hard to breathe’.

(Participant 8)

When the suffering that accompanies breathlessness is not confirmed, the experience is one of feeling existentially violated. Frustration and agitation arise when the experience of something seriously wrong with the body is questioned.

‘I get a little annoyed when they think I am walking around with anxiety or something non-physical like that. I do not normally have anxiety, and here I feel like I have difficulty breathing’.

(Participant 12)

Along with this exposure to an objectifying presence in care, there is a feeling of having disturbed the ACs. It is highlighted especially in situations where the ACs perceive the condition as non-life-threatening. The feeling that the condition is not being taken seriously is extremely frightening.

‘I felt like they did not really believe me because it [the oxygenation parameter] showed that I had full oxygenation. So, I felt like I may have bothered them’.

(Participant 12)

When the ACs are distanced or uncertain in providing care, insecurity and feelings of being exposed and abandoned are evoked. Fears that the ACs are incapable of seeing

unique needs and vulnerability, and that a serious condition may be unnoticed, are also elicited.

‘They did not hurry to check how I was right away. I stood and focused on breathing. My pulse rate was very high. The first thing that they should have done is to check how bad my condition was’.

(Participant 13)

When ACs do not have the ability to meet individual needs, and instead expect patients to adjust their needs or expectations, feelings of being insignificant or invisible are evoked.

‘I kind of tried to hiss out to “please pound me on the back”, and he pounded twice, and said ‘I have to write the report’. Then, it was over. // You feel pretty insignificant. He may write the report when he arrives, but if they have even one terminally ill person, it is not right to sit around and write a report’.

(Participant 14)

Feeling invisible or insignificant to the ACs engenders a sense of loneliness, despite their physical presence. It is also experienced as an existential violation, along with a sense of powerlessness arising from not feeling heard. The anxiety caused by feeling insecure in the fight for survival is thus escalated.

‘And then I hear her mobile phone sounds of some movie or a clip. I think that “she does not even see me”. It felt too evil. // So, I could have been lying there and dying or vomiting or whatever, and she would not have noticed me’.

(Participant 5)

Being embraced by a genuine presence is relieving

Being truly cared for can be described as the relieving experience of being embraced by a genuine presence. It means being confirmed as a human being by ACs who do not downplay the experience of breathlessness but rather perceive the condition as requiring their careful attention. Therefore, there is no need to expend unnecessary energy in constantly trying to convince the ACs of the severity of the experience.

‘They confirmed in some way that I was so ill, I actually had to go to the emergency

department. // I felt relieved. It felt nice that we called at the right time, and that we did not call unnecessarily’.

(Participant 7)

Feeling safe and secure is essential to the provision of care when experiencing breathlessness, and helps to create a trusting, caring relationship with the ACs. Such a relationship is fostered when the ACs demonstrate the ability to meet individual needs with a genuine presence, which involves paying attention to both physical and existential needs in an integrated manner. It is reassuring that the ACs understand the lived experience and the need for relief when the body feels out of control.

‘They understand that this is a terrible experience. You feel that you cannot breathe in or out. Yes, it is on the life and death level. They can help me get better’.

(Participant 10)

When ACs confirm what the condition may entail, patients feel respected. There is relief, as it confirms the experience even if the condition is not serious. Despite its cause, the goodwill of the ACs is relied on completely because breathlessness is described as extremely frightening.

‘Someone genuinely present who sees you and touches you is a relief because I can let go of all the responsibility and hand it over to someone else. I need to focus only on my breathing’.

(Participant 5)

Being supported by the ACs to believe in inner strength to cope with breathlessness is also relieving as it brings confidence and a sense of safety to the efforts to handle the situation.

‘Just that they say that they believe in me and are here for me is very important. // I have oxygenation, so I managed it; and that, in combination with the fact that I am welcome to call again if it gets worse, makes me feel safe’.

