

## RESEARCH ARTICLE

# Patients' lived experiences of breathlessness prior to prehospital care – A phenomenological study

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## Abstract

**Aims and objectives:** The study aimed to describe how breathlessness is experienced by patients prior to prehospital care.

**Design:** A qualitative phenomenological design.

**Methods:** Lifeworld interviews were conducted with 14 participants. The analysis was carried out within the descriptive phenomenological framework.

**Results:** The essential meaning of the breathlessness phenomenon is described as an existential fear in terms of losing control over one's body and dying, which involves a battle to try to regain control. This is further described by four constituents: being in an unknown body, striving to handle the situation, the ambiguity of having loved ones close and reaching the utmost border.

**Conclusions:** Patients describe a battling for survival. It is at the extreme limit of endurance that patients finally choose to call the emergency number. It is a challenge for the ambulance clinician (AC) to support these patients in the most optimal fashion.

## KEYWORDS

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

## 1 | INTRODUCTION

This study is a part of a larger prehospital research project exploring patients with breathlessness who are in need of prehospital care. As breathlessness (also known as dyspnoea) is one of the most common reasons why patients are in need of prehospital care (Hodroge et al., 2020; Kelly et al., 2016), this phenomenological study is focused on patients' experiences of suffering from breathlessness to such an extent that prehospital care is required. In this study, the prehospital situation includes the event prior to patients' contact with the emergency number (112) and their time awaiting help from the ACs while experiencing breathlessness. This period of waiting

for help is defined as "prior to prehospital care". All ambulances in Sweden have at least one registered nurse with or without specialist training in prehospital emergency care and one ambulance technician who is mostly educated as an assistant nurse. In this study, ACs refer to these nurses of differing roles.

### 1.1 | Background

Breathlessness is defined as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" (Parshall et al., 2012) and is manifested in various ways,

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such as shortness of breath, air hunger and chest tightness (Alteri et al., 2020). Breathlessness is caused by a number of different conditions, among which cardiac, respiratory and infectious-related are the most common (Kauppi, Herlitz, Magnusson, et al., 2020b). Some conditions are considered life-threatening and are hence associated with a high risk of death (Kauppi, Herlitz, Karlsson, et al., 2020a; Lindskou et al., 2019).

The previous research on patients' lived experiences of breathlessness mostly has focused on their experiences of living with specific chronic conditions in which breathlessness is present, e.g. heart failure, cancer or respiratory diseases. The studies were obtained from patients' home environments, in primary care or in connection with hospital care (Hutchinson et al., 2020; Nordfonn et al., 2019; Steindal et al., 2017; Stowe & Wagland, 2018; Tieck et al., 2018; van der Meide et al., 2020). Patients with breathlessness have mostly been assessed by objective measurements (Carel, 2016) – for example, by using different assessment tools to evaluate the intensity of breathlessness during prehospital treatment (Lindskou et al., 2020) or to evaluate the physical and affective components of breathlessness in daily life (Ekstrom et al., 2019).

In Sweden, emergency medical dispatchers and ACs, who are the first to arrive at the scene of a patient with breathlessness, have a major challenge in providing care due to the large number of different diagnoses that can present with breathlessness (Kauppi, Herlitz, Magnusson, et al., 2020b). The existing knowledge mostly provides an understanding of breathlessness from the medical perspective, including various diagnoses and clinical manifestations. However, breathlessness also needs to be understood from a caring science perspective, i.e., from the patient's perspective, in order to support and strengthen health processes in connection with this condition (Arman et al., 2015). Such a perspective involves supporting patients' health and well-being in tandem with recognizing and alleviating their suffering (Dahlberg et al., 2009; Galvin & Todres, 2012), and it therefore demands extensive knowledge and skills from the emergency medical dispatchers, who are the first to receive patients' calls, and the ACs, who are the first healthcare providers at the patient's side. Thus, their skills should include not only medical knowledge but also existential knowledge of what a patient with breathlessness may be experiencing, and according to this, how the optimal care should be organized in order to strengthen their health and well-being. In other words, knowledge that intertwines medical science with caring science is needed, in order to optimize the patient's comfort (Holmberg, 2021). The current study is therefore aimed at generating a deeper understanding and knowledge about the phenomenon of breathlessness from the patient's unique point of view, that of being in such a severe state of breathlessness that prehospital care is required. To our knowledge, patients' experiences of suffering from breathlessness prior to prehospital care are not well described in previous research. Therefore, this study is intended as a starting point to decrease this knowledge gap. Knowledge from the patient's point of view may lead to an increased awareness among ACs, as well as among emergency medical dispatchers, on how to meet patients' individual needs from a holistic perspective,

e.g. by integrating medical knowledge with knowledge from a caring science perspective in order to meet patients' individual needs and provide the right level of care.

