Exploring patients’ and relatives’ needs following acute myocardial infarction—A qualitative study

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Abstract

Background For patients after acute myocardial infarction, a gap exists in Austrian care in the early period following hospital discharge. The patients’ and their relatives’ perspectives are crucial for developing nursing interventions.

Objective To investigate patients’ and their relatives’ experiences from the onset of acute myocardial infarction symptoms until the early period following hospital discharge.

Methods This qualitative study used in-depth individual and couple interviews with acute myocardial infarction patients \( n = 14 \) and their relatives \( n = 7 \) for data collection and a phenomenological hermeneutical analysis method.

Results Four phenomena, i.e., “Understanding of living with heart disease,” “Omnipresent anxiety,” “Being there for each other,” and “Being understood as an individual,” showed participants’ needs. “Understanding of living with heart disease” described the process participants underwent to understand coronary heart disease, including the sub-phenomena of “Perceiving having heart disease,” “Getting familiar with heart disease,” and “Living life against the backdrop of heart disease.” It implied the participants’ strong need to get information on disease causes at the individual level and reshape their lives after the event to ensure a normal life.

Conclusion Healthcare professionals should involve patients and their relatives in care and provide communication based on their needs. Such endeavors may allow those affected to understand coronary heart disease and prepare for and adapt to the needed lifestyle changes. Nursing interventions that consider the four phenomena highlighted in this study may ensure enhanced care for those affected in their lives after acute myocardial infarction, improving nursing care quality.

Keywords Acute coronary syndrome · Patients’ experience · Advanced nursing practice · Secondary prevention · Heidegger’s ontology

Exploration der Bedürfnisse von Patient*innen und Angehörigen nach akutem Myokardinfarkt – eine qualitative Studie

Zusammenfassung

Hintergrund Für Patient*innen nach akutem Myokardinfarkt besteht eine Versorgungslücke in der Frühphase nach der Krankenhausaufnahme in Österreich. Die Perspektive der Patient*innen und ihrer Angehörigen ist für die Entwicklung von Pflegeinterventionen entscheidend.

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**Ziele** Die Erfahrungen von Patient*innen und ihren Angehörigen vom Auftreten der Symptome eines akuten Myokardinfarkts bis zur Frühphase nach der Krankenhausaufenthaltssoll untersucht werden.

**Methodik** In der vorliegenden qualitativen Studie wurden vertiefende Einzel- und Paarinterviews mit Myokardinfarktpatient*innen (n=14) und ihren Angehörigen (n=7) zur Datenerhebung durchgeführt. Die Datenanalyse erfolgte nach einer phänomenologisch-hermeneutischen Methode.

**Ergebnisse** Vier Phänomene – „Das Leben mit Herzkrankheit verstehen“, „Omnipräsenz der Angst“, „Für einander da sein“ und „Als Individuum verstanden werden“ – zeigten die Bedürfnisse der Patiententeilnehmenden. „Das Leben mit Herzkrankheit verstehen“ beschrieb den erlebten Prozess des Verstehens, der koronaren Herzkrankheit, der drei Subphänomene – „Herzkrankheit wahrnehmen“, „Sich mit der Herzkrankheit auseinandersetzen“ und „Leben vor dem Hintergrund der Herzkrankheit führen“ – umfasste. Dieser implizierte das starke Bedürfnis der Studienteilnehmenden, Informationen zu den individuellen Krankheitsursachen zu erhalten und ihr Leben nach dem Ereignis neu zu gestalten, um ein normales Leben führen zu können.

**Schlussfolgerung** Das Gesundheitspersonal sollte Patient*innen und ihre Angehörigen in die Behandlung einbeziehen und ihnen bedürfnisgerechte Kommunikation anbieten. Solche Bemühungen können es Patient*innen und ihren Angehörigen ermöglichen, die koronare Herzkrankheit zu verstehen, sich auf die erforderlichen Lebensstiländerungen vorzubereiten und diese vorzunehmen. Pflegeinterventionen, welche die vier in dieser Studie aufgezeigten Phänomen berücksichtigen, können die Unterstützung Betroffener bei der Lebensführung nach akutem Myokardinfarkt optimieren und die Qualität der Pflege verbessern.

**Schlüsselwörter** Akutes Koronarsyndrom · Erlebnisse der Patient*innen · Advanced Nursing Practice · Sekundärprävention · Heideggers Ontologie

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**Introduction**

Coronary heart disease (CHD) is the leading cause of death worldwide (WHO 2020). Acute myocardial infarction (AMI) is the most common life-threatening manifestation of CHD (Reed et al. 2017). Among the revascularization therapies (e.g., aortocoronary bypass surgery) for AMI, primary percutaneous coronary intervention (PCI) is the most rapid and effective treatment. PCI reduces mortality rates (Smilowitz and Feit 2016), improves patient prognosis, and minimizes hospitalization time (Ibanez et al. 2018). Despite the rapidness and effectiveness of PCI, patients that undergo this treatment still retain the risk factors of CHD and they also enter the high-risk post-AMI group (Piepoli et al. 2016). Indeed, in the first year post-AMI, 18.3% of patients experience a second cardiovascular event (Jernberg et al. 2015). Therefore, as a complement to PCI, AMI patients should receive secondary prevention interventions, including biomedical risk management, pharmacotherapy, assessments regarding lifestyle and psychological risk factors, and support for initiating/maintaining lifestyle change (Piepoli et al. 2016). To prevent recurrent cardiac events in AMI patients, secondary prevention should be offered through cardiac rehabilitation programs and continuously accompanied by healthcare professionals, especially in the early post-AMI phase (Biga 2021).