(Participant 12)

Additionally, when the ACs demonstrate that they will do everything in their power to help alleviate the condition, it brings hope for survival. This expectation, in turn, triggers the existential vitality that enhances the capacity to cope with the condition and battle further, regardless of exhaustion.

‘... You are like “please let me die soon. I cannot stand it”, but these amazing people gave me my strength back somehow’.

(Participant 5)

Knowing is dwelling

Being cared for is also described as knowing is dwelling. It means that the ACs' sensitive communication around what is transpiring with the body makes it possible to feel at home in an existentially demanding situation. This feeling of at-homeness means being reconciled in an inner bodily peacefulness.

‘... calm, factual information, talk to me about that. “This is going to go well”, “we have this”, “we will help you” make me hopeful. I'm dying. I'm hoping I can live’.

(Participant 5)

When the preparation for various practical nursing measures is in place, it is easier to draw on inner capacity when experiencing breathlessness. It makes it easier to cooperate with the ACs' expectations about what to do for self-relief.

‘Because you are more prepared [after being warned of upcoming adjustment of body position]. When you move, it hurts, so you know that then they will do so, that it will hurt, and you are more prepared for things that will happen, and it is very positive’.

(Participant 2)

Receiving knowledge from the ACs, including the basis on which they form their decisions, and honest communication regarding why the condition cannot be immediately relieved, generates feelings of safety and hope.

‘It was reassuring that they took the easy way around it, that they said “we see that you oxygenate yourself so there is no danger to you”. It is reassuring to hear this’.

(Participant 12)

On the contrary, receiving information that indicates no possibility for the ACs to alleviate the suffering elicits feelings of being exposed and abandoned. Thereby leading the person to feel completely alone in an unbearable situation.

‘Then I felt that, if they cannot do anything, I will die. They could not help me. // So, I just

tried to breathe. // Yes, I just panted as I did not get any help’.

(Participant 9)

When the condition does not require ambulance transport, clear self-care advice promotes confidence in the ability to individually manage the situation.

‘To get a paper with some important information was great. // Because they said “do not hesitate to call if you get worse”, it felt like they provided psychological safety’.

(Participant 12)

DISCUSSION

The current study may be the first to describe patients' experiences of being cared for by ACs when experiencing breathlessness. The most surprising result pertained to the existential dimension described by patients, which is important knowledge in this context. Existentially humanising care, which, in our study, involved meeting patients with a genuine presence, stands in contrast to the dehumanising and objectifying presence in care. The patients in our study were extremely dependent on the ACs' behaviour in handling the situation. Unlike other studies among patients with various conditions [12, 20, 21], the new knowledge through our study shows that patients treated in an objectifying or dehumanised manner and felt existentially violated, and as a result, could not surrender trust to the ACs. Instead, the suffering became even worse among these patients, with various consequences. When patients feel violated at their core as human beings, the care is considered humiliating rather than helpful [22].

Previous studies [13, 14] have shown that it is essential that ACs make patients feel cared for to reduce their anxiety and fear. In our study, this feeling of being cared for also reduced bodily stress levels among patients with breathlessness. We argue that the management of our patients significantly influenced their control over their breathing. We also contend that ACs' behaviour in the care of patients with breathlessness does not always include confirmation of their experiences. Thus, the challenge for ACs is to meet the patients' existential needs on an individual level.

A previous study among patients using an ambulance due to various conditions [23] showed that patients felt free of onerous responsibility when they could surrender their bodies to the ACs. This process envisaged being treated and respected by the ACs [12, 15, 20], which created trust in the overall situation. However, when existential support was missing [23], patients felt less safe. This

condition is also described by patients in our study. When they felt disrespected and not taken seriously by the ACs, it caused feelings of being insecure thus making the situation worse. Respect from the ACs becomes especially important when patients feel themselves losing control of their bodies [9]. When a patient puts their life into the ACs' hands, it creates an ethical demand on their part [24]. The ACs are given power over the patient's fate, and therefore have the responsibility to meet the patient's needs. Thus, ACs should use their competence for the benefit of the individual patient [9]. As ACs mostly work without physician support, their competence is expected to be sufficient to handle the task at hand. Thus, ACs should be able to decide how care should be conducted, which is a requirement for Registered Nurses in general [24] including ambulance care in Sweden [25]. This is also consistent with international requirements, according to the International Council of Nurses (ICN) [26].