## 1.2 | Aim

The aim of the study is to describe how breathlessness is experienced by patients prior to prehospital care.

## 2 | METHODS

### 2.1 | Design

This phenomenological study is based on the Reflective Lifeworld Research (RLR) approach, as described by Dahlberg et al. (2008). The aim of the RLR approach is to describe meanings according to the phenomenon studied. In using this approach, the researcher attempts to uncover the phenomenon through the methodological principals' openness, flexibility and bridling, i.e. reflection on and problematizing of the understanding in relation to the phenomenon. To be able to understand another person's lifeworld, the researcher's own experiences of related issues must be held in check. For the researcher, this means questioning one's understanding of the phenomenon under study so that it can be uncovered in all of its variations, as well as keeping an open mind and attitude towards what meanings participants express in relation to their own lifeworlds and how they do this. We applied the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007; File S1).

### 2.2 | Participants and data collection

Data were collected in lifeworld interviews (Dahlberg et al., 2008) from patients living in mid to southern Sweden between January and October of 2020. The participants were strategically selected to achieve as much variation of the data as possible. Strategic selection aims to select participants who have lived experiences of the phenomenon, and who in terms of that can provide rich descriptions of the phenomenon to be investigated. Therefore, the inclusion criteria were lived experiences of breathlessness to the extent that ambulance care was needed, various reasons for the onset of breathlessness, age  $\geq 18$  years, variation in gender, ability to speak Swedish, no memory loss, have called the emergency number (112) and were cared for by ACs.

The participants were recruited either through nurses in the ambulance service or the emergency department ( $n = 4$ ) and through social media ( $n = 10$ ). Interested participants were then contacted by the first author, who provided information about the study in more detail both verbally and in writing (by email). If they agreed to participate, the interviews took place at a day and time suitable to the participants.

In total, 14 participants were included in the study, 12 women and 2 men, ranging in age from 35 to 85, with various reasons for their onset of breathlessness (Table 1). The time interval between the participants' care from the ACs and the interviews varied from 1 week to 2 years (median 6 months). Two interviews were performed at locations that suited the participants' preferences. Due to the ongoing pandemic in the community, the remaining 12 interviews were conducted through telephone calls, using the speaker function. A lifeworld interview is phenomenon-oriented, which means that the focus is on the meanings of lived experiences (Dahlberg et al., 2008). In line with the RLR approach, the interviews were initiated by inviting the participants to talk about their experience of the phenomenon. The interviews started with the question: "The day when you or another person next to you contacted the ambulance, can you describe how it felt to experience breathlessness?" Thereafter, follow-up questions further explored the phenomenon, such as "What do you mean by ...", "Can you describe it more?" and "How did you feel in that situation?". The interviews lasted between 15 and 50 min (median 30 min.). One of the interviews, which lasted only 15 min, had to be interrupted due to deterioration of the participant's health. All the interviews were conducted and audiotaped by the first author and later transcribed verbatim.

## 2.3 | Data analysis

The analysis was performed following the RLR principles, in accordance with Dahlberg et al. (2008). It was characterized by movement between the whole (the interviews) and its parts (data units) and then towards a new whole (the essential meaning). During these

movements, the goal was to remain as open and reflective as possible, in an approach characterized by closeness and a flexible and open attitude to the text. This was done in order to prevent the researchers' pre-understandings from prevailing and thereby determining the participants' meanings in advance. Firstly, the transcribed interviews were read through several times to obtain a comprehensive understanding of them as a whole. Then, the analysis of the parts began by searching for meaning units, i.e. meanings related to the phenomenon in focus. These meanings formed patterns consisting of clusters, in which meanings that were related to one another were linked. This creation of clusters was an ongoing process of testing different possibilities in search of the essential structure of meanings in relation to the breathlessness phenomenon. The essential meaning of the phenomenon (the essence) is the most abstract level that describes how the meanings in all the identified clusters related to each other, that is, meanings that all the informants talked about but in different ways. The constituents of the meaning further elucidated the essential meaning. These constituents are exemplified by quotes from the interviews (Dahlberg, 2006).