In Austria, rehabilitation services for AMI patients are mainly provided through inpatient rehabilitation centers rather than outpatient centers. In an inpatient rehabilitation center, patients must stay an average of 3–4 weeks for completing the cardiac rehabilitation program (Mittag and Welti 2017). At the General Hospital of the City of Vienna, on average, post-AMI and PCI patients currently have an inpatient stay of 5.6 days (Qin et al. 2021); then, before discharge, these patients are asked whether they would like to participate in rehabilitation. Upon acceptance of rehabilitation, an application is made for patients. However, after discharge, patients have to wait to engage in inpatient rehabilitation for 29.7 days on average (Großschädlik et al. 2014). The waiting time was extended even further during the coronavirus disease 2019 pandemic (Schlitt et al. 2021). Upon not wanting or not being able to wait for this duration, or even not wanting to engage in inpatient rehabilitation, patients most commonly do not engage in any rehabilitation, and this is due to varied reasons (e.g., patients may become afraid of losing their jobs owing to the length of stay; Sulzgruber et al. 2019). Hence, sometimes there is implementation of non-timely rehabilitation and at other times there is pure neglect of it, underpinning a gap in Austrian healthcare regarding nonpharmacological secondary prevention in the early period following discharge from hospital for this patient population.

According to Kotseva et al.’s (2019) study, most European patients do not adjust their health behaviors after suffering an AMI. Especially PCI-treated patients often underestimate the disease progression risk and lack knowledge about CHD and on the importance of health-improving behaviors (Peterson et al. 2014). Moreover, their motivation for lifestyle change depends on understanding disease severity, chronicity, and its consequences (Aazami et al. 2014).
Concomitantly, patients and their families are often shocked by AMI and forced to learn to live with the disease’s unpredictability; this situation causes anxiety, which may evolve into efforts at making multiple lifestyle changes (Andersson et al. 2013; Fors et al. 2014; Merritt et al. 2017; Smith et al. 2017).

Although nursing interventions have been recommended by the European guidelines on cardiovascular disease prevention (Piepoli et al. 2016) and described by the American Association of Cardiovascular and Pulmonary Rehabilitation guidelines (Dolansky and Mola 2021), it remains difficult to determine whether these recommendations would be appropriate in Austria because the effects of nursing interventions depend on the context of its implementation (Craig et al. 2018). It thus seems necessary to develop an evidence-based nursing intervention for AMI patients that is tailored to the Austrian context. This may assist in establishing a robust support system that improves adherence to secondary prevention measures and promotes health. To this end, it is crucial to understand AMI patients’ and their relatives’ perspectives and needs in such settings (Rushton et al. 2017).

To better understand people experiencing an illness, Svenæus (2011), while following Heidegger’s ontology, describes health as “homelike being-in-the-world” and illness as “unhomelike being-in-the-world.” In the opinion of this cited author, Heidegger’s ontology offers the conceptuality that describes human experience related to the lived body, attunement, temporality, and being-toward-death. Therefore, he suggests that healthcare professionals should approach the human experience through Heidegger’s ontology in order to have a better understanding of the patients’ experiences. Heidegger’s magnum opus, Being and Time (1962), describes his ontological focus on the central phenomenon of “being-in-the-world,” which in turn forms the fundamental structure of Dasein (human Being). He said, “Understanding of Being is itself a definite characteristic Dasein’s Being.” (Heidegger 1962, p. 12) And “Dasein is its disclosedness” (Heidegger 1962, p. 133). To designate disclosedness, Heidegger describes three inseparable existential constitutions: state of mind, understanding, and discourse; the state of mind and understanding are articulated through discourse. These are the constitutive ways by which Dasein is disclosed, emphasizing that human beings endeavor to plan a new future life to make the alienation (“unhomelikeness”) familiar to oneself (Heidegger 1962).

With this theory in mind, we can see that AMI can trigger an existential crisis in patients’ and their relatives’ lives and confound their self-evidence in life. Therefore, patients feel like they are in an unhomelike being-in-the-world, leading them to plan a new future life that makes the alienation familiar to them. Moreover, relatives can contribute to CHD patients’ psychological well-being (Hansen et al. 2017), although they are also affected by AMI and incur psychological burdens related to it (Andersson et al. 2013; Gullick et al. 2017).

**Aim and research questions**

This study investigated AMI patients’ and their relatives’ experiences from the onset of AMI symptoms until the early period following discharge. In this study, “relatives” refers to patients’ spouses, partners, parents, and children. We aimed to demonstrate the needs of post-AMI patients and their relatives and expect this study to contribute to the development of nursing interventions that address their needs. The research questions were:

- How did patients and their relatives perceive the sudden life-changing situation evoked by the AMI, acute treatment, and inpatient care delivery?
- How is their awareness of the disease?
- What do they need to gain more awareness of the disease?
- What do they require from healthcare professionals to be able to cope with CHD in future life and engage in lifestyle changes to modify their unhealthy behaviors?