Martinsen [27] emphasises that individual ACs have an ethical requirement to meet the unwritten and unspoken demands of patients whose ability to breathe is compromised. The perceived competence of the ACs was important in the patients' experiences in our study. It is not unique to patients with breathlessness; studies have established [14, 28] that patients felt insecure when they regarded ACs as not competent enough. Importantly, our patients with breathlessness emphasised that this competence not only included medical skills but also existential skills. Galvin and Todres [29] argue that caregivers require existential knowledge and the ability to understand patients' suffering from an individual perspective, to be truly caring. If ACs are unable to meet the patient with a genuine presence, which includes a reflective and sensitive approach, the person may feel that they are being treated like an object, and the care becomes dehumanised [9]. As Galvin [30] asserts, protocols do not always provide sufficient guidance about what to do in complicated care situations, as patients often require more than just technical solutions. In our study, the patients never gave up trying to regain control of their breathing even when exhausted. They mainly desired a sense of security and safety in their struggle. As Dahlberg [31] points out, people cannot 'own' or take the body for granted. It means that its function or expression cannot be fully controlled. This realisation was the experience of our patients, who expressed the feeling of being alone in a body out of control. According to Jaspers [32], this feeling of loneliness is of great importance when patients' vulnerability is heightened due to breathlessness. This vulnerability reflects their uncertainty around the outcome of the condition, including the possibility of death, which our patients were not prepared for. The ACs were thus considered the last lifeline in their battle for continued existence. Therefore, the ACs' professional

judgement in balancing the care they provided was crucial to how the patients responded to and handled the overall situation.

METHOD DISCUSSION

This study described the lived experiences of being cared for by ACs when experiencing breathlessness. A phenomenological approach was chosen, the strength of which is the rich description of the phenomenon under investigation [17]. As trustworthiness in phenomenology is associated with the meanings derived in the whole research process [33], both interviews and analyses were used to search for meanings. We reflected on the findings repeatedly to ensure objectivity. Data were collected from the same participants at the same time as in a previous study [34]. However, the data analysis was based on other research questions, and the studies are, therefore, separated from each other. The majority of the data were obtained through telephone interviews rather than in person, which may have influenced their development and content. The time interval between the AC care and the interviews ranged from 1 week to 2 years. In the longer time intervals, the participants' ability to remember the event may have been affected. Nevertheless, the participants in this study exhibited clear memories of their breathlessness event. Their recollection of these incidents and the care they received from ACs may have elicited unpleasant memories during the interviews. Importantly, we sought a trusting relationship with the participants to create a feeling of safety when sharing their experiences.

CONCLUSION

Patients who received ambulance care due to breathlessness were dependent on the ACs' ability to engender trust, which was crucial for them to feel safe in the situation. The ACs' ability to provide humanising, existential trusting care is the foundation for professional judgement and was essential for the patients to regain control over their breathing. This means that ACs have a responsibility to respond to patients' individual needs. The stress caused to patients when their needs are ignored can have negative consequences on an existential level and can be physically devastating to fragile patients.

AUTHOR CONTRIBUTION

WK, JH, CA, and LP were involved in the study design. WK collected data, analysed the data, and performed the first draft of the manuscript while LP supervised the process. WK, LP, JH, CA, and MJ-H critically revised it.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.

FUNDING INFORMATION

The study has not received any funding.

ETHICS STATEMENT

This study was approved by the Swedish Ethical Review Authority (Dnr 2019–03283). The authors declare that they have no conflict of interests.

ORCID

Wivica Kauppi  <https://orcid.org/0000-0002-2729-1923>

Lina Palmér  <https://orcid.org/0000-0002-4319-4584>

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