## 2.4 | Ethical considerations

This study was approved by the Swedish Ethical Review Authority (Dnr 2019-03283). The ethical standards of the Helsinki Declaration were followed (World Medical Association, 2013). All the participants received verbal and written information about the aim of the study and were assured that their identities would remain confidential. Confidentiality was also emphasized in the interviews. Moreover, the voluntary nature of participation and the ability to

TABLE 1 Participants' characteristics (n = 14)

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

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

withdraw from the study at any time were discussed. Two of the participants signed a written consent document, and the rest ( $n = 12$ ) gave their recorded verbal consent in conjunction with the telephone interview. Recorded verbal consent is permitted according to the Swedish ethical board.

### 3 | RESULTS

#### 3.1 | Essence

The essential meaning of patients' lived experiences of breathlessness prior to prehospital care is conceptualized as an intense existential fear of coming close to the finality of life. Breathlessness is experienced as a movement that begins with the physical sense of breathing difficulties, intensifies into anxiety and panic as the symptom continues and finally turns into existential fear. In this movement, there is an intertwining of all these aspects. In the situation of breathlessness, a sense of vulnerability is present, which manifests as a feeling of not recognizing oneself or one's body, in which a powerlessness associated with not being able to sufficiently cooperate with or control the body emerges. This reinforces the powerlessness in terms of being trapped in an unpredictable body that is fighting a losing battle. The existential fear is directed towards the unknown, which manifests as a difficulty in understanding what is happening in the body and in losing the ability to predict what will come next in the struggle to breathe. In turn, the existential fear evokes an existential vitality, which supports the battle to regain control of one's breathing. At the same time, an ambiguity arises regarding the capability of handling the situation on one's own versus needing the presence of a loved one or healthcare professional. Experiencing oneself as alone, on the edge of not being able to regain control over one's body, evokes an intense existential fear and the sense that one's existence is threatened to the point of potential annihilation. The essential meaning is further described in terms of four constituents: being in an unknown body, striving to handle the situation, ambiguity of having loved ones close and reaching the utmost border (Figure 1). These four constituents are interrelated and allow for a better understanding of the whole from the perspective of the different parts, according to the analysis methodology that was used.

#### 3.2 | Being in an unknown body

Experiencing breathlessness prior to prehospital care is described as struggling to breathe in a body that is no longer recognized. This leads to feelings of a body that is not functioning properly and is thus highly precarious. There is the sense of restrained breathing or resistance when breathing, along with being frightened while trying to get air into the lungs and that one's lung size is too small for the air to fit into. In the worst case, being suffocating, which is a terrifying experience as it is an indication of impending death.

I cannot inhale air ... the feeling that someone is standing and pressing with their thumbs on my throat and just squeezing and squeezing, and nobody is removing them.

(14)

Breathing through a body that feels unknown, as it is unpredictable, entails a withdrawing from oneself and instead looking at one's body from an outside perspective. A mistrust of the body ensues since it no longer has the ability to handle the breathing automatically. Instead, the breathing must be performed through a conscious action in order to establish a normal breathing pattern or get enough air into the lungs, or an autonomic attempt from the body to get more air. Thus, a battle towards regaining control over the breathing is underway.

I do not trust that the body can handle this automatically, because I have to force in the air ... so that ... because it is experienced as ... that it is stopping.

(12)

Such feelings evoke a sense of being trapped in an unknown body that is betraying one's self and which can no longer be taken for granted. This causes extreme fear and a sense of powerlessness that escalates in intensity, an uncontrolled feeling that manifests in the body.

I was scared ... partly because I did not really know what was broken. I thought that maybe it was a punctured lung because it was so difficult to breathe.