**Methods**

**Design**

This study followed a phenomenological hermeneutical approach by using in-depth interviews—individual interviews (II; patient only) or couple interviews (CI; patient and relative)—for data collection. A study by Bjerhnolt and Farstad (2012) suggests that couple interviews enable enhanced data collection on couples’ lives by allowing them to reflect together during the interview. In addition, by using open-ended questions, the interviews can target the participants’ perspectives (Froschauer and Lueger 2020). The data were analyzed using the phenomenological hermeneutical method developed by Lindseth and Norberg (2004). This analytical method is suitable for understanding the participants’ experiences and to “disclose truths about the essential meaning of being in the life world” (Lindseth and Norberg 2004, p. 151). Furthermore, it enables the basic assumptions in Heidegger’s ontology to be used in the analysis.

**Participants and setting**

Through purposive sampling, from October 2018 to June 2019, patients were identified and selected by the first author from two cardiology wards at the General Hospital of the City of Vienna, in Austria. The first author had no role...
Table 1  Examples of naive reading and thematic structural analysis

| Quotes from interviews | Pre-understanding |
|------------------------|-------------------|
| **Naive reading**      |                   |
| II1: I wanted to go home earlier because I just didn’t feel good in the hospital owing to the food and the environment. It’s unusual for me. I felt I would get better faster if I was at home. | Being in hospital is unusual to me |
| II3: Then, all of a sudden, there were six, seven nurses; it was like a series. I was not familiar with this situation. I didn’t quite realize that I had really had a heart attack. | Shock, not familiar |
| II13: I did not acknowledge the first heart attack | Not familiar |
| **Thematic structural analysis** |                   |
| **Meaning units**      | **Condensation units** | **Sub-theme** | **Main theme** |
| II1: So, I didn’t feel like I was a heart attack patient or (feel) weak. | Do not perceive oneself as being ill | Perceiving having heart disease | Understanding of living with heart disease |
| II3: I actually didn’t perceive, at the beginning, that I had had a heart attack. | Do not perceive oneself as having a heart disease |
| II1: I would like someone to explain to me, as a lay person, why I am lying here now. | Want to receive layperson-friendly explanations about disease causes | Getting familiar with heart disease |
| C16 (wife): But, as a relative, (I would have liked to have had answers to questions like) what happens now? What will happen further? I didn’t get any information | Need for information on the disease and its consequences |
| II10: I said (to the general practitioner): “This (her general practitioner only wrote her a prescription and didn’t have time to talk with her) is not possible. I want to be examined, and I need information.” | Need for information on the disease and its consequences |
| II10: I go on living my life despite having a heart disease, I live normally. If you think about the disease every day, you will get sicker. I am relaxed and I do therapy for my husband (laughter) | Live normally | Living life against the backdrop of heart disease | Omnipresent anxiety |
| C12: The pressure increased. Then there was a bit of fear. I sensed a state of fear. | Manifested anxiety |
| II11: (After discharge from the hospital, this patient would like to know) How far can I go in terms of physical activities or exertion? To what extent is my heart’s capacity limited? | Uncertainty |
| C14 (husband): If something should happen (if his wife has a cardiac arrest), (I should) turn my wife on her side, because you must presuppose that something (a cardiac arrest) can happen | Provide support |
| C15 (wife): These questions ... when I ask: did you go jogging? Or, please, don’t eat that (candy or sausage); it’s late. Or when he eats more, [...] And then, sometimes, these questions are uncomfortable for him | Overprotection |
| C14 (wife): From my profession (pharmacist), I have (acquired) many nutrition books. The studies in America show that the disease can be prevented by certain diets. So, I gave him those books | Advice or action |
| II12: I say that’s a cheek (she received a standardized discharge letter. It said that she should stop smoking. However, because she has never smoked, she felt that the letter’s content was a cheek). I have never smoked in my life. [...] That’s just the standard sentence | Medical information provision is not individualized |
| C16 (wife): Somehow, (I wanted) more conversations than are currently possible [...] and that are offered | Need for face-to-face conversation |

CI couple interviews (patient and relative). If individual interviews (only the patient)
in the clinical care of patients, despite working at the hospital. The eligibility criteria were being aged 18–70 years, hospitalized for an AMI (I.21 [ICD 10]), in a stable physiological condition, able to read and speak German, having undergone PCI, and no medically diagnosed cognitive impairment. Our sampling procedures aimed at reaching the maximum possible variation of experiences. Therefore, the sample comprised both sexes and a wide range of social and cultural backgrounds. The first author delivered information on the study for participants and invited 16 AMI patients and their relatives for an interview one day before hospital discharge. Two patients and three relatives declined owing to time constraints.

Data collection

All interviews took place 1–11 months after discharge from the hospital at a location chosen by the participants (e.g., the participants’ home, a restaurant, or a café). The first author conducted the interviews in German using open-ended interview questions; these questions were previously tested with two AMI patients and checked for comprehensibility and content acceptance. First, the first author explained the aim of the study to participants, starting the interview with the following opening question: “Could you tell me about your experience at the onset of illness?” To encourage narration, the author further posed the following questions regarding their illness experience: “Could you tell me how you experienced the hospital admission?” “Could you tell me how you experienced your hospital stay?” “How did your heart disease change your daily life? Please, give me an example.” “How was your experience as your sick relative returned home after hospitalization?” The interviews lasted 59 min on average, were audiotaped using a voice recorder, transcribed verbatim using Microsoft Office Word (Microsoft Corporation, Redmond, WA, USA) according to the transcription rules of Kallmeyer and Schütze (Mayring 2002, p. 92), and pseudonymized. If the situations narrated by the interviewees were not represented comprehensibly in the transcripts, additional information was written in round brackets. The first author wrote field notes during the interviews to record the specificity of the interactions with participants and subsequently included them in the analysis.