(2)

When breathlessness continues unabated, the fear escalates and advances to a state that feels unbearable. This initiates the sense of beginning to lose control over the body. The fear that arises manifests either from a remembering of how it feels to lose control or a fear of not knowing what is going to happen next in the body. This elicits feelings of being on the edge between life and death, engulfed in an invisible threat.

It's a huge fear because I think a person who drowns experiences this ... we do not ... but this is something you get ... drowning again and again ... and it's terrible. It's impossible to put into words ... horrible.

(14)

#### 3.3 | Striving to handle the situation

There is an attempt to handle the situation in terms of reducing anxiety and panic in order to get air into the lungs. The sense of breathlessness can easily become impossible to handle and therefore must be avoided before escalating in intensity. To counteract this impending threat, an existential vitality awakens beyond one's



FIGURE 1 Overview over the essence and its constituents

control, which is manifested through a sense of inner strength and the courage to challenge the body to become calm. This battle to avert anxiety and panic by creating a sense of calmness is crucial in order to regain control over the body.

I try to not have thoughts ... instead concentrating on keeping calm. // I really do not want to have any thoughts.

(11)

Striving to handle the situation entails a collaboration within one's body, which means being compliant with the body by listening to what it needs in order to regain control over the breath. In seeking a state of calmness, the aim is to avoid unnecessary bodily effort, to reduce the stress that can cause even worse breathlessness and to avoid totally losing control over the body.

Then I collapsed on a sidewalk and just sat there next to a house wall because I had to bring my breath under control. // I did not want to strain myself ... but to sit down so I could calm down, and try to relax my body ... and be able to breathe ... take deep breaths so everything could go down.

(10)

Self-trust developed through managing breathlessness in different situations translates into knowing what to do when breathlessness occurs again and how to manage the situation. When one has a greater understanding of how one's own body reacts, it is easier to focus on regaining control over the body. Also, despite the extreme fear, a greater courage to challenge the body in the state of breathlessness arises.

You really try ... I know when ... I know my body if you say so ... so I know when "No, I can't handle it anymore."

(3)

Furthermore, the battle to regain control often consciously occurs in a state of aloneness, which means that one has the need to prove to oneself or to others that one can handle the situation alone without any help from others. Even though there is a self-understanding that the breathlessness may be a sign of something serious happening to the body, there are still a distancing from it or a denial of its seriousness. There is also an uncertainty in terms of how to determine the severity of the symptoms.

I thought that "no I'm waiting for the primary care centre to open". // No it's because you ... really ... you do not want to exaggerate and go by ambulance. It feels a bit excessive I thought in that moment.

(5)

In striving to handle the situation in aloneness, feelings arise of not wanting to be an inconvenience to the ACs, because one does not want to be perceived as a burden or as taking others' time unnecessarily. One also wants to avoid being ashamed in front of the ACs, if the situation turns out to be not as serious as it seems. Therefore, before calling the emergency number, all one's efforts are put into trying to alleviate the situation alone, and the giving up occurs only when the situation is out of control and all attempts to cope with it independently are exhausted.

I felt quite lonesome. // I did not want to be a burden especially towards the ambulance workers ... because I was awake and like ... I did not feel very sick, but at the same time I had extreme death anxiety.

(9)

### 3.4 | Ambiguity of having loved ones close

Closeness towards loved ones when experiencing breathlessness evokes ambiguity, which means that their presence can be perceived as either calming or worrying and disturbing. Closeness to loved ones can be calming in the sense that their supportive presence can create a feeling of safety and relieve the experience of aloneness when the situation is perceived as urgent or uncontrollable. Feelings of security arise when someone close understands the urgency when they are called and knows what to do without being told.

Because they know ... when I call ... then I do not have to say anything ... they know what it is. // It leads to the feeling that I am not completely alone ... and if I die now ... I'm not lying here by myself.

(14)

On the other hand, experiencing breathlessness while being forced to meet the expectations of others who do not understand how it feels causes mixed feelings of vulnerability and the need to be alone. There is an innermost desire to let go of all obligations to meet others' needs when one's utmost need is to control the breathing.

And I just wanted my husband close to me. // He ran around and tried to keep track of the kids. I felt very exposed and a feeling of being very naked and not able to breathe ... such a fundamental thing as breathing.

(9)

At the same time, there is an understanding that loved ones needs in the situation also have to be met and a desire that this be done. This awareness of being able to support loved ones despite being in a body that is out of control also can reduce the stress level one is experiencing.

"Breathe .. breathe" ... my mother shouted a couple of times because she was standing by the road guiding the ambulance. "Can you handle it, XX?"... and it was very difficult to answer her ... so I raised my hand with "thumbs up" showing that my breathing works. She was terribly scared.

(5)

### 3.5 | Reaching the utmost border

Regardless of whether the experience of breathlessness is new or familiar, it can reach a limit in intensity when it is no longer possible to manage the situation alone. This evokes a powerlessness and fear that the body has totally taken over and is beyond one's control, that the body is giving up and no longer has the strength to even manage to breathe or handle the stress that breathlessness causes. This is accompanied by an awareness of the risk when the body is unable to function properly. This sense of bodily limitation arises when all efforts to regain control over one's breathing feel futile. There is the sense that the battle towards regaining control over the breathlessness independently is ineffective and that the body is screaming out for help from a healthcare professional.

I felt somehow completely exposed ... I have no chance to do anything about it myself ... just wait for the ambulance clinicians. Very exposed and alone ... and scared.

(4)

There is a self-awareness of one's bodily capacity when the breathlessness reaches the limit when it cannot be handled autonomously.

This manifests as a sense of completely losing control, accompanied by fear that is escalating and leading to uncontrollable feelings of anxiety and panic. At this stage, there is an awareness of when it is time to seek professional help, since one knows the situation will become much worse if help is not received in time. This makes it easier to make the decision to call 112.

It is not the case that when you get breathlessness you immediately throw yourself on the phone ... instead you ... It takes a while when you feel that you cannot ... I cannot come back [regain control].

(6)

When all forces are mobilized in trying to regain control of the breathing, feelings arise as to whether to wait a while to call 112. It is easier to make the decision to call the emergency number in situations where there is no hesitation, when it is obvious that the situation is urgent, as it is clear that the body is no longer functioning properly. In this situation, the fear can also arise through thoughts that it may be too late before help arrives, a fear of the consequences of not listening sooner to the body's signals.

It was getting worse as well while ... and then ... well, I cannot wait any longer. This ... now I take a big stupid risk ... "this is a stupid risk", I thought ... because I noticed the escalation. It was very irrational.

(13)

In terms of being justified to call 112, especially when healthcare professionals or family members advise that there is a need for professional help, the realization that the situation is actually very serious makes it easier to call emergency because there is no need to worry about calling unnecessarily.

I can only say one or two words and then need to breathe ... and then she continues [the operator at the healthcare counselling] ... [she] noticed this is not possible ... this is serious ... so she said "call 112 ... you must get an ambulance".

(13)

Reaching the limit of having lost control over the body causes an acute awareness of one's mortality and that one's very existence is threatened. This sense, that one's life could prematurely end, is very hard to fathom. It evokes feelings of grief and existential fear at being forced to leave one's life and loved ones behind and having to face death without any preparation, either for oneself or for loved ones.

I felt grief and a stress that I was going to die ... and leave my family behind. That is the feeling you have then ... when you fight ... grief and death anxiety.

(12)

## 4 | DISCUSSION

Our results have similarities with previous findings (Hutchinson et al., 2020), in which chronically ill patients attempted to handle their breathlessness alone before seeking professional help from an emergency department, including seeking help when they were afraid of dying from breathlessness (Harrison et al., 2014). The difference and contribution of this study lies in gaining understanding and insight from the patients' perspectives, among the various reasons for the onset of breathlessness, as to how they experience and manage the situation prior to prehospital care. In patients with breathlessness, regardless of the reasons and mechanisms behind it, there is a limit on how long their strength and vitality will last in their battle to regain control. It is the lack of vitality that ultimately leads to the realization that professional help is needed, as they no longer have the ability to handle the situation and are in full panic mode. Therefore, this study provides an understanding of the phenomenon as a transition from self-care to the need for professional care. Also, our study highlights that the initial support patients receive when they call the emergency number should be directed at alleviating the existential threat they are experiencing, i.e. reduce their severe anxiety and panic around the prospect of death.