Data analysis

We used MAXQDA 2020 (VERBI Software, Consult-Sozialforschung GmbH, Berlin, Germany) software for data organization, specifically to create an overview of the data, its structures, and log the analysis process. The phenomenological hermeneutical method includes three steps: naive reading, structural analysis, and comprehensive understanding (Lindseth and Norberg 2004).

Naive reading entails obtaining a broad picture of the data; accordingly, the transcripts and field notes were read several times to grasp a pre-understanding of the whole text (Table 1).

The transcripts and field notes were also read sentence-by-sentence to identify meaning units in the texts, and condensation units were extracted from them using thematic structural analysis. These units were validated using a pre-understanding of the topic and the first author’s previous knowledge of over 20 years of experience caring for patients with cardiac disease. However, being critical of the first author’s knowledge, continuous reflection between the authors was conducted during data analysis. Then, the condensation units were sorted by similarities and differences, forming main themes and sub-themes (Table 1).

In the comprehensive understanding step, we interpreted and discussed the results from the structural analysis using Heidegger’s ontology and relevant research. This step aims to gain a comprehensive understanding of the participants’ experiences regarding the analyzed topic. The first author conducted the comprehensive understanding procedures alone. Then, the first author’s interpretation was discussed/validated by the co-authors.

Ethical considerations

The investigation conformed to the principles outlined in the Declaration of Helsinki. All participants provided written informed consent before participation. Participants were assured that they could decline participation at any time and that participation or non-participation would not influence their further treatment. This study was approved by the Ethics Committee of the Medical University of Vienna approved this research project (EC No. 1811/2018).

Results

Sample characteristics

Participants comprised 14 AMI patients (four female and 10 male; mean age 57.4 years; range 35–70 years) and seven relatives (six female and one male; mean age 56.3 years; range 35–67 years). The average length of hospital stay was 4.2 days. Nine patients were married or living with a partner. Nine patients were still active workers before the AMI event, and 14 participants were born in Austria and had German as their mother language (Table 2).

Based on the analysis, four central phenomena emerged: “Understanding of living with heart disease,” “Omnipresent anxiety,” “Being there for each other,” and “Being under-
Table 2  Participants’ characteristics

| Individual or couple interview (relationship) | Participant ID | Age | Sex | Marital status | Work status | Birthplace | Medical diagnosis | CR attendance | Waiting Time for CR (days) | Time of the interview AD |
|-----------------------------------------------|----------------|-----|-----|----------------|-------------|------------|-------------------|---------------|--------------------------|--------------------------|
| II1                                           | P1             | 50  | Male| Living alone   | Working     | Austria    | 1. STEMI          | No            | –                        | 2 months                 |
| CI2 (with wife)                               | P2             | 59  | Male| Married        | Working     | Austria    | 1. STEMI          | Yes           | 21                       | 4 months                 |
| P2's wife                                     |                | 57  | Female| Married      | Working     | Austria    | 1. STEMI          | Yes           | 28                       | 11 months                |
| II3                                           | P3             | 42  | Male| Partnership   | Working     | Austria    | 1. STEMI          | Yes           | 21                       | 7 months                 |
| CI4 (with wife)                               | P4             | 61  | Male| Married        | Working     | Poland     | 1. STEMI          | Yes           | 84                       | 4 months                 |
| P4's wife                                     |                | 58  | Female| Married     | Working     | Poland     | 1. STEMI          | Yes           | 70                       | 5 months                 |
| II5                                           | P5             | 61  | Male| Married        | Working     | Afghanistan| 1. STEMI          | Yes           | 42                       | 4 months                 |
| P5's wife                                     |                | 56  | Female| Married      | Working     | Afghanistan| 1. STEMI          | No            | –                        | 1 month                  |
| CI6 (with wife)                               | P6             | 63  | Male| Married        | Retired     | Austria    | 1. NSTEMI         | Yes           | 77                       | 4 months                 |
| P6's wife                                     |                | 63  | Female| Married     | Retired     | Austria    | 1. NSTEMI         | Yes           | 42                       | 4 months                 |
| CI7 (with wife)                               | P7             | 60  | Male| Married        | Working     | Austria    | 1. NSTEMI         | Yes           | 105                      | 6 months                 |
| P7's wife                                     |                | 58  | Female| Married     | Working     | Austria    | 1. NSTEMI         | No            | –                        | 1 month                  |
| CI8 (with wife)                               | P8             | 35  | Male| Married        | Working     | Serbia     | 1. STEMI          | Yes           | 77                       | 4 months                 |
| P8's wife                                     |                | 35  | Female| Married     | Working     | Serbia     | 1. STEMI          | No            | –                        | 1 month                  |
| CI9                                           | P9             | 67  | Female| Living alone| Retired     | Austria    | 1. STEMI          | No            | –                        | 1 month                  |
| CI10                                          | P10            | 63  | Female| Married      | Retired     | Turkey     | 1. STEMI          | Yes           | 112                      | 6 months                 |
| CI11                                          | P11            | 52  | Male| Living alone  | Working     | Austria    | 1. STEMI          | Yes           | 77                       | 4 months                 |
| CI12                                          | P12            | 70  | Female| Widowed      | Retired     | Austria    | 3. STEMI          | Yes           | 105                      | 6 months                 |
| CI13                                          | P13            | 61  | Male| Divorced      | Unemployed  | Austria    | 2. STEMI          | No            | –                        | 1 month                  |
| CI14 (with husband)                           | P14            | 60  | Female| Married      | Retired     | Austria    | 1. STEMI          | No            | –                        | 2 months                 |
| P14’s husband                                |                | 67  | Male | Married       | Retired     | Austria    | 1. STEMI          | No            | –                        | 2 months                 |