This study contributes additional knowledge in terms of broadening the definition of breathlessness, which was a focus of Williams and Carel's (2018) research. In line with their suggestions for differentiating the specific types of breathlessness depending on the underlying cause of its onset, our results point to variations of the existential dimension of breathlessness in the acute situation prior to prehospital care. Especially, the existential fear that is described by these patients when they are losing control over the body is a valuable contribution to the definition.

Furthermore, the understanding of the essence of breathlessness in this study has been deepened by the influence of caring science and existential philosophy. This understanding contributes to the relevant deep knowledge that is applicable in clinical nursing and allows for the appropriate development in the care of these patients. The existential fear permeates and affects patients in different ways in our study, and the stronger the impact of the fear, the more difficult it is to regain control of the body. This existential fear exposes people's vulnerability when their body is experienced as unknown and unable to control. This constant battling against something unknown, which has no focus, is experienced as extremely frightening. Galvin and Todres' (2012) description of suffering as embodied discomfort relates here to the sense of existential fear and losing control, which manifests in an awareness that something is seriously wrong with the body, the source of which cannot be located. At its most extreme, this suffering can become too overwhelming to manage. However, the essence of bodily discomfort is, according to Galvin and Todres (2012), located within the individual's experience rather than in the actual medical condition. Therefore, from a clinical nursing perspective, it is important to consider patients' experiences of suffering and how caring can be provided that enables well-being despite ongoing breathlessness.

In terms of how patients' well-being can be facilitated while they are in a state of existential fear, as described in our results, Galvin and Todres (2012), as well as Arman et al. (2015), emphasize that vulnerability and freedom are always possible in any human condition. Galvin and Todres (2012) describe the ongoing tension between these states, in which well-being can be experienced; in other words, suffering expresses one's vulnerability while well-being expresses one's freedom. Freedom connects with one's ability to make own decisions, even if within certain limits. Reassurance from the ACs, both in terms of the vulnerability they are experiencing and the options available to them, encourages patients' sense of well-being (Galvin & Todres, 2012). Thus, ACs need to be aware of the existential dimensions of breathlessness, and therefore to aid these patients in sensitive and appropriate ways to ensure they are providing the most beneficial caring.

We also found that existential fear contributes to the stance of not taking one's life for granted when battling to regain control over breathlessness. Being close to death were described in different ways among the patients in our study. In previous studies on hospitalized patients with breathlessness (Banzett et al., 2020; Schmid-Mohler et al., 2019), this condition generated panic and was directly related to a fear of dying of suffocation and not being comforted. This was also described as an existential threat, a foretelling of how impending death might feel. This relates to Heidegger's (1993) description of *losing freedom*, which here is related to one's vulnerability when confronting the fact of one's mortality. When forced to confront one's own death, Heidegger (1993) emphasizes that there is always anxiety. The existential fear around one's vulnerability can also be related to what Carel (2016) describes as *bodily doubt* in serious illness. Bodily doubt constitutes a transition from having bodily capacity to bodily incapacity due to the severe dysfunction caused by illness. In terms of our results, the idea of bodily doubt is in line with the feeling of losing control of the body when unable to breathe. In this situation, as Carel (2016) describes, the physical sensations related to doubt and hesitation arise in one's body, as the body feels unpredictable and unreliable.

Our results also show that in the state of breathlessness, there is a driving force to live, and this is where existential vitality comes in as a support, an additional inner force that extends bodily capacity. At this stage, the existential vitality that emerges takes place beyond patients' own control, but inwardly and not as a result of external forces. According to Dahlberg (2019), when being out of control or unfamiliar with the body manifests, the desire to control it further may arise, giving additional strength to cope with the situation. This process is described by Galvin and Todres (2011) as an attunement that brings an embodied energy. From a clinical nursing point of view, however, it is important for the ACs who care for these patients to be aware that this additional vitality is a temporary resource that arises in managing their situation.

Embodied vitality can also be described as an aid to manage one's existential fear or as a means to flee from one's existential fear. Heidegger (1992) emphasizes that the existential fear that is experienced leads to a desire to flee when it becomes too threatening.

In relation to our results, patients express fear of the threat of the unknown and of something serious happening. As mentioned earlier, losing control over one's own body in the battle with breathlessness is terrifying, as the struggle is against something unknown that has no end. Heidegger (1992) mentions situations in which threatening events are experienced acutely, even though they have not yet happened; for example, in waiting for an event that is "in fact not yet, but at any moment", the fear can escalate to the point of panic. This experience of fear intensifying in an uncontrolled manner can lead to surrender in accepting one's inability to handle the situation alone. In this study, when feelings arose among the patients of having reached the utmost border, the existential vitality that brought extra strength is no longer supportive. Something is now happening beyond the patients' control that makes the situation unbearable to manage any longer. At this stage, a powerlessness arises, which turns into despair, along with the desire to surrender oneself into safe professional hands. Toombs (1987, 1993) describes this situation as the loss of certainty, which means that one is forced to surrender to others in the realization that when the body is out of control to this extent, one is not indestructible. As in our study, this forces patients to confront their own vulnerability, which is a distressing experience. This can also be perceived, as Dahlberg (2019) describes, as being totally out of control, which arises from the sense of being exposed to outer forces that cannot be managed. Heidegger (1992) refers to  *dread*, which means that something terrible is happening or "can be" happening. The feeling of absolute helplessness in coping with this threat is likely related to one's experience of losing control of the situation. The experiences of breathlessness, the strategies around managing the situation and the awareness of when it was necessary to call for help were different for the patients in this study. This is consistent with other authors (Hutchinson et al., 2020; Karasouli et al., 2016; Larsen et al., 2018), who found that it was difficult for patients to know when their condition was serious enough to require medical attention. Some people who had previous experience with breathlessness (Karasouli et al., 2016; Larsen et al., 2018) found it easier to determine when this was necessary, while others (Karasouli et al., 2016) tried to avoid going to the hospital as long as possible, despite their deteriorating clinical situation. In the latter study, none of the patients wanted to be admitted to the hospital, but they were eventually forced to accept the situation because all other options had been exhausted. Even if there was a hesitation for the patients in our study to call 112, which is consistent with previous findings (Kauppi, Herlitz, Magnusson, et al., 2020b), the difference at this stage is the readiness to surrender to prehospital care. Once the patients in our study surrendered to this, there was no return, as they now put their trust in others' hands, i.e. had faith that the ACs had their best interests in mind in providing care. Galvin and Todres (2012) describe this as acceptance and peace in the situation despite physical deterioration. When helpless in managing the situation, relying on others became the only option among the patients in our study. Before this stage, however, self-trust seems an important factor behind the defence mechanisms (repression and denial of one's condition) that patients use to justify their ability to handle the situation on their own. We argue that this

tendency represents human behaviour, in general, since the results of previous studies, including those with patients whose breathlessness had different cardiac aetiologies (Banharak et al., 2020; McCabe et al., 2016; Wu et al., 2017), showed that patients did not differ in their behaviour in seeking help. Also, among these results, the common reasons why patients delayed contacting medical help were that they did not perceive their symptoms as very serious. In the Wu et al. (2017) study, the patients' decisions to seek care were mainly triggered by persistent symptoms or, as in our study, by another person making the decision that medical care was required.

The behaviour of neglecting the seriousness of breathlessness, as shown in our results, is described by Dahlberg (2019), who highlights that in these situations, there is a kind of self-defence which can be seen as a distancing from one's body. Therefore, our result can be interpreted as that the patients neglect breathlessness in order to avoid the reality of it. This can be understood as a way to protect oneself from the existential fear and the loss of control that is unbearable to handle. Also, this can plausibly be explained, as Galvin and Todres (2011) describe, as trying to use one's embodied vitality in managing the situation, which in our results, relates to using coping strategies. This involves placing oneself in a false reality with the aim of avoiding an existentially uncontrollable situation and, thereby, feeling some degree of well-being in the face of it.