AD after discharge from the hospital, CI couple interview, CPR cardiopulmonary resuscitation, CR cardiovascular rehabilitation, II individual interview, NSTEMI non-ST-segment elevation myocardial infarction, STEMI ST-segment elevation myocardial infarction, St.p. status post

stood as an individual.” The phenomena represented the “being-in-the-world” of AMI patients and their relatives (Fig. 1) from the seven II and seven CI.

**Understanding of living with heart disease**

The AMI came unexpectedly, all of a sudden throwing the lives of patients and their relatives into a state where the AMI’s unpredictability prevailed. Thus, they gradually processed the AMI during the disease trajectory to gain an understanding of CHD. For example, “(I was) completely unprepared; (it) unexpectedly hit (me). I had no signs of it before. On July 15, (however,) the whole thing changed” (C12).

**Perceiving having heart disease**

The process of understanding began with symptomatic awareness, diagnosis confrontation, and the PCI. Patients first attributed the symptoms to other diseases, describing them as nothing serious; thereafter, they searched for information on the disease and its outcomes. Here is an example excerpt on this: “We read a lot on the internet. [...] We want to be informed. So, you already roughly know when...”
Fig. 1 Needs of acute myocardial infarction patients and their relatives while becoming aware of coronary heart disease and their coping strategies

something like that is happening; (nonetheless, we keep on wondering) what could it be (exactly)? How should you deal with it?” (CI14).

Generally, patients only sought professional help after no longer bearing the condition and becoming afraid of what could happen to them: “I felt as if someone was sitting on my chest. My mouth gradually became drier, and I had jaw spasms. [...], and I called the rescue” (II9).

The relatives reacted differently, mostly because they watched their sick relatives suffer from the symptoms, urging the sick relatives to seek immediate treatment: “I told him all the time: please go; go (and seek treatment)” (CI5; wife).

During treatment, patients reported having to rely on the competence of the treatment team. Nonetheless, in the period surrounding the first AMI, patients were not completely aware of their, nor could they correctly assess the risk of, CHD. Additionally, participants reported that the treatment team provided information mainly regarding the AMI diagnosis. At the same time the doctors assured them that the narrowed blood vessels had widened again through the implanted stents: “(The doctor said) Go on living normally. You have basically been restored” (II2).

Getting familiar with heart disease

Both patients and relatives deemed it important to not only recognize but also understand potential coping strategies: “When something is explained to you, and you understand something, then you can deal with it more easily” (II1).

During the hospital stay, patients could not absorb all information, finding it hard to ask specific questions because of their health status. Nonetheless, they wanted layperson-friendly information about their disease, individual-level causes, and future management: “Specifically, what should I actually do or what do I have to do after discharge?” (II11).

When at home, patients’ efforts were placed on knowledge acquisition regarding AMI from various sources: “So, should I get to know what a heart attack is? Or how should I eat? I understood it practically only through (reading) books, not from (surfing on) the Internet” (II11).

While some described fighting back their disease, others did not want to know anything about it. They reportedly followed doctors’ instructions as much as possible: “Well, that (the AMI) has done it for me, and it (the AMI) is over. So, I go to a check-up every 6 months and … I will do it (go to the check-up)” (CI14).

Owing to time constraints, general practitioners provided little information to patients or, sometimes, only a prescription. Still, in the rehabilitation centers, through intensive contact with healthcare professionals, patients received more information about their disease, health status, and coping strategies for daily use. However, inpatient rehabilitation meant psychological stress owing to constant confrontation with the disease for weeks.

Living life against the backdrop of heart disease

After returning to everyday life, participants had ambivalent feelings. For one, patients were relieved that they could continue a normal life without physical limitations; some even believed that they got healthier post-AMI compared with before it. Here is an example: “I now have six stents. I see it this way: I got a great service, like with a car when the engine is dismantled; everything is lubricated and reassembled, and now everything is fine again” (CI7).

For another, the AMI made them aware of the end of life, and they described it as a turning point in their lives. They started to rethink their lifestyle and future. The motivation for lifestyle change, notwithstanding, was dependent on the
amount of time passed since the AMI event, the patient’s perspective about the disease, and life experiences. During the hospital stay, participants wanted to discover the disease causes at the individual level, often saying that they had to change their unhealthy lifestyle. For example: “[...] it (the AMI) was a shot across the bow. I must go through one or more changes immediately and maintain them over a long period” (II1).