What ultimately initiated the 112 calls in our study was that the patients came to the point at which the situation felt completely unbearable and out of control, and they could no longer handle it alone. This is also described among patients admitted to an emergency department with severe breathlessness (Harrison et al., 2014; Hutchinson et al., 2020). These patients described a need to feel safe, as they experienced breathlessness as overwhelming, and their need for safety overrode all other concerns in the midst of their confusion as to what was happening with their body. The patients in our study saw the emergency medical dispatcher as a direct link to accessing help from the ambulance services. We assume that the patients did not reflect upon whether they would receive the highest priority level or not. Instead, when experiencing breathlessness to such a severe degree that they needed ambulance care, they took it for granted that professional help would come to the rescue within a short time. However, as the operators in one study (Ek & Svedlund, 2015) describe, their responsibility in assigning the right priority level according to a person's individual needs and conveying medical advice without seeing the patient is often challenging.

#### 4.1 | Methodological considerations and reflections

The aim of this study was to describe how breathlessness is experienced by patients prior to prehospital care, and therefore a phenomenological approach was chosen. The results contribute to gaining a deeper understanding of how patients experience breathlessness to such a degree that prehospital care is sought. These findings provide important insights into patients' experiences of the phenomenon and



thereby contribute to the knowledge in this area, as this topic has not been well described in previous prehospital research. The strength of the phenomenological approach is the rendering of rich descriptions of the phenomenon at hand rather than focusing on external aspects, such as the number of participants in a study (Dahlberg & Dahlberg, 2019). The advantages of a descriptive method are that the application possibilities can increase with the degree of abstraction. However, a very high degree of abstraction makes it more difficult to demonstrate the uniqueness of a particular phenomenon. Therefore, the aim has been to refrain from abstracting at too high a degree and instead attempting to balance the abstraction in order to narrow the context (van Wijngaarden et al., 2017). According to the RLR approach, validity is associated with meaning in data, e.g. the lived experiences of the phenomenon in focus and not just the content of an experience (Dahlberg et al., 2008). The research process in this study is characterized by a search for meaning in both the interviews and the analysis in which the phenomenon is the focus. The quotes represent variations of the phenomenon rather than the participants as subjects. Members of the research group repeatedly discussed and reflected on the findings, and reviewers with broad experience in phenomenology reviewed the manuscript. The majority of the authors have experience in emergency care, which promoted openness in understanding the phenomenon, while the bridling of pre-understandings helped to ensure objectivity. Most of the interviews took place by telephone rather than in person, which may have influenced their development and content. Sometimes, the informants had trouble describing their experiences, perhaps due to difficulties in finding the appropriate words to convey how they felt in the situation. In addition, some informants may have felt sensitive during the interview and could have been affected when reminded of the event with breathlessness in such a way that they felt stuck in their communication around it. It was therefore important that a trustworthy relationship was established in which the informants felt safe to share their lived experiences. Despite these possible drawbacks, however, the data collected in this study consist of a rich description of the phenomenon of breathlessness, as experienced by patients.

## 5 | CONCLUSIONS

The current study reveals that patients with breathlessness are strongly affected by their situation before they call 112, e.g. prior to prehospital care. It is only when they experience extreme existential fear and severe anxiety from the sense of having lost control over their body, despite all efforts to manage the situation, that they seek emergency help. At this stage, the situation has become unbearable and impossible to deal with alone. However, somewhat surprisingly, our study also found that despite this extreme situation, patients sometimes deny the severity of their condition and thus delay calling 112, with the consequence that their condition can deteriorate drastically. It is only at the very outer limits of endurance that the emergency call is made, when all the person's strength and reserves of vital energy have been exhausted.

This result contributes important knowledge for clinical practitioners to consider in relation to patients who call 112 due to breathlessness and are in need of ambulance care. For the patients, regardless of the reasons for its onset, the experience of breathlessness is terrifying and overwhelming. The type of support they need from the emergency medical dispatcher and the ACs, therefore, must be emotionally responsive and efficient in a technical and practical sense at the same time, with the intention of alleviating the existential threat they are experiencing, i.e. lessening their severe anxiety and even panic. Therefore, in order for emergency workers to meet patients' needs fully and appropriately, they need to communicate with these patients with openness and sensitivity, without relying on predetermined judgements and measures.

## AUTHOR CONTRIBUTION

All the authors listed have substantially contributed to conducting the underlying research and drafting this manuscript. Study design: WK, LP, JH, CA; data collection: WK; data analysis: WK, LP; critical revision and final approval of the manuscript: WK, LP, MFJH, JH, CA.

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## CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available upon a reasonable request only from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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