During rehabilitation, by exchanging their experiences with other inpatients, the participants regained confidence in their condition and acquired self-knowledge: “During rehab, I saw people of the same height weighing 100 kg, which is extreme; (that is) so overweight. (So, I thought) Okay, my diet was not extremely healthy. I must change it” (II11).

Moreover, they gathered much information that described the association among CHD, unhealthy lifestyles, and unchangeable pre-determined factors (e.g., genetics). After rehabilitation, patients tried to implement the strategies they had learned regarding lifestyle change. Nonetheless, they had concomitantly learned that unhealthy lifestyles are not fully responsible for CHDs, and this knowledge made them ponder whether these strategies would indeed ensure prevention. Participants also tended not to understand the chronicity of CHD; they deemed a chronic illness to be only one which causes a constant handicap/confrontation. Hence, they understood the chronicity of their situation exclusively upon being instructed to take lifelong medication or after suffering a recurrent AMI.

Some participants believed that the AMI was their fate and described that everyone had a particular end date. It was vital for them to have a positive attitude toward the disease and to look ahead: “We take it as it is. I always say that every person has a stage in their life, like when someone buys a ticket on the tram and then has to get off” (CI14; husband).

Omnipresent anxiety

The AMI triggered existential anxiety in participants during the disease trajectory; in some it was manifested, in others it was latent. Either way, it affected their entire lives. At symptom onset, patients’ anxiety was obvious: “The pressure increased. Then there was a bit of fear; I sensed a state of fear” (CI2). When confronting the diagnosis, participants became shocked. Upon health status recovery, they first felt relieved; then, they became uncertain and insecure.

Patients reported regularly attending preventive check-ups, emphasizing their health, and actively engaging in sports. For them, nonetheless, the unpreparedness of an AMI event was inconceivable; such unpredictability intensified their anxiety owing to loss of control over their future life, leading to unsureness and uncertainty: “From my point of view, I lived quite a healthy life; what should I change now?” (CI2).

Patients’ anxiety rose further upon realizing the need for lifelong medication intake and the possible accompanying side effects; such intake represented a life impairment. Moreover, they reported that the anxiety of death or of another AMI event dominated their lives, especially shortly after discharge. This feeling was exacerbated by the long waiting time for inpatient rehabilitation. They also incurred in increased psychosocial stress owing to the fear of losing one’s identity and social role, especially among those in the middle of life (i.e., 35–52 years) and with broad family obligations. For instance: “In the beginning, he (her husband) was very relaxed and actually quite okay. Then, it became worse and worse; he got very nervous. Then, everything bothered him” (CI8; wife).

The relatives concomitantly reported having been affected by the AMI and bearing severe stress. Although participants’ lives were slowly returning to normal after discharge, some relatives provided reports about sex life that resembled the following: “I don’t like doing it (sex) since he had the heart attack because I’m scared that something will happen to him again” (CI8; wife).

Being there for each other

The interviews analyzed showed that relatives tried, as far as they were concerned, to support the sick relatives physically and psychologically during and after AMI. Relatives described being very grateful for the sick relative’s return home, talking about how the “fateful day” ended well thanks to family cohesion. Moreover, to prevent the sick relative’s physical exertion and re-infarction, relatives relieved them from daily chores: “In the beginning, I did not let him drive a car. [...] I drove him everywhere.” (CI8; wife).

The relatives wanted to support the sick relative’s lifestyle changes. Some behaved overprotectively, constantly maintaining the relatives close or checking their status; others were happy about the positive development of their sick relative post-AMI regarding lifestyle changes and were there to support them through advice or action.

Being understood as an individual

Participants reported that they would appreciate being informed individually about their status and included in decision-making processes by healthcare professionals. Although some reported that professionals’ empathic attitude helped them reduce their anxiety during crises, others described the hospital service as an “assembly line” (II1), providing complaints that resembled the following example:
“I say that’s a cheek (She received a standardized discharge letter. It said that she should stop smoking. However, because she had never smoked, she felt that the letter’s content was a cheek). I have never smoked in my life. [...] That’s just the standard sentence” (II12).

Most participants were in the hospital for the first time. They described needing “support in navigating the hospitalization situation” (II11), as such support would ease their burden in understanding professionals’ responsibilities and whom to ask specific questions. Furthermore, they provided phrases similar to the following excerpt regarding their needs for communication: “Somehow, (I wanted) more conversations than are currently possible [...] and that are offered” (CI6; wife).

Participants also reported the occurrence of hectic activity both in the emergency room and on the wards and not wanting to burden healthcare professionals with their concerns. Additionally, they lacked the necessary knowledge about the disease to ask specific questions: “Well, during the ward visit, I always have the feeling ... you ask a question, and then later it occurs to you that the question actually leads to another question” (III1).

Conversations with doctors were mainly focused on medical examinations and instructions. Owing to their physical and psychological conditions, patients were often overwhelmed by the amount of information passed on by doctors. Additionally, they described that when asking questions of their interest on topics surrounding their condition, the information provided by medialics was often poor, evasive, and sometimes contradictory. For example, patients wanted to know if they could return to work after discharge, to which doctors often responded by talking around the topic.

Discussion

We identified four central phenomena: “Understanding of living with heart disease,” “Omnipresent anxiety,” “Being there for each other,” and “Being understood as an individual.” The first phenomenon, “Understanding of living with heart disease,” described the process participants underwent to understand CHD and includes three intertwined sub-phenomena: “Perceiving having heart disease,” “Getting familiar with heart disease,” and “Living life against the backdrop of heart disease.” The phenomena shown in Fig. 1 were interdependent and constantly influenced each other. They showed the constitutive ways of the openness with which AMI patients and their relatives make the unhomelike life in the AMI situation familiar to themselves and highlighted their needs while becoming aware of CHD and their coping strategies.

The theme “Understanding of living with heart disease” refers to participants’ reports on their ambivalent experiences. Specifically, it refers to the participants’ lack of illness perception and endeavors to understand their CHD since the onset of their first AMI; it also describes their needs to be able to understand the disease causes at the individual level and to shape up their future. Mentrup and Schneppe (2014) reported that the limited receptivity due to the shock experienced from AMI and the sedative and analgesic therapies administered as emergency treatment could lead to a lack of illness perception among patients. Moreover, patients often experience a certain delay in becoming aware of CHD chronicity due to the lack of physical discomfort and limitations after PCI (Mentrup and Schneppe 2014). Regarding the need to understand own disease, other researchers show that patients try to prepare to sustain their future health by becoming aware of their illness during the acute phase in the hospital (Barnason et al. 2012; Fors et al. 2014). Andersson et al. (2013) further underlined that relatives often feel ignored by medical staff, receiving little information about the disease and future disease-prevention measures. The aforementioned conforms to the theme “Understanding of living with heart disease”. According to Heidegger’s ontology, the existential constitution “understanding” is a process of interpretation; first, for one to design a future life, one forms a relationship with an experienced event, looking for answers on its wherefores while endeavoring to connect the experience with one’s previous understanding (Heidegger 1962). In our evidence, owing to the lack of involvement of the inpatients in the treatment processes and the accelerated rate of these processes, patients seemingly lacked opportunities to clearly grasp their CHD.

“Omnipresent anxiety” refers to anxiety that came in both manifest and latent forms during the disease trajectory, affecting the lives of both patients and their relatives after the AMI event. Some patients reported being motivated to change their unhealthy lifestyles owing to anxiety—others tried to deny their anxiety. The anxiety of losing their own identity and their social roles made them feel lonely; their relatives concomitantly reported having been affected by the AMI at the same proportion as the patients, as well as bearing severe stress. This evidence concurs with past qualitative literature. Early after discharge, it is common for patients to show concerns (e.g., feelings of isolation, fear, etc.; Smith et al. 2017), while relatives feel highly uncertain and have to deal with emotional stress (Andersson et al. 2013; Gullick et al. 2017; Pedersen et al. 2021). According to Heidegger’s ontology, “anxiety” is seen as an opportunity to redesign one’s own life. However, “in anxiety, one feels ‘uncanny’” (Heidegger 1962, p. 188). Additionally, Heidegger said that the state of mind serves as an access to the world, enabling people to focus on what is happening.
to understand the interrelationships that unfold; the state of mind concomitantly serves to indicate concern, which is the prerequisite for forming an understanding about something (Heidegger 1962).

In our study, anxiety seemingly played a significant role in individual coping with CHD—based on Heidegger’s ontology, it is a prerequisite for understanding and serves as a motivation to deal with a disease. Nonetheless, those concerned about the disease may also close themselves off out of fear, not accepting help thereafter. Moreover, our evidence underpins that the combination of a medical confirmation regarding a successful PCI and a lack of explanations about the treatment process is not likely to lead to anxiety reduction among AMI patients and their relatives. Instead, patients and their relatives may be left with the impression that dealing with CHD is unwarranted. Accordingly, healthcare professionals should talk to patients and their relatives about this anxiety, provide relevant responses to their needs, and offer need-based information by acknowledging the patient’s situation. Exemplifying: suppose a male patient has a fear of recurrent heart attacks; the healthcare staff can explain how he should respond to a future emergency and give him an emergency card containing clear instructions on how to deal with such a situation. This patient empowerment may enable patients to devise strategies to cope with symptomatic recurrence.

“Being there for each other” refers to the relatives’ reports on their provision of physical and psychological support to their sick relatives and to the latter’s lifestyle change endeavors. Owing to such support provision, relatives reportedly wanted information about the disease and potential coping strategies. They also described being more worried about and sometimes even controlling their sick relatives. On this topic, Heidegger described:

Thus as Being-with, Dasein ‘is’ essentially for the sake of Others [...] in Being with and towards Others, there is thus a relationship of Being from Dasein to Dasein. But it might be said that this relationship is already constitutive for one’s own Dasein [...] (Heidegger 1962, pp. 123–124)

Hence, based on Heidegger’s ontology, healthcare professionals should endeavor to understand the relatives’ situations, concurrently considering patients and their relatives as persons affected by the disease. Two studies which examined the experience of being the relative of someone who has suffered an AMI validate this view based on Heidegger’s ontology (Andersson et al. 2013; Pedersen et al. 2021). Indeed, relatives need to change their future life to meet the situation of their sick relative (Andersson et al. 2013). Accordingly, the relatives’ dual roles (i.e., as supporters of the sick relative and as people who need support) should be addressed, and support should be made available to them (Gullick et al. 2017; Pedersen et al. 2021).

“Being understood as an individual” refers to participants’ yearning for healthcare professionals to respond to their individual needs during communication. Specifically, they would have liked to have the opportunity to talk with healthcare professionals during hospitalization and receive individualized information. However, professionals’ information provision most often did not meet patients’ personal needs. Moreover, participants reported non-adherence to medication, rejection of warranted therapy, and post-AMI life uncertainty. Fors et al. (2014) reported that patients have concerns and uncertainty before knowing the cause of their symptoms. That is why healthcare professionals should provide early dialogical interventions. On the topic, Heidegger remarked: “The intelligibility of Being-in-the-world—an intelligibility which goes with a state-of-mind—expresses itself as Discourse” (Heidegger 1962, p. 161). Further, discourse has both a communicative function (i.e., conveying information) and a participatory function (i.e., one’s hearing and understanding what was heard; Posselt and Flatscher 2018).

Additionally, participants in our study asked questions about disease causes at the individual level because they were looking for an explanation for it in both their past and present lives. Concurrently, they wanted to avoid the disease and were worried about their future. Heidegger’s ontology can justify this information-seeking behavior regarding disease cause by explaining that we develop an understanding of what we are experiencing through our immediate life experiences. The extent to which our understanding of situations, actions, and persons is shaped by tradition presupposes the degree of familiarity with oneself or others (Demmerling 2015; Heidegger 1962). On the topic, Heidegger emphasized: “understanding is the being of such potentiality-for-Being” (Heidegger 1962, p. 144).

**Comprehensive understanding**

Through critical interpretation based on Heidegger’s ontology and relevant research, we gain the following comprehensive understanding: the phenomena expressed through the unit titled “Understanding of living with heart disease” implied that the participants had strong needs to get information on disease causes at the individual level and to reshape their lives after the event in a way that would ensure they could go back to their normal life rhythms.

**Strengths and limitations**

The strengths of this research reside in the application of the phenomenological hermeneutical method and critical
reflection during data analysis, through which researchers’ previous knowledge was continuously applied. Another strength is related to our interpretation of the findings based on Heidegger’s ontology, which we believe led to a more in-depth understanding of the evidence and to identifying the core of the four identified phenomena. The inclusion of relatives in the sample is another strength of this study, as it helped us gain a broad awareness of patients’ post-AMI life.

Nevertheless, all interviewed study participants were recruited from a single hospital, in good clinical condition, and read and spoke in German. This denotes that our evidence is limited in its generalizability. Therefore, we suggest for future research to examine the perspective of patients and their relatives amid acute crisis and with various cultural and nationality backgrounds. Further, our findings were not validated by the patients and their relatives; hence, we observe a limitation regarding the trustworthiness of the findings. To reduce this limitation, we may conduct future research in which we perform longitudinal interviews with the same post-AMI participants within 1 year after the AMI event. Still, by promoting detailed descriptions of the research methods as well as by discussing the qualitative findings within the group of authors, we sought to reach credibility. We also see a research field for researchers from other nationalities and/or who speak other languages to interview participants who do not read and speak German.

**Implications for theory and practice**

Our results demonstrate that the participants had strong needs to get information on disease causes at the individual level and to reshape their lives after the event—so as to ensure a normal life. Hence, nurses or other healthcare professionals should take their time when communicating with patients and their relatives during acute phases, as this may allow for these two latter parties to gradually grasp the disease causes and possible secondary prevention measures. Such communication may also improve their awareness of the disease. Specifically, such efforts can reveal patients’ and their relatives’ resources for coping with the disease, help them feel involved in the treatment, and allow for them to reach a consensus with healthcare professionals about further treatment. Thereafter, they may be able to better cope with the psychological stress and anxiety associated with AMI, as well as to more holistically understand CHD. In the end, these measures may allow for the reshaping of their future lives.

Since we analyzed the initial experiences of AMI patients and their relatives in depth, this research contributes to evidence-based knowledge in nursing practice and research. Future education programs related to the topic should aim at both patients and their relatives and focus on helping all those affected to lead their lives against the background of CHD.

**Conclusion**

Our findings suggest that healthcare professionals should start involving patients and their relatives in the care processes from the first medical contact, responding to their needs, offering individual health information, and providing continuous support in the early period following discharge. Such endeavors may allow those affected to understand CHD and prepare for and adapt to the needed lifestyle changes.

Our report on the needs of patients and their relatives makes an important contribution to person-centered nursing care. Specifically, we see the need for nonpharmacological secondary nursing interventions applied in the post-AMI period to follow the person-centered approach and consider the four central phenomena mentioned above; this methodology may improve the quality of care by ensuring that those affected are accompanied in their lives after this harsh event.

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**Declarations**

**Conflict of interest** H. Qin, D. Bonderman, S. Brunner, T. Großbichler, E. Scharinger, and H. Mayer declare that they have no competing interests.

**Ethical standards** The investigation conformed to the principles outlined in the Declaration of Helsinki. All participants provided written informed consent before participation. Participants were assured that they could decline participation at any time and that participation or non-participation would not influence their further treatment. This study was approved by the Ethics Committee of the Medical University of Vienna approved this research project (EC No. 1811/2018).